Research article

Views of individuals with spinal cord injury on the use of wearable cameras to monitor upper limb function in the home and community

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Objective: Hand function impairment after cervical spinal cord injury (SCI) can significantly reduce independence. Unlike current hand function assessments, wearable camera systems could potentially measure functional hand usage at home, and thus benefit the development of neurorehabilitation strategies. The objective of this study was to understand the views of individuals with SCI on the use of wearable cameras to track neurorehabilitation progress and outcomes in the community.
Design: Questionnaires.
Setting: Home simulation laboratory.
Participants: Fifteen individuals with cervical SCI.
Outcome Measures: After using wearable cameras in the simulated home environment, participants completed custom questionnaires, comprising open-ended and structured questions.
Results: Participants showed relatively low concerns related to data confidentiality when first-person videos are used by clinicians (1.93 ± 1.28 on a 5-point Likert scale) or researchers (2.00 ± 1.31). Storing only automatically extracted metrics reduced privacy concerns. Though participants reported moderate privacy concerns (2.53 ± 1.51) about wearing a camera in daily life due to certain sensitive situations (e.g. washrooms), they felt that information about their hand usage at home is useful for researchers (4.73 ± 0.59), clinicians (4.47 ± 0.83), and themselves (4.40 ± 0.83). Participants found the system moderately comfortable (3.27 ± 1.44), but expressed low desire to use it frequently (2.87 ± 1.36).
Conclusion: Despite some privacy and comfort concerns, participants believed that the information obtained would be useful. With appropriate strategies to minimize the data stored and recording duration, wearable cameras can be a well-accepted tool to track function in the home and community after SCI.

KEYWORDS: Wearable technology, Egocentric cameras, Upper limb, Outcome measures, Community-based functional assessment, Surveys and questionnaires, Privacy, Spinal cord injury

Introduction

The impairment of arm and hand function is a major factor in the loss of independence after cervical spinal cord injuries (SCI). Even modest amounts of motor recovery in the upper limb can translate into functional benefits,[1] making upper limb rehabilitation a key priority after cervical SCI. In order to develop effective interventions for restoring upper limb function, it is important to have the means to measure function as it changes over time. A number of clinical assessments currently exist for this purpose.[2–7] However, assessments that must be administered in person by a clinician or investigator have an important limitation, namely that they cannot directly measure a person's use of their upper limb in their home and community. While instruments do exist that seek to quantify a person's independence in their daily life (e.g. the Spinal Cord Independence Measure III – SCIM[8]), they often rely on self-report, and do not distinguish between what a person is able to do and what they actually do on a

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daily basis. The importance of monitoring hand function at home is highlighted for example in a study by Van Den Berg-Emons *et al*., which found that rehabilitation physicians underestimated the amount of inactivity in individuals with chronic physical conditions, including SCI.[9] There is therefore a gap between current assessment tools and the ultimate goal of the rehabilitation process, which is independence and high quality of life in the community. Methods to directly measure use of the upper limb in the home would therefore be of great benefit in the development of new neurorehabilitation strategies.

Wearable technologies have recently undergone rapid development, and offer a promising avenue for extending neurorehabilitation assessments beyond the clinic. Notably, recent studies in the SCI population have used inertial measurement units (IMUs) to quantify wheeling actions[10] and the laterality of the injury (dominant use of one hand over the other),[11] and shown that the activity measures from these devices are related to injury characteristics and independence.[12] Similarly, in the stroke literature, accelerometers have been used to compare the amount of movement between the impaired and unimpaired arms in hemi-paretic individuals.[13] A drawback of these devices is that they focus on arm movements, and provide little information about hand grasps and patterning. Magnetometry can supplement wrist-worn accelerometry with some finger tracking,[14] however the relationship between the amount of finger, wrist and arm movements and functional abilities is complex and requires further investigation.[15] In order to obtain an accurate picture of upper limb use in the community after cervical SCI, there is still a need for wearable sensors capable of describing how the hand is being used in a wide range of functional activities.

