Designing a framework to measure patient-reported health effects and outcomes from using person-generated health data: A simulated rehabilitation system use case

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Abstract

There is rising availability and growing adoption of a variety of health information technologies (HIT) that promote participatory health, by enabling people to access and use a form of health data called person-generated health data (PGHD). PGHD is produced when people use HITs to track, manage, and make sense of their health data; and which often occurs outside of traditional health care settings or with minimum intervention of health professionals. Reported effects from PGHD utilisation vary in the literature. While positive health effects have been reported when people utilise their PGHD, PGHD utilisation could also result in neutral or negative effects. For instance, PGHD utilisation may increase the motivation of PGHD users to adhere to healthy behaviours and self-manage their care. However, it may also make them feel frustrated or discouraged with their progress.

In order to build the evidence base about PGHD for health informatics research, it is imperative that a more systematic assessment of PGHD utilisation effects is developed. Therefore, the objective of this thesis has been to design a framework that enables PGHD users to routinely report standard measures of how PGHD utilisation may affect them. The overarching research question posed to fulfill this objective is: How could users' reporting of PGHD effects be standardised, for any given PGHD technology and health condition?

In the process of answering the research question, it was determined that among the different types of patient-reported measures (PRMs), a patient-reported outcome measure of utilising PGHD (PROM-PGHD) should be developed for the exemplar case of simulated stroke rehabilitation technology. This is because a PROM-PGHD would allow for a more precise, patient-centred assessment of a variety of PGHD technologies; and could increase understanding on how such technologies could impact the health status of people. To develop the PROM-PGHD, the author designed a PROM-PGHD Development Method, comprised of multi-step qualitative activities with three main sources of data collection: a literature review to contextualise the problem, a conceptual review of patient-reported measures and development best practice, and audio-recorded focus groups and interviews to elicit input from people with the case health condition.

Abstract

In answering the research question through the development of a PROM-PGHD, a new framework emerged for developing PRM types of utilising PGHD. The framework has four components: 1) problem contextualisation through a literature review, 2) selection of a PRM, 3) review of selected PRM development best practice, and 4) multi-step qualitative development of a type of PRM of utilising PGHD, consolidation of insights, and reporting. This thesis contributes to health informatics research by providing early, significant steps towards the goal of using systematic, validated processes to generate evidence on PGHD utilisation health effects and improve PGHD technology design.

Declaration

This is to certify that:

i. the thesis comprises only my original work towards the Doctor of Philosophy in Engineering degree;
ii. due acknowledgement has been made in the text to all other material used; and
iii. the thesis is fewer than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices.

Gerardo Luis C. Dimaguila

June 2020

Preface

Publication Status of Thesis Chapters and Author Contributions

This is a thesis with publications. There are six peer-reviewed publications included in this thesis. The peer-reviewed publications appear in Chapters 1-6. Gerardo Luis Dimaguila is the primary author of all publications, and contributed more than 50% for each publication.

The following list summarises the publication status of major chapters and sections in this thesis. The contributions of the authors involved in those publications and any relevant collaborations with other entities are also outlined.

Chapter 1, Section 1.3.2: Contextualising the Problem: Person-Generated Health Data Use in Simulated Rehabilitation for Stroke (peer-reviewed publication).

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> Author contributions: GLD contributed to the study planning and design, data collection, analysis and interpretation, and writing of the manuscript. KG contributed to the study design, interpretation of the data, and revision of the manuscript. MM contributed to the study design, interpretation of the data, and revision of the manuscript.
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revision of the manuscript. MM contributed to the study planning, ethics application, data interpretation, and revision of the manuscript.

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- *Technologies for Patient Empowerment.*
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- *Alumni Profile and Introduction to Health Informatics.*
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- *Refinement of a Tool to Measure Person-Generated Health Data.*

Melbourne, Australia: Austin Health Hospital, February 2018.

- *Person-Generated Health Data in a Stroke Rehabilitation Programme: Measuring Effects on Patients.*
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- School of Computing and Information Systems Conference Travel Scholarship to present at the Health Informatics Conference, Australia (2019)

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Academic Memberships and Activities

- Melbourne Networked Society Institute Doctoral Academy (2017)

- Australasian Institute of Digital Health (formerly the Australasian College of Health Informatics) Fellowship by Training program Candidate (2018-Present)

- Peer Reviewer, Journal of Medical Internet Research (2018)

- Peer Reviewer, European Conference on Information Systems (2018)

- Peer Reviewer, International Conference on Information Systems (2018)

- Founding Executive Committee Member, Graduate Research Students Group of the School of Computing and Information Systems, University of Melbourne (2017)

- Conference Chair, School of Computing and Information Systems Doctoral Colloquium, University of Melbourne (2017)

- President (2019), Vice-President (2017-2018), Committee Head (2015-2016) of the graduate student cohort of Newman College (University of Melbourne)

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Gerardo Luis (Ikee) C. Dimaguila

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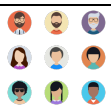
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List of Third-Party Copyright Materials

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1 Introduction

This chapter introduces the key concepts and topics of the thesis, and describes the intersection between the main themes of interest, namely person-generated health data (PGHD), participatory health informatics, simulated rehabilitation, and stroke therapy.

It provides context to the overarching objective and research question of the thesis. A peer-reviewed, published literature review contextualises the motivation for the study by highlighting the lack of evidence-based reporting on how PGHD utilisation may affect people, and the lack of participation by stroke survivors on the design and evaluation of a range of simulated rehabilitation technologies for stroke. Consequently, this chapter establishes the need for a framework for systematically measuring the effects of PGHD use from people's own perspective.

1.1 Person-Generated Health Data and Its Potential to Influence Health Outcomes

Health information technologies (HITs) that enable people to access information related to their health produce varying levels of personalised data [1], and these data are called PGHD. These technologies range from web-based health sites that enable people to look for health information online and interact with other people; through to mobile applications [2] and consumer wearable technologies that track people's health, such as physical activity, sleeping patterns, and heart rate [1]. People produce PGHD when they use HITs to track, manage, and make sense of their own health data; often outside of traditional health care settings or where there is minimum intervention of health professionals [3, 4].

PGHD are health, wellness and clinical data that people generate, record and analyse for themselves [3]. Examples of technologies that support PGHD include journaling tools, activity tracking devices or mobile applications, networked health data-gathering devices such as weighing scales, and simulated rehabilitation technologies. The examples highlight the availability of PGHD in health information technologies. In particular, they show the prevalence of PGHD's availability in consumer devices such as Fitbit© and stroke rehabilitation system Jintronix (jintronix.com), which uses Microsoft Kinect© to track stroke survivor movements.

PGHD from HITs that people access and utilise has been suggested to have different effects on people's health outcomes. For instance, people's ability to understand and manage their own health may be improved [1, 2, 5]. It is also known that when people understand their illness, they may become active problem solvers and improve their health behaviour; for example, people could stop smoking when they personally see the connection between activity and illness [6]. People's utilisation of PGHD has also been suggested to improve health management coordination between them and their health care providers and treatment teams, assist them in self-managing their care, increase their engagement, and increase the social support they receive and their sense of social connectedness [7-12].

PGHD enables people to manage their own health by making decisions and lifestyle changes based on their analysis of their data [13], and as such exemplifies a modern participatory health paradigm. PGHD utilisation affords people the ability to be accountable for their own actions, and therefore promotes participatory health [13]. It is therefore imperative to build the evidence about PGHD for health informatics research and practice.

PGHD may be especially relevant and accessible to people who use a particular form of home-based health care, namely simulated rehabilitation systems.

1.2 Person-Generated Health Data in Simulated Rehabilitation Technologies

Simulated rehabilitation is a type of telerehabilitation that uses computer technologies and interfaces to allow the real-time simulation of rehabilitation activities or a rehabilitation environment in clinical or at-home settings [14]. Simulated setups employ various technologies – both hardware and software – to provide users rehabilitation tasks or exercises to accomplish, facilitate completion of those tasks, and record their performance. Feedback and progress about users' health status are provided back to them through their PGHD.

Users interact with the simulation through multiple sensory channels [15-17]. The technologies are varied and diverse, depending on the task to be accomplished. Some of the technologies used for stroke rehabilitation include Microsoft's Kinect, Wii balance board, IREX

VR, Rutgers Ankle, PlayStation EyeToy, GestureTek, stereoscopic glasses, stylus, motorised wheelchair, and treadmill. 2D and 3D games, either bespoke or off-the-shelf, have also been used to provide the tasks [15-17].

This thesis recognises that simulated rehabilitation employs types of virtual (VR) or augmented reality technology setups [15-18]. This is consistent with an early, well-known definition of VR which argues that VR should not be defined in terms of technology, but the extent to which a user senses being in a simulated environment [19]. Thus the term simulated rehabilitation in this thesis is differentiated from a technology-centric definition of VR stressing a three-dimensional environment generated by a computer [20-22], with restricted technical and technological requirements, e.g., $\geq$ 10 video frames per second [23].

An important application area for simulated rehabilitation technologies is stroke rehabilitation. This is primarily due to the high global burden of stroke that necessitates effective home-based treatment options requiring less professional and financial resources for stroke survivors [24, 25]. The following section highlights the author's particular interest in the area, and provides additional context to the importance of improving the access and outcomes for stroke rehabilitation, particularly in under-resourced areas.

1.3 Potential of Person-Generated Health Data to Influence Health Outcomes in Simulated Rehabilitation for Stroke Therapy

1.3.1 Importance of Improving Stroke Therapy Outcomes through Simulated Rehabilitation

The author is personally interested in contributing to the improvement of health outcomes for stroke survivors because of the impact of stroke on his home country, the Philippines. The following provides more context on stroke's impact on the global population, specifically in the Philippines.

Stroke is a leading cause of death and disability across the globe [26, 27]. A type of cardiovascular disease, which represents 31% of deaths globally, stroke is the 2nd highest cause of death (6.7 million) [28] just behind coronary heart disease (7.4 million) [27]. In total, stroke accounts for 46.6 million Disability Adjusted Life Years (DALYs) [26], which is a composite data of life years lost and lived with disability [29]. Stroke impacts all facets of a

victim's life [30]; causing disability, limiting independence, and affecting quality of life [24, 31, 32]. Stroke primarily affects movement and strength. Due to the loss of function, the ability of stroke survivors to communicate are also affected, which results in poorer health-related quality of life (QoL) [30]. This makes social participation difficult for them, especially for those whose memory and primary arm are also impacted.

In the Philippines, a lower-middle income country (LMIC), [33] stroke is the 2nd highest cause of mortality [34, 35]. 348 DALYs are lost for every 100,000 people [35], and the annual stroke-related cost amounts to US$350 million to US$1.2 billion, with most of that expense shouldered privately, by people and their families.

Access to rehabilitation and therapy exercises is essential for stroke survivors to gain positive health outcomes, and the timing and frequency of those exercises are critical to the motor function recovery of stroke survivors. 70% of recovery usually occur within the first 26 weeks post-stroke, after which recovery starts to plateau [36, 37], although continued rehabilitation has been shown to continue providing motor and functional benefits for stroke survivors [38].

Access to stroke rehabilitation is difficult in the Philippines. Costs for rehabilitation are not subsidised; and private insurance have a cap on the number of rehabilitation treatments stroke survivors can have reimbursed [39]. Moreover, while access to most government hospitals are free, subsidies are not available for medicines [34]. The Philippine government spends only 3.2% of the country's Gross Domestic Product (GDP) on healthcare [35], below the 5-6% recommended by the World Health Organization (WHO) [40]. The health budget has also recently been lowered by 25% [41]. This results in treatment often being delayed by families to minimise costs [39], especially because Philippine government and insurance agencies combined cover less than 10% of the cost of healthcare in the country [34].

Additionally, access to acute stroke and tertiary care is difficult in LMICs due to the limited number of neurologists and specialists [42]. Particularly, in the Philippines there are only 287 certified neurologists, which is 1 for every 330,000 people – 349.8 times lower than the WHO recommended 1 neurologist for every 943.3 people (106:100,000) [34]. The distribution of neurologists is also uneven, as 67% of them are in urban areas [34], where only 44% of the

Philippine population reside as of 2015 [43]. Moreover, only 15.8% of the 1,834 hospitals treating stroke have rehabilitation units [39].

The difficulty of gaining access to appropriate treatment at the right time has resulted in lower functional outcomes in developing countries. Rehabilitation in those countries is mostly done in outpatient settings, leading to reduced lower outcomes compared with those in developed countries [44]. It has been shown that stroke survivors in developing countries perform worse at gross motor activities, and recover much slower than their counterparts in developed countries, despite receiving similar therapies. The differential factor was compliance and intensity of therapy due to variability in rehabilitation access [44].

As indicated earlier, the burden of stroke is especially exacerbated in developing countries. A high proportion of stroke deaths (40%) occur in under-resourced South Asia, where stroke occurs in people 10 years younger than average [42]. This is due to rapid socioeconomic changes, increasing urbanisation, and diet changes; coupled with a limited public awareness of stroke risk factors and management. There is also a lack of attention or priority given by government health agencies and policy makers – leading to a lack of national stroke control programmes [42].

All these have led to a disparity in stroke incidence between high-income countries and LMICs in the past four decades [45]. There has been a 42% decrease in stroke incidence in high-income countries, while there was a 100% increase in stroke incidence in LMICs. From having a lower stroke incidence than high-income countries, LMICs now have a 20% higher stroke incidence rate [45].

The challenges to accessing effective, timely stroke rehabilitation options highlight the need for an intervention that provides stroke survivors with other treatment options, such as home-based rehabilitation programmes. However, compliance to home-based exercises is weak due to the monotony of exercises [46-48]. The small number of successful home-based exercise trials are personnel intensive [49], indicating that therapists are still necessary in home-based rehabilitation, already shown to be impractical in most cases. Home-based rehabilitation is needed because of the dearth of healthcare professional and financial

resources, and yet home-based rehabilitation is more successful when therapists are involved.

This section has shown that simulated rehabilitation through HITs that require minimal clinician involvement, has immense potential to benefit stroke survivors; especially those from areas where physical facilities are under-resourced or geographically remote. PGHD may further optimise simulated rehabilitation due to its reported effects of engaging stroke survivors, and helping them self-manage their care, as described in Section 1.1-2.

1.3.2 Contextualising the Problem: Person-Generated Health Data Use in Simulated Rehabilitation for Stroke (peer-reviewed publication)

This section presents a published literature review that explored how a range of simulated stroke rehabilitation systems have utilised PGHD, and what benefits it had on stroke survivors as a result. The review sought to answer four questions: What types of PGHD were produced? How did people have access to their PGHD? Who else used the PGHD, and for what purpose? What effects were reported from people's use of their PGHD?

The review is the first to examine the literature on how PGHD has been used or managed for a particular range of simulated stroke rehabilitation systems, and highlights the lack of evidence on the kinds of effects that may occur when stroke survivors utilise their PGHD. It also lists the types of outcome measures used in the literature, and puts emphasis on the need to use clinical outcome measures when evaluating such technologies.

This is a peer-reviewed publication, appearing in JMIR Journal of Rehabilitation and Assistive Technologies (doi:10.2196/rehab.9123). The accepted version of the article is presented here, ready for examination following university guidelines for thesis with publications. To see the individual contribution of the authors, please see the Preface.

The multimedia appendices of the publication are presented in this thesis as Appendix A. Any figures and tables that appear in this published manuscript have been renumbered for the purpose of this thesis.

Person-Generated Health Data in Simulated Rehabilitation Using Kinect for Stroke: Literature Review

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Abstract

Background: Person- or patient-generated health data (PGHD) are health, wellness, and clinical data that people generate, record, and analyze for themselves. There is potential for PGHD to improve the efficiency and effectiveness of simulated rehabilitation technologies for stroke. Simulated rehabilitation is a type of telerehabilitation that uses computer technologies and interfaces to allow the real-time simulation of rehabilitation activities or a rehabilitation environment. A leading technology for simulated rehabilitation is Microsoft's Kinect, a video-based technology that uses infrared to track a user's body movements.

Objective: This review attempts to understand to what extent Kinect-based stroke rehabilitation systems (K-SRS) have used PGHD and to what benefit.

Methods: The review is conducted in two parts. In part 1, aspects of relevance for PGHD were searched for in existing systematic reviews on K-SRS. The following databases were searched:

IEEE Xplore, Association of Computing Machinery Digital Library, PubMed, Biomed Central, Cochrane Library, and Campbell Collaboration. In part 2, original research papers that presented or used K-SRS were reviewed in terms of (1) types of PGHD, (2) patient access to PGHD, (3) PGHD use, and (4) effects of PGHD use. The search was conducted in the same databases as part 1 except Cochrane and Campbell Collaboration. Reference lists on K-SRS of the reviews found in part 1 were also included in the search for part 2. There was no date restriction. The search was closed in June 2017. The quality of the papers was not assessed, as it was not deemed critical to understanding PGHD access and use in studies that used K-SRS.

Results: In part 1, 192 papers were identified, and after assessment only 3 papers were included. Part 1 showed that previous reviews focused on technical effectiveness of K-SRS with some attention on clinical effectiveness. None of those reviews reported on home-based implementation or PGHD use. In part 2, 163 papers were identified and after assessment, 41 papers were included. Part 2 showed that there is a gap in understanding how PGHD use may affect patients using K-SRS and a lack of patient participation in the design of such systems.

Conclusions: This paper calls specifically for further studies of K-SRS—and for studies of technologies that allow patients to generate their own health data in general—to pay more attention to how patients' own use of their data may influence their care processes and outcomes. Future studies that trial the effectiveness of K-SRS outside the clinic should also explore how patients and carers use PGHD in home rehabilitation programs.

Keywords

health care information systems; Kinect; patient-generated health data; person-generated health data; review; simulated rehabilitation; stroke; stroke rehabilitation; video games; virtual rehabilitation

Introduction

Understanding the Effects of Person-Generated Health Data

Person- or patient-generated health data (PGHD) are health, wellness, and clinical data that people generate, record, and analyze for themselves [1]. Examples of technologies that

support PGHD include online health journals, activity-tracking devices or mobile apps, networked health data-gathering devices such as weighing scales, and simulated rehabilitation technologies. However, PGHD integration into clinical use is hampered by the lack of theoretical foundation, strategies, and data models [1]. The availability of PGHD technologies has been increasing, and so has their adoption. However, implementation and evaluation research has not kept up.

PGHD's effects on the health of the individual have yet to be demonstrated or defined. It is known that when patients understand their illness, they may become active problem solvers and improve their health behavior; for example, it has been suggested that people will stop smoking when they personally see the connection between activity and illness [2]. Moreover, patients' use of PGHD has been suggested to improve health management coordination between them and their health care providers and treatment teams, assist patients in self-managing their care, engage patients, and increase the social support they receive and their sense of social connectedness [3-8].

In particular, PGHD may make home-based health care more efficient and effective. If not only clinicians but also patients are able to access health data generated from the use of home-based health care technologies, this may improve patients' engagement in their own care and optimize their use of clinical supervision, thus contributing to more effective outcomes across the health system overall [7,9,10].

PGHD may be especially relevant and accessible to patients who use a particular form of home-based health care, simulated rehabilitation systems. Simulated rehabilitation is a type of telerehabilitation that uses computer technologies and interfaces to allow the real-time simulation of rehabilitation activities or a rehabilitation environment [11]. Users interact with the simulation through multiple sensory channels [12-14].

Person-Generated Health Data Use Case: Simulated Rehabilitation After Stroke

One important PGHD use case may be in home-based poststroke rehabilitation that uses body-tracking simulated rehabilitation technologies [15]. Stroke is an important application area for rehabilitation systems because of the burden and complexity of the care required. It

is a leading cause of death and disability across the globe and accounts for 46.6 million disability-adjusted life years [16,17]. Stroke patient motor function recovery is a long and complicated process, requiring patients to undergo extensive rehabilitation therapy that involves frequent, regular movement exercises matched to their impairments [18,19]. Regular rehabilitation exercises, especially in the first few weeks poststroke, are essential in helping patients recover and reduce long-term impact on their quality of life. However, clinical rehabilitation can be costly and may not be readily available for some patients [20].

More practical and convenient rehabilitation options for patients are needed. Access to an effective home-based rehabilitation program is important in a patient's journey to recovery. Moreover, patients recovering after a stroke may prefer home-based rehabilitation rather than traveling to a clinic [20]. However, patient compliance with home-based exercise programs may be weak, in part due to the perceived monotony of exercises as well as lack of guidance in completing them [21-23]. The small number of successful trials reporting home-based exercises for stroke are also personnel intensive [20], indicating that therapists' close involvement remains necessary.

The potential benefit of simulated rehabilitation systems poststroke has been documented in select systematic reviews [12-14,24]. This form of rehabilitation can provide simulation of activities of daily living [24]. At the same time, it can allow the treating therapist a semicontrolled, consistent format for observing and documenting patient performance and progress [24] and for assessing any performance changes [13]. There is potential to decrease rehabilitation costs while increasing accessibility to rehabilitation exercises for patients in areas where there is a dearth of rehabilitation services [21-23]. Since these systems are interactive, many of them gamified, they add enjoyability to exercises, help motivate patients, and encourage adherence to the rehabilitation tasks [24]. As such, they are seen as optimizing the benefits of conventional therapy [12].

Implementing PGHD technologies might further optimize these systems. Simulated setups employ various hardware and software technologies including a range of off-the-shelf technologies [25] to set tasks (which in rehabilitation are often a form of physical exercise), facilitate the accomplishing of tasks, and—crucially for the relevance of PGHD—record the

user's performance [26,27]. Using PGHD tools, performance data could be made accessible to the patient at home and, in Internet-connected settings, could be shared online (in rehabilitation, typically with the therapist) [27].

Use Case System of Choice: Microsoft Kinect

Microsoft's Kinect is a video-based technology that uses infrared to track a user's body movements. It has been suggested as a leading technology for simulated rehabilitation [26] for several reasons: it has good movement range and demands, which helps in rehabilitation; it has been shown to be reliable and accurate; and it demonstrates consistent performance in tracking user movements [28-30]. Also, it is a relatively affordable product that is available to consumers for home entertainment. These factors have led to its adoption for patient therapy in cerebral palsy [31], assessment of foot posture [32], and cardiovascular diseases [33].

Kinect has been used extensively in simulated rehabilitation systems for stroke. Commercial examples used by physical therapists with stroke patients include Limbs Alive and Jintronix. However, little is known about how effectively such systems may facilitate not only clinical data use by therapists but also PGHD use by patients themselves. There is no clear body of evidence about the impact the patient's experience using PGHD could have on their overall experience of rehabilitation in such systems.

Objectives of This Review

There is potential to realize greater engagement, efficiency, and effectiveness benefits of Kinect-based stroke rehabilitation systems (K-SRS) deployed in patient's homes under clinical supervision by allowing each patient to access their own PGHD from the system. Hence, the objective of this review is to answer the questions: To what extent do K-SRS enable PGHD? And to what effect?

Methods

The literature review was conducted following the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [34], as appropriate to our objectives.

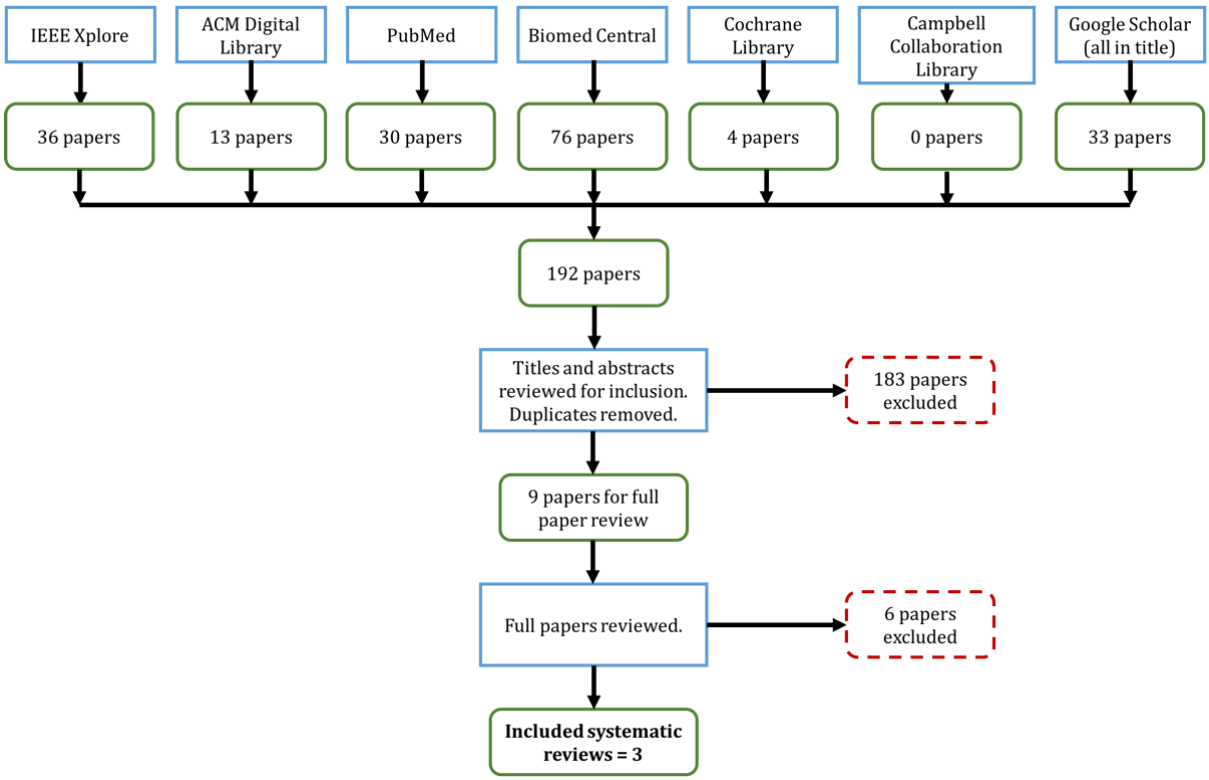
The review is structured in 2 parts:

1. Analysis of existing systematic reviews of K-SRS [25,27,29]. This reveals which aspects of relevance for PGHD have been prioritized by previous studies.
2. Systematic review of the use of PGHD in existing K-SRS.

Part 1: Analysis of Systematic Reviews

An exhaustive search strategy (Multimedia Appendix 1) resulted in 3 systematic reviews. Figure 1 illustrates this search process. The inclusion criteria include articles written in English, systematic or literature reviews, reviews of systems that used.

Figure 1. Search process for part 1.



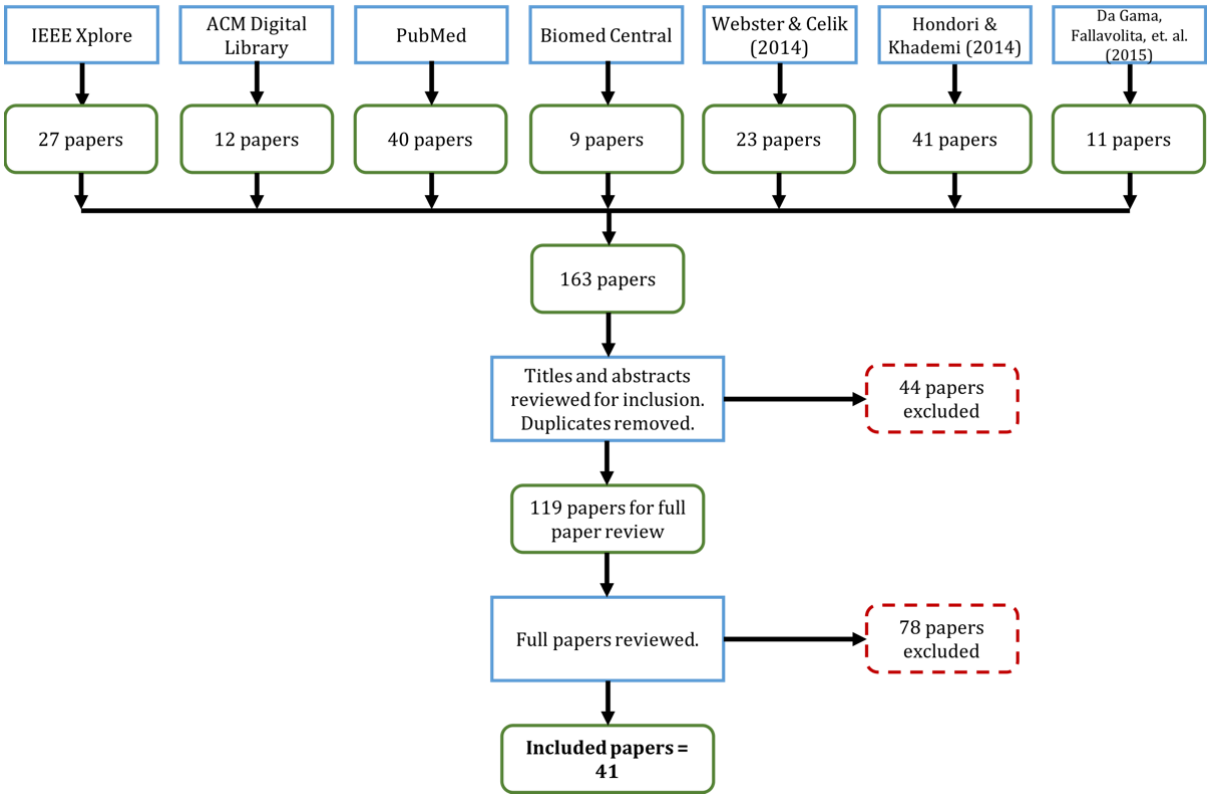
Kinect, and systems for stroke rehabilitation. The exclusion criteria include reviews for nonstroke rehabilitation purposes (eg, assess Kinect's gesture recognition) or broad scoping reviews that primarily take inventory of a suite of technology-based rehabilitation systems. The content of each systematic review was analyzed based on (1) method for analysis vis-à-

vis objectives; (2) focus on use of patient-generated health data, including feedback given to users or patients; (3) the extent to which the systems included in the review are usable at home, including the challenges and recommendations for implementing at home; and (4) the effectiveness of the systems in the review based on patient outcomes as well as technological limitations that may affect those outcomes.

Part 2: Review of Person-Generated Health Data Use in Kinect-Based Stroke Rehabilitation Systems

An exhaustive search strategy (Multimedia Appendix 2) resulted in 41 original research reports for review. Figure 2 illustrates this search process. The inclusion criteria include those full papers written in English that present rehabilitation systems for stroke using Kinect. Exclusion criteria include white papers or systematic or literature reviews, primary purpose of study not being rehabilitation or primary disease case not being stroke, or not using Kinect in any way. Based on our objectives, content of the included papers was primarily analyzed using the following questions: (1) What types of data did patients generate? (2) Did they have access to their PGHD, and if yes in what form? (3) How were these data used by patients, clinicians, developers, and researchers? (4) What effects were observed from PGHD use?

Figure 2. Search process for part 2.



Results

Part 1 highlights gaps in information collected in previous systematic reviews of K-SRS, particularly the use of PGHD and home use of K-SRS. Moreover, it shows that previous reviews mainly provided technical descriptions of K-SRS, while suggesting that more studies are needed to ascertain their clinical effectiveness. Part 2 of this review addresses the PGHD use gap.

Part 1: Analysis of Systematic Reviews of Kinect-Based Stroke Rehabilitation Systems

The objectives, methods, and structure of each systematic review are detailed in Multimedia Appendix 3. A summary of these systematic reviews vis-à-vis the themes of interest can be found in Multimedia Appendix 4.

Review of Person-Generated Health Data Use

None of the 3 systematic reviews examined the literature on use or management of patient-generated data, although system feedback methods were briefly described. Webster et al

[26], however, noted the need for future research to look into the data-gathering potential of Kinect and provide proper feedback to patients, especially when they fail to accomplish a task. Hondori et al [25] focused on describing the technical and technological aspects and features of Kinect and other body-tracking technologies. Da Gama et al [27] were more comprehensive in their analysis and presentation of papers.

Review of Home Use

None of the reviews included a home usability criterion. However, Hondori et al [25] noted the need to assess Kinect's safety and efficacy when implemented at home. Moreover, Da Gama et al [27] briefly noted some challenges that can be encountered in a home implementation, such as space and lighting conditions. These authors recommended future studies into the effects and benefits of a home-based implementation. How patients might interact with their data outside of clinical settings is a significant gap in our understanding, particularly because K-SRS are touted as beneficial and advantageous for home use [35].

Review of Effectiveness

These 3 reviews confirmed the accuracy and reliability of Kinect when used for poststroke rehabilitation, particularly for providing and tracking movement exercises. They also highlighted Kinect's weaknesses, including occlusion and inability to track fine motor function such as those including fingers, and suggested that Kinect should be focused only on the whole hand or be used with other technologies such as sensors. Webster et al [26] noted that Kinect may not be suitable for patients with extremely severe impairments because they are only capable of performing minute movements.

All reviews noted that more work is needed to verify the clinical effectiveness of K-SRS and describe their possible benefits for patients. Webster et al [26] discussed the potential physical and mental benefits of K-SRS (ie, faster and better supported rehabilitation and increased enjoyability of exercises and motivation due to the highly interactive interfaces). Kinect-based systems can also extend guidance and correction of patient movements. Moreover, exercises can be tailored to the needs of patients. Hondori et al [25] found that patients preferred Kinect over other off-the-shelf, consumer body-tracking devices, Kinect-based systems can assist in improving balance, and they have the potential to improve

functional ability of patients. Da Gama et al [27] echoed the findings of Webster et al [26] that enjoyability increased motivation.

Part 2: Person-Generated Health Data Use in Kinect-Based Stroke Rehabilitation Systems

Part 1 highlighted gaps in information collected in previous systematic reviews of K-SRS, particularly the use of PGHD and home use of K-SRS. Moreover, it showed that previous reviews mainly provided technical descriptions of K-SRS, while suggesting that more studies are needed to ascertain their clinical effectiveness. Part 2 of this review addresses the PGHD use gap.

Article Types

To assist future studies in assessing the clinical effectiveness of K-SRS, papers are categorized as either clinical- or technical-focused. Clinical-focused papers prioritize the clinical effectiveness, feasibility, or safety of K-SRS. They include cohort studies (n=2), case reports (n=2), and randomized controlled trials (n=5). Technically oriented papers prioritize the design, development, and evaluation of the systems. They include a survey (n=1), proofs of concept (n=5), development of an app (n=17) or platform (n=6), and assessment of reliability and precision (n=3). The list of papers categorized according to their clinical or technical type is in Multimedia Appendix 5.

Participants

Health Status

Nearly half of the papers (17/41, 42%) recruited only stroke patients [22,35-50], 15% (6/41) recruited only healthy participants [51-56], and 17% (7/41) recruited both patients and healthy participants [23,30,57-61]. One paper recruited participants for a requirements-gathering phase but no details were provided regarding their health status and demographics [62], and 20% (8/41) of papers did not recruit any participants [63-70]. Both study protocols will be recruiting patients [71,72].

Demographics

While 33% (11/33) of papers with subjects did not report ages [45-47,52-54,56,59,60,62,70], there was considerable variation in the ages of both patients and subjects in those that did.

For papers that recruited patients, the combined mean age was 59.2 (SD 19.6) years. For papers that recruited healthy subjects, combined standard deviation (39.9 years) was greater than the combined mean (37.3 years), indicative of how spread out the age ranges were. While 38% (9/24) of papers with patients did not record gender [23,44-47,57,59,60,70], the majority of patients in those that did were male and 2 had an equal distribution [39,48]. Meanwhile, 54% (7/13) of papers with healthy subjects did not record gender [52,53,55-57,59,60]; the majority of patients in those that did were male. None had more females, and only 1 had an equal distribution [54].

Stroke Details

Only 12% (5/41) of papers recorded the stroke types of patients [38,40-42,49], and of those all patients had infarct or ischemic strokes except for one, which had 10 ischemic and 5 hemorrhagic patients [49]. More than a quarter (11/41, 27%) of papers recorded hemiparetic side of patients [23,36-42,48-50], and the majority of recorded hemiparesis was the right side (7/11, 64%). Only 20% (8/41) of papers recorded the duration poststroke of the patients at the time of the study [22,37-41,49,50]. The combined standard deviation (25.2 months) was greater than the combined mean (12.8 months), indicating the wide range of duration poststroke.

Outcome Measures

Outcome measures are documented and categorized to give an overview of how clinical, technical, and home use aspects, if any, were assessed in the literature. The measures were categorized as either measures of patient activity, balance, motor function, and quality of life or measures of system usability or other technical aspects. Most papers used multiple measures under different categories. Activity outcome measures assessed the ability of patients to perform activities (ie, exercise tasks and activities of daily living). Balance measures assessed the balance ability of patients, motor function measures assessed physical function capabilities, and quality of life measures assessed the quality of physiological and psychological well-being of patients. System usability measures assessed the usability of Kinect-based systems. Other technical measures, variables, or methods assessed the accuracy, design, and reliability of the K-SRS used. Multimedia Appendix 6 shows the measures categorized and ranked according to studies that used them.

Person-Generated Health Data

This section focuses on the data generated by patients and other study participants (such as healthy volunteers) through their use of K-SRS. Study descriptions of the papers can be found in Multimedia Appendix 7.

What Data Did People Generate by Using a Kinect-Based Stroke Rehabilitation System?

The types of data generated by patients when using a K-SRS can be broadly categorized as human performance data or system variable data. These PGHD were, in most cases, not provided to patients as feedback. The types of feedback provided to patients are described in the next section. Human performance data (n=25) are those used to indicate movement or exercise performance of the individual [22,36-40,42,45-48,52, 53,57,59,60,62,64-67,69-72]. Most of these data were generated directly from the Kinect sensor; others were from different sensors such as accelerometers. System variable data (n=20) were unsynthesized to indicate system or patient performance [23,30,35,39,41,44,49,50,53-56,58,60,61,63,67-69,71]. These types of data were used to evaluate a system's accuracy, feasibility, reliability, and effectiveness. Many papers generated such data directly from Kinect-based systems (n=12) [23,30,39,41,44,49,55,56,61,63,68,69]. Ten papers generated data from other sensors [35,50,53,56,58,60,61,67,69,71] such as an inertial wrist strap, 6 papers reported both performanceand variable data [39,53,60,67,69,71], and 2 papers did not report data from individuals' use of the rehabilitation systems [43,51]. For more detailed descriptions of these data, please see Multimedia Appendix 7.

How Did People Have Access to Their Data?

People were provided with various forms of feedback, but in no cases did they access their complete data, data similar to those seen by their attending clinicians, from the K-SRS. For example, while clinicians may see a patient's calculated reaching distance, patients would only see game task scores. It is unknown why this is so; of the 33 papers that provided feedback, only 11 papers provided reasons for giving any feedback at all. These included following good game design for a better user experience [67,70], guiding movements [49,56,60,61,69,70], reducing user errors [35,60,63], and assisting users in meeting exercise

goals [35,46,50]. Figures 3 and 4 show sample clinician views, while Figure 5 shows a sample patient view after an exercise illustrating one of the systems in use [71,72].

Figure 3. Clinician view: patient-generated health data outcomes summary.

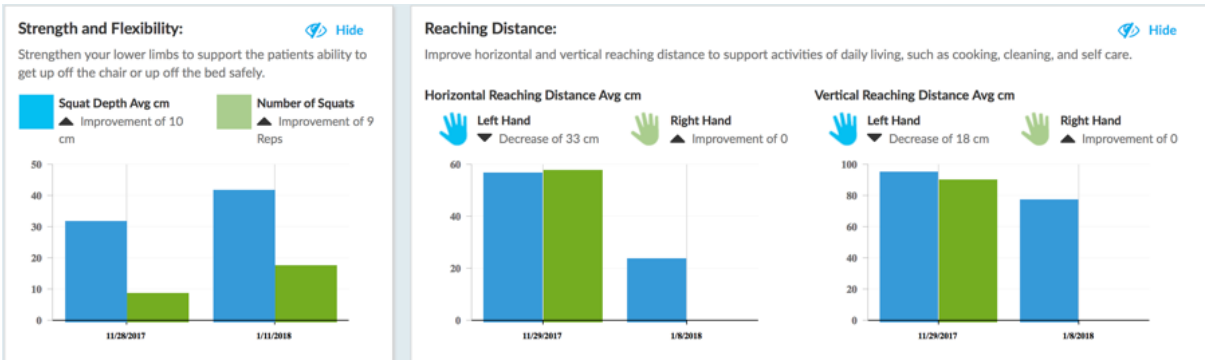
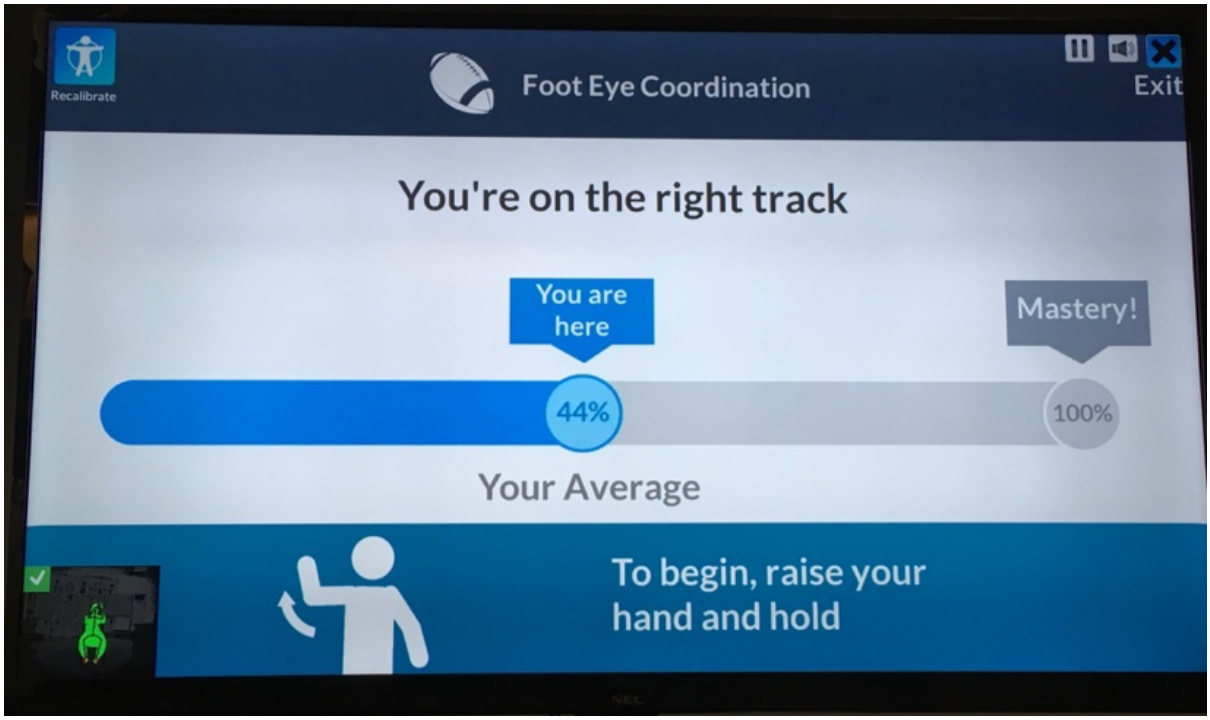


Figure 4. Clinician view: detailed patient performance data.



Figure 5. Patient view: sample postexercise game score.



The types of feedback provided can be categorized as guidance, progress, or task scores. Guidance feedback (n=19) is in the form of visual and auditory information, intended to facilitate performing an exercise or task. In 13 papers, patients were guided in performing a task through a visual interface [44,45,49,52,53,60-62,64,67,70-72]; in 1 paper, through auditory feedback [30]; and in 5 papers, through both visual and auditory guidance [23,35,54,56,66]. Progress feedback (n=4) tracked patient progress in terms of number of exercises or tasks completed or to be completed [42,46,63,65]. Task score feedback (n=10) was in the form of game scores provided as-is, without any interpretation of the user's performance. These papers simply provided people with their scores at the end of a task execution [22,37-39,47,50,55,57,59,69]; 8 papers did not describe provision of feedback or any other mode of patient access to their data [36,40,41,43,48,51,58,68]. For more detailed descriptions of these data, please see Appendix 7.

Who Else Used the Data and for What Purposes?

Use of PGHD can be categorized based on the purpose of use, which was for patient benefit, comparison of effects, assessment of K-SRS, or evaluation of other technologies. For patient-

benefit use papers, 63% (12/19) were in the form of therapists using the data to prescribe or tailor rehabilitation to individual patient needs [23,46-49,58,65-67,69,70,72]. Comparison papers used PGHD for researchers to study the different effects of a K-SRS in different groups of people [57,72]. Use of K-SRS assessment research (n=13) was done to study system effectiveness, feasibility, accuracy, or reliability [22,23,30,41,42,44,45,50,54-56,61,71]. PGHD use for evaluation of other technologies employed the generated data to assess other technologies used in their K-SRS [35,40]; 5 papers used data for 2 purposes [23,35,56,61,72] and 10 papers did not describe use of PGHD [36-38,43,51,53,59,60,62,63]. For more detailed descriptions of PGHD use, please see Appendix 7.

What Effects Were Reported From People's Use of Their Own Data?

Only 1 paper [22] described any effects on a patient from using PGHD. This paper observed that when the patient was provided with her performance scores daily she remembered them and was motivated to improve the next day.

Discussion

Principal Findings

No prior systematic reviews have examined the literature for evidence about use or management of the patient health data that K-SRS users generate. In our own review of the K-SRS literature, we found that while more than three-quarters of the papers used PGHD in some way, only 1 described the effects of PGHD use [22]. Moreover, the fact that use was mainly for technical evaluation and secondarily for clinicians to prescribe exercises shows that patient participation was not a priority in the design of K-SRS. Additional evidence of this can be found in the data access provided to patients, which was mainly in the form of feedback to provide guidance. The focus of data provision has been to prescribe tasks and guide patients to perform movements rather than to allow patients to access and make sense of their own performance data. This represents a missed opportunity from the literature to engage poststroke patients in their own health care, as it has been shown that when patients have direct access to their PGHD they become more engaged and improve their health outcomes [7,9,10,73]. The lack of patient access to data also suggests that patient-centered design was not part of developing these Kinect-based systems [74], a key consideration in a

modern participatory health paradigm. This factor could overlook PGHD and undermine the rehabilitation experience of patients [75].

The use of data overwhelmingly for technological development and assessment is clearly shown by 78% (32/41) of papers having a technical primary objective. Even if we acknowledge that it is necessary to assess the accuracy and reliability of Kinect-based systems, this technical focus confirms the finding of Webster et al [26] that this field of rehabilitation is still in its infancy. This presents an opportunity and challenge to evaluate clinical outcomes [25-27] (eg, effectiveness and safety of such systems), a challenge that only a few papers have taken up [36-39,49,50,57,71,72].

The focus of existing K-SRS papers was on upper extremities. It is interesting that while Kinect has the ability to track the whole body, only upper extremity software is described [25]. None of the papers in this review used lower extremity outcome measures.

Results of this review show that there is insufficient attention given to PGHD from K-SRS. While most studies provide some form of feedback, they do not allow patients to actively engage with data about their own rehabilitation, nor do the papers try to understand the health behavior impact of providing data access to patients.

Limitations

While most papers described the data types collected in their papers and available feedback, often they were glossed over in the descriptions and discussion. As mentioned previously, this shows a lack of attention to PGHD and to health data management generally in K-SRS papers. The lack of documentation may also have limited the details into PGHD this review gathered (ie, some other benefit of PGHD may have occurred but was not documented or described). As such, while this review attempted to provide a snapshot of the PGHD types, access, and benefits, it may be incomplete. In short the lack of attention given to PGHD in the papers confirms the need for papers to pay attention to the PGHD of their K-SRS but also limits the PGHD evidence obtained. Due to time constraints, the authors of the papers reviewed were not directly contacted for more information on the PGHD they have given patients.

With regard to patients recruited, the majority of patients had infarct or ischemic type of stroke, and patients were not separated based on their stroke type. Given that there is some evidence that hemorrhagic patients benefit from rehabilitative therapies faster than infarct and ischemic patients [76], this could produce some stroke-type bias in the effectiveness results, where results derived largely from infarct patients are generalized for hemorrhagic patients as well.

Conclusions

Reviewing current K-SRS literature through the lens of PGHD showed that there is a significant gap in our understanding of what it may contribute to the experience of patients who use K-SRS. Most papers provide some feedback but do not allow patients to engage with all of their PGHD (eg, for self-management of their health journey). This provides further evidence of the need for studies that contribute to the theoretical foundation of PGHD use [1]. It is also indicative of the need for future researchers of technology-based rehabilitation to consider PGHD and patient access to information in their system design and implementation. Improving our understanding of the effects of using PGHD could help in designing systems where the benefits of PGHD access are made available to patients. This paper calls for future studies on K-SRS—and studies that have the potential for generating patient health data in general—to pay more attention to how those data may influence the process of care.

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Conflicts of Interest

None declared.

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Abbreviations

K-SRS: Kinect-based stroke rehabilitation systems

PGHD: person-generated health data

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

1.4 Significance of the Thesis and Research Questions

The preceding published review shed light on the lack of evidence-based reporting around the effects of PGHD use on stroke survivors; with only one paper describing one survivor's increased motivation to improve therapy performance after accessing their PGHD. Moreover, the types of outcome measures used in evaluating the range of Kinect-based stroke rehabilitation systems (K-SRS), the limited PGHD access provided to stroke survivors, and the mostly technical use of PGHD all point to the dearth of studies assessing the clinical impact on stroke survivors as a result of accessing and utilising their PGHD, a significant gap in the health informatics literature. It also underlines the lack of participation by survivors in the design, implementation, and evaluation of K-SRS that produce PGHD. This is a key consideration in a modern participatory health paradigm that could overlook PGHD and thus undermine the rehabilitation experience of stroke survivors [50].

HITs often suffer from disconnected research, development, and assessment activities, which occurs due to the lack of a systematic, consistent feedback process [51]. Designing useful, effective systems requires concurrent understanding of problems and their solutions [51]. Thus, it is necessary for HIT management to include a systematic and iterative 'build-and-evaluate loop' that enables users to participate in a HIT's design and evaluation [52]. In design science for HIT, this loop refers to the integration of inputs or decisions made about HIT design and the intended health outcomes using participatory or user-centred methods [51], a key responsibility of health informatics research [53].

The rising popularity and ubiquity of HITs that produce PGHD [4], the varying reported effects of PGHD utilisation [3, 11, 54-57], and the need to engage people in the design and evaluation of HITs make it imperative to increase the evidence base about outcomes from the practical use of PGHD technologies.

Thus, the objective of this thesis is to design a framework that enables PGHD users to routinely report standard measures of how PGHD utilisation may affect them.

To fulfill this objective, the overarching research question is posed: How could users' reporting of PGHD effects be standardised, for any given PGHD technology and health condition?

To answer the research question, the following secondary research questions are posed, below. The chapters that correspond with each question are indicated (Table 2).

i. What evidence is reported in the literature on the effects of PGHD utilisation? (Chapter 1)
ii. How may we develop a systematic measurement of PGHD utilisation effects? (Chapter 2, Chapter 3, Chapter 7)
iii. What perceptions and perspectives do PGHD users and clinicians report about the effects of PGHD utilisation in the case of K-SRS? (Chapter 4, Chapter 5)
iv. How can we translate the insights gained from eliciting input from PGHD users and clinicians regarding PGHD utilisation effects, to improve the way we design and evaluate PGHD technologies? (Chapter 6)
v. How can we make the process of developing a systematic measurement of PGHD utilisation effects generalisable for people with different health conditions, using other PGHD technologies? (Chapter 7)

Table 2. The secondary questions mapped with chapters in this thesis that correspond to them

Chapters	**Secondary Questions**				
	i	**ii**	**iii**	**iv**	**v**
Chapter 1	x				
Chapter 2		x			
Chapter 3		x			
Chapter 4			x		
Chapter 5			x		
Chapter 6				x	
Chapter 7		x			x

1.5 Overview of the Remainder of this Thesis

This thesis consists of six further chapters. In all, the thesis includes 6 peer-reviewed publications and 10 appendices. This section presents an overview of the following chapters, also illustrated in Figure 6.

Chapter 2 describes the research design of the thesis. It describes the selection of the interpretivist paradigm within which this thesis is conducted and the qualitative method followed. It discusses the selection of a type of patient-reported measure to develop following a qualitative method. It then presents a peer-reviewed publication, which argues that among the different types of patient-reported measures, a patient-reported outcome measure is needed to help build evidence about PGHD utilisation effects. The publication presents a 5-step qualitative method designed for this thesis, to develop a PROM of utilising PGHD, called the PROM-PGHD Development Method. The method is designed for the exemplar case of a range of simulated stroke rehabilitation technologies, and built on existing PROM development best practice. The chapter also describes how the data collection and analysis for the qualitative activities of the method are conducted. The application of the Method's first three steps is presented through a peer-reviewed publication in **Chapter 3**. In Step 1, the peer-reviewed, published literature review (Section 1.3.2) identified existing patient-reported measures within the simulated rehabilitation technology category, and the health condition stroke. In Step 2, individual measure items from Step 1 were assessed for inclusion to the preliminary PROM-PGHD, and categorised. In Step 3, the retained measure items from the previous step were revised, where necessary, for appropriateness to the target health condition and technology category, and for clarity and item independence. Some items were also revised to test additional response types, to allow stroke survivors to comment on in the next step of the development process. This chapter results in a preliminary PROM-PGHD item bank.

With the goal of improving the preliminary PROM-PGHD item bank, **Chapter 4** presents a peer-reviewed publication reporting on 1 of 3 studies conducted as part of the application of Step 4 of the PROM-PGHD Development Method. In this step, the input of people with the

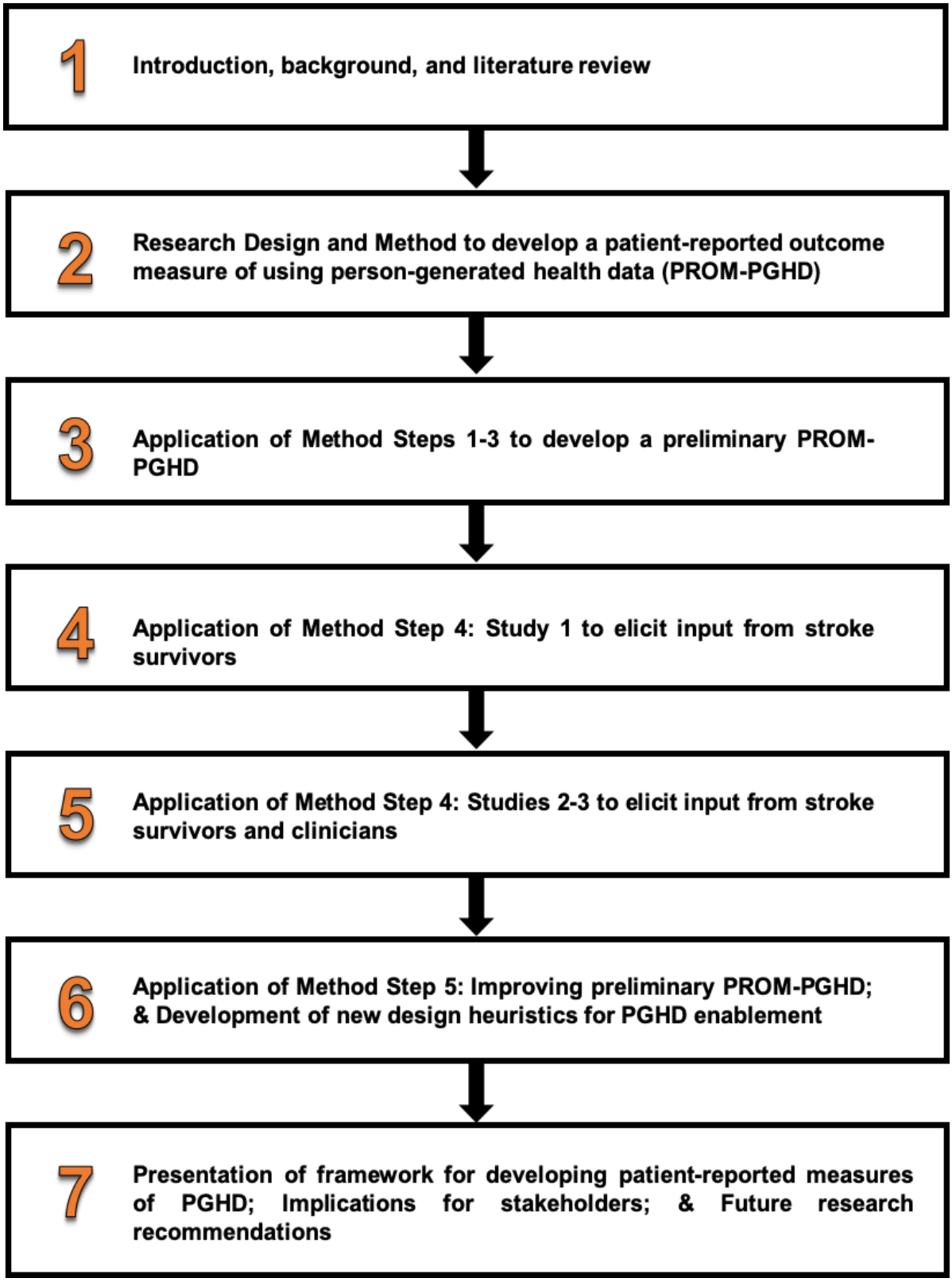
case health condition is elicited through discussions held with stroke survivors. The survivors have previously used a case simulated stroke rehabilitation system called Jintronix as part of a randomised controlled trial. The findings showed that outcomes of utilising PGHD can be measured, and provided a deeper understanding of PGHD utilisation effects and broadened their scope. Step 4 of the PROM-PGHD Development Method is continued in **Chapter 5**. A peer-reviewed publication is presented, reporting on the remaining 2 of 3 studies. In one study, stroke survivors who have voluntarily used Jintronix as an outpatient in a rehabilitation service were recruited. In the other study, participants were stroke survivors and physiotherapists who participated in a demonstration of Jintronix. The studies' findings further demonstrated that outcomes of utilising PGHD can be measured as well as highlighting the varying perspectives that stroke survivors and clinicians could have about certain aspects of health and the care process. The findings from these chapters were later used in Step 5 of the PROM-PGHD Development Method (Chapter 6, Section 6.1) to further refine and validate the preliminary PROM-PGHD item bank.

The insights and findings gained from the studies were consolidated in **Chapter 6** to improve the preliminary PROM-PGHD item bank. In applying Step 5 of the PROM-PGHD Development Method for this thesis, the preliminary PROM-PGHD item bank was revised based on the input from stroke survivors and clinicians, gathered in the previous step (Chapter 4, Chapter 5). They were also revised to ensure that the items were worded appropriately and reflected levels of an effect or outcome, and for clarity, consistency and accuracy. New PGHD utilisation effects that were identified after analysis were added into the PROM-PGHD item bank. Finally, the item bank was run through Lexile Analyzer®, which confirmed that it was within the average reading level of stroke survivors.

In order to contribute to the need for a 'build-and-evaluate loop' to integrate inputs or decisions made about HIT design and the intended health outcomes using participatory or user-centred methods [51], this chapter presents a peer-reviewed publication, describing the development of a new set of design heuristics for the design and evaluation of how well remote therapeutic technologies enable people to use PGHD. Eight new heuristics for PGHD enablement were created. A systematic and detailed process was applied in each step of heuristic development, which could aid future developers of specialised heuristics.

The thesis culminates in **Chapter 7** with a synthesis of thesis chapters and research findings, which proceeds to present the resulting framework for developing types of patient-reported measures of utilising PGHD, illustrated through a figure showing the process (Figure 14). It discusses the implications, challenges, and recommendations of the key thesis research concepts (PGHD, participatory health informatics, patient-reported measures, design and evaluation of PGHD technologies) as they relate to stakeholders (PGHD users, clinicians, health informatics researchers, and health information technology developers). Finally, this chapter provides recommendations for future research, in particular applying the framework to other case health information technologies, and PROM-PGHD and simulated rehabilitation technologies in low-resource environments.

Figure 6. Overview of the thesis.



2 Research Design

The objective of the research is to design a framework to systematically measure the effects on people who utilise their PGHD, through a method that enables them to participate in the development and the measurement. Thus, it is essential that this research develops understanding of those effects from people's own lived experience. As such, this research is conducted within the Interpretivist research paradigm.

2.1 Selection of the Interpretivist Paradigm

The Interpretivist paradigm derives meaning from social action primarily from the perspective of people taking the action, and the context in which they live [58]. It seeks to understand the world for what it is subjectively, and generate a framework of meaning from the perspective of the participants, rather than from an observer. Studies following this paradigm benefit from developing knowledge that is appropriate for and aligns with the perspectives of participants [59].

In contrast, the Positivist paradigm, popular within health research, seeks to discover scientific laws through an objective observation of the natural world. It considers participants, and their bodies, as entities and objects for research from which information is collected and evidence assessed [58, 60]. A Positivist stance that takes an objective, external position from the research subjects would not be as insightful in developing a deep understanding of the choices that people make, based on their individual contexts and experiences [58]. In Information Systems research, the Positivist paradigm has also been shown to be insufficient in showing the richness of the continued interaction of people with technologies [61].

Only an Interpretivist stance can capture the subjective responses of people, beyond specific data points that may not adequately represent people's experiences [59].

2.2 Selection of the Qualitative Method Followed

Following an Interpretivist approach requires the research to utilise naturalistic methods, i.e., interviews, observations, and textual analysis. Such methods ensure that researchers hold

dialogues with the target group of interest, to capture and construct a meaningful reality in a collaborative way. Relevant themes or meanings then emerge from the research process [62].

This research aims to design a framework that enables PGHD users to routinely report standard measures of how PGHD utilisation may affect them. Instruments enabling people to participate in the evaluation of their own health outcomes or experiences, developed using qualitative methods, already exist. Standardised patient-reported measures (PRMs) enable people to contribute to more precise evaluation of the effects of a variety of health interventions, and their contribution to improving the evidence base in many areas of clinical care is well recognised [63]. Such measures allow for the evaluation of people's health status as well as outcomes from and experiences of health care services and interventions, from their own perspective.

Gathering the perspectives of PGHD users is particularly important since people are increasingly shifting towards taking more initiative and responsibility for their health and wellbeing [64, 65], with significant implications for health informatics research [65]. Largely driven by people, or patients themselves and aided by the rising ubiquity of PGHD technologies, this shift enables them to self-manage their health and contribute to making national health systems more sustainable and efficient [64]. However in order for this shift towards collaborative health to be successful, there needs to be an increase in shared information, accountability, and engagement between patients and clinicians [64], and active patient engagement and partnership can be achieved through patient participation [66].

The following sections describe different types of PRMs.

2.3 Selection of a Patient-Reported Measure to Develop Following a Qualitative Method

PRMs systematically gather data reported by patients about their health, or their experience of health care services [67]. These types of data include patient health outcomes, experiences, and health care accounts as narratives or comments. They are self-reported by patients using distinct types of standardised PRMs [67], described in the following sub-sections.

2.3.1 Patient-Reported Measures of Satisfaction

Evaluating different patient experiences such as levels of satisfaction has a long history in healthcare [68]. Evaluating satisfaction involves assessing patient satisfaction with care settings, services, and systems within their care pathway, from assessment to treatment [69]. Patients self-rate their satisfaction with a health care provider [70] using indicators such as coordinated care, timeliness of treatment, and communication [69]. Such patient-reported measures of satisfaction assist health care providers in improving patient services and systems for improved outcomes [68, 69]. Increasing satisfaction could improve patient adherence to treatment regimens, promote well-being, and lead to increased financial viability of health care providers due to patient preference for their services [71].

A key limitation of measuring patient satisfaction is the inconsistent definition of satisfaction itself. This results in a lack of consensus on which indicators or domains are most important [70]. Moreover, patients' evaluation of their satisfaction could be quite strongly affected by factors outside the control of health care providers [68]; such as patient preferences, expectations, personal characteristics, cultural norms, and health status [70]. An additional limitation is that measures of patient satisfaction have usually been developed following the priorities of the managers or the clinicians, and not those of the patients [70]. Moreover, because the measures only gather patients' ratings of existing aspects of a health care service, e.g., waiting times and interpersonal communication [69, 71], they are not able to specifically indicate what service improvements might potentially be introduced. The value of such measures has therefore been limited [70].

Patient-Reported Experience Measures are suggested to complement, and supplement the limitations of patient satisfaction measures, by providing more specific information about the patient experience [68].

2.3.2 Patient-Reported Experience Measures

Patient-Reported Experience Measures (PREMs) ask patients to describe in more detail their experiences of a health care service, system, or setting [70]. Patients may also be asked to report the context of those experiences, such as the time period and setting [70]. As such,

PREMs are capable of gathering more specific information and guide the introduction of quality improvements [68].

PREMs could provide better insight into the patient experience, and may additionally describe factors that contributed to that experience. They are able to gather more factual information about events in patients' care pathway, are less affected by patient expectations and personal characteristics, and contribute to a better understanding of the service. These allow service providers to respond more specifically to quality improvement demands [70].

PREMs complement patient satisfaction measures, and utilising both such measures allows for the identification of aspects that highly influence patients' experiences [68]. However, both measures are not able to specifically indicate health status or effects resulting from those experiences. Assessing health status or effects for clinical assessment of a health care service, treatment, or experience requires a distinct type of PRM, called Patient-Reported Outcome Measure (PROM) [68, 70].

2.3.3 Patient-Reported Outcome Measures

PROMs are instruments that enable patients to independently self-report their health condition status, and experience with an illness or treatment [68, 72-74]. They enable patients to self-report outcomes of a health care service such as from an intervention, or their health status such as symptoms [68, 72]. PROMs are important in understanding what difference health care modalities may have on the status and quality of life of patients [73], and are thus useful in guiding best clinical practices. PROMs may be distinctly categorised according to their breadth of measurement. Generic PROMs measure common aspects of patients' health or QoL. They enable patients to self-report a single health concept such as pain, or multiple dimensions such as physical, social, or sexual functioning [75]. Condition-specific PROMs may measure patient outcomes in relation to a health diagnostic domain (such as mental health and illness), or in relation to a health therapy domain (such as a physical rehabilitation programme) [75]. Meanwhile, disease-specific PROMs measure health aspects of patients with a particular disease or condition (such as a specific cancer) [72, 75]. They gather more detailed information of a patient's disease status, from treatment to recovery [75].

PROMs may help determine the cost-effectiveness of different treatments for different health conditions, and thus may also aid in resource allocation [75]. For instance, the European QoL-5D, a generic quality of life PROM, may be used to measure dimensions of a patient's health and produce health values. These health values may then be used as a metric for how interventions have improved the QoL of patients [75, 76]. When incorporated into assessment of performance and effectiveness of care provision, it may potentially enable the shift from a volume-based model in health resource management to one that is value-based [73].

Moreover, PROMs may contribute in developing government policies [75] due to their utility in generating first-hand evidence of the impact of health care services that are able to reflect the real world diversity of actual patients and management approaches [77, 78]. PROM data, whether disease- or condition-specific, are increasingly being added into clinical registries to track health outcomes over a longer period of time than randomised controlled trials. This allows for longitudinal assessments of health care services [77]. The U.S. Food and Drug Administration suggests using PROMs to test the health effects of a product, and support claims made in medical product labeling [72].

Data collected from distinct PROMs may also be aggregated. Called Patient-Reported Outcomes Performance Measurement (PRO-PM), PRO-PMs interpret aggregated PROM data to better reflect performance, further promoting accountability of a health care entity [79]. Data from PRO-PMs could be routinely collected from patients throughout their care pathway in a hospital or health service [75]. They aid clinicians in managing symptoms better and understanding where they could improve, and could guide in identifying educational needs for health systems. They may also provide patients with a better understanding of which health service would help with better managing their health [79].

Additionally, PROMs may be used complementarily as a set with other types of measures to assess health conditions under particular situations; such as monitoring patients with dementia in community care settings [75]. Such sets of PROMs are called outcome measurement suites, and are essentially groups of items from PROMs, clinical-based outcome

measures, and other patient and treatment data [76]. For example, the International Consortium for Health Outcomes Measurement (http://www.ichom.org) standard set for dementia brings together PROMs to measure outcomes across the care cycle; from symptoms, functioning and quality of life to disease progression and overall survival. They include QoL PROMs, clinician-reported outcomes, and other clinical data to track overall patient survival [80].

The next section presents a peer-reviewed publication that discusses the selection and development of a type of PRM of utilising PGHD.

2.4 Designing a Method to Develop a Patient-Reported Outcome Measure of Utilising Person-Generated Health Data (peer-reviewed publication)

Chapter 1 has shown that there is no existing measure of PGHD utilisation effects in the literature, establishing the need to develop a type of PRM of utilising PGHD, which could enable PGHD users to routinely and systematically report how access and use of their PGHD affects them. This section contains a peer-reviewed publication that argues the need for a PROM of utilising PGHD, or PROM-PGHD, to help build evidence-based practice in clinical work with PGHD. The key difference between PREMs and PROMs is that the former, along with patient satisfaction measures, assesses patients' experiences of the care process. Meanwhile PROMs measure patients' self-reported health status, and health outcomes of a care service or intervention. In fact, some aspects of patient satisfaction may be considered an outcome that patients can self-report in a PROM, such as satisfaction with their health status post-intervention [70].

The publication presents a method for developing PROMs for people who are using PGHD in conjunction with their clinical care, illustrated through the exemplar case of a range of stroke rehabilitation systems. The method builds on existing PROM development best practice, rather than attempting to develop a PROM-PGHD from scratch. The worked example presented as the results in the publication are mapped to relevant chapters and sections of this thesis in Table 3:

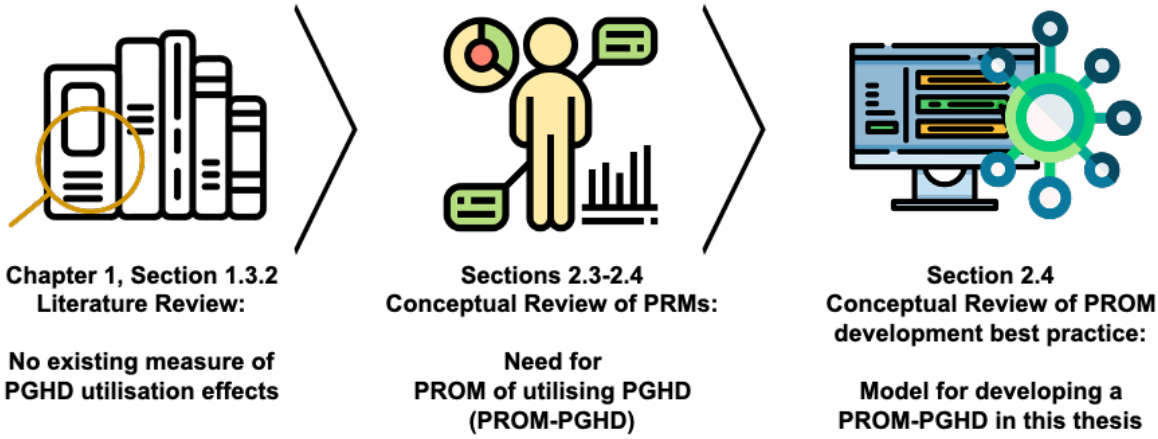
Table 3. PROM-PGHD method steps mapped to chapters and sections of thesis

Steps of the PROM-PGHD Development Method	Chapters/Sections of this Thesis
Step 1: Literature Review	Chapter 1, Section 1.3.2: Literature Review (peer-reviewed publication)
Analysis of Step 1 Step 2: Binning and Winnowing Step 3: Initial Item Revision	Chapter 3: Development of a PROM of Utilising PGHD: Preliminary Item Bank (peer-reviewed publication)
Step 4: Eliciting Patient Input	Chapter 4: Eliciting Stroke Survivors' Perceptions on the Effects of Utilising PGHD (peer-reviewed publication)
	Chapter 5: Varying Perspectives of Stroke Survivors and Clinicians on the Effects of Utilising PGHD (peer-reviewed publication)
Step 5: Final Item Revision	Chapter 6, Section 6.1: Improving the Patient-Reported Outcome Measure of Utilising Person-Generated Health Data Preliminary Item Bank

The peer-reviewed publication synthesises existing best practice PROM development processes to identify one that could serve as the basis for developing a PROM-PGHD. This activity is essential given the lack of an established framework for the development of PROMs [75]. Involving people with the case health condition in the development process is generally considered essential [72, 81, 82], with nearly three-quarters of PROM-development papers including them during the process [83]; however there is a lack of consensus on when and how they should be involved throughout PROM development [83]. Nonetheless, the similarities between the best practices described in the literature enabled the author to identify generally accepted elements in the PROM development process.

Figure 7 illustrates the link between key review results in this thesis that formed the basis for designing a method for developing a PROM-PGHD.

Figure 7. Key review results as basis for designing a method for developing a PROM-PGHD.



This is a peer-reviewed publication, appearing in JMIR Research Protocols (doi:10.2196/16827). The accepted version of the article is presented here, ready for examination following university guidelines for thesis with publications. To see the individual contribution of the authors, please see the Preface.

Any figures and tables that appear in this published manuscript have been renumbered for the purpose of this thesis.

Patient-Reported Outcome Measures of Utilizing Person-Generated Health Data in the Case of Simulated Stroke Rehabilitation: Development Method

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Abstract

Background: Person-generated health data (PGHD) are health data that people generate, record, and analyze for themselves. Although the health benefits of PGHD use have been reported, there is no systematic way for patients to measure and report the health effects they experience from using their PGHD. Patient-reported outcome measures (PROMs) allow patients to systematically self-report their outcomes of a health care service. They generate first-hand evidence of the impact of health care services and are able to reflect the real-world diversity of actual patients and management approaches. Therefore, this paper argues that a PROM of utilizing PGHD, or PROM-PGHD, is necessary to help build evidence-based practice in clinical work with PGHD.

Objective: This paper aims to describe a method for developing PROMs for people who are using PGHD in conjunction with their clinical care—PROM-PGHD, and the method is illustrated through a case study.

Methods: The five-step qualitative item review (QIR) method was augmented to guide the development of a PROM-PGHD. However, using QIR as a guide to develop a PROM-PGHD requires additional socio-technical consideration of the PGHD and the health technologies from which they are produced. Therefore, the QIR method is augmented for developing a PROM-PGHD, resulting in the PROM-PGHD development method.

Results: A worked example was used to illustrate how the PROM-PGHD development method may be used systematically to develop PROMs applicable across a range of PGHD technology types used in relation to various health conditions.

Conclusions: This paper describes and illustrates a method for developing a PROM-PGHD, which may be applied to many different cases of health conditions and technology categories. When applied to other cases of health conditions and technology categories, the method could have broad relevance for evidence-based practice in clinical work with PGHD.

Introduction

Understanding the Effects of Person-Generated Health Data

Person- or patient-generated health data (PGHD) are health, wellness, and other biometric data that people generate, record, and analyze for themselves [1]. Examples of technologies that support PGHD include Web-based journaling tools, activity-tracking devices or mobile apps, networked health data–gathering devices such as weighing scales, and simulated rehabilitation technologies. Patients who use PGHD-enabled technologies may experience positive, negative, or nil effects.

PGHD use has been reported to increase patients' interest in their own health care processes [2-4] and the management of their own health status [5]. It is known that when patients

understand their illness, they may become active problem solvers and improve their health behavior [6]. However, PGHD use can also cause feelings of frustration and discouragement [7], and may even make some patients feel excluded from the benefits of PGHD use [5].
Although such varying health effects of PGHD use have been reported for a variety of health conditions and technology types, there is no systematic way for patients to measure and report health effects that they experience from utilizing their PGHD—whether positive, negative, or nil. This may hamper the integration of PGHD into clinical workflows [1]. In addition, PGHD technologies may be designed to support clinicians' utilization of these data at the expense of functionality that supports patients to use their data for self-management and shared decision making [8]. Thus, it is necessary to consider the patient's perspective in the design and development of health technologies [9], particularly those that generate PGHD [8].

Patient-Reported Outcome Measures

In health care services and interventions in general, the measurement of effects on patients, by patients themselves, is not new. Patient-reported outcomes are self-reported status updates of a patient's health condition, experience with an illness, or treatment without additional interpretation of the report, for example, by clinicians [10-12]. They may be used to indicate health status, such as state of a disease, at a single point in time, and any changes over time from previous patient-reported outcomes [10,13].

Standardized instruments that measure patient-reported outcomes, Patient-Reported Outcome Measures (PROMs) contribute to a more precise evaluation of the effects of a variety of health interventions and improve the evidence base in many areas of clinical care [14,15]. PROMs are used to determine the effectiveness of health care practices and to set standards for health care providers' performance, and their importance is highlighted by several national projects [15,16].

PROMs are developed systematically [10,11,13], and this formalism makes PROMs valuable to complement clinician-reported outcome measures used in reporting as part of standardized treatment assessments, such as clinician assessments of patient health, health

outcome indicators collected routinely by health care organizations, and physiological or other biomedical indicators [15]. Their utility in generating first-hand evidence of the impact of health care services enables them to reflect the real-world diversity of actual patients and management approaches [17,18]. Thus, PROMs may provide a more comprehensive and accurate assessment of patient outcomes and the effectiveness of health care services and interventions [11,15,19,20].

Patient-Reported Outcome Measures of Utilizing Person-Generated Health Data

A systematic way for patients to measure and self-report the health effects they experience from utilizing their PGHD is lacking. A PROM of utilizing PGHD, or PROM-PGHD, is necessary to help build evidence-based practice (EBP) in clinical work with PGHD. Measuring outcomes of PGHD utilization using PROMs has been suggested [21]. Patient participation is considered essential in developing PROMs [10,22,23], with nearly three-quarters of PROM-development papers including patients during the process [24]. Given PGHD's person- or patient-centric approach to health data, it is useful and appropriate to involve patients in developing a standard way of using PROMs to capture the effects of PGHD. The participatory health paradigm recognizes the value of having patients contribute to the creation of knowledge in such ways [25].

PROMs-PGHD may deepen our understanding of how PGHD impact the health status and quality of life of patients, in an era of mobile and wearable remote patient monitoring [26]. PROMs-PGHD could also be used as a complement to existing clinician-reported and patient-reported outcomes, similar to how many PROMs are used alongside other health outcome indicators [15]. While many PROMs allow patients to report outcomes that correlate with their quantifiable PGHD [26], specific PROMs-PGHD would allow more direct self-reporting of the effects on patient health of utilizing PGHD. PROMs-PGHD could contribute to a more holistic and accurate assessment of whether and how patients' use of PGHD from health self-monitoring technologies actually has health benefits. This would provide a triangulated measurement of patients' experiences and outcomes resulting from their use of health information technology.

Objective

The aim of this paper was to describe and illustrate a method for developing PROMs for people who are utilizing PGHD in conjunction with their clinical care—PROM-PGHD.

Methods

The aim of this paper was to describe and illustrate a method for developing PROMs for people who are utilizing PGHD in conjunction with their clinical care—PROM-PGHD.

Patient-Reported Outcome Measure Development Practices

PROMs are developed in many different ways, but generally accepted elements in the process can be discerned [15]. Reviewing recognized methods for PROM development (Table 4; *published Table 1*) and their commonalities put into context the selection of a particular method to guide PROM-PGHD development.

Table 4. Patient-reported outcome measure (PROM) development: the best practice activities

#	Phases (review paper [23])	Steps (US Food and Drug Administration Guide [10])	Stages (Scientific Advisory Committee of the Medical Outcomes Trust [21,22,26])
1	Establish correct health outcomes to measure	Hypothesize conceptual framework • Concepts hypothesized • Target population and application of the PROM identified • Literature or expert review conducted	Conceptual model for the PROM and its Initial Items are developed • Includes literature review to identify existing PROMs within the target domain • Interviews and/or focus groups with the target population, condition, or disease

			• Identification of relevant areas as a basis for PROM development • Pilot testing of initial PROM items on a small cohort of patients
2	Develop PROM items	Adjust conceptual framework and draft instrument • Patient input obtained • New PROM items generated • Method of data collection/administration determined • PROM draft items pilot tested	Revised PROM items from stage I are field-tested on a larger cohort of patients • Results in further item revisions to improve item validity • Reductions to eliminate redundancy, endorse- ment frequency, and absent data
3	Test the PROM items on comprehensibility and a range of psychometric criteria, for example, ac- ceptability, internal con- sistency, and reliability	Confirm conceptual framework and assess other measurement properties • Developed conceptual framework confirmed via a scoring rule • PROM items assessed using psychometric criteria and finalized for content and format	Psychometric field-testing of the PROM being developed • Resulting PROM administered to a large cohort of patients and tested based on a psychometric criterion, for example, acceptability, internal consistency, and reliability

4	N/A	Collect, analyze, and interpret data • Protocol and statistical plan for PROM data collec- tion and analysis developed • Product treatment responses evaluated and benefits interpreted	N/A
5	N/A	Modify instrument • PROM items revised again using psychometric cri- teria • PROM items translated and adapted culturally for multiple languages; this fifth step then leads back iteratively to the first step	N/A

We found a scoping review of 189 PROM development papers from 1980 to 2014 that outlined the development processes of 193 PROMs retrieved from the PubMed, Cochrane Methodology, MEDLINE, and EMBASE databases [24]. This review noted that PROM development follows three broad, distinct phases, as shown in Table 4, although the review paper itself provided limited information on those phases. One of the included papers was the highly cited US Food and Drug Administration (FDA) industry guide to use PROMs for medical product labeling [10]. Many of the suggested activities in its first three steps align

with the three phases described in the review paper [24]. However, the FDA guide suggests a more detailed, 5-step iterative process for developing PROMs [10], as shown in Table 4.

Another highly cited guide for PROM development, not included in the review paper, is that of the Scientific Advisory Committee (SAC) of the Medical Outcomes Trust [22]. This defines a set of attributes for developing and assessing instruments for measuring health status and quality of life, and recommends a 3-stage process for developing PROMs [23,27], as shown in Table 4.

We observed that the steps of the FDA guide [10] align with many of the activities outlined by the SAC [23,27], and consequently both align with the three phases described in the review paper (Table 5; *published Table 2*) [24]. This indicated consensus on the best practice in PROM development and gave us an understanding of what the developers of a PROM-PGHD must do so as to adhere to the best practice.

Table 5. Parallels between patient-reported outcome measure (PROM) development processes in the literature

Phases (review paper [23]) and steps (US Food and Drug Administration Guide [10])	Stages (Scientific Advisory Committee of the Medical Outcomes Trust [21,26])
Phase 1: Establish correct health outcomes to measure	
Step 1: Hypothesize conceptual framework	Stage I: Conceptual model for the PROM and its initial items are developed
Phase 2: Develop PROM items	
Step 2: Adjust conceptual framework and draft instrument	Stage I: Conceptual model for the PROM and its initial items are developed
Phase 3: Test the PROM items on comprehensibility and a range of psychometric criteria	
Step 3: Confirm conceptual framework and assess other measurement properties	Stage III: Psychometric field-testing of the PROM being developed

Step 4: Collect, analyze, and interpret data	Stage III: Psychometric field-testing of the PROM being developed
Step 5: Modify instrument	All stages: PROM item revision activities
Iteration back to Step 1, with further testing	Stage II: Revised PROM items from Stage I are field-tested on a larger cohort of patients

Qualitative Item Review

The systematic QIR process was designed to develop PROM items for the Patient Reported Outcomes Measurement Information System (PROMIS), a US National Institutes of Health initiative to provide a PROMs infrastructure for clinical research and practice [15,16]. QIR was intended to identify and develop items that could precisely estimate the traits being measured, and to represent the range of experiences relevant to the domains of interest. QIR is based on the best practices of PROM development and is committed to involving patients in the process, as described below. All of these factors make it suitable as a foundation for developing a PROM-PGHD.

PROM development falls within the participatory health paradigm, as the patient's perspective is central to the value of PROMs [14]. Thus, patient participation should be deliberate in the development of a PROM-PGHD. QIR was developed with a commitment to involving patients, with a reference to the recommendation in the FDA guide [10]. It specifically suggests when and how patients are included in the development process. It also examines how patient perspectives influence the concepts measured and the items constructed, and aims to bridge gaps between them. Moreover, it gathers patient input to increase the suitability of the items so that they reflect patient experiences closely, facilitating the correct understanding and interpretation of patients' responses to the items [16]. QIR provides the necessary attention to patient participation to make it a sound choice as a method for developing a PROM-PGHD.

QIR was specifically designed to optimize a set of PROM items in preparation for field testing. It was meant to develop an initial set of PROM items qualitatively and revise them by eliciting patient participation. Quantitative field testing, for example, using psychometric criteria, may then follow QIR, according to good practice guidelines [16].

Comparing QIR with the PROM development process described in the literature reveals that it closely aligns with early stage qualitative activities, that is, Stage I of the process suggested by the SAC [22], and thus with phases/steps 1 and 2 of the review paper [24] and FDA guide [10]. The QIR steps are summarized in Table 6 (*published Table 3*).

Table 6. Activities of the qualitative item review

#	Step name	Activities
1	Literature review to identify existing items	Scan literature around established PROMsa within target domain/s; it will guide building proposed outcome measure items. Items identified represent the range of domain-relevant experiences.
2	Binning and winnowing	Binning involves categorizing selected items according to meaning and intrinsic structure. Winnowing excludes items that do not fit target domains and characteristics of PROM being developed.
3	Item revision process	Retained items are appropriately revised to ensure they are independent, have similar contexts, concise and simple, and worded to encourage the use of available response options to reduce cognitive burden on respondents.
4	Focus groups and cognitive interviews with target patient cohort	It ensures patient input is elicited in the development of PROM item sets. It enables PROM designers to un- derstand vocabulary and thinking processes of target group and gathers feedback on individual items. It is aimed to bridge relevant gaps between current items and target domain or concepts to be measured. It highlights other measurement areas expressed by patients that are not covered in initial item set.

5	Final item revisions	Items are revised again based on patient input gathered from previous step. Items are tested with the Lexile Analyzer® (MetaMetrics, Inc) to assess readability. After revisions are completed, field testing on items may begin, to understand their quantitative characteristics.

Augmenting the Qualitative Item Review Process for the Socio-Technical Context of Person-Generated Health Data

The development of a PROM-PGHD requires socio-technical consideration of PGHD and the health technologies from which they are produced. Health-related activities of patients are influenced by the social and health context of the patient and their family and community [28]. This contributes to the complexity of what is known as the socio-technical system in health care, referring to the social system that influences and is influenced by implementations of technical systems. Thus, a socio-technical approach to health informatics interventions is crucial [29]. The health tools and technologies that patients use are most effective if they align with the patients' goals for completing health-related activities within the context of their health conditions. Moreover, health information technology interventions need to be responsive to the biomedical realities and personal characteristics of the target patient population [28].

Therefore, in developing a PROM-PGHD, it is important to recognize two domains influencing the outcome to be measured [30,31]: the health condition and the technology category. The evaluation of PGHD's role in self-management and clinical care should draw upon the body of knowledge from both domains [32]. There are different possible effects on health conditions in patients who use data from a web portal, a smart phone app, or a wearable sensor, just as there are different possible health effects of using data from a smartphone app in patients with diabetes, a mental illness, or asthma [1]. This is an important consideration, as the value of a PROM is dependent on its appropriateness based on the needs of the patient population [33].

Our development also factored in a key difference between the objectives of the PROMIS initiative for which the QIR was designed and the objective of PROM-PGHD. The PROMIS initiative's item banks, that is, PROM item sets, were developed to capture patient-reported outcomes from mainstream interventions, in particular health conditions, for example, chronic diseases [16]. Meanwhile, PROM-PGHD items are meant to capture patient-reported outcomes of accessing and utilizing PGHD they themselves have produced with various types of health technology in relation to a particular health condition.

An important consideration of this socio-technical approach is that when it comes to the technology category, outcome measures may extend beyond traditional PROMs of the health condition to include self-reported measures that capture the effects of a patient's interaction with their data, as this interactivity is designed into a type of technology. Thus, we augmented the QIR process of developing PROMs to consider both the health condition and the technology category for which a PROM-PGHD is being developed.

Results

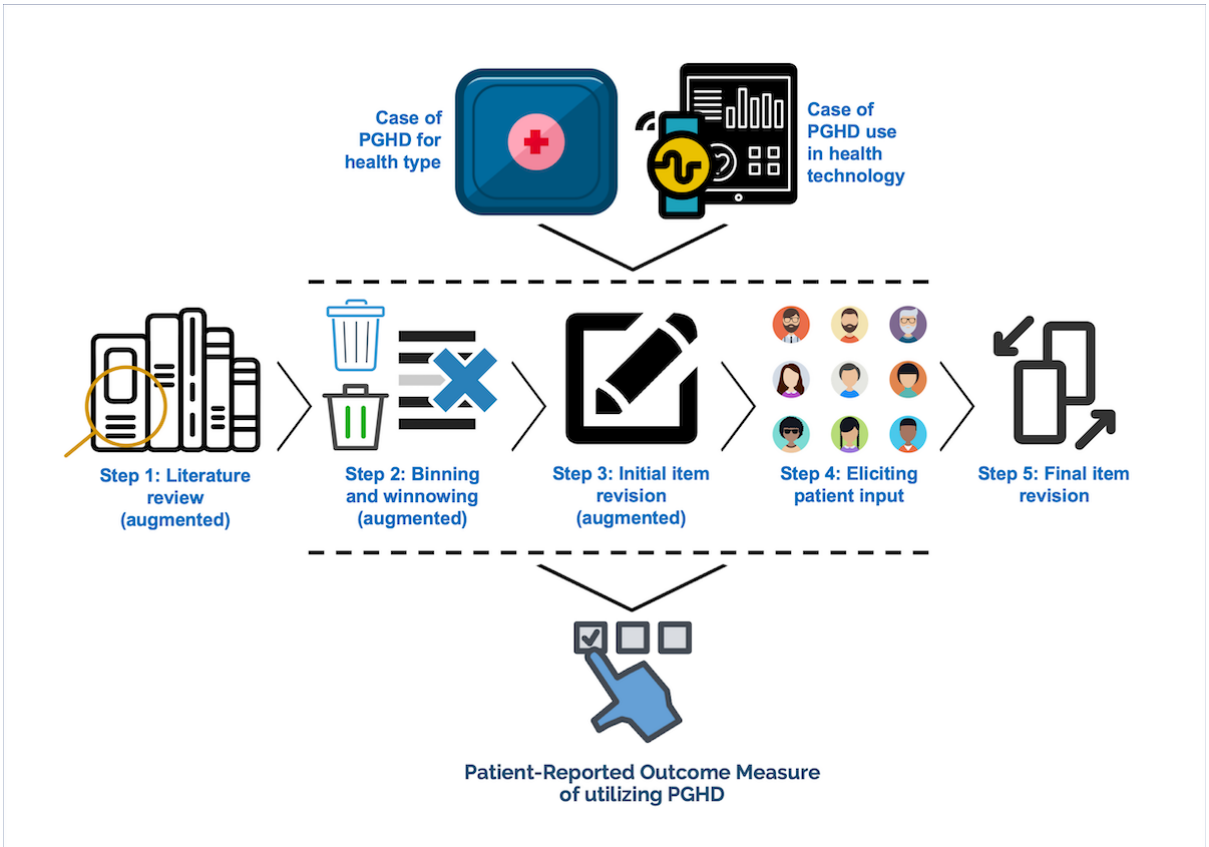
A Worked Example of the Patient-Reported Outcome Measure of Utilizing Person-Generated Health Data Development Method

To illustrate how the PROM-PGHD development method may be used to develop a PROM-PGHD, a worked example is presented based on the steps presented in Table 6. This is further augmented as described above. This example demonstrates how augmenting the first QIR step guides the identification and development of items within the domains of interest and influences the development process. Each of the five steps is outlined, with references to work on each step that we have reported elsewhere. These references to papers published to date are summarized below:

- Step 1, literature review: Dimaguila et al [8].
- Analysis of Step 1 and implementation of Steps 2 and 3: Dimaguila et al [34].
- Step 4, eliciting patient input: Dimaguila et al [7].

Figure 8 (*published Figure 1*) outlines the steps of the PROM-PGHD development method and indicates how the socio-technical context influences the process from the beginning.

Figure 8. The steps of the patient-reported outcome measure of utilizing person-generated health data (PGHD) development method, which was augmented from the qualitative item review. Icon sources: Iconfinder and Flaticon.



Case Study

An exemplar PGHD use case is home-based stroke rehabilitation (the health condition) using body-tracking simulated technologies (the technology category) [8]. Stroke is a leading global cause of death and disability [35,36]. Clinical rehabilitation is lengthy and costly; thus, home-based rehabilitation may improve outcomes, and patients may prefer home-based options rather than traveling to clinics [37]. Simulated stroke rehabilitation systems, in particular using the industry-leading Kinect (Microsoft), simulate rehabilitation activities in a clinical environment in real time [38]. These systems use a video gaming console, which may be well suited for home-based rehabilitation. Patients may generate data through different forms of

interaction [39-41]. More information on Kinect, for example, how it was designed and types of rehabilitation tasks available, is provided in previously published literature [42-44]. Utilizing PGHD in conjunction with such systems has the potential to generate important new evidence about the efficacy of stroke telerehabilitation. Therefore, a PROM-PGHD of Kinect-based stroke rehabilitation systems is our example of step-by-step item development.

Step 1: Literature Review (Augmented)

The first step, that is, literature review, is key in identifying concepts and items within the domain of interest for the PROM being developed. It identifies items representing the range of domain-relevant experiences [16].

Augmenting it to include the health condition and the technology category recognizes the socio-technical context of PGHD-enabled technologies and ensures that relevant items from both domains are included. This was implemented for the worked example, and as such, influenced the identification of outcome measures from the literature. An extensive literature review was conducted for this example combination of a health condition and a technology type detailed in Dimaguila et al [8]. The review examined the extent of PGHD utilization in studies of Kinect-based simulated rehabilitation systems for stroke and identified outcome measures from which candidate items were drawn for assessment. Outcome measures identified from papers selected in the review include the Game Experience Questionnaire [45] and the Stroke Impact Scale [46].

Step 2: Binning and Winnowing (Augmented)

The second step is Binning and Winnowing. The overall objective of the binning (ie, including) activity is to build sets of items that represent an aspect of a particular health condition, for example, walking within a physical function condition [16]. For PROM-PGHD, we endeavored to develop sets of items that instead represented reported effects of PGHD utilization [34]. This is to match the objective of PROM-PGHD. Moreover, an additional exclusion criterion was introduced for winnowing activity. Originally, this step excluded (winnowed) items that were too narrow, disease specific, redundant, or confusing [16]. For the purposes of the PROM-PGHD, an additional criterion was added to winnow items whose content would not

be able to measure the effects of utilizing PGHD, as described here [34]. These effects include influencing interest in their care processes [2-4], and changing feelings about health status [3], and were derived from key themes that occurred in a key journal special issue on PGHD [1].

The outcome measure items identified in the previous step with consideration of the socio-technical context of the case study were assessed for appropriateness to PROM-PGHD, that is, their relevance to the reported effects of PGHD [34]. Items were winnowed according to the criteria described earlier. Retained items were binned by aligning existing items selected from Step 1, with reported effects on patients who used PGHD in controlled settings [34].

Step 3: Initial Item Revision (Augmented)

In the third step, that is, item revision, PROM items are revised to ensure consistency of their response options, similarity in wording contexts, conciseness and simplicity of wording, their independence from other questions, and that they encourage the use of available response options [16]. In addition, for PROM-PGHD, it may be necessary to revise some terminology used in the items, so they would better match the target health condition and technology category. Items may be worded quite generally, and revision would make them more specific to the target domains [34]. In the worked example, after Step 2, the preliminary item bank was revised to better match the target domains of Kinect-based stroke rehabilitation systems. Revisions were also conducted to address inconsistent response options and experience-recall time frames for the purpose of maintaining consistency [34]. Suggested uniform response options for the PROMIS rating scales [16] were followed.

Implementing the first step typically results in a number of diverse PROM items (eg, the question) and corresponding response options (eg, range of likelihood from agree to disagree, or a scale of 1-5) [16]. The optimal response options may vary based on the individual items they correspond with, and there is no empirical evidence suggesting that some sets of response options are clearly superior to others, that is, are consistently more accurate at capturing respondent experiences. Thus, it may be necessary to determine the response options through a consensus process with domain experts [16] or with the target patient

cohort [34]. Additional response options were added to gather feedback from patients themselves in Step 4, on the appropriateness of the item response types [34]. The revised items were then grouped according to their alignment with a PGHD effect, and according to their response option types, that is, true/false statements, rating scales, and multiple-choice questions [34]. The subsequent step, which elicits patient participation, is expected to improve the suitability of the items [16].

This step resulted in a preliminary PROM-PGHD item bank, which was then presented to patients in the next step [34]. Augmenting the first step of QIR, to consider the socio-technical context of health technologies from which PGHD are produced, ensured that the outcome measures and items considered were drawn from the domains of interest, that is, the health condition and the technology category. Thus, the items that were considered for binning and winnowing, underwent initial item revision and eventually were presented to the patients for comment, covered relevant concepts from both domains [34].

Step 4: Eliciting the Patient Input

In this step, stroke survivors participated in focus groups and semistructured interviews, where they were asked to comment on the concepts and items of the preliminary PROM-PGHD item bank, for example, on the items' clarity and suitability to their experience. Detailed analysis and reporting of the data collected in these studies are presented elsewhere [7]. They were also asked open-ended questions about their experience of accessing and utilizing PGHD for the purpose of gathering concepts that may not have been covered by the current items. Based on the exemplar health and technology case being investigated, the target patient cohort was stroke patients with varying levels of experience with Jintronix (Montreal, Canada), a simulated rehabilitation software system using Kinect version 2 [43] and which is FDA approved [47]. Patient recruitment was conducted at three different sites, with ethics approval granted by the Human Research Ethics Committees of Deakin University (2017-087), Austin Health (HREC/17/Austin/492), and the University of Melbourne (1852259.1).

Some of the PGHD effects previously reported in the literature were reaffirmed by the patients, for example, that PGHD access can increase engagement with the recovery process.

However, patient input showed that some effects were dependent on the status of their PGHD, for example, they felt satisfaction only when their PGHD showed an improvement trend [7]. This highlights the importance of eliciting patient input to gather a richer understanding of patient-reported outcomes [12,16].

Step 5: Final Item Revision

This step includes improving the PROM-PGHD items' accuracy in representing the perspectives and experiences of the target patient cohort, and their suitability and clarity. In the worked example, revisions took the form of direct changes to the wording of the items, reduction or addition of response options or scales, and reduction or addition of outcome items. For example, we have learned from our discussions with patients that our preliminary PROM-PGHD lacks an item to measure levels of frustration, which patients experience when they see their PGHD fluctuate, that is, indicators of their health status that go up and down over time [7]. The current PROM-PGHD was therefore revised to add levels of frustration as an outcome measure.

Finally, the items were run through the Lexile Analyzer® (MetaMetrics, Inc) to assess their readability based on sentence length and the commonness of words. This provides an extra layer of assessment to determine if any items could be problematic during implementation, and to conduct revisions as necessary to improve readability [16]. The full revision related to this step in our worked example, to be reported elsewhere, will prepare the PROM-PGHD item set for quantitative field testing [16].

Discussion

Relevance

This paper has argued that a PROM of utilizing PGHD is necessary to provide clearer evidence about the value of implementing related health technologies. PROMs-PGHD would provide a systematic way for patients to gain insights into the health effects they experience from utilizing their PGHD. PROMs-PGHD could also be included routinely as part of the patient record, where PGHD are produced within a patient's care plan. This is similar to how PROMs

in general are used together as a set of performance measures to assess the performance of health entities and the services they provide [48,49]. As such, PROMs-PGHD could inform strategies for improving health outcomes.

As highlighted, PROMs-PGHD would fill an evidence gap and promote participatory health by recognizing the value of the patient experience when considering the use and effect of PGHD and the technologies they are produced from. They might generate more evidence about the clinical effectiveness and cost-effectiveness of PGHD-enabled technologies to aid clinicians in choosing appropriate health technologies, and for patients to understand how certain health technologies affect their health management. Moreover, PROMs-PGHD could guide technology designers in developing PGHD-enabled technologies that are more inclusive of patient perspectives, similar to how PROMs could improve the design of clinical registries [15]. Ultimately, PROMs-PGHD could contribute to building evidence-based practice in clinical work with PGHD and facilitate the creation of relevant clinical guidelines.

This paper described, and illustrated via a worked example, a method for developing a PROM-PGHD. The method was guided by an established PROM development process and a participatory health paradigm. As a result, it followed a step-wise approach of involving patients, which iteratively influences the resulting items of the PROM-PGHD as it is developed. Participatory approaches such as this can generate a rich, deep understanding of the effects of a health technology intervention [12] and ensures that the patient perspective is embedded into the resulting PROM-PGHD, which is central to the value of PROMs [14].

The PROM-PGHD development method follows the best practice as it is distilled from the literature, adding to its credibility in producing legitimate measures of patient-reported outcomes. In addition, its consideration of the socio-technical context of health technology interventions increases its sensitivity to personal characteristics and the physiological and health-related factors affecting the target patient cohort [28]. The recognition of the two domains inherent in health informatics [30,31], that is, health condition and technology category, increases the appropriateness of the resulting PROM-PGHD for assessing the effects experienced by the patient cohort.

This worked example has shown that the PROM-PGHD development method is meaningfully applied to a PGHD-enabled technology category used in a specific health condition. It has identified existing PROM items relevant to the chosen domains: stroke and Kinect-based simulated rehabilitation technology. This helps ensure that the resulting PROM-PGHD is reflective of the experiences of patients who are using a technology within the context of their health condition. This allows the PROM-PGHD development method to be used in other cases where health technologies are implemented in health conditions.

It is important for practitioners and developers of health technologies to prioritize the patient's perspective and to be sensitive to how PGHD may affect people differently [8,9]. Future studies should therefore apply the PROM-PGHD development method in other relevant contexts where it may be important to understand how the health condition and technology category have interrelated effects on patients' outcomes from using PGHD [31,32]. Revising and retesting the resulting item banks in clinical samples would also increase the validity of the method [50], and it could be valuable to further explore how other socio-technical factors, such as health literacy, influence responses to the PROM-PGHD.

Limitations

One limitation of the QIR process [16], and thus with the PROM-PGHD development method, is the necessity to change the existing items selected from the literature review. The changes considered to be minor are conducted during the item revision steps. They are necessary to improve the uniformity of the response options that are designed to be read and interpreted by patients [16,34]. However, this process is not believed to substantially alter any existing outcome measure items. Moreover, the subsequent steps that elicit patient participation are expected to improve the suitability of the items [16].

Conclusions

This paper highlights the need for a systematic way of measuring the effects of PGHD on the health of people who utilize them. A method was presented for developing such a measure, called PROM-PGHD, based on best practice within the participatory health paradigm and in

consideration of the socio-technical context of PGHD utilization. A new PROM-PGHD development method was illustrated through the example of stroke survivors using Kinect-based poststroke simulated rehabilitation technologies. It was shown that the method can be applied successfully to develop an initial set of items from the domains of the health condition and technology category. This method may be applied to other cases that combine a health condition and a technology category, and thus, this method could have broader relevance for EBP in clinical work with PGHD. Future studies should apply the PROM-PGHD development method within other relevant socio-technical contexts, and revise and retest the resulting item banks.

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Icons used to create Figure 8 (*published Figure 1*) have been sourced from Iconfinder.com and Flaticon.com.

Conflicts of Interest

None declared.

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Abbreviations

EBP: evidence-based practice

FDA: United States Food and Drug Administration

PGHD: person-generated health data

PROM: patient-reported outcome measure

PROM-PGHD: patient-reported outcome measure of utilizing person-generated health data

PROMIS: Patient-Reported Outcomes Measurement Information System

QIR: qualitative item review

SAC: Scientific Advisory Committee of Medical Outcomes Trust

2.5 Data Collection and Analysis for the Qualitative Activities of the Method Followed

2.5.1 Data Collection

The data collection of this thesis was conducted through the lens of a range of simulated stroke rehabilitation technologies for stroke, thus it applied a case study approach to enquiry.

The approaches used to collect the data needed to develop a PROM-PGHD were:

- A literature review (peer-reviewed publication) to contextualise the thesis problem, highlighting the lack of participatory evidence on the clinical impact of PGHD use on stroke survivors (Chapter 1, Section 1.3.2).
- A conceptual review of PRMs (Chapter 2, Section 2.3), and development best practice (peer-reviewed publication, Chapter 2, Section 2.4) to serve as a model for developing a PROM-PGHD.
- Audio-recorded focus groups and interviews (Chapters 4 and 5). These studies formed Step 4 of the PROM-PGHD Development Method, described below. They were aimed to gather direct feedback from people with the case health condition, stroke survivors and their treating clinicians on how accessing and using PGHD may have affected stroke survivors.

The data were collected from three appropriate sites in Australia where gaining ethical access was feasible; and where stroke survivors, and physiotherapists who have treated or are treating stroke survivors, could be recruited. These three sites are: Deakin University in Victoria (stroke survivors), Austin Health hospital in Victoria (stroke survivors and physiotherapists); and Headway ABI in Queensland (stroke survivors).

2.5.2 Data Analysis

Data analysis followed a two-layer process. The first layer consisted of common data analysis practices such as organising the data for analysis, familiarisation with the data through re-reading, and generation of analytical notes. The second layer of analysis applied procedures more specific to the research approach of the study [84].

The second layer employed the Framework Method of data analysis, [85] which should not be confused with the framework that this thesis aims to develop (Chapter 1, Section 1.4). The Framework Method is a specific set of procedures applicable to qualitative case study research. In case study research it is important to aggregate collected data into categories, and discover relationships and patterns between those categories; from which interpretation is conducted. Later, naturalistic generalisations are produced, applied to a population or context similar with the case. Hence, it is also important to describe aspects or the facts of the case, and its setting [84]. In the Framework Method, categorical aggregation is conducted in Stage 4, patterns and relationships formed in Stage 6, and interpretations in Stage 7. These stages are described in more detail below.

2.5.3 The Framework Process

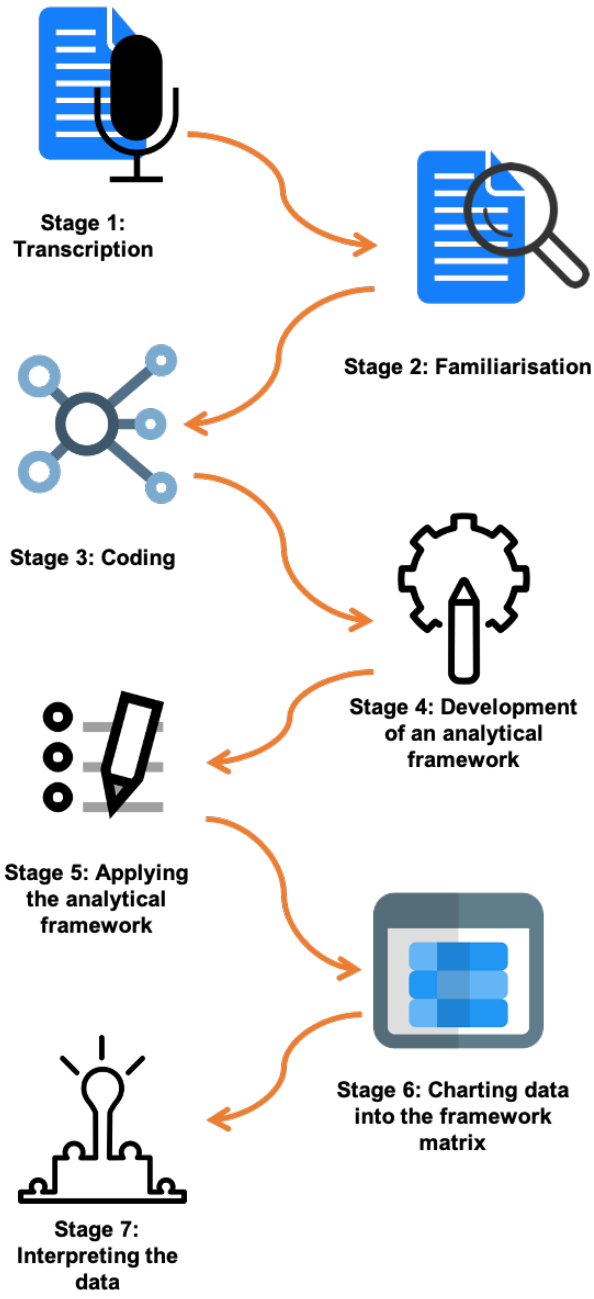
The framework method, henceforth called a process in this thesis to reduce confusion with the main method, provides a stepwise approach to summarising and analysing data, and is widely used in health research. It allows for systematically organising and categorising seemingly unwieldy data. As such it is most often used in analysing data collected through semi-structured interviews [85] which, along with focus group discussions, are the primary method of data collection in this thesis. Its defining output is a matrix of summarised data comprising of cases and codes, through which researchers can then analyse each case and code individually. This also allows for inter- and intra-case analysis of data, e.g., if a case is an interviewee, the views of each interviewee could be compared with those of other interviewees as well as with their own [85].

The framework process is only suitable for research where the data collected all relate to similar topics or areas of interest, as its main activity includes categorisation of the data [85]. It is therefore applicable to this thesis as the data collected are stroke survivors' perspectives, perceptions and reported outcomes as a result of utilising their PGHD from Jintronix. Moreover, the stepwise nature of the framework process makes it useful for diverse research teams where some members may not have experience in qualitative research. The author of this thesis was in this position, which made the framework process especially appropriate for analysing the collected data in this research.

The following stages below will describe the data analysis stages taken in this thesis, following the framework process. It is important to note that while the data analysis process is mainly sequential, it follows a 'spiral', i.e., researchers may have to go back to previous stages of activities, in analytic circles. In each spiral, researchers use strategies to generate specific analytic outcomes [84].

Specific analysis activities conducted for each study site are reported within each of the Chapters 4 (peer-reviewed publication) and 5 (peer-reviewed publication). Figure 9 below illustrates the framework process. Once more, this should not be confused with the framework that this thesis aims to develop (Chapter 1, Section 1.4).

Figure 9. The Qualitative Framework Process



Stage 1: Transcription

Verbatim transcriptions of most audio-recorded data were made by the author using NVivo 11 (http://www.qsrinternational.com/nvivo/nvivo-products). NVivo is a data analysis software for qualitative research. It supports transcriptions and data organisation, e.g.,

coding and retrieval of data based on codes; and was therefore used at different stages of data analysis in this research.

Transcriptions for the first study, at Deakin University (Chapter 4), were conducted by the author and a research assistant. Focus groups (n=2) were transcribed by the former, while all interviews (n=5) were transcribed by the latter. For data immersion it would have been ideal for the author to transcribe all focus groups and interviews [85], but the research timelines of research collaborators from Deakin required transcriptions to be conducted sooner, necessitating the assistance of the research assistant. The author and the research assistant met twice to ensure consistency of the transcriptions, i.e., with the process of assigning participants IDs and recording dialogues, as explained below.

All transcriptions for the other study sites, i.e., Austin Health hospital and Headway ABI (Chapter 5), were conducted by the author.

The process used to assign participant IDs were as follows: **FG** + **[*focus group number within the study site*]** or **INT** + **[*interview number within the study site*]** + **_** + **[*site code*]** + **C[*study site cohort number, if any*]** + **_** + **[*participant number within a FG or interview, and thus within a transcription file*]** + **C** if participant is a stroke survivor's carer. Carer numbers are matched with their stroke survivors, e.g., **1C** is participant **1**'s carer and **2C** is participant **2**'s carer. While comments made by carers were transcribed and appropriately coded, their responses were not included in the analysis.

Site codes for this thesis are as follows: **STC** for the study conducted at Deakin University (Chapter 4); **AH** for the study conducted at Austin Health hospital (Chapter 5); and **HW** for the study conducted with Headway ABI Australia (Chapter 5). For the Austin Health study, stroke survivors and clinicians were recruited; thus a 'P' was appended after the site code HW for stroke survivors, and 'C' was appended if the participant was a clinician.

Here is an example of how the process of assigning participant IDs was applied: A participant in the first focus group conducted in the Deakin site is given the code **FG1**. The participant is from the first cohort of the study, so the code **STC1** is applied. Finally, the participant is the

first to speak in the discussion, and so the code **1** is applied to the end. Putting all this together, the participant's code was **FG1_STC1_1**. If the participant had a carer, then that carer's ID would have a 'C' appended to the end and matched with their ward's number. Thus, the participant ID of **FG1_STC1_1**'s carer would be **FG1_STC1_1C**. Questions were always directed to stroke survivors first, thus the first speaker is always a stroke survivor and not a carer.

A straightforward process of recording non-verbal dialogues was also used. Actions were recorded by enclosing them in parentheses, e.g., laughs, chuckles, coughs, and redirection of conversation to another participant. Mentions of participant names were changed to their respective participant IDs. Moreover, any sensitive details that might reveal the identity of the participants were omitted, e.g., other rehabilitation units that they have attended in the past, as well as names of clinicians who have treated them in the past.

Stage 2: Familiarisation

Data familiarisation is an important part of interpretation [85]. The author listened to the audio recordings, and read the transcripts of all interviews and focus groups at least twice, and analytical notes or thoughts were typed down as memos [86] in the process. Any reflective notes and memos recorded during the interviews and focus groups were also reviewed. Appendix B shows some of these reflective notes and memos. Some quotes that stood out as interesting, e.g., clearly fits a code or requires discussion, were also noted down in a coding journal shown in Appendix C. This is discussed further in Stage 4 below.

Stage 3: Coding

In the coding stage, the transcripts are read carefully, to apply codes in the form of a paraphrase or label [85]. These codes serve as short descriptions of interpretations of passages deemed important by researchers, classify data, and enable systematic comparison of those data [85].

The primary process of coding in this thesis was done deductively. This is due to the deductive nature of this thesis that aims to understand how utilising PGHD from a stroke rehabilitation technology affects stroke survivors. Data were collected through semi-structured interviews

and focus group discussions, using questions framed around the literature review conducted as part of the PROM-PGHD Development Method. Hence the codes were pre-defined based on specific outcome areas of interest; as opposed to inductive studies where all transcripts are open coded. These codes are introduced in Chapters 4 and 5, and are presented in Appendix D.

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 [85].

Manual coding was applied to the transcripts using NVivo 11. NVivo allows coding of selected content through assignment of nodes, which can be pre-defined before coding, or created during the coding process.

Stage 4: Development of an analytical framework

In this thesis excerpts from the first few transcripts were coded independently by the author, and two PhD supervisors who are experienced qualitative researchers (K Gray and M Merolli). Any disagreements with regards to codes applied were discussed in coding meetings until common understanding was achieved. The author also used a coding journal to clarify any contentious quotes with K Gray and M Merolli. Appendix C shows the coding journal, which lists quotes that were interesting and needed to be discussed with K Gray and M Merolli. Some of the quotes were also noted during the Familiarisation stage (Stage 2).

Any new codes applied to the transcripts were also discussed in the coding meetings, to agree on their meanings, and how they were applied to the transcripts. The developed codes were then formed into an analytical framework by grouping codes together into categories. The analytical framework was iteratively added to or revised, until the last transcript has been coded [85], and adheres to the recommended spiral process of data analysis [84].

Stage 5: Applying the analytical framework

In this stage, the remaining transcripts were coded by the author using the analytical framework. As earlier described codes were applied through NVivo 11, which facilitated the organisation and storage of the data. Using NVivo also made it easier to retrieve the data later, according to codes and categories.

Stage 6: Charting data into the framework matrix

Charting the coded data into a matrix helps to summarise and manage the text transcribed from recorded interviews or focus groups [85]. For the data collected from the thesis, this matrix was formed through the use of a spreadsheet; with each sheet representing a category of codes, and each sheet containing columns for codes, and rows for quoted text. Using a qualitative analysis software like NVivo was very helpful here because NVivo could generate all text assigned to a particular code [85]. Appendix D shows these quotes mapped to the analytical matrix.

Stage 7: Interpreting the data

The author generated themes by reviewing the matrix and establishing connections across the data. The process was deductively influenced by the study objectives, and by additional concepts generated from selectively open coding a few transcripts, i.e., identifying any new PGHD utilisation effects (Stage 3). Ideas that were generated from reviewing the matrix were discussed with K Gray and M Merolli. Following best practice [85], reflective notes and memos recorded during the interviews and focus groups, and noted in Stage 2 were also reviewed, and any emerging ideas captured in analytical memos.

Gradually, characteristics and differences between the data were identified; and used to generate classifications, and investigate emerging theoretical concepts [85]. From here any additional themes were identified.

3 Applying the Method to Develop a Preliminary Item Bank of a Patient-Reported Outcome Measure (peer-reviewed publication)

The previous chapter has established that developing a specific type of PRM, i.e., a PROM-PGHD, is appropriate to enable PGHD users to routinely and systematically report how access and use of their PGHD affects them. It proceeded to introduce a 5-step PROM-PGHD Development Method, augmented through an analysis of best practice PROM development methods.

This chapter presents a peer-reviewed publication reporting on the activities conducted in applying the first three steps of the PROM-PGHD Development Method, for the exemplar case of Kinect-based stroke rehabilitation systems: Literature Review (Step 1), Binning and Winnowing (Step 2), and Initial Item Revision (Step 3).

The three steps result in a preliminary item bank of PROM-PGHD for K-SRS. This preliminary item bank is later presented to participants as part of the Method's Step 4: Eliciting Patient Input (Chapters 4 and 5).

For reference, this chapter is mapped to the steps of the PROM-PGHD Development Method that it implements in Table 7 below.

Table 7. Mapping Chapter 3 with the PROM-PGHD method steps it implements

Steps of the PROM-PGHD Development Method	Chapters/Sections of this Thesis
Step 1: Literature Review	Chapter 1, Section 1.3.2: Literature Review (peer-reviewed publication)
Analysis of Step 1 Step 2: Binning and Winnowing Step 3: Initial Item Revision	Chapter 3: Development of a PROM of Utilising PGHD: Preliminary Item Bank (peer-reviewed publication)

Step 4: Eliciting Patient Input	Chapter 4: Eliciting Stroke Survivors' Perceptions on the Effects of Utilising PGHD (peer-reviewed publication)
	Chapter 5: Varying Perspectives of Stroke Survivors and Clinicians on the Effects of Utilising PGHD (peer-reviewed publication)
Step 5: Final Item Revision	Chapter 6, Section 6.1: Improving the Patient-Reported Outcome Measure of Utilising Person-Generated Health Data Preliminary Item Bank

This is a peer-reviewed publication, appearing in British Medical Journal Health and Care Informatics (doi:10.1136/bmjhci-2019-100070). The accepted version of the article is presented here, ready for examination following university guidelines for thesis with publications. To see the individual contribution of the authors, please see the Preface.

Any figures and tables that appear in this published manuscript have been renumbered for the purpose of this thesis.

Measuring the outcomes of using person-generated health data: a case study of developing a PROM item bank

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Abstract

Introduction: Patient-reported outcome measures (PROMs) allow patients to self-report the status of their health condition or experience independently. A key area for PROMs to contribute in building the evidence base is in understanding the effects of utilising person-generated health data (PGHD), and using PROMs to measure outcomes of utilising PGHD has been suggested in the literature. Key considerations inherent in the stroke rehabilitation context makes the measurement of PGHD outcomes in home-based post-stroke rehabilitation, that uses body-tracking technologies, an important use case.

Objective: This paper describes the development of a preliminary item bank of a PROM-PGHD for Kinect-based stroke rehabilitation systems (K-SRS), or PROM-PGHD for K-SRS.

Methods: The authors designed a method to develop PROMs of utilising PGHD, or PROM-PGHD. The PROM-PGHD Development Method was designed by augmenting a key PROM development process, the Qualitative Item Review, and follows PROM development best

practice. It has five steps, namely, Literature Review; Binning and Winnowing; Initial Item Revision; Eliciting Patient Input; and Final Item Revision.

Results: A preliminary item bank of the PROM-PGHD for K-SRS is presented. This is the result of implementing the first three steps of the PROM-PGHD Development Method within the domains of interest, i.e., stroke and Kinect-based simulated rehabilitation.

Conclusions: This paper has set out a case study of our method, showing what needs to be done to ensure that the PROM-PGHD items are suited to the health condition and technology category. We described it as a case study because we argue that it is possible for the PROM-PGHD method to be used by others to measure effects of PGHD utilisation in other cases of health conditions and technology categories. Hence, it offers generalisability and has broader clinical relevance for evidence-based practice with PGHD. This paper is the first to offer a case study of developing a PROM-PGHD.

Keywords

person generated health data; patient reported outcome measures; patient monitoring; telemedicine; questionnaire design

Figure 10. Chapter 3 (peer-reviewed publication) Summary

Summary

What is already known?

- PROMs offer a standardised approach to evaluating and improving health care services by enabling patients to contribute to more precise evaluation of the effects of various health interventions; and they contribute to improving the evidence base in various areas of clinical care.
- Utilisation of PGHD by patients promotes participatory health, as it has been suggested to increase their engagement, improve health management coordination with their care providers, and increase their sense of social support and connectedness.
- Measuring PGHD outcomes in home-based post-stroke rehabilitation, that uses body-tracking technologies, is an important use case due to key considerations inherent in the stroke rehabilitation context.

What does this paper add?

- This paper has demonstrated a case study of our PROM-PGHD Development Method, using Kinect-based stroke rehabilitation systems as the case study, resulting in a preliminary item bank of PROM-PGHD for K-SRS.
- The PROM-PGHD method may be used by others to measure effects of PGHD

Introduction

Patient-reported outcome measures (PROMs) allow patients to self-report the status of their health condition or experience independently [1-3]. As such, PROMs enable patients to contribute to more precise evaluation of the effects of various health interventions, and they contribute to improving the evidence base in various areas of clinical care [4]. PROMs offer a standardised approach to evaluating and improving health care services, and this is highlighted by key national projects to develop suites of PROMs for various health conditions in the US, Europe, and Australia [5].

A key area for PROMs to contribute in building the evidence base is in understanding the effects of utilising person-generated health data (PGHD) [6]. PGHD are created, recorded, and analysed by people, who are monitoring their health outside of a clinical care setting. They include health, wellness, and other biometric data produced from technologies such as mobile applications, activity tracking devices, and simulated rehabilitation technologies [7-9]. Utilisation of PGHD by patients promotes participatory health, as it has been suggested to increase their engagement, improve health management coordination with their care providers, and increase their sense of social support and connectedness [10-15]. When patients better understand their illness, it may make them more active in improving their health behaviour [16].

Using PROMs to measure outcomes of utilising PGHD has been suggested [9]. A PROM of utilising PGHD, or PROM-PGHD, would allow patients to directly self-report their health outcomes or status as result of accessing and utilising their own PGHD. This may generate a deeper understanding of how PGHD may impact patients' health status and quality of life, and has significance in an era of increasing remote wearable and mobile patient monitoring. Similar to PROMs being used as a complement to other health outcomes indicators [5], PROMs-PGHD could also be used to complement existing patient-reported, and clinician-reported, outcome measures. This could contribute to a more accurate and comprehensive assessment of patients' experiences of utilising PGHD from existing and new health information technologies. Consequently, PROMs-PGHD may offer a deeper understanding of the health outcomes and related impacts of those technologies.

Measuring PGHD outcomes in home-based post-stroke rehabilitation, that uses body-tracking technologies, is an important use case due to key considerations inherent in the stroke rehabilitation context [8]. These may include its high cost over a long period of time; difficulties in access to therapy [17]; the complexity of care required [18, 19]; and the need for patients to undertake frequent, repetitive movement exercises appropriate to their condition to support improved health outcomes [20, 21]. Therefore, more convenient, practical, and effective options for patients are needed, which technology interventions may provide. Simulated rehabilitation systems, for example, using Kinect© (Microsoft, Redmond

WA) provide patients with simulated activities of daily living [22]. Stroke therapy benefits from such systems have been previously reported [22-25].

As patients use such systems, they produce PGHD in the form of therapeutic progress data. Those PGHD have the potential to be used, not only by clinicians but also by patients themselves to monitor and evaluate patients' recovery more consistently [22, 24]. Similar to how PROMs allow for a more holistic evaluation of the effects of various health services and interventions [4], a PROM-PGHD for simulated post-stroke rehabilitation technologies could provide a more precise assessment of those systems, and also increase understanding of how those systems impact the health status of patients [6].

Objective

This paper describes the development of a preliminary item bank of a PROM-PGHD for Kinect-based stroke rehabilitation systems (K-SRS), or PROM-PGHD for K-SRS.

Methods

In response to the lack of a systematic way for patients to measure and self-report health effects they experience from utilising their PGHD – whether those effects are positive, negative, or nil – the authors designed a method to develop PROMs of utilising PGHD, or PROM-PGHD. The PROM-PGHD Development Method was designed by augmenting a key PROM development process, the Qualitative Item Review (QIR) [26], and follows PROM development best practice. Table 8 (*published Table 1)* presents the steps of the PROM-PGHD Development Method.

Table 8. Activities of the PROM-PGHD Development Method

#	Step Name	Activities
1	Literature review to identify existing items	This is a search of the literature surrounding established patient-reported outcome measures (PROMs) within the target health condition, and relevant self-reported measures within the target technology category. This considers the socio-technical context of the target domains, and serves as the foundation for building

		proposed outcome measure items. Items that represent the range of domain-relevant experiences are identified.
2	Binning and winnowing	Binning involves categorising the selected items according to the effects of PGHD utilisation that they could measure. Winnowing excludes items that would not be able to measure effects of utilising PGHD. It also excludes items based on QIR criteria: items that are too narrow, disease-specific, redundant, or confusing [87].
3	Item revision process	In this step, retained items are revised according to QIR criteria to ensure: consistency of item response options; similarity in wording contexts; concise and simple items; item independence from other questions; and that items encourage use of available response options to reduce cognitive burden on respondents [87]. Additionally for PROM-PGHD, some item terminologies may be revised to better match the target health condition and technology category, to make them more specific to the target domains.
4	Focus groups and interviews with target patient cohort	This step ensures that patient input is elicited in the development of item banks. It enables the developers to understand the vocabulary and thinking processes of the target group, and to gather feedback on individual items. It is aimed to bridge relevant gaps between the current items and the target domain or concepts to be measured. This may also highlight other measurement areas expressed by patients that are not covered in the preliminary item bank.
5	Final item revisions	Based on patient input gathered from the previous step, the items are revised once more. They are tested with the Lexile Analyzer® (MetaMetrics, Inc., NC) to assess their readability; to catch items that may still be difficult to read. After the revisions are completed, field testing on the items may begin, in order to understand their quantitative characteristics.

This paper describes the use of the first 3 steps of the method, to develop a preliminary item bank of a PROM-PGHD for K-SRS. Validation and subsequent revision of the preliminary PROM-PGHD through the Methods' last 2 steps, i.e., eliciting patient input [6], and final item revision, are reported elsewhere. The following sections are organised accordingly.

Step 1. Literature Review

In this step, a literature review relating to the two domains of the focus area, the health condition and the technology category, was conducted. This is to consider the socio-technical system context of the focus area, necessary for designing a PROM-PGHD that is appropriate for the needs of the patient cohort. Based on the objectives of this paper, the target health condition of this paper is stroke, and the technology category is Kinect-based simulated rehabilitation. Through the literature review, existing PROM items within the domains of interest were identified.

A consideration in this step is that PROMs are not generally found in the literature reporting on research in the technology category. However, this research may report patient experience or satisfaction with a health intervention measured in ways that are similar to PROMs [27]. Hence, a variety of measures of satisfaction or experience from the literature in the technology category are included in the identification of PROMs for PGHD.

The authors conducted an extensive literature review, that examined the extent of PGHD utilisation in 41 included studies of Kinect-based simulated rehabilitation systems for stroke; full details appear here [8]. The review identified existing PROMs within the post-stroke health condition, and self-reported measures within the Kinect-based simulated rehabilitation technology category. These are listed in Table 9 (*published Table 2*).

Table 9. Patient-reported outcome measures identified through the first step of the PROM-PGHD Development Method, the literature review

Study	PROM or similar instrument
Bird et. al., 2016	Borg rating of perceived exertion scale

	Visual Analogue Scale (pain & fatigue) 5-point Likert scales on enjoyment, and on perceived benefit
Proffitt & Lange, 2015	Game Experience Questionnaire from IBM System Usability Questionnaire Activities-Specific Balance Confidence Scale Stroke-Specific Quality of Life Scale
Song & Park, 2015	Beck Depression Inventory Relationship Change Scale
Allen, Hoermann, Piumsomboon, & Regenbrecht, 2015	Mixed Reality Experience Questionnaire
Kizony et. al., 2013	Motor Activity Log
Kairy et. al., 2016	Stroke Impact Scale (Quality of Life) Personal log of exercise time, feelings (motivation/appreciation), other services received, and adverse events

The end of step 1 resulted in a range of possible PROMs or similar instruments to capture both the post-stroke and the simulated rehabilitation domains of interest. The individual items of the PROMs were analysed for appropriate 'binning' or 'winnowing' as described in the next step.

Step 2. Binning and Winnowing

In this step, individual items of the identified PROMs were assessed for inclusion to the preliminary PROM-PGHD, and then categorised in a process called 'binning', explained next. 'Winnowing' is the process of assessing the PROM items and determining whether they should be 'winnowed', or removed. Many of the items were removed as they could not be used to measure the effects of utilising PGHD. The criteria for winnowing items are as follows: 1) item content would be inconsistent with the PROM-PGHD objective of measuring effects of utilising PGHD; 2) the item content was too specific to be applicable elsewhere, for example it was too disease-specific; or 3) items were redundant or confusing.

Table 10 (*published Table 3*) shows examples of items that were removed from the winnowing process, and the reasons for their removal. Meanwhile, Table 11 (*published Table 4*) shows the list of PROM items that were retained after winnowing, and their reasons for inclusion.

Table 10. Examples of items removed from the winnowing process

PROM	Removed Item	Reason for removal
Game Experience Questionnaire	Overall, I am satisfied with the ease of completing the tasks in this scenario.	Inconsistent with the objective of measuring effects of PGHD utilisation.
Beck Depression Inventory	I have not noticed any recent change in my interest in sex.	Too narrow or specific.
Stroke-Specific Quality of Life Scale	Did you have trouble walking?	Disease-specific.
System Usability Questionnaire	I found the product very awkward to use.	Inconsistent with the objective of measuring effects of PGHD utilisation.
Relationship Change Scale	Within the last four weeks, I feel my friend views me as a satisfactory friend: (1) much less; (2) less; (3) no change; (4) more; (5) much more.	Too narrow or specific.

The retained items after winnowing were categorised in a process called ‘binning’. Binning, a term used in statistics to mean grouping items together, is the process of aligning the retained PROM items with reported effects on patients who have utilised PGHD. As an efficient way of targeting reported effects for this purpose, articles from a major journal special issue on PGHD [7] were analysed inductively [34]; to categorise ways used in them to describe reported effects of utilising PGHD. The derived themes are a representative sample of PGHD utilisation effects from a variety of health information technologies, for different health conditions. These effects are listed below:

1. Influence health-related behavioural or attitude changes in patients [35].
2. Influence patient management of their own care, due to changes in feelings about their health status [36].
3. Influence interest in their care processes [14, 36, 37].
4. Facilitate personal care goals [36, 38].
5. Influence relationship with care providers [10, 11, 36, 37].

The PROM items retained after winnowing were matched against these categories of effects of PGHD utilisation. Table 11 shows the PROMs identified from step 1, and their outcome measure items, with corresponding response options that were retained after the winnowing process. It also lists the reasons for the items' inclusion. The reasons column describes why the items may be appropriate in measuring self-reported outcomes of patients' utilisation of PGHD. The final column shows the alignment of the retained items with the thematically derived PGHD utilisation effects after the binning process. Only effects 1, 2, and 4 had items binned, or aligned with them.

PGHD has been used to describe data that have been not only generated and recorded by people, but also interpreted by them [7], i.e., people are accessing and utilising their own health information. Thus, PROM items that use the terms data and information both were included.

Table 11. Alignment of identified PROM items with PGHD effects, and reasons for their inclusion

Included PROM Item/s	**Reason for Inclusion**	**Alignment with PGHD Effects**
Game Experience Questionnaire Post-Study items:	These items could rate whether/how patients correct an action or behaviour, depending on the ease of	Effect 1: Influence health-related behavioural or

Included PROM Item/s	Reason for Inclusion	Alignment with PGHD Effects
9. The system gave error messages that clearly told me how to fix my problems. 10. Whenever I made a mistake using the system, I could recover easily and quickly. Response options: Scale of 1 (strongly agree) to 7 (strongly disagree), and N/A.	resolving issues with the way PGHD is provided to them.	attitude changes in patients.
Beck Depression Inventory: A (Mood) 0 I do not feel sad 1 I feel blue or sad B (Pessimism) 0 I am not particularly pessimistic or discouraged about my future. 1a I feel discouraged about my future. C (Sense of Failure) 0 I do not feel like a failure 1 I feel I have failed more than the average person	These items could rate whether/how patients' attitude may be affected by access to their PGHD.	

Included PROM Item/s	**Reason for Inclusion**	**Alignment with PGHD Effects**
G (Self Hate) 0 I don't feel disappointed in myself 1a I am disappointed in myself Response options: Among a list of options, tick a statement if true.		
Stroke-Specific Quality of Life Scale, Mood items: 1. I felt hopeless about my future. 2. I was discouraged about my future. 7. I had little confidence in myself. Response options: Strongly agree, Moderately agree, Neither agree nor disagree, Moderately disagree, or, Strongly disagree.		
Game Experience Questionnaire Post-Study items: 11. The information (such as on-line help, on-screen	These items could rate whether/how patients completed tasks depending on the quality of PGHD provided.	Effect 2: Influence patient management of their own care, due to changes in feelings

Included PROM Item/s	Reason for Inclusion	Alignment with PGHD Effects
messages, and other documentation) provided with this system is clear. 12. It was easy to find the information I needed. 13. The information provided for the system was easy to understand. 14. The information was effective in helping me complete the tasks and scenarios. After-Scenario items: 3. Overall, I am satisfied with the support information (on-line help, messages, documentation) when completing the tasks. Response options: Scale of 1 (strongly agree) to 7 (strongly disagree), and N/A.		about their health status.
System Usability Questionnaire: 2. I found the product unnecessarily complex.	These items could rate whether/how patients' understanding of PGHD was affected by the interface to and presentation of their data.	

Included PROM Item/s	**Reason for Inclusion**	**Alignment with PGHD Effects**
4. I think that I would need the support of a technical person to be able to use this product. Response options: Scale of 1 (strongly disagree) to 5 (strongly agree).		
Relationship Change Scale: 1. Within the last four weeks, my satisfaction with myself as a person has become: (1) much less; (2) less; (3) unchanged; (4) greater; (5) much greater.	This item could rate the personal satisfaction of the patient after accessing PGHD.	
Game Experience Questionnaire Post-Study item: 18. This system has all the functions and capabilities I expect it to have. Response option: Scale of 1 (strongly agree) to 7 (strongly disagree), and N/A.	This item could rate whether/how patients' personal preferences for access to their data were supported by the system.	Effect 4. Facilitate personal care goals.

Step 3. Item Revision

The retained PROM items from step 2 were selected from pre-existing PROMs identified in the literature; as such they were not worded consistently, and their response options differed. To ensure that the resulting PROM-PGHD can be presented as one coherent test, and to reduce cognitive burden on respondents, the retained PROM items were revised in this step.

They were revised, where necessary, to better match the target health condition and technology category. Further revisions may also occur to ensure that the different PROM item response options are consistent; their content has similar wording; are concise and simple; are able to stand alone separately from the other questions; and are worded to encourage use of available response options [26].

A consequence of collecting several existing items from PROM instruments is the resulting variability of response options present [26]. However, there is a lack of empirical evidence that any particular set of response options is better than others. Optimal response options may vary based on the individual items in question [26]. Thus, to ensure that the resulting PROM-PGHD is capable of measuring the experiences of future respondents within the target domains, some response options of the retained items also were revised to include additional response types. This is to provide patients with varying response options to comment on in the fourth step. The fourth step is the process of eliciting patient input on the preliminary PROM-PGHD item bank, which is out of scope for this paper, and is reported elsewhere.

Table 12 (*published Table 5*) shows the included PROM items from Table 11. It then depicts any revisions conducted on the PROM items and their corresponding response options. Furthermore, it provides the reason/s for the revision.

Table 12. Revision of Identified Items

Included PROM Item/s	**Revised PROM Item/s** ***Changes are italicised***	**Reason for Revision/s**
Game Experience Questionnaire Post-Study items: 9. The system gave error messages that clearly told me how to fix my problems. 10. Whenever I made a mistake using the system, I could recover easily and quickly. Response options: Scale of 1 (strongly agree) to 7 (strongly disagree), and N/A.	9. The system gave error messages that clearly told me how to fix my *posture or movement*. Response option: *Always, Often, Sometimes, Rarely, or, Never.* 10. Whenever I made a *movement mistake*, I could recover easily and quickly. Response option: *Without any difficulty, With a little difficulty, With some difficulty, With much difficulty, or, Unable to do.*	Item contents and response options revised: Item contents changed to better reflect target health condition and technology category. Response options changed to match contents better, from levels of agreement to levels of frequency and capability. Chosen scales follow best practice uniform response options for frequency and capability [87].
Beck Depression Inventory: A (Mood) 0 I do not feel sad 1 I feel blue or sad	A (Mood) 0 I *felt okay* 1 I *felt* blue or sad B (Pessimism)	Item contents revised: Item contents changed to better

Included PROM Item/s	**Revised PROM Item/s** ***Changes are italicised***	**Reason for Revision/s**
B (Pessimism) 0 I am not particularly pessimistic or discouraged about my future. 1a I feel discouraged about my future. C (Sense of Failure) 0 I do not feel like a failure 1 I feel I have failed more than the average person G (Self Hate) 0 I don't feel disappointed in myself 1a I am disappointed in myself Response options: Among a list of options, tick a statement if true.	0 I *was fairly upbeat* about my *progress*. 1a I *felt pessimistic* about my *progress*. C (Sense of Failure) 0 I *felt like I was succeeding fairly well* 1 I *felt that* I *had* failed more than the average person G (Self Hate) 0 I *felt satisfied with* myself 1a I *was* disappointed in myself Response options: Among a list of options, tick a statement if true.	reflect rehabilitation context of the health condition. Changed from present to past tense for consistency with other items.
Stroke-Specific Quality of Life Scale, Mood items: 1. I felt hopeless about my future. 2. I was discouraged about my future.	1*a.* I felt hopeless about my *progress*. *1b. I felt hopeful about my progress.* 2*a*. I was discouraged about my *progress*.	Item contents and response options revised: These items, similar with the Beck Depression Inventory items, could indicate how

Included PROM Item/s	**Revised PROM Item/s** ***Changes are italicised***	**Reason for Revision/s**
7. I had little confidence in myself. Response options: Strongly agree, Moderately agree, Neither agree nor disagree, Moderately disagree, or, Strongly disagree.	*2b. I was encouraged about my progress.* *3a.* I had little confidence in myself. *3b. I was pretty confident in myself.* Response options: *Among a list of options, tick a statement if true.*	patients' access to their PGHD may affect their mood. Item contents changed to better reflect stroke rehabilitation context. Response options changed for consistency in presenting these items with items of the Beck Depression Inventory.
Game Experience Questionnaire Post-Study items: 11. The information (such as on-line help, on-screen messages, and other documentation) provided with this system is clear. 12. It was easy to find the information I needed. 13. The information provided for the system was easy to	11. *The on-line* help, on-screen messages, and other *documentation that that* this system *gave me made it clear to me what to do*. 12. It was easy *for me* to find the information I needed *from the system*. 13. The information provided *by* the system was easy *for me* to understand. 14. The information *from the*	Item response options revised: Numeric response options revised to six, from seven, to be consistent with best practice uniform response options for rating scales [87]. This also reduces cognitive

Included PROM Item/s	**Revised PROM Item/s** ***Changes are italicised***	**Reason for Revision/s**
understand. 14. The information was effective in helping me complete the tasks and scenarios. Response options: Scale of 1 (strongly agree) to 7 (strongly disagree), and N/A.	*system helped* me *to* complete the tasks and scenarios. Response option: Scale of 1 (strongly agree) to *6* (strongly disagree), and N/A.	burden on respondents.
System Usability Questionnaire: 2. I found the product unnecessarily complex. 4. I think that I would need the support of a technical person to be able to use this product. Response options: Scale of 1 (strongly disagree) to 5 (strongly agree).	2. I found *that* the *data about me were more* complex *than I needed*. 4. I *thought* that I would need the support of a technical person to *be able to understand my data*. Response options: *Among a list of options, tick a statement if true.*	Item contents and response options revised: Item contents revised to reflect patient access to data. Response option type was varied to elicit patient input on acceptability of response formats [87].
Game Experience Questionnaire After-Scenario items: 3. Overall, I am satisfied with the support information (on-line	 3. Overall, I *was* satisfied with *the way* the information (on-line	Item contents and response options revised:

Included PROM Item/s	**Revised PROM Item/s** ***Changes are italicised***	**Reason for Revision/s**
help, messages, documentation) when completing the tasks. Response options: Scale of 1 (strongly agree) to 7 (strongly disagree), and N/A.	help, messages, documentation) *supported me* when completing the tasks. Response option: Among a list of options, tick if true.	Item contents changed to past tense, for consistency with other items. Response option type was varied to elicit patient input on acceptability of response formats [87].
Relationship Change Scale: 1. Within the last four weeks, my satisfaction with myself as a person has become: (1) much less; (2) less; (3) unchanged; (4) greater; (5) much greater.	1. Within the last four weeks, my satisfaction with myself as a person has become: (1) Much less; (2) S*omewhat* less; (3) Unchanged; (4) *Somewhat more*; (5) Much *more*.	Item response option revised: Response option improved for clarity.
Game Experience Questionnaire Post-Study item: 18. This system has all the functions and capabilities I expect it to have.	18. This system *has shown me all rehabilitation information* I expect to have *about myself*. Response option: True, or False.	Item content and response option revised: Item changed to better reflect rehabilitation context.