Wearable cameras that record video from the user's perspective ("egocentric video") offer a very rich source of data about an individual's interactions with their environments, and therefore may be of great value in tracking functional recovery in the home and community after SCI. Techniques for the automated analysis of egocentric video have been increasing rapidly,[16] as have investigations of their applications in healthcare.[17] Wearable cameras are being explored in the context of upper limb rehabilitation after SCI,[18,19] because they may provide a means to capture information about functional use of the hand that cannot easily be obtained through other wearable technologies. On the other hand, a potential obstacle involving this technology is the privacy and confidentiality concerns that may be engendered by video recordings obtained in the home or community.

The privacy implications of wearable cameras have been previously discussed in the context of lifelogging applications, where pictures taken at regular intervals can be used to document a person's daily activities. Lifelogging may be related to social media use by able-bodied individuals, and has also been investigated as a strategy to ease recall in individuals with dementia or memory issues.[20,21] From a social media perspective, studies have collected views on how sharing images from wearable cameras might impact the privacy of the users as well as those of bystanders.[22,23] For healthcare applications, the discussion has focused on the trade-offs between privacy challenges and the benefits of the information provided by this technology.[24,25] Kelly and colleagues proposed an ethical framework to help guide health researchers in their use of wearable cameras.[26] Some recurring privacy concerns include: recordings of bystanders,[22,25] washroom and personal care activities,[22,24,26] and areas where recording is not permitted (e.g. workplace).[22,26] In the present study, we investigated the views of individuals with SCI on the use of wearable cameras at home as a tool to track functional progress and outcomes in the community after SCI, both in research and in clinical practice.

Methods

Study Participants

Fifteen participants with spinal cord injuries participated in this study. The inclusion criteria were to have a neurological level of injury between C2 and T1 according to the International Standards for the Neurological Classification of Spinal Cord Injury (ISNCSCI), with an ASIA Impairment Scale (AIS) grade between A and D. No restrictions were placed on the amount of time since injury, or on the etiology of the injury (traumatic or non-traumatic). Participants had to be able to communicate in English. Participants were excluded if they had wrist or hand deformities or injuries, were unable to sit upright for the duration of the study session (approximately 2 hours), or were not able to perform any of the tasks in the experiments (see below), for example as a result of severe spasticity.

Study Procedures

Participants attended a single experimental session in which they were asked to perform 35 upper limb activities of daily living (ADLs) in a home simulation laboratory. These activities were performed in 5 different locations in the home simulation laboratory: kitchen (e.g. picking up a sponge, pouring water), washroom (e.g. washing hands, replacing toilet paper), living room (e.g. opening a newspaper, using a remote

control), bedroom (e.g. opening doors, hanging/folding clothes), and in the front of the house (e.g. picking up a tennis ball). Before the session, the Upper Extremity Motor Score (UEMS) component of the International Standards for the Neurological Classification of SCI (ISNCSCI)[27] was measured for the participant's dominant hand. While performing the activities, participants wore 3 wearable cameras. One camera was mounted on the forehead using a specialized strap (GoPro Hero 4, GoPro, Inc., San Mateo, CA, USA), while the other two cameras were worn over the ears (Looxcie 2, Looxcie, Inc., Sunnyvale, CA, USA). The purpose of these experiments was to build a dataset with which to develop algorithms for the automated analysis of hand use in egocentric video. The results of these algorithms will be reported elsewhere. Once the participants had completed all of the object manipulation tasks, questionnaires were administered to collect their views on the use of wearable cameras in neurorehabilitation, which is the focus of the present study. Participation in the recording experiments provided participants with personal experience using wearable cameras, allowing them to provide informed answers to the questionnaire. All study procedures were approved by the Research Ethics Board of the University Health Network.