Included PROM Item/s	**Revised PROM Item/s** ***Changes are italicised***	**Reason for Revision/s**
Response option: Scale of 1 (strongly agree) to 7 (strongly disagree), and N/A.		Response option type was varied to elicit patient input on acceptability of response formats [87].

The final thing to do in this step is to group the revised items according to their alignment with a PGHD effect. For this item bank, they are also numbered as a group according to their response options, i.e., true/false statements, rating scales, and multiple choice questions. The result is a preliminary item bank of a PROM-PGHD for K-SRS.

Results

Figure 11 (*published Figure 1*) presents the preliminary item bank of the PROM-PGHD for K-SRS. This is the result of implementing the first three steps of the PROM-PGHD Development Method within the domains of interest, i.e., stroke and Kinect-based simulated rehabilitation.

The items were categorised into the three PGHD effects that they were aligned with, represented as 'sections'. The items under the second section (aligned with the second PGHD utilisation effect) could indicate how PGHD influences patient decisions on the management of their own care, due to how they felt about their health status. Thus, this effect was rephrased as the 'Self-management of care' section. The item under the third section, aligned with the fourth effect, could indicate whether patients have sufficient access to their PGHD in a way they prefer, to facilitate personalised self-care strategies. Hence, this effect was rephrased as the 'Personalisation' section.

Nine items fell under the first section on 'Behavioural or attitude changes,' eight items under the second section on 'Self-management of care,' and one item under the third section

'Personalisation.' All items under each section were then grouped according to their response types, to improve the flow of items when read.

Figure 11. Preliminary PROM-PGHD Item Bank for K-SRS

I. Behavioural or attitude changes

1) Rate the following: (circle one rating for each statement)

The system gave error messages that clearly told me how to fix my posture or movement.
Always / Often / Sometimes / Rarely / Never

Whenever I made a movement mistake, I could recover easily and quickly.
Without any difficulty / With a little difficulty / With some difficulty / With much difficulty / Unable to do

2) At any time during the Jintronix trial, which of the feelings below were triggered for you based on seeing the information that Jintronix provided about your rehabilitation? (Please tick all that applied, at any time)

( ) I felt hopeless about my progress.
( ) I felt hopeful about my progress.
( ) I was discouraged about my progress.
( ) I was encouraged about my progress.
( ) I had little confidence in myself.
( ) I was pretty confident in myself.
( ) I felt okay.
( ) I felt blue or sad.
( ) I was fairly upbeat about my progress.
( ) I felt pessimistic about my progress.
( ) I felt I like I was succeeding fairly well.
( ) I felt that I had failed more than the average person.
( ) I felt satisfied with myself.
( ) I was disappointed in myself.

II. Self-management of care

3) Rate the following: (circle one rating for each statement)

The online help, onscreen messages, and other documentation that this system gave me made it clear to me what to do.
Strongly agree ←----------→ Strongly disagree
1 2 3 4 5 6
or N/A (encircle)

It was easy for me to find the information I needed from the system.
Strongly agree ←----------→ Strongly disagree
1 2 3 4 5 6
or N/A (encircle)

The information provided by the system was easy for me to understand.
Strongly agree ←----------→ Strongly disagree
1 2 3 4 5 6
or N/A (encircle)

The information from the system helped me to complete the tasks and scenarios.
Strongly agree ←----------→ Strongly disagree
1 2 3 4 5 6
or N/A (encircle)

4) Are any of the statements true? Please tick all that applied at any time during the trial.

( ) I found that the data about me were more complex than I needed.
( ) I thought that I would need the support of a technical person to be able to understand my data.
( ) Overall, I was satisfied with the way the information (online help, messages, documentation) supported me when completing the tasks.

5) Within the last four weeks, my satisfaction with myself as a person has become: (please circle one only)
Much less / Somewhat less / Unchanged / Somewhat more / Much more

III. Personalisation

6) Is the statement below true or false?
This system has shown me all rehabilitation information I expect to have about myself.

( ) True ( ) False

Discussion

This paper has demonstrated a case study of our PROM-PGHD Development Method, using K-SRS as the case study. The result is a preliminary item bank of PROM-PGHD for K-SRS. It demonstrated the implementation of each step of the PROM-PGHD development process.

The next step is to present the developed item bank to patients, not only to elicit their input on the items themselves but to discuss their experiences with accessing and utilising PGHD. This is to gather concepts that may not have been covered by the current item bank, and is the fourth step of the PROM-PGHD method. This step is reported elsewhere [6].

An interesting consideration discovered in this case study is the necessity of including, in the identification of PROMs, measures from the technology category to self-report satisfaction or experience. This is to ensure coverage of relevant items within the socio-technical context of the domains being measured. It is still a disciplined approach to the selection of outcome measures within the technology category, as the process identifies - through the literature review - those measures that have been used in a K-SRS setting. This is a unique and valuable aspect to the PROM-PGHD development process that future developers of a PROM-PGHD will need to consider.

Using PROMs to measure outcomes of utilising PGHD has been suggested [9]. PROMs allow for a more holistic evaluation of the effects of various health services and interventions [4]. Similarly, a PROM-PGHD would allow for a more precise, patient-centred assessment of such systems; and may increase understanding on how they could impact the health status of patients. It promotes participatory health within the K-SRS domain as it recognises the value of the patient experience in the assessment and evaluation of PGHD, and the technologies that produce them [39]. PROMs may be used to understand the impact health care services have on the status and quality of life of patients [2]. Similarly, it is hoped that the item bank would, in the future, assist clinicians in selecting appropriate K-SRS based on PGHD utilisation effects on patients; and for patients to understand how certain K-SRS could affect their management of their own health. Moreover, the method's applicability for a variety of health conditions and technology categories make it broadly relevant for evidence-based practice in clinical work with PGHD.

This paper is the first to offer a case study of developing a PROM-PGHD for a target health condition and technology category. While there are studies that present the development of PROMs of a health condition [3, 40], and measures to self-report experience or satisfaction with health technologies [27, 41, 42], there have been no studies presenting the development of a PROM of utilising PGHD.

Limitations

It was necessary to revise the content of existing PROM items identified from the literature review, due to the collection of several, existing items from PROM instruments, resulting in a variety of response options present [26]. Moreover, to elicit patient input on acceptability of response formats, some of the response option types were revised. While revisions of the response options for uniformity is considered minor and unlikely to alter the items substantially [26], we recognise that changing the content of the items may introduce changes to the items' function. This revision is essential, however, to develop a preliminary item bank to measure self-reported outcomes of PGHD utilisation. This process still follows best practice of searching the literature for existing concepts and items, and eliciting patient input [1, 26, 43, 44]. We believe this is preferable to starting the item development completely from scratch. Nonetheless, the suitability of the items is expected to be improved in the next step, where patient perspectives on their PGHD utilisation experience are gathered.

As described, the method used to identify the PGHD utilisation effects in step 2 (binning and winnowing) was an inductive thematic analysis of a recent, authoritative source (JAMIA special issue on PGHD [7]). The special issue compiled a range of applications and effects of PGHD across a variety of health conditions and technology categories. However, the list may not have covered all effects reported in the literature. The effects that should be measured however, will be verified and/or supplemented by patients in the next step. Open-ended questions will be asked of the patients around their experience of accessing and utilising PGHD from a K-SRS, to elicit any effects that may not have been covered in the initial list in step 2. The authors have already reported on one such discussion with patients here [6].

While the preliminary item bank of the PROM-PGHD for K-SRS was organised as described for the purpose of presentation here, this is not its final, or complete form. The objective of this paper was to describe a formal process of developing a preliminary item bank, which could then be presented to patients to elicit their input on the items' readability, appropriateness of wording, and relevance to their experiences of accessing and utilising their PGHD in a K-SRS. Moreover, because the items were categorised according to the effects they align with, the resulting item bank seems unbalanced in terms of the number of items under each section. The third section in particular has only one item. It should also be noted that only PGHD utilisation effects 1, 2, and 4 had items binned or aligned with them. Consequently, effects 3 and 5, which measure changes in patient engagement with formal care, were not represented in the items identified from the literature. This will be a key area of enquiry, which will be explored in the fourth step of the PROM-PGHD method.

Conclusion

This paper has set out a case study of our method, showing what needs to be done to ensure that the PROM-PGHD items are suited to the health condition and technology category. We described it as a case study because we argue that it is possible for the PROM-PGHD method to be used by others to measure effects of PGHD utilisation in other cases of health conditions and technology categories. Hence, it offers generalisability and has broader clinical relevance for evidence-based practice with PGHD.

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Competing Interests

There are no competing/conflict of interests.

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4 Improving the Preliminary Item Bank: Findings of a Study to Elicit Stroke Survivors' Perceptions (peer-reviewed publication)

The previous chapter reported on the activities conducted in applying the first 3 steps of the PROM-PGHD Development Method for the exemplar case of Kinect-based stroke rehabilitation systems. A PROM-PGHD is needed to enable PGHD users to routinely and systematically report how access and use of their PGHD affects them.

The next step of the Method elicits the input of people with the case health condition, i.e., stroke survivors, are elicited. This is necessary to ensure that the preliminary PROM-PGHD, developed through the previous three steps, closely represents the range and intensity of effects that stroke survivors experience.

The peer-reviewed publication in this chapter presents the results of discussions held with stroke survivors who have used the simulated stroke rehabilitation system Jintronix in a clinical study setting. Appendix E presents the focus group and interview guide used in the discussions. Later, Chapter 5 presents results of discussions held with stroke survivors who have used Jintronix as an outpatient, and those who were given a demonstration of Jintronix, and compares findings from all the discussions.

For reference, this chapter is mapped to the step of the PROM-PGHD Development Method that it implements in Table 13 below.

Table 13. Mapping Chapter 4 with the PROM-PGHD method step it implements

Steps of the PROM-PGHD Development Method	Chapters/Sections of this Thesis
Step 1: Literature Review	Chapter 1, Section 1.3.2: Literature Review (peer-reviewed publication)

Analysis of Step 1 Step 2: Binning and Winnowing Step 3: Initial Item Revision	Chapter 3: Development of a PROM of Utilising PGHD: Preliminary Item Bank (peer-reviewed publication)
Step 4: Eliciting Patient Input	Chapter 4: Eliciting Stroke Survivors' Perceptions on the Effects of Utilising PGHD (peer-reviewed publication)
	Chapter 5: Varying Perspectives of Stroke Survivors and Clinicians on the Effects of Utilising PGHD (peer-reviewed publication)
Step 5: Final Item Revision	Chapter 6, Section 6.1: Improving the Patient-Reported Outcome Measure of Utilising Person-Generated Health Data Preliminary Item Bank

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Patient-Reported Outcomes of Utilising Person-Generated Health Data in Simulated Rehabilitation Technology: Perceptions of Stroke Survivors

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Abstract

Patient-reported outcome measures (PROMs) contribute to improving the evidence base in many areas of clinical care. An area where PROMs can help build the evidence base is in person-generated health data (PGHD) that is available to people who engage with many health technologies. An important use case for PGHD outcomes is in simulated poststroke rehabilitation that use body-tracking technologies. This study gathered stroke survivor perceptions—through 2 focus groups and 5 interviews—on PGHD effects from a leading poststroke simulated rehabilitation technology. Deductive thematic analysis was performed. The findings show that PGHD outcomes of utilising PGHD can be measured. Moreover, the findings provided a deeper understanding of PGHD effects and broadened the scope through the perceptions of stroke survivors themselves. This work will further refine and validate the development of a PROM for utilising PGHD for poststroke simulated rehabilitation systems, and has wider relevance and application.

Keywords

Patient reported outcomes; stroke; telerehabilitation

Introduction

Patient-reported outcomes are independently self-reported status of a patient's health condition or experience [1-3]. Instruments that measure patient-reported outcomes are patient-reported outcome measures (PROMs). PROMs allow patients to contribute to more precise evaluation of the effects of a variety of health interventions, and their contribution to improving the evidence base in many areas of clinical care is well recognised [4]. The important role PROMs have in assessing and improving health care services are marked by key national projects that sought to develop suites of PROMs for different health domains or conditions. In the US, the National Institutes of Health sought to produce a suite of PROMs for various chronic conditions [5]; in Europe, the Netherlands is leading the push to include outcomes data in clinical registries; and closer to home, the Australian Commission on Safety and Quality in Health Care commissioned scoping studies, towards supporting the use of PROMs to improve quality of health care at a national level [6].

One area where PROMs could contribute to building the evidence base is in understanding person-generated health data (PGHD). PGHD are available to people who engage first-hand with a range of ubiquitous, user-friendly health information technologies such as mobile apps, wearable sensors and interactive computer games [7]. Various kinds of positive effects have been reported on patients who used PGHD in controlled settings [7], e.g., encouraging positive health behaviour change [8] and increasing patients' interest in their care processes [9-11]. However, there is currently no systematic way for patients to measure and report health effects that they experience from utilising their PGHD – whether positive, negative or nil. This hinders building the evidence base about the value of PGHD in conjunction with clinical care. Currently, PGHD outcomes are not integrated into existing clinical workflows [7]. If PGHD outcomes can be systematically measured and clinically integrated, similar to patient-reported outcomes of health conditions [5], PGHD may lead to more efficient and beneficial home-based health care services [12- 14].

An important use case for measuring PGHD outcomes is in home-based poststroke rehabilitation, that uses body-tracking technologies [15]. Stroke is a pertinent area for applying rehabilitation systems due to its high global burden, and the complexity of care involved [16; 17]. Rehabilitation can be costly and availability may be scarce for some patients

[18], hence the need for convenient and more practical rehabilitation choices for patients. Simulated rehabilitation systems offer a potentially effective option, with some benefits for stroke therapy previously documented [19-22]. These systems offer simulated activities of daily living [20], and – relevant to PGHD – may allow for a semicontrolled, consistent method of recording and assessing patients' therapeutic progress data [20; 21].

Implementing PGHD tools could further optimise these systems [15], by making performance data more accessible to patients at home – and their effects documented and available to therapists. More specifically, a PROM of utilising PGHD (PROM-PGHD) for simulated poststroke rehabiltiation technologies could measure self-reported outcomes of patients' access and use of health data they generate. Similar to how PROMs provide a more precise evaluation of the effects of health interventions [4], a PROM-PGHD could more precisely evaluate the effects of PGHD from poststroke simulated rehabilitation systems, and lead to a better understanding of their impact on the health status of patients.

This study presents the perceptions of stroke survivors, on the effects of PGHD from a poststroke simulated rehabilitation technology in order to refine a PROM-PGHD that has wider relevance and application.

Methods

Focus groups and semi-structured interviews were conducted with stroke survivors who have used a leading poststroke simulated rehabilitation technology [15]. Focus groups and interviews are a key step in a larger study of developing a PROM-PGHD, following the Qualitative Item Review (QIR) process of patient-reported outcome item development [5]. The entire process is described elsewhere.

Ethics Approval

This study was approved by the Deakin University Human Research Ethics Committee (Deakin HREC, ID 2017-087).

Participants

Stroke survivors with experience of utilising PGHD were recruited for convenience from participants in a randomised controlled trial (RCT) called STRIVE, which sought to determine the efficacy of a selected poststroke simulated rehabilitation technology, Jintronix [23]. These participants used Jintronix which utilises Kinect, a leading body-tracking technology [15, 23], and generates PGHD, see example in [15]. Participants were from the Melbourne metropolitan Area, Victoria, and Launceston, Tasmania (Australia). After the RCT lasting 8 weeks, participants in the intervention arm were invited to participate in focus groups of 3-6 people (or semi- structured interviews for participants who could not meet at the same day and time as other participants). There were 3 males and 7 females. All interviewees (5) were females.

Procedure

Participants were asked two categories of semi-structured questions: the first for the purposes of the STRIVE study and the second for the purposes of this study.

The first category for the STRIVE study gauged perceptions for the whole trial in terms of system usability, patient engagement, and intervention impact. Sample questions participants were asked included what parts of Jintronix were easy or difficult to use; whether use of Jintronix resulted in any behavioural changes to daily tasks; and whether Jintronix helped them in understanding and achieving their rehabilitation goals. Participant responses to the questions in this category, if they were also relevant to the second category of questions below, were included in our analysis.

The second category of questions was to conceptualise patient- reported outcomes of PGHD and ask participants to comment on any outcomes their PGHD may have had. Questions included what emotions or reactions they may have from seeing their PGHD; whether they felt more or less engaged after seeing their PGHD; and if any of their rehabilitation goals changed. Participants were also asked to comment on sample patient- reported outcome items. These questions and sample patient- reported outcome items were developed from steps 1-3 of QIR [5], where different effects of PGHD were identified:

1. Influence health-related behavioural changes in patients [8].
2. Change feelings about health status [10].
3. Influence interest in their care processes [9-11].
4. Facilitate personal care goals [10; 24].
5. Influence relationship with care providers [10; 11; 25; 26].

These effects were also used to guide the deductive thematic analysis conducted, as described in the next sub-heading. Steps 1-3 of QIR involved a literature review to scan established PROMs within the areas of interest; and selecting, categorising, and revising relevant PROM items to form initial themes that would guide the discussion with the target cohort.

All focus groups and interviews were held in meeting rooms at Deakin University at days and times that suited the participants. Participants who could meet at similar days and times were organised into focus groups, everyone else was organised into semi-structured interviews. In total there were 2 focus groups with 3 and 2 participants each. In each group, there was one participant who could not make it on the day. Additionally, there were 5 semi-structured interviews. All focus groups and interviews were audio-recorded.

Data Analysis

Nearly 10 hours of focus groups and interviews were transcribed verbatim; the former by GLD and the latter by a research assistant of the STRIVE project. GLD checked all transcriptions for accuracy, and de-identified them. The transcriptions and data management (including coding) were done using NVivo 11 (QSR International Pty Ltd, Melbourne, Australia).

Deductive thematic analysis was initially conducted independently by all authors on a few transcripts. Once common understanding was achieved for how themes are applied, GLD proceeded to analyse the rest of the transcripts; using a coding journal to clarify contentious quotes with the co- authors. Themes were derived deductively from the identified PGHD effects from the literature. The different themes are presented in the results below as subheadings.

Results

The results below show perceptions of stroke survivors on the effects of PGHD from a poststroke simulated rehabilitation technology.

Health-Related Behaviours

While stroke survivors mentioned some improvement with their ability to do some daily tasks as a result of their use of Jintronix, few of them mentioned any behavioural changes as a result of their PGHD. One of them did mention adjusting movement based on the scores they received at the end of an activity: “I automatically adjust what I was doing, if I couldn't burst every balloon I, I had to adjust.. To work out what I was doing wrong” (FG1_STC2-3). Seeing an improvement in performance data encouraged a stroke survivor to do more of the activities: “if I can see the improvement I'm making then it would...encourage me to maybe have more of those sessions” (INT1_STC3). However one stressed that positive health data was not enough, and would not have done the exercises “that long if there hadn't been somebody driving me” (INT1_STC1).

Feelings About Health Status

Most stroke survivors felt either “disappointed” (FG1_STC2-3) or pleased with themselves depending on their PGHD. Seeing their performance data go down, or “wanting to achieve and not achieving, or you not doing it the way you want” (INT2_STC1) resulted in feelings of being “disheartened” (INT2_STC1), with one going as far as describing the experience as “offensive” (INT1_STC1). “Levels of frustration” were also experienced when their data fluctuated: “sometimes you went backwards, sometimes you went forwards” (INT2_STC1). It could also be discouraging, making one think that they may have reached their limit: “I would think well surely this is the benchmark, and so I probably thought, would have thought nah, I’m probably not gonna to [sic] get any better” (INT1_STC1), with the same survivor cautioning that “it would depress me”. Positive feelings such as “happy” and “satisfying” (INT2_STC3) abound where their PGHD were also positive. One described the experience as feeling “good about yourself” when the data was “improving” (FG1_STC2-1). Positive PGHD was also “reassuring” (INT2_STC3) and “exciting” (INT1_STC1). It could make them feel “hopeful” and “confident” because “it was encouraging,” (INT2_STC3) “saying okay you can perform” (INT3_STC1). A survivor humorously shared that it gave the assurance that “you’re not totally

dead" (INT3_STC1). It can therefore be observed that positive or negative PGHD correlated respectively with positive or negative emotions.

There were however a few stroke survivors who were neither disappointed nor pleased based on their PGHD, with one saying "it doesn't really matter", and that the data neither "encouraged (n)or discouraged" (FG2_STC1_1). There was a sense of acceptance that their performance can go up or down: "I was very, very upbeat about my progress, I was very pessimistic about my progress. And different times I felt, different" (FG2_STC1_1). Meanwhile one survivor described seeing gains in their PGHD as "kind of surprising how much you can achieve, you know you kind of surprise yourself what you can achieve" (INT3_STC1).

Finally, while some stroke survivors associated their PGHD with their performance: "Yeah you'd know if you didn't get a hundred" (FG1_STC2-3), others relied on their own feelings about their health to assess their performance: "numbers on the screen isn't going to tell me the other, one thing or the other" (INT1_STC1). However one had lesser trust on their PGHD and more on other people describing their improvement for them: "when they say, oh, you're doing this a lot better than you were, that you actually, realise that you have improved" (FG1_STC2-3).

Interest in Care Processes

Stroke survivors reported interest in how the exercises contributed to the progress of their therapy, as a result of seeing their PGHD. They wanted "to see whether there were any gains" (FG1_STC2-3), or some "improvement" (FG2_STC1_2); asserting that "there must be some things that have, that have improved from that, even if" (FG2_STC1_1) they were tired. Others expressed interest in "having an indicator of previous performance" (FG1_STC2-3), a "comparison point" (INT2_STC1), and see how they would "stack up at the end" (FG1_STC2-3). Still others liked "tracking" (FG2_STC1_1) their progress, whether good or bad: "because I understand it, um, some days are bad, some days are good" (FG2_STC1_1). A few survivors also wanted to see when they "weren't so good" (FG1_STC2-1) that week, and when they were: "it told me when you were right it's, it's um.. If you are doing okay or or not" (INT2_STC3). They also wanted to know why: "because you realise that you know you're not going as far because you have the disability part of it" (INT3_STC1); and whether "there's a

bit more to do" (INT2_STC3) to improve. Some of them especially remarked on things they could have done better, with one remarking that "I should have been standing up, hmm, longer for weeks" (FG1_STC2-1). As such, their PGHD could "be helpful" to know what they needed "to do (to) improve" (INT2_STC3), comparing it with teacher-student feedback: "it's like uh, you know student getting feedback from...their teacher or something...it's important to get feedback" (INT2_STC3). One described the experience as "a bit like having a physio visit you at home, or having an OT visit you at home" (FG1_STC2-3).

Some stroke survivors also reported interest in understanding where they "were at in the program" (INT2_STC3), to see "how far there was to go if you can, by what percentage was showing" (FG1_STC2-3), and feel better when they were close to finishing an exercise: "I see the percentage, and when I was getting to seventy percent, I would think uh, this is good I'm getting towards the end" (FG1_STC2-1). This could be important for self-management, as described by one survivor: "It was certainly something that I watched, to see where I was at. 'Cause um, y- you need to think about this, we have some sort of a budget of energy that you have to manage yourself, and you can't afford to get to empty" (FG1_STC2-3).

There were a few survivors who didn't "really care" (FG2_STC1_1), didn't "take that much notice" (FG1_STC2-1) of their PGHD, and that they were just "going with the flow" (FG2_STC1_1). A survivor described seeing their data but not perceiving any benefit from it: "it was just information...I didn't feel I was involved in any way" (INT2_STC3). This lack of feeling involved was also true even when the PGHD was informative: "You knew what you had to do to improve or not, but I I didn't feel involved really" (INT2_STC3).

Interestingly, a few stroke survivors reported how seeing their PGHD affected their perceptions towards their therapy. Positive PGHD gave the impression that the therapy was effective, and "the confidence of actually doing the exercises" (FG1_STC2-3); whereas negative PGHD could imply that the therapy was "pretty useless" (INT1_STC1). However there was also one stroke survivor whose perceptions of the exercises was unaffected: "I wouldn't say I was more engaged or less engaged by it, I took it for what it was" (INT2_STC1). Finally, another survivor found that the data helped with self-assessment: "I'm good in this game but I'm not good in the other game, it gives that sort of feeling you know" (INT3_STC1).

Personal Care Goals

Stroke survivors reported receiving "an extra percentage of motivation" (FG1_STC2-1) and an "incentive to do better" (FG1_STC2-3) when they see their PGHD. Seeing how their data changed over time would make therapy more "motivational", because it "feels like a bit of a competition? To see if we can do better" (FG1_STC2-3). It helped them develop "short term and long term goals" or a new "benchmark to try and achieve next time", and kept one "focused to some extent" (INT2_STC1). However, it was cautioned that a downward slope could be detrimental: "you can get hard on yourself or feel 'Oh I didn't get that right' and if you keep doing that and you're not achieving 100% and the score keeps flashing at you, that can be a positive motivator, but can also (be) a negative one" (INT2_STC1). There was one survivor however whose motivation remained unchanged: "I know when I haven't done well. And numbers on the screen isn't going to tell me the other, one thing or the other" (INT1_STC1). Meanwhile, some survivors reported being motivated to simply finish the therapy, "to get to somewhere in time" and to concentrate on trying to "achieve it" (FG1_STC2-3).

Relationship with Care Provider/s

Some stroke survivors were prompted to ask their therapists when they "haven't been doing well," and why so they can improve: "what [sic] reason to it, and then they tell me off for certain things" (INT3_STC1). However, while they "wanted to know why it was so different so...low" (INT2_STC3), they were less prompted to ask about their performance when it was good: "when it was good I didn't ask questions" (INT2_STC3). Surprisingly good data however prompted one to ask how it could have happened: "a couple of times I was surprised that I had a higher score when I thought I'd done badly" (INT1_STC1). Regardless, one survivor reported being prompted to ask for more assistance: "If they were always bad then I would need uh more assistance and even if they (were) good um, they (are) not perfect, right so I would want to have more, more assistance to um, to to improve" (INT2_STC3).

Discussion

This study is the first to gather perceptions of stroke survivors on the effects of PGHD for PROM development. In fact to our knowledge, this is the first study that gathered patient-reported outcomes of utilising PGHD. While there have been studies presenting patient-reported outcomes of a health condition [3, 27] such as quality of life as a result of using a PGHD-enabled device [28], and patient-reported experiences or satisfaction with health interventions and technologies [29-31], there have been no studies systematically soliciting patient-reported outcomes of utilising PGHD. This study begins to understand how PGHD may affect the health outcomes of people who use them, from their own perspective. More specifically, this contributes to the missed opportunity of the poststroke simulated rehabilitation literature to engage patients in their own health care [15].

The findings of this study demonstrate that we can measure outcomes of utilising PGHD, and have shown some similarities with PGHD effects reported in the literature. Moreover, the findings have also provided a richer understanding of the effects, and at times broadened the scope. This is a strength of conducting qualitative data collection for patient-reported outcomes of a health domain of interest [3].

The findings show that while in general patients are affected positively or negatively based on their PGHD, some are not affected at all. First, while stroke survivors' perceptions confirm previous findings that PGHD may influence positive behavioural changes [8], it has also shown that some patients may only be influenced when encouraged personally by their therapists. Second, the findings confirmed that PGHD could increase patient satisfaction with their health [10], but for the most part only when they are positive. Negative PGHD can, in the stroke survivors' own words, be offensive or depressing. Still, other survivors reported indifference to their PGHD. This emphasises the need to utilise patient-centered design when developing health technologies [32], particularly when PGHD is produced [15].

Third, this study affirms reports that direct access to PGHD can increase patient engagement [9-11]; however, we have learned that for some stroke survivors PGHD is just information that does not make them feel involved. Fourth, development of new goals or benchmarks as a result of their PGHD were also reported by stroke survivors, supporting assertions that PGHD

facilitates personalised health strategies [10, 24], but others relied on their own feelings about their health to formulate their goals and were neither motivated nor demotivated by their PGHD. Finally, while the literature showed that PGHD may improve health management coordination between patients and their care providers [10, 11, 25, 26], stroke survivors using a simulated rehabilitation system may only ask questions when their PGHD shows poor results, or when their results surprise them.

These findings have direct implications for PROMs to utilise PGHD. As mentioned before, this paper is part of a larger study to develop a PROM-PGHD with poststroke simulated rehabilitation systems as a use case. For example, we noted that previous literature on effects of PGHD have not addressed "levels of frustration". This will be added as an item to accommodate for stroke survivors' experience of seeing their PGHD go up and down. This study demonstrates how the focus groups and interviews will be used to broaden the coverage of the PROM.

One limitation to our study is that all of the focus groups and interviews were moderated by the same person (GLD), which has the risk of a narrower array of themes and ideas. However, this method's advantage is that it increases the chance of thematic saturation, as GLD would have learned relevant themes as the discussions progressed [3]. Additionally, our sample was never intended to represent all stroke survivors; it was meant to elicit the input of survivors who have used a leading poststroke simulated rehabilitation technology to guide the development of the PROM-PGHD. The PROM will be refined and validated further as per the next step of QIR [5].

Poststroke simulated rehabilitation systems were selected as the use case for measuring PGHD outcomes because of the global burden of stroke and the potential benefits of simulated rehabilitation systems. However research into applicability of a PROM-PGHD for the wider spectrum of health technologies are ongoing. The authors will report elsewhere on how these PROMs are proving their validity in other cases of technology and health domains. Practitioners and developers of health technologies need to understand how PGHD affect people differently. Therefore, when considering PGHD-enabled devices the patient perspective has to be given priority [15, 32]. Future studies should consider relevant health

domain and technology use cases for applying a PROM-PGHD and evaluate their implications on the care process.

Conclusions

This study has described the importance of patients self- reporting the effects of utilising PGHD through a PROM. It has identified a pertinent use case in poststroke simulated rehabilitation systems, and gathered perceptions from stroke survivors. The findings highlight five key themes that demonstrate that PGHD outcomes of utilising PGHD can be measured. Moreover, this study has provided a deeper understanding of those effects and broadened the scope through the words of the stroke survivors themselves. The perceptions gathered here will further refine and validate the development of a PROM-PGHD for poststroke simulated rehabilitation systems and has wider relevance and application.

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5 Improving the Preliminary Item Bank: Varying Perspectives of Stroke Survivors and Clinicians (peer-reviewed publication)

The previous chapter presented results of discussions held with stroke survivors who have used the simulated stroke rehabilitation system Jintronix in a clinical setting. The discussions were held to elicit input from people with the case health condition, which is Step 4 of the method to develop a PROM-PGHD to enable PGHD users to routinely and systematically report how access and use of their PGHD affects them.

In this chapter, a peer-reviewed publication is presented, which further reports on discussions held with stroke survivors who have voluntarily used Jintronix as an outpatient in Headway ABI, a rehabilitation service in Queensland, Australia; and with stroke survivors and physiotherapists who participated in a demonstration of Jintronix, recruited from Austin Health hospital in Melbourne, Australia.

The appendices of the publication are presented in this thesis in Appendix F. The full discussion guides are presented for this thesis in Appendix G.

For reference, this chapter is mapped to the step of the PROM-PGHD Development Method that it implements in Table 14 below.

Table 14. Mapping Chapter 5 with the PROM-PGHD method step it implements

Steps of the PROM-PGHD Development Method	Chapters/Sections of this Thesis
Step 1: Literature Review	Chapter 1, Section 1.3.2: Literature Review (peer-reviewed publication)
Analysis of Step 1 Step 2: Binning and Winnowing Step 3: Initial Item Revision	Chapter 3: Development of a PROM of Utilising PGHD: Preliminary Item Bank (peer-reviewed publication)

Step 4: Eliciting Patient Input	Chapter 4: Eliciting Stroke Survivors' Perceptions on the Effects of Utilising PGHD (peer-reviewed publication)
	Chapter 5: Varying Perspectives of Stroke Survivors and Clinicians on the Effects of Utilising PGHD (peer-reviewed publication)
Step 5: Final Item Revision	Chapter 6, Section 6.1: Improving the Patient-Reported Outcome Measure of Utilising Person-Generated Health Data Preliminary Item Bank

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Any figures and tables that appear in this paper have been renumbered for the purpose of this thesis.

"We are very individual": Anticipated effects on stroke survivors of using their person-generated health data

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Abstract

Background: Person-generated health data (PGHD) are produced by people when they use health information technologies. People who use PGHD may experience changes in their health and care process, such as engagement with their own health care, and their sense of social support and connectedness. Research into evaluating those reported effects has not kept up; thus a method for measuring PGHD outcomes was previously designed and applied to the exemplar case of Kinect-based stroke rehabilitation systems. A key step of the method ensures that the patient's voice is included. Allowing stroke survivors to participate in the development and evaluation of health services and treatment can inform health care providers on decisions about stroke care, and thereby improve health outcomes.

Objective: This paper presents the perspectives of stroke survivors and clinicians on the anticipated effects of stroke survivors' use of PGHD from a poststroke simulated rehabilitation technology.

Methods: This study gathered the perspectives of stroke survivors and clinicians through three focus groups and three interviews, recruited for convenience. Participants were also asked questions intended to encourage them to comment on the initial items of the PROM-PGHD. Deductive thematic analysis was performed.

Results: This paper has further demonstrated that outcomes of utilising PGHD can be measured. For instance, stroke survivors described that using PGHD could result in positive, negative, and nil effects on their health behaviours. Survivors and clinicians had varying perspectives in three of the six themes presented, and emphasises the importance of allowing stroke survivors to participate in the evaluation of digital health services.

Keywords

person generated health data; patient reported outcome measures; questionnaire design; qualitative research; interviews; focus groups; stroke rehabilitation; information technology; consumer health informatics; evidence-based practice

Background

Person-generated health data (PGHD) are produced by people when they use health information technologies (HITs) such as activity tracking devices and applications, and simulated rehabilitation technologies, to monitor their health outside of a clinical setting. People may also record and analyse their PGHD for themselves, which includes wellness and other biometric data [1-3]. It has been reported that people who use PGHD have changes in their engagement with their own health care, their relationship with their healthcare providers, and their sense of social support and connectedness [4-11]. Thus PGHD utilisation promotes participatory health.

Research into evaluating those reported effects however, has not kept up [1, 2, 12], and there is a need for a systematic way of measuring health outcomes for people who access and utilise their PGHD [1, 13, 14]. In response, a method for developing patient-reported outcome measures (PROMs) of utilising PGHD, called the PROM-PGHD Development Method, was designed by the authors [15, 16]. Using PROMs has also been suggested as a way to

standardise the measurement of PGHD outcomes and strengthen the empirical evidence around PGHD [3].

PROMs allow people to self-report their health status or experience with an illness or treatment, without the need for additional clinician interpretation of the report [17-19]. A patient-reported outcome may indicate status at a single point of time, or be compared with previous patient-reported outcomes to show changes over time [17, 20]. PROMs enable patients to participate in improving the evidence base of a variety of HITs, as patients contribute to more precise evaluation of the effects of those technologies [21]. The value of using PROMs to standardise evaluation of health status for increased quality of health care provision is marked by key projects around the world [22, 23].

Similar to how PROMs may be used in conjunction with other health indicators [22], PROMs-PGHD can complement existing patient- or clinician-reported outcomes of interventions or monitoring plans involving HITs. PROMs-PGHD can measure health outcomes or status as a result of people accessing, using and reporting their own PGHD. This would allow people to participate in evaluation of HITs, and the effects of using health data they generate themselves [15].

The PROM-PGHD Development Method was applied to the exemplar case of Kinect-based stroke rehabilitation systems (K-SRS) [15]. The complexity of care involved in stroke, and its high global burden make it an important area for implementing rehabilitation systems [24, 25]. Barriers to access and availability, such as cost and distance, necessitate more convenient and practical rehabilitation options for stroke survivors [26]. Simulated rehabilitation technologies such as K-SRS offer stroke survivors an alternative, effective option to perform simulated activities of daily living [27]. Moreover, they allow for a more consistent and semicontrolled process of monitoring and evaluating survivors' therapeutic progress [27, 28]. For instance, U.S. Food and Drug Administration (FDA) approved Jintronix^{TM} provides users with games that simulate clinical exercises [29, 30], and produces PGHD [2]. Benefits of such systems to stroke therapy have been reported [27, 28, 31, 32]. Therefore, measuring PGHD outcomes in K-SRS is an important use case [2].

A key step of the PROM-PGHD Development Method ensures that the patient's voice is included through focus groups and/or semi-structured interviews [15]. This allows the target cohort to provide feedback on the initial items of the PROM-PGHD. It also allows developers to understand the thinking processes and vocabulary of the target cohort, and to identify any measurement areas that are not covered by the PROM-PGHD's initial item bank. This would bridge current gaps between the initial items and the target domain to be measured [15]. For reference, the PROM-PGHD Development Method is illustrated in Figure 1 (*Figure 8 in this thesis;* previously published in [16]).

Allowing stroke survivors to participate in the development and evaluation of health services and treatment has been shown to inform health care providers on decisions about stroke care, and thereby improve health outcomes [33]. In particular, qualitative activities such as focus groups and interviews can be valuable in revealing aspects of stroke survivors' health care and rehabilitation process that is most important to them, such as types of therapy they think are most effective [33] and factors that will help motivate them to perform therapeutic exercises over the long-term [34]. Additionally, stroke survivors may also provide direct insights into considerations that would enable a stroke self-management program to be effective [35], such as their readiness, support and collaborations needed for them to successfully self-manage their care [36]. This also includes stroke survivors' complex, changing nature of self-management where their carers could be either encouraging or constraining [37]; the influence of interpersonal care practices on their overall recovery [38]; and primary rehabilitation outcomes they want to achieve [33].

Eliciting the input of stroke survivors is particularly important because there could be differences in their perspectives and that of their care providers, regarding treatment and management. For instance, differences in stroke survivors and their therapists' understanding of self-management and accompanying barriers could result in conflicting expectations of the role that patients and their therapists have of each other. This could undermine the success of self-management strategies [39]. Desired health outcomes from physical activities such as structured exercises and activities of daily living could also differ between stroke survivors and those of health professionals involved in their rehabilitation. While the former may value the outcome of participation in personally meaningful activities, resulting in a continued

sense of self post-stroke, clinicians may value the outcome of functional or physical movement which may not be as personally meaningful for the stroke survivors [40]. These differences may also present challenges to the design and evaluation of HITs that produce PGHD. For example, a 'tension' between the needs and preferences of patients with surgical site infections and their care providers has been documented, and has implications for the design and implementation of a web-based wound management application that produce PGHD [8].

Objective

This paper presents the perspectives of stroke survivors and clinicians on the anticipated effects of stroke survivors' use of PGHD from a poststroke simulated rehabilitation technology.

Methods

As part of the PROM-PGHD Development Method, focus groups were conducted with stroke survivors and clinicians, or semi-structured interviews for those who could not agree on a similar day or time with others.

This study was conducted as part of a larger research project, in order to refine the preliminary item bank of a PROM-PGHD [15, 16]. Other activities to develop the PROM-PGHD are reported elsewhere, including in [2, 13, 15]. Earlier discussions with a different cohort of stroke survivors [13] are discussed briefly in the results section to show parallels and variety of how PGHD may affect health outcomes.

The presentation of this paper was largely guided by recommendations for qualitative research in eHealth [41]. The procedure for conducting the discussions are outlined in Appendix 1 (*Appendix G in this thesis*).

Setting

Participants were recruited from two sites in Australia: Headway ABI in Queensland and a large metropolitan hospital in Melbourne, Victoria. Headway ABI is a not-for-profit outpatient

clinic providing rehabilitation services to people who have an Acquired Brain Injury. Their clients usually come from the cities of Brisbane and Gold Coast. The metropolitan Melbourne hospital is a tertiary and quaternary health service, and specialises in areas such as cancer, infectious diseases, and rehabilitation.

As far as the authors know, Headway ABI is the only health and fitness centre in Australia where Jintronix simulated rehabilitation services is available to stroke survivors. Thus, participants recruited through Headway would be the only ones in Australia who would have voluntarily opted to use Jintronix as part of their ongoing therapy.

Ethics Approval

Recruitment through the Melbourne health service was approved by the relevant Health Human Research Ethics Committee (AU RED HREC: HREC/17/Austin/492). Recruitment of participants through Headway ABI was approved by the University of Melbourne Medicine and Dentistry Human Ethics Sub-Committee (ID: 1852259.1).

Participants

The researchers aimed to include two groups: stroke survivors themselves, and physiotherapists who had experience of working with such clients. At Headway ABI only one client was available to be recruited. We aimed to also include staff but this did not occur because of their limited availability.

Headway ABI

Eligible stroke survivors were adults who used Jintronix^{TM}, an FDA-approved [29, 30], simulated rehabilitation system using a leading body-tracking technology, Kinect© [42], as part of usual outpatient therapy provided by Headway ABI. They were eligible if they had not used any other stroke rehabilitation software, e.g., an exercise platform using consumer technology Nintendo Wii© [43], were proficient in English, and did not have any mental, visual, or verbal medical conditions that may impact their participation. Eligible participants were identified by a staff, who initiated first contact with potential participants, and collected their consent to release contact information to the authors, i.e., e-mail, or telephone/mobile

number. After receiving the details of eligible participants, GLD contacted the eligible participants to discuss the project, invite them to participate, and secure their verbal consent.

Only one stroke survivor (age group 60-64) could be recruited from Headway ABI. The exact age is concealed as per BMJ requirement. The semi-structured interview was conducted through a Zoom™ video call. It had been 5 months since her last stroke, and 4 years since her first.

Melbourne Health Service

Eligible stroke survivors were adults who underwent usual therapy provided by the Melbourne health service, have not used any other stroke rehabilitation software, were proficient in English, and did not have any cognitive, visual or speech impairments that impacted their participation. Eligible participants were identified by a clinician collaborator from the Melbourne health service. The collaborator initiated first contact with potential participants, to gather potential interest. After receiving the contact information of participants, GLD and FB contacted the eligible participants to discuss the project, and invite them to participate. Eligible physiotherapists were those who provided therapeutic services to stroke survivors, and had not used any other stroke rehabilitation software.

All participant focus groups and interviews were conducted at a rehabilitation campus of the Melbourne health service. 5 clinicians were able to participate in a focus group, conducted in January 2019. The most experienced clinician had 37 years of experience, with 35 of those working with stroke survivors. The least experienced had 2 years, with 1 year working with stroke survivors. Table 15 (*published Table 1*) presents each clinician's number of years working as a physiotherapist, and with stroke survivors. Meanwhile, 4 stroke survivors were able to participate in 2 separate focus groups; and another 2 stroke survivors participated in semi-structured interviews. All focus groups and interviews with stroke survivors occurred in April and May, 2019. The oldest was within the age group of 75-79 years old, and it was 11.5 years since their first stroke. The youngest was within the age group of 55-59 years old, and it was 2 years since their first stroke. Table 15 (*published Table 1*) shows each survivor's age groups and number of years since their first stroke. Their exact ages are concealed as per BMJ requirement.

Table 15. Clinicians' length of experience, and stroke survivors' age groups and years since stroke

Participant #	Clinicians		Stroke Survivors	
	Years as Physiotherapist	Years working with stroke survivors	Age group	Years since first stroke
1	37	35	75-79	11.5
2	33	28	70-74	20
3	28	25	65-69	3.5
4	7	7	65-69	4
5	2	1	60-64	2.5
6			55-59	2

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 deductively from the identified PGHD effects from the literature [15]. 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.

Additional information on conducting the discussions is outlined in Appendix 1 (*Appendix G in this thesis*).

Results

The results are summarised and categorised below as subheadings according to the different themes [15]. Throughout the coding process, however, a sixth theme on relationship with family and carers emerged and is presented below.

As earlier discussed, stroke survivors' perspectives on health-related aspects could be different from those of care providers, which might produce tensions [8] that could undermine the success of self-management strategies [39] and the technologies that support them [8]. Therefore any variations in the perspectives of stroke survivors and the clinicians are also important, and described briefly.

To see more description of the health effects including example quotes, please see Appendix 2.

Health-Related Behaviours

This section summarises the different effects that PGHD utilisation may have on health-related behaviours of stroke survivors, that were raised during the discussions (Table 16; *published Table 2*). It also briefly discusses how the perspectives of stroke survivors and clinicians are similar. To see more description of the health effects including example quotes, please see Appendix 2.

Table 16. Discussed PGHD utilisation effects on health-related behaviours of stroke survivors

Health-Related Behaviours	
Stroke Survivors	Clinicians
• Seeing their progress through their PGHD could potentially encourage them to keep going and do more of their rehabilitation exercises.	• Clinicians mainly anticipated that PGHD would be potentially encouraging for stroke survivors, but for slightly different reasons.

• If their PGHD shows that the system is helping their recovery, they would use it more and more. • PGHD may help them know their movement mistakes, and correct themselves. • It may be important for the PGHD to be positive, as low PGHD would indicate that the system was not helping with their rehabilitation. • Low PGHD could cause survivors to be less inclined to continue using the system. • If they felt they did not perform an exercise as well as their resulting PGHD showed, they would lose confidence on the system. • A few survivors felt that PGHD would have no effect at all on their health behaviour.	• PGHD would inform survivors of how much they've exercised and increase their understanding on why they have to do the exercises. • Increased understanding could encourage them to be more complaint. • They agree that negative PGHD could be discouraging.

Similar Perspectives

Stroke survivors and clinicians recruited through the Melbourne hospital health service reported positive and negative potential effects of PGHD use on their health behaviours. Additionally, survivors described neutral potential effects of PGHD on their health behaviours. The stroke survivor from Headway ('Site 2 survivor') did not have any comment relevant to the theme.

Feelings About Health Status

This section summarises the different effects that PGHD utilisation may have on stroke survivors' feelings about their health status, that were raised during the discussions (Table

17; *published Table 3*). It also briefly discusses how the perspectives of stroke survivors and clinicians are similar. To see more description of the health effects including example quotes, please see Appendix 2.

Table 17. Discussed PGHD utilisation effects on stroke survivors' feelings about their health status

Feelings About Health Status	
Stroke Survivors	Clinicians
• Seeing health progress and gradual improvements makes stroke survivors feel so much better, and gives them a sense of achievement, accomplishment, and satisfaction. • The Site 2 survivor reported feeling more confident as a result of seeing her PGHD. • Some stroke survivors also reported potentially feeling self-awareness about their health through PGHD. • PGHD could allow them to measure levels of improvement or deterioration, and see if they're heading in the right direction. • One survivor did not think it would make them more self-aware. • PGHD could potentially raise feelings of disappointment and confusion. • If their PGHD indicates that their performance is declining, it would be discouraging and might even cause a	• Seeing PGHD progress might provide satisfaction for stroke survivors. • A clinician noted that survivors could have increased confidence. • Clinicians agree that simply providing percentages to survivors at the end of an exercise could cause confusion, as they may not understand whay they mean. • Clinicians think that PGHD might cause some to doubt the effectiveness of the system. • Two clinicians also thought that some survivors might feel indifferent, that it wouldn't worry some people.

mental health issue such as depression. • A mismatch between how they felt they performed and what their PGHD was showing could make them feel dejected. • Simply seeing percentages at the end of an exercise, as is the case with Jintronix, might also cause confusion, as it wouldn't be clear what those percentages are measuring. • A Site 1 survivor felt indifferent towards PGHD, because it's how they feel about doing their activities that matter. • PGHD could also elicit different emotions at different times.	

Similar Perspectives

Participants reported that using PGHD could result in positive, negative, and neutral effects on survivors' feelings about their health status. These feelings were differentiated from the previous theme because they did not specifically describe actions that indicate changes in behaviour, i.e., undergoing more exercises, or changing movement actions to improve performance.

New Theme: Relationship with Family and Carer/s

This section summarises the different effects that PGHD utilisation may have on stroke survivors' relationship with their family and carer/s, that were raised during the discussions (Table 18; *published Table 4*). It also briefly discusses how the perspectives of stroke survivors

and clinicians are similar. To see more description of the health effects including example quotes, please see Appendix 2.

Table 18. Discussed PGHD utilisation effects on stroke survivors' relationship with family and carer/s

Relationship with Family and Carer/s	
Stroke Survivors	Clinicians
• Site 1 survivors could potentially be compelled to share their PGHD with family to include them in their state of health. • PGHD might help with describing their therapy progress with family, as it's something visual they can show. • Sharing positive PGHD to family could be a pleasant experience. • The Site 2 survivor and some Site 1 survivors would not really be prompted and would not bother contacting loved ones.	• Clinicians agree that stroke survivors can share PGHD with family, and could be a chance to brag about their progress. • PGHD might help older survivors connect with younger family members.

Similar Perspectives

Clinicians and survivors felt that PGHD may generally have positive effects on the relationship of stroke survivors and their family.

Interest in Care Processes

This section summarises the different effects that PGHD utilisation may have on stroke survivors' interest in their care processes, that were raised during the discussions (Table 19; *published Table 5*). It also briefly discusses how the perspectives of stroke survivors and clinicians vary. To see more description of the health effects including example quotes, please see Appendix 2.

Table 19. Discussed PGHD utilisation effects on stroke survivors' interest in their care processes

Interest in Care Processes	
Stroke Survivors	Clinicians
• Site 1 survivors indicated that seeing rehabilitation progress would help them know whether the system was working and that their effort was worthwhile. • Seeing their PGHD could help them understand the process they're undergoing, and see if they're improving everyday. • PGHD could be better than relying on clinician's feedback, which could be slow and limited to what they tell survivors. • PGHD could potentially increase their interest in knowing their therapy status, as it would give them a better picture of the progress they've made, and how far they have have to go. • PGHD could help survivors with self-management of energy. • For one Site 1 survivor, PGHD does not interest them at all. • Interest may also change over time, from detailed interest to big picture,	• The sentiments of stroke survivors about PGHD affecting interest in the care process were strongly reinforced by the clinicians. • Stroke survivors would potentially understand their rehabilitation progress by comparing results of their exercises over time. • Clinicians believed that survivors would be more interested in how PGHD could have positively impacted achievement of their activities of daily living (ADL) goals or functional activity. • Clinicians try to make their therapy goal-focused, and PGHD could help survivors understand how their exercises related to their goals. • A question in the PROM-PGHD could be related to understanding the purpose of the exercise in their recovery. • A clinician felt that even if survivors didn't fully understand the data, they would like to see something.

i.e., whether they're improving or their treatment needs to change. • PGHD would be a form of feedback to inform survivors where they've done well, and where they need to do better. • PGHD could potentially affect Site 1 survivors' trust about their care process.	• Clinicians agree that PGHD could affect survivors' sentiments about the care they receive, i.e., if they were using the system and they just stopped without the data they would wonder why they had to do the exercises in the first place.

Varying Perspectives

While clinicians largely discussed how PGHD could potentially increase stroke survivors' interest in how their exercises contributed to their therapy progress, survivors also discussed their interest in knowing their recovery progress for self-management of energy, and in improving their movement and performance. All participant groups described interest about the care or system processes, as a result of seeing PGHD.

Personal Care Goals

This section summarises the different effects that PGHD utilisation may have on stroke survivors' personal care goals, that were raised during the discussions (Table 20; *published Table 6*). It also briefly discusses how the perspectives of stroke survivors and clinicians vary. To see more description of the health effects including example quotes, please see Appendix 2.

Table 20. Discussed PGHD utilisation effects on stroke survivors' personal care goals

Personal Care Goals	
Stroke Survivors	Clinicians
• Seeing PGHD encouraged the Site 2 survivor to try harder to improve the score each time.	• Some clinicians agreed that PGHD could potentially encourage stroke survivors, to keep them striving and motivated.

• Some Site 1 survivors shared that PGHD could potentially affect them in a similar way, that they would likely want to improve their score.	• A clinician felt that PGHD would not worry about their PGHD at all. • A clinician did not think that PGHD would help survivors form new goals based solely on their PGHD, without liaising with their therapist.

Varying Perspectives

All participants described how PGHD could potentially motivate stroke survivors to improve their therapy performance, although one clinician perceived otherwise. Additionally, a survivor felt that PGHD might help them form new goals, although a clinician disagreed.

Relationship with Care Provider/s

This section summarises the different effects that PGHD utilisation may have on stroke survivors' relationship with their care provider/s, that were raised during the discussions (Table 21; *published Table 7*). It also briefly discusses how the perspectives of stroke survivors and clinicians vary. To see more description of the health effects including example quotes, please see Appendix 2.

Table 21. Discussed PGHD utilisation effects on stroke survivors' relationship with their care provider/s

Relationship with Care Provider/s	
Stroke Survivors	Clinicians
• After seeing her PGHD, the Site 2 survivor was prompted to ask her therapist, to ask what she could do better. • Most Site 1 survivors agree that PGHD could potentially prompt them to contact their clinician,	• Clinicians agreed that stroke survivors would potentially be prompted to contact them if they did badly, to ask how they can improve. • Some clinicians also agreed that survivors would ask for more explanation about how the scores

especially if it's at odds to how they think they're performing. • Interestingly, if their PGHD is better than how they felt they did, it could potentially prompt them to tell their clinician that the results are not quite right. • For one survivor, seeing PGHD would not be the instigator of seeking more help. • There was also some interest with what happens to their PGHD, i.e., what it's going to be used for. • Another survivor would be prompted to ask their therapist if they're making progress.	were calculated, and how their PGHD relates to their progress. • Some clinicians felt that if survivors know their PGHD, it might stimulate them to be more compliant as it promotes accountability, like doing homework.

Varying Perspectives

Clinicians and stroke survivors agreed that PGHD could potentially prompt survivors to contact their therapists to ask what they could do better. However, while clinicians shared that PGHD will need to be discussed with survivors to help them understand, survivors stressed that they would want to see their PGHD regardless, and may even be prompted to ask their therapists what happens to the PGHD they produce. Additionally, some survivors may be prompted to ask what their therapists are doing incorrectly with regards to the treatment they receive, and whether their therapists are happy with their progress.

Discussion

This study is the first to gather and compare the perspectives of stroke survivors and clinicians, in order to develop a PROM-PGHD for a simulated rehabilitation system. The perceived PGHD potential outcomes described by Site 1 survivors who received a demonstration of Jintronix were mostly similar to those reported by the Site 2 survivor, who

has used Jintronix in a real-life, voluntary, outpatient setting. Moreover as earlier described this paper is part of a larger study, and there were significant parallels to the results of this study to the experiences of stroke survivors who have used Jintronix for 8 weeks in a RCT, reported previously [13]. This indicates that the technology demonstration provided to the Site 1 cohort, coupled with their lived experience with stroke was a valuable way of gathering perspectives about the potential effects of PGHD utilisation.

Stroke survivors and clinicians had varying perspectives in three of the six themes presented. This puts emphasis on the importance of allowing stroke survivors to participate in the evaluation of digital health services. Consideration of how their perspectives differ with that of clinicians has relevance to the success of patient self-management strategies [39], and to the design and evaluation of PGHD technologies [8, 44].

The findings show that stroke survivors are interested in their PGHD to better self-manage their energy during therapy, something that clinicians did not raise in the discussions. Moreover, while clinicians expect survivors to contact them in order to understand how their PGHD relates to their therapy, survivors would prefer to have the opportunity to understand it for themselves. Stroke survivors would prefer to have access to all of their PGHD, so that their therapy process is open and transparent. This highlights the differences that patients and clinicians could have in their understanding of self-management strategies, which could lead to conflicting expectations in the roles that patients and their clinicians have of each other [39].

Interestingly, while it has been suggested that clinicians valued functional or physical movement outcomes more than patient gains in activities of daily living (ADL) [40], the clinicians we spoke to understood that survivors personally valued how their therapy contributed to an improved performance of ADL. As such, they seek to tailor their therapy based on the ADL goals of their clients. This indicates that while patients and clinicians may indeed have varying perspectives [39], the potential for tensions to occur between the needs and preferences of patients and their care providers [8] could be reduced through a similar understanding of health treatment goals.

This paper has further demonstrated that outcomes of utilising PGHD can be measured [13]. For instance, stroke survivors described that using PGHD could result in positive, negative, and nil effects on their health behaviours. PGHD use also has the potential to increase feelings of self-awareness about their health. Additionally, the potential for survivors' interest to change over time from detailed PGHD towards a big picture view, i.e., whether they're improving or their treatment needs to change, is indicative of the fact that a 'one size fits all' approach to HIT design will not be beneficial [35]. The reported PGHD utilisation outcomes would directly inform the development of a PROM-PGHD for K-SRS, of which this paper is a key step [15, 16]. For example, it might be necessary to remove or revise items that sounded negative, e.g., 'I felt blue or sad'. Such items may evoke negative thoughts or feelings from survivors and may thus pose a risk. Items that asked survivors if they felt sad or pessimistic could be revised to ask, using a scale, to what extent they felt happy or not happy. The process of revising the preliminary PROM-PGHD is Step 5 in the development process, and is fully reported elsewhere.

The PGHD utilisation outcomes gathered in this study could also help inform health care providers on decisions about stroke care, e.g., understanding which health outcomes are personally important for stroke survivors, and how survivors can be motivated to perform their exercises for the long-term [33, 34]. This is particularly relevant in the area of poststroke simulated rehabilitation technologies, where there is a dearth of studies that engage survivors in their own health care [2].

Limitations

While FB co-moderated some of the discussions, most were moderated by GLD. This introduces the risk of eliciting a narrower array of themes and ideas; however an advantage to this method is that the chance of thematic saturation is increased, as GLD learnt relevant themes as the discussions progressed [19]; and meant that the moderation of the discussions were consistent.

It should also be noted that in our sample, only the participant from Headway had voluntarily used the case K-SRS in an outpatient setting. However, that person's perspectives were similar to the Site 1 survivors, indicating that the technology demonstration provided to the

Site 1 cohort, coupled with their lived experience with stroke was a valuable way of gathering perspectives about the potential effects of PGHD utilisation. This highlights the strength of qualitative data collection activities in identifying patient-reported outcomes of a health domain of interest [19]. Moreover our sample, recruited for convenience, and consisting of stroke survivors who had no significant residual visual, verbal or cognitive impairments is not representative, nor was it ever meant to represent all stroke survivors; it was meant to elicit the input of stroke survivors to guide the development of the PROM-PGHD, which will be further refined and validated [23].

Conclusion

This paper has described how utilisation of PGHD from a key K-SRS may affect health outcomes of stroke survivors, in the words of survivors themselves and concerned clinicians. It has confirmed that perspectives of patients and clinicians may vary, emphasising the necessity of using participatory methods in the design, development, and evaluation of HITs. The findings have direct implications for the development of a PROM-PGHD for K-SRS, which will be further refined and validated.

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Contributors

GLD contributed to the study planning and design, ethics applications, organisational collaborations, data collection, analysis and interpretation, and writing of the manuscript. FB contributed to the study design, ethics applications, organisational collaborations, data collection, data interpretation and manuscript revision. MM contributed to the study design, ethics applications, data interpretation and manuscript revision. KG contributed to the study design, ethics applications, and manuscript revision.

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Competing Interests

There are no competing/conflict of interests.

Patient Consent for Publication

Granted through signed consent forms. Recruitment through the Melbourne health service was approved by the relevant Health Human Research Ethics Committee (AU RED HREC: HREC/17/Austin/492). Recruitment of participants through Headway ABI was approved by the University of Melbourne Medicine and Dentistry Human Ethics Sub-Committee (ID: 1852259.1).

Abbreviations

ADL: activities of daily living

FDA: United States Food and Drug Administration

HIT: health information technology

K-SRS: Kinect-based stroke rehabilitation system

PGHD: Person-Generated Health Data

PROM: Patient-Reported Outcome Measure

PROM-PGHD: Patient-Reported Outcome Measure of utilising Person-Generated Health Data

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6 Consolidating Outcomes and Insights to Improve the Preliminary Item Bank and PGHD Technology Design

This chapter presents Step 5 of the PROM-PGHD Development Method, which produces a revised and refined PROM-PGHD item bank for K-SRS. (Section 6.1). As a complement to the PROM-PGHD development process, a new set of design heuristics to enable people to effectively use PGHD is presented as a peer-reviewed publication (Section 6.2). The heuristics were developed as a result of identifying features that a PGHD technology should have, in order to enable the positive effects of PGHD utilisation. These features were discovered as a result of reflecting on the activities and results of the PROM-PGHD Development Method.

6.1 Improving the Patient-Reported Outcome Measure of Utilising Person-Generated Health Data Preliminary Item Bank

Step 4 of the PROM-PGHD Development Method (Chapters 4 and 5) elicited the feedback and input of stroke survivors and clinicians, to further refine and improve the preliminary PROM-PGHD for K-SRS. In Step 5 presented here, the feedback and input were considered to inform any necessary revisions that needed to be applied to the preliminary PROM-PGHD item bank. Additionally, the preliminary items were reviewed to ensure that they were worded to reflect PGHD utilisation effects or outcomes, and that redundant items were avoided to reduce cognitive load on the respondents. Finally, the items were run through the Lexile Analyzer® (MetaMetrics, Inc) [93] to assess their readability based on sentence length and commonness of words. This provided an extra layer of assessment to determine if any items could be problematic during implementation, and to conduct revisions as necessary to improve readability [94]. Appendix H presents matching quotes from stroke survivors and clinicians that informed the revisions of each PROM-PGHD item, as well as the revisions that were eventually applied.

For reference, this section is mapped to the step of the PROM-PGHD Development Method that it implements in Table 22 below.

Table 22. Mapping Chapter 6, Section 6.1 with the PROM-PGHD method step it implements

Steps of the PROM-PGHD Development Method	Chapters/Sections of this Thesis
Step 1: Literature Review	Chapter 1, Section 1.3.2: Literature Review (peer-reviewed publication)
Analysis of Step 1 Step 2: Binning and Winnowing Step 3: Initial Item Revision	Chapter 3: Development of a PROM of Utilising PGHD: Preliminary Item Bank (peer-reviewed publication)
Step 4: Eliciting Patient Input	Chapter 4: Eliciting Stroke Survivors' Perceptions on the Effects of Utilising PGHD (peer-reviewed publication)
	Chapter 5: Varying Perspectives of Stroke Survivors and Clinicians on the Effects of Utilising PGHD (peer-reviewed publication)
Step 5: Final Item Revision	Chapter 6, Section 6.1: Improving the Patient-Reported Outcome Measure of Utilising Person-Generated Health Data Preliminary Item Bank

6.1.1 Refinements and Revisions Based on Input from Stroke Survivors and Clinicians

A number of stroke survivors and clinicians provided direct comments and suggestions about the wordings, structure, and content of a number of the preliminary PROM-PGHD items. This resulted in a few revisions; the most important of these was to remove or revise items that sounded negative, e.g., 'I felt blue or sad'. Such items may evoke negative thoughts or feelings from survivors and may thus pose a risk. Thus, items that asked survivors if they felt sad or pessimistic were revised so that they now asked, through a scale, to what extent stroke survivors felt happy or not happy. Other revisions included redirecting some items' content to focus on feelings about stroke survivors' therapy and movement, instead of their recovery overall or feelings about themselves. The items' clarity of content was also improved; some items that seemed redundant were removed or combined to reduce cognitive load; and all response options were changed into a numbered scale for consistency. A scale was chosen as

it was preferred by some survivors and clinicians. To see which items were revised and why, please see Appendix H.

The focus groups and interviews with stroke survivors and clinicians also provided the opportunity to review whether all the items reflected the experiences and perspectives of stroke survivors on the effects of PGHD utilisation. Each item was carefully assessed by reviewing the coded transcripts, and items that were not supported by stroke survivors during the discussions were not included. Only one item was removed as it was not directly reported by survivors or clinicians in the discussions, and it seemed redundant. To see which item was removed, please see Appendix H.

Additionally, the discussions with stroke survivors and clinicians gathered new PGHD utilisation effects that may not have been covered by the preliminary PROM-PGHD item bank. The coded transcripts were reviewed, and discussions pertaining to PGHD utilisation effects were assessed against each item of the preliminary item bank. Effects that were not currently reflected in the item bank were added as a new item. New items that were added include measures of stroke survivors' levels of frustration, motivation to perform better in and to do more exercises, trust in the care process, understanding of the purpose of their exercises, and their desire to talk to a clinician or a loved one. Response options chosen for the new items reflected best practice [94]. To see which items were added, please see Appendix H.

6.1.2 Refinements and Revisions Based on Further Assessments

The preliminary PROM-PGHD item bank was then subjected to a few more assessments. First, it was ensured that the items were worded to measure PGHD utilisation effects or outcomes. Second, the items' response options were reviewed to ensure that they reflected levels of an effect or outcome with two extremes (positive or negative), and a neutral or indifferent state. Thus, the scales were reduced from a maximum of six, to five; so that the middle number three can measure indifference. The scale was reduced to five instead of being increased to seven, as increasing the scale subsequently increases the cognitive load on the respondents [94]. The option not applicable (N/A) was also moved up to the right of the scale. Both changes were suggested by stroke survivors. Third, the items were reviewed once more to

double-check that their wording, content, structure, and response options were clear, consistent, and reflected the comments and feedback elicited from stroke survivors and clinicians. Instances of the term 'information' were revised to 'health data' for clarity, and instances of the term 'Jintronix' were revised to 'the system' to enable the applicability of the item bank to other types of K-SRS. To see which items were further revised and why, please see Appendix H.

The items were then categorised into four PGHD utilisation effects (Chapter 3) that they aligned with, represented as sections. The three sections from the initial items were retained, however a new section 'Relationships' was created. Under the new section were added some of the items that reflected possible changes in stroke survivors' relationship with clinicians or loved ones, as a result of using PGHD. Moreover, the first section was renamed to 'Behavioural changes' from 'Behavioural or attitude changes'. As explained in Chapter 3, how stroke survivors felt about their health status could influence their ability to self-manage their care. Thus, items that fall under 'attitude changes' were appropriately categorised under the section 'Self-management of care'. The resulting PROM-PGHD item bank is shown in Figure 12 below.

Figure 12. Resulting PROM-PGHD item bank from the activities of the qualitative PROM-PGHD Development Method

Rate the following: (circle one rating for each statement, with 1 being the highest)

I. Behavioural changes

The system made me realise when I needed to change my posture or movement, to improve them.

Strongly agree ←----------→ Strongly disagree

1 2 3 4 5 or N/A

The system made me realise how to improve my posture or movement, so I could improve them easily and quickly.

Strongly agree ←----------→ Strongly disagree

1 2 3 4 5 or N/A

How much did you feel either motivated or not motivated to do more rehabilitation exercises, based on seeing the health data that the system provided about your rehabilitation?

Very motivated ←----------→ Not motivated at all

1 2 3 4 5 or N/A

How much did you feel either motivated or not motivated to perform better at the exercises, based on seeing the health data that the system provided about your rehabilitation?

Very motivated ←----------→ Not motivated at all

1 2 3 4 5 or N/A

II. Self-management of care

How much did you feel either encouraged or discouraged about your progress, based on seeing the health data that the system provided about your rehabilitation?

Very encouraged ←----------→ Not encouraged at all

1 2 3 4 5 or N/A

How much did you feel either confident or not confident about your progress, based on seeing the health data that the system provided about your rehabilitation?

Very confident ←----------→ Not confident at all

1 2 3 4 5 or N/A

How much did you feel either happy or not happy about your progress, based on seeing the health data that the system provided about your rehabilitation?

Very happy ←----------→ Not happy at all

1 2 3 4 5 or N/A

How much did you feel either frustrated or not frustrated about your progress, based on seeing the health data that the system provided about your rehabilitation?

Not frustrated at all ←----------→ Very frustrated

1 2 3 4 5 or N/A

Based on seeing my health data from the system, my satisfaction with my health progress has become:

Much more ←----------→ Much less

1 2 3 4 5 or N/A

Seeing my health data from the system increased my interest about my rehabilitation progress.

Strongly agree ←----------→ Strongly disagree

1 2 3 4 5 or N/A

Seeing my health data provided by the system increased my understanding of my rehabilitation progress.

Strongly agree ←----------→ Strongly disagree

1 2 3 4 5 or N/A

I felt that I would need the support of an expert to be able to understand health data about my progress.

Strongly agree ←----------→ Strongly disagree

1 2 3 4 5 or N/A

The health data from the system helped me to budget my energy and complete the activities.

Strongly agree ←----------→ Strongly disagree

1 2 3 4 5 or N/A

Overall, I was satisfied with the way the health data provided by the system supported me when completing the activities.

Strongly agree ←----------→ Strongly disagree

1 2 3 4 5 or N/A

III. Personalisation

This system has shown me all rehabilitation or health data about my progress that I expect to see.

Strongly agree ←----------→ Strongly disagree

1 2 3 4 5 or N/A

After seeing my rehabilitation or health data available to me from the system, my trust in my care process has increased.

Strongly agree ←----------→ Strongly disagree

1 2 3 4 5 or N/A

Seeing health data about my progress helped me understand the purpose of the exercise for my own recovery.

Strongly agree ←----------→ Strongly disagree

1 2 3 4 5 or N/A

IV. Relationships

I felt the need to talk to a clinician after seeing my health data.

Strongly agree ←----------→ Strongly disagree

1 2 3 4 5 or N/A

I felt like contacting a loved one or friend after seeing my health data.

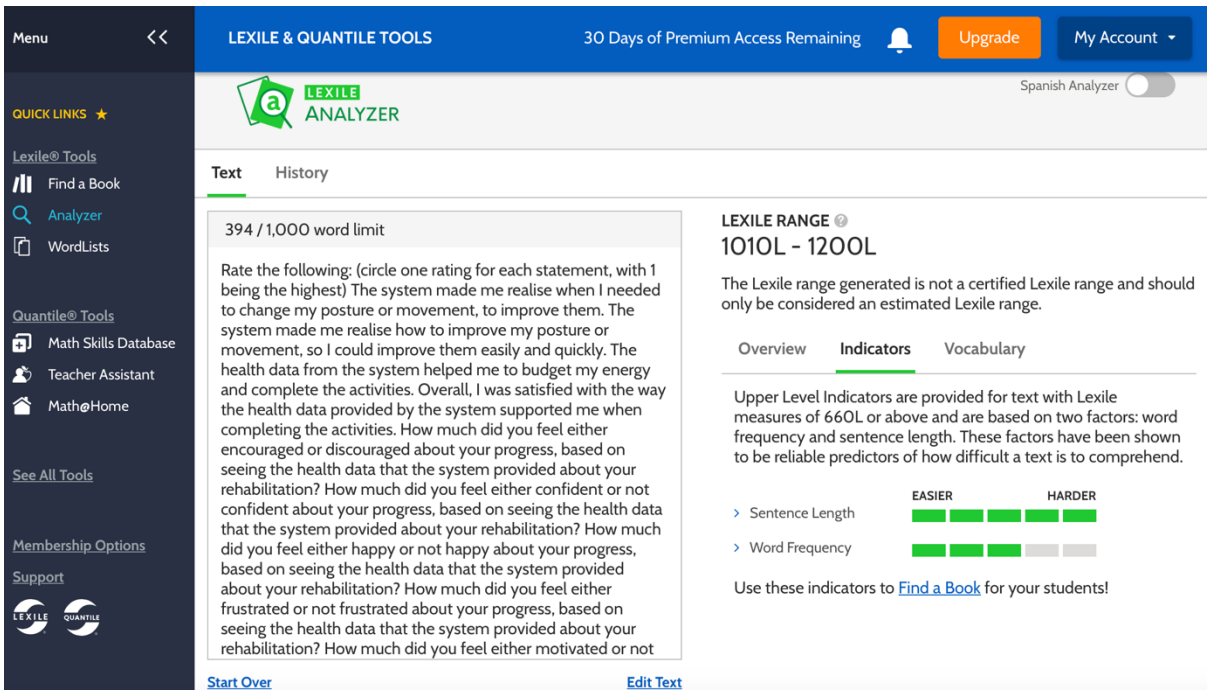
Strongly agree ←----------→ Strongly disagree

1 2 3 4 5 or N/A

6.1.3 Final Assessment Through Lexile Analyzer®

Finally, the PROM-PGHD item bank was run through the MetaMetrics, Inc. Lexile Analyzer® (https://hub.lexile.com/analyzer), as per best practice [93], to assess their readability based on sentence length and commonness of words. The analyser could only accurately evaluate full sentences [93], and thus the response options were not included in the assessment. The PROM-PGHD item bank was rated with a lexile range of 1010L to 1200L, which corresponds to a reading grade level of five [95]. Stroke survivors are reported to have a mean reading level of around seven to eight, while survivors with combined aphasia are reported to have a reading level of between four to six [96]. That our PROM-PGHD item bank has a reading level of five, increases our confidence that stroke survivors would be able to understand the items of the PROM-PGHD. Further field testing is recommended to be conducted on the items [94]; and in case survivors still report some reading difficulty, we suggest reducing the items' sentence length. The Lexile Analyzer® regards the sentence length as a cause for increasing the reading level of the items. To see the result of the lexile analysis, please see Figure 13 below.

Figure 13. Results of the Lexile Analysis of the PROM-PGHD item bank



6.2 Improving the Design and Evaluation of Person-Generated Health Data Technologies through a Set of Specialised Heuristics (peer-reviewed publication)

The process of developing a PROM-PGHD also identified some design features that a domain or type of PGHD technology, i.e, stroke rehabilitation systems, should have. These features would improve the technology's effectiveness in producing positive effects on people who use PGHD to self-monitor or manage a specific health condition. These features could contribute to the need for a 'build-and-evaluate loop' that enables people with the case health condition or PGHD users to participate in a HIT's design and evaluation [52].

This inspired the development of a new set of design heuristics; revealing a valuable dimension to the process of developing a type of PRM of utilising PGHD. It demonstrates how, in exploring the ways in which PGHD utilisation may affect people, characteristics that allow for better use of PGHD may be identified, which could be used in the design and evaluation of PGHD technologies. These heuristics would contribute to efforts in design science for HIT, to integrate inputs or decisions made about HIT design and the intended health outcomes using participatory or user-centred methods [51].

This section presents a peer-reviewed publication describing how the features and characteristics identified through the PROM-PGHD development process, served as the basis to develop a new set of design heuristics for PGHD technologies.

This is a peer-reviewed publication, appearing in Journal of Medical Internet Research Publications (doi: 10.2196/17132). The accepted version of the article is presented here, ready for examination following university guidelines for thesis with publications. To see the individual contribution of the authors, please see the Preface.

The multimedia appendix of the publication is presented in this thesis as Appendix I.

Enabling Better Use of Person-Generated Health Data in Stroke Rehabilitation Systems: Systematic Development of Design Heuristics

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Abstract

Background: An established and well-known method for usability assessment of various human-computer interaction technologies is called heuristic evaluation (HE). HE has been adopted for evaluations in a wide variety of specialised contexts, and with objectives that go beyond usability. A set of heuristics to evaluate how health information technologies incorporate features that enable effective patient use of person-generated health data (PGHD) is needed in an era where there is a growing demand and variety of PGHD-enabled technologies in healthcare; and where a number of remote patient monitoring technologies do not yet enable patient use of their PGHD. Such a set of heuristics would improve the likelihood of positive effects from patients' use of PGHD, and lower the risk of negative effects.

Objective: In this paper, we describe the development of a set of heuristics for the design and evaluation of how well remote patient therapeutic technologies enable patients to use PGHD (PGHD enablement). We use the case of Kinect-based stroke rehabilitation systems (K-SRS).

Methods: The development of a set of heuristics to enable better use of PGHD was primarily guided by the R3C methodology. Closer inspection of the methodology reveals that neither its development, nor its application to a case study were described in explicit detail. Thus where relevant, each step was grounded through best practice activities in the literature; and using Nielsen's heuristics as a basis for determining the new set of heuristics. As such, this paper builds on the R3C methodology, and the implementation of a mixed process is intended to result in a robust and credible set of heuristics.

Results: Eight new heuristics for PGHD enablement in K-SRS were created. A systematic and detailed process was applied in each step of heuristic development, which bridged the gaps described above. It is hoped that this would aid future developers of specialised heuristics, who could apply the detailed process of heuristic development for other domains of technology; and additionally for the case of PGHD enablement, for other health conditions. The R3C methodology was also augmented through the use of qualitative studies with target users and domain experts, and is intended to result in a robust and credible set of heuristics, prior to validation and refinement.

Conclusions: This paper is the first to develop a new set of specialised heuristics to evaluate how HITs incorporate features that enable effective patient use of PGHD, with K-SRS as a key case study. Additionally, it is the first to describe how the identification of initial HIT features and concepts to enable PGHD could lead to the development of a specialised set of heuristics.

Keywords

person generated health data; patient reported outcome measures; heuristics; stroke rehabilitation; consumer health informatics; evidence-based practice; information technology

Introduction

Varying Effects of Person-Generated Health Data

Person-Generated Health Data (PGHD) are produced from technologies that allow people to access and utilise health data that they themselves generate outside of a health clinic setting,

and to share these data with healthcare providers and others, typically via the Internet. These technologies are designed to generate data about a range of health conditions and in pursuit of a range of health outcomes for remote patient monitoring [1, 2]. Example technologies include home-based, web-based, mobile and wearable applications, that cater for a range of health conditions such as irritable bowel syndrome [3], diabetes [4, 5], bipolar disorder [6]; text reminders for asthma management [7]; and social networking sites for mental well-being of cancer patients [8].

It is possible for PGHD utilisation to have positive, negative or nil effects on patients who use these technologies. PGHD use has been reported to provide patients a range of benefits, such as increasing interest in their own health care processes [5, 9, 10], allowing them to monitor and manage their own health status [11], and motivating them to undergo positive behaviour change [1, 12]. However PGHD utilisation can also cause patients to feel frustrated and discouraged [1], and some patients may feel excluded from the benefits of PGHD [11]. This highlights the need to consider the patient perspective in the design and development of health technologies [13], and particularly those that generate PGHD [14].

Measuring PGHD Effects

The varying effects of PGHD use on patients necessitates the development of a patient-reported outcome measure (PROM) of utilising PGHD, or PROM-PGHD [15], to provide a standardised way of measuring PGHD outcomes and build empirical evidence about PGHD [16]. PROMs are used to assess the health status or experience of health services and interventions by patients themselves [17-19], and have been shown to improve the precision of evaluating health information technologies (HITs) [20]. Similarly, PROMs-PGHD would measure patients' health outcomes or status as a result of accessing and using PGHD. Moreover, they could complement other clinical health outcomes indicators, similar to how PROMs are used alongside other biometric measurements of patient health [21].

The authors previously developed a PROM-PGHD which entailed establishing health outcomes that should be measured for a specific technology category, and a health condition [15, 22]. The process identified some features that a domain or type of PGHD-enabled technology, i.e, stroke rehabilitation systems, should have to evaluate their effectiveness in

producing positive effects on patients who use PGHD to self-monitor or manage a specific health condition. For example, simulated stroke rehabilitation technologies should provide patients real-time information on the remaining exercise repetitions they need to do, in order for them to self-manage their limited energy [1].

Evaluation of Technologies Using Heuristics

Using a list of features based on predetermined criteria to assess technology categories is called heuristic evaluation (HE). First introduced by Nielsen and Molich [23], HE is an established and well-known method for usability assessment of various human-computer interaction technologies [24]. Using a set of guidelines, called heuristics, expert evaluators are able to quickly and efficiently identify issues that could affect the usability of technology artifacts [25]. In practice, it could also be conducted during the design process to identify potential problems before launch [24, 25].

HE has since been adopted for evaluations in a wide variety of specialised contexts, and with objectives that go beyond usability. This has resulted in specialised heuristics, which could be used to direct evaluators to focus on assessing technologies according to specific concepts of interest [24]. Nielsen's original set of heuristics have been adopted or augmented to assess the quality of novice programming systems [26], identify common mistakes caused by novice and experienced users of an online health record system for nurses [27], and assess the safety of a health information technology [28]. Such specialised heuristic evaluations have identified problems beyond the original scope of the original heuristics [29], and could therefore increase the effectiveness of evaluations in varied contexts [30] and improve the quality of insights gained [26].

Heuristics for PGHD Enablement

Developing a set of heuristics for use in the formative stages of development of patient and consumer health technologies could ensure more deliberate PGHD enabling designs. This would improve the likelihood of positive effects from patients' use of PGHD, and lower the risk of negative effects. Such heuristics would also offer healthcare providers a standard way to evaluate technologies as part of selecting and implementing PGHD programs with their patients [11]. HE would complement other in-depth PGHD evaluation methods [2, 15] to

explore PGHD outcomes [14, 16], integration with clinical tools [2], and assessment of quality management [31]. A set of heuristics to evaluate how HITs incorporate features that enable effective patient use of PGHD is needed in an era where there is a growing demand and variety of PGHD-enabled technologies in healthcare; and where a number of remote patient monitoring technologies do not yet enable patient use of their PGHD. Further, research into the outcomes and benefits of PGHD has not kept up [2, 11, 14]. Specifically, methods are only just emerging for systematic measurement of patient reported health outcomes from accessing and utilising PGHD [11, 15]. In contrast to the already strong standardisation of patient reported outcome measures in many aspects of healthcare [21], PGHD outcome evaluation methods are idiosyncratic and reported research is fragmented [11].

Objective

In this paper, we describe the development of a set of heuristics for the design and evaluation of how well remote patient therapeutic technologies enable patients to use PGHD (PGHD enablement). We use the case of Kinect-based stroke rehabilitation systems, to illustrate how the development of PROM-PGHD has led to the creation of these heuristics.

Methods

Case Study

An important use case for evaluating PGHD effects is in simulated rehabilitation technologies for stroke, in particular those using body-tracking technology Kinect© (Microsoft, Redmond WA) [15]. Key considerations within the context of stroke rehabilitation include the inherent complexity of care necessary to improve health outcomes [32, 33]; the requirement for stroke survivors to frequently conduct repetitive movement exercises [34, 35]; and the difficulties of accessing therapy accompanied by the high cost of care over an extended period of time [36].

Kinect-based stroke rehabilitation systems (K-SRS) offer a more convenient and cost-effective option [14]. They allow stroke survivors to undertake prescribed movement exercises simulating activities of daily living (ADL) [37-40]. As survivors use these systems, they produce PGHD in the form of data indicating their therapeutic progress. These data, generally designed

to be used by clinicians, have the potential to be used by stroke survivors themselves for health self-monitoring [14, 38, 39].

Methodology to Develop Specialised Heuristics

A number of heuristic development processes have been employed in the literature. This includes literature reviews, analysis of usability problems, mixed processes, use of guidelines, interviews, and analysis of theories related to a specific domain [41]. Of these, only one methodology known as the R3C [42] has been used extensively (14 times) [41, 43, 44]. The authors have since improved it [45]. Another widespread approach is to point out the limitations of existing heuristics, in particular [23], and build on these by exploring other aspects that need to be considered for the target domain. The original set of usability heuristics did not detail the steps taken to develop them [23, 46]. Subsequently reported processes for developing heuristics for specific application domains have varied.

Procedure for Heuristics Development

The development of a set of heuristics for PGHD enablement was primarily guided by the R3C methodology most utilised and applied in the literature [45]. However, closer inspection of the methodology reveals that neither its development [44], nor its application to a case study [47] were described in explicit detail, leaving room for flexibility and interpretation for future implementations. There are also overlaps between its steps and other heuristic development processes, as described above [41]. For instance, Step 1 explores and describes the target technology domain, followed by Step 2 where the meaning of usability is re-examined within the context of the target technology domain. Thus a literature review may be conducted for these steps [47]. Moreover, while those steps do not specify conducting qualitative activities such as interviews and focus groups, their goals may indeed be augmented by such activities.

Thus, the development of a specialised set of heuristics for K-SRS technologies was guided by the R3C [45]. Where relevant, each step was grounded through best practice activities in the literature, i.e., analysis of the context of use through a literature review, interviews and focus groups; and using the original heuristics [23] as a basis for determining the new set of heuristics. As such, this paper builds on the R3C methodology, and the implementation of a mixed process is intended to result in a robust and credible set of heuristics. Moreover, its

detailed implementation of each step is intended to aid future developers of specialised heuristics for PGHD enablement within various contexts of health conditions and technology domains.

The steps of the R3C are described in Table 23 (*published Table 1)*. The objective of this paper is to develop an initial set of heuristics for PGHD enablement, thus only steps 1-4 are implemented in this paper. Evaluation of the heuristic set (Step 5) and further refinement (Step 6) is an area for future research.

Table 23. Methodology to develop a specialised set of heuristics

Steps of the R3C methodology to develop a specialised set of heuristics [44, 45, 47]
Step 1: Exploratory stage Examine literature related to the main topics or technology domain of the research.
Step 2: Descriptive stage Highlight key concepts from Step 1. Connect the information, and assign weights.
Step 3: Correlational stage Identify the characteristics that the heuristics should have. Original heuristics [23] may be used as a basis. Clarify the need to consider the target technology domain.
Step 4: Specification stage Formally specify the set of proposed specialised heuristics, using a standard template. Prioritise heuristics, and report any missing elements that need to be added.
Step 5: Validation or experimental stage The new set of heuristics is tested on the target domain, and usability problems or issues found are compared with those that would be found using traditional heuristics.
Step 6: Refinement stage The new set of heuristics is refined or improved following analysis of the results of Step 5. However, this occurs iteratively, i.e., if no more changes are recommended after Step 5 then the development ends there.

Results

Step 1: Exploratory Stage

A literature review was conducted as part of the PROM-PGHD development process to understand how K-SRS have been designed to enable PGHD, and what benefits, if any, were recorded [14] using them. Similar to how this step was applied for this case [47], the review also analysed features of this domain, such as effectiveness of K-SRS. Moreover, the types of PGHD generated by K-SRS were reviewed, how people were able to access data, intended users and uses of PGHD, and any effects on patients from using PGHD [14].

The literature review described the context under which PGHD is produced and used, relevant for Step 4 when the heuristics are specified. As part of this step, factors that may influence the outcomes resulting from accessing and using PGHD were analysed. The review has shown that PGHD was given to patients to guide them, e.g., change movement behaviour or actions to perform correct exercise movements. PGHD were also provided to help them achieve their short and long term goals [14]. However, while people were in general provided with some form of PGHD as feedback, they did not have access to all their PGHD which clinicians have access to. Other uses of PGHD included clinicians analysing them to tailor rehabilitation programs for patients; researchers analysing the effects on patients when they use a K-SRS; and to assess a variety of K-SRS, e.g., how effective and reliable they are, and even compare them with other domains of technologies [14]. The review also highlighted one study which reported that a patient's daily access to her PGHD caused her to remember them over time and be motivated to improve [48].

The review also highlighted the lack of patient-centred design in the development of K-SRS, given that the focus of providing data back to patients was for prescribing tasks and not to allow patients to access and make sense of their PGHD themselves. This is a missed opportunity to encourage patients to be more involved in their own health care [14], as patients who have direct access to their PGHD may become more engaged and thus improve their health outcomes [5, 9, 10, 49]. Indeed, the lack of patient participation in the design of such PGHD systems may undermine patients' rehabilitation experience [50]. This is indicative

of the need for developers of technology-based rehabilitation systems to consider PGHD in their design, implementation, and evaluation; and allow patients to access them [14].

Step 2: Descriptive Stage

This step is described as having three tasks: highlighting, connecting, and assigning weights to the concepts found in Step 1. First, concepts found through the literature review that could enable the effective patient use of PGHD were identified. Second, the concepts were categorised based on their inherent meaning according to five different reported effects of PGHD use thematically derived from the literature. Articles from a significant journal special issue on PGHD were inductively analysed as an efficient and targeted way to identify reported effects of PGHD utilisation from a range of health information technologies for different health conditions [15]. This process identified five different effects that may result from patients' use of their PGHD. PGHD may influence health-related behavioural or attitude changes; influence patients' management of their own care due to changes with how they feel about their health status; influence interest in their health care processes; facilitate their personal care goals; and influence their relationship with care providers. Concepts that did not match any of these effects were assigned a different category.

Table 24 (*published Table 2*) shows the categorised concepts highlighted from the literature review. More example quotes are shown in Multimedia Appendix 1.

Table 24. Weighted key concepts identified from Step 1: Exploratory Stage

Categories	Key Concepts	Weight
Stroke survivor health-related behaviours	PGHD can guide stroke survivors to make appropriate movement behaviour or action changes in order to perform an exercise correctly.	2 – stroke survivors. "I automatically adjust what I was doing, if I couldn't burst every balloon I, I had to adjust.. To work out what I was doing wrong" (FG1_STC2-3)

Stroke survivor personal care goals	PGHD can help stroke survivors achieve their short- and long-term goals.	0 – Not described.
Functional effectiveness of therapy	PGHD can help inform clinicians, to analyse the functional effects of simulated rehabilitation therapy, and tailor programs for stroke survivors.	0 – Not described.
Evaluation of the PGHD-enabled K-SRS	PGHD can be used to assess the effectiveness and reliability of a K-SRS, compared with other types of simulated rehabilitation technologies.	0 – Not described.
Stroke survivor interest in care processes	PGHD may be remembered by stroke survivors over time, and provide them with more motivation to improve their therapy performance.	3 – stroke survivors and clinicians. PGHD may provide “an extra percentage of motivation” (FG1_STC2-1) and an “incentive to do better” (FG1_STC2-3). Clinician: “something to keep striving” (FG3_AHC1_3)
Stroke survivor interest in care processes	PGHD needs to be accessible to the stroke survivors who produce them, in order to allow them to be more	3 – stroke survivors and clinicians. “it helped me understand my rehabilitation progress” (INT1_HWC1)

	involved in their own health care.	"quite often you learn more when you've done something wrong" (FG2_AHP_2) Clinician: "[survivors] would understand better after a second session where they could compare their results..it's good for them to have a comparison, to see how they've changed from one session to another" (FG3_AHC1_5)

In the third activity of this stage, the concepts were assigned weights through qualitative studies. As part of the PROM-PGHD development process, the input of target users (stroke survivors) and experts (physiotherapists) was elicited through focus groups and interviews [51]. Based on the health and technology case under consideration, stroke survivors with experience interacting with a leading K-SRS called Jintronix [14, 52] were asked to respond to open-ended questions around effects resulting from their access to and utilisation of PGHD. Meanwhile, the clinicians were asked how they thought access and utilisation of PGHD would affect the stroke survivors they were working with. Participant recruitment was conducted in Australia at three different sites, with ethics approval granted by the Human Research Ethics Committees of Deakin University (2017-087), Austin Health (HREC/17/Austin/492), and the University of Melbourne (1852259.1). 10 stroke survivors (7 females, 3 males) were recruited through Deakin University; 5 clinicians (4 females, 1 male) and six stroke survivors (1 female, 5 males) were recruited through Austin Health hospital; and one stroke survivor (female) was recruited through Headway ABI in Queensland, Australia.

The qualitative studies enabled the authors to receive direct feedback from PGHD users to assign weights to the concepts found from Step 1. Additionally, the studies also bridged any relevant gaps between those concepts described in the literature, those perceived by clinicians, and those reported as important by stroke survivors themselves [1]. New PGHD outcomes were documented that were not previously identified through the review and analysis of the literature described above [14], leading to the identification of new features

that should be incorporated in technologies to enable effective patient use of PGHD. Concepts identified through the literature review but not described by either stroke survivors or clinicians were assigned a weight of 0; concepts described by clinicians only were assigned with 1; concepts described by stroke survivors only were assigned with 2; and concepts described by both stroke survivors and clinicians were assigned with 3. Table 24 shows the key concepts identified through the literature review assigned with weights, and example quotes describing the concept, if any. Table 25 (*published Table 3*) shows new concepts identified through the qualitative studies, also assigned with weights and listing example quotes.

The categories were initially applied by GLD, then independently reviewed by the co-authors. Any disagreements in the categories applied were discussed in a meeting until agreement was reached for each concept. More example quotes are shown in Multimedia Appendix 1.

Table 25. Weighted new concepts identified from qualitative studies

Categories	Key Concepts	Weight
Stroke survivor health-related behaviours	PGHD can encourage stroke survivors to do more exercises related to their therapy.	3 – stroke survivors and clinicians. “if I can see the improvement I'm making then it would...encourage me to maybe have more of those sessions” (INT1_STC3) Clinician: “that might stimulate them to be more compliant” (FG3_AHC1_5)
Stroke survivor health-related behaviours	PGHD can discourage stroke survivors from doing more exercises if it’s negative or low.	3 – stroke survivors and clinicians. “probably lose faith in the system” (INT2_AHP) [unless there is] “some explanation […] that you need to consider looking” (INT2_AHP)

		Clinician: “They might get over it, or might not be willing to participate” (FG3_AHC1_3)
Feelings about health status	PGHD can cause positive or negative emotions, correlated with whether their PGHD is positive or negative.	3 – stroke survivors and clinicians. “going backwards, that would be a little bit depressing” (INT1_AHP) seeing “yourself gradually making improvements, it just makes you feel so much better. Okay, I'm achieving something” (INT1_AHP) Clinician: “a score can motivate you or please you” (FG3_AHC1_5)
Stroke survivor personal care goals	PGHD can demotivate stroke survivors if it’s negative.	2 – stroke survivors. “that can be a positive motivator, but can also (be) a negative one” (INT2_STC1) “I'm thinking well, are normal people at a hundred percent? And I'm only at 60?” (FG1_AHP_2)
Stroke survivor interest in care processes	PGHD can interest stroke survivors in how their exercises are contributing to their activities of daily living.	1 – clinicians. “any relevance to a functional activity. You know like washing the dishes, or hanging the washing out or..climbing a flight of stairs” (FG3_AHC1_4)
Feelings about health status	PGHD can make stroke survivors feel confused about their health progress.	3 – stroke survivors and clinicians. “the percentages to me is more difficult to understand […] are we trying to be a hundred percent at these things?” (FG1_AHP_2)

		Clinician: “scope to put in something about, I didn't really understand” (FG3_AHC1_4)
Feelings about health status	PGHD can make stroke survivors feel more self-aware about their health care.	2 – stroke survivors. “to measure your improvement…or measure your, deterioration…You could see it in cold hard figures.” (FG2_AHP_2)
Stroke survivor interest in care processes	PGHD can help stroke survivors to self-manage their energy while undergoing therapy.	2 – stroke survivors. “It was certainly something that I watched, to see where I was at. 'Cause you need to think about this, we have some sort of a budget of energy that you have to manage yourself, and you can't afford to get to empty” (FG1_STC2-3)
Stroke survivor interest in care processes	PGHD can affect stroke survivors’ perception about their therapy.	3 – stroke survivors and clinicians. Mismatch between PGHD and feeling of performance: “you probably think oh, the system's not doing its job” (INT2_AHP) “nothing going on in the background about anyone judging me…that there isn't anything that's being kept from me” (FG1_AHP_2) Clinician: if you just did the computer thing and they..just stopped without data they'd be like, why do I do it?” (FG3_AHC1_2)
Stroke survivor relationship with care provider/s	PGHD can prompt stroke survivors to contact their therapists about their therapy performance.	3 – stroke survivors and clinicians. “If they were always bad then I would need more assistance and even if they [were] good, they [are]

		not perfect, right so I would want to have more, more assistance to improve" (INT2_STC3) Clinician: how can I get a better score..why did I..not do very well" (FG3_AHC1_4)
Stroke survivor relationship with care provider/s	PGHD can make stroke survivors be more conscious of the exercises prescribed by their clinicians.	1 – clinicians. "maybe if they're not being compliant, they might get a phone call from the therapist" (FG3_AHC1_5)
Relationship with Family and Carer/s	PGHD can assist stroke survivors in communicating their rehabilitation progress with their loved ones.	3 – stroke survivors and clinicians. "you could show them something, it's easier for them to visualize" (INT1_AHP) Clinician: "share it with family.. it's that..bragging power as well, perhaps" (FG3_AHC1_4)

Step 3: Correlational Stage

In this stage, the characteristics that the new set of heuristics should have are defined, which are later specified in Step 4.

The key concepts identified through the first 2 steps are used as the basis to define the characteristics. As opposed to concepts, characteristics read as features that K-SRS should have to enable stroke survivors to use PGHD. These characteristics are also matched with the original heuristics [23] to identify any similarities. Some of the concepts were defined with similar characteristics, and therefore combined. To further increase the credibility of the resulting heuristics, any characteristic matching an original heuristic is reworded using the original heuristic as a guide. Moreover, concepts with a weight of 0, i.e., not described by stroke survivors nor clinicians, were not defined as a characteristic and correspondingly not specified as a heuristic.

The characteristics were initially defined by GLD, then independently reviewed by the co-authors. Any disagreements were discussed in a meeting until agreement was reached for each characteristic.

Table 26 (*published Table 4*) lists the characteristics defined from the concepts identified previously that match an original heuristic [23], and as we have reworded them. Table 27 (*published Table 5*) lists the characteristics that did not have a matching original heuristic. The numbering (#) continues from Table 26 through to Table 27, to indicate which characteristics were combined in the next step. To see which concepts were defined as which characteristics, please see Multimedia Appendix 1.

Table 26. Characteristics defined from the key concepts identified from Steps 1-2, that matches an original heuristic [23]

#	Characteristic	Reworded using original heuristic as guide
1	PGHD-enabled systems should assist users in performing more exercises or actions, in a correct way. Matched with original heuristic #9.	Help stroke survivors in performing more exercises or actions; and to recognise, understand, and recover from errors they make. Guidance or error messages should be expressed in plain language (no codes), precisely indicate the problem, and constructively suggest a solution.
2	PGHD-enabled systems should provide PGHD to stroke survivors for increased understanding about their rehabilitation or therapy process. Matched with original heuristic #1.	PGHD-enabled systems should always provide PGHD to stroke survivors to keep them informed about what is going on with their health status, through appropriate feedback within reasonable time.

		This would increase their understanding about their rehabilitation or therapy process.
3	PGHD-enabled systems should avoid formatting PGHD through a scale that represents a completeness or an endpoint, e.g., 100% as much as possible, as it would likely represent failure. Instead, PGHD should resemble the ongoing functional therapeutic progress of stroke survivors. Matched with original heuristic #2.	PGHD-enabled systems should present PGHD in a format that matches the real world context, therapy progress, and goals of the stroke survivors.
4	PGHD-enabled systems should ensure that PGHD is, or could be, presented in a way that is clearly understandable to a stroke survivor. Matched with original heuristic #2.	PGHD-enabled systems should ensure that PGHD is clearly understandable to stroke survivors. The system should speak their language, with words, phrases and concepts familiar to them, rather than system-oriented terms. PGHD-enabled systems should follow real-world conventions, making information appear in a natural and logical order.
5	PGHD-enabled systems should provide PGHD to stroke survivors for increased self-awareness about their health care. Matched with original heuristic #1.	PGHD-enabled systems should always provide PGHD to stroke survivors to keep them informed about what is going on with their health status, through appropriate feedback within reasonable time. This would increase their self-awareness about their health care.
6	PGHD-enabled systems should provide patients real-time PGHD that allow	PGHD-enabled systems should always provide PGHD to stroke survivors to keep

	them to self-manage their energy while performing therapy exercises. Matched with original heuristic #1.	them informed about what is going on with their health status, through appropriate feedback within reasonable time. This would allow them to self-manage their energy while performing therapy exercises.
7	Notwithstanding the need for PGHD to be as accurate as possible, PGHD-enabled systems should inform the patients of its limitations or potential inaccuracies in the PGHD produced by stroke survivors. PGHD-enabled systems should also provide PGHD to stroke survivors to foster an increased sense of trust about their rehabilitation or therapy process. Matched with original heuristic #1.	PGHD-enabled systems should always provide PGHD to stroke survivors to keep them informed about what is going on with their health status, through appropriate feedback within reasonable time. This would foster an increased sense of trust about their rehabilitation or therapy process.
8	PGHD-enabled systems should allow stroke survivors to contact their/a clinician about their PGHD; or at least provide survivors with the option of viewing functional, action-based suggestions for them to improve their performance. Matched with original heuristic #10.	Even though it is better if the system can be used without additional help or documentation, it may be necessary to provide them. PGHD-enabled systems should provide stroke survivors the option to contact a clinician about their PGHD and vice-versa; or at least provide survivors with the option of viewing functional, action-based suggestions for them to improve their performance. Any such information should be easy to search, focused on the survivors'
9	PGHD-enabled systems should provide stroke survivors the option of allowing their clinicians to contact them based on the progress of their PGHD.	

	Matched with original heuristic #10.	exercises, list concrete steps to be carried out, and not be too lengthy.

Table 27. Characteristics defined from key concepts identified from Steps 1-2, that do not have a matching original heuristic [23]

#	Characteristic
10	PGHD-enabled systems should present PGHD that indicates negative or decreasing therapy progress carefully, and in a form that elicits a stroke survivors' competitiveness with the self.
11	PGHD-enabled systems should highlight PGHD indicating positive or improving therapy progress more, and providing them with more frequency than negative or decreasing progress.
12	PGHD-enabled systems should provide PGHD to stroke survivors for increased understanding about how their rehabilitation is contributing to their functional ability.
13	PGHD-enabled systems should provide stroke survivors with the option to share their PGHD with loved ones in a secure manner.

Step 4: Specification Stage

In this stage, the characteristics defined in Step 3 are specified as a heuristic, following a structured format: ID, name, definition, explanation of how the heuristic was developed, example/s of when a system being evaluated complies or violates the heuristic, expected benefits if the system complies with the heuristic, and anticipated problems of heuristic misunderstanding [45]. The ID applied to the heuristics were structured as: #[Number]-PGHD-W[Weight]. The weights were indicated to provide implementers an idea of the process that went through developing the heuristics. The heuristic names were written succinctly, in a similar fashion with the original heuristics [29]. The characteristics were written as the heuristic definition. The explanation of each heuristic described how they were developed from one or more heuristic, and example descriptions of those concepts by stroke survivors and/or clinicians. The example and benefits of each heuristic was described based on the

literature review [14] and the qualitative studies [1]. The anticipated problems indicated where heuristic definitions may be quite close and may be misunderstood.

A number of characteristics were either similar or tightly complemented each other, and were therefore combined into one heuristic. Characteristics #3 and #12 described the need for K-SRS to match the health and therapy context of the stroke survivors. Characteristics #5, #2, #6 and #7 described the need for K-SRS to always provide PGHD to stroke survivors. Finally, characteristics #8 and #9 both described the need for K-SRS to provide options for stroke survivors to seek more information, contact their clinicians, and to allow their clinician to contact them.

In combining the characteristics, considerations had to be taken with the individual weights and the categories of those characteristics. Where the weights of the characteristics being combined were different, the highest weight was indicated for the resulting heuristic's ID. Meanwhile, the categories were added as tag/s under each heuristic, and reworded to indicate how the heuristic informs implementers to enable PGHD use. This is a necessary augmentation of this step. It preserves the categories identified in Step 2 as metadata that could aid implementers in understanding the concepts underlying each heuristic. Interestingly, the R3C methodology did not describe how the categories were relevant to the resulting heuristics [41].

The heuristics were initially specified by GLD, then independently reviewed by the co-authors. Any disagreements were discussed in a meeting until agreement was reached for each specified heuristic. Moreover, Steps 5 and 6 are expected to refine the example, expected benefits, and anticipated problems of each heuristic, and therefore the heuristics presented here may still be revised later on [45]. The next section shows the new, initial set of heuristics for PGHD enablement.

Design Heuristics to Enable Better Use of PGHD for Testing

Eight new heuristics for PGHD enablement in K-SRS were created. Heuristics with higher weights are presented first, to highlight heuristics that should be prioritised. The first six heuristics have a weight of three and the last two have weights of two. There are six tags

used: Improve health-related behaviours; Increase positive feelings about health status; Facilitate positive personal care goals; Increase interest in care processes; Improve relationship with care providers; and Improve relationship with family and carers.

For brevity, only the ID, name, tag/s, definition and explanation are presented in Table 28 (*published Table 6*). This could also be the short form that implementers may use when evaluating HITs, similar to how brief definitions are presented for the original heuristics [29]. However, as with the original heuristics, implementers ought to understand the underlying concepts and anticipated problems of each heuristic, and should therefore view the full specifications in Multimedia Appendix 1.

Table 28. Short form of the specified heuristics for PGHD enablement

1-PGHD-W3: Encouraging PGHD Tag/s: Improve health-related behaviours; Increase positive feelings about health status Definition: The system should highlight PGHD indicating positive or improving therapy progress, and provide them with more frequency than negative or decreasing progress. Explanation: This heuristic was formed from three concepts identified through a literature review and confirmed by stroke survivors and clinicians. Stroke survivors and clinicians commented on how PGHD can cause positive or negative emotions, correlated with whether the PGHD is positive or negative, e.g., when survivors frequently see their PGHD improve, it encourages them to do more of the exercises. A clinician described how seeing PGHD could help survivors be more compliant. On the other hand, if survivors see their PGHD decline they might lose faith in the system and not perform their exercises.
2-PGHD-W3: Evoking competitiveness with self Tag/s: Facilitate positive personal care goals Definition: The system should present PGHD that indicates negative or decreasing therapy progress carefully, and in a form that elicits a stroke survivors' competitiveness with the self. Explanation: This was a concept identified through a literature review and confirmed by stroke survivors and clinicians. Stroke survivors described how seeing their PGHD can motivate them to try harder, sometimes even when their PGHD indicates that they are

not doing very well with their therapy exercises, because it can feel like a competition with themselves. Clinicians agree that it can give survivors something to keep them striving to be better.

3-PGHD-W3: Understandable health data

Tag/s: Increase positive feelings about health status

Definition: PGHD-enabled systems should ensure that PGHD is clearly understandable to stroke survivors. The system should speak their language, with words, phrases and concepts familiar to them, rather than system-oriented terms. They should follow real-world conventions, making information appear in a natural and logical order.

Explanation: This was a concept identified through a literature review and confirmed by stroke survivors and clinicians. A stroke survivor found that simply having percentages as feedback for performing an exercise could be confusing, as it could be misunderstood as being compared with people who have not had stroke. Clinicians also agreed that PGHD may not be understood by survivors.

4-PGHD-W3: Visibility of health progress

Tags: Increase positive feelings about health status; Increase interest in care processes

Definition: PGHD-enabled systems should always provide PGHD to stroke survivors to keep them informed about what is going on with their health status, through appropriate feedback within reasonable time.

Explanation: This heuristic was formed from four concepts identified through a literature review and confirmed by stroke survivors and clinicians. Stroke survivors described how PGHD could help them understand their rehabilitation progress, to determine whether their functional progress was headed in the right direction and learn when they have made a mistake. PGHD could also help them self-manage their energy as they perform their exercises, and increase their trust in their therapy process.

5-PGHD-W3: Help and support

Tag/s: Improve relationship with care providers

Definition: Even though it is better if the system can be used without additional help or documentation, it may be necessary to provide them. PGHD-enabled systems should provide stroke survivors the option to contact a clinician about their PGHD, allow their clinicians to contact them, or at least provide survivors with the option of viewing

functional, action-based suggestions for them to achieve their therapy goals. Any such information should be easy to search, focused on the survivors' exercises, list concrete steps to be carried out, and not be too lengthy. Explanation: This heuristic was formed from two concepts identified through a literature review and confirmed by stroke survivors and clinicians. Stroke survivors described how they would want to contact their therapists particularly if they have not been doing well to ask for assistance and ask for advice on what they could do better. Clinicians also described how it would be good if therapists could contact survivors when they're not being compliant. They also described how stroke survivors would likely ask for more explanation, and for advice on how they can do things differently in order to improve their PGHD.
6-PGHD-W3: Communication of health data Tag/s: Improve relationship with family and carers Definition: PGHD-enabled systems should provide stroke survivors with the option to share their PGHD with concerned parties, e.g., loves ones, in a secure manner. Explanation: This was a concept identified through a literature review and confirmed by stroke survivors and clinicians. Stroke survivors described how it could help them communicate their health status to people they would like to share it to, particularly when they are tired or when they 'run out of words'. Clinicians described how survivors might want to share their PGHD with family, particularly with the younger generation who are more technologically inclined.
7-PGHD-W2: Guide for correct exercise movement or actions Tag/s: Improve health-related behaviours Definition: The system should help stroke survivors in performing more exercises or actions; and to recognise, understand, and recover from errors they make. Guidance or error messages should be expressed in plain language (no codes), precisely indicate the problem, and constructively suggest a solution. Explanation: This was a concept identified through a literature review and confirmed by stroke survivors. A stroke survivor commented on how PGHD can help them work out what they were doing wrong, and adjust accordingly.
8-PGHD-W2: Match between system PGHD and real world context of stroke survivors

Tag/s: Facilitate positive personal care goals; Increase interest in care processes
Definition: PGHD-enabled systems should present PGHD in a format that matches the real world context, therapy progress, and goals of the stroke survivors. When presenting PGHD, e.g., as a score, percentage, or a graph, they should be matched to the therapy goals of the survivors. These goals may change over the course of a survivors' therapy, from gaining functional progress in the first few months or years, to maintaining function to perform ADL when their progress starts to plateau [1]. PGHD needs to be connected with the needs of the stroke survivors, and where they are clinically.
Explanation: This heuristic was formed from two concepts identified through a literature review and confirmed by stroke survivors and clinicians. Stroke survivors described how receiving a percent score that did not indicate a 100% could be a negative motivator. Achieving 100% given their condition could be very difficult or even impossible. Clinicians also described how PGHD should help survivors understand how their therapy is contributing to improved performance of ADL.

Discussion

This paper is the first to develop a new set of specialised heuristics to evaluate how HITs incorporate features that enable effective patient use of PGHD, with K-SRS as a key case study. Additionally, it is the first to describe how the identification of initial HIT features and concepts to enable PGHD could lead to the development of a specialised set of heuristics. As such, it uncovers a valuable dimension to the PROM-PGHD Development Method, which considers the socio-technical context of HITs [15, 22]. This context is the complex nature of interactions between people's unique health conditions and behaviour, and that of the technologies and tools they use within their environment [53]. The prior development of a PROM-PGHD for the key case of K-SRS was guided by this context [15]. While PROMs have long been known to support the evaluation of health interventions, which may be supported by HITs [20], they are developed to consider only the health condition of patients. Conversely, the nature of PGHD requires the development of a PROM-PGHD to consider the socio-technical context of the patient experience, i.e., both the health condition and technology category [15].

Subsequently, this paper highlights the value of considering the socio-technical context of HITs in their design and evaluation. While unexpected consequences and even failures can occur from design flaws and technical limitations, they are also often the result of sociotechnical factors [54]. Thus HIT usability testing and evaluation can benefit from frameworks, standards, and guidelines that consider the socio-technical context of those technologies [53, 55]. In particular, PROMs-PGHD [15], heuristics for PGHD enablement, and the cognitive work analysis [56] ensure that understanding of the complexities of care is incorporated in HIT design and implementation [56].

The R3C methodology [45] guided the heuristic development process, however, it was not applied without some difficulty. The methodology's development, description, and application to a case study [44, 47] were not described in explicit detail, which left too much room for flexibility. More specifically, it did not specify how the concepts identified from Step 1 were going to be connected in Step 2; how weights were going to be determined and applied to those concepts, and what influence those weights would have on the succeeding steps; how the characteristics were going to be identified in Step 3 and how they differed from the concepts previously identified; and how the original heuristics were going to be 'used' as a basis, after matching them with the defined characteristics. Moreover, while R3C presented a structured template for the specification of the heuristics in Step 4, resulting case heuristics only presented summaries or abbreviated versions [47, 57, 58]. Subsequently, implementations of R3C's steps to develop other specialised heuristics have varied [59-61].

A step-by-step implementation of the R3C methodology was presented. A systematic and detailed process was applied in each step of heuristic development, which bridged the gaps described above. It is hoped that this would aid future developers of specialised heuristics, who could apply the detailed process of heuristic development for other domains of technology; and additionally for the case of PGHD enablement, for other health conditions. Throughout the process, it was observed that the concepts and characteristics may need to be combined; and this paper presents a way to retain the weights and categories applied to them as heuristic metadata to aid implementers in understanding their underlying concepts. While the last two heuristics have a weight of two, implementers should still aim to conduct

the evaluation using all eight heuristics; although in case of any resource constraint, the first six heuristics should be prioritised.

The R3C methodology [44] was also augmented through the use of qualitative studies with target users (stroke survivors) and domain experts (physiotherapists) in order to determine the weights, discover new concepts, and ensure the defined characteristics and resulting heuristics were as close to the experiences of the users as possible. This is intended to result in a robust and credible set of heuristics, prior to the Validation Stage (Step 5) after which the specified heuristics may be improved through the Refinement Stage (Step 6). This is especially valuable, as the Methodology's recommended iteration of the process leads from Step 6 back to Step 4 [45]; implying that Steps 1-3 need to be rigorously implemented. Subsequently, the initial set of heuristics presented here will be validated and refined following Steps 5 and 6.

Limitations

Data gathered from the qualitative studies were used as an important augmentation to the heuristic development process. However, since those studies were primarily meant to support the development of a PROM-PGHD, it is possible that not all relevant questions around PGHD enablement features were asked of the participants. In the event, most concepts found through the literature review were supported by the qualitative studies, and indeed, most of the resulting heuristics were formed from new concepts found through those studies. So although it might appear to be a limiting factor, it actually indicates the robustness of the process followed, and highlights the importance of this suggested augmentation. Moreover, the Validation Stage (Step 5) still allows for possible additional heuristics to be identified.

The flexibility of the R3C methodology [44] meant that it is possible that the process followed in this paper deviated from the original intent of the authors. However, we believe that the detailed, step-by-step implementation of R3C and the suggested augmentation, have in effect modelled a way to build on and strengthen it.

Conclusions

The new set of heuristics for PGHD enablement, following a detailed, systematic development process augmented from best practice that we have presented could serve as a guide for future developers of specialised heuristics in general, and specifically for developers of heuristics for PGHD enablement of a variety of technology domains and health conditions. The new set of heuristics is needed in a period of rising demand for, supply of and variety of PGHD-enabled technologies in healthcare. It offers healthcare providers a standard way to evaluate technologies as part of selecting and implementing PGHD programs with their patients [11], complementing other in-depth PGHD evaluation methods [2, 15], and has broader relevance for design and implementation of HITs. Additionally, an interesting dimension to the PROM-PGHD development process was discovered, and highlights the value of considering the socio-technical context of HITs in their design and evaluation.

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Conflicts of Interest

There are no competing/conflict of interests.

Multimedia Appendix

Multimedia Appendix 1. Steps 1-4, transforming concepts to heuristics.

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7 Conclusions

The overarching research question of this thesis is: How could users' reporting of PGHD effects be standardised, for any given PGHD technology and health condition? It led to designing a framework that enables users to routinely report standard measures of how PGHD utilisation may affect them, to support evidence-based practice. This framework encompasses PRMs, participatory health informatics, and health information technologies within the case study setting of simulated stroke rehabilitation.

This chapter presents:

- The framework for developing PRMs of utilising PGHD.
- Research implications, challenges, and recommendations for relevant stakeholders.
- Future research recommendations.

7.1 Framework for Developing Patient-Reported Measures of Utilising Person-Generated Health Data

As illustrated in Table 2 (Chapter 1, Section 1.4), the studies conducted in this thesis corresponded with the secondary questions posed to answer the main research question. Consequently, those studies have answered the main research question and outlined a framework that could be applied for a variety of PGHD technologies for different health conditions.

A synthesis of the main findings of this thesis is first provided to illustrate how the framework is designed through this thesis. Each of the main components of the framework are then discussed.

7.1.1 Synthesis of Thesis Findings

7.1.1.1 Introduction (Chapter 1)

This chapter introduced the concept of PGHD and its potential to optimise the benefits of a range of stimulated stroke rehabilitation technologies. It presented a published literature

review that highlighted the dearth of evidence of the effects of PGHD utilisation, with only one paper reporting a motivational effect on one person.

Furthermore, this chapter described the need for health informatics research to design a framework to measure PGHD utilisation effects.

7.1.1.2 Research Design and Method (Chapter 2)

There is a need to design a framework that enables PGHD users to routinely report PGHD utilisation effects using qualitative data collection methods. Chapter 2, Section 2.4 argued for developing a PROM-PGHD to build evidence of the various effects of PGHD utilisation, and described through a peer-reviewed publication a new method for developing PROMs-PGHD that considered the sociotechnical context of the case HIT. This method outlined five major steps: a literature review (Chapter 1, Section 1.3.2), analysis of existing self-reported measures as basis for developing the new PROM-PGHD (Chapter 3), initial item revision of the PROM-PGHD item bank (Chapter 3), eliciting patient input (Chapters 4 and 5), and final item revision (Chapter 6, Section 6.1).

7.1.1.3 Development of a Patient-Reported Outcome Measure of Utilising Person-Generated Health Data Preliminary Item Bank (Chapter 3)

This chapter presented a peer-reviewed publication describing how the first three steps of the PROM-PGHD Development Method (Chapter 2, Section 2.4) was implemented for the case HIT within the domains of interest, i.e., stroke and a range of simulated rehabilitation technologies. It showed what needs to be done to ensure that the resulting PROM-PGHD items are suited to the case health condition and technology category, and notes the generalisability of the PROM-PGHD Development Method. This Method, originated in this thesis, can be used systematically to formulate criteria and measures to report PGHD utilisation effects for other health conditions and technology categories.

7.1.1.4 Item Bank Validation, Refinement, and Revision (Chapters 4 and 5, and Chapter 6, Section 6.1)

The author sought participation from three stroke survivor groups who had varying experiences with a leading simulated stroke rehabilitation technology, Jintronix. One group used Jintronix in a clinical setting (Chapter 4); another group was given a demonstration of

Jintronix (Chapter 5); and another voluntarily signed up, as an outpatient, to using Jintronix through a rehabilitation centre (Chapter 5). Clinicians were also recruited to elicit their perspectives on how PGHD utilisation may affect stroke survivors (Chapter 5). The studies showed that PGHD outcomes of utilising PGHD can be measured, provided a deeper understanding of those outcomes, and broadened their scope. The studies also provided the opportunity to discover PGHD utilisation effects not covered by the preliminary PROM-PGHD items (from Chapter 3), and confirmed whether those items were supported by actual experiences or perspectives of stroke survivors and clinicians. Additionally, the importance of enabling stroke survivors to participate in the evaluation of digital health services was emphasised, as stroke survivors and clinicians were found to have varying perspectives (Chapter 5).

The results of the studies directly informed the next step, Final Item Revision (Chapter 6, Section 6.1). Revisions included changes to the wordings, content, and structure of some items and response options; and removal and addition of a few items. The resulting PROM-PGHD items were then run through Lexile Analyzer® to assess their readability based on sentence length and commonness of words. The analysis showed that the items are appropriately readable for stroke survivors.

7.1.1.5 Improving the Design and Evaluation of Health Information Technologies to Enable Better Use of Person-Generated Health Data (Chapter 6, Section 6.2)

The process of developing a PROM-PGHD identified some features that a domain or type of PGHD technology should have, to be effective in producing positive effects on people who use PGHD to self-monitor or manage a specific health condition. These features served as the basis for developing a new set of heuristics for the design and evaluation of how well remote therapeutic technologies enable people to use PGHD (PGHD enablement). The heuristics were developed following a systematic and detailed process, which could guide future developers of specialised heuristics for other domains of technology; and additionally for the case of PGHD enablement, for other health conditions.

This chapter also illustrated how the identification of initial HIT features and concepts to enable PGHD could lead to the development of a specialised set of heuristics. As such, it

uncovered a valuable dimension to the PROM-PGHD Development Method, which considers the socio-technical context of HITs.

7.1.2 Framework Component 1: Literature Review with Consideration of Socio-Technical Context

Consideration of the socio-technical context of the case PGHD technology influences the process of PROM-PGHD development from the beginning. A literature review that appropriately considers the relevant domains, i.e., health condition and the technology category of the case HIT is conducted. This provides the opportunity to examine the types of PGHD being developed; how they are being accessed and utilised; and whether any effects or outcomes of PGHD utilisation have been reported. The literature review should also identify the types of evaluation measures that have been employed in assessing the technologies included in the review, important later when a type of patient-reported measure of utilising PGHD is being developed.

7.1.3 Framework Component 2: Selection of a Patient-Reported Measure

A type of PRM of utilising PGHD is then selected to enable PGHD users themselves to contribute to a more precise evaluation of the case HIT.

This thesis has described the necessity of developing a PROM-PGHD (Chapter 1, and Chapter 2, Section 2.4). PREMs or patient satisfaction measures would not have provided the same level of understanding as PROMs, about effects of utilising PGHD for K-SRS. However, each type of PRM serves a distinct purpose. Similar to how existing PRMs complement each other [70], PROMs-PGHD, when used as complement to PREMs or satisfaction measures, may provide an even more wholistic and accurate assessment of the patient experience as a result of using PGHD technologies.

Thus, the selection of either a PROM, PREM, or satisfaction measure of utilising PGHD needs to be considered carefully depending on the objectives and target data from evaluating a range of PGHD technologies. Other researchers may find, based on the results of their

literature review, that another type of PRM is needed for their case technology, e.g., a PREM of utilising PGHD (example in Section 7.3.1).

7.1.4 Framework Component 3: Review of Patient-Reported Measure Development Best Practice

Once a type of PRM is selected, best practice development methods should then be reviewed, in order to select one or more methods that could serve as the basis for developing the target measure. Rather than attempting to develop the new measure from scratch, it would be valuable for researchers to consider building on existing PRM development best practice. In this thesis, a qualitative method for developing PROMs was selected (QIR) as it was based on best practice, and is committed to involving people with the case health condition in the process.

After an appropriate method has been chosen, its steps then need to be assessed for suitability to the objectives of the new PRM type being developed, and its consideration of the socio-technical context of the case HIT. In this thesis, the first three steps of the QIR method were augmented, to make it appropriate for the development of the new PROM-PGHD, which was then called the PROM-PGHD Development Method.

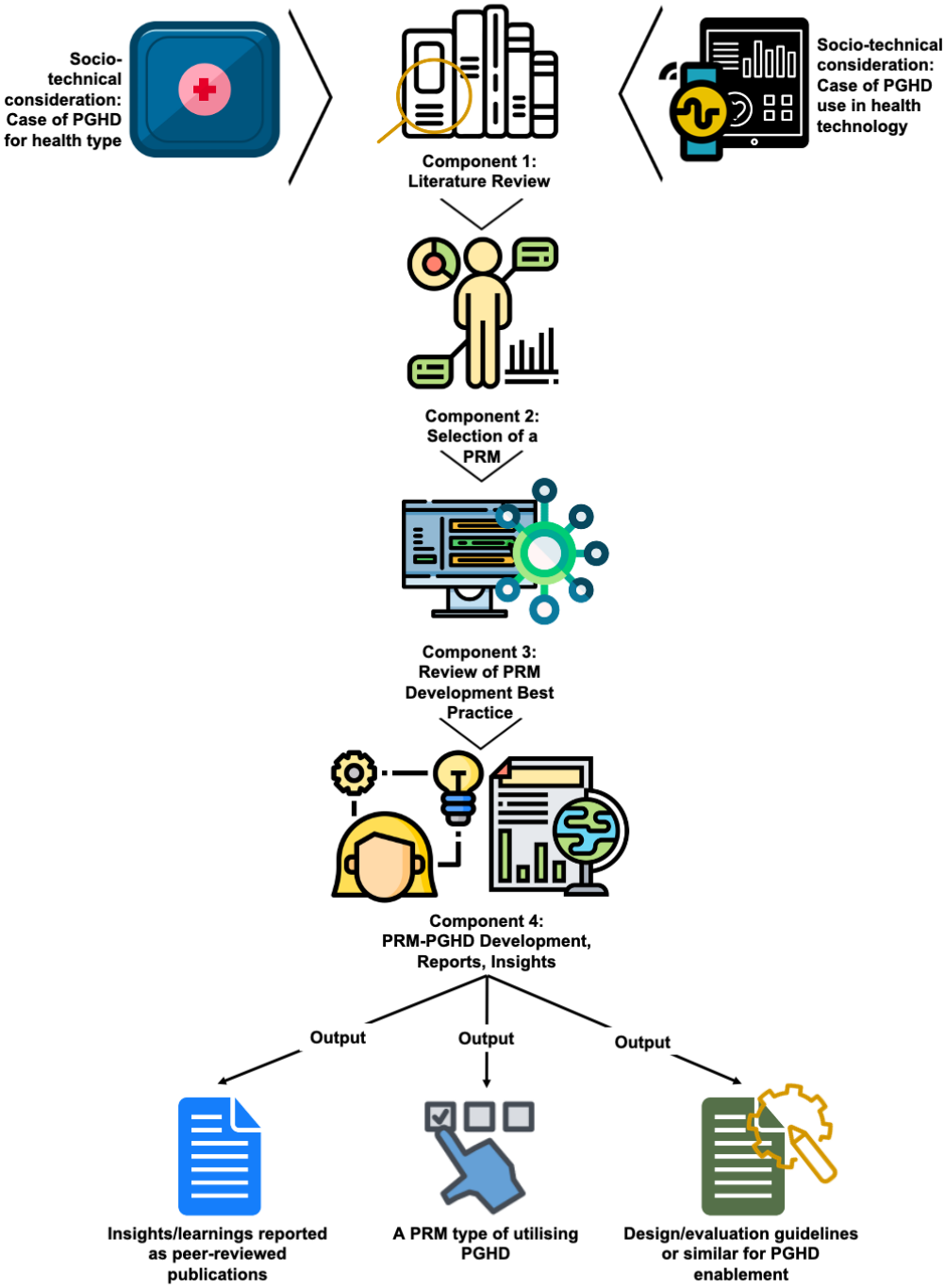
7.1.5 Framework Component 4: Patient-Reported Measure Development, Reports, and Insights

Finally, the steps of the chosen method, augmented as necessary, should then be followed in order to develop the new type of PRM of utilising PGHD. Where relevant, researchers should aim to report the detailed process followed, and the findings of major steps as this thesis has done. This is to ensure that appropriate rigour has been followed throughout the development process, and provides the opportunity for researchers to identify, consolidate, and report new insights gained at each major step. This is exemplified by the PROMIS project [74, 94, 97]. In this thesis, the peer-reviewed publications have identified and reported interesting new insights relevant to PGHD utilisation and the case HIT.

In addition, health informatics researchers should consolidate the insights gained from developing any new PRM types of utilising PGHD, and analyse how they could inform designers and evaluators of PGHD technologies. Those insights may form the basis for a new set of guidelines, design heuristics, policy paper, or a peer-reviewed publication.

Figure 14 illustrates the Framework for developing PRM types of utilising PGHD (PRM-PGHD framework).

Figure 14. The PRM-PGHD Framework



7.2 Research Implications, Challenges, and Recommendations for Stakeholders

The implications, challenges, and recommendations of the key research concepts of this thesis are discussed, and related to relevant stakeholders (PGHD users, clinicians, health informatics researchers, and health information technology developers). Appendix J presents a table that summarises this section.

7.2.1 Person-Generated Health Data

Implications

This research has furthered understanding of how PGHD may affect people's health outcomes. The process of PROM-PGHD development has recognised the value of an individual's experience in the context of PGHD use, assessment of utilisation effects, and evaluation of PGHD technologies. It demonstrated that PGHD utilisation effects can be measured. These effects should be considered by clinicians and researchers when assessing PGHD technologies. Additionally, this research has gained insights into features that a PGHD technology should have to promote positive effects. This has resulted in a new set of design heuristics that could be used by developers of PGHD technologies.

Challenges

The evidence base around PGHD utilisation effects is still lacking, although the framework presented in this thesis is a significant contribution to systematically measuring those effects. Thus, studies and projects around PGHD technologies will need to provide more attention to how PGHD may affect users, and more research is needed to help build understanding about PGHD.

Recommendations

Types of PRM-PGHD should be developed and used to document and evaluate the effects on people of PGHD utilisation from a wider range of PGHD technologies. Regardless, it would be important for clinicians to consider how their patients who use such technologies may be affected by their access to and use of their PGHD. It would also be valuable for PGHD users to place more importance on how their health data may influence their health outcomes.

7.2.2 Participatory Health Informatics

Implications

This thesis has highlighted the importance of building understanding of PGHD through the lens of PGHD users and their experiences. The approach taken to design the framework ensured that the input of people with the case health condition was elicited, and it validated and broadened the concepts gathered from the literature. It also confirmed that PGHD utilisation effects can be measured. Consideration of the socio-technical context increased the item bank's sensitivity to personal characteristics, and physiological and health-related factors affecting people with the case health condition. The resulting PROM-PGHD offers researchers a precise, patient-centred instrument for assessment of PGHD technologies, and could help PGHD users to understand how certain health technologies could affect their self-management of care. PROMs-PGHD could also help inform clinicians on decisions regarding patient care, e.g., understanding which health outcomes are important, and how patients can be motivated. The identification of features that could enable PGHD, and which led to the development of a new set of design heuristics, encourages developers to design PGHD technologies that are more inclusive of the perspectives of PGHD users.

Challenges

Patient participation is still not consistently sought in the assessment and evaluation of PGHD technologies. PGHD is not being provided to patients consistently and systematically, implying that data from a type of PRM-PGHD may also encounter the same issue and which could limit PGHD users from understanding how certain PGHD affect them. This thesis is the first to develop a type of PRM-PGHD for a case study, and the PROM-PGHD for K-SRS will need to be implemented and further assessed before it can be widely used in research and evaluation. Thus, the evidence base of PGHD utilisation effects is still lacking, in particular for other types of PGHD technologies. This thesis has also pointed out how patients' perspectives on health-related aspects could be different from those of clinicians, which might produce tensions [11] that could undermine the success of self-management strategies [98] and the technologies that support them [11].

Recommendations

Clinicians, researchers, and developers need to ensure that the value of the patient experience is recognised, particularly in studies that seek to understand the impact of PGHD utilisation. Clinicians and PGHD users are encouraged to participate in the co-development of other types of PRM-PGHD, to document and evaluate a wider range of PGHD technologies and build the evidence base of PGHD utilisation effects. Data produced from PRMs-PGHD could later be included routinely as part of the patient record, similar with PROMs. In order for PGHD users to be more involved in their own health care, they should have the option to receive any and all relevant health data; and they should be able to use this data in partnership with their clinicians in a robust feedback loop.

7.2.3 Patient-Reported Measures

Implications

The thesis has further demonstrated how qualitative research activities, i.e., focus groups and interviews can be used to broaden and deepen the concepts around PGHD, and the subsequent coverage of a PROM. Moreover, it has emphasised the need for health informatics researchers to consider the socio-technical context in building our understanding about PGHD, i.e., assessing how concepts from the technology category and health condition may affect people with the case health condition. PROMs-PGHD has the potential to inform clinician strategies to improve health outcomes or clinical and cost-effectiveness of HITs. It could help PGHD users to understand how certain health technologies could affect their self-management of care, and assist health care providers in choosing appropriate health technology for their patients.

Challenges

This thesis begins to systematically measure and understand the varying effects of PGHD utilisation, however the evidence base is still lacking, and more research is needed for PROM-PGHD results to be integrated as part of patient self-management. Currently, PGHD is not being provided to PGHD users in a consistent and systematic manner, thus the provision of PROM-PGHD results to PGHD users may encounter the same issue. Participation of PGHD users is also not consistently sought in the assessment and evaluation of PGHD technologies,

and there is a lack of attention given to PGHD utilisation effects in the literature, particularly for the case of simulated rehabilitation systems for stroke survivors.

Recommendations

Clinicians, PGHD users, and developers are encouraged to support efforts to develop PROMs-PGHD, necessary to furnish clearer evidence about the value of implementing HITs. It could also be valuable for health informatics researchers to further explore how other socio-technical factors such as health literacy influence responses to the PROM-PGHD. Later PROMs-PGHD data could be integrated as part of patient records, as has been done with PROMs, to ensure that the value of the patient experience is recognised in the assessment of health interventions and outcomes.

7.2.4 Design and Evaluation of Person-Generated Health Data Technologies

Implications

This thesis has shown that understanding PGHD utilisation effects could improve the design of HITs, in particular by helping HIT designers in identifying features that could enable the benefits of PGHD. The new design heuristics for PGHD enablement could contribute to the selection and implementation of PGHD programmes by clinicians, complementing other PGHD evaluation methods. Its systematic process of developing a new set of heuristics for PGHD-enablement provides researchers with a detailed guide for developing other specialised heuristics for other technology types; and for PGHD-enablement, other health conditions. It also highlighted the value of considering socio-technical context of HITs in their design and evaluation. In effect this thesis has emphasised the importance of enabling people with the case health condition to participate in evaluation of digital health services, and encourages technology designers in developing PGHD technologies that are more inclusive of the perspectives of PGHD users.

Challenges

At the moment there is still a lack of attention around how PGHD utilisation may affect PGHD users, which initially limited the documented effects gathered in the literature review (Chapter 1, Section 1.3.2). Moreover, their participation is still not consistently sought in the

assessment and evaluation of PGHD technologies. The focus on technical rather than health outcomes evaluation in the stroke simulated rehabilitation literature indicates that the field is still immature, confirming an earlier finding [99] and presents a challenge to evaluate clinical outcomes of those technologies.

Recommendations

Developers should consider how the benefits of PGHD could be designed into the HIT, e.g., through the use of the heuristics for PGHD enablement. Heuristics could ensure that understanding of complexities of care are incorporated in HIT design and implementation. The patient experience should also be recognised in understanding the impact of PGHD utilisation. This has relevance to the success of patient self-management strategies; and design and evaluation of PGHD technologies. Health informatics researchers should consider PGHD and PGHD access in system design, implementation, and evaluation of HITs; and field testing the newly developed heuristics for PGHD enablement. Researchers and developers alike are also encouraged to take up the challenge of evaluating clinical outcomes of PGHD technologies.

7.3 Future Research Recommendations

This thesis has presented a new framework for developing PRM types of utilising PGHD, and whose application in the case study of developing a PROM-PGHD for K-SRS also resulted in a new set of design heuristics for PGHD enablement. Thus, the framework is a significant step forward in health informatics research for systematically building evidence about PGHD. Moreover, it assists in designing HITs that enable the benefits of PGHD.

The author recommends, and hopes, that the framework will be applied to other case HITs to further our understanding of PGHD and its utilisation effects. The following sections identify other exemplar cases where developing a type of PRM-PGHD could have significant impact; and discuss potential hurdles that efforts to optimise PGHD benefits in low-resource environments will need to overcome. The cases described below are considered exemplars due to their high global burden and their impact on patient lives, and the potential for PGHD technologies to contribute to improving health outcomes. However, this list is not meant to

be exhaustive, and there are other case HITs for other health conditions where the PRM-PGHD Framework could be applied.

7.3.1 Applying the Patient-Reported Measure of Utilising Person-Generated Health Data Framework to Other Case Health Information Technologies

Digital Self-Tracking for Bipolar Disorder

Bipolar disorder (BD) is a severe mental disorder [100] that accounts for 9.9 million DALYs [101]. An important part of health self-management for people with BD is tracking elements about their emotional and physical wellbeing such as amount and quality of sleep, exercise, and social interactions. Technology-based health tracking (e.g., through fitness applications and digital notebooks) could significantly improve on traditional paper-based tracking (e.g., through journals, charts, and calendars) [8]. Self-tracking these types of PGHD could therefore help people with BD in self-managing symptoms and effects. People with BD could have an increased understanding about BD triggers such as negative social media content, be empowered with a greater sense of control, and have increased confidence. However, digital self-tracking tools could also be demotivating if they become too complex [8].

Following the PRM-PGHD Framework would allow for a more systematic way of measuring the influence that PGHD could have on people with BD. After understanding the use case, that is the health condition and technology category, through a literature review, a type of PRM-PGHD is then selected. For the case of digital self-tracking for BD, the development of a PROM-PGHD would provide a systematic way of understanding the effects that PGHD utilisation from digital self-tracking tools may have on people with BD, and to what extent. This is particularly relevant, due to how essential self-tracking is for people with BD, to stay on top of their condition [8]. Alternatively, a PREM-PGHD may also be considered. This is due to the importance people with BD place on user experience: a cumbersome experience could lead them to increased feelings of hopelessness particularly during an episode [8].

After carefully considering the type of PRM to be developed, best practice development practices of either PROM or PREM should then be assessed and augmented for BD, as necessary. Input of people with BD must be elicited; if the chosen PRM development method

does not elicit their input then it must be augmented. Insights should then be consolidated, to aid in the design and evaluation of digital technologies used in BD self-tracking through a set of guidelines, policies, or design heuristics.

Digital Weight Management for Obesity and Type 2 Diabetes

Obesity is a significant risk factor for type 2 diabetes [102], which comprises the majority of global diabetes cases. Moreover, prevalence of adult diabetes cases around the world has been increasing, from only 4.7% in 1980 to 8.5% in 2014; and causing 1.5 million deaths in 2012 [103]. Using self-tracking technologies such as mobile applications has the potential to improve on traditional lifestyle modification programmes. These programmes could be difficult to sustain by people with diabetes due to barriers such as cost and access. For example, a mobile application that records activity levels, weight, and calorie intake has been reported to encourage people with diabetes to change their behaviour and increase their activity, while reducing their intake of high-fat and high-sugar food [102]. However, gains in motivation have also been reported to diminish over time [104].

Developing a PROM-PGHD following the PRM-PGHD Framework could broaden understanding of those effects. It could provide a way to systematically evaluate the impact that PGHD utilisation from digital weight self-management could have on people with diabetes. Moreover, consolidating the insights gained from the PROM-PGHD development process could result in guiding the design and evaluation of such technologies, for PGHD enablement.

7.3.2 Applying the Patient-Reported Outcome Measure of Utilising Person-Generated Health Data and Simulated Rehabilitation Technologies in Low-Resource Environments

This thesis has previously described the potential of PGHD to enhance the benefits of simulated stroke rehabilitation systems, and the author's personal interest in the area (Chapter 1, Section 1.3.1).

The author had earlier attempted to collect data in his hometown, to assess the feasibility and effectiveness of the Jintronix simulated stroke rehabilitation system, and to refine the PROM-PGHD in that setting.

Research Delays

An earlier iteration of this thesis sought to conduct the data collection phase in the author's hometown of Zamboanga City, Philippines. The author coordinated with a neurologist who was interested in providing simulated stroke rehabilitation options to stroke survivors at home. The study would have tested the feasibility and effectiveness of implementing Jintronix in a low-resource setting, aside from the objective of eliciting stroke survivors' input for the development of a PROM-PGHD. The plan had been to recruit outpatient stroke survivors, and provide them with a PC, Kinect, and a Jintronix subscription for them to perform simulated rehabilitation in their own homes. To conduct the study, an ethics application was submitted in 2017 to the Zamboanga Consortium for Health Research and Development (ZCHRD); and in 2018 the author was requested to submit another one to the Ateneo de Zamboanga University Research Ethics Committee, which might assist with administering the research grant. In early 2019, the ZCHRD ethics application was approved. Additionally, in early 2019 a research grant of nearly PHP 700,000 (~AUD 20,000) was approved in principle by ZCHRD. Due to the author's PhD timeline, the author went ahead with Plan B of collecting data in Melbourne, and the results of this change of plan have been included in this thesis.

The likely cause of the unfortunate delays is the limited resource in terms of personnel and time in Zamboanga. The author's research collaborator is the only neurologist in a region of around 3.6 million people [105], significantly worse than the national average of 1:330,000 people; which in turn is lower than the WHO recommended ratio 1:943 [34]. It also confirms the uneven distribution of neurologists in the country [34]. Moreover, the difficulty of recruiting research ethics committee members and the lack of administrative support in Asian developing countries [106] may have contributed to increasing the length of the ethics review process.

Looking Forward

Despite these challenges, the potential benefits of implementing a PGHD simulated rehabilitation option for stroke survivors in LMICs, e.g., the Philippines, remain (Chapter 1, Section 1.3.1). Moreover, early work conducted by the author shows some promising results for the feasibility of using Jintronix at home for those who live in the urbanised areas of the city, even for those without a Wi-Fi connection. Jintronix requires an Internet connection to be used.

Testing by the author in November 2017 showed that the average exercise game requires 0.53mb (SD: 0.15) of data per session. Tests conducted in Zamboanga in January 2018 using only a 4G mobile connection showed that Jintronix could be used with negligible issues. Appendix K describes how the tests were conducted. Using Jintronix could be challenging, however, if only 3G is available or when Jintronix requires an online update. Some games could not be played right away when only 3G was used, and many people in the city only have access to 3G [107]. As for updating Jintronix, the size of an update pushed in November 2017 was 65.62mb.

These early tests show the limited potential of Jintronix in providing a viable, home-based rehabilitation alternative for stroke survivors in low-resource, urban environments. It is suggested that formal enquiries are conducted to establish the feasibility and effectiveness of Jintronix or other similar simulated rehabilitation technologies in LMICs, particularly in rural areas. Such a feasibility and effectiveness study may still be implemented by the author in Zamboanga in the future, and that may also serve as a platform for field-testing the PROM-PGHD for K-SRS.

7.4 Conclusion

This thesis has designed a framework for evidence-based research and practice with PGHD technologies, to benefit multiple stakeholders. It has built on the foundations of PGHD, PRM, participatory health informatics, and design heuristics to create new knowledge about:

- PGHD utilisation and stroke survivor participation in simulated stroke rehabilitation.
- Influence of PGHD on simulated stroke rehabilitation health outcomes.

- Systematic development of a PROM of utilising PGHD for an exemplar case.
- Importance of participatory health in the design and evaluation of PGHD technologies.
- Design considerations and characteristics for PGHD enablement.
- Systematic development of design heuristics for PGHD enablement.

The increasing availability and growing adoption of PGHD technologies require systematic, validated processes to generate evidence about the effects of utilising personal health data and to improve technology design. This thesis provides early, significant steps towards this goal.

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Abbreviations

ADL: activities of daily living

BD: bipolar disorder

DALY: disability adjusted life year

EBP: evidence-based practice

FDA: United States Food and Drug Administration

HE: heuristic evaluation

HIT: health information technology

K-SRS: Kinect-based stroke rehabilitation system

LMIC: lower-middle income country

PGHD: person-generated health data

PRM: patient-reported measure

PREM: patient-reported experience measure

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PROM: patient-reported outcome measure

PROMIS: Patient-Reported Outcomes Measurement Information System

PROM-PGHD: patient-reported outcome measure of utilising person-generated health data

PRO-PM: patient-reported outcomes performance measurement

QIR: Qualitative Item Review

QoL: quality of life

RCT: randomised controlled trial

SAC: Scientific Advisory Committee of the Medical Outcomes Trust

VR: virtual reality

Appendix A. Chapter 1, Section 1.3.2 Literature Review Multimedia Appendices

These 'multimedia appendices' were originally published as part of the publication presented in Chapter 1, Section 1.3.2 Literature Review. Any figures and tables that appear in these appendices have NOT been renumbered for this thesis.

Multimedia Appendix 1

Search strategy for Part 1, analysis of systematic reviews.

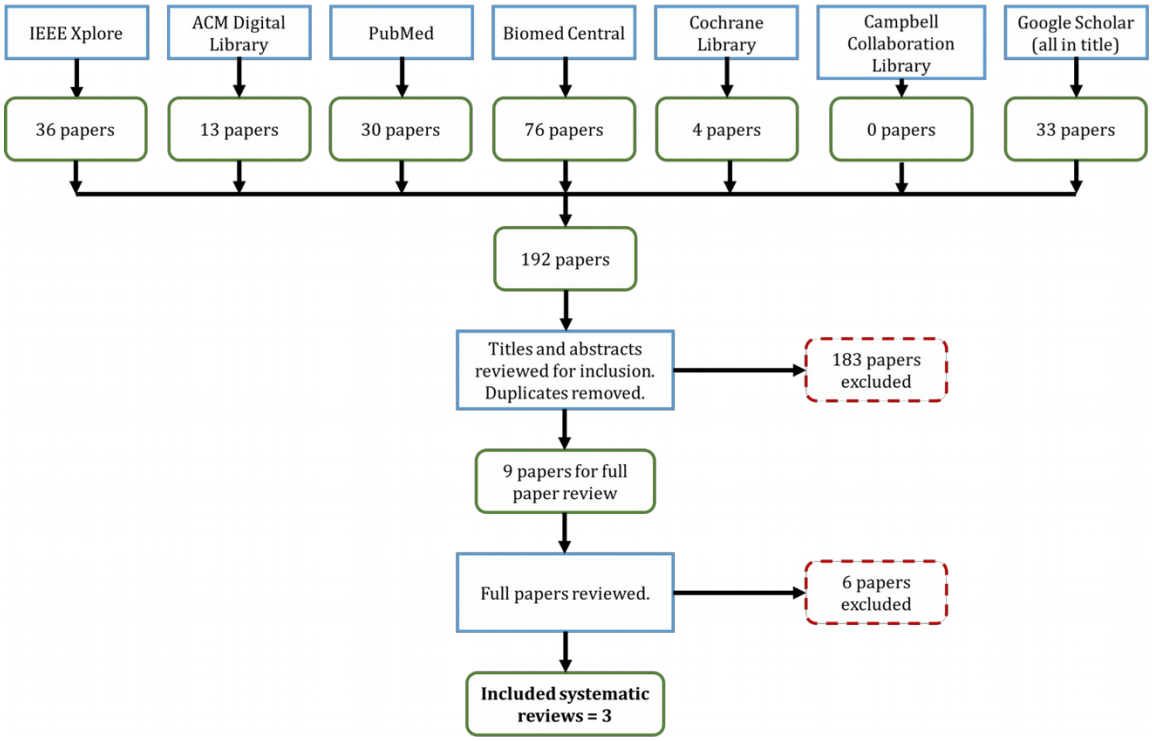
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Search Strategy

The search phrase used was: kinect AND review. Search was conducted through six databases: IEEE Xplore, and ACM Digital Library for sources from the computing and engineering field; PubMed, and Biomed Central for sources from the health field; and the Cochrane, and Campbell Collaboration digital libraries to search for detailed reviews. Finally, Google Scholar was also utilised for a broader search of revelant papers [77,78]. It was necessary that the search returned reviews that mentioned Kinect, thus all text searches were conducted. For Google Scholar, only all title search was conducted. There was no date restriction. The search was closed in June 2017. The quality of the papers were not assessed, as it was not deemed critical to understanding PGHD access and utilisation in studies that utilised K-SRS.

The search returned 192 papers in total. GLD reviewed the titles of the papers, and their abstracts when necessary. Non-systematic reviews, or reviews of Kinect for non-rehabilitation purposes, were excluded (183 papers). The remaining nine were reviewed by GLD in full using the inclusion and exclusion criteria in the next section, where six more papers were excluded; resulting in the three systematic reviews that were analysed in this paper. This search process is illustrated below (Figure 1).

Figure 1. Search process for Part 1



Inclusion and Exclusion Criteria

The inclusion and exclusion criteria (Table 1) ensured that the systematic reviews were focused on K-SRS, and examined articles in sufficient detail. This is necessary to meet the three points for analysis in part 1: PGHD utilisation, home based rehabilitation, and effectiveness. Papers were included if they reviewed systems primarily for stroke rehabilitation and used Kinect. Meanwhile, reviews for non-rehabilitation purposes such as measuring clinical outcomes, or assessing Kinect's gesture recognition capability were excluded. Broad scoping reviews that mainly took inventory of a general suite of technologies, and thus did not describe Kinect-based systems in detail, were also excluded.

Table 1. Inclusion and exclusion criteria for part 1

Inclusion Criteria Exclusion Criteria	Inclusion Criteria Exclusion Criteria
Written in English.	Reviews for non-stroke rehabilitation purposes, e.g., assess Kinect's gesture recognition.

Systematic or literature reviews.	Broad scoping reviews that primarily took inventory of a suite of technology-based rehabilitation systems.
Reviews of systems that used Kinect. Reviews of systems for stroke rehabilitation.	
Reviews of systems that used Kinect. Reviews of systems for stroke rehabilitation.	

Data Extraction and Analysis

The content of each systematic review paper was analysed based on (1) their method for analysis vis-à-vis their objectives; (2) their focus on utilisation of patient-generated health data, including feedback given to users or patients; (3) the extent to which the systems included in their review are usable at home, including the challenges and recommendations of implementing at home; and (4) the effectiveness of the systems in their review based on patient outcomes as well as technological limitations that may affect those outcomes.

The objectives, methods and structure of each systematic review are detailed in Table 3 (Appendix 3). A summary of these systematic reviews vis-à-vis the themes of interest above can be found in Table 4 (Appendix 4).

---

77. Walters W. Google Scholar coverage of a multidisciplinary field. Information Processing and Management. 2007;43(4):1121-32. DOI: 10.1016/j.ipm.2006.08.006 78. Falagas M, Pitsouni E, Malietzis G, Pappas G. Comparison of PubMed, Scopus, Web of Science, and Google Scholar: strengths and weaknesses. The FASEB Journal. 2007;22(2):338-42. DOI: 10.1096/fj.07-9492LSF

Multimedia Appendix 2

Search strategy for Part 2, review of PGHD use in K-SRS.

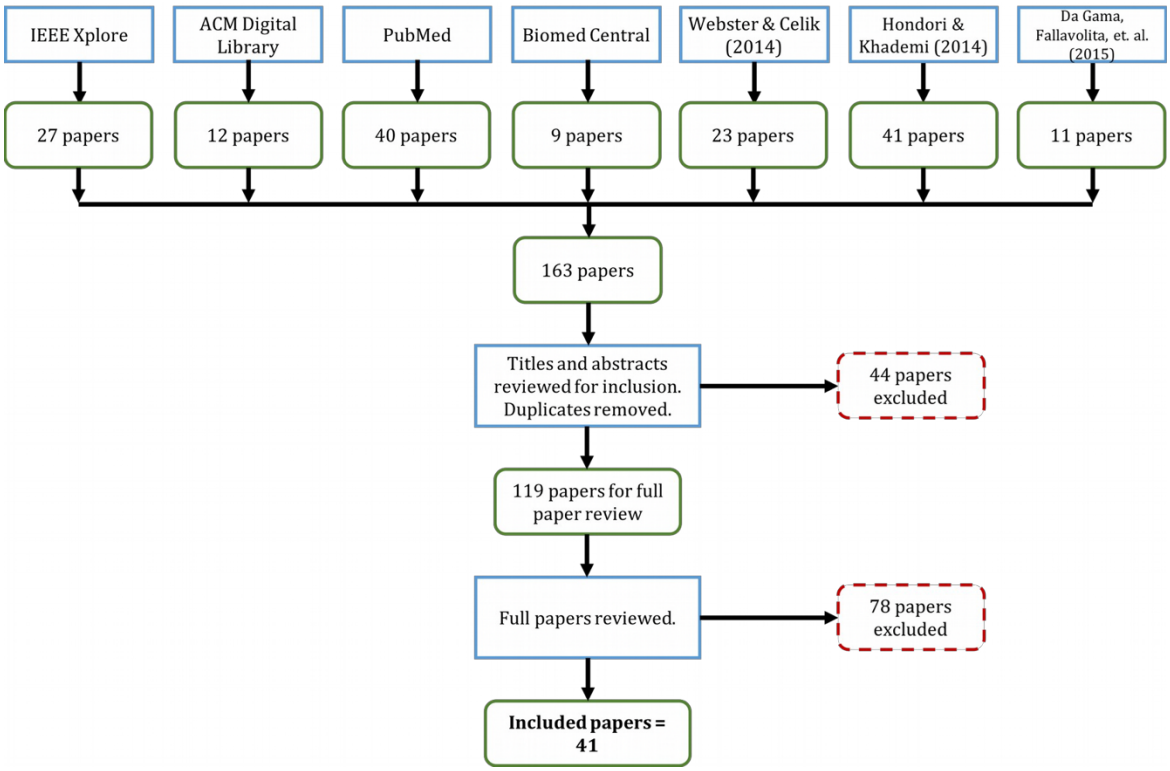
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Search Strategy

The search was conducted in four major databases: IEEE Xplore, ACM Digital Library, PubMed, and Biomed Central. The terms used were “Kinect”, “stroke”, “cerebrovascular accident”, “CVA”, and “rehabilitat*”. These were selected with the help of a University of Melbourne librarian. Keywords found in an initial search were also scanned for relevant terms (where “cerebrovascular accident” and “CVA” were discovered). The search phrase used was: Kinect AND (stroke OR “cerebrovascular accident” OR cva) AND rehabilitat* for PubMed, Biomed Central, and IEEE Xplore. For ACM, the wildcard symbol “*” was not used as the resulting articles numbered more than 444,000, mostly unrelated. Rehabilitat* was instead replaced with the phrase “rehabilitate OR rehabilitation”. Reference lists on K-SRS of the reviews found in Part 1, were also included in the search for Part 2. There was no date restriction. The search was closed in June 2017. The quality of the papers were not assessed, as it was not deemed critical to understanding PGHD access and utilisation in studies that utilised K-SRS.

A total of 163 papers were found. GLD reviewed the titles of the papers, and their abstracts when necessary. 44 papers were excluded from this process. The remaining 119 papers were then examined by GLD in full using the inclusion and exclusion criteria outlined below. 78 papers were excluded in this phase, leaving 41 papers included for thematic analysis. This search process is outlined below (Figure 2).

Figure 2. Search process for Part 2



The quality of the papers were not checked prior to inclusion, as whether or not the papers were of high quality was not critical to understanding how PGHD were generated, accessed, utilised, and whether they resulted in any effects.

Inclusion and Exclusion Criteria

The inclusion and exclusion criteria for part 2 (Table 2) ensured that English full papers that presented rehabilitation systems for stroke, using Kinect, are included. Such systems may use other technologies as well, for example, in a rehabilitation environment that included the use of sensors. Papers were excluded if: their study focus was not on using or developing a rehabilitation system, e.g., evaluation of an algorithm; disease case was non-stroke; system did not use Kinect in any way; type was literature or systematic review; or if they were white papers. For papers that presented an update from previous publications, the latest paper was selected.

Table 2. Part 2 inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria

Full papers written in English.	Primary purpose of study is not on rehabilitation.
Presented rehabilitation systems for stroke.	Stroke was not the primary disease case.
Kinect was used for the system.	Kinect was not used in any way.
	Literature or systematic reviews.
	White papers.

Data Extraction and Analysis

Data were extracted from the papers based on a structured form that included the participants, outcome measures, and PGHD focus. For the focus on PGHD, the papers were analysed using the following questions: 1) What types of data did patients generate? 2) Did they have access to their PGHD, and if yes in what form? 3) How were these data utilised by patients, clinicians, developers and/ or researchers? 4) What effects were observed from PGHD utilisation? Appendix 6 shows the outcome measures categorised, and ranked according to references that used them. Detailed data extracted for the focus on PGHD can be found in Appendix 7.

To assist future studies in assessing the clinical effectiveness of K-SRS, papers were also categorised as either clinical- or technical-focused. The list of papers categorised according to their clinical/technical type is in Appendix 5 (Tables 5 and 6).

Multimedia Appendix 3

Objectives, methods, and structure of existing systematic reviews of Kinect-based stroke rehabilitation systems.

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Table 3. Summary of existing systematic reviews

Summary	Webster and Celik (2014)	Hondori and Khademi (2014)	Da Gama, Fallavollita, Teichrieb and Navab (2015)
Objectives	Gather relevant information on Kinect-based systems for stroke and elderly care.	Review notable motion capture systems. Term *notable* not specified.	Uncover research status of Kinect as a body-tracking tool for motor rehabilitation. Term *status* not specified.
Methods			
Databases	IEEE/IET Electronic Library, PubMed, ACM Digital Library, Computer Science Index, Safari Tech Books Online, and ISIS Web of Science.	PubMed, Google Scholar (title only).	IEEE Xplore, PubMed.
Inclusion	English, peer-reviewed papers directy or indirectly related to stroke or elderly care. This meant other reviews were included.	Not indicated.	English papers that are more than four pages in length, and which described a system for assistive interaction, clinical evaluation, or evaluation and improvement of Kinect's movement recognition and tracking.

Exclusion	No exclusion criteria.	Not indicated.	No exclusion criteria.
Search terms	Kinect (and combined sets of), stroke, rehabilitation, gesture, posture, clinical, geriatrics, elderly, ageing, aged, alert, fall, gait, exergame, serious game.	Kinect, rehabilitation	Kinect AND rehabilitation.
Analysis/ Structure	Categorised papers into stroke rehabilitation, with sub-categories spatial accuracy assessment, and methodological study; elderly care, with sub-categories falls detection or falls risk reduction; and serious/exercise games.	Four main points of discussion were rehabilitation systems using devices before the advent of Kinect; accuracy and stability considerations for Kinect developers; discussion on Kinect-based systems with or without patients; and other body-tracking sensors similar to Kinect.	Categorised papers into assistive, for papers that described systems for assistive interaction; evaluation, for papers that evaluated a measure, or used a measure; applicability, for papers that recruited patients; validation, for papers that used gold standard measures; and improvement, for papers that presented a technical improvement in design or implementation of a system.
Visual Presentation of Data	Tables summarised subject demographics and number (if available);	Tables and graphs. Table columns for papers that recruited patients	Tables that summarised the tracking software used (Microsoft Software Development Kit/Open NI);

	descriptions of systems; measures used (if available); and main findings. For serious/exercise games, feedback provided was very briefly described, e.g., warnings, and game scores.	were targeted disability, study type, purpose, evaluation, conclusion. Table columns for studies without patients were one-liner findings, comparison of depth sensors. There were also four graphs to show number of papers in PubMed that mentioned Kinect alone, then Kinect and rehabilitation; and number of papers in Google Scholar that mentioned Kinect alone, then Kinect and rehabilitation.	movement analysed (e.g., any movement, upper limbs, hand trajectory or reach); system interface/visualition and feedback; features (e.g., therapist-configurable, auto-reporting of results to clinician); measure that was evaluated/used to evaluate; technique in improving the system; user evaluation (type of evaluation, e.g., survey, pre- and post-study); type (virtual/guidance/interactive game); target (stroke/other neurologic diseases); and results of the system (e.g., detection of correct exercises).
Results/ Discussion	Kinect has potential for physical and mental benefits, i.e., faster and better supported rehabilitation as well	Kinect and other depth-based tracking sensors are better than earlier RGB-based sensors. Kinect's	Interaction in the papers were mostly in the form of avatars, or game characters. Popular movement exercises were reaching exercises, and

	as enjoyability. Kinect-based systems can also extend guidance and correction of patient movements. Main limitations noted is on technological capability of Kinect, e.g., its difficulty to track fine motor function such as fingers.	weakness lies in occlusion, in that sometimes other objects are mistaken as part of the user's limbs. However, with proper calibration Kinect was shown to be more precise and sensitive than other systems. It is particularly best for whole-body tracking. One study also showed that patients preferred Kinect over other off-the-shelf, consumer body-tracking devices Nintendo Wii and PlayStation 3 Move.	mimicking movements in a screen. For home interactive systems, there is a need to assess the capability of such systems to assess patient performance of exercises, and comparatively evaluate Kinect-guided movements vis-à-vis clinical measures. Studies with patients reported that patients tended to perform exercises more often with Kinect-based systems because of the game/fun component. Limitations of Kinect included occlusion; accuracy based on user position (standing), and movement (planar motions); and hands are depicted only as a point in space, hence finger movement tracking is impossible, unless Kinect is hung from above, focused on the hands alone, and trained to recognise the fingers.

Multimedia Appendix 4

Analysis of PGHD, home use, and effectiveness in existing systematic reviews of Kinect-based stroke rehabilitation systems.

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Table 4. Existing systematic reviews vis-à-vis themes of interest

Themes	Webster and Celik (2014)	Hondori and Khademi (2014)	Da Gama, Fallavollita, Teichrieb and Navab (2015)
Did the review analyse PGHD utilisation in the literature?	No	No	No
Did the review analyse home use in the literature?	No	No	No
Did the review analyse effectiveness in the literature?	Yes	Yes	Yes

Multimedia Appendix 5

Types of papers.

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Table 5. Clinical-focused papers

Clinical-focused papers (N=9)	
Reference	Description
Cohort Studies (N=2)	
[36]	Compared the physical and psychological effects on patients who either used a Kinect-based rehabilitation, or a bicycle ergometre training system.
[57]	Compared the effects of using Kinect-based training games on stroke patients with varied cerebral hemisphere-affected areas.
Case Reports (N=2)	
[49]	Evaluated a developed reaching exercise game for clinical effectiveness with 15 patients in a non-controlled setting.
[50]	Evaluated the clinical effectiveness of an off-the-shelf Kinect-based game for rehabilitation. Changes in the activated brain regions were also observed.
Randomised Controlled Trials (N=5)	
[71]	Study protocol: will evaluate the feasibility, efficacy and saftey of a Kinect-based system.
[72]	Study protocol: will assess the impact on patients who will use an interactive system at home, with a traditional home exercise programme.
[37,38]	Compared the effects of using Kinect-based games along with usual therapy on patient muscle strength and tone, against patients who only performed traditional therapy.
[39]	Assessed the clinical effectiveness of a tele-motion rehabilitation system by comparing the effects on patients who used the system, against those who performed traditional home-based exercises.

Table 6. Technical papers

Technical papers (N=32)	
Reference	Description
Survey (N=1)	
[51]	Used a questionnaire to gather user perceptions, and preferences to design a mode of interaction with a visual object in an augmented reality environment.
Proof of concept (N=5) *Tested the concept of K-SRS, and using other technologies with Kinect, for stroke rehabilitation.*	
[48]	Assessed the feasibility of using a gamified, home-based rehabilitation system for stroke patients.
[40]	Investigated the feasibility of using functional electrical stimulation to upper limb muscles for completion of tasks; and using iterative learning control algorithms to control the FES signals applied to the muscles.
[45]	Tested the concept of using body machine interfaces with Kinect.
[41]	Tested a Kinect-based model for assessing individual components of the timed-up and go test, followed by an assessment of the system's reliability.
[61]	Assessed the feasibility of a system for robot-assisted rehabilitation through gaze tracking, a brain-computer interface, and Kinect.
Application Development (N=17) *Primarily described the process of designing or building a system for stroke rehabilitation.*	
[22,35,43,47,52,56,63,64,65,68]	Developed a system to provide movement or posture therapy. *Additionally*: [66] included a monitoring component for falls prevention among the elderly; [47] provided speech therapy; [43] re-engineered a previously-developed immersive multimedia rehabilitation environment for improved control; and [56] used 'intelligent objects' with sensors to aid in ADL recovery.
[46,55]	Developed a system to assess movement capabilities of patients. *Additionally:* [46] provided rehabilitation for motor function.

[23]	Developed a system to assist patients in improving movement, and predicted their recovery.
[53]	Developed a hybrid system that incorporated a low cost brain computer interface system called MindWave for brain signal input, with Kinect tracking user movement.
[65]	Digitised box-and-blocks test, where a traditional BBT was used but the progress, quantified by the number of blocks moved within a period of time, was tracked by Kinect.
[42]	Virtualised BBT, with patients controlling a virtual hand to move virtual blocks.
[69]	Proposed an exercise game system framework that provides online biofeedback to patients and therapists based on patient movements for safer and better exercise sessions.
Platform Development (N=6) *Explained how multiple body-tracking technologies could be integrated in one system.*	
[54,70]	Developed platforms that made use of multiple consumer body-tracking devices, e.g., Kinect and Nintendo Wii, as input devices.
[59]	Developed a platform that made use of multiple consumer body-tracking devices, i.e., Kinect, Leap Motion, and Orbotix Sphero to be used simultaneously to track multiple parts of the body.
[67]	Offered gamified rehabilitation exercises to patients (which therapists can prescribe], monitor their performance, and connect with online health records to share information with clinicians; while wearables send updates for regular monitoring of patients' well-being.
[58]	Developed a K-SRS, and a cuffless blood pressure device with a chair-based electrocardiogram and photoplethysmograph for monitoring.
[60]	Developed a smart glove in-house to work with Kinect and track fine motor finger movement.
Assessment (N=3) *Conducted technical assessments of Kinect as a body-tracking device for stroke rehabilitation.*	

[44]	Assessed its tracking and evaluation of components of spatiotemporal gait movements.
[30]	Assessed Kinect's test-retest reliability in finding movement indices.
[62]	Compared the precision of Kinect against another device, Shimmer, in tracking exercise movements.

Multimedia Appendix 6

Outcome measures.

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The outcome measures presented are categorised, and ranked according to the number of papers that used them as measures.

Table 7. Technical measures

Technical Measures (Reference count =18)	
Outcome Measures	Reference
To assess accuracy (Ref. count =13)	
Comparison of cursor movement with Trunk Impairment Scale results	[45]
Frequency stimulation and refresh rate	[54]
Kinect-tracked Timed-Up and Go Test variables	[41]
Number of movements tracked by Kinect versus Shimmer	[62]
Standing, sitting, and lying posture variables	[64]
Dynamic Time Warping	[23,55]
Sensor ability to track posture	[66]
System validation tests	[67]
Analysis of personal dead reckoning algorithm in tracking body and hand/fingers	[60]
Arbitrary direct observation of system errors	[58]
Analysis of sensor data attached to 'intelligent' objects	[56]
Images over time to track occlusion and gaze tracking of moving objects	[61]
Computational speed of tracking algorithm	[61]
Comparison of gaze, proxy, and end-effector positions	[61]
To assess system design (Ref. count =4)	
Feedback questionnaire	[22]
User requirements	[52]
Semi-structured interviews	[40]

User workflow	[67]
To assess reliability (Ref. count =3)	
Standard Error of Measurement and Minimum Detectable Change	[41]
Kinect-tracked kinematics variables	[30]
Event-related desynchronisation and scalp activation maps	[61]
Classifier performance of patients	[61]
Support vector machine classifier	[61]
Velocity of the brain-controlled interface signals	[61]
To predict patients' recovery progress (Ref. count =1)	
Auto-Regressive Integrated Moving Average model	[23]
Observe rehabilitation effects on brain (Ref. count =1)	
Brain Regions of Interest activated	[50]

Table 8. Motor function measures

Motor Function Measures (Reference count = 14)	
Outcome Measures	Reference
To assess upper extremity movement (Ref. count =13)	
Fugl-Meyer Upper Extremity Assessment	[22,38-40,42,47,48,50,72]
Box-and-Blocks Test	[38,42,65,72]
Action Research Arm Test	[23,40]
Motor Activity Log	[39,72]
Modified Motor Assessment Scale (Upper Arm)	[71]
Trunk Impairment Scale	[45]
Shoulder and Elbow Flexion data from the Qualisys Motion Capture System	[57]
Goniometre data	[38]
Kinect-tracked kinematics data	[23]
Brunnstrom Stage (haemiplegic arm and hand)	[42]
Korean National Institute of Health Stroke Scale	[42]
Chedoke Arm and Hand Activity Inventory	[39]
Wolf Motor Function Test	[50]

To assess muscle tone (Ref. count =2)	
Modified Ashworth Scale	[37,57]
To assess muscle strength (Ref. count =1)	
Manual Muscle Test	[37]

Table 9. Activity measures

Activity Measures (Reference count = 7)	
Outcome Measures	Reference
To assess gait (Ref. count=3)	
Timed Up and Go Test	[36,41,44]
10-Metre Walking Test	
Step Test	[41,44]
To assess abilities of patients to perform activities of daily living (Ref. count =3)	
Canadian Occupational Performance Measure	[48]
Record of errors and error patterns	[35]
System-generated movement variables	[67]
To assess physical activity (Ref. count =2)	
Functional Independence Measure	[37,57]
To assess safety (Ref. count =1)	
Borg Rating of Perceived Exertion Scale	[71]
Visual Analogue Scale (pain & fatigue)	
To measure energy expenditure (Ref. count =1)	
ActivPal accelerometre	[71]

Table 10. System usability measures

System Usability Measures (Reference count = 8)	
Outcome Measures	Reference
To assess user experience (Ref. count =4)	
IBM Game Experience Questionnaire	[48]
IBM System Usability Questionnaire	

Other questionnaires (not described)	[45,51,68]
To assess system usability (Ref. count =3)	
Reasons of patients for missing sessions	[71]
Use eye gaze and duration qualitative data, utterances or verbal responses, general body actions, and initiated actions	[43]
User feedbacks (Method undescribed)	[46]
To assess feasibility (Ref. count =1)	
Ratio of session completion	[71]
To assess enjoyment and benefits (Ref. count =1)	
5-point likert scales	[71]
For economic evaluation (Ref. count =1)	
Incremental cost-effectiveness ratio	[72]
To assess system attractiveness and appeal (Ref. count =1)	
Semi-structured interviews	[48]

Table 11. Balance measures

Balance Measures (Reference count = 6)	
Outcome Measures	Reference
To assess standing balance (Ref. count =4)	
Functional Reach Test	[41,71]
Lateral Reach Test (medio-lateral balance)	[71]
Standing Double-Legged Balance (eyes closed)	[44]
Standing Weight Bearing Asymmetry	
Berg Balance Scale	[49]
Tinetti Performance Oriented Mobility Assessment - balance	
Brunnel Balance Assessment	
To assess sitting balance (Ref. count =2)	
Standardised Four-point Sitting Balance Test	[71]
Medial-Lateral Weight Shifting Test	[44]
To assess mobile balance (Ref. count =2)	

Activities-Specific Balance Confidence Scale	[48]
Biofeedback Analysis from AP1153 BioRescue system	[36]

Table 12. Quality of life measures

Quality of Life Measures (Reference count = 4)	
Outcome Measures	Reference
To assess psychological well-being (Ref. count =3)	
Beck Depression Inventory	[36]
Relationship Change Scale	
Korean Mini-Mental Status Examination	[42]
Patients self-log exercise time, feelings (qualitative), other health services received, and any adverse events	[72]
To assess quality of life (Ref. count =2)	
Stroke-Specific Quality of Life Scale	[48]
Stroke Impact Scale	[72]

Multimedia Appendix 7

Review of Person-Generated Health Data.

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Table 13. Data generated from systems

What data are generated from using the system?	
Reference	Description
Performance Data (N=25)	
[22,36-39,46-48,53,57,59,60,69,70]	Generated data in the form of game scores, i.e., how much of a task was completed well by the user.
[52]	Recorded the number of incorrect positions executed by the user.
[62,64,67]	Recorded both correct and incorrect movement executions. *Additionally*: [64] also recorded exercise history and progress; [67] also recorded patient compensation movements.
[66]	Generated task counts that recorded progress, posture duration, and errors committed.
[42,65]	Counted the number of blocks moved from one side to the other. *Additionally*: [65] also recorded the hand movement accuracy and speed.
[40]	Used functional electrical stimulation in a platform that produced arm and shoulder reach and flexion data; and time to complete tasks.

[57]	Measured the shoulder and elbow flexion range from the Qualisys Motion Capture System.
Variable Data (N=20)	
[23,30,49,56,61]	Collected kinematic variables, which are data used for motion tracking. These data included hand velocity, acceleration, and jerkiness. *Additionally*: [23] kept video recordings of users, movement distance and predicted stroke recovery duration; [56] recorded hand orientation, grasp, and haptic interaction; and [61] recorded gaze direction and objects selected, and motor imagery based on EEG signals.
[41]	Generated timed-up and go test variables, i.e., standing peak trunk flexion angle, standing angular velocity, lengths of first stride and first step, gait speed, turn time, and total TUG time, including the variables' standard error of measurement (SEM), and minimum detectable change (MDC).
[44]	Recorded 3D skeletal position data (ankles and shoulder centre), gait velocity, centre of pressure path velocity, force distribution (lower limbs).
[55]	Collected range of movement, position, and rotation values of users.

[39]	Collected shoulder flexion and abduction, elbow flexion, and compensatory movements.
[63]	Recorded the number of user attempts and an error summary.
[53]	Monitored brain signals from a brain computer interface and electroencephalographic data.
[58]	Monitored electrocardiogram and photoplethysmograph data as well as blood pressure.
[67]	Used wearble sensors to monitor inertial and acceleration data.
[60]	Used a smart glove they developed to produce a detailed hand skeleton image that includes finger movement.
[71]	Study protocol: will use a wearable sensor to monitor energy expenditure.
[35]	Used weight and accelerometre sensors at the bottom of tea saucers and jugs to track errors and error patterns.
[54]	Used a training platform that consisted of the Nintendo Wii Balance Board, Microsoft Kinect, TEREFES electrosimulator, and a computer. Data generated from the platform included frequency stimulation and muscle synergies.
[68]	Color image, 3D depth image, and voice signal
[69]	Biosignals for muscle activity

[50]	Cortical activation pattern, blood-oxygen-level dependent signal volume

Table 14. Patient access to PGHD

Did patients have acccess to their PGHD?	
Reference	Description
Guidance (N=19)	
[44,45,49,52,53,60-62,64,67,70-72]	Guided patients in performing a task through a visual interface. *Additionally*: [67,70-72] also provided game scores, i.e., number/percent of tasks performed correctly; and [67] provided the compensatory movements patients made.
[30]	Provided auditory feedbacks.
[23,35,54,56,66]	Provided both visual and auditory guidance. *Additionally*: [23] also provided game scores; [66] showed patients the duration they were able to hold a certain position; [54] provided patients their centre of pressure information as they stand on a balance platform; and [56] also provided tactile feedback.
Progress (N=4)	
[42,65]	Technologised the box-and-blocks test. Progress was tracked through the number of blocks patients needed to move from one side to the other.
[63]	Showed red and green balloons to show progression for uncompleted and completed tasks, respectively. Also showed users the number of attempts they took to do an exercise, as well as their errors.

[46]	Informed patients when they have met exercise goals.
Task Scores (N=10)	
[22,37-39,47,50,55,57,59,69]	All the papers simply provided scores at the end of a task execution. *Additionally*: [39] showed patients the compensatory movements they made; [47] informed patients whether the images they selected were correct or not.

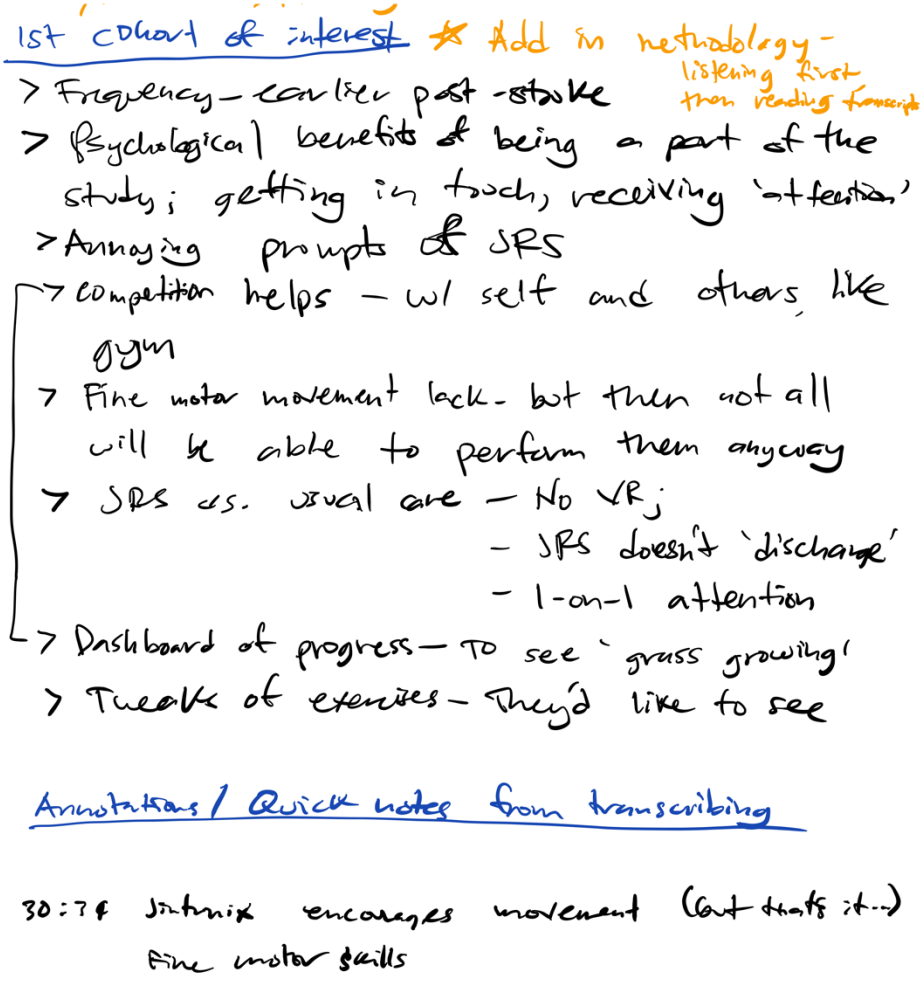
Table 15. PGHD utilisation

How was PGHD Utilised?	
Reference	Description
Patient (N=19)	
[46,48,70]	Using data for therapists to prescribe or tailor-fit rehabilitation to individual patient needs through *calibrating game intensity or duration*.
[23,49,65,66,69]	Using data for therapists to prescribe or tailor-fit rehabilitation to individual patient needs through *prescribing appropriate exercises*.
[47,58,67,72]	Using data for therapists to prescribe or tailor-fit rehabilitation to individual patient needs through *monitoring and evaluation of patient progress*.
[35,39,49,52,56, 61,64,68]	Utilised PGHD primarily to guide patients as they perform rehabilitation exercises. *Additionally:* [39] utilised data for evaluation of patient progress.
Comparison (N=2)	
[57]	Utilised the data to compare performance between four different groups of participants (20 patients - 10 left, 10 right hemiparesis; 20 healthy - 10 left, 10 right trained) on a set of exercises.
[72]	Will compare system-generated data with clinical outcome measures, e.g., Fugl-Meyer scores and BBT.
Kinect-based Systems (N=13)	

[22,55]	Utilised data to assess their Kinect-based systems on their effectiveness *of assessing patient improvement*.
[42,45]	Utilised data to assess their Kinect-based systems on their effectiveness *through evaluation of their system's performance as compared with traditional rehabilitation*.
[50]	Utilised data to assess their Kinect-based systems on their effectiveness *to activate significant brain regions*.
[23]	Assessed the feasibility of their system to predict the duration of patients to recovery.
[71]	Assessed both feasibility and effectiveness of their system.
[30,41,44,56]	Utilised PGHD to assess the reliability of their systems in tracking movement, and motor function of patients. [56] assessed reliability of interaction between their exercise games and intelligent objects.
[54,61]	Assessed their platform's accuracy, i.e., timing and synchronisation.
Other Technologies (N=2)	
[40]	Used PGHD to observe the effects of applying functional electrical stimulation to patient muscles as they attempt to complete functional tasks.
[35]	Used PGHD produced by weight and accelerometre sensors to record the errors patients make, and observe their error patterns.

Appendix B. Reflective Notes and Memos

These are reflective notes and memos noted down during some of the discussions with stroke survivors. These have not been previously published.



Learning: Very, very useful to have a list of topics to check. I'm familiar w/ the questions as I've read through them many times; so it helps make the questioning more fluid, natural. Also gives me a birds eye view of w/c topics we've already discussed, w/c topics we still need to discuss. Esp. came in handy because (cc) Patient 2 was late and we had to start already. When he arrived, we continued w/ the questions and afterwards, when Patient 1(c) left I knew which ones I hadn't asked Patient 2 yet as I marked using highlighter.

☆ Add in paper report/ thesis

Moving forward: ☆ What if we give data (outcomes summary) to cohorts 1 and 2, and we called them for an interview?
→ Might not be useful or accurate. Patients 1 and 2 already mentioned difficulty w/ remembering their experience w/ Jintronix and needed prompts by their carers.

☆ Discuss w/ KG/ MM/MLB

☆ Ask less re 3rd/

4th cohort So giving them data and asking them to remember how those might have affected them during their use of Sintranit might likely be a stretch.

> Thought of this because of the limited info I can really get re PGHD. They can't really share much because they haven't seen much data.

> Perhaps the best way to go about this, also mentioned by Cecily, is to simply ask less and wei to share outcomes summary regularly for 3rd/4th cohort.

Experience w/ Carers:

Quite difficult as they had to do a lot of talking. The patients needed constant prompting and in the case of patient 2, he had difficulty talking. However I made sure I was

looking at both patients and asking them for confirmation. Patient 2 usually agrees w/ what's being said – vigorous nodding. I make sure both patients agreed, or not.

Off the record observation

Patient 1 and her carer (mother) commented how they loved fitbit a lot and have been using a while because of the 'numbers' they see.

Appendix C. Coding Journal

Coding journal used to discuss interesting, contentious quotes with supervisors. They are presented as images as the in-text comments were important to the analysis process. These have not been previously published.

NB: Resolved comments mean they've already been coded in NVivo.

FG1_STRIVE Cohort 2

Familiarisation: Listening to the audio plus reading transcript. Also error-checking; making small changes where some mistakes are found in the transcript.

Analytical memos/notes: Listening/reading with a focus on PGHD/feedback data effects. Ignoring, (perhaps for now?), other interesting notes such as Jintronix being easy to use.

NOTES

Request for PGHD; could also be indicative of perception of what PGHD can do, i.e., follow own progress.
Start time: 00:21:40.1
Speaker: FG1_STC2-03
Maybe having an indicator of previous performance might be a good thing to have. You know, last time you did this, you scored this, or you, even if you did it as a graph or a, uh, I think that would have been a good thing to.. 'cause um, a bit.. Feels like a bit of a competition? To see if we can do better..

Commented [ID1]: This would change goals; so likely 'personal care goals'
+'Interest in care processes'

Start time: 00:46:02.2
Speaker: FG1_STC2-01
Um.. Look, uh, a little bit, I would say I had, improved, kind of, overall. As a result of.. doing it. But nothing really.. specific.

Start time: 00:46:18.2
Speaker: FG1_STC2-03
That's where a visual dashboard would be a good, good thing to have. So you can see we- we've been here eight weeks. So, over eight weeks, you'd expect the dashboard to at least show some improvement, ideally. Uh, and, and, again that would improve the confidence of actually doing the exercises as well. 'Cause a lot of the exercises I do, if I don't see the benefit..

Commented [ID2]: Interest in care processes; not feelings of health status, but feeling of their care processes

---
Start time: 00:49:09.0
Speaker: FG1_STC2-01
Well last couple of sessions I, s- stood up, and, I felt, I got, well I did get better results, and I thought, oh perhaps I should have been standing up, hmm longer for weeks, but.. mm.

Commented [ID3]: Interest in care processes

***Start time: 01:14:51.0
Speaker: FG1_STC2-03
Well [FG1_STC2-01]'s made a very good point about, some of the percentages were about how much was left, and you can actually judge how far there was to go if you can, by what percentage was showing but some of the percentages were also about, you know, how many apples you caught, how many tomatoes you, kind of, picked. But um, I've forgotten about the um, um percentages about how close you are to the end? Yes. It was certainly something that I watched, to see where I was at. 'Cause um, y- you need to think about this,

Commented [ID4]: Interest in care processes?

we have some sort of a budget of energy that you have to manage yourself, and you can't afford to get to empty.

Commented [ID5]: Interest in care processes + personal care goals

Start time: 01:15:30.5
Speaker: FG1_STC2-03
Yes. Yes.. But um, that's particular to stroke survivors I suspect. 'Cause we just have to manage the energy that we have, so we've got enough to do what we need to do. Although I do find that um, having to do something like you said, having to get to somewhere in time, tends to um, motivate you a bit more.

Commented [ID6]: Personal care goals

Desire for a quantitative tracking of stroke progress
Start time: 00:19:58.9
Speaker: [FG1_STC2-02]
I wasn't really conscious of (clears throat), improving at all. I sometimes, I think I'd handle a task better and then I go the next day, and I don't know I think it was a bad day, but i- my performance seemed to be quite inconsistent. Quite often based on how tired the arm was. I don't know.. I but, I've been to gym one day. Just before I went to the session. And I-I couldn't reach this hand as, as high as I normally could; I-I must have tired it out doing a little whack work in the gym. Uh, I guess we all need to see [Physiotherapist 1] figures to see whether we've improved or not.

Commented [ID7]: Feelings about health status (or not based on figures – some days you feel good and some days bad)

Start time: 00:29:25.1
Speaker: FG1_STC2-02
[FG1_STC2-03] talked about being competitive before; one one, good thing or bad thing about going to the gym is it's all very quantitative, so you're always pushing yourself to the next level you know when you, when you can handle a ten-kilogram weight, you can't wait until you've put on the fifteen-kilogram so, my gym is not like that, it's sort of like that. When you do twenty repetitions, the next thing you wanna do is twenty-four so.

Commented [ID8]: Personal care goals

Start time: 00:46:41.4
Speaker: FG1_STC2-03
I just do 'em, 'cause, somebody, somebody's got the training said they would be beneficial.

Commented [ID9]: Relationship with care provider/s

Start time: 00:46:45.6
Speaker: FG1_STC2-03
Whereas, whereas I think what [FG1_STC2-02] mentioned was that it's quite gradual. You don't necessarily see the changes yourself. It's often when you meet people you haven't met for a while when they say, oh, you're doing this a lot better than you were, that you actually, realise that you have improved.

Commented [ID10]: Feelings about health status

Start time: 01:18:29.7
Speaker: FG1_STC2-03
So with the outcome of the physical testing, then it progressed towards the end and the results, comparing the end results, the end of the physical testing, to the initial one, that would be useful too. Just to see whether there were any gains.

Commented [ID11]: N/A

Start time: 01:18:39.9

Speaker: FG1_STC2-03
And.. and it doesn't really matter whether it was the percentage or just a number that's a gain. As long as it's positive. 'Cause if it's negative I'm not so interested of course.

Start time: 01:18:48.0
Speaker: FG1_STC2-01
Well I think that, even if it is, you need to know. And, that's it. (chuckles) Even if you don't want to know.

Start time: 01:21:34.0
Speaker: FG1_STC2-03
Well I got really disappointed when I didn't get a hundred percent.

Commented [ID12]: Feelings about health status

Start time: 01:21:34.0
Speaker: GLD
In the rock climbing?

Start time: 01:21:39.5
Speaker: FG1_STC2-03
No, not in the rock climbing, rock climbing's quite difficult for me. That was probably the most difficult one. But um, even catching apples, I got quite disappointed when I didn't catch a hundred percent of the apples, or bursting the balloons. So. And I, and I automatically adjust what I was doing, if I couldn't burst every balloon I had to adjust.. to work out what I was doing wrong.

Commented [ID13]: Feelings about health status

Commented [ID14]: Health-related behaviours

Start time: 01:28:19.6
Speaker: FG1_STC2-03
But it would be useful to see your data, a data point for last week's performance, or your average over time, and how you performed this week. I think it would be a bit more motivatio- motivational.

Commented [ID15]: Personal care goals

Start time: 01:28:26.5
Speaker: FG1_STC2-01
Mm, and you would possibly know why you weren't so good this week-

Commented [ID16]: Interest in care processes

Start time: 01:28:29.9
Speaker: FG1_STC2-03
Yes, exactly yes.

Desire for more feedback prompts based on performance
***(PROMPTS) Start time: 00:36:53.5
Speaker: FG1_STC2-03
***Relationship (Information exchange, communication)
Yes, so it's not, not very expensive. And if it's self-calibrating, we did all the things that we were talking about, and self-cali- calibrating a bit better and it gave you prompts, it would

be a bit like having a physio visit you at home, or having an OT visit you at home. And clearly, at a much lower base cost.

Commented [ID17]: Interest in care processes

Motivation/encouragement from PGHD (perception)
Start time: 00:47:04.3
Speaker: FG1_STC2-03
Well a dash-, well a dash- dashboard, based on the results of each session would have been very useful. 'Cause then, y'know, it might motivate you more for the next session as well.

Commented [ID18]: Personal care goals
+
(motivation is not a health behaviour!)

Start time: 00:47:15.9
Speaker: FG1_STC2-03
It will show you how high the grass grew. That would be useful.

Commented [ID19]: N/A Doesn't tell us how it's useful. Look at measures of usefulness.

>>**Add quotes that are contentious here to show later**<<

Not taking note of PGHD? New code/possible new PROM item
Start time: 01:10:02.4
Speaker: FG1_STC2-01
Well, I guess I didn't really take that much notice of my score and so forth. 'Cause you're concentrating on trying to, achieve it. And then, when you got to the end I was always, pleased.

Commented [ID20]: Interest in care process (take that much notice)
SPLIT
+ goals (just to finish the rehab; concentrating on achieving)

To code later or possible open coding
Start time: 01:24:08.8
Speaker: FG1_STC2-02
Most of my percentages w- were reasonably close to a hundred, so y- you'd know if y-

Commented [ID21]: Feelings of health status

Start time: 01:24:13.7
Speaker: FG1_STC2-03
Yeah you'd know if you didn't get a hundred.

Start time: 01:24:15.0
Speaker: FG1_STC2-02
If you were really, closer to a ninety or a hundred.

***Start time: 01:29:18.7
Speaker: FG1_STC2-03
I would share it, but, it's not, it's usually, I just like to see, from where we started, to see the end point. You know how do we, how do we stack up at the end.

Commented [ID22]: Interest in care processes. Interest in how exercises/treatment improved their performance. Feelings of health status – no, because this doesn't indicate feeling but interest.

***Start time: 01:29:40.6
Speaker: FG1_STC2-01
No I wouldn't share it. Because it's.. Because to some degree, it's of no interest to, other people, because they, if I say, judge you on what they see, and how you are when you with them, and I don't see the point in, sharing, the, what is it? Jin..

Commented [ID23]: Argument for open coding

Start time: 01:30:13.0
Speaker: FG1_STC2-01
Yes, and I don't think.. You know, they don't really know much about.. What you'd been, doing, even if you describe it, they're probably going to have a different idea in their mind, because they hadn't seen it, and I think it's probably just irrelevant, to them. And if you improve, well, that's.. That's the main thing.

Start time: 01:30:56.1
Speaker: FG1_STC2-02
(chuckles) There's, there's more.. Big issues to communicate with, your nearest and dearest than (chuckles), something as, the- the details.

***Add bits about 'I am trying, but just because I don't seem to be getting better' etc.
Hesitant to share; who you share with, and what frame of reference seeing data/numbers create in other people's minds
---
-Effect/reaction based on prompts, e.g., to straighten hand not considered PGHD

FG2_STRIVE Cohort 1

To check codes applied:

Start time: 00:14:48.3
Speaker: FG2_STC1_1
Yeah, it was good, it was good they gave me examples of what to do and what, if you're not doing it properly they'll tell you again.

Start time: 01:32:40.1
Speaker: FG2_STC1_1
O-on that day, mm! B-but then the next day, oh it didn't go well, mm oh well. (chuckles)

Start time: 01:33:00.9
Speaker: FG2_STC1_1
Uh, um, it must be very much like, I think most people would be like, 'Oh well, it didn't go well on that day.'

Start time: 01:33:09.1
Speaker: FG2_STC1_1
It doesn't really matter.

Commented [ID24]: Just UX; not coded

Commented [ID25]: Feelings about health status

Commented [ID26]: Feelings about health status

Commented [ID27]: Feelings about health status

To code later or possible open coding

Start time: 01:13:23.6
Speaker: FG2_STC1_1
I liked it, and I liked to show, show it to mum, and mum would tell me whether.. I improved..

Start time: 01:16:43.1
Speaker: FG2_STC1_1C
-and then, yeah, and then I'd, I'd analyse it, and sort of what I can understand and, explain it to [FG2_STC1_1], and things like that, that I, I think it's helpful. But you need the, basic information 'cause you're the important people so you need to have it.

Start time: 01:29:50.9
Speaker: FG2_STC1_1
Uh, anyone else, I'd just say.. I don't think anyone else would be interested. (chuckles)

PROM Wording (2nd piece; first piece are the outcomes; content and form – for revision)

Start time: 00:48:37.3
Speaker: FG2_STC1_1
We'd just like, the, but um, the last question, we're a bit confused about it.

Start time: 00:48:52.9

Speaker: FG2_STC1_1C
Yeah, I think we've answered it, but I think it's a bit complicated-

Start time: 00:48:53.6
Speaker: FG2_STC1_1
Some of these ones were um, really confusing.

Start time: 00:48:56.9
Speaker: FG2_STC1_1C
We didn't agree, so we put our own answers in.

Start time: 01:07:59.3
Speaker: FG2_STC1_2C
S-so things, wording like, 'My satisfaction with myself as a person'. That's wordy. Y'know. So you could say, um, in the last four weeks I have felt.. Y'know, and keep it, make it more easy like that.

Start time: 01:08:19.7
Speaker: FG2_STC1_2C
Um.. Y'know like, 'Are any of the statements true, tick all that apply.' Y'know. You can even just say tick, tick the statements that means the most to you or something like that. Really simple. Sorry, that's the teacher in me. (laughs)

Start time: 01:08:33.9
Speaker: FG2_STC1_1
Yeah, that's true. And, also the, the teacher in me now. (laughs) The um, have like, they're all spaced apart, rather than all bunched together.

Carer only for open coding
Start time: 00:45:34.7
Speaker: FG2_STC1_2C
What, what sort of data were you the um, um, is that the results?

Start time: 00:46:50.5
Speaker: FG2_STC1_2C
Yeah, I'm not even sure what that means.

Start time: 00:46:55.0
Speaker: FG2_STC1_2C
This system has shown me all rehabilitation information I expect to have about myself.

Start time: 01:07:27.1
Speaker: FG2_STC1_1C
I think this format of questions is too hard.

Start time: 01:07:49.6
Speaker: FG2_STC1_1C

Yeah. But, uh, [FG2_STC1_1]'s already, uh, language understanding and everything is, is pretty good, it's improved out of sight, it's just the same, but if in the early days, she would have had a hard- well she couldn't have read it in the first place.

Start time: 01:09:14.8
Speaker: FG2_STC1_2C
Y- y- y'know. 'Succeeding fairly well.' What's it, what's that mean? I think there's too many there. I could have just, you know.. T- um..

Carer only input that matches deductive coding

This is where carers provided relevant input, but without patients bouncing off/validating the input in conversation.

Start time: 00:47:38.6
Speaker: FG2_STC1_2C
Yeah, yeah. And that- uh, yeah it makes the person feel better when they can see how the, it's actually, um, in paper form? This is where you started.. You know.

Start time: 00:48:06.0
Speaker: FG2_STC1_2C
Okay, yeah. Showing the beginning to the end, sort of thing. 'Cause I think that would help, it might, he can take it back to, he could've taken it back to his OT, and, things like that. They could see, you know..

Start time: 00:53:16.4
Speaker: FG2_STC1_2C
Is, is, is, is there, is there anyway that, after each session, that you could get a, a print out sort of, of, okay, today you started.. So that over the eight weeks you could see, the first week one, and week two, uh, week eight, and then you'd be able to compare. So, this is where I was there-
---
Start time: 00:53:33.7
Speaker: FG2_STC1_2C
-where have I improved and stuff. 'Cause, I think we all need those little encouragement steps, and, visually. Not just see it on the screen, go home and then you forget.

Start time: 00:53:54.0
Speaker: FG2_STC1_1C
But I don't think you should get it every week, because one week you might be tired, and your, your report will go down-

Start time: 00:54:04.7
Speaker: FG2_STC1_2C
I like, in eight weeks, I might get disheartened-

Start time: 01:14:31.7

Commented [ID28]: Interest in care processes

Commented [ID29]: Interest in care processes

Commented [ID30]: Relationship with care providers

Commented [ID31]: Interest in care processes

Commented [ID32]: Feelings about health status

Commented [ID33]: Feelings about health status

Speaker: FG2_STC1_2C
Week, week one's the little finger, week eight's the last.. A- and even in the one's in between, uh uh, uh good to see too, but, with some sort of little report like, if he, if he's gone down hill, in one, could say. Just, an off day. You know. But I think, um, I would c- and y- you'd be able to correct me if I'm wrong too but I think, visual, is so much better, than words.

Commented [ID34]: Feelings about health status

Start time: 01:15:19.1
Speaker: FG2_STC1_2C
Everything you could give. Because for [FG2_STC1_2], balance was an issue, and, the coordinations. So, that that would be encouraging to you, wouldn't it, to see?

Commented [ID35]: Personal care goals

INT1 STRIVE Cohort 1

PROM Wording

Where it says, I felt that I had failed more than the average person, so you're comparing myself, to an able-bodied person?
INT1_STC1_1

No, um, other patients, as well.
GLD

Uh, well, you need to, reiterate that.
INT1_STC1_1

I don't, understand the last question.
INT1_STC1_1

171
Well I don't think I would include 'I felt hopeless about my progress'. And I think 'I had little confidence in myself, I was pretty confident in myself' isn't relevant.

177
Although, you probably should, well you, and that's 'I was discouraged, discouraged about my progress' would probably cover it. But hopelessness is just reinforcing, a thought that 'god I'm never gonna recover'. You don't want to enforce or reinforce that

179
Well I, have yeah well I have a problem where you say 'the average person'. Um.. Uh more than somebody who has my type of injury or something.

181
Yep, because average to me says able-bodied.

INT1 STRIVE Cohort 3

PROM Wording

The online help, and online messages, on-screen messages, would they be like the scores, or the the messages about posture and-
INT1_STC3_1C

It was easy for me to find the information I needed from the system, so uh, sorry, Ikee, is that, is that question more designed for someone who's operating it at home, themselves, turning it on, and-
INT1_STC3_1C

Yeah.. Sorry Ikee, this, um, this reference to the data, sort of the on-screen data, um, I can't remember seeing data apart from her name would come up, which-
INT1_STC3_1C

INT2 STRIVE Cohort 1

PROM Wording

Just one question. I think the last four weeks, my satisfaction with myself has become.. Is that in relation to the program or just in general?
INT2_STC1_1

INT3 STRIVE Cohort 1

PROM Wording

I don't think I quite understand this question here though. You know, what the section says, section of uh, this is the. Yes that question there.
INT3_STC1_1

Right, so um.. You can just sort of mark here, somewhere here, whether you strongly agree or actually I think it's.. So there's a number here, sorry about that, it got cut, so there's a number here from one to six? Um, from you know, strongly agree to either strongly disagree, um.. Whether the online help, or the on-screen messages and other documentation in Jintronix, uh gave, made it easier for you to, um understand what to do.

Now just wanna, still didn't understand, when you say, look uh.. Yeah the last question. System has showed me all the rehab patient information I expect to have about myself.
INT3_STC1_1

HWY

To check codes applied:
(Interest in Care Processes) – **DONE – Feelings about health status**
GLD: when you get, when you improve your scores do you feel that those are connected in some way to your, to your improvement of balance.
INT1_HWC1: Yeah, yeah. They are.
GLD: And have you noticed the um, have you noticed that your balance has been improving, similar to the your scores that have been improving?
INT1_HWC1: Um, no.

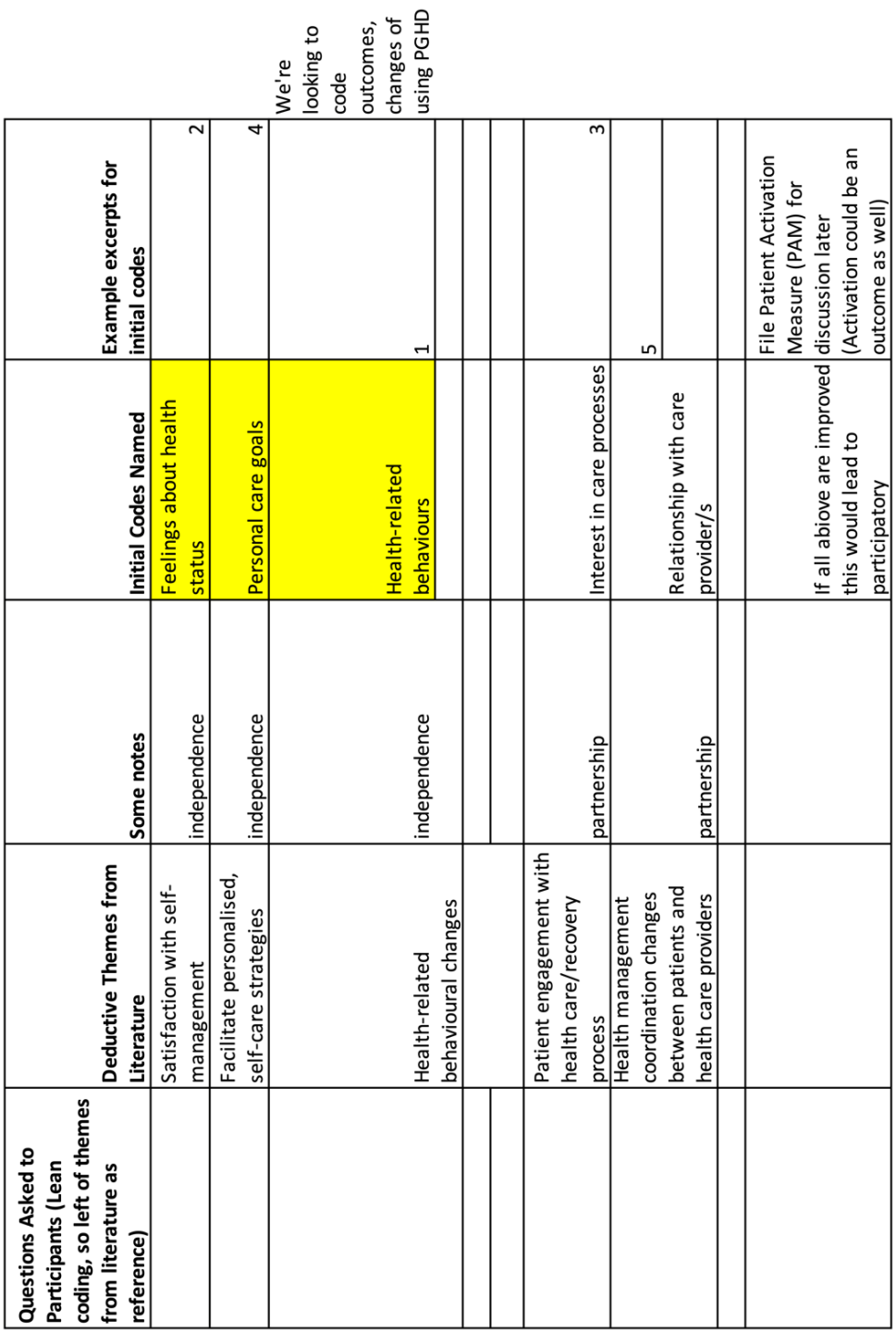
FG1_AH

To check codes applied:
FG1_AHP_2 (Interest in Care Processes) **– DONE – Feelings about health status**
Seeing that you managed to do that six times, with no um judgement beside it, just that that's a practical, result. That's okay. Erm, when you're looking at percentages, I'm thinking well, are normal people at a 100%? And I'm only at 60? So, what what is, the percentages to me is more difficult to understand. So percentage of what? I mean, are we are we um, trying to be a hundred percent at these things?

Appendix D. Analytical Framework

These are the quotes mapped to the analytical framework. These have not been previously published.

Codes



Questions Asked to Participants (Lean coding, so left of themes from literature as reference)	Deductive Themes from Literature	Some notes	Initial Codes Named	Example excerpts for initial codes
	Satisfaction with self-management	independence	Feelings about health status	2
	Facilitate personalised, self-care strategies	independence	Personal care goals	4
	Health-related behavioural changes	independence	Health-related behaviours	1
	Patient engagement with health care/recovery process	partnership	Interest in care processes	3
	Health management coordination changes between patients and health care providers	partnership	Relationship with care provider/s	5
			If all abiove are improved this would lead to participatory	File Patient Activation Measure (PAM) for discussion later (Activation could be an outcome as well)

We're looking to code outcomes, changes of using PGHD

Health-related behaviours

Adjusting actions	FG1_STC2-3 I automatically adjust what I was doing, if I couldn't burst every balloon I, I had to adjust.. To work out what I was doing wrong.		
Encourage to do more exercises	INT3_STC1_1 they helped to a certain extent so it just let you know how far you can go you know kind of like show that, hey you can do this and you know nothing you know, this is disabled, get out and do something and you can improve yourself.	if you saw that it improved do you think that you would be more motivated to use jintronix then? GLD 227 INT1_STC1_1 Possibly.	INT1_STC3_1 Well the benefits will be if I can see the improvement I'm making then it would would, it would encourage me to maybe have more of those sessions.
No change in desire to do exercises	if I was using Jintronix by myself, I would probably not bother because there'd be nothing driving me. INT1_STC1 248 Okay, okay, hmm-mm. Even seeing the game scores? GLD 249 No, umm.. Doing the physiotherapy, um, again I probably wouldn't have done it that long if there hadn't been somebody driving me.		

Description: Changes to behaviour or action to 1) do exercises correctly or to 2) do more of the exercises. Excludes desire to improve performance data/scores.		Added to paper
Adjusting actions during exercise based on feedback	when I was training my feet you could hear the scrape. And, that does a little bit of feedback, um, it was enough to help me, you know, walking better. INT2_AHP I assume, something like that is going to have the same, um positive effects, that you're wanting. INT2_AHP especially when you get it back straight away so you can know to um, um, to correct yourself, um yeah. INT2_AHP	

Encouraged to progress, to keep going, e.g., do more exercises	(Positive) if you were to see these kinds of data, um, either one of, on a regular basis, do you think there would be any changes in your behaviour to daily tasks? Yeah I think there would be, yeah. FG2_AHP_2	As long as your numbers are going up, yeah, it just keeps you positive and.. Yeah, keep going. FG2_AHP_1	it's a tool you you get used to you, you wouldn't rely on it but it, it would, you'd be using it more and more, that's my opinion, yes. INT1_AHP seeing the progress of time and how that encourages you to, to do more? Yes, yep. INT1_AHP because you would see that you're having your progress- Yes! INT1_AHP

Sentiments of discouragement about progress **(Discouraged about progress)**	I think also that once the program is finished, if you know it was helpful, you'd be more inclined to keep it up. FG2_AHP_2 ...if it wasn't helping then you'd be less inclined to to keep it up- That's right. FG2_AHP_2	do you think you would be prompted to ask your therapist if it was the other way around? You didn't feel you were doing so well but the data seems like, it's really good? you probably think oh, the system's not doing its job. (chuckles) I know I know I'm not as good as it's telling me. And you probably lose faith in the system. INT2_AHP	seeing your data that overall score, say, go down, do you think that would make you disc- less uh less uh motivated the system, because your um data is going down? If you just got a raw number, it probably would, but if you had some, some, explanation of, um something that you need to, consider looking INT2_AHP	
Sentiments about progress unchanged, e.g., nil change in desire to do exercises	...any effects it may have on your attitudes, to your um rehab behaviour or um actions. Do you think those data would um, have any effect? Whether good or bad. Or none. I don't think so. FG1_AHP_1	you think that would encourage you to um, do your activities more, or your rehabilitation progress, your exercises and the games that are available more? Or less? Or, no effect? No effect. FG1_AHP_1	if you were to see these kinds of data, um, either one of, on a regular basis, do you think there would be any changes in your behaviour to daily tasks? ...personally, no. FG2_AHP_1	you think that would have, that would have um some.. Possible changes in your behaviours, or attitudes or actions? I don't know, I think again, that it's, more information the better, yeah. INT1_AHP

Description: Changes to behavioural or action to 1) do exercises correctly or to 2) do more of the exercises. Excludes	With some conditions, not (yet) added to paper	With some conditions, added to paper
Adjusting actions during exercise based on feedback		

Encouraged to progress, to keep going, e.g., do more exercises	do you think that being able to see these kinds of data would be able to, encourage you to do your um, to do these kinds of rehabilitation exercises or activities? Well it like I said, it seems that, um do it, do it for my wife, so I should.. INT2_AHP Yeah yeah, so you think that it would have some positive effect in terms of encouragement. Yeah, yeah yeah. INT2_AHP But not s-, not, sufficiently, or not um adequately sufficient as compared with um having, um that feedback loop between the clinician and and you. Yeah, yeah. INT2_AHP	I think if you can see it's helping, it's going to, um, encourage you to keep going. INT2_AHP	would affect any changes in your behaviour, or daily tasks? I'm sure it would, I know it has, when my wife, has done it, and it did when I was doing the walking, did so I guess yeah, anything that keeps popping up in front of you, to remind you, is g- is gonna help. INT2_AHP And, those changes you think would be more positive than negative, in general? Well, you'd hope so. (chuckles) Um, yeah. INT2_AHP	I could see progress, and that encouraged me to do more when I was on my own. FG1_AHP_2

Sentiments of discouragement about progress (Discouraged about progress)	
Sentiments about progress unchanged, e.g., nil change in desire to do exercises	if in a setting, maybe there's, I don't know, you've been away or something and there's four days that you haven't done anything, would that um, change your behaviour to say, oh oh look I haven't done anything.. Oh, no no, I'm, definitely not that motivated. (laughs) INT1_AHP

	Added to paper	With some conditions, not (yet) added to paper	With some conditions, added to paper	

Description: Changes to behaviour or action to 1) do exercises correctly or to 2) do more of the exercises. Excludes desire to improve performance data/scores.

Adjusting actions during exercise based on feedback				
Encouraged to progress, to keep going, e.g., do more exercises	I've written it down, the data presented motivates me to do my exercise program, agree or disagree. FG3_AHC1_1	feel like, patients are **more likely to be compliant** if they understand the purpose and the reason why they're doing it. FG3_AHC1_5	it records compliance, like if they know, I feel like an incentive is that if the patients know that the therapist is saying, the quantity or the amount they've exercised, so **that might stimulate them to, be more compliant.** FG3_AHC1_5 Yeah, accountability. FG3_AHC1_2 Yes there's accountability, yeah. FG3_AHC1_4 It's like doing your homework you know. FG3_AHC1_5 Yeah, and um maybe if they're not being compliant, they might get a phone call from the therapist. FG3_AHC1_5	I'm asking uh physios about how the data would presented, would motivate you **to keep using the system**? FB yes I do. FG3_AHC1_4 'Cause it, yeah. FG3_AHC1_3 so it's, whether something's missing, in the survey about whether the data presented would help motivate the person to **want to use the system again and again**? FB

Sentiments of discouragement about progress	Do you think that the type of data that they also see, you know whether it's positive or negative or whether it's fluctuating at some points, do you think that would also affect how involved or engaged they are? Potentially, like if they're always getting like.. FG3_AHC1_2 20%. FG3_AHC1_3 20%. FG3_AHC1_2 They might get over it, or might not be willing to participate. FG3_AHC1_3
Sentiments about progress unchanged, e.g., nil change in desire to do exercises	

Feelings about health status

Check **Bold Underline***for new emotions*

Description: Feelings about personal health status. Key words include: my; own. Excludes feelings about the exercise, the game, or the care process.

In doing this, I ended up recoding some texts, i.e., adding a quote to a node/s, or removing it and transferring to a different node/s. Also helped me to understand the codes (and category of codes?) better

Disappointed	FG1_STC2-03 But um, even catching apples, I got quite disappointed when I didn't catch a hundred percent of the apples, or bursting the balloons.	FG1_STC2-03 Well I got really disappointed when I didn't get a hundred percent.	FG2_STC1_1 B-but then the next day, oh it didn't go well, mm oh well.
Feel good - generic | 'Pleased/Satisfied'	FG1_STC2-1 if you were improving, uh you'd feel good about yourself	FG2_STC1_1C Yeah, I did all right!	FG2_STC1_1 B-but then the next day, oh it didn't go well, mm oh well.
Neither disappointed nor satisfied	FG2_STC1_1 it must be very much like, I think most people would be like, 'Oh well, it didn't go well on that day.'	FG2_STC1_1 It doesn't really matter.	INT1_STC3_1 Do you remember feeling any positive or negative reactions from seeing those hundred or ninety percent? No, no feelings, no.
Feelings (or 'sense' / idea of) about health status (or not based on figures – some days you feel good and some days bad)	FG1_STC2-2 Uh, I guess we all need to see [Physiotherapist 1] figures to see whether we've improved or not.	FG1_STC2-3 It's often when you meet people you haven't met for a while when they say, oh, you're doing this a lot better than you were, that you actually, realise that you have improved.	FG1_STC2-3 Yeah you'd know if you didn't get a hundred. FG1_STC2-2 If you were really, closer to a ninety or a hundred.
Neither encouraged/Discouraged	FG2_STC1_1 I what's this, I was discouraged about my progress, I was encouraged about my progress. Well I put neither.	FG2_STC1_1 I wasn't encouraged or discouraged.	if your data went up and down, how do you think, you would take it? INT1_STC1_1 Well that would be fine.
Encouragement	if you saw that it improved do you think that you would be more motivated to use jintronix then? INT1_STC1_1 Possibly.	INT2_STC3_1 when I was able to do a more difficult one it was quite um reassuring, that I could do this, these exercises.	INT3_STC1_1 kind of encourage you saying okay you can perform.

Discouragement	INT1_STC1_1 I don't like it 'cause I, um.. I would think well surely this is the benchmark, and so I probably thought, would have thought nah, I'm probably not gonna to get any better.	INT1_STC1_1 It would depress me, yeah.	
Hopeless/Hopeful	FG2_STC1_1 I was very, very upbeat about my progress, I was very pessimistic about my progress. And different times I felt, different.	INT1_STC1_1 Well I don't think I would include 'I felt hopeless about my progress'.	
Neither confident/Self-doubt	I think 'I had little confidence in myself, I was pretty confident in myself' isn't relevant.		
Confidence	INT2_STC3_1 the results that you got was made you be confident if if they were good.	INT3_STC1_1 it sort of gave you that you know confidence, or give you that, information that you know, you're not totally dead. (laughs)	You feel more confidence I guess, you know you talk about different things, and look hey I could do this, you know I could do that you know. You likely know that oh I think I can improve different things, I could this and I could do that and you talk about it.
Self-doubt			
Excited	INT1_STC1_1 Yeah, it was quite exciting when I got a lot		

Check **Bold Underline** *for new emotions health status. Key words include: my; own. Excludes feelings about the exercise, the game, or the care some texts, i.e., adding a quote to a node/s, or removing it and transferring to a different node/s. Also helped me to understand the codes (and category of codes?) better*

Disappointed	INT1_STC1_1 I know I played one game and I thought I'd done well, and I got what three out of five or something and that was disappointing. Right, okay, and you didn't like seeing them? No, well no, it doesn't matter to me but that was, offensive.	INT2_STC1_1 would you say that there were, there are any more emotions that are not here in this, section? **Levels of frustration.** You're wanting to achieve and not achieving, or you not doing it the way you want it to	INT2_STC1_1 which could at times be, **frustrating** because sometimes you went backwards, sometimes you went forwards, um, on the day, you don't know.
Feel good - generic | 'Pleased/Satisfied'	INT2_STC3_1 it was quite satisfying in a way.	INT2_STC3_1 But they they usually they were okay so I was quite happy.	INT2_STC3_1 when you can see the levels go up and you can still do them, the exercises it's it's um, satisfying.
Neither disappointed nor satisfied	did you find that when you saw your scores, your percentages, did you find that um, sometimes they also made you frustrated? INT2_STC3_1 No, they didn't, but um sometimes they were not as good as I was hoping	INT3_STC1_1 kind of surprising how much you can achieve, you know you kind of surprise yourself what you can achieve.	
Feelings (or 'sense' / idea of) about health status (or not based on figures – some days you feel good and some days bad)	INT2_STC1_1 It's just at times it **frustrated** me but it wasn't just the percentages, it was, you knew you didn't go so well. (chuckles) It wasn't just the numbers.	**Interest in care processes? Since interest re comparison** I would have wanted to see my scores in comparison to all the other people who had used it sort of thing. INT1_STC1_1 218 Why do you think you would have liked to see that? GLD 219 Well then I would know whether I was any good, whether, whether my arm was working any good or not.	if you would have seen, um you know your percentages from previous, previous um weeks or previous days and then that would have helped you be more engaged and involved? GLD 245 INT1_STC1_1 No, I don't think so. I know when I've done well, I know when I haven't done well. And numbers on the screen isn't going to tell me the other, one thing or the other.
Neither encouraged/Discouraged	INT2_STC3_1 it was hard to do but the levels got up so um, yeah it wasn't um, I wasn't depressed		
Encouragement	INT3_STC1_1 it's kind of more encouraging I think seeing the scores that you're doing well.	INT2_STC3_1 when I couldn't do it well I thought, well next next time will be better	INT2_STC3_1 it was, was hopeful and help help I was becoming, it was encouraging

Discouragement			
Hopeless/Hopeful			
Neither confident/Self-doubt			
Confidence	they helped to a certain extent so it just let you know how far you can go you know kind of like show that, hey you can do this and you know nothing you know, this is disabled, get out and do something and you can improve yourself.		
Self-doubt			
Excited			

Check **Bold Underline** *for new emotions health status. Key words include: my; own. Excludes feelings about the exercise, the game, or the care in doing this, I ended up reading some texts, i.e., adding a quote to a node/s, or removing it and transferring to a different node/s. Also helped me to understand the codes (and category of codes?) better*

Disappointed	INT2_STC1_1 Once I started to see a few going down I would get a bit disheartened probably	INT2_STC1_1 A few times I could have thrown a book at the blooming thing. (chuckles) Because it was **frustrating** me and trying to work out how I can improve it. So it's once again that **frustration level**	INT2_STC3_1 when you saw um any feedback that you received from Jintronix, were there any other reactions or emotions that you had that were not there? **Frustration, sometimes.** Yeah, but uh first, first frustrating when um, I couldn't do it and then there was there were a couple of times but but um.. Um **but there wasn't too much.**
Feel good - generic | 'Pleased/Satisfied'	INT2_STC3_1 for some of the exercises I was going, I was getting faster so um that was good to, to know.	INT3_STC1_1they helped to a certain extent so it just let you know how far you can go you know kind of like show that, hey you can do this	
Neither disappointed nor satisfied			
Feelings (or 'sense' / idea of) about health status (or not based on figures – some days you feel good and some days bad)			
Neither encouraged/Discouraged			
Encouragement			

Check ***Bold Underline****for new emotions*

Description: Feelings about personal health status. Key words include: my; own. Excludes feelings about the exercise, the game, or the care process.

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Positive Feelings, e.g., 'Pleased/Satisfied' or sense of achievement (Positive - achievement)	if you could see yourself gradually making improvements, it just makes you feel so much better. Okay, I'm achieving something. Whereas if you're going backwards, you know, 'Ohh boy'. Yeah. INT1_AHP Yeah, yeah that's right. So it gives you that idea that, that feeling that you're, um- Progressing. And that's a big thing, that's you know, that's a mental thing. Yeah. INT1_AHP	at least you could look back and say 'Hang on, last week I was only doing it at half the pace'. That, that was good. Yeah. INT1_AHP		

				Well just having some.. Empirical data to look at, it gives you something to, to think about. INT1_AHP Given instructions, willy nilly, you just, you do the task, you don't even think about it. Whereas that sort of thing, when you're getting feedback like that, it forces you to actually, think about it. INT1_AHP you think that thinking about the data that's available to you, um helps you become more involved in the, in your rehabilitation progress? I think so, yeah. Well it does for me INT1_AHP
Positive feeling - Enouragement **(I've decided to skip this for the paper)**	And, and you think that seeing your progress, would be encouraging, and would give you more confidence? Oh, for sure. Yeah. INT1_AHP	I emphasise the bit about um, if you get yourself really down in the dumps, and you think you're not making progress, it's very hard to deal with. Whereas this if you can at least see, oh yeah, I'm getting a little bit better. That's a big positive thing. Yeah. Yeah so mentally, yes. INT1_AHP	What do you like best? It would be the, the encouragement of making progress, yes. INT1_AHP	
Positive feeling - Confidence (confident)	if your numbers are improving, you're getting better, more confident, to move on to another activity, yeah. FG2_AHP_1	it helps because it's feedback to you, and you know um what you can improve on? Exactly. And it just gives you confidence. INT1_AHP	And, and you think that seeing your progress, would be encouraging, and would give you more confidence? Oh, for sure. Yeah. INT1_AHP	

Negative feelings, e.g., disappointment (disappointed)	what do you think you would like least about seeing these kinds of data, if any? If I'm not improving. FG2_AHP_1 You wouldn't like that because, um, um, it's not a good feeling or-? That's right! Yeah it's not, you won't improve, yeah. FG2_AHP_1	if you're going backwards, that would be, a little bit depressing. INT1_AHP	(Note: Dejection, feeling bad about something) if the data for example was um very low, is that what you're um, what you think would happen? I could understand if someone was really, mentally depressed and that, that that would, uh geez, you know, 'I'm not getting any- anywhere.' INT1_AHP	(Note: Dejected) do you think you would be prompted to ask your therapist if it was the other way around? You didn't feel you were doing so well but the data seems like, it's really good? you probably think oh, the system's not doing its job. (chuckles) I know I know I'm not as good as it's telling me. And you probably lose faith in the system. INT2_AHP
Negative feelings - confusion (confused)	you think having percentages might be quite confusing? Because you don't know what it means? Yes. Yes. FG1_AHP_2	Seeing that you managed to do that six times, with no um judgement beside it, just that that's a practical, result. That's okay. Erm, when you're looking at percentages, I'm thinking well, are normal people at a 100%? And I'm only at 60? So, what what is, the percentages to me is more difficult to understand. So percentage of what? I mean, are we are we um, trying to be a hundred percent at these things? FG1_AHP_2		
Negative feelings - not confident	(Note: Indifference, but could be different) do you think that would make you more confident in explaining your rehabilitation progress to anyone who might be interested? No. FG1_AHP_1 it's really based on how you feel, um and how well you do your activities rather than the data? Hmm. Yeah. FG1_AHP_1			

Indifference **(Neither positive nor negative feeling)**	Do you think these kinds of data would have any effect on your involvement or engagement? I don't think so. FG1_AHP_1			
Mixed emotions **(Varying - Positive/Negative)**	it's I guess black and white you know, maybe one day I felt okay, and the next day I felt blue and sad you know INT2_AHP			
Feelings of self-awareness through PGHD **OLD:** **Feelings (or 'sense' / idea of) about health status (or not based on figures – some days you feel good and some days bad)**	**NOTE: Negative** if you were to see all of these kinds of data, do you think that um, these, these kinds of data would help your, help you understand your rehabilitation progress in any way, or not? I don't think so, FG2_AHP_1	if you were to see all of these kinds of data, do you think that um, these, these kinds of data would help your, help you understand your rehabilitation progress in any way, or not? Yeah, I would have thought so. FG2_AHP_2	Yeah well I think if if if you can see percentages are going up, you know that you're doing all right. FG2_AHP_2	What do you like best about, seeing these kinds of data? it allows you to measure your improvement. O- or your, or measure your, deterioration one way, or other. FG2_AHP_2
Discouragement	CONSOLIDATED			
Hopeless/Hopeful				
Neither confident/Self-doubt	CONSOLIDATED			
Self-doubt	CONSOLIDATED			
Excited				

Feeling of comparison with others	(percentages as confusion above) At the same time, it would make you feel like you're being compared to someone? Is that-? Yes, exactly. Exactly. FG1_AHP_2	

Feelings of self-awareness through PGHD **OLD:** **Feelings (or 'sense' / idea of) about health status (or not based on figures – some days you feel good and some days bad)**	So it helps you measure improvement, and deterioration. Yep, yep. FG2_AHP_1	do you think that these would help you understand whether you're achieving your rehabilitation goals or not? Yeah because it's something concrete, you can actually see the increase in your percentage, so. It's not, I think this is what happened when I did this balance thing. You could see, you could see th- they've taken measurements and things, and you could see it was improving, it wasn't in your mind am I getting better or aren't I getting better. You could see it in cold hard figures. FG2_AHP_2	it helps you understand how how well you're doing so far? Yeah. FG2_AHP_2	would help you understand your progress in what way you think? These kinds of data? just with that percentage, if you're, improving each day. FG2_AHP_1	**NOTE: Negative** Do you think that the data that we have here, that's available for Jintronix, would um, in some way, help you understand your rehabilitation progress? I think we all know what we have to do, but we can't do it. FG1_AHP_1 Okay. So you don't think that that seeing your data, your rehabilitation data, would help you understand, it's whether you can do it or you can't. Hmm. FG1_AHP_1	Why do you think you would um like to see um a progress score? So that, we can see, if we're heading in the right direction. FG2_AHP_1
Discouragement						
Hopeless/Hopeful						
Neither confident/Self-doubt						
Self-doubt						
Excited						
Feeling of comparison with others						

Check ***Bold Underline****for new emotions*

Description: Feelings about personal health status. Key words include: my; own. Excludes feelings about the exercise, the game, or the care process.

In doing this, I ended up recoding some texts, i.e., adding a quote to a node/s, or removing it and transferring to a different node/s. Also helped me to understand the codes (and category of codes?) better

Disappointed	CONSOLIDATED		
Positive Feelings, e.g., 'Pleased/Satisfied' or sense of achievement	it's supposed to be in the recovery phase, it is, **it's a means to achieve something, is it, you know, within the last four weeks, my satisfaction with my progress again,** or something like that- FG3_AHC1_1	Everybody likes to get a score, I feel. And and a score can motivate you or **please** you, and- FG3_AHC1_5	
Positive feeling - Enouragement			
Positive feeling - Confidence	Confidence, walking in the community, or confidence being out on the community FG3_AHC1_4		
Negative feelings, e.g., disappointment	(Note: self-doubt) as far as, rehab progress, and what that means.. I'm not sure that, and that changes of.. FG3_AHC1_2 I feel that the, the reporting that they're going to do it's like, the physios, this is my physio, they've set me up with this, or whatever my clinician or whatever my therapy is.. I've improved on this, I'm doing better with my therapy. Does it, but, that's what I feel would be the response, **I'm doing better with my therapy, they don't say I'm doing better with my walking, because I'm being better with my Jintronix.** FG3_AHC1_4		

Negative feelings - confusion	what do you think they would not like about seeing their data? the confusion- FG3_AHC1_2 Confusion- FG3_AHC1_1 -about all the, like, yeah. FG3_AHC1_2 Don't understand it. FG3_AHC1_1	I wonder if you could put something in in number 2, um, I mean you've sort of followed it in number 1 where it says it was clear, they gave you clear um.. Whether there's scope to put in something about, I didn't really understand FG3_AHC1_4 I was confused- FG3_AHC1_4	
Negative feelings - not confident			
Indifference (Neither positive nor negative feeling)	Some people, some people, it wouldn't worry them. FG3_AHC1_4	do you think they would feel more or less confident in explaining their rehabilitation progress to loved ones, friends, or their carers? I'm not sure it really shows what their rehab progress is because, the data doesn't specifically relate to their goals. FG3_AHC1_2	Some people, some people, it wouldn't worry them. FG3_AHC1_4
Mixed emotions (Varying - Positive/Negative)			
Feelings of self-awareness through PGHD **OLD:** **Feelings (or 'sense' / idea of) about health status (or not based on figures – some days you feel good and some days bad)**			
Discouragement	CONSOLIDATED		
Hopeless/Hopeful			
Neither confident/Self-doubt	CONSOLIDATED		
Self-doubt	CONSOLIDATED		
Excited			
Feeling of comparison with others			

Check ***Bold Underline*** *for new emotions*

Description: Feelings about personal health status. Key words include: my; own. Excludes feelings about the exercise, the game, or the care process.

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Disappointed	CONSOLIDATED			
Positive Feelings, e.g., 'Pleased/Satisfied' or sense of achievement	I felt okay. I was fairly upbeat about my progress. INT1_HWC1	I felt satisfied with myself. INT1_HWC1	would you say that there were any negative um, emotions or reactions that you have, so far? From seeing those game scores? No. INT1_HWC1	You liked them. What did you like best about seeing the data? I just, like seeing them. 'Cause it makes me feel good. INT1_HWC1
Positive feeling - Enouragement	After seeing the information about you, from your use of Jintronix, what emotions or reactions did you have that are not included in the list? So after seeing those game scores, are there any other emotions or reactions that are not included in the list? I would say encourage, but uh there's nothing on the list. INT1_HWC1	I would find it encouraging.	So when you see that your scores are not as high as you would like them to be, you don't like seeing that? Um, he, I get encouraged to try harder. INT1_HWC1	Have you ever felt discouraged [INT1_HWC1], from seeing scores that are quite low? No. INT1_HWC1

Positive feeling - Confidence	Do you feel more or less confident, in explaining how well you're improving with your rehabilitation, after seeing those game scores? More uh um, improved. Confident, yeah. INT1_HWC1 So you feel confident- Yeah. INT1_HWC1		
Negative feelings, e.g., disappointment	what do you not like about seeing the data, if any? I don't like um, I don't like not doing well. INT1_HWC1		
Negative feelings - confusion			
Negative feelings - not confident			
Indifference **(Neither positive nor negative feeling)**			
Mixed emotions **(Varying - Positive/Negative)**			
Feelings of self-awareness through PGHD **OLD:** **Feelings (or 'sense' / idea of) about health status (or not based on figures – some days you feel good and some days bad)**	when you get, when you improve your scores do you feel that those are connected in some way to your, to your improvement of balance. Yeah, yeah. They are. INT1_HWC1 And have you noticed the um, have you noticed that your balance has been improving, similar to the your scores that have been improving? Um, no. INT1_HWC1		
Neither encouraged/Discouraged	CONSOLIDATED		

Discouragement	CONSOLIDATED	
Hopeless/Hopeful		
Neither confident/Self-doubt	CONSOLIDATED	
Self-doubt	CONSOLIDATED	
Excited		
Feeling of comparison with others		

Check **Bold Underline***for new emotions health status. Key words include: my; own. Excludes feelings about the exercise, the game, or the care process. texts, i.e., adding a quote to a node/s, or removing it and transferring to a different node/s. Also helped me to understand the codes (and category of codes?) better*				
Disappointed				
Positive Feelings, e.g., 'Pleased/Satisfied' or sense of achievement				
Positive feeling - Enouragement	just to confirm, um, you've mentioned that when you see those game scores, you feel more engaged? Yeah. INT1_HWC1 in your rehabilitation progress? Yeah. INT1_HWC1 Have there any been, have there been any cases where you felt less engaged after um, seeing those data? Um, no. INT1_HWC1	In what ways would you say that you are more involved or engaged in, in your rehabilitation? I'd like to try to improve them. INT1_HWC1 So every time you see those scores, you are more involved because you'd like to improve those scores. Yes. INT1_HWC1		

Interest in Care Processes

Description: Interest in care process; the games, the progress. Includes feelings about the care process. Key words include: game, exercises. Excludes feelings about self based on health data received.

Interest in how exercises contributed to therapy progress	FG1_STC2-3 comparing the end results, the end of the physical testing, to the initial one, that would be useful too. Just to see whether there were any gains.	FG1_STC2-3 Maybe having an indicator of previous performance might be a good thing to have. You know, last time you did this, you scored this, or you, even if you did it as a graph
Interest in where they are in the recovery/exercise process (?)	FG1_STC2-1 I see the percentage, and when I was getting to seventy percent, I would think uh, this is good I'm getting towards the end.	FG1_STC2-3 you can actually judge how far there was to go if you can, by what percentage was showing
Lack of Interest	FG1_STC2-1 I didn't really take that much notice of my score and so forth.	FG2_STC1_1 You don't really care.

Interest in doing right/doing well/performance (?)	FG1_STC2-3 it gave you prompts, it would be a bit like having a physio visit you at home, or having an OT visit you at home.	FG1_STC2-1 I thought, oh perhaps I should have been standing up, hmm longer for weeks
Lack of interest in doing right/doing well	did it help you understand your progress in any way? GLD 211 Um.. Sigh. Well, to be honest, no. 'Cause I could do, I feel that my recovery is enough that I don't have a lot of problem with that sort of thing, so. INT1_STC1_1 212 Hmm-mm, hmm-mm. Okay. But did you notice that the scores improved over time? And do you feel like that, that was relevant to you, the scores? GLD 213 The scores? No. INT1_STC1_1 214 Whether they improve or, or, whether they increase or decrease did you feel like it was relevant for you at all? GLD 215 No.	
Feelings about care processes	INT3_STC1 Sometimes it felt good with different games that hey I'm good in this game but I'm not good in the other game, it gives that sort of feeling you know.	INT1_STC1 I would say ugh, obviously this is pretty useless.

Description: Interest in care process; the games, the progress. Includes feelings about the care process. Key words include: game, exercises. Excludes feelings about self based on health data received.

Interest in how exercises contributed to therapy progress	FG1_STC2-1 you would possibly know why you weren't so good this week-	FG1_STC2-3 I just like to see, from where we started, to see the end point. You know how do we, how do we stack up at the end.	FG2_STC1_1 There must be some things that have, that have improved from that, even if you, even if I was very tired.
Interest in where they are in the recovery/exercise process (?)	FG1_STC2-3 percentages about how close you are to the end? Yes. It was certainly something that I watched, to see where I was at. 'Cause um, y- you need to think about this, we have some sort of a budget of energy that you have to manage yourself, and you can't afford to get to empty.	INT2_STC3 it gives you um.. Uh um, some information on where you were at in the program.	
Lack of Interest	Did you feel more engaged, with your, rehabilitation? No, it was.. (inaudible, FG2_STC1_2 continues to cough) but it didn't prompt you, to like, for example, you would see your percent will be going, whatever percent you received, did it make you say like, 'uh, I think I wanna as [Phsyiotherapist 1] something related to that,' with regards to your rehabilitation goal? FG2_STC1_1 No.. Just also going with the flow. Yeah.	INT2_STC3 The, the data was given to me and um, um but it was just information, yeah I didn't uh, um, no I didn't feel, um I, bit, I didn't feel I was involved in any way	

Interest in doing right/doing well/performance (?)	INT2_STC3 It would um certainly, yeah it would it would be helpful to know where um, where I should go to do improve.	INT2_STC3 it gives you more details I suppose, and um, it it shows where what what you need to do to to to improve some areas and uh, yeah definitely it would be helpful, it's it's like a, you know student getting feedback from uh from uh their teacher or something, you, it's important to get feedback.	INT2_STC3 I suppose just being, by giving you this information, um.. You knew what you had to do to improve or not, but I I didn't feel involved really.
Lack of interest in doing right/doing well			
Feelings about care processes	FG1_STC2-3 improve the confidence of actually doing the exercises as well	INT2_STC1 I wouldn't say I was more engaged or less engaged by it, I took it for what it was	

the games, the progress. Includes feelings about the care process. Key words include: game, exercises. Excludes feelings about self based on			
Interest in how exercises contributed to therapy progress	FG2_STC1_1 Because I understand it, um, some days are bad, some days are good.	FG2_STC1_1 keep tracking, just to sh- show, something today	FG2_STC1_2 So I know, um, i- improvement. By doing thing.
Interest in where they are in the recovery/exercise process (?)			
Lack of Interest			

Interest in doing right/doing well/performance (?)	this information can only be beneficial because um yeah you tell them where where you need to work.	INT2_STC3 it told me when you were right it's, it's um.. If you are doing okay or or not	the amount of balance you have, amount of reach of your arm, they could be um you know the degrees to which your arm could lift. Are those the kind of information that you feel you would also have wanted to see aside from the game scores? GLD 258 INT3_STC1 Yes, yes, I think so yes, because you realise that you know you're not going as far because you have the disability part of it
Lack of interest in doing right/doing well			
Feelings about care processes			

the games, the progress. Includes feelings about the care process. Key words include: game, exercises. Excludes feelings about self based on					
Interest in how exercises contributed to therapy progress	wants to see is, week one, week uh, I don't know, week one, week eight, progress. Yeah, sorry but th- the, the, good for me.	FG2_STC1_2 Having to see im-improvement.	INT2_STC1_1 I, perhaps actively engaged with this, and not passively engaged, but not everybody's the same, not everybody understands the questions to ask or the enquiring but I might have so we are all different in that regard. Um, but I think it's nice to just have that comparison point and just see what it shows you but what it means. But it's only relevant for the point in time from which it's been taken as we know.	INT2_STC3 If you can see, it goes up, and obviously you're doing okay. And, um.. And if you go um, (inaudible) there's a bit more to do.	you get the scores and hey I did well, quite well today with this game, I'm improving, I can see that I'm improving with different games and your score you know
Interest in where they are in the recovery/exercise process (?)					
Lack of interest					
Interest in doing right/doing well/performance (?)	it will give you some knowledge that you know you can reach that far, how how what progress what what way can you improve yourself to be able to achieve that				

Description: Interest in care process; the games, the progress. Includes feelings about the care process. Key words include: game, exercises. Excludes feelings about self based on health data received.

Interest in/understanding of how exercises contributed to therapy progress, i.e., that therapy is 'working' (How/that therapy works)	this would help you understand your progress in what way you think? These kinds of data? Oh uh, just with that percentage, if you're, improving each day. FG2_AHP_1	Why do you think you would um like to see um a progress score? you could tell it was working, and all your effort was worthwhile. FG2_AHP_2	you- you're 10 seconds less. You know, you're improving. But it was, very slow, and quite often it's, you- you're bound by what they tell you, not you, you you don't, if if I wanted to, sort of look at one detail straight away, it could, quite often be quite hard to get them to tell me. Whereas here, I can just, look at it, yep. INT1_AHP
Interest in where they are in the recovery/exercise progress, and to manage energy (Where you are / how to manage progress)	that's a picture for me to look at, to see. Changes. And hopefully progress. But it you know, it might not be. It might be a negative result, I don't know...the summary can give us uh, more of a picture of the progress that we've made. That would make more sense to me. FG1_AHP_2	I could see that, that sort of thing, while you're doing an activity, it's great to be able to reference it. INT1_AHP it's just to, uh you mentioned as a reference, so that you would know um how far you're going? Is that what you're, thinking of? That's right...With um repe- repetitive sort of exercises, um, one thing that's obvious you know, it's your heart rate, you know. You're trying to not to, let that go berserk, if you're exerting yourself too much, that's what they were always looking at, the the physios, 'Is he okay?' Because, the other thing is, I'm a diabetic. And, one thing I would have been keeping at the back of my mind, if I'm doing vigorous exercise, I gotta watch out, my sugar doesn't go too low. INT1_AHP	Do I need to, save my energy, or do I need to um, I I can go for it? INT2_AHP So it's about management of your um sort of energy. Energy. INT2_AHP
DisInterest/indifference Lack of Interest in progress (Indifference to state of progress)	I think it would be of interest, but it's not, it's not vital. FG1_AHP_2	there any other data or information that you would have liked to see aside from what's on offer? Uh it doesn't, no it doesn't, interest me. FG2_AHP_1	You're probably interested in the end um, um, am I going okay, I'm not going, is my treatment going to change, or is it staying the same? That sort of level. Um initially, you may be concerned to, get the information, 'cause people asking you, how are things going, what are you doing you know. But as you, as you get more and more into the, program, that's sort of detail becomes less and less important I think. INT2_AHP



Feedback, performance, e.g., interest in doing right/doing well/performance (?) (Feedback on how to progress)	it's always nice to see when you've done things right, but but, I mean, quite often you learn more when you've done something wrong. FG2_AHP_2	usually, the good ones, um.. They will talk you through those sorts of things. So uh look you've, done really good in this today. Or, or not so good at that, and.. They, they identify what needs refining. But, that again, that's more feedback to you, and every bit helps, for sure. INT1_AHP	do you think that, seeing your data would help you understand better your rehabilitation goals and where you need to get to? I think so, yes. 'Cause.. Basically what I got given was a, a book full of exercises, and there's, that gets very boring very quickly. Just, reading, okay.. 10 of these, 10 of that. You know, that's, there's no feedback, it's it's all by yourself, very boring. INT1_AHP so if you would see this, you'd have that feedback- Yup! INT1_AHP
Lack of interest in doing right/doing well			
(Sentiments about care) or system processes **OLD: Feelings about care processes**	what are your feelings in terms of receiving the same kinds of data that your therapists would see? So instead of having to ask them for it, it's available to you you can view it all the time? Just everything is open and clear and there's, there's nothing going on in the background about anyone judging me or you know just what what has happened is easy for me to see, and that there isn't anything that's being kept from me, really. FG1_AHP_2 -gives you that sense of, transparency? Yeah, that's the word. FG1_AHP_2	do you think that you would also have been, do you think you would also trust the process more, um if you saw more of your data that's available? A bit, a bit more. A bit more. FG1_AHP_2 **NOTE: Uncertain** No.. As I go through it, I thought about it, yeah... It also depends on where the data is going. FG1_AHP_1	**NOTE: Uncertain** Do you think that seeing these kinds of data would help you understand why um your clinician might have given you a different kind of game? Or not? Uh, I don't know. FG2_AHP_1

the games, the progress. Includes feelings about the care process. Key words include: game, exercises. Excludes feelings about self based on			
Interest in/understanding of how exercises contributed to therapy progress, i.e., that therapy is 'working' (How/that therapy works)	I guess any information is gonna help you um, understand your your, the process you're under. So I guess it's all, positive in that way. INT2_AHP	it just confirms whether you're improving or not improving. Um, it gives you um some sort of um, understanding how your treatment's going. INT2_AHP	this would help you understand your progress in what way you think? These kinds of data? Oh uh, just with that percentage, if you're, improving each day. FG2_AHP_1
Interest in where they are in the recovery/exercise progress, and to manage energy (Where you are / how to manage progress)			
Disinterest/Indifference Lack of Interest in progress (Indifference to state of progress)			

Feedback, performance, e.g., Interest in doing right/doing well/performance (?) (Feedback on how to progress)	So you think that seeing these kinds of data would actually help you um understand, um what you need to do better? Yeah. INT2_AHP
Lack of interest in doing right/doing well	
(Sentiments about care) or system processes **OLD: Feelings about care processes**	do you think you would be prompted to ask your therapist if it was the other way around? You didn't feel you were doing so well but the data seems like, it's really good? you probably think oh, the system's not doing its job. (chuckles) I know I know I'm not as good as it's telling me. **And you probably lose faith in the system.** INT2_AHP

Description: Interest in care process; the games, the progress. Includes feelings about the care process. Key words include: game, exercises. Excludes feelings about self based on health data received.	
	I I actually think that there, that, question 4, I actually think is some of the most important information that you'll get from this questionnaire. I think that, that stuff is the stuff you wanna know about. Like, thinking about our stroke patients, and all the rest of the stuff on it, about how complex the data was, and whether they could understand it- FG3_AHC1_2
Interest in/understanding of how exercises contributed to therapy progress, i.e., that therapy is 'working'	I feel like they, they would understand better after a second session where they could compare their results, like they may not understand what 40% of the thing, I think you could understand I got 40% of the gates right, or, whatever but I feel like um, it's good for them to have a comparison, to see how they've changed from one session to the, the other one FG3_AHC1_5
	Or yeah, and adherence to, adherence to my exercise program like has the has my, has has this actually positively impacted like, um, you know, even your ADL like your achievement of your goals than anything else, yeah. FG3_AHC1_2
	why do you think it's the most important part, number 4? they're not really understanding what what the information is meaning to them. And, all that sort of stuff. They just kind of bumble along with it. So I think, you know, to, whether or not this, like to make this outcome measure judge whether or not this is working for the patients, I think that's important, yeah. FG3_AHC1_2
Interest in where they are in the recovery/exercise progress, and to manage energy	I guess tne thing about wnat we were saying about goals, cause we try to make our therapy goal-focused, it would be nice, I don't know if you could word one about the information helped relate to my goals FG3_AHC1_1
	Improve my walking, or improve my balance, um. Am I using, factual terms in, they understand or, reduce my falls risk. FG3_AHC1_5
	Yeah I do, I think goals definitely need to be something right there. FG3_AHC1_4
Disinterest/indifference Lack of interest in progress	Even if it says you know, the information- FG3_AHC1_3

Feedback, performance, e.g., Interest in doing right/doing well/performance (?)	What do you think they would like best about seeing the data? And if the data is simplified, um these graphs, or the performance data that we have here. It would be just some knowledge of performance, wouldn't it be? FG3_AHC1_2 Yeah. I think based on their own performance, yeah. FG3_AHC1_4	
Lack of interest in doing right/doing well		
Sentiments about care or system processes **OLD: Feelings about care processes**	if you just did the computer thing and they didn't get it, they'd be like, and just stopped without data they'd be like, why do I do it? FG3_AHC1_2 Why do it? Why all this? FG3_AHC1_4	And the thing is even if they didn't fully understand the data I think they'd still like to see, something? FG3_AHC1_2

Description: Interest in care process; the games, the progress. Includes feelings about the care process. Key words include: game, exercises. Excludes feelings about self based on health data received.		
	Interest in/understanding of how exercises contributed to therapy progress, i.e., that therapy is 'working'	I like to see the base level I was at, and what I've achieved. INT1_HWC1 it helped me understand my rehabilitation progress. INT1_HWC1

Interest in where they are in the recovery/exercise progress, and to manage energy	it helped me understand my rehabilitation progress. INT1_HWC1 how would you say that it helped you understand? **I realised that um, my limitations. And, how far I've got to go.** INT1_HWC1
Disinterest/indifference **Lack of Interest in progress**	

	Did you, say, understand better..? **Um I understood what movements um, I had to do.** INT1_HWC1 Okay. All right. Because you saw those scores, and you saw, would you say that those scores, whether they were going up or whether they were going down, they helped you understand why you had to do these games, why you had to to play these exercises and these games? Yeah. INT1_HWC1 they helped you do that because if you don't get a perfect score yet, you know that you haven't perfected it? Is that how it's, how you're thinking about it? Yeah, yeah. That's right. INT1_HWC1
Feedback, performance, e.g., Interest in doing right/doing well/performance (?)	I want to know how well I'm going. INT1_HWC1
Lack of interest in doing right/doing well	
Sentiments about care or system processes **OLD: Feelings about care processes**	

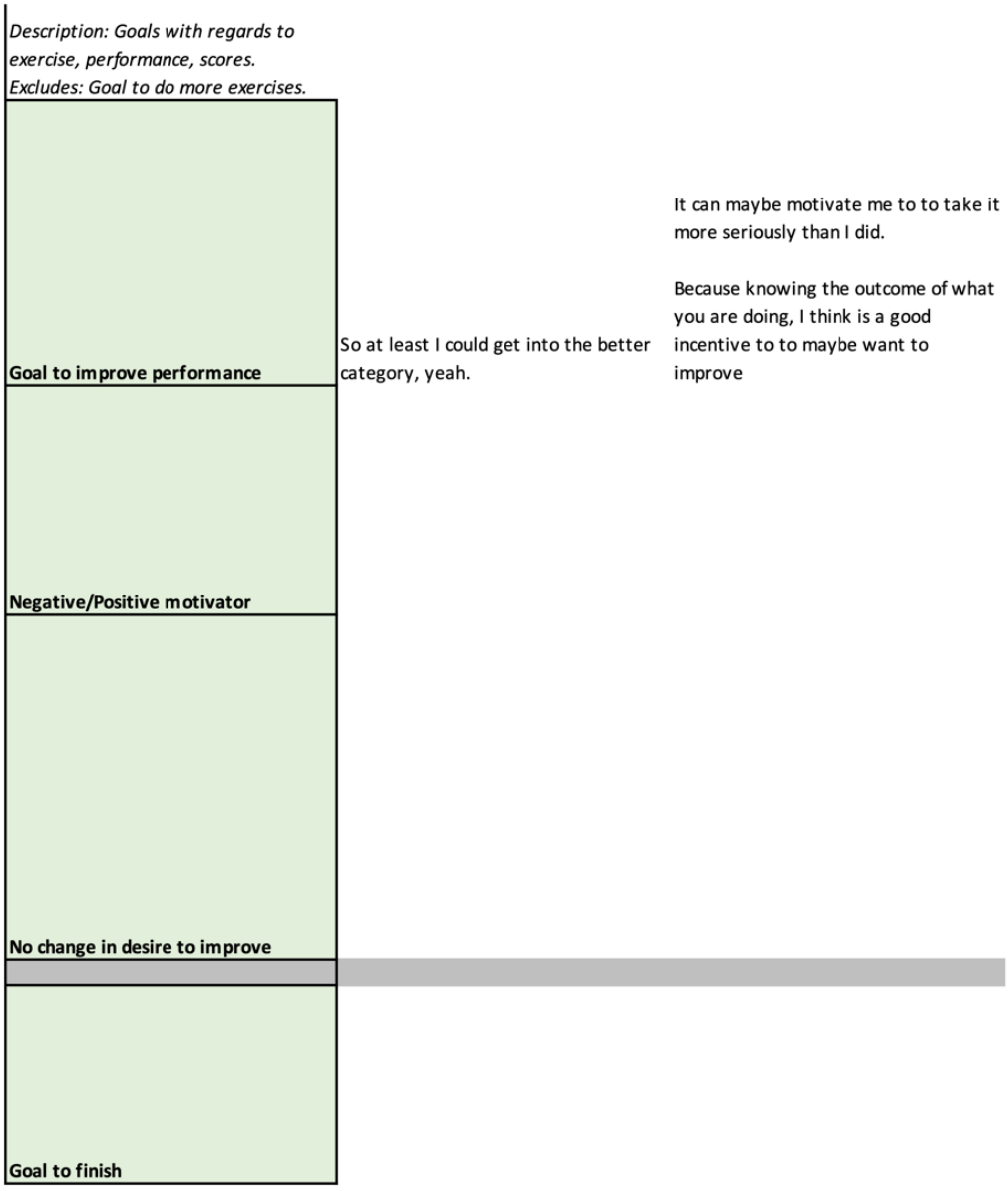
Personal care goals

Description: Goals with regards to exercise, performance, scores. Excludes: Goal to do more exercises.

Goal to improve performance	FG1_STC2-3 it would be useful to see your data, a data point for last week's performance, or your average over time, and how you performed this week. I think it would be a bit more motivatio- motivational.	FG1_STC2-1 you'd feel more motivated I think, although, you know I think, i- the program, does motivate you, but you might be able to get an extra percentage of motivation.
Negative/Positive motivator	INT2_STC1 you can get hard on yourself or feel 'Oh I didn't get that right' and if you keep doing that and you're not achieving 100% and the score keeps flashing at you, that can be a positive motivator, but can also a negative one	
No change in desire to improve	your percentages from previous, previous um weeks or previous days and then that would have helped you be more engaged and involved? GLD 245 INT1_STC1 No, I don't think so. I know when I've done well, I know when I haven't done well. And numbers on the screen isn't going to tell me the other, one thing or the other.	
Goal to finish	It was certainly something that I watched, to see where I was at. 'Cause um, y- you need to think about this, we have some sort of a budget of energy that you have to manage yourself, and you can't afford to get to empty.	FG1_STC2-3 having to get to somewhere in time, tends to um, motivate you a bit more.

Description: Goals with regards to exercise, performance, scores. Excludes: Goal to do more exercises.		
Goal to improve performance	FG1_STC2-3 'Cause then, y'know, it might motivate you more for the next session as well.	FG1_STC2-3 I think that would be useful, 'cause that would be, it gives you a bit of an incentive to do better.
Negative/Positive motivator		
No change in desire to improve		
Goal to finish	FG1_STC2-1 'Cause you're concentrating on trying to, achieve it.	Keeps you motivated too, doesn't it

Description: Goals with regards to exercise, performance, scores. *Excludes: Goal to do more exercises.*		
Goal to improve performance	FG1_STC2-3 having an indicator of previous performance might be a good thing to have. You know, last time you did this, you scored this, or you, even if you did it as a graph or a, uh, I think that would have been a good thing to.. 'cause um, a bit.. Feels like a bit of a competition? To see if we can do better..	It would, it would be, it would actually be much more motivating if you showed progress over time, I suspect. You know you f- you feel much more um, motivated if, you know 'last time you did ninety-five percent, see if you can do ninety-six percent this time.
Negative/Positive motivator		
No change in desire to improve		
Goal to finish		


Description: Goals with regards to exercise, performance, scores.
Excludes: Goal to do more exercises.
Goal to improve performance
Negative/Positive motivator
No change in desire to improve
Goal to finish
So at least I could get into the better category, yeah.
It can maybe motivate me to to take it more seriously than I did.
Because knowing the outcome of what you are doing, I think is a good incentive to to maybe want to improve

Description: Goals with regards to exercise, performance, scores. Excludes: Goal to do more exercises.				
Goal to improve performance	INT2_STC1 what the data is telling us, okay, so it's like, developing short term and long term goals.	it just gave me a, a new goal to work towards, short term goal.	INT2_STC1 gave it as a bit of a goal, as a, asa benchmark to try and achieve next time.	INT2_STC1 kept me at a level at which I could aim for as a target so it kept me focused to some extent.
Negative/Positive motivator				
No change in desire to improve				
Goal to finish				

Description: Goals with regards to exercise, performance, scores. Excludes: Goal to do more exercises.

				do you think that, seeing your data would help you understand better your rehabilitation goals and where you need to to get to? I think so, yes. 'Cause.. Basically what I got given was a, a book full of exercises, and there's, that gets very boring very quickly. Just, reading, okay.. 10 of these, 10 of that. You know, that's, there's no feedback, it's it's all by yourself, very boring. INT1_AHP
Goal to improve performance (Performance)	I'm saying if if it didn't match up what I thought I should be doing it means I would have to try harder. FG2_AHP_2	You'd like to improve it, you'd try try your best, yeah. FG2_AHP_1	Okay, and if they were going down? Well then you'd have to work harder again. FG2_AHP_2	so if you would see this, you'd have that feedback- Yup! INT1_AHP
Negative/Positive motivator (Motivation - toward goal?)	do you think that would also help you develop new goals? Um new concrete goals towards uh to work towards? If you were seeing these kinds of data? Yeah it might. FG2_AHP_2			
No change in desire to improve				
Goal to finish				
Understand goals				

Description: Goals with regards to exercise, performance, scores. Excludes: Goal to do more exercises.	
Goal to improve performance (Performance)	I guess the thing about what we were saying about goals, 'cause we try to make our therapy goal-focused, it would be nice, I don't know if you could word one about the information helped relate to my goals FG3_AHC1_1 Improve my walking, or improve my balance, um. Am I using, factual terms in, they understand or, reduce my falls risk. FG3_AHC1_5 Yeah I do, I think goals definitely need to be something right there. FG3_AHC1_4 Even if it says you know, the information- FG3_AHC1_3 -and exercises related to my goals. And then on the scale, they can, determine. FG3_AHC1_3

Negative/Positive motivator (Motivation)	if you just did the computer thing and they didn't get it, they'd be like, and just stopped without data they'd be like, why do I do it? FG3_AHC1_2 Why do it? Why all this? FG3_AHC1_4	Like it doesn't have to be too detailed or complex, but just something to show, yeah. Today I got 50%- FG3_AHC1_3 Progress. FG3_AHC1_5 -yesterday I got- FG3_AHC1_3 And that would be motivating as well- FB Yeah! Just something to keep striving. FG3_AHC1_3	Everybody likes to get a score, I feel. And and a score can motivate you or please you, and- FG3_AHC1_5
No change in desire to improve			*Everybody likes to get a score, I feel. And and a score can motivate you or please you, and-* *FG3_AHC1_5* Some people, some people, it wouldn't worry them. FG3_AHC1_4
Goal to finish			

Understand goals	did you mean that it also relates to how they see their goals when they see your data, how they perceive their goals or whether their data um, allows them to develop new goals? Or whether it helps them inform, or helps inform them, whether they're r- whether they're achieving their goals or not? I think it's about informed, informs, and whether they're achieving their goals or not. FG3_AHC1_2 The last bit. Informs and achieving their goals. FG3_AHC1_1 'Cause I don't, they're never gonna form new goals based solely on that data without info- without like liaising with their therapist. FG3_AHC1_2 Or they might, but it's unlikely. FG3_AHC1_1

words include: game, exercises. Excludes feelings about self based on				
Interest in/understanding of how exercises contributed to therapy progress, i.e., that therapy is 'working'	NOTE: Negative? I don't know that it's still functionally relevant, to them, it's still, like it might tell them that they did this on their wrist, but it doesn't, doesn't, then translate to putting that in will I now be able to pick up my shopping on my own or pull up my trousers on my own. Um, it doesn't, you know, squatting maybe, it might I think, it's another thing to think that I can bend down and pick something up off the floor if I've squatted at a hundred percent of the time. FG3_AHC1_4 for you what's what you think is, really important is whether they can perform some, you know activities of daily living Rather than the data provided on the screen, yeah. FG3_AHC1_4	after seeing the available data that Jintronix may provide your patients, in what ways do you think they would feel more or less involved or engaged in their rehabilitation progress. if you can get the information and that records what they were doing from different days they actually can, they actually do see the improvement. They can also share it with family, 'Oh I did 10 today, I only did 5', you know so there's actually you know, it's that, chance to, bragging power as well, perhaps, a little bit? FG3_AHC1_4	What do you think they would like best about seeing the data? And if the data is simplified, um these graphs, or the performance data that we have here. The graph across the day, then they could see change. FG3_AHC1_2 -then they could see change. FG3_AHC1_3	just on the other data, I'm not quite sure how you could do it but if if there's any relevance to a functional activity. You know like washing the dishes, or hanging the washing out or.. I don't know, climbing a flight of stairs, maybe or something like that you know like in a Fitbit you get, well you've actually climbed 10 flight of stairs, well you can actually do it but you know could they actually mean or you know.. FG3_AHC1_4

Description: Goals with regards to exercise, performance, scores. Excludes: Goal to do more exercises.

Goal to improve performance (Performance)	I get a score. And, I have to um.. Um.. Improve my score, each time. I try too. INT1_HWC1	it encouraged me, to try harder. INT1_HWC1	would you imagine that there would be any downsides from seeing all those kinds of data? I, I don't think so. If I wasn't doing, well, I would, I would work harder. INT1_HWC1	In what ways would you say that you are more involved or engaged in, in your rehabilitation? I'd like to try to improve them. INT1_HWC1 So every time you see those scores, you are more involved because you'd like to improve those scores. Yes. INT1_HWC1	when you see that your scores are not as high as you would like them to be, you don't like seeing that? I get encouraged to try harder. INT1_HWC1
Negative/Positive motivator (Motivation)					
No change in desire to improve					
Goal to finish					
Understand goals					

Relationship with care provider/s

Regardless of PGHD..?	I just do 'em, 'cause, somebody, somebody's got the training said they would be beneficial.	<-- Not too sure about this.	
No change - questions asked	it didn't prompt you, to like, for example, you would see your percent will be going, whatever percent you received, did it make you say like, 'uh, I think I wanna as [Phsyiotherapist 1] something related to that,' with regards to your rehabilitation goal? No.. Just also going with the flow. Yeah.	INT2_STC3 when it was good I didn't ask questions.	
Prompted to ask re performance data	INT3_STC1 I say look I haven't been doing well because what reason to it and then they tell me off for certain things so.	a couple of times I was surprised that I had a higher score when I thought I'd done badly. INT1_STC1 275 Right, okay, hmm-mm, hmm-mm. And you asked [Physiotherapist 1] about, about them? GLD 276 Yeah, but that's about all I can think of.	INT2_STC3 I wanted to know why it was so different so um, low and um she said well she told me the level had increased so um but I I otherwise I had no question.
Need for assistance	INT2_STC3 If they were always bad then I would need uh more assistance and even if they good um, they not perfect, right so I would want to have more, more assistance to um, to to improve		

Not prompted to ask any questions	regardless of how well the data looks like, you wouldn't be um prompted to ask any questions? Okay. well as long as the numbers are going up yeah. FG2_AHP_1
Prompted to ask clinician re performance data (Ask clinician about data)	if you were to see these kinds of data, are there any, uh would would you be, would you, might you have any questions to um.. That you want to ask your therapist? If you were to see these kinds of data? I would be asking w- what happens to this data? Where is it going, what's it going to be used for. Is it going to be helpful to other people, I mean w- what is the purpose of gathering this data? FG1_AHP_2 No, no. FG1_AHP_1
Not prompted to ask	And if it was going down, do you think you would- Oh yeah, what are we doing now? FG2_AHP_1 Yeah I I'd say to the therapist, what are you doing wrong, 'cause I know I'm not doing anything wrong, yeah. FG2_AHP_2 All right, so you'd be more prompted to ask them if it's going down because it's worrying? Well yeah, yeah. FG2_AHP_1 You'd, you'd expect it to be going up. FG2_AHP_2

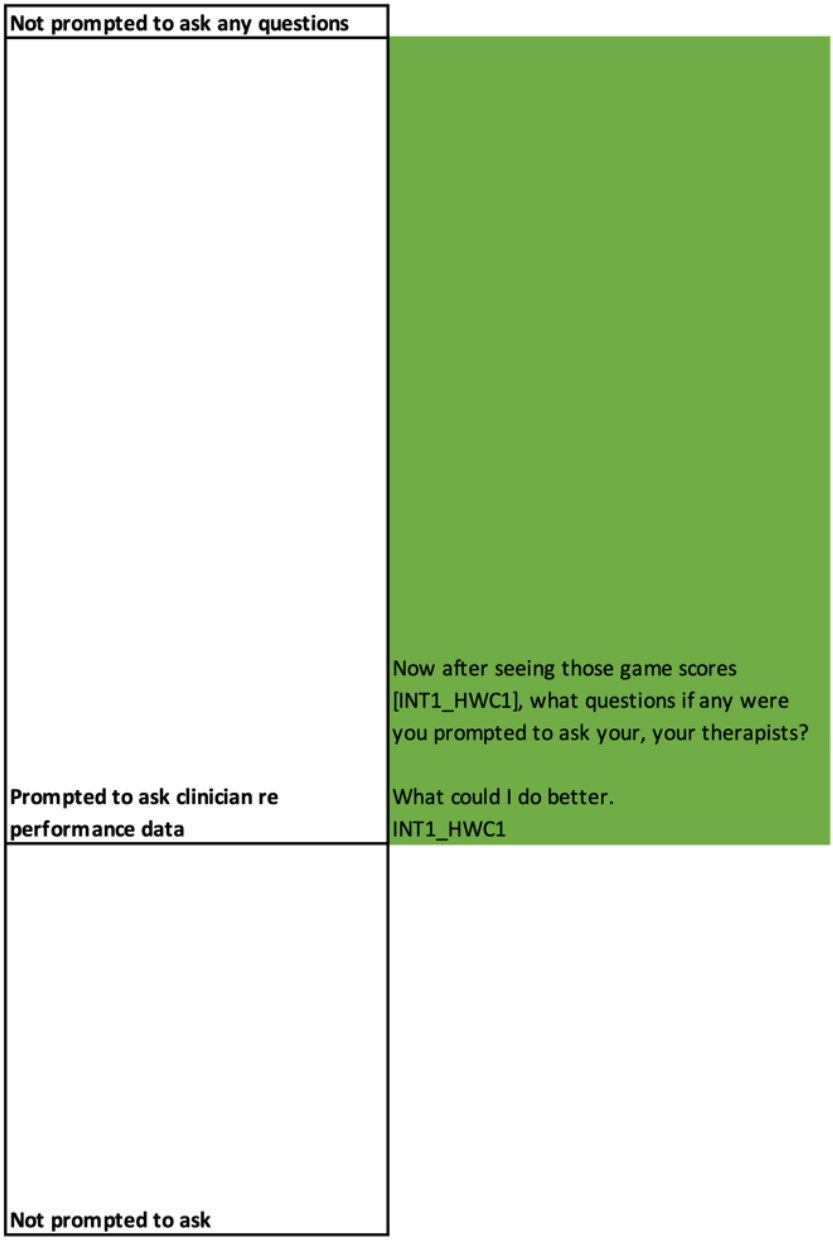
Identifying need for assistance (Request clinician assistance)	Do you think that these kinds of data would aid you in, in determining, in understanding whether you need more help um, for assistance with your rehabilitation? No. FG1_AHP_2 it wouldn't, i- it might back up what I'm thinking, but it wouldn't be the instigator of the, um, seeking more help. FG1_AHP_2	do you think that would also help you realise whether you need more assistance from therapists or clinicians? Yep. FG2_AHP_2 Yeah. FG2_AHP_1
Understand exercises provided by therapists (Understand exercises - Overlap with interest in care process?)	After seeing these kinds of data, that's available, the end of um, you know, every game, or the exercise, do you have any perceptions on, do you think you would form any perceptions or ideas on why your therapist would have assigned these particular exercise games for you to perform? to see that it's improving, yeah. Just keep you motivated. FG2_AHP_1	Do you think that seeing these kinds of data would help you understand why um your clinician might have given you a different kind of game? Or not? Uh, I don't know. FG2_AHP_1
Compliance with therapist-prescribed exercises		

Not prompted to ask any questions			
Prompted to ask clinician re performance data (Ask clinician about data)	I would personally be asking them you know, am I making progress, are you happy with my progress? Um 'cause again, sometimes it's very hard to get any feedback out of the person, directly. INT1_AHP So it would strengthen that kind, of two-way communication, yep. FB I think so, yeah yeah. Definitely. INT1_AHP seeing the data would prompt you to ask you know how much progress you're making? Yep. INT1_AHP Even if it's not as complete? You know, just- just what you see? That's right. INT1_AHP because you see that hey, I'm actually active or I see, I got this um, percent and you now want to ask more about it. Yes. INT1_AHP	if you were to see these kinds of data that's available to you, do you think you would be prompted to ask your therapist um a question or two? in my case, only if it's sort of, at left field, type of stuff. Or it's at odds to what I think I'm, doing...I thought I was doing all right, but I'm obviously not, so what do I gotta do? INT2_AHP	do you think you would be prompted to ask your therapist if it was the other way around? You didn't feel you were doing so well but the data seems like, it's really good? you probably think oh, the system's not doing its job. (chuckles) I know I know I'm not as good as it's telling me. And you probably lose faith in the system...(BUT) ...you wouldn't get out of your way to ask the question, but **the next time you saw you'd uh, say uh, I don't think this is quite all right.** INT2_AHP
Not prompted to ask			

	you'd be prompted to tell them that you need more assistance? Simply based on the kinds of data that you see from Jintronix?
Identifying need for assistance (Request clinician assistance)	I guess, I guess so, 'cause you know.. Yeah. INT2_AHP
Understand exercises provided by therapists (Understand exercises - Overlap with interest in care process?)	
Compliance with therapist-prescribed exercises	

Not prompted to ask any questions					
Prompted to ask clinician re performance data	I need I need um, my therapist to explain, things more to me or I don't know like, understand, I don't know that- FG3_AHC1_5	What questions if any, do you think your patients would have or would be prompted to to ask um their therapists, you, if they saw some of those data- Why did I do so badly? FG3_AHC1_4 What is it, what does it mean, and that, some of them will ask, like what what is this, how is this, affect my, you know, my.. FG3_AHC1_2 Or how c- why how can I get a better score, might be. Or why did I, why did I not do very well. FG3_AHC1_4 Or can I do something more differently. FG3_AHC1_5	Yeah but yeah, what does it mean, they'll (ask), what does it mean. FG3_AHC1_4	And they might ask for more explanation. FG3_AHC1_5	Or they might say, where did that score come from? 'Cause they might not know FG3_AHC1_3 Yeah. How did they score it? FG3_AHC1_4
Not prompted to ask					
Identifying need for assistance	Would it be worth the therapists being able to have like, normative data, and then, showing, the patient, when they see them, and saying, this is what you've gotten, this is what we.. Our average or something works, and **this is why you're at a higher risk of falling, or I don't know, if you'd have that discussion.** FG3_AHC1_3				

Understand exercises provided by therapists	Do you think that after seeing the data um, that they get back from Jintronix, after using the activities or exercises, do you think that those are sufficient in helping them understand why they're doing these exercises or activities? no I don't think it helps them understand. FG3_AHC1_4 Not about why they're doing it. FG3_AHC1_2 'Cause the value they might not really, grasp the concept of that I think. They'll need a bit more a bit of education of, this is why we're doing it- FG3_AHC1_3 Uh, I thought that. FG3_AHC1_5
Compliance with therapist-prescribed exercises	it records compliance, like if they know, I feel like an incentive is that if the patients know that the therapist is saying, the quantity or the amount they've exercised, so that might stimulate them to, be more compliant. FG3_AHC1_5 Yeah, accountability. FG3_AHC1_2 Yes, so I feel that, that's always a good thing I think. Um, in a positive way. FG3_AHC1_5 Yes there's accountability, yeah. FG3_AHC1_4 So the awareness that their physiotherapists know whether they've been doing the exercise or not? It's like doing your homework you know. FG3_AHC1_5 Yeah, and um maybe if they're not being compliant, they might get a phone call from the therapist. FG3_AHC1_5


Not prompted to ask any questions
Now after seeing those game scores [INT1_HWC1], what questions if any were you prompted to ask your, your therapists?
Prompted to ask clinician re performance data
What could I do better.
INT1_HWC1
Not prompted to ask

Identifying need for assistance	Do you think that those data would um, help you in understanding, whether you need um, more assistance? Yeah. INT1_HWC1 Okay. Yeah. Could you tell me um how, those game scores could help you understand whether you need more help or not? Um.. I just know they would. INT1_HWC1	Now after seeing those game scores [INT1_HWC1], what questions if any were you prompted to ask your, your therapists? What could I do better. INT1_HWC1
Understand exercises provided by therapists		
Compliance with therapist-prescribed exercises		

Direct comments on PROM-PGHD wording

	S-so things, wording like, 'My satisfaction with myself as a person'. That's wordy. Y'know. So you could say, um, in the last four weeks I have felt.. Y'know, and keep it, make it more easy like that. FG2_STC1_2C		
Inappropriate words used **Risk? i.e., to patients when they read the**	Yeah, that's true. And, also the, the teacher in me now. (laughs) The um, have like, they're all spaced apart, rather than all bunched together. FG2_STC1_1	Where it says, I felt that I had failed more than the average person, so you're comparing myself, to an able-bodied person? INT1_STC1_1	Well I don't think I would include 'I felt hopeless about my progress'. And I think 'I had little confidence in myself, I was pretty confident in myself' isn't relevant. INT1_STC1_1
Words/phrases that are difficult to understand **Words/content/concepts that may be added** **Appropriate words used**	We'd just like, the, but um, the last question, we're a bit confused about it. FG2_STC1_1	Some of these ones were um, really confusing. FG2_STC1_1	I don't, understand the last question. INT1_STC1_1
	S-so things, wording like, 'My satisfaction with myself as a person'. That's wordy. Y'know. So you could say, um, in the last four weeks I have felt.. Y'know, and keep it, make it more easy like that. FG2_STC1_2C		
Structure/format - for improvement **Preference for scales as**	Yeah, that's true. And, also the, the teacher in me now. (laughs) The um, have like, they're all spaced apart, rather than all bunched together. FG2_STC1_1		

Inappropriate words used **Risk? i.e., to patients when they read the**	Although, you probably should, well you, and that's 'I was discouraged, discouraged about my progress' would probably cover it. But hopelessness is just reinforcing, a thought that 'god I'm never gonna recover'. You don't want to enforce or reinforce that INT1_STC1_1	Well I, have yeah well I have a problem where you say 'the average person'. Um.. Uh more than somebody who has my type of injury or something. Yep, because average to me says able-bodied. INT1_STC1_1	Just one question. I think the last four weeks, my satisfaction with myself has become.. Is that in relation to the program or just in general? INT2_STC1_1	
Words/phrases that are difficult to understand **Words/content/concepts that may be added** **Appropriate words used**	The online help, and online messages, on-screen messages, would they be like the scores, or the the messages about posture and- INT1_STC3_1C	Yeah.. Sorry Ikee, this, um, this reference to the data, sort of the on-screen data, um, I can't remember seeing data apart from her name would come up, which- INT1_STC3_1C	I don't think I quite understand this question here though. You know, what the section says, section of uh, this is the. Yes that question there. INT3_STC1_1 Right, so um.. You can just sort of mark here, somewhere here, whether you strongly agree or actually I think it's.. So there's a number here, sorry about that, it got cut, so there's a number here from one to six? Um, from you know, strongly agree to either strongly disagree, um.. Whether the online help, or the on-screen messages and other documentation in Jintronix, uh gave, made it easier for you to, um understand what to do.	Now just wanna, still didn't understand, when you say, look uh.. Yeah the last question. System has showed me all the rehab patient information I expect to have about myself. INT3_STC1_1
Structure/format - for improvement **Preference for scales as**				

	Are there any words that could be improved? Yeah! Movement mistake. FG1_AHP_2 We're not making mistakes. FG1_AHP_2 They're doing the best they can. FG1_AHP_1C		So b- bottom of the first page.. I felt I had failed, more than the average person- FG1_AHP_2	That is awful! Even to, have that as an option, I was disappointed in myself. I felt blue or sad. This is..
Inappropriate words used	Yeah! I don't wanna be told oh you got it wrong. FG1_AHP_2	Yeah, so error and, movement mistake, this is very negative. FG1_AHP_2	I mean just give me a gun and I'll shoot myself! I mean, come on! FG1_AHP_2	You'll have them running into the toilet in tears. FG1_AHP_2

Risk? i.e., to patients when they read the PROM-PGHD items	So b- bottom of the first page.. I felt I had failed, more than the average person- FG1_AHP_2 I mean just give me a gun and I'll shoot myself! I mean, come on! FG1_AHP_2	That is awful! Even to, have that as an option, I was disappointed in myself. I felt blue or sad. This is.. You'll have them running into the toilet in tears. FG1_AHP_2	Or you're not as good as even the average person? Oh my god! FG1_AHP_2 they already feel that, they already feel that, they're devastated. They don't need that. FG1_AHP_1C	so just to confirm, you wouldn't want um any wording that seems to compare you with, anyone else, um and um you don't find wordings that um elicit negative emotions um helpful? No. FG1_AHP_1 In fact they're really detrimental to us. FG1_AHP_2
Words/phrases that are difficult to understand	The second one it was easy for me to find the information I needed from the system. So, h- how would, how would the patient be finding information? FG1_AHP_2 in this context we can say, it was easy for you to see, the information that you needed from the system? so it's a different word then, is it? FG1_AHP_2	I'm just looking that one there, the information from the system helped me to complete the tasks and scenarios. So what scenarios, what's that referring to? FG1_AHP_2 To me that's, to me that's the same tasks and scenarios. It's just the activity, you know. But it made me think that maybe I've missed something, because of the, scenario. FG1_AHP_2		

Words/content/concepts that may be added	The only.. Um, would be be an option, to say I I think I need to talk to a clinician or.. Maybe. So, um, so that's the only that, so that's about the only.. INT2_AHP			
Appropriate words used	so, the first one. Under three, under one two, third one, are straightforward questions. So I don't see anything to, improve on those. FG1_AHP_2	You think that it's clear and it's it's all um, fine? Yeah. Yeah. FG2_AHP_1	Felt hopeless about my progress, I like that. (chuckles) That's what I started on. INT1_AHP When you say hopelessness here, that's actually happens, because nobody can give you an answer. My first thing was, how long is it gonna take till I move my hand again. No answer. 'Oh everybody's different'. INT1_AHP	with the depression, you felt blue or sad, you know, that's what I was trying to describe. That could happen. But in my particular case, no no problems. INT1_AHP

	question two I found, looking at that, you trying to get too much information to, you need to um, pare it down, to um.. Um maybe, two tops questions you know. Or say, one's about the progress, one's, per- perhaps your personal feelings, INT2_AHP	(Note: Question 2): things can um take a bit more to get through...to, a patient, it's not.. Uh		
	you're trying to get too much information from one question. ...I would break that up into smaller, options.	fine with all that sort stuff. It can get a bit confusing, and I I think that question is just um.. Needs to be broken up into smaller bits.	View, on the second page..,Using um bars and one to fives, and, maybe if you were consistent?	iPad thing that you sort of um, tick your emotions and so on, some standard, test um.. I I just use it as a dart board. (laughs)
Structure/format - for improvement	INT2_AHP	INT2_AHP	INT2_AHP	INT2_AHP
				Mmm scales is probably, yeah.. Y-better I think. INT2_AHP
	I wouldn't say I felt helpless, I would say, um, one to 10, how are you feeling? FG1_AHP_1C		I really think that's important, because when you look over on the second page, you've got a a grid there- FG1_AHP_2	rather than having a list of sort of emotions um that someone might experience?
	Sad, all right, or, good. Uh and the person can choose their own, number, of how they would- FG1_AHP_1C	it would be then, a clear picture of where that person's at. FG1_AHP_1C	that that means I could go in there and ch- well I'm not quite a one or a two, I'm a three-and-a-half, and that's individual to me. So it has the flexibility, to accommodate as, you know everyone.	Hmm, yeah. INT2_AHP perhaps you can, um put in the middle of four, neutral, or something and that sort of, yeah.
	Yeah yeah.	Yes, hmm-mm.		
Preference for scales as response type	FG1_AHP_2	FG1_AHP_1	FG1_AHP_2	INT2_AHP

Inappropriate words used
This is not for stroke patients.
FG1_AHP_2
It's it's not appropriate for stroke patients. Would you agree?
FG1_AHP_2
Yeah, yeah.
FG1_AHP_1
should be, encouraging, and you know, any movement, is a great big deal.
FG1_AHP_1C
Yep.
FG1_AHP_2
it should be applauded and not, you didn't quite make it.
FG1_AHP_1C
Or you're not as good as even the average person? Oh my god!
FG1_AHP_2
they already feel that, they already feel that, they're devastated. They don't need that.
FG1_AHP_1C

	I mean even that's quite interesting in terms of, you know, a person who's had a stroke, and then reading some of those items, that clearly brings up some stuff of.. Brings those feelings back? FB Oh yeah, definitely. Yeah, yeah. INT1_AHP
Risk? i.e., to patients when they read the PROM-PGHD items	The words that are negative. FB
Words/phrases that are difficult to understand	

Words/content/concepts that may be added				
Appropriate words used	I think you've got everything basically covered. INT1_AHP	Did you want to have, did you have any comments on the readability of the, the the survey at this point? You went through it, did you think that some of them were confusing, or do you think some of them could be worded better? it's perfectly clear to me. INT1_AHP	maybe one day I felt okay, and the next day I felt blue and sad you know INT2_AHP	
Structure/format - for improvement	I noticed the NA or NA option, I don't know how you can, get it all together. INT2_AHP 'Cause i- it's at the bottom, and um people may not see it the first time? Yeah, yeah. INT2_AHP	some of the questions seem to be, repeating what was asked here. INT2_AHP You asked about the error messages, later you asked about the error, messages, again. Um.. Again it's asking about messages, and then it's asking, about the information provided. INT2_AHP	I think consistency, so that you can get through the forms, you know. INT2_AHP	
Preference for scales as response type	And you would prefer scales in this sense? You get more meaningful information I think. INT2_AHP			

			just going back again to um, the wording uh sorry the kinds of um emotions or reactions, you think that um, um, a measure of progress is better, than a measure of comparison? Is that what you were trying to-?
			Yeah.
			FG1_AHP_1
	so just to confirm, you wouldn't want um any wording that seems to compare you with, anyone else, um and um you don't find wordings that um elicit negative emotions um helpful?		
		No.	
	you're taking me back to school. You know what mark did I get.. You know, I was less than the average. I was average.	FG1_AHP_1	
Inappropriate words used	FG1_AHP_2	In fact they're really detrimental to us.	
		FG1_AHP_2	

			do you think there would be a difference between satisfaction as a person and satisfaction with, um, how the activity went
			Yeah, yeah. FG1_AHP_2
			So you would rather that it's more on satisfaction of how the data looks like, rather than as a person?
		I'm just reading over question five, my satisfaction with myself as a person. That's a strange..statement. FG1_AHP_2	Or, or my progress or.. FG1_AHP_2
			How did I feel I went? FG1_AHP_1C
Inappropriate words used		Well there's a great, judgement there, isn't there? FG1_AHP_2	Yeah. FG1_AHP_2

							Well I think my satisfaction with myself as a person is once again is very, I mean if this is, if this is health-related data then it most probably needs to be related a little bit to their condition. And I think that satisfaction with myself as a person is a little bit too generalised, it's, I mean I know some of you PDQs are a little bit like that when you're looking in that, but I think most probably it is, it's supposed to be in the recovery phase, it is, it's a means to achieve something, is it, you know, within the last four weeks, my satisfaction with my progress again, or something like that- FG3_AHC1_1
	even just the upbeat and pessimistic, y'know- FB	There's another, the third, uh the word failed. Uh I I wasn't sure you would say I made more mistakes than the average person. FG3_AHC1_5	(laughs) I come into the physio, and they sent me home and I'm absolutely deflated now! I'm hopeless! FG3_AHC1_4	No no no, I can understand them, you want to understand if they feel like they didn't do well compared to the average person, but uh, I don't know whether failed is the right word. FG3_AHC1_5	yeah disappointed, yes, did you think there was I guess that's it yeah. I'm just thinking, would it be better you know I didn't perform as well as I thought I might do. Or something like that, rather than, than the average person because, they may not have any idea what an average person could do. FG3_AHC1_4	And, succeeding or or performed, I don't know like, um.. Just the choice of words, um.. FG3_AHC1_5	-or my physical recovery or my participation, most probably would be better, my my participation in the community or something like that that's a little bit more- FG3_AHC1_1
Inappropriate words used	They're quite complex words, yeah. FG3_AHC1_1 (laughs) I come into the physio, and they sent me home and I'm absolutely deflated now! I'm hopeless! FG3_AHC1_4	It's black and white I suppose. FG3_AHC1_5	And I failed! (chuckles) FG3_AHC1_4				
Risk? i.e., to patients when they read the PROM-PGHD items	And I failed! (chuckles) FG3_AHC1_4						
Words/phrases that are difficult to understand	The system gave error messages, I'm not so sure, that the patients would that, I think that's quite jargonised. I think you most probably need to put that in the, that would be better if it was, you know they, the game told me I had made a mistake or something, yeah yeah. FG3_AHC1_4	The 2nd question down there, the 2nd, it was easy for me to find the information I need in the system. Does anyone else think that? Like what other information would someone need to find in the system? What that's actually referring to? FG3_AHC1_2					

Words/content/concepts that may be added	I wonder if you could put something in in number 2, um, I mean you've sort of followed it in number 1 where it says it was clear, they gave you clear um.. Whether there's scope to put in something about, I didn't really understand or.. I wasn't, um- FG3_AHC1_4 I wrote down something sim- similar, I thought (clears throat), one question could be, I could understand the purpose of the exercise in my recovery I I wasn't sure, I felt like..getting feedback about the, why they're exercising it, that they understand how it would fit in to their recovery- FG3_AHC1_5 You could possibly say, is there any- anything that stopped them performing at the level that they thought they could, or did they feel that they performed to the best of their ability. FG3_AHC1_4	Could they even write, three feelings? Of how they felt when they got the data? FG3_AHC1_3 Or you could have that like initially, this, and like a 1 to 5 scale of those. And then a comments box? FG3_AHC1_2 And then they could add their own emotions as well? Yes. FG3_AHC1_2	M-maybe you change the word data, and put I found that the results about me are complex. Maybe that's a word- FG3_AHC1_4 Yeah, results might be more, user friendly. FG3_AHC1_4
Appropriate words used	I like that one about whenever I made a movement mistake, I could recover easily and quickly. That sort of covers that little bit. I like that one. FG3_AHC1_1 That's that sort of that safety, yeah yeah yeah. FG3_AHC1_5	A lot of that information about, information about understanding is actually covered in question three... I quite like that bit, I think that's nice and straightforward. FG3_AHC1_1	

		do you need this many questions, to get the health-related data? There's a lot				
	I think only other thing I would say, is that that, to me, especially for stroke patients that might, there's a lot of information here, would that information be better generated like this? FG3_AHC1_1	there, a lot of them might go, you're asking me the same question ten times over. FG3_AHC1_4		No no no, I can understand them, you want to understand if they feel like they didn't do well compared to the average person, but uh, I don't know whether failed is the right word.		
	-at one end, I felt hopeless, at this end I felt hopeful, like I think, I think they find that a lot easier. Yeah. Like, unless I understand here you just want them to talk about their feelings about it, whether you're gonna get too much information, that's a lot of information for a stroke patient who might be cognitively impaired, um, have trouble reading-	Is this based on any, you know, they're tired and sort of thinking, they go oh here I go again well you know pessimistic, okay, sad, probably. You know it's all the same. FG3_AHC1_4	So reduce the number of items. FB	'Cause, they were attempting uh to do the task and maybe found it more difficult? Or I don't know um.. FG3_AHC1_5	On question, section 4, are any of the statements true, please tick all that apply at any time during the trial, I'm not sure if that's, I I quite like what you're asking there, but I wondered if it could be a yes no or, um just ask a little bit more succinctly or clearly. FG3_AHC1_1	The other thing is too, number 1 and number 4 are very similar. What's the difference between 1 and 4, uh and 3? FG3_AHC1_4
		Disappointed. Is it, you know. They're not complex people, a lot of our patients they might, you just asked me the same question five different ways. FG3_AHC1_4	Yeah I think so. FG3_AHC1_2 I think so. FG3_AHC1_4	I think it, it overlaps a bit with um, the bottom two, I felt satisfied, or disappointed in myself? FG3_AHC1_5		They are all similar in gain really aren't they? FG3_AHC1_4
Structure/format - for improvement						
Preference for scales as response type						

Inappropriate words used **Risk? i.e., to patients when they read the PROM-PGHD items**	So, um, do you find that any of that the the questions that we had there, could be improved in how we wrote them? Are any unclear, are any um confusing perhaps, or do you think any are a bit too complicated to um.. I didn't understand this, question six. INT1_HWC1 It's this statement about true or false. INT1_HWC1
Words/phrases that are difficult to understand **Words/content/concepts that may be added**	Okay, so that's the very last question. looking back again at the questionnaire that you have just been, that you have just filled up, are there, do you have any other comments on the readability of the questionnaire, on their wordings? Um, no. I understand written words. INT1_HWC1
Appropriate words used **Structure/format - for improvement** **Preference for scales as response type**	

Possible new themes/codes

NOTE: Not theme, just noted to use in discussion re importance of participatory health/patient perspective		
Uniqueness/ Patient Perspective		
	I liked it, and I liked to show, show it to mum, and mum would tell me whether.. I improved.. FG2_STC1_1	
	and then, yeah, and then I'd, I'd analyse it, and sort of what I can understand and, explain it to [FG2_STC1_1], and things like that, that I, I think it's helpful. But you need the, basic information 'cause you're the important people so you need to have it. FG2_STC1_1C	Uh, anyone else, I'd just say.. I don't think anyone else would be interested. (chuckles) FG2_STC1_1
Family/carer involvement, e.g., prompted to contact loves ones		
NOTE: Not theme, just noted to use in limitation		
Constructive feedback about study conditions, i.e., technology demo		
NOTE: Not theme, just noted to use in limitation		
Limitation of a PROM		

NOTE: Not theme, just noted to use in discussion re importance of participatory health/patient perspective **Uniqueness/ Patient Perspective**	every single stroke patient is completely, unique. ...Because we are very individual, um, my circumstances are different from yours, my background's different from yours, what's going on in my head is different from, everyone else's.. I- it's so unique, that we don't want to be treated like a group FG1_AHP_2	you would like more um sort of, patient perspective into, into this? Uh completely! Yeah. FG1_AHP_2 Before you write it down. FG1_AHP_1	...when you've been through that experience, that nobody would want, under any circumstances, then the language that is used has a major impact on the patients and on their family, on their carers their friends, anyone that's uh you know close to them. FG1_AHP_2

Family/carer involvement, e.g., prompted to contact loves ones	do you think seeing these kinds of data would prompt you to contact loved ones, and talk about um your rehabilitation progress more Not really. FG1_AHP_1	do you think seeing these kinds of data would prompt you to contact loved ones, and talk about um your rehabilitation progress more it would let me see, well look I can sh-, can I share this with you, to my son or my daughter-in-law. Erm.. To, keep them included in my state of health. FG1_AHP_2	would help you become more or less confident, in explaining your rehabilitation progress to your loved ones or to your friends? Yeah, if it was going up yeah. FG2_AHP_1 Definitely. FG2_AHP_2	if you could show them something, it's easier for them to visualise, 'cause, again, with my speech, especially when it first happened.. Um.. I'd get very fatigued, and quite often, you- you'd just seize up. You're trying to explain something and you run out of words. INT1_AHP	would you be prompted to contact a loved one or a friend to discuss your rehabilitation progress? Would you be more, sorry, or would you feel less like doing this? I think more, yeah. INT1_AHP why do you think you'd be prompted more when it's positive? it's just, you know, it it's building you up. INT1_AHP	do you think you would be prom- more prompted to share these kinds of um data with, with her? Or with any other loved ones or any other friends? Wouldn't bother me, but I wouldn't get out of my way to, to.. INT2_AHP
NOTE: Not theme, just noted to use in limitation						
Constructive feedback about study conditions, i.e., technology demo	it's all hypothetical really, isn't it? Until you've actually started doing it you don't know anything. FG2_AHP_2					
NOTE: Not theme, just noted to use in limitation	iPad thing that you sort of um, tick your emotions and so on, some standard, test um.. I I just use it as a dart board. (laughs) INT2_AHP					
Limitation of a PROM						

NOTE: Not theme, just noted to use in discussion re importance of participatory health/patient perspective			
Uniqueness/ Patient Perspective			
		do you think that using or seeing some of the data that they can receive from Jintronix would you know prompt them to contact some of their loved ones? Yeah! FG3_AHC1_4	Can you read my score? (chuckles) FG3_AHC1_5
Family/carer involvement, e.g., prompted to contact loves ones	They can also share it with family, 'Oh I did 10 today, I only did 5', you know so there's actually you know, it's that, chance to, bragging power as well, perhaps, a little bit? FG3_AHC1_4	Yes. FG3_AHC1_3 Yeah. FG3_AHC1_1	it gives them something that, 'cause it, I just think especially with the younger generation, they're so tech-savvy and it engages them. FG3_AHC1_1
NOTE: Not theme, just noted to use in limitation			
Constructive feedback about study conditions, i.e., technology demo			

NOTE: Not theme, just noted to use in discussion re importance of participatory health/patient perspective	
Uniqueness/ Patient Perspective	
Family/carer involvement, e.g., prompted to contact loves ones	now after seeing those game scores, from your use of Jintronix, were you prompted to contact a loved one or a friend at any point to discuss your rehabilitation progress, or did you feel less like doing this? No. I I, no. INT1_HWC1

Appendix E. Discussion Guide for Chapter 4 Study

This is the discussion guide used in the interviews and focus groups with stroke survivors recruited through Deakin University's STRIVE project (Chapter 4). This has not been previously published.

STRIVE QUALITATIVE STUDY (FOCUS GROUPS)

Moderator introduction:

"Hi, good [morning/afternoon].

We are researchers from the University of Melbourne, and we are working with Deakin University for this study. This is Cecily Gilbert, and I'm Gerardo Luis Dimaguila; but please do call me Ikee.

I am going to lead our discussion today. As you might already have been told, we will be talking about your experiences with using Jintronix. If you would recall, Jintronix is a system where you performed physical therapy games over 8 weeks, from October to November.

We would also just like to let you know that we are audio recording this session.

Our conversation today has two parts.

In the first part, we would like to to learn from you, in your own words, how it was like to use the Jintronix system. We are trying to find out whether or not it is a good idea to use this technology more widely, so it is important for us to hear about all of your experiences – good, bad, or indifferent – neither good or bad.

In this part, we would like for you to tell us things like:

How easy or difficult it was to use Jintronix.

What you think the pros or cons are of using Jintronix.

And, as a result of using Jintronix, if anything has changed about the way you looked after your own rehabilitation.

The second part of this focus group is to get your help with a questionnaire that we are designing. This questionnaire would let people like you to report back on your experiences of accessing your own health data,

which you, yourselves generated from using a health technology such as Jintronix.

For this part of our conversation, we are going to ask you to take a few minutes to fill a pilot version of the questionnaire, and then to talk to us, not just about your answers, but about the survey questions themselves. Here we would like you to tell us about things like:

Do the questions make sense to you?
Would you ask them in a different way?
Should we add something?
Have we left something out?
Should we leave something out?

All right, so we'll begin now with the first part, where we would like you to share with us, using your own words, your experience of using Jintronix.

Please remember that all of your responses are important. Moreover, to help us have a productive conversation, we ask that we allow only one person to speak at a time.

Please speak frankly about what you think, and not what someone else might want to hear. There are also no correct or incorrect responses."

[Useability Assessment questions]

Can you describe parts of the technology that were easy to use? For example, how easy was it to log in, and to start a game?
[Prompts: Logging in; starting a game to play; selecting a game to play; calibration: positioning yourself within the 'red spot' for the right distance; playing the games themselves]

Thank you. Now how about parts of the technology that were not easy to use – could you describe that for us please?

Follow up questions (if not addressed during open discussion):
Based on what you have just shared with us, how would you make Jintronix better to use?

And what would you change with Jintronix, in terms of usability or as a system overall, to make it better as a physical therapy system to help with your physical recovery?

[Impact of Intervention questions]
What kinds of benefits, if any, do you think using Jintronix has brought you?

Follow up questions (if not addressed during open discussion):
Are these benefits Physical, Emotional, Social or other?
[Prompts: Physical – improved function/ADL;
Emotional – improved motivation to perform physical therapy, positive feelings before, during, or after using Jintronix;
Social – Feelings of better understanding/connection with therapist/person who assigned the exercises, Feelings of better connectedness with family members]

What kinds of difficulties, if any, do you think using Jintronix has brought you?

Follow up questions (if not addressed during open discussion):
Are these difficulties Physical, Emotional, Social or other?
[Prompts: Physical – decreased function/ADL;
Emotional – decreased motivation to perform physical therapy, negative feelings before, during, or after using Jintronix;

Social – Feelings of decreased understanding/connection with therapist/person who assigned the exercises, Feelings of decreased connectedness with family members]

Did you notice, if any, changes in behaviour with regards to your approach to daily tasks as a result of your use of Jintronix? What are they?

Follow up questions (if not addressed during open discussion):
Did you notice any changes in your activity or activeness as a result of your use of Jintronix?

Throughout your participation in the study, from the beginning to the end, what changes in your attitude to your health or rehabilitation did you notice?

How would you compare your experience of using Jintronix as a form of physical therapy, compared with your experience of attending therapy in hospitals?

Follow up questions (if not addressed during open discussion):
Where in your physical therapy or recovery process, from when you had stroke until now, do you think using Jintronix is most valuable or beneficial?

Where in the process do you think it is no longer valuable or beneficial?

Now would you recommend this technology to other people, to use for their physical therapy? Why or why not?

[Patient Engagement questions]
In what ways, if any, has using Jintronix changed the way you manage your rehabilitation?

In what ways, if any, has using Jintronix changed the way in which you interact with your health professionals?

In what ways, if any, has using Jintronix assisted you in understanding your goal of rehabilitation?

In what ways, if any, has using Jintronix assisted you in achieving your goal of rehabilitation?

After the end of this study, how likely is it that you will keep going on with a program of activity like Jintronix?

What, if any, do you think are the longer term effects of using Jintronix?

“Thank you very much.

Now we’d like you to take a few minutes to try out the questionnaire that we talked about at the start of today’s session.

As we mentioned earlier, this questionnaire would let people like you to report back on your experiences of accessing your own health data, which you generated from using a health technology such as Jintronix.

Your feedback on this questionnaire would be very helpful to us in designing a systematic way for patients like you to have a voice in sharing such experiences.

Now please take a copy of the questionnaire and a pen, and write your responses to the 6 items as best you can based on your experience with using Jintronix.

There is no need to put your name on your copy of the questionnaire. Don’t worry at all if there are questions that you can’t answer.

We would like you to leave your completed questionnaire with us at the end of today’s meeting, please.

Also, now is a good time to get a drink or have a stretch if you need to. We’ll start our group conversation again in 15 minutes.”

Appendix E: Discussion Guide for Chapter 4 Study

[Show preliminary PROM-PGHD]

”All right, now it’s time for us to start our group discussion again.

We’ll be talking about the questions that you have just responded to. 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 access to their own health data.

So please, 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 questions of our survey; and revise or remove some as necessary.”

Now let us first talk about the types of data you received from Jintronix. Could you tell us about what kinds of health data or feedback you received from your use of Jintronix?
[Take note of who received outcomes summary, to ensure she/he responds to following quesitons.]

Follow up questions (if not addressed during open discussion):
How did you gain access to your data? Did someone give it to you, and how?

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 from your use of Jintronix, 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 about you from your use of Jintronix, are there any other things you would say about 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 data about you from your use of Jintronix, 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 helped 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 data about you from your use of Jintronix, what other data or information related to your rehabilitation would you have liked to see?

Follow up questions (if not addressed during open discussion):
How would you feel about being able to see all the same data about you that you generate from your use of Jintronix, which therapists can see?

If you saw all the health data you generated from your use of Jintronix that your clinicians can see, what benefits, if any, do you think that would have? What downsides do you imagine there could be?

“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 completed.”
After seeing the available data about you from your use of Jintronix, 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 after using Jintronix?

How would you describe your involvement or engagement in your own rehabilitation after seeing the data about you from your use of Jintronix?

After seeing the data about you from your use of Jintronix, what perceptions, if any, did you have on why your therapist assigned you the exercise games you performed?

Follow up questions (if not addressed during open discussion):
After seeing the data about you from your use of Jintronix, what questions, if any, were you prompted to ask your therapist?

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

Follow up questions (if not addressed during open discussion):
After seeing the available data about you from your use of Jintronix, were you prompted to contact a loved one or a friend to discuss your rehabilitation progress, or did you feel less like doing this? For example, similar to how you might share your fitness tracking data from a device like Fitbit to friends or family.

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 about you from your use of Jintronix, how do you think those data will aid in determining if you need further assistance with your rehabilitation, 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, and if so how would you like this to work; or if not, why not?

Please comment on whether you liked or disliked seeing the data about you from your use of Jintronix.

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 your data?
What did you like least about seeing your data?

Are there any other data or information, if any, related to your use of Jintronix that you would 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?

“Thank you 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. We then incorporate our findings into the way we use Jintronix with other groups of patients.

This would also help us understand how we should ask other patients to give feedback on their experiences of seeing and working with their own health data from a technology system.

You will not be identifiable as an individual in any of this work.

And 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. ”

Appendix F. Chapter 5 Improving the Preliminary Item Bank Study Appendices

These appendices were originally included as part of the peer-reviewed publication presented in Chapter 5, Improving the Preliminary Item Bank: Varying Perspectives of Stroke Survivors and Clinicians.

The full discussion guides are presented for this thesis in Appendix G. Any figures and tables that appear in these appendices have NOT been renumbered for this thesis.

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.

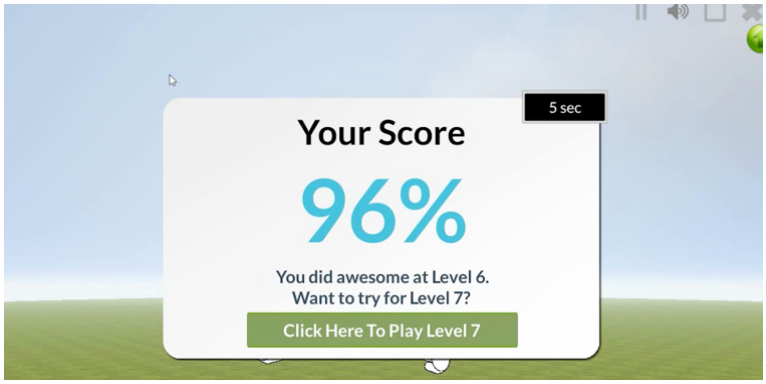
Melbourne Health Service

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

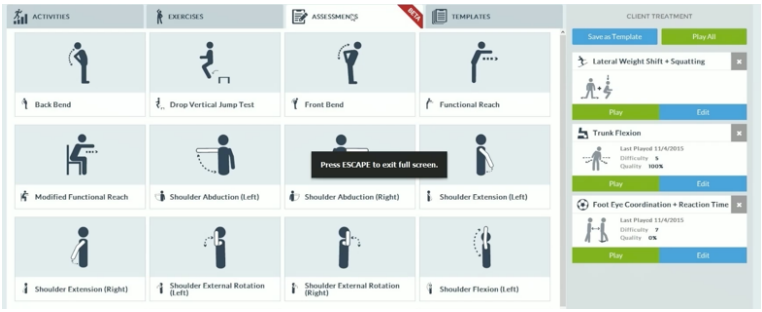


Figure 4. Sample patient outcomes summary data



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.

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Appendix 2. Description of PGHD Utilisation Health Effects Including Example Quotes

The quotes presented below have been cleaned for readability. For instance, where words or syllables are repeated, the duplicates are removed, e.g., "to remind you, is g- is gonna help" became "to remind you, is gonna help". Fillers such as 'um' or 'yeah' have also been removed. Quotes from the Melbourne Health Service stroke survivors are marked with 'AHP', and the quotes from the Headway stroke survivor is marked with 'HWC'.

Health-Related Behaviours

Stroke Behaviours

Most of the stroke survivors from the Melbourne Health Service ('Site 1 survivors') shared that seeing their progress through their PGHD could potentially encourage them to "keep going" (INT2_AHP), and "to do more" (FG1_AHP_2) of their rehabilitation exercises. Although they would not "rely on it" (INT1_AHP), they would use the rehabilitation system "more and more" (INT1_AHP) because they "can see it's helping" (INT2_AHP). Frequency of PGHD access may also help, because PGHD "that keeps popping up in front of you, to remind you, is gonna help" (INT2_AHP). They also felt that PGHD may help them know their movement mistakes, so they "can know to correct yourself" (INT2_AHP).

It may be important for the PGHD to be positive, however. As one survivor put it, "As long as your numbers are going up, it just keeps you positive and keep going" (FG2_AHP_1). Conversely, two survivors described how low PGHD would indicate that the system was not helping with their rehabilitation, and therefore they would be less inclined to continue using it; unless there was "some explanation of something that you need to consider looking" (INT2_AHP). If they felt they did not perform an exercise as well as their resulting PGHD showed, they would "probably lose faith in the system" (INT2_AHP). Finally, a few survivors felt that PGHD would likely have "no effect" (FG1_AHP_1) on their health behaviour. Another indicated that PGHD would not encourage any behavioural changes with their activities of daily living (ADL).

Clinicians

On the other hand, clinicians mainly anticipated that PGHD would be potentially encouraging for stroke survivors, but for slightly different reasons. PGHD would inform survivors of "the quantity or the amount they've exercised, so that might stimulate them to be more compliant" (FG3_AHC1_5) because of the sense of "accountability" (FG3_AHC1_2, FG3_AHC1_4) it would give them. Moreover, clinicians thought that survivors might be more compliant because they better "understand the purpose and the reason why they're doing"(FG3_AHC1_5) the exercises. However, clinicians agree that negative PGHD, especially if it's consistent, would be discouraging: "They might get over it, or might not be willing to participate" (FG3_AHC1_3).

Feelings About Health Status

Stroke Survivors

A Site 1 survivor mentioned that seeing health progress through their PGHD is "a big thing, that's a mental thing" (INT1_AHP) because seeing "yourself gradually making improvements, it just makes you feel so much better. Okay, I'm achieving something" (INT1_AHP). Seeing progress could potentially provide a feeling of accomplishment: "at least you could look back and say 'Hang on, last week I was only doing it at half the pace'" (INT1_AHP). The Site 2 survivor agreed, describing how seeing her progress made her feel "upbeat" and "satisfied": "I just like seeing them. 'Cause it makes me feel good" (INT1_HWC1). PGHD could potentially make stroke survivors more "confident" (INT1_HWC1): "if your numbers are improving, you're getting better, more confident" (FG2_AHP_1). "It just gives you confidence" (INT1_AHP).

On the flip side, PGHD could potentially raise feelings of disappointment and confusion. If their PGHD indicates that they're "not improving" (FG2_AHP_1), that they're "going backwards, that would be, a little bit depressing" (INT1_AHP). As the Site 2 survivor put it: "I don't like not doing well" (INT1_HWC1). A mental health comorbidity might increase the potential of this happening: "if someone was really, mentally depressed that would, geez, you know, 'I'm not getting anywhere'" (INT1_AHP). Moreover, a mismatch between how they felt they performed and what their PGHD was showing could make them feel dejected: "you probably think oh, the system's not doing its job" (INT2_AHP).

Simply seeing percentages at the end of an exercise, as is the case with Jintronix, might also cause confusion: “I'm thinking well, are normal people at a hundred percent? And I'm only at 60? So the percentages to me is more difficult to understand. […] I mean, are we trying to be a hundred percent at these things?” (FG1_AHP_2).

Some stroke survivors also reported potentially feeling self-awareness about their health through PGHD, because it allows them “to measure your improvement or your deterioration. […] You could see it in cold hard figures.” (FG2_AHP_2). PGHD would help them them understand “if you're improving each day” (FG2_AHP_1), so they can see if they’re “heading in the right direction” (FG2_AHP_1). However, one survivor didn’t think PGHD would provide that sense of awareness: “we all know what we have to do, but we can't do it” (FG1_AHP_1).

Meanwhile a Site 1 survivor felt indifferent towards PGHD, because it’s how they feel about doing their activities that matter. PGHD could also elicit different emotions at different times: “maybe one day I felt okay, and the next day I felt blue and sad” (INT2_AHP).

Clinicians

Clinicians shared the same perspective, that progress might provide “satisfaction” (FG3_AHC1_1): “Everybody likes to get a score, I feel. And a score can motivate you or please you” (FG3_AHC1_5). A clinician noted that survivors’ increased confidence could be relevant to when they are “out on the community” (FG3_AHC1_4).

Clinicians agree that simply providing percentages to survivors at the end of an exercise could cause “confusion” (FG3_AHC1_2, FG3_AHC1_1), because they may not “understand” (FG3_AHC1_1) what their PGHD mean; thus there may be “scope to put in [the PROM-PGHD] something about, I didn't really understand” (FG3_AHC1_4). Additionally, clinicians think that PGHD might cause some to doubt the effectiveness of the system: “I'm doing better with my therapy, they don't say I'm doing better with my walking, because I'm being better with my Jintronix” (FG3_AHC1_4).

Two clinicians also thought that some survivors might feel indifferent, “because, the data doesn't specifically relate to their goals” (FG3_AHC1_2), then “some people, it wouldn't worry them” (FG3_AHC1_4).

New Theme: Relationship with Family and Carer/s

Stroke Survivors

A few Site 1 survivors shared that they could potentially be compelled to “share” their PGHD with family “to keep them included in my state of health” (FG1_AHP_2). PGHD might help them in describing their progress to family: “you could show them something, it's easier for them to visualize”; especially when they get “fatigued” and they’re “trying to explain something and” they “run out of words” (INT1_AHP). Sharing positive PGHD with family could be a pleasant experience: “it's building you up” (INT1_AHP). However, the Site 2 survivor and some Site 1 survivors would “not really” (FG1_AHP_1) be prompted and “wouldn't bother” (INT2_AHP) to contact loved ones.

Clinicians

Clinicians agreed that stroke survivors can “share it [PGHD] with family. […] It's that chance to, bragging power as well, perhaps” (FG3_AHC1_4). It might help older survivors to connect with younger family members: “especially with the younger generation, they're so tech-savvy and it engages them” (FG3_AHC1_1).

Interest in Care Processes

Stroke Survivors

Site 1 survivors indicated that it would be beneficial seeing rehabilitation progress through their PGHD, because it would help them know whether that system “was working, and all your effort was worthwhile” (FG2_AHP_2). They liked seeing it because “any information is gonna help you understand the process you're under” (INT2_AHP), to see if they’re “improving each day” (FG2_AHP_1). The Site 2 survivor shared a similar experience: “I like to see the base level I was at, and what I've achieved” because “it helped me understand my rehabilitation progress” (INT1_HWC1). It could be better than relying on clinician’s feedback, which could be “very slow, and quite often you're bound by what they tell you. […] If I wanted

to sort of look at one detail straight away, it could, quite often be quite hard to get them to tell me. Whereas here, I can just look at it" (INT1_AHP).

Stroke survivors also described how PGHD could potentially increase their interest in knowing their therapy status: "the summary can give us uh, more of a picture of the progress that we've made" (FG1_AHP_2). More importantly for a survivor, it could help them know "how far I've got to go", based on their "limitations" (INT1_HWC1). "With repetitive sort of exercises, […] you're trying to not to, let that go berserk, if you're exerting yourself too much" (INT1_AHP). This is necessary for self-management of energy: "Do I need to save my energy, or […] I can go for it?" (INT2_AHP).

For one survivor, however, "it's not vital", although "it would be of interest" (FG1_AHP_2); and for another "it doesn't interest" (FG2_AHP_1) them at all. Interest might also change over time: "initially, you may be concerned to get the information, 'cause people asking you, how are things going, what are you doing", but later that "sort of detail becomes less and less important" and what matters is "the end, am I going okay, I'm not going, is my treatment going to change, or is it staying the same? That sort of level" (INT2_AHP).

PGHD would also be a form of "feedback" (INT1_AHP) to inform survivors where they've done well: "I want to know how well I'm going" (INT1_HWC1), but also what they need to do better. "It's always nice to see when you've done things right, but quite often you learn more when you've done something wrong" (FG2_AHP_2). PGHD helped the Site 2 survivor understand "what movements I had to do" (INT1_HWC1).

Finally, PGHD could potentially affect Site 1 survivors' sentiments about their care: "everything is open and clear and there's nothing going on in the background about anyone judging me or you know, just what what has happened is easy for me to see, and that there isn't anything that's being kept from me" (FG1_AHP_2). However this trust could vary: "As I go through it, I thought about it, it also depends on where the data is going" (FG1_AHP_1).

Clinicians

The sentiments of stroke survivors were strongly reinforced by the clinicians. Stroke survivors would potentially "understand better [their rehabilitation progress] after a second session where they could compare their results. […] It's good for them to have a comparison, to see how they've changed from one session to [an]other one" (FG3_AHC1_5). Survivors "could see change" (FG3_AHC1_2, FG3_AHC1_3) and their "improvement" as a result of performing the exercises, and they may even want to "share it with family" (FG3_AHC1_4).

Clinicians also believed that survivors would be more interested in how PGHD could have "positively impacted […] your ADL like your achievement of your goals than anything else" (FG3_AHC1_2), i.e., if it had "any relevance to a functional activity. You know like washing the dishes, or hanging the washing out or climbing a flight of stairs" (FG3_AHC1_4). Clinicians "try to make [their] therapy goal-focused" (FG3_AHC1_1), and PGHD could potentially help survivors understand how the exercises related to their "goals" (FG3_AHC1_1): "Improve my walking, or improve my balance […] or reduce my falls risk" (FG3_AHC1_5). In fact, it may not be "functionally relevant" (FG3_AHC1_4) to them otherwise. Thus "one question [in the PROM-PGHD] could be, I could understand the purpose of the exercise in my recovery, I wasn't sure" (FG3_AHC1_5), to "judge whether or not this [exercise] is working for the patients" (FG3_AHC1_2). However, one clinician thinks that "even if they didn't fully understand the data I think they'd still like to see, something" (FG3_AHC1_2).

Two phsyiotherapists agreed that PGHD could help survivors understand how they're performing, because PGHD could give "some knowledge of performance" (FG3_AHC1_2). Clinicians agree that PGHD could affect survivors' sentiments about the care they receive: "if you just did the computer thing and they […] just stopped without data they'd be like, why do I do it?" (FG3_AHC1_2) "Why do it? Why all this?" (FG3_AHC1_4)

Personal Care Goals

Stroke Survivors

Seeing PGHD "encouraged" the Site 2 survivor "to try harder": "I get a score. And, I have to improve my score, each time. I try to", even "if I wasn't doing well, I would work harder" (INT1_HWC1). Some Site 1 survivors shared that PGHD could potentially affect them in a similar way: "if it didn't match up [to] what I thought I should be doing it means I would have

to try harder" (FG2_AHP_2). A survivor would likely want "to improve it, you'd try your best" (FG2_AHP_1).

Clinicians

Some clinicians agreed that PGHD could potentially encourage stroke survivors: "it doesn't have to be too detailed or complex, but just something to show..Today I got 50%" (FG3_AHC1_3) to give them "something to keep striving" (FG3_AHC1_3) and to "motivate" or "please" (FG3_AHC1_5) them. One clinician, however, thought that "some people, it [PGHD] wouldn't worry them" (FG3_AHC1_4).

Finally, a clinician didn't think that PGHD would help survivors "form new goals based solely on that data without like liaising with their therapist" (FG3_AHC1_2), although one survivor felt that "Yeah it might" (FG2_AHP_2).

Relationship with Care Provider/s

Stroke Survivors

After seeing her PGHD, the Site 2 survivor was prompted to ask her therapist, to ask "what could I do better" (INT1_HWC1). Most Site 1 survivors agree that PGHD could potentially prompt them to contact their clinician: "if it's sort of, at left field […] or it's at odds to what I think I'm doing, I thought I was doing all right, but I'm obviously not, so what do I gotta do" (INT2_AHP), "what are we doing now?" (FG2_AHP_1) One survivor would even question the treating clinician: "I'd say to the therapist, what are you doing wrong, 'cause I know I'm not doing anything wrong" (FG2_AHP_2).

Interestingly, if their PGHD is better than how they felt they did, it could potentially prompt them "next time you saw [the clinician] you'd say, I don't think this is quite all right" (INT2_AHP). For one survivor, however, seeing the PGHD would not "be the instigator of seeking more help" (FG1_AHP_2). There was also some interest with "what happens" to their PGHD: "where is it going, what's it going to be used for?" (FG1_AHP_2) While another survivor would be prompted to ask if they're "making progress", and if their clinician is "happy with my progress" (INT1_AHP).

A Site 1 survivor also felt that seeing their PGHD could potentially help them understand why their exercises were prescribed to them, i.e., “just [to] keep you motivated” (FG2_AHP_1).

Clinicians

The clinicians agreed that stroke survivors would potentially be prompted to ask them why they did “so badly? How can I get a better score, why did I not do very well” (FG3_AHC1_4), and “can I do something more differently” (FG3_AHC1_5). Some clinicians also agreed that survivors would “ask for more explanation” (FG3_AHC1_5) “where [the] score [had] come from”, and “to explain things more” (FG3_AHC1_4) how their PGHD would affect their progress.

While a Site 1 survivor felt that seeing their PGHD could potentially help them understand why their exercises were prescribed to them, clinicians thought that survivors would need to talk to them in order to understand their therapy better. “They might not really, grasp the concept of that I think. They'll need a bit more of education” (FG3_AHC1_3). Additionally, some clinicians felt that if survivors know their PGHD, “the quantity or the amount they've exercised, so that might stimulate them to be more compliant” because it promotes “accountability” (FG3_AHC1_2, FG3_AHC1_4). It might be similar to doing “homework”; “maybe if they're not being compliant, they might get a phone call from the therapist” (FG3_AHC1_5).

Appendix G: Discussion Guide for Chapter 5 Study

This appendix presents the full discussion guide used in the interviews and focus groups with stroke survivors and physiotherapists recruited through Austin Health hospital and Headway ABI (Chapter 5). The wording for the physiotherapists were tweaked to ask them their perceptions on how PGHD utilisation may affect stroke survivors. Meanwhile both guides are also slightly different from the discussion guide used for STRIVE stroke survivors (Appendix E) because of the Jintronix demonstration at the beginning.

Focus Group Questions and Guide - Patients

Version 2.0 – 03 November 2017

Title	Validation of a Tool to Measure the Effects of Person-Generated Health Data
Short Title	Validation of a PGHD tool
Protocol Number	1
Coordinating Principal Investigator/ Principal Investigator	Dr. Frances Batchelor
Associate Investigator(s)	Mr. Gerardo Luis Dimaguila, Dr. Kathleen Gray, Dr. Mark Merolli
Location	Austin Health/Northern Health

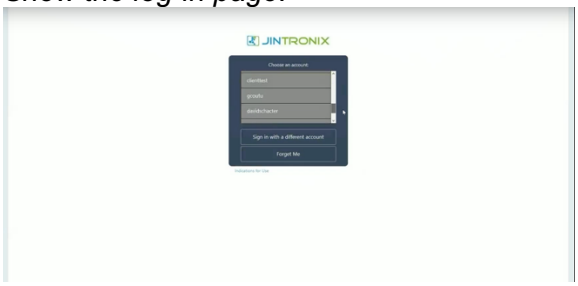
This is the moderator guide for the focus group discussions of the study.

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.

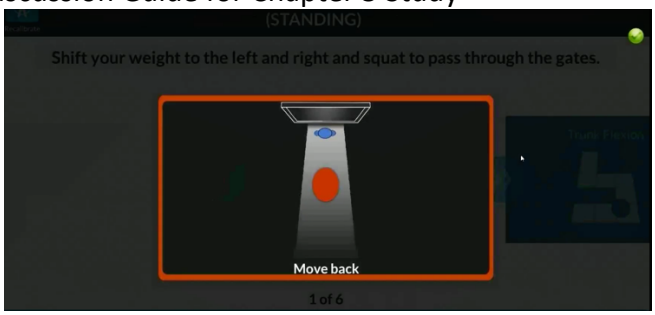
"We shall now proceed with the demonstration of Jintronix. We invite you to pay attention to the data Jintronix makes available."

Proceed with demonstration:

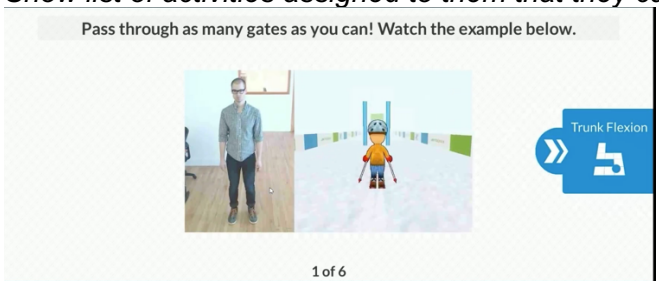
1. *Show the log-in page.*



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).*



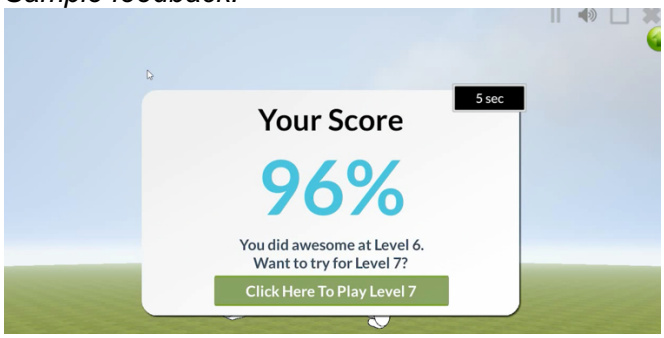
c. *Show a sample exercise and game. Show feedback score provided at the end.*
Sample exercise:



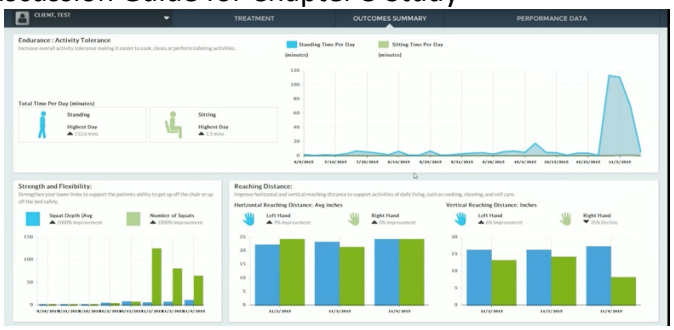
Sample game:



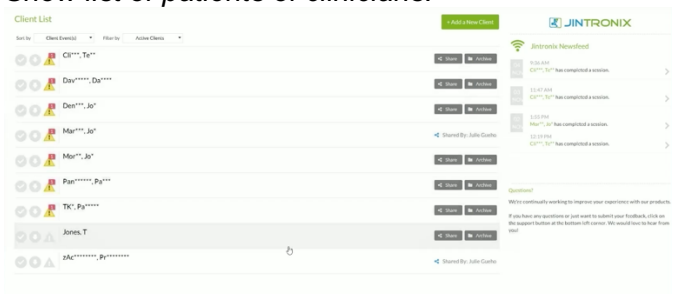
Sample feedback:



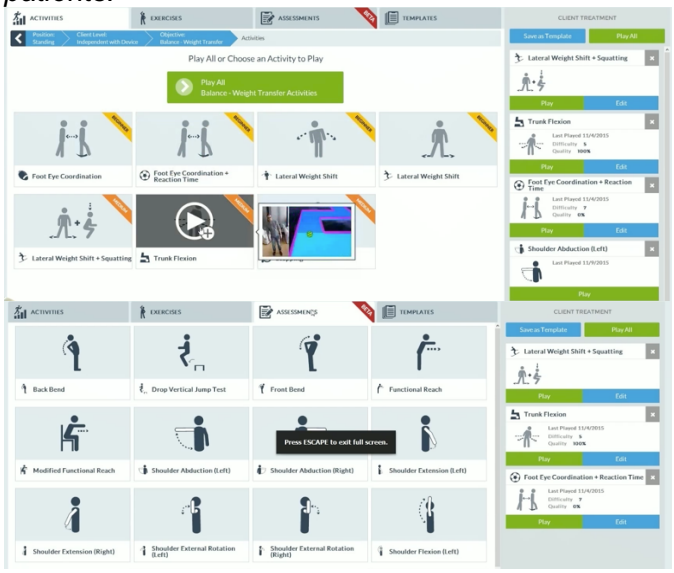
d. *Show performance outcomes summary data available to patients.*



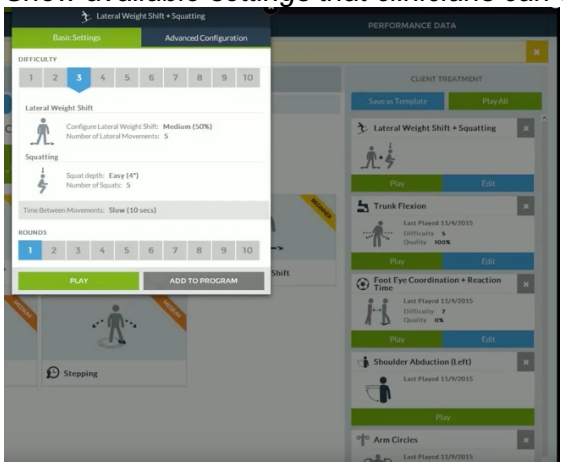
3. *Show clinician-facing interface.*
    a. *Show list of patients of clinicians.*



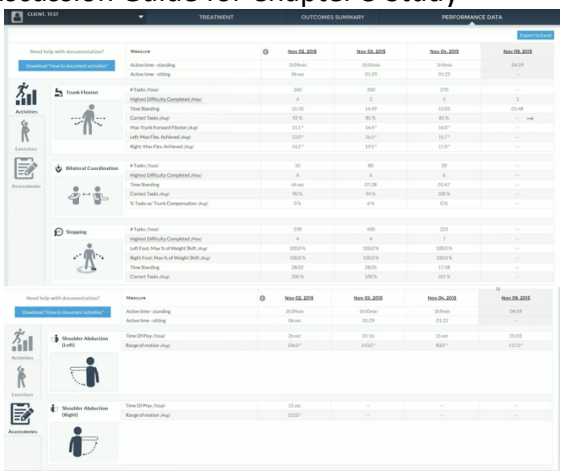
    b. *Show list of activities, exercises, and assessment tasks that can be assigned to patients.*



    c. *Show available settings that clinicians can customise for each activity and exercise.*



    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 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?

Appendix G: Discussion Guide for Chapter 5 Study

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."

Focus Group Questions and Guide - Clinicians

Version 2.0 – 03 November 2017

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Short Title	Validation of a PGHD tool
Protocol Number	1
Coordinating Principal Investigator/ Principal Investigator	Dr. Frances Batchelor
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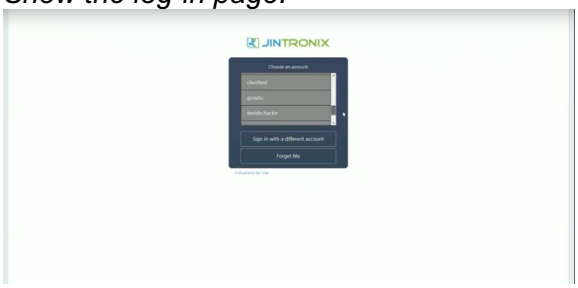
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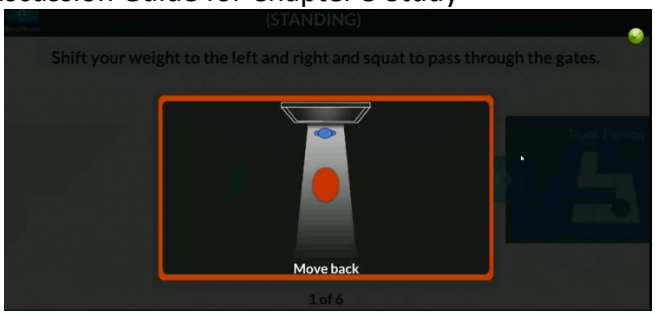
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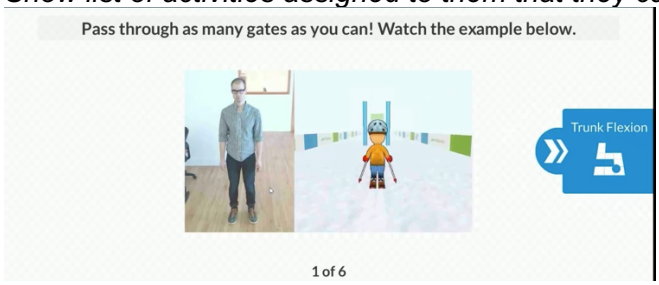
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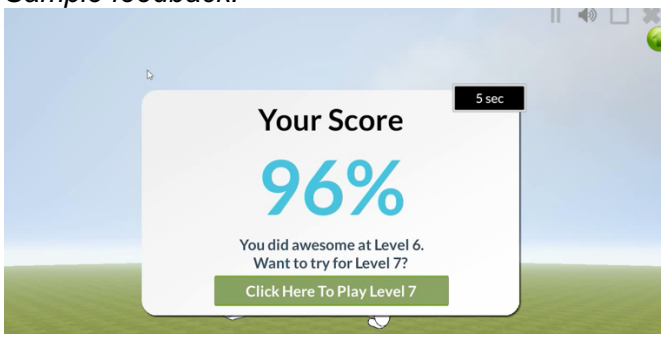
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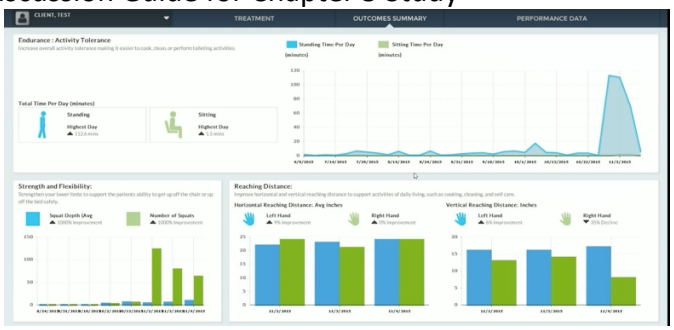
Sample game:



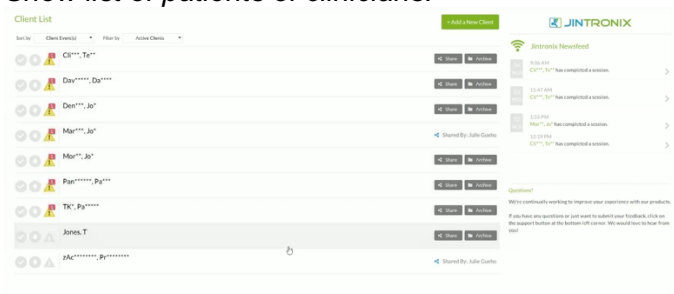
Sample feedback:



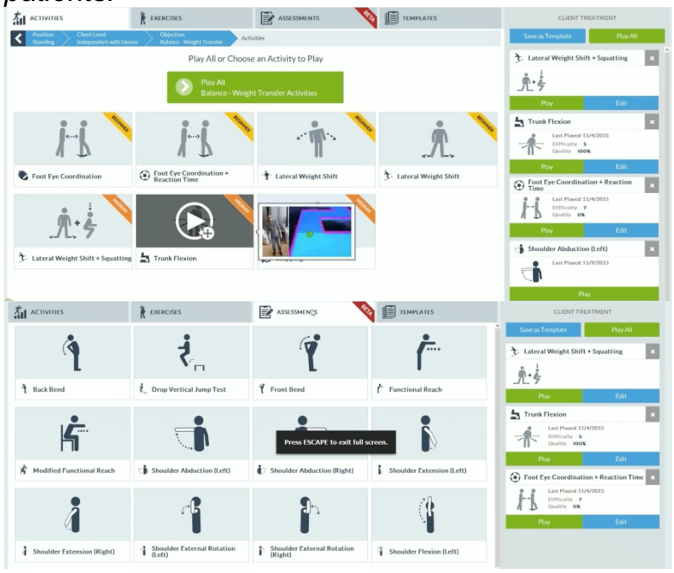
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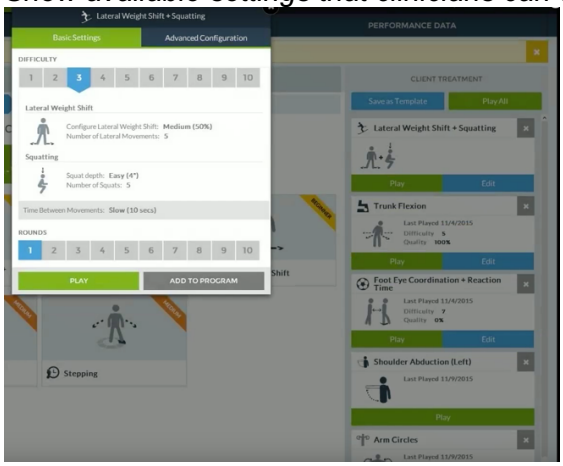
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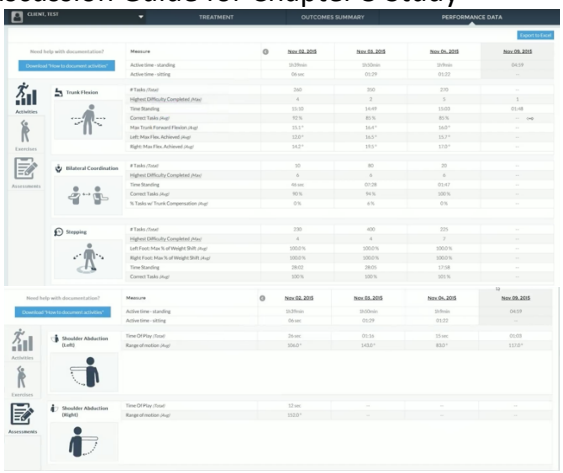


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Appendix G: Discussion Guide for Chapter 5 Study



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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 wouldbe 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 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.”

Appendix H. Changes to the Preliminary PROM-PGHD as Part of Final Item Revision

This appendix presents matching quotes from stroke survivors and clinicians that informed the revisions of each PROM-PGHD item, as well as the revisions that were eventually applied. These have not been previously published.

Matching Quotes that Informed the Revisions

Item	Response	Rating Scale	Category/Theme	Changes	Sample quotes from this column onwards		
The system gave error messages that clearly told me how to fix my posture or movement.	Rate the following: (circle one rating for each statement)	*Always / Often / Sometimes / Rarely / Never*	Behavioural or attitude changes	Reduction			PHYSIO
						The system gave error messages, I'm not so sure, that the patients would that, I think that's quite jargonised. I think you most probably need to put that in the, that would be better if it was, you know they, the game told me I had made a mistake or something, yeah yeah. FG3_AHC1_4	
				Revision	Yeah, so error and, movement mistake, this is very negative. FG1_AHP_2		
				Addition			
					some of the questions seem to be, repeating what was asked here. INT2_AHP		
					You asked about the error messages, later you asked about the error, messages, again. Um.. Again it's asking about messages, and then it's asking, about the information provided. INT2_AHP		
				Re-categorisation			
Whenever I made a movement mistake, I could recover easily and quickly.	Rate the following: (circle one rating for each statement)	*Without any difficulty / With a little difficulty / With some difficulty / With much difficulty / Unable to do*	Behavioural or attitude changes	Reduction			

| | | |

At any time during the Jintronix trial, which of the feelings below were triggered for you based on seeing the information that Jintronix provided about your rehabilitation?	(Please tick all that applied, at any time)	( ) I felt hopeless about my progress. ( ) I felt hopeful about my progress. ( ) I was discouraged about my progress. ( ) I was encouraged about my progress. ( ) I had little confidence in myself. ( ) I was pretty confident in myself. ( ) I felt okay. ( ) I felt blue or sad. ( ) I was fairly upbeat about my progress. ( ) I felt pessimistic about my progress. ( ) I felt I like I was succeeding fairly well. ( ) I felt that I had failed more than the average person. ( ) I felt satisfied with myself. ( ) I was disappointed in myself.	Behavioural or attitude changes	Reduction	so just to confirm, you wouldn't want um any wording that seems to compare you with, anyone else, um and um you don't find wordings that um elicit negative emotions um helpful? No. FG1_AHP_1 In fact they're really detrimental to us. FG1_AHP_2	I mean even that's quite interesting in terms of, you know, a person who's had a stroke, and then reading some of those items, that clearly brings up some stuff of.. Brings those feelings back? FB Oh yeah, definitely. Yeah, yeah. INT1_AHP The words that are negative. FB	do you need this many questions, to get the health-related data? There's a lot there, a lot of them might go, you're asking me the same question ten times over. FG3_AHC1_4 Is this based on any, you know, they're tired and sort of thinking, they go oh here I go again well you know pessimistic, okay, sad, probably. You know it's all the same. FG3_AHC1_4 Disappointed. Is it, you know. They're not complex people, a lot of our patients they might, you just asked me the same question five different ways. FG3_AHC1_4

						should be, encouraging, and you know, any movement, is a great big deal. FG1_AHP_1C Yep. FG1_AHP_2 it should be applauded and not, you didn't quite make it. FG1_AHP_1C
					That is awful! Even to, have that as an option, I was disappointed in myself. I felt blue or sad. This is.. You'll have them running into the toilet in tears. FG1_AHP_2	
				So b- bottom of the first page.. I felt I had failed, more than the average person- FG1_AHP_2 I mean just give me a gun and I'll shoot myself! I mean, come on! FG1_AHP_2		
			Revision			
			Addition			
			Re-categorisation	(Note: Question 2): things can um take a bit more to get through...to, a patient, it's not.. Uh fine with all that sort stuff. It can get a bit confusing, and I I think that question is just um.. Needs to be broken up into smaller bits. INT2_AHP	iPad thing that you sort of um, tick your emotions and so on, some standard, test um.. I I just use it as a dart board. (laughs) INT2_AHP	I wouldn't say I felt helpless, I would say, um, one to 10, how are you feeling? FG1_AHP_1C Sad, all right, or, good. Uh and the person can choose their own, number, of how they would- FG1_AHP_1C Yeah yeah. FG1_AHP_2

					OKAY	Felt hopeless about my progress, I like that. (chuckles) That's what I started on. INT1_AHP When you say hopelessness here, that's actually happens, because nobody can give you an answer. My first thing was, how long is it gonna take till I move my hand again. No answer. 'Oh everybody's different'. INT1_AHP	with the depression, you felt blue or sad, you know, that's what I was trying to describe. That could happen. But in my particular case, no no problems. INT1_AHP	maybe one day I felt okay, and the next day I felt blue and sad you know INT2_AHP
	The online help, onscreen messages, and other documentation that this system gave me made it clear to me what to do.	Rate the following: (circle one rating for each statement)	1 2 3 4 5 6 or N/A (encircle)	Self-management of care	Reduction			

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It was easy for me to find the information I needed from the system.	Rate the following: (circle one rating for each statement) 1 2 3 4 5 6 or N/A (encircle)	Self-management of care	Reduction	The second one it was easy for me to find the information I needed from the system. So, h- how would, how would the patient be finding information? FG1_AHP_2 in this context we can say, it was easy for you to see, the information that you needed from the system? so it's a different word then, is it? FG1_AHP_2	The 2nd question down there, the 2nd, it was easy for me to find the information I need in the system. Does anyone else think that? Like what other information would someone need to find in the system? What that's actually referring to? FG3_AHC1_2			
			Revision					
			Addition					
			Re-categorisation					
The information provided by the system was easy for me to understand.	Rate the following: (circle one rating for each statement) 1 2 3 4 5 6 or N/A (encircle)	Self-management of care	Reduction	A lot of that information about, information about understanding is actually covered in question three... I quite like that bit, I think that's nice and straightforward. FG3_AHC1_1				
			Revision					
			Addition					
			Re-categorisation					
			OKAY					

The information from the system helped me to complete the tasks and scenarios.	Rate the following: (circle one rating for each statement)	1 2 3 4 5 6 or N/A (encircle)	Self-management of care	Reduction	I'm just looking that one there, the information from the system helped me to complete the tasks and scenarios. So what scenarios, what's that referring to? FG1_AHP_2 To me that's, to me that's the same tasks and scenarios. It's just the activity, you know. But it made me think that maybe I've missed something, because of the, scenario. FG1_AHP_2			
				Revision					
				Addition					
				Re-categorisation					
Are any of the statements true?	Please tick all that applied at any time during the trial.	( ) I found that the data about me were more complex than I needed. ( ) I thought that I would need the support of a technical person to be able to understand my data. ( ) Overall, I was satisfied with the way the information (online help, messages, documentation) supported me when completing the tasks.	Self-management of care	Reduction					

						Revision	M-maybe you change the word data, and put I found that the results about me are complex. Maybe that's a word- FG3_AHC1_4 Yeah, results might be more, user friendly. FG3_AHC1_4	On question, section 4, are any of the statements true, please tick all that apply at any time during the trial, I'm not sure if that's, I I quite like what you're asking there, but I wondered if it could be a yes no or, um just ask a little bit more succinctly or clearly. FG3_AHC1_1	The other thing is too, number 1 and number 4 are very similar. What's the difference between 1 and 4, uh and 3? FG3_AHC1_4 They are all similar in gain really aren't they? FG3_AHC1_4
						Addition			
						Re-categorisation			
Within the last four weeks, my satisfaction with myself as a person has become:	(please circle one only)	Much less / Somewhat less / Unchanged / Somewhat more / Much more			Self-management of care	Reduction			

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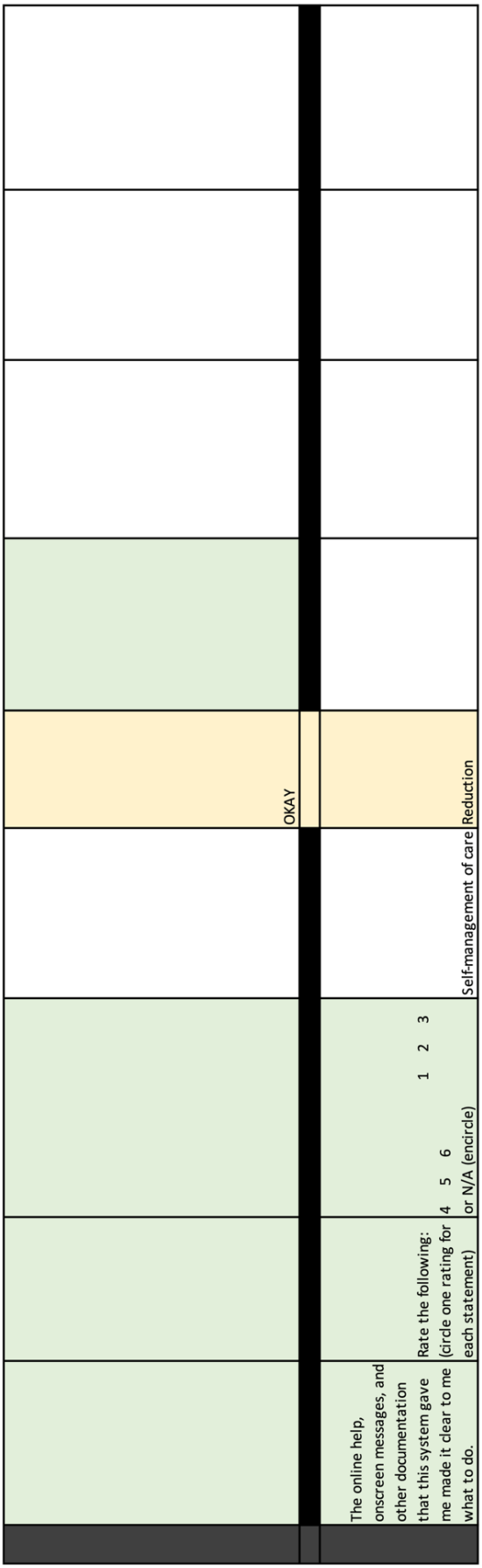
					Revision	So, um, do you find that any of that the the questions that we had there, could be improved in how we wrote them? Are any unclear, are any um confusing perhaps, or do you think any are a bit too complicated to um.. I didn't understand this, question six. INT1_HWC1 It's this statement about true or false. INT1_HWC1 Okay, so that's the very last question.	We'd just like, the, but um, the last question, we're a bit confused about it. FG2_STC1_1	I don't, understand the last question. INT1_STC1_1
					Addition					
					Re-categorisation					
				NEW BELOW						
				Need to contact clinician		The only.. Um, would be be an option, to say I I think I need to talk to a clinician or.. Maybe. So, um, so that's the only that, so that's about the only.. INT2_AHP		

				I wonder if you could put something in in number 2, um, I mean you've sort of followed it in number 1 where it says it was clear, they gave you clear um.. Whether there's scope to put in something about, I didn't really understand or.. I wasn't, um- FG3_AHC1_4 I wrote down something sim-similar, I thought (clears throat), one question could be, I could understand the purpose of the exercise in my recovery I I wasn't sure, I felt like..getting feedback about the, why they're exercising it, that they understand how it would fit in to their recovery- FG3_AHC1_5	
					Could they even write, three feelings? Of how they felt when they got the data? FG3_AHC1_3 Or you could have that like initially, this, and like a 1 to 5 scale of those. And then a comments box? FG3_AHC1_2 And then they could add their own emotions as well? Yes. FG3_AHC1_2	
Understanding of PGHD (?)						
Additional comments or feelings						

					They can also share it with family, 'Oh I did 10 today, I only did 5', you know so there's actually you know, it's that, chance to, bragging power as well, perhaps, a little bit? FG3_AHC1_4	Can you read my score? (chuckles) FG3_AHC1_5 it gives them something that, 'cause it, I just think especially with the younger generation, they're so tech-savvy and it engages them. FG3_AHC1_1	
Contact loved ones (check wording in Austin paper)					"Levels of frustration" were also experienced when their data fluctuated: "sometimes you went backwards, sometimes you went forwards" (INT2_STC1).		
Levels of frustration							

At any time during the Jintronix trial, which of the feelings below were triggered for you based on seeing the information that Jintronix provided about your rehabilitation?	(Please tick all that applied, at any time)	( ) I felt hopeless about my progress. ( ) I felt hopeful about my progress. ( ) I was discouraged about my progress. ( ) I was encouraged about my progress. ( ) I had little confidence in myself. ( ) I was pretty confident in myself. ( ) I felt okay. ( ) I felt blue or sad. ( ) I was fairly upbeat about my progress. ( ) I felt pessimistic about my progress. ( ) I felt I like I was succeeding fairly well. ( ) I felt that I had failed more than the average person. ( ) I felt satisfied with myself. ( ) I was disappointed in myself.	Behavioural or attitude changes	Reduction	Well I don't think I would include 'I felt hopeless about my progress'. And I think 'I had little confidence in myself, I was pretty confident in myself' isn't relevant. INT1_STC1_1	Although, you probably should, well you, and that's 'I was discouraged, discouraged about my progress' would probably cover it. But hopelessness is just reinforcing, a thought that 'god I'm never gonna recover'. You don't want to enforce or reinforce that INT1_STC1_1	Well I, have yeah well I have a problem where you say 'the average person'. Um.. Uh more than somebody who has my type of injury or something. Yep, because average to me says able-bodied. INT1_STC1_1	

		Revision	Or you're not as good as even the average person? Oh my god! FG1_AHP_2 they already feel that, they already feel that, they're devastated. They don't need that. FG1_AHP_1C	you're taking me back to school. You know what mark did I get.. You know, I was less than the average. I was average. FG1_AHP_2	just going back again to um, the wording uh sorry the kinds of um emotions or reactions, you think that um, um, a measure of progress is better, than a measure of comparison? Is that what you were trying to ? Yeah. FG1_AHP_1	even just the upbeat and pessimistic, y'know- FB They're quite complex words, yeah. FG3_AHC1_1	
		Addition					
		Re-categorisation	it would be then, a clear picture of where that person's at. FG1_AHP_1C Yes, hmm-mm. FG1_AHP_1	I really think that's important, because when you look over on the second page, you've got a a grid there- FG1_AHP_2 that that means I could go in there and ch- well I'm not quite a one or a two, I'm a three-and-a-half, and that's individual to me. So it has the flexibility, to accommodate as, you know everyone. FG1_AHP_2	Mmm scales is probably, yeah.. Y- better I think. INT2_AHP rather than having a list of sort of emotions um that someone might experience? Hmm, yeah. INT2_AHP perhaps you can, um put in the middle of four, neutral, or something and that sort of, yeah. INT2_AHP	And you would prefer scales in this sense? You get more meaningful information I think. INT2_AHP

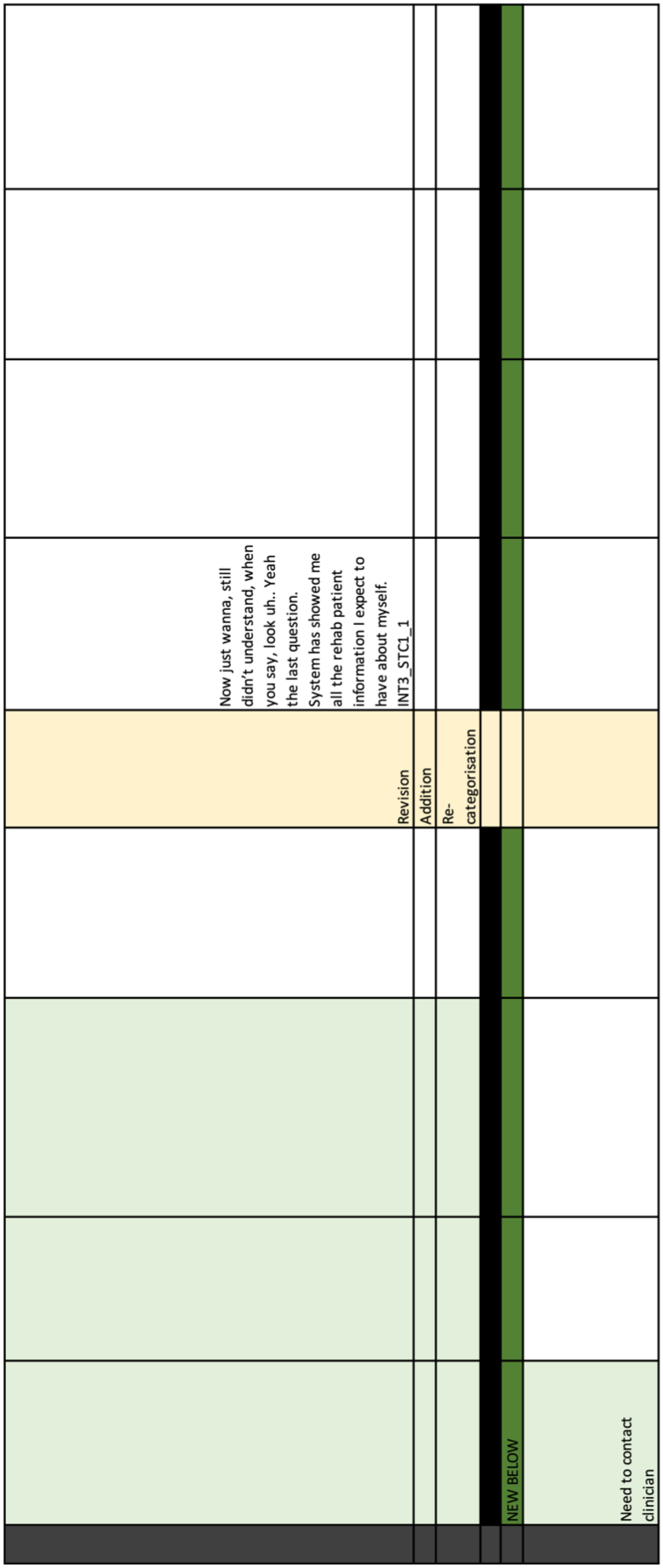

The online help, onscreen messages, and other documentation that this system gave me made it clear to me what to do.
Rate the following: (circle one rating for each statement)
1 2 3 4 5 6 or N/A (encircle)
OKAY
Self-management of care
Reduction

| | | |

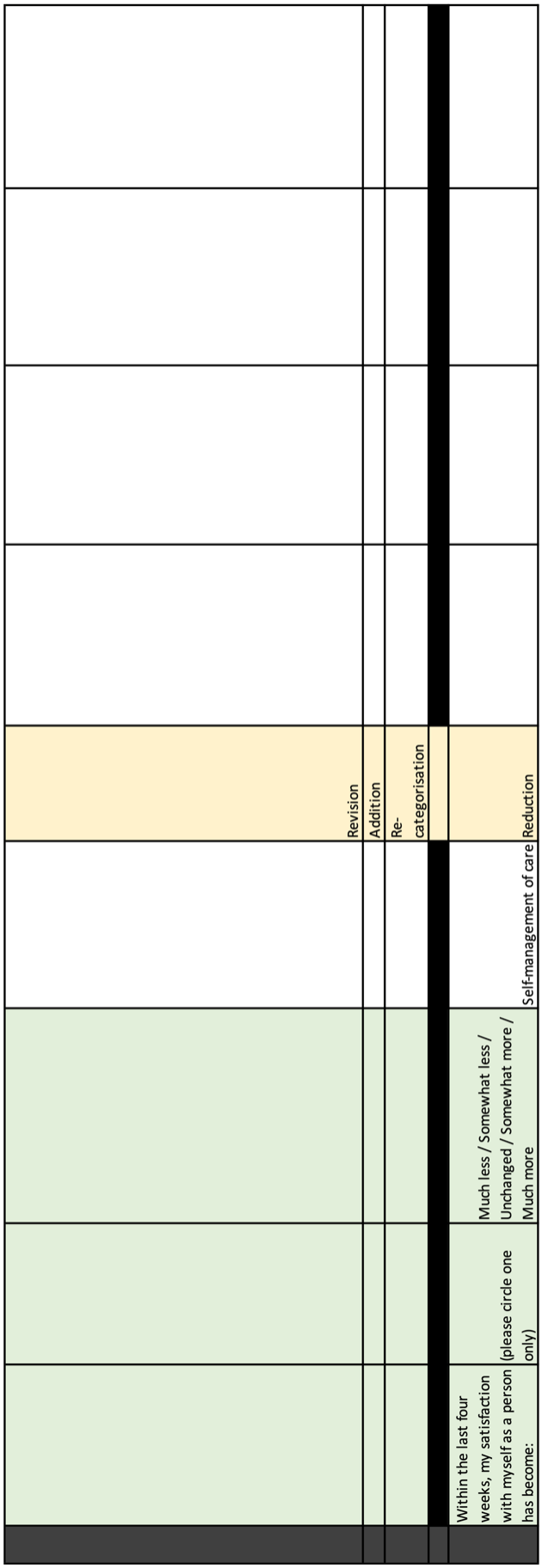
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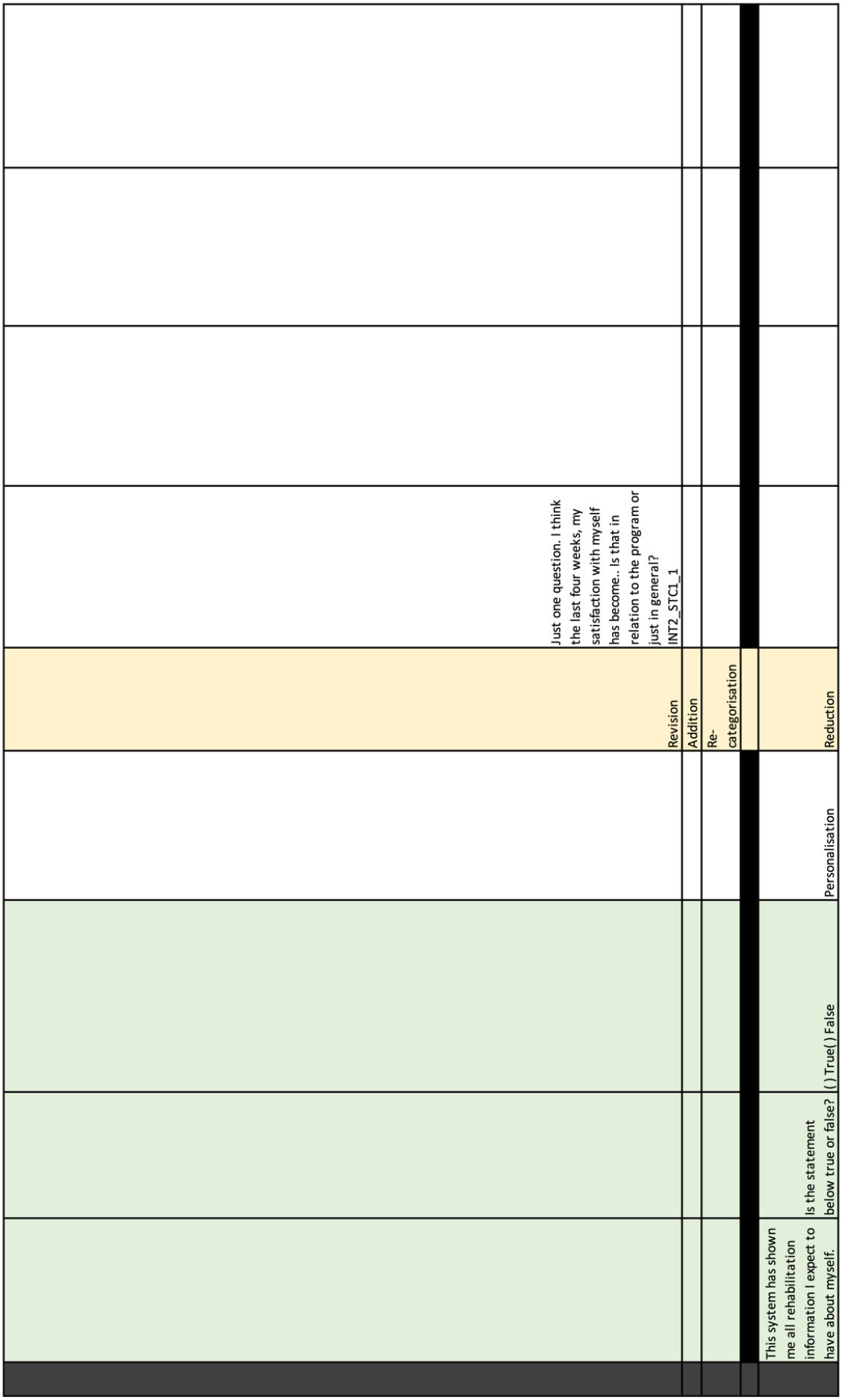
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Revision
Addition
Re-categorisation
Now just wanna, still didn't understand, when you say, look uh.. Yeah the last question. System has showed me all the rehab patient information I expect to have about myself.
INT3_STC1_1
NEW BELOW
Need to contact clinician

				Revision	There's another, the third, uh the word failed. Uh I I wasn't sure you would say I made more mistakes than the average person. FG3_AHC1_5 It's black and white I suppose. FG3_AHC1_5	(laughs) I come into the physio, and they sent me home and I'm absolutely deflated now! I'm hopeless! FG3_AHC1_4 And I failed! (chuckles) FG3_AHC1_4	No no no, I can understand them, you want to understand if they feel like they didn't do well compared to the average person, but uh, I don't know whether failed is the right word. FG3_AHC1_5	yeah disappointed, yes, did you think there was I guess that's it yeah. I'm just thinking, would it be better you know I didn't perform as well as I thought I might do. Or something like that, rather than, than the average person because, they may not have any idea what an average person could do. FG3_AHC1_4
				Addition				
				Re-categorisation	I think only other thing I would say, is that that, to me, especially for stroke patients that might, there's a lot of information here, would that information be better generated like this? FG3_AHC1_1 -at one end, I felt hopeless, at this end I felt hopeful, like I think, I think they find that a lot easier. Yeah. Like, unless I understand here you just want them to talk about their feelings about it, whether you're gonna get too much information, that's a lot of information for a stroke patient who might be cognitively impaired, um, have trouble reading- FG3_AHC1_1	do you need this many questions, to get the health-related data? There's a lot there, a lot of them might go, you're asking me the same question ten times over. FG3_AHC1_4 Is this based on any, you know, they're tired and sort of thinking, they go oh here I go again well you know pessimistic, okay, sad, probably. You know it's all the same. FG3_AHC1_4 Disappointed. Is it, you know. They're not complex people, a lot of our patients they might, you just asked me the same question five different ways. FG3_AHC1_4		

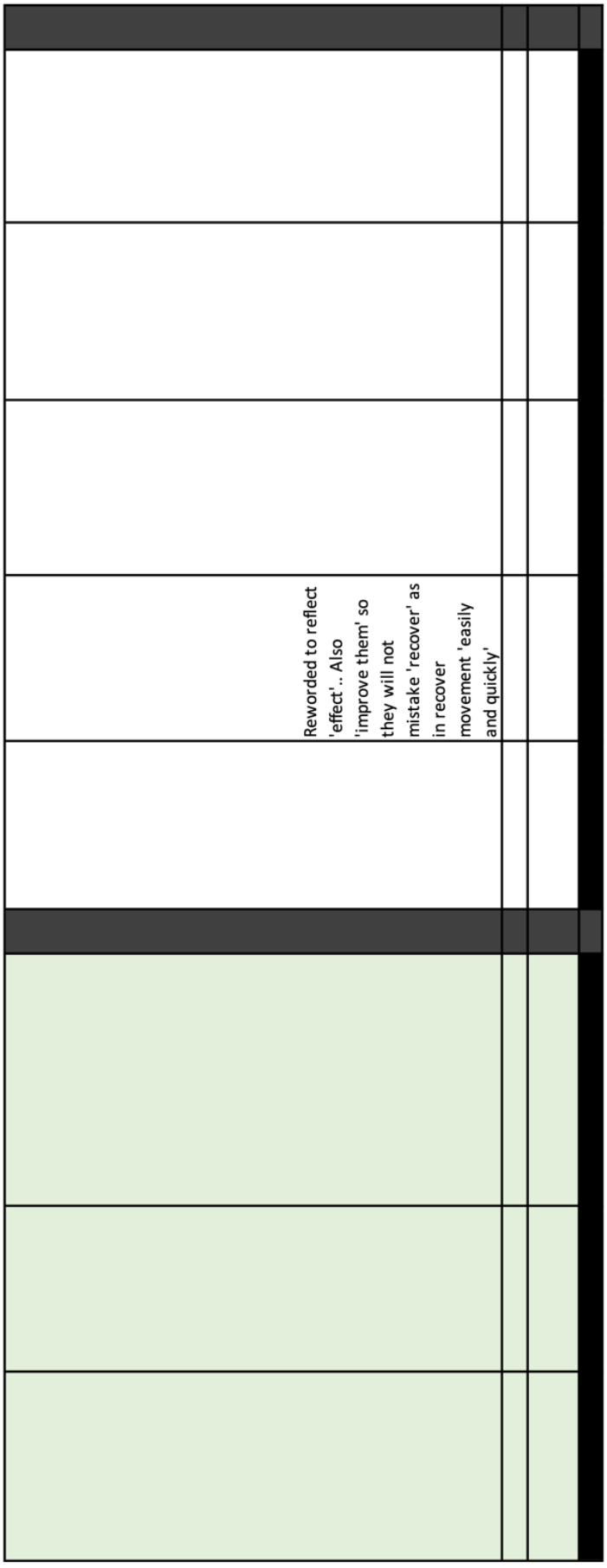

Revision
Addition
Re-categorisation
Reduction
Self-management of care
Much less / Somewhat less / Unchanged / Somewhat more / Much more
(please circle one only)
Within the last four weeks, my satisfaction with myself as a person has become:


Revision
Addition
Re-categorisation
Reduction
Personalisation
Just one question. I think the last four weeks, my satisfaction with myself has become.. Is that in relation to the program or just in general?
INT2_STC1_1
This system has shown me all rehabilitation information I expect to have about myself.
Is the statement below true or false?
( ) True( ) False

Appendix H: Changes to the Preliminary PROM-PGHD as Part of Final Item Revision

Revisions Applied

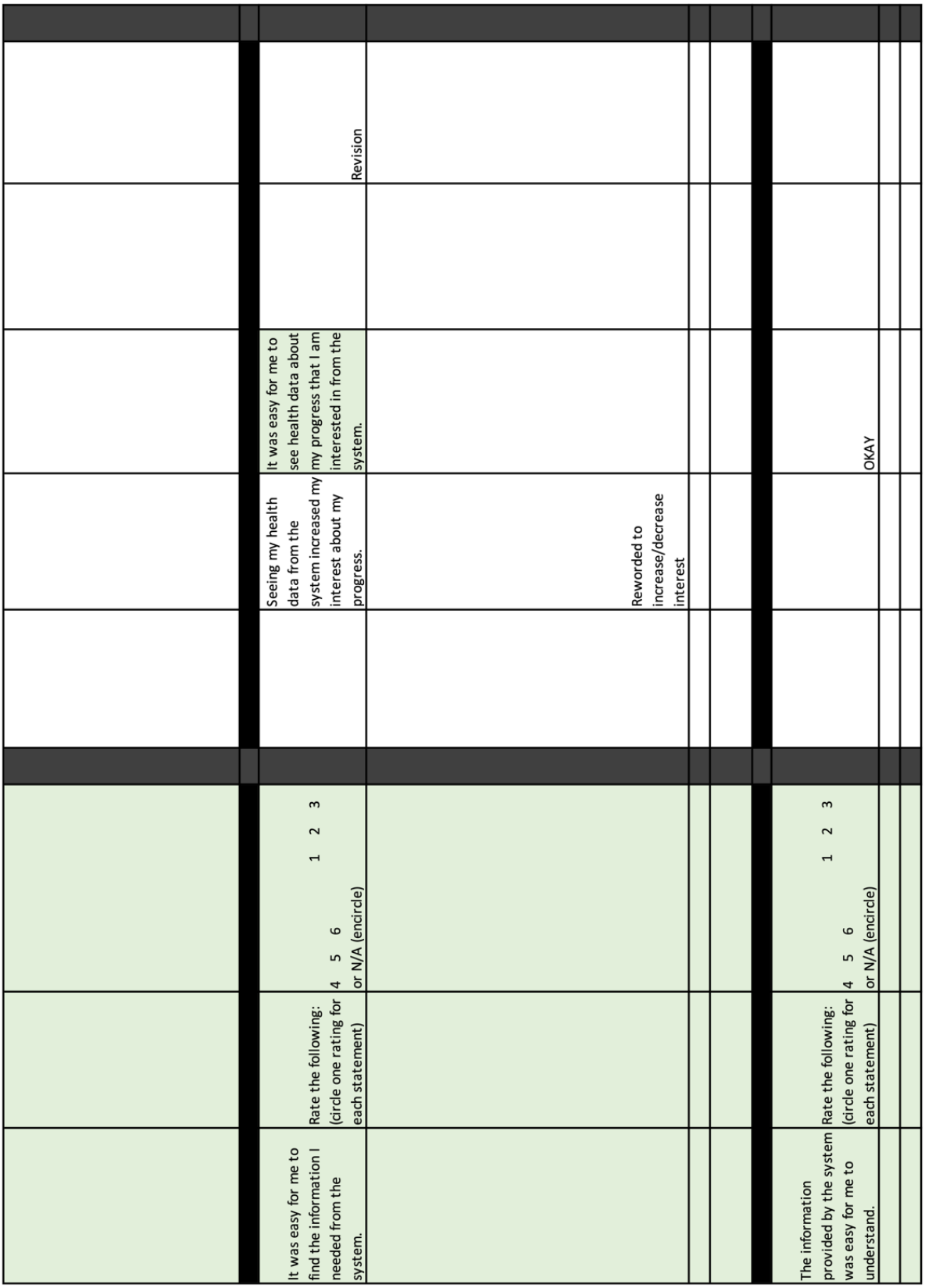
Item	Response	Rating Scale		Revised Rating Scale	Revised Response	Revised Item	Reason	Type of Change
The system gave error messages that clearly told me how to fix my posture or movement.	Rate the following: (circle one rating for each statement)	*Always / Often / Sometimes / Rarely / Never*			The system made me realise when I needed to change my posture or movement, to improve them.	The system told me if I need to change my posture or movement.		Revision
					Reworded to reflect 'effect'..			
Whenever I made a movement mistake, I could recover easily and quickly.	Rate the following: (circle one rating for each statement)	*Without any difficulty / With a little difficulty / With some difficulty / With much difficulty / Unable to do*			The system made me realise how to improve my posture or movement, so I could improve them easily and quickly.	The system told me clearly how to improve my posture or movement, so I could recover easily and quickly.		Revision


Reworded to reflect 'effect'.. Also 'improve them' so they will not mistake 'recover' as in recover movement 'easily and quickly'

At any time during the Jintronix trial, which of the feelings below were triggered for you based on seeing the information that Jintronix provided about your rehabilitation? (Please tick all that applied, at any time)	( ) I felt hopeless about my progress. ( ) I felt hopeful about my progress. ( ) I was discouraged about my progress. ( ) I was encouraged about my progress. ( ) I had little confidence in myself. ( ) I was pretty confident in myself. ( ) I felt okay. ( ) I felt blue or sad. ( ) I was fairly upbeat about my progress. ( ) I felt pessimistic about my progress. ( ) I felt I like I was succeeding fairly well. ( ) I felt that I had failed more than the average person. ( ) I felt satisfied with myself. ( ) I was disappointed in myself.	( ) I felt hopeless about my progress. ( ) I felt hopeful about my progress. (encouragement) ( ) I was discouraged about my progress. ( ) I was encouraged about my progress. ( ) I had little confidence in myself. ( ) I was pretty confident in myself. ( ) I felt okay.(NOW happy or not happy) ( ) I felt blue or sad. ( ) I was fairly upbeat about my progress. ( ) I felt pessimistic about my progress. (happy) ( ) I felt I like I was succeeding fairly well. ( ) I felt that I had failed more than the average person. (confidence) ( ) I felt satisfied with	Rate the following: (circle one rating for each statement)	At any time during your use of the system, which of the feelings below were triggered for you based on seeing the information that Jintronix provided about your rehabilitation?			Revision, Reduction

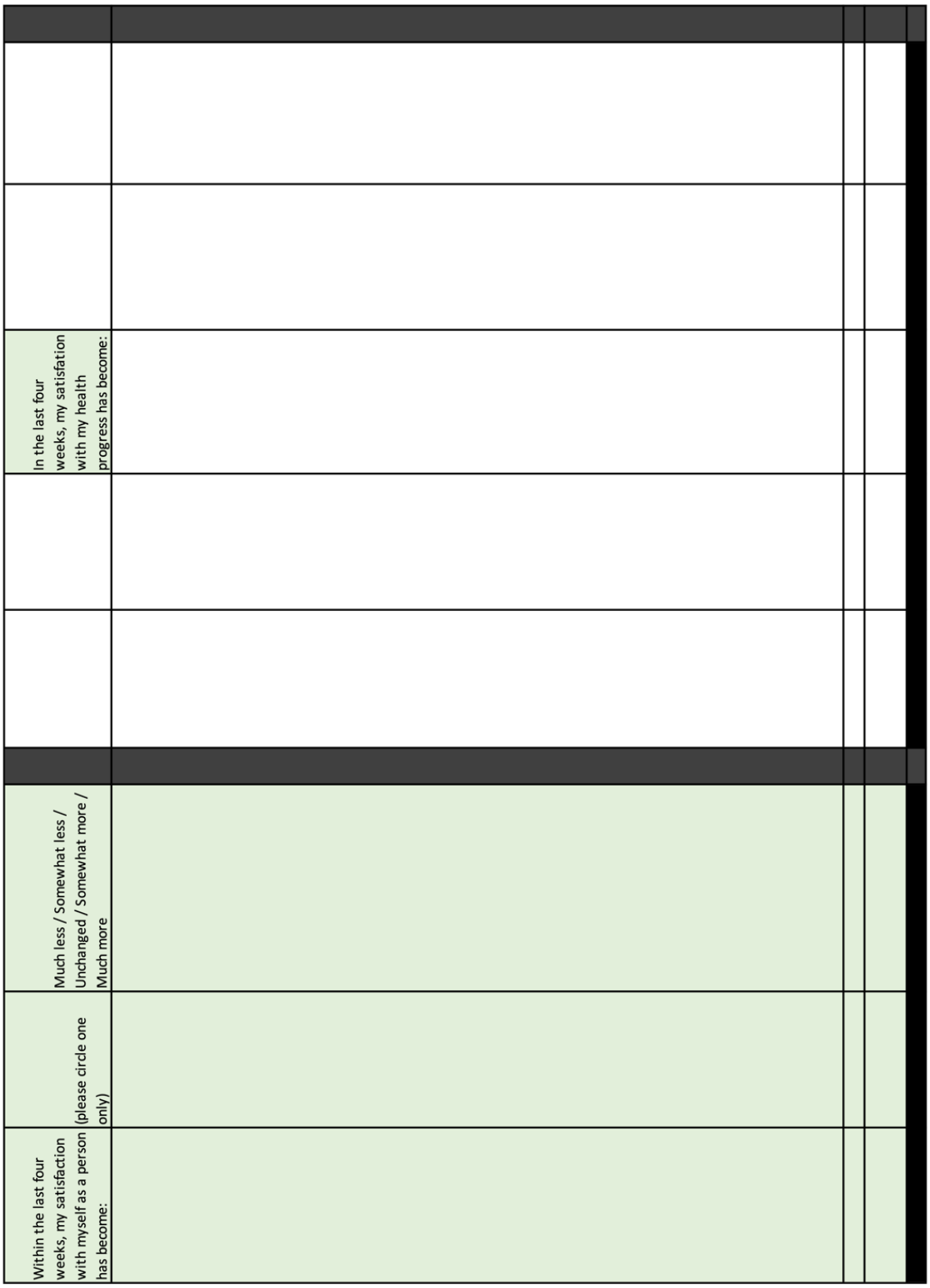
					How much did you feel either encouraged or discouraged about your progress, based on seeing the health data that the system provided about your rehabilitation?	
				How much did you feel either confident or not confident about your progress, based on seeing the health data that the system provided about your rehabilitation?		
			How much did you feel either happy or not happy about your progress, based on seeing the health data that the system provided about your rehabilitation?			
		Further reworded to health data:				
	Changed from Jintronix to make it applicable to other K-SRS					

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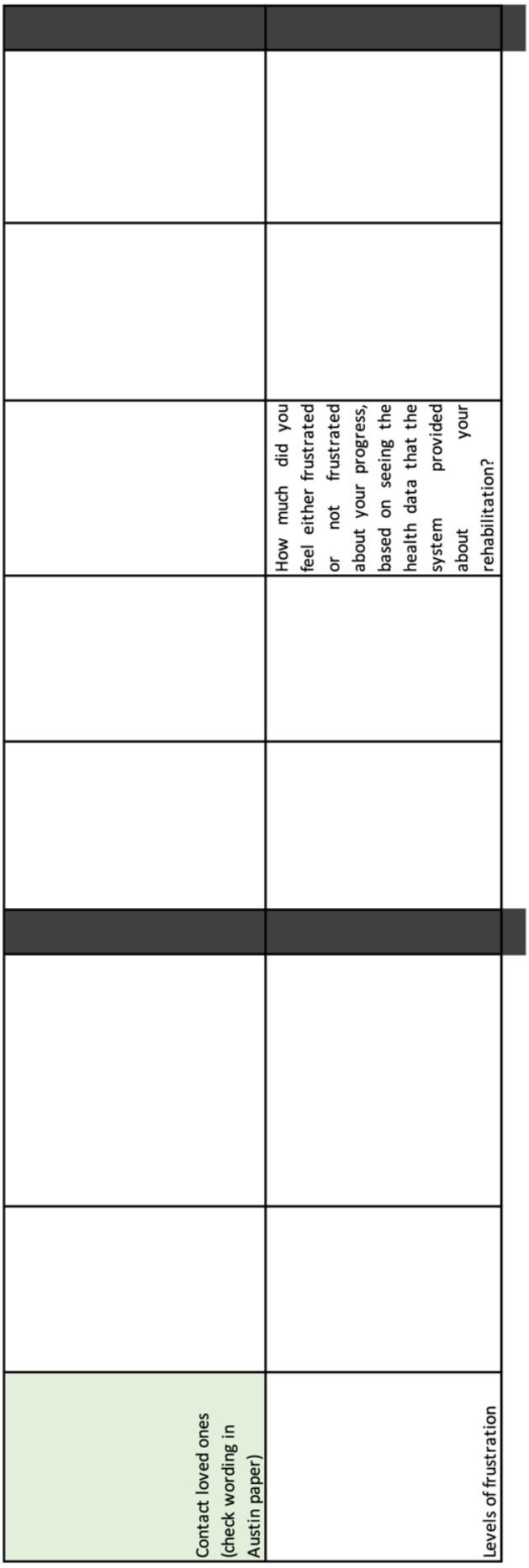
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Are any of the statements true?	Please tick all that applied at any time during the trial.	( ) I found that the data about me were more complex than I needed. ( ) I thought that I would need the support of a technical person to be able to understand my data. ( ) Overall, I was satisfied with the way the information (online help, messages, documentation) supported me when completing the tasks.	( ) I found that the health data results about me were more complex than I needed. ( ) I thought that I would need the support of a technical person to be able to understand my health data results. ( ) Overall, I was satisfied with the way the information provided by the system supported me when completing the activities.	Yes/no OR scale	I felt that I would need the support of an expert to be able to understand health data about my progress.	the information provided by the system supported me when completing the activities.	I found that the health data results about me were more complex than I needed.
					Reworded: Changing feeling about needing expert help.	Reworded: The health data from the system helped me to budget my energy and complete the activities. Reworded into energy management	Removed: Redundant


Within the last four weeks, my satisfaction with myself as a person has become:
(please circle one only)
Much less / Somewhat less / Unchanged / Somewhat more / Much more
In the last four weeks, my satisfation with my health progress has become:

| | | |

The health data provided by the system was easy for me to understand.	
Reworded: More design. Could be reworded to understanding progress Seeing my health data provided by the system increased my understanding of my rehabilitation progress.	
Understanding of PGHD (?)	Additional comments or feelings


How much did you feel either frustrated or not frustrated about your progress, based on seeing the health data that the system provided about your rehabilitation?
Levels of frustration
Contact loved ones (check wording in Austin paper)

Appendix I. Chapter 6, Section 6.2 Design Heuristics Peer-Reviewed Publication Multimedia Appendix

This ‘multimedia appendix’ was originally part of the peer-reviewed publication presented in Chapter 6, Section 6.2, the development of a specialised heuristics.

Step 2: Descriptive Stage

Steps	Step 2: Descriptive Stage				
#	Categories	Key Concepts	Weights	Described by	Examples
1	Stroke survivor health-related behaviours	PGHD can guide stroke survivors to make appropriate movement behaviour or action changes in order to perform an exercise correctly.	2	Stroke Survivors	"I automatically adjust what I was doing, if I couldn't burst every balloon I, I had to adjust.. To work out what I was doing wrong" (FG1_STC2-3)

4	Stroke survivor health-related behaviours	PGHD can encourage stroke survivors to do more exercises related to their therapy.	3	Stroke Survivors Clinicians	"if I can see the improvement I'm making then it would...encourage me to maybe have more of those sessions" (INT1_STC3) Frequency of PGHD access may also help, because PGHD "that keeps popping up in front of you, to remind you..is gonna help" (INT2_AHP) C: "the quantity or the amount they've exercised [will inform], so that might stimulate them to be more compliant" (FG3_AHC1_5)
	Stroke survivor health-related behaviours	PGHD can discourage stroke survivors from doing more exercises if it's negative or low.	3	Stroke Survivors Clinicians	"probably lose faith in the system" (INT2_AHP) [unless there is] "some explanation of um, something that you need to consider looking" (INT2_AHP) C: "They might get over it, or might not be willing to participate" (FG3_AHC1_3)
	Feelings about health status	PGHD can cause positive or negative emotions, correlated with whether their PGHD is positive or negative.	3	Stroke Survivors Clinicians	"I would think well surely this is the benchmark, and so I probably thought, would have thought nah, I'm probably not gonna to [sic] get any better" (INT1_STC1) "going backwards, that would be, a little bit depressing" (INT1_AHP) "I don't like not doing well" (INT1_HWC1) seeing "yourself gradually making improvements, it just makes you feel so much better. Okay, I'm achieving something" (INT1_AHP) "I just like seeing them. 'Cause it makes me feel good" (INT1_HWC1) "okay you can perform" (INT3_STC1) "you're not totally dead" (INT3_STC1) C: "Everybody likes to get a score...and a score can motivate you or please you" (FG3_AHC1_5)

2	Stroke survivor personal care goals	PGHD may be remembered by stroke survivors over time, and provide them with more motivation to improve their therapy performance.	3	Stroke Survivors Clinicians	PGHD may provide “an extra percentage of motivation” (FG1_STC2-1) and an “incentive to do better” (FG1_STC2-3). “feels like a bit of a competition? To see if we can do better” (FG1_STC2-3) “I get a score. And, I have to um..improve my score, each time. I try to”, even “if I wasn't doing, well..I would work harder” (INT1_HWC1) C: “something to keep striving” (FG3_AHC1_3)
5	Stroke survivor personal care goals	PGHD can demotivate stroke survivors if it’s negative.	2	Stroke Survivors	“you can get hard on yourself or feel ‘Oh I didn’t get that right’ and if you keep doing that and you're not achieving 100% and the score keeps flashing at you, that can be a positive motivator, but can also (be) a negative one” (INT2_STC1) “I'm thinking well, are normal people at a hundred percent? And I'm only at 60? …the percentages to me is more difficult to understand…I mean, are we are we um, trying to be a hundred percent at these things?” (FG1_AHP_2)
6	Stroke survivor interest in care processes	PGHD can interest stroke survivors in how their exercises are contributing to their activities of daily living.	1	Clinicians	C: “any relevance to a functional activity. You know like washing the dishes, or hanging the washing out or..climbing a flight of stairs” (FG3_AHC1_4)

7	Feelings about health status	PGHD can make stroke survivors feel confused about their health progress.	3	Stroke Survivors Clinicians	"I'm thinking well, are normal people at a hundred percent? And I'm only at 60? …the percentages to me is more difficult to understand…I mean, are we are we um, trying to be a hundred percent at these things?" (FG1_AHP_2) C: "scope to put in [the PROM-PGHD] something about, I didn't really understand" (FG3_AHC1_4)
8	Feelings about health status	PGHD can make stroke survivors feel more self-aware about their health care.	2	Stroke Survivors	"to measure your improvement…or measure your, deterioration…You could see it in cold hard figures." (FG2_AHP_2) "heading in the right direction" (FG2_AHP_1)
3	Stroke survivor interest in care processes	PGHD needs to be accessible to the stroke survivors who produce them, in order to allow them to be more involved in their own health care.	3	Stroke Survivors Clinicians	"any information is gonna help you..understand..the process you're under" (INT2_AHP) "it helped me understand my rehabilitation progress" (INT1_HWC1) "there must be some things that have, that have improved from that, even if [I was tired]" (FG2_STC1_1) "it told me when you were right it's, it's um.. If you are doing okay or or not" (INT2_STC3). "It's always nice to see when you've done things right, but..quite often you learn more when you've done something wrong" (FG2_AHP_2) C: "would understand better [their rehabilitation progress] after a second session where they could compare their results..it's good for them to have a comparison, to see how they've changed from one session to..[an]other one" (FG3_AHC1_5)
9	Stroke survivor interest in care processes	PGHD can help stroke survivors to self-manage their energy while undergoing therapy.	2	Stroke Survivors	"It was certainly something that I watched, to see where I was at. 'Cause um, y- you need to think about this, we have some sort of a budget of energy that you have to manage yourself, and you can't afford to get to empty" (FG1_STC2-3) With um repe- repetitive sort of exercises..You're trying to not to, let that go berserk, if you're exerting yourself too much" (INT1_AHP)

10	Stroke survivor interest in care processes	PGHD can affect stroke survivors' perception about their therapy.	3	Stroke Survivors Clinicians	"[gave] the confidence of actually doing the exercises" (FG1_STC2-3) "pretty useless" (INT1_STC1) Mismatch between PGHD and feeling of performance: "you probably think oh, the system's not doing its job" (INT2_AHP) "everything is open and clear and there's..nothing going on in the background about anyone judging me or you know just what what has happened is easy for me to see, and that there isn't anything that's being kept from me" (FG1_AHP_2) C: if you just did the computer thing and they..just stopped without data they'd be like, why do I do it?" (FG3_AHC1_2) "Why do it? Why all this?" (FG3_AHC1_4)
11	Stroke survivor relationship with care provider/s	PGHD can prompt stroke survivors to contact their therapists about their therapy performance.	3	Stroke Survivors Clinicians	When they "haven't been doing well [...] what [sic] reason to it, and then they tell me off for certain things" (INT3_STC1) "when it was good I didn't ask questions" (INT2_STC3) "If they were always bad then I would need uh more assistance and even if they [were] good um, they [are] not perfect, right so I would want to have more, more assistance to um, to to improve" (INT2_STC3) "I'd say to the therapist, what are you doing wrong, 'cause I know I'm not doing anything wrong" (FG2_AHP_2 C: how can I get a better score..why did I..not do very well" (FG3_AHC1_4) "can I do something more differently" (FG3_AHC1_5) "ask for more explanation" (FG3_AHC1_5)
12	Stroke survivor relationship with care provider/s	PGHD can make stroke survivors be more conscious of the exercises prescribed by their clinicians.	1	Clinicians	"maybe if they're not being compliant, they might get a phone call from the therapist" (FG3_AHC1_5)
13	Relationship with Family and Carer/s	PGHD can assist stroke survivors in communicating their rehabilitation progress with their loved ones.	3	Stroke Survivors Clinicians	"you could show them something, it's easier for them to visualize"; especially when they get "fatigued" and they're "trying to explain something and" they "run out of words" (INT1_AHP) C: "share it with family.. it's that..bragging power as well, perhaps" (FG3_AHC1_4) "especially with the younger generation, they're so tech-savvy and it engages them" (FG3_AHC1_1)

Step 3: Correlational Stage

Steps	Step 3: Correlational Stage		
#	Concepts turned to characteristics/features	Matching Nielsen's original heuristics	Reworded to closely resemble Nielsen's original heuristics
1	PGHD-enabled systems should assist users in performing more exercises or actions, in a correct way.	#9 Help users recognize, diagnose, and recover from errors Error messages should be expressed in plain language (no codes), precisely indicate the problem, and constructively suggest a solution.	Help stroke survivors in performing more exercises or actions; and to recognise, understand, and recover from errors they make. Guidance or error messages should be expressed in plain language (no codes), precisely indicate the problem, and constructively suggest a solution.

4	PGHD-enabled systems should highlight PGHD indicating positive or improving therapy progress more, and providing them with more frequency than negative or decreasing progress. (Deleted: should encourage stroke survivors to do more exercises related to their therapy, by providing and emphasising PGHD that is indicating positive health progress in a sufficiently frequent manner.)	NA - New	

2	PGHD-enabled systems should present PGHD that indicates negative or decreasing therapy progress carefully, and in a form that elicits a stroke survivors' competitiveness with the self .	NA - New	
5	PGHD-enabled systems should avoid formatting PGHD through a scale that represents a completeness or an endpoint, e.g., 100% as much as possible. Instead, PGHD should be presented as a continuously progressing scale, resembling the ongoing functional therapeutic progress of stroke survivors.	#2 Match between system and the real world The system should speak the users' language, with words, phrases and concepts familiar to the user, rather than system-oriented terms. Follow real-world conventions, making information appear in a natural and logical order.	PGHD-enabled systems should present PGHD in a format that matches the real world context, therapy progress, and goals of the stroke survivors.
6	PGHD-enabled systems should provide PGHD to stroke survivors for increased understanding about how their rehabilitation is contributing to their functional ability.	NA - New	

7	PGHD-enabled systems should ensure that PGHD is, or could be, presented in a way that is clearly understandable to a stroke survivor.	#2 Match between system and the real world The system should speak the users' language, with words, phrases and concepts familiar to the user, rather than system-oriented terms. Follow real-world conventions, making information appear in a natural and logical order.	PGHD-enabled systems should ensure that PGHD is clearly understandable to stroke survivors. The system should speak their language, with words, phrases and concepts familiar to them, rather than system-oriented terms. PGHD-enabled systems should follow real-world conventions, making information appear in a natural and logical order.
8	PGHD-enabled systems should provide PGHD to stroke survivors for increased self-awareness about their health care.	#1 Visibility of system status The system should always keep users informed about what is going on, through appropriate feedback within reasonable time.	PGHD-enabled systems should always provide PGHD to stroke survivors to keep them informed about what is going on with their health status, through appropriate feedback within reasonable time. *This would increase their self-awareness about their health care.*
3	PGHD-enabled systems should provide PGHD to stroke survivors for increased understanding about their rehabilitation or therapy process.	#1 Visibility of system status The system should always keep users informed about what is going on, through appropriate feedback within reasonable time.	PGHD-enabled systems should always provide PGHD to stroke survivors to keep them informed about what is going on with their health status, through appropriate feedback within reasonable time. *This would increase their understanding about their rehabilitation or therapy process.*
9	PGHD-enabled systems should provide patients real-time PGHD that allow them to self-manage their energy while performing therapy exercises.	#1 Visibility of system status The system should always keep users informed about what is going on, through appropriate feedback within reasonable time.	PGHD-enabled systems should always provide PGHD to stroke survivors to keep them informed about what is going on with their health status, through appropriate feedback within reasonable time. *This would allow them to self-manage their energy while performing therapy exercises.*

10	Notwithstanding the need for PGHD to be as accurate as possible, PGHD-enabled systems should inform the patients of its limitations or potential inaccuracies in the PGHD produced by stroke survivors. — PGHD-enabled systems should provide PGHD to stroke survivors to foster an increased sense of trust about their rehabilitation or therapy process.	N/A - New — #1 Visibility of system status The system should always keep users informed about what is going on, through appropriate feedback within reasonable time.	— PGHD-enabled systems should always provide PGHD to stroke survivors to keep them informed about what is going on with their health status, through appropriate feedback within reasonable time. *This would foster an increased sense of trust about their rehabilitation or therapy process.*
11	PGHD-enabled systems should allow stroke survivors to contact their/a clinician about their PGHD; or at least provide survivors with the option of viewing functional, action-based suggestions for them to improve their performance.	#10 Help and documentation Even though it is better if the system can be used without documentation, it may be necessary to provide help and documentation. Any such information should be easy to search, focused on the user's task, list concrete steps to be carried out, and not be too large.	Even though it is better if the system can be used without additional help or documentation, it may be necessary to provide them. PGHD-enabled systems should provide stroke survivors the option to contact a clinician about their PGHD and vice-versa; or at least provide survivors with the option of viewing functional, action-based suggestions for them to improve their performance. Any such information should be easy to search, focused on the survivors' exercises, list concrete steps to be carried out, and not be too lengthy.
12	PGHD-enabled systems should provide stroke survivors the option of allowing their clinicians to contact them based on the progress of their PGHD.	#10 Help and documentation Even though it is better if the system can be used without documentation, it may be necessary to provide help and documentation. Any such information should be easy to search, focused on the user's task, list concrete steps to be carried out, and not be too large.	
13	PGHD-enabled systems should provide stroke survivors with the option to share their PGHD with loved ones in a secure manner.	NA - New	

Step 4: Specification Stage

Steps	Step 4: Specification Stage
#	Specifying the characteristics into new heuristics, following a template
1	ID: 7-PGHD-W2 Name: Guide for correct exercise movement or actions. Tag/s: Improve health-related behaviours Definition: The system should help stroke survivors in performing more exercises or actions; and to recognise, understand, and recover from errors they make. Guidance or error messages should be expressed in plain language (no codes), precisely indicate the problem, and constructively suggest a solution. Explanation: This was a concept identified through a literature review and confirmed by stroke survivors. A stroke survivor commented on how PGHD can help them work out what they were doing wrong, and adjust accordingly. This was augmented from Nielsen's 9th heuristic. Example: The system will violate this heuristic if PGHD shows a therapy performance score that does not indicate where problems, if any, contributed to a lower score. Benefits: The system will be able to guide stroke survivors in making appropriate therapy movement behaviour or action changes. Anticipated problems: This should not be misunderstood as heuristic 1-PGHD-W3, on encouraging positive behaviour change for stroke survivors, i.e., for them to do more of their therapy exercises. This heuristic focuses on stroke survivors' ability to identify and recover from a movement mistake.

4	ID: 1-PGHD-W3 Name: Encouraging PGHD. Tag/s: Improve health-related behaviours; Increase positive feelings about health status Definition: The system should highlight PGHD indicating positive or improving therapy progress, and provide them with more frequency than negative or decreasing progress. Explanation: This heuristic was formed from three concepts identified through a literature review and confirmed by stroke survivors and clinicians. Stroke survivors and clinicians commented on how PGHD can cause positive or negative emotions, correlated with whether the PGHD is positive or negative, e.g., when survivors frequently see their PGHD improve, it encourages them to do more of the exercises. A clinician described how seeing PGHD could help survivors be more compliant. On the other hand, if survivors see their PGHD decline they might lost faith in the system and not perform their exercises. This is a new heuristic. Example: The system will comply with this heuristic if improvements with stroke survivors' PGHD are shown to them frequently as a reminder of the benefits of therapy; and how inactivity may impact their functional progress. Benefits: Stroke survivors will understand how their therapy contributes to the improvement of their health as shown by their PGHD, and as a result be encouraged to do more of their exercises. Anticipated problems: This should not be misunderstood as heuristic 7-PGHD-W2, on helping stroke survivors in performing more exercises in a correct way; or 5-PGHD-W3, on providing survivors suggestions to improve therapy outcomes and/or get in touch with clinicians. This heuristic focuses on encouraging positive behaviour change for stroke survivors, i.e., for them to do more of their therapy exercises.

2	Name: Evoking competitiveness with self. Tag/s: Facilitate positive personal care goals Definition: The system should present PGHD that indicates negative or decreasing therapy progress carefully, and in a form that elicits a stroke survivors' competitiveness with the self. Explanation: This was a concept identified through a literature review and confirmed by stroke survivors and clinicians. Stroke survivors described how seeing their PGHD can motivate them to try harder, sometimes even when their PGHD indicates that they are not doing very well with their therapy exercises, because it can feel like a competition with themselves. Clinicians agree that it can give survivors something to keep them striving to be better. Examples: The system will comply with the heuristic if PGHD indicating negative therapy progress is presented with an encouragement to try harder, and if any progress, no matter how small, is highlighted. Benefits: The risk of making stroke survivors discouraged from receiving PGHD that indicates negative progress will be lowered; and might even motivate survivors to try harder. Anticipated Problems: This heuristic is not anticipated to be misunderstood with another heuristic, but heuristic implementers should document if this occurs in practice.
5	ID: 8-PGHD-W2 Name: Match between system PGHD and real world context of stroke survivors. Tag/s: Facilitate positive personal care goals; Increase interest in care processes Definition: PGHD-enabled systems should present PGHD in a format that matches the real world context, therapy progress, and goals of the stroke survivors. When presenting PGHD, e.g., as a score, percentage, or a graph, they should be matched to the therapy goals of the survivors. These goals may change over the course of a survivors' therapy, from gaining functional progress in the first few months or years, to maintaining function to perform ADL when their progress starts to plateau [1]. PGHD needs to be connected with the needs of the stroke survivors, and where they are clinically. Explanation: This heuristic was formed from two concepts identified through a literature review and confirmed by stroke survivors and clinicians. Stroke survivors described how receiving a percent score that did not indicate a 100% could be a negative motivator. Achieving 100% given their condition could be very difficult or even impossible. Clinicians also described how PGHD should help survivors understand how their therapy is contributing to improved performance of ADL. This was augmented from Nielsen's 1st and 2nd heuristic. Example: The system would comply with this heuristic if it avoided formatting PGHD through a scale that represents a completeness or an endpoint, e.g., 100%. Instead, PGHD is presented as a continuously progressing scale, resembling the ongoing functional therapeutic progress of stroke survivors, until their progress plateaus. At which point PGHD is contextually matched to the goals of the survivors, e.g., maintaining arm function to a certain extent in order to wash dishes. Benefits: Stroke survivors would not find their PGHD as disconnected from their needs and from their clinical or health status. Anticipated Problems: This heuristic is not anticipated to be misunderstood with another heuristic, but heuristic implementers should document if this occurs in practice.
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	ID: 3-PGHD-W3 Name: Understandable health data. Tag/s: Increase positive feelings about health status Definition: PGHD-enabled systems should ensure that PGHD is clearly understandable to stroke survivors. The system should speak their language, with words, phrases and concepts familiar to them, rather than system-oriented terms. They should follow real-world conventions, making information appear in a natural and logical order. Explanation: This was a concept identified through a literature review and confirmed by stroke survivors and clinicians. A stroke survivor found that simply having percentages as feedback for performing an exercise could be confusing, as it could be misunderstood as being compared with people who have not had stroke. Clinicians also agreed that PGHD may not be understood by survivors. This was augmented from Nielsen's 2nd heuristic. Example: A system would violate this hueristic if PGHD was not presented in a form that is relatable to stroke survivors' perceptions about their health, e.g., presenting a percentage as progress without communicating it in a contextualised way. Benefits: Stroke survivors would find their PGHD to be more meaningful, and would help them in making sense of their own health status and progress. Anticipated Problems: This heuristic is not anticipated to be misunderstood with another heuristic, but heuristic implementers should document if this occurs in
7	
	ID: 4-PGHD-W3 Name: Visibility of health progress. Tags: Increase positive feelings about health status; Increase interest in care processes Definition: PGHD-enabled systems should always provide PGHD to stroke survivors to keep them informed about what is going on with their health status, through appropriate feedback within reasonable time. Explanation: This heuristic was formed from four concepts identified through a literature review and confirmed by stroke survivors and clinicians. Stroke survivors described how PGHD could help them understand their rehabilitation progress, to determine whether their functional progress was headed in the right direction and learn when they have made a mistake. PGHD could also help them self-manage their energy as they perform their exercises, and increase their trust in their therapy process. This was augmented from Nielsen's 1st heuristic. Example: The system would violate this heuristic if relevant PGHD is not presented as the stroke survivors are performing their exercises, which would not help them self-manage their energy. Meanwhile the system would comply with this heuristic if they are given the option to view all of their PGHD produced as a result of using the system. Benefits: Stroke survivors' awareness about their health care would increase, which would also improve their understanding about their rehabilitation or therapy process. This would also allow them to self-manage their energy while performing therapy exercises, and would foster an increased sense of trust about their rehabilitation or therapy process. Anticipated Problems: This heuristic is not anticipated to be misunderstood with another heuristic, but heuristic implementers should document if this occurs in practice.
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11	ID: 5-PGHD-W3 Name: Help and support. Tag/s: Improve relationship with care providers Definition: Even though it is better if the system can be used without additional help or documentation, it may be necessary to provide them. PGHD-enabled systems should provide stroke survivors the option to contact a clinician about their PGHD, allow their clinicians to contact them, or at least provide survivors with the option of viewing functional, action-based suggestions for them to achieve their therapy goals. Any such information should be easy to search, focused on the survivors' exercises, list concrete steps to be carried out, and not be too lengthy. Explanation: This heuristic was formed from two concepts identified through a literature review and confirmed by stroke survivors and clinicians. Stroke survivors described how they would want to contact their therapists particularly if they have not been doing well to ask for assistance and ask for advice on what they could do better. Clinicians also described how it would be good if therapists could contact survivors when they're not being compliant. They also described how stroke survivors would likely ask for more explanation, and for advice on how they can do things differently in order to improve their PGHD.
12	Example: The system would violate this heuristic if stroke survivors were not provided with concrete, actionable steps to improve the outcome of their therapy exercises; or the option to reach out to their clinicians and vice-versa. Benefits: Stroke survivors would be provided with an option to contact and seek for more assitance from their clinicians, or to allow their clinicians to contact them, potentially improving their clinical relationship with their therapists. Survivors would also have an overview of how their therapy goals can be improved, and facilitate health self-management. Anticipated Problems: This should not be misunderstood with 1-PGHD-W3, which focuses on real-time PGHD provided as feedback, for survivors to adjust movements and perform therapy exercises correctly.
13	[illegible] Name: Communication of health data. Tag/s: Improve relationship with family and carers Definition: PGHD-enabled systems should provide stroke survivors with the option to share their PGHD with concerned parties, e.g., loves ones, in a secure manner. Explanation: This was a concept identified through a literature review and confirmed by stroke survivors and clinicians. Stroke survivors described how it could help them communicate their health status to people they would like to share it to, particularly when they are tired or when they 'run out of words'. Clinicians described how survivors might want to share their PGHD with family, particularly with the younger generation who are more technologically inclined. Example: The system would comply with this heuristic if stroke survivors are given the option to share some or all of their PGHD with concerned parties in a secure manner, ideally after registration of those parties not unlike how health data is shared through the MyHealth Record [50]. Benefits: Stroke survivors would have the option to securely share their health or therapy progress with loved ones, or relevant care providers.

Appendix J. Implications, Challenges, and Recommendations

The tables presented here summarise the discussion in Chapter 7, Section 7.2. These have not been previously published.

PGHD

Key Research Concepts	Implications	Challenges	Recommendations
PGHD	**PGHD users:** -Increased understanding on how PGHD may affect health outcomes of people, from their own perspective. -Recognised value of PGHD user experience in the context of PGHD use, assessment of utilisation effects, and evaluation of PGHD technologies.	**PGHD users:** -Evidence base of PGHD utilisation effects still lacking, in particular for other cases of PGHD technologies.	**PGHD users:** -Self-assess outcomes of PGHD use, e.g., through a health journal. -Develop and use PRMs-PGHD to document and evaluate effects of PGHD utilisation from a wider range of PGHD technologies. -Include PRMs-PGHD data routinely as part of patient record, similar with PROMs.
	Clinicians: -Increased understanding of PGHD utilisation effects for a patient-centred assessment of PGHD technologies.	**Clinicians:** -Evidence base of PGHD utilisation effects still lacking, in particular for other cases of PGHD technologies.	**Clinicians:** -Consider PGHD utilisation effects of patient-facing HITs. -Include PRMs-PGHD data routinely as part of patient record, similar with PROMs.
	Health Informatics Research Community: -Demonstrated that PGHD effects and outcomes can be measured.	**Health Informatics Research Community:** Evidence base of PGHD utilisation effects still lacking, in particular for other cases of PGHD technologies.	**Health Informatics Research Community:** -Develop and use PRMs-PGHD to document and evaluate effects of PGHD utilisation from a wider range

	-Understanding how PGHD may affect health outcomes of people, from their own perspective.	-More studies needed to contribute to evidence base of PGHD effects. -Need to consider socio-technical context of PGHD technologies.	of PGHD technologies. -Ensure that the value of PGHD user experience is recognised in understanding the impact of PGHD utilisation. -Due to nature of PGHD; consider both health condition and technology category. PROMs only consider health condition.
	HIT Developers and Designers: -Provided richer understanding of PGHD utilisation effects and broadened their scope. -Consolidating insights into guidelines or design heuristics to form part of selection or implementation of PGHD programmes, complementing other PGHD evaluation methods.	**HIT Developers and Designers:** -Insufficient attention given to PGHD utilisation effects.	**HIT Developers and Designers:** -Consider how the benefits of PGHD could be designed into the HIT, e.g., through the use of the heuristics for PGHD enablement. -Consider PGHD utilisation effects in evaluation of PGHD technologies, e.g., through use of the heuristics for PGHD enablement. This could complement other PGHD eval methods.

Appendix J: Implications, Challenges, and Recommendations

Participatory Health

Key Research Concepts	Implications	Challenges	Recommendations
Participatory Health	**PGHD users:** -Recognising the value of PGHD user experience in the context of PGHD use, assessment of utilisation effects, and evaluation of PGHD technologies. -Emphasises importance of enabling people or the cohort of interest to participate in evaluation of digital health services. -PROM-PGHD offers a precise, patient-centred assessment of such systems. -PROM-PGHD could help PGHD users to understand how certain health technologies could affect their self-management of care.	**PGHD users:** -Patient participation not consistently sought in assessment and evaluation of PGHD technologies. -Provision of PGHD to PGHD users not consistent; provision of PRM-PGHD results to PGHD users may also encounter the same issue.	**PGHD users:** -Pursue a robust feedback loop with clinicians. -PROMs-PGHD could be included routinely as part of patient record, similar with PROMs. -Request option to receive any and all relevant health data.
	Clinicians: -PROMs-PGHD could assist in choosing appropriate health technology. -PROMs-PGHD could help inform health care providers on decisions regarding patient care, e.g., understanding which health outcomes are	**Clinicians:** -This is the first to develop a PRM-PGHD for a case study, and resulting PROM-PGHD will need to be implemented and further assessed. -Perspectives about health could vary between patients and clinicians.	**Clinicians:** -Support the development and use of PRMs-PGHD to document and evaluate effects of PGHD utilisation from a wider range of PGHD technologies. -Ensure that the value of PGHD user

	important, and how patients can be motivated.		experience is recognised. -Ensure similar understanding of health treatment goals with patients, to reduce potential for tensions to occur due to varying perspectives.
	Health Informatics Research Community: -PROMs-PGHD offer a precise, patient-centred assessment of such systems. -Consideration of the socio-technical context increased sensitivity to personal characteristics, and physiological and health-related factors affecting people or cohort of interest. -Further demonstrates how qualitative activities, i.e., focus groups and interviews can be used to broaden coverage of a PROM. -Varying perspectives about health between patients and clinicians emphasises importance of enabling the people or cohort of interest to participate in	**Health Informatics Research Community:** -This is the first to develop a PRM-PGHD for a case study, and resulting PROM-PGHD will need to be implemented and further assessed. -Evidence base of PGHD utilisation effects still lacking, in particular for other types of PGHD technologies. -Participation of PGHD users not consistently sought in assessment and evaluation of PGHD technologies.	**Health Informatics Research Community:** -Develop and use PRMs-PGHD to document and evaluate effects of PGHD utilisation from a wider range of PGHD technologies. -Ensure that the value of PGHD user experience is recognised in studies that seek to understand the impact of PGHD utilisation.

	evaluation of digital health services.		
	HIT Developers and Designers: -Guide technology designers in developing PGHD technologies that are more inclusive of the perspectives of PGHD users. -Emphasises importance of enabling people or the cohort of interest to participate in evaluation of digital health services.	**HIT Developers and Designers:** -Participation of PGHD users not consistently sought in assessment and evaluation of PGHD technologies.	**HIT Developers and Designers:** -Ensure that the value of PGHD user experience is recognised, particularly in understanding the impact of PGHD utilisation.

Appendix J: Implications, Challenges, and Recommendations

Patient-Reported Measure

Key Research Concept	Implications	Challenges	Recommendations
Patient-Reported Measure	**PGHD users:** -PROMs-PGHD could help PGHD users to understand how certain health technologies could affect their self-management of care.	**PGHD users:** -Provision of PGHD to PGHD users not consistent; provision of PRM-PGHD results to PGHD users may also encounter the same issue.	**PGHD users:** -Request option to receive any and all relevant health data, including results of PROM-PGHD.
	Clinicians: -PROMs-PGHD could assist in choosing appropriate health technology. -PROMs-PGHD could inform strategies to improve health outcomes or clinical and cost-effectiveness.	**Clinicians:** -Evidence base of PGHD utilisation effects still lacking, in particular for other types of PGHD technologies.	**Clinicians:** -Support efforts to build evidence base of PGHD. -Consider routinely adding PROMs-PGHD data as part of patient record, similar with PROMs.
	Health Informatics Research Community: -Concepts or measures from technology category and health condition need to be included when examining a PGHD device. -Consideration of the socio-technical context increased sensitivity to personal characteristics, and physiological and health-related factors affecting the people or cohort of interest.	**Health Informatics Research Community:** -Need to consider socio-technical context of PGHD technologies. -Patient participation not consistently sought in assessment and evaluation of PGHD technologies.	**Health Informatics Research Community:** -Develop and use PRMs-PGHD to document and evaluate effects of PGHD utilisation from a wider range of PGHD technologies. -Explore how other socio-tech factors, e.g., health literacy may influence responses to the PROM-PGHD. -Ensure that the value of PGHD user experience is recognised.

	-Further demonstrates how qualitative activities, i.e., focus groups and interviews can be used to broaden coverage of a PROM.		
	HIT Developers and Designers: -A valuable dimension to the PROM-PGHD development method, which considered socio-technical context, was discovered.	**HIT Developers and Designers:** -Insufficient attention given to PGHD utilisation effects.	**HIT Developers and Designers:** -Support efforts to develop PROMs-PGHD, necessary to furnish clearer evidence about value of implementing HITs.

PGHD Technologies

Key Research Concept	Implications	Challenges	Recommendations
PGHD Technologies	**PGHD users:** -PROMs-PGHD could help PGHD users to understand how certain health technologies could affect their self-management of care.	**PGHD users:** -Provision of PGHD to PGHD users not consistent; provision of PRM-PGHD results to PGHD users may also encounter the same issue. -Participation of PGHD users not consistently sought in assessment and evaluation of PGHD technologies.	**PGHD users:** -Consider self-assessing outcomes of PGHD use, to understand how certain health technologies can affect self-management. -Request option to receive any and all relevant health data produced from HITs.
	Clinicians: -PROMs-PGHD could assist in choosing appropriate health technology.	**Clinicians:** -More studies needed to contribute to evidence base of PGHD effects.	**Clinicians:** -Include PRMs-PGHD data routinely as part of patient record. -Consider PGHD utilisation effects in evaluation of PGHD technologies. -Support efforts to build evidence base of PGHD.
	Health Informatics Research Community: -Systematic, detailed guide to develop other specialised heuristics for other technology types; and for PGHD-enablement,	**Health Informatics Research Community:** -Need to consider socio-technical context of PGHD technologies. -Lack of attention to PGHD limited the data collected	**Health Informatics Research Community:** -Consider PGHD and PGHD access in system design, implementation, and evaluation. -Consider field testing the newly developed heuristics for PGHD enablement.

	other health conditions. -Value of considering socio-technical context of HITs in their design and evaluation.	from literature on PGHD utilisation.	
	HIT Developers and Designers: -Understanding of PGHD utilisation effects could improve design of HITs. -Guide technology designers in developing PGHD technologies that are more inclusive of perspectives of PGHD users. -Varying perspectives about health between patients and clinicians emphasises importance of enabling the people or cohort of interest to participate in evaluation of digital health services. -Value of considering socio-technical context of HITs	**HIT Developers and Designers:** -Field of simulated rehabilitation for stroke is still in infancy. -Insufficient attention given to PGHD utilisation effects. -Participation of PGHD users not consistently sought in assessment and evaluation of PGHD technologies.	**HIT Developers and Designers:** -Develop and use PRMs-PGHD to document and evaluate effects of PGHD utilisation. -Ensure to use patient-centred design when developing PGHD technologies. -Ensure that the value of PGHD user experience is recognised in understanding the impact of PGHD utilisation. This has relevance to success of patient self-management strategies; and design and evaluation of PGHD technology. -Consider how the benefits of PGHD could be designed into the HIT, e.g., through the use of the heuristics for PGHD enablement. Heuristics could ensure understanding of complexities of care incorporated in HIT design and implementation.

	in their design and evaluation. -Design heuristics for PGHD enablement could contribute to selection and implementation of PGHD programmes, complementing other PGHD evaluation methods.		

Appendix K. Simulated Stroke Rehabilitation Network Tests in a Low-Resource Environment

Any figures and tables that appear in this appendix have NOT been renumbered for this thesis.

Low-resource environments may have limited network coverage and speed. As discussed in Chapter 7, Section 7.3.2, the initial data collection site for this thesis was in Zamboanga City, Philippines. To test the feasibility of using Jintronix in Zamboanga, the network demands or consumption of 13 Jintronix games were recorded and averaged. It was then compared to the recorded and averaged mobile speeds in Zamboanga city. All the games of Jintronix was tested in the author's home relatively close to the city centre.

The network demands of Jintronix was tested in the Academic Centre of Newman College within the University of Melbourne on November 2017. The PC where Jintronix was installed was connected via Ethernet cable to a dedicated LAN port, so the IT manager could record the network traffic. No other applications were running in the background during the tests. 13 Jintronix games were tested three times. The exact time each test began and ended were recorded, and there was a gap of at least five minutes before another test, even for the same game, was conducted. After all the tests were conducted, the IT manager sent the author the time-stamped network traffic of the dedicated LAN port for the duration of the tests. The author then noted the network traffic for the beginning and end times for each test. Notably, there were usually no network traffic during the times the games were not played, except for one or two spikes. These spikes were not included in the analysis.

Table 1 below lists the 13 games, the network traffic or consumption for each test, and the average.

Table 1. Network traffic/consumption for each test.

Game category	Game title	Test 1 Network Traffic (in MB)	Test 2	Test 3	Average Network Traffic (in MB)	Standard Deviation
Sitting_Moderate_Balance-Reaching	5_HITTING BALLS_Reaching all	0.892652512	0.964373589	1.023409843	0.960145315	0.065481132

	directions + obstacles_Advanced					
Sitting_Moderate_Balance-Reaching	2_APPLE CATCHING_Bilateral Coordination_Medium	1.816106796	0.418359756	0.418183327	0.884216626	0.807040565
Sitting_Moderate_Weight Transfer	2_SOCCER_Foot eye coordination + Reaction time_Beginner	0.438030243	0.409552574	1.232011795	0.693198204	0.466843452
Sitting_Moderate_Balance-Reaching	4_PLANTING TOMATOES_Lateral Reaching_Medium	0.681188583	0.656320572	0.538041115	0.625183423	0.076484906
Standing_Moderate_Balance-Weight Transfer	2_ROUND CIRCLE NUMBERS TOUCH_Stepping_Medium	0.54706192	0.540966988	0.538132668	0.542053859	0.004562768
Standing_Independent_Balance weight Transfer	1_NUMBERS CIRCLES PRESS_Stepping+Weight shift all directions_Advanced	0.537220955	0.547730446	0.537293434	0.540748278	0.006046843
Sitting_Moderate_Weight Transfer	3_MOTORCYCLE_Lateral Trunk Flexion_Beginner	0.532175064	0.543981552	0.40613842	0.494098345	0.076403924
Sitting_Moderate_Balance-Reaching	1_FISH_Controlled Movement_Beginner	0.70775795	0.290813446	0.419529915	0.472700437	0.213497092
Sitting_Moderate_Balance-Reaching	3_BALLOON CLAPPING_Bilateral Coordination_Beginner	0.414106369	0.42166996	0.418087959	0.417954763	0.003783554
Sitting_Moderate_Cognition	1_MATCHING SHAPES_Advanced	0.412561417	0.404360771	0.432645798	0.416522662	0.014552638

Standing_Moderate_Gait	1_STEPPING MOLES_Ambulating in all directions_Advanced	0.273884773	0.411870956	0.408892632	0.364882787	0.07882066
Sitting_Moderate_Weight Transfer	4_BALL MAZE_Trunk flexion_Medium	0.13155365	0.412393557	0.279788971	0.27457873	0.140492438
Sitting_Moderate_Weight Transfer	1_FOOTBALL_Foot eye coordination_Beginner	0.188542366	0.276006699	0.283271179	0.249273618	0.052720102
TOTAL					**0.533504388**	**0.154363852**

As the tests show, a Jintronix game session requires an average of about 0.53mb (SD: 0.15) of data. This is reasonably low, and it is assumed that this is because Jintronix only requires a network connection to send the results of each game session. The author had tried to set up an interview with Jintronix personnel to confirm this among other things but was unsuccessful.

The author went home to Zamboanga City, Philippines, a few weeks after the tests were conducted. In January 2018, all Jintronix games were tested at least three times in the author's home using a mobile connection that was used as a wireless hotspot for the PC to connect. The author's home does not have a wired Wi-Fi connection.

Unsurprisingly, there were no documented issues when using a 4G connection, given that the upload and download speeds were generally higher than the data transfer of Jintronix games. Table 2 below lists the recorded 4G upload and download speeds during the tests using Speedtest by Ookla©, which were taken at the beginning and in the middle of a game session.

Table 2. Recorded 4G download and upload speeds during the test sessions.

Date	Download Speed (Mbps)	Upload Speed (Mbps)
10/1/18	10.736	5.603
10/1/18	15.469	3.113
10/1/18	10.894	7.548
10/1/18	12.599	6.527
10/1/18	9.257	10.027
10/1/18	13.338	6.517
10/1/18	9.277	0.162
10/1/18	6.076	6.74
10/1/18	8.946	1.733
10/1/18	11.202	4.295
10/1/18	6.541	9.4
10/1/18	6.614	1.248
10/1/18	1.129	3.022
10/1/18	11.722	4.975
10/1/18	14.906	4.758
10/1/18	7.333	8.691
10/1/18	12.546	18.111
10/1/18	14.454	6.174
9/1/18	18.148	11.203
9/1/18	15.071	9.432
9/1/18	16.67	11.688
9/1/18	11.89	5.51
9/1/18	13.43	14.952
9/1/18	10.192	8.709
9/1/18	15.456	8.484
9/1/18	9.791	4.337
9/1/18	13.78	14.344
9/1/18	4.996	6.814
9/1/18	14.011	14.115

9/1/18	8.029	7.005
9/1/18	13.704	8.128
9/1/18	4.438	11.995
9/1/18	15.851	7.797
9/1/18	12.996	13.156
9/1/18	11.715	11.623
9/1/18	1.198	0.101
9/1/18	18.388	7.819
AVERAGE	**5.65469863**	**3.91583562**

The author then proceeded to test all of Jintronix games using only a 3G mobile connection. While most of the time the games would still play, several issues were encountered:

- Jintronix would log the user out after a game due to connection issues. However, the game results were still recorded after logging back in and viewing the results.
- Some games would take a long time to load or seem to freeze until the mouse is clicked.
- Jintronix would issue an error message and refuse to continue, as Figure 1 below shows.

Figure 1. Jintronix error message due to weak network connection.



These issues are likely caused by the slow network speeds of a 3G connection. Table 3 below lists the recorded 3G upload and download speeds during the tests using Speedtest by Ookla©, which were taken at the beginning and in the middle of a game session.

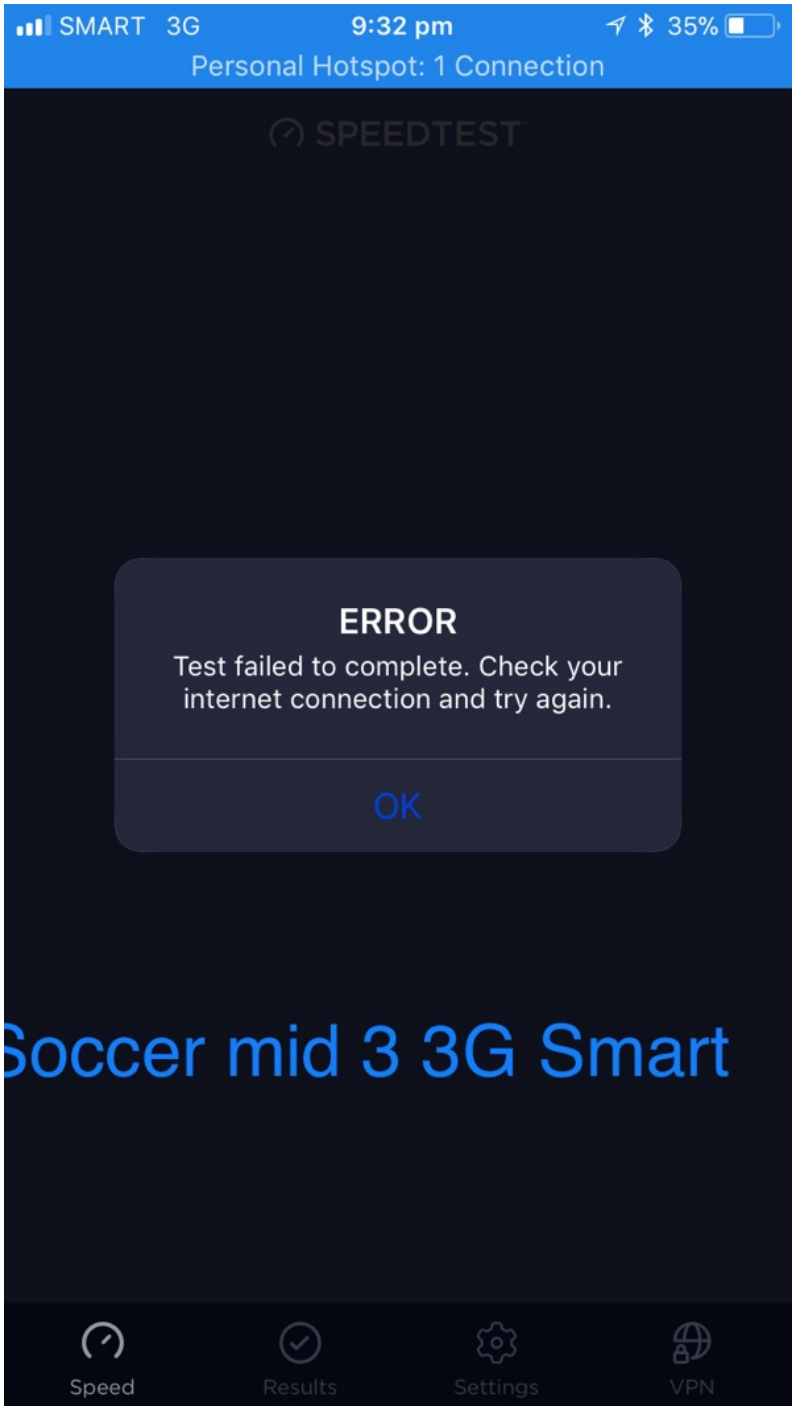
Table 3. Recorded 3G download and upload speeds during the test sessions.

Date	Download Speed (Mbps)	Upload Speed (Mbps)
11/1/18	0.383	0
11/1/18	0.304	0.281
11/1/18	0.415	0
11/1/18	0.2	0
10/1/18	0.929	0.159
10/1/18	0.735	0.399
10/1/18	0.643	0.109
10/1/18	0.352	0
10/1/18	0.58	0.119
10/1/18	0.45	0.935
10/1/18	0.442	0.555
10/1/18	3.32	0.985
10/1/18	0.913	1.673
10/1/18	0.053	0.28
10/1/18	0.434	0
10/1/18	0.362	0
10/1/18	0.517	0
10/1/18	0.407	0
10/1/18	0.381	0
10/1/18	0.033	0
10/1/18	0.448	0
10/1/18	1.266	0
10/1/18	0.206	0
10/1/18	0.263	0
10/1/18	0.004	0.026

10/1/18	0.268	0.023
10/1/18	0.367	0.084
AVERAGE	**0.27688679**	**0.10618868**

In many instances, the 3G upload speed was recorded as 0, i.e., no data could be sent. There were also a number of times that the Speedtest app could not even establish a connection, as Figure 2 below shows.

Figure 2. Speedtest app failing to establish a connection due to weak 3G network connection.



Appendix K: Simulated Stroke Rehabilitation Network Tests in a Low-Resource Environment

These tests show that while Jintronix is a feasible alternative to stroke rehabilitation for areas with a 4G connection in the Philippines, issues can be encountered where 4G is not available. Unfortunately, 4G availability is quite limited in Zamboanga City [107], as shown in Figure 3.

Figure 3. Network coverage in Zamboanga City, Philippines.