The questionnaires were constructed to explore three main topics relating to the use of wearable cameras: privacy, perceived usefulness of having access to the information obtained, and usability. Each section consisted of structured questions on a 5-point Likert scale, as well as an opportunity for open-ended comments. The full text of the questions is provided in the Appendix. The privacy questions focused on concerns over sharing the information from the wearable cameras with different stakeholder groups (clinicians, researchers), as well as the distinction between sharing raw videos and sharing only metrics automatically extracted from these videos (i.e. measure such as frequency of hand use that would be extracted by a video processing algorithm, without the videos being watched by a human). The second set of questions focused on how useful the participants felt that the information would be for different stakeholder groups (clinicians, researchers, family members, and participants themselves). Lastly, the usability questions focused on factors that might encourage or dissuade participants from using the system. These three categories (privacy, usefulness and usability) were chosen because it is anticipated that any wearable technology that fails to meet one of these requirements is unlikely to be translated into practice.

Analysis

Descriptive statistics (mean, standard deviation, and distribution) were used to summarize the results of the structured questions. The information obtained through the semi-structured interview questions was not subjected to a formal qualitative analysis because of the small quantity of data (most participants provided no more than 2–3 sentences per question), but participant comments are reported to gain insights into factors that might influence the adoption of this technology.

Results

The demographic and injury characteristics of the participants are provided in Table 1. The summary of the responses for all Likert scale questions is shown in Table 2, along with the associated means and standard deviations.

The response distributions to questions regarding privacy are shown in Fig. 1. Participants expressed relatively low levels of concern about egocentric video being stored and used by clinicians (mean ± standard deviation of 1.93 ± 1.28), or by researchers (2.00 ± 1.31). The concept of storing only automatically extracted metrics, rather than the videos themselves, reduced these concerns further (1.27 ± 0.59 for use by clinicians and 1.20 ± 0.56 for use by researchers). This decrease was found to be significant, using a Wilcoxon signed-rank test ($S = -14$, $n = 15$, $p = 0.0156$ and $S = -14$, $n = 15$, $P = 0.0156$, respectively). Nonetheless, the participants expressed moderate concerns about being asked to wear a camera in their daily life (2.53 ± 1.51). In their open-ended comments, participants raised some concerns about recordings of bystanders ($n = 3$), washroom and personal care activities ($n = 2$), or the workplace and computer screens ($n = 1$). Conversely, participants also expressed trust that the information would be used appropriately ($n = 1$), saw benefits for research and teaching ($n = 1$), and stated that they would be willing to use the technology if it could help others with SCI ($n = 1$).

The responses to questions regarding the usefulness of the information collected are summarized in Fig. 2. Overall, participants felt that having information about hand use at home was very useful (4.40 ± 0.83). They felt that the information would be most useful to researchers (4.73 ± 0.59), and highly relevant to clinicians (4.47 ± 0.83), though somewhat less to family members (3.73 ± 1.16). The participants also felt that getting access to this information for their own use would be beneficial (4.33 ± 0.90). In this category of questions, some participants' open-ended comments

Table 1 Participant Demographics and Injury Characteristics

Participant	Age (Years)	Sex	Level of injury	AIS grade	Traumatic (T) / Non-traumatic (NT)	Time since injury (Years)	Upper Extremity Motor Score (UEMS)
1	63	Male	C5–C6	A*	T	8	15
2	58	Male	C3–C5	D	T	1	24
3	51	Male	C4–C6	D	T	1	22
4	59	Male	C2–C6	D	T	1	20
5	55	Male	C7–T1	C/D*	T	4	18
6	56	Male	C2–C7	D	T	2	19
7	56	Male	C5–C6	D	T	2	16
8	20	Male	C5	B	T	3	9
9	58	Male	C5	C/D*	T	32	13
10	44	Female	C6–C7	A	T	20	20
11	34	Male	C5–C6	C	T	5	21
12	40	Female	C2–T1	D	NT	2	20
13	70	Male	C4–C6	C	T	1	24
14	42	Male	C4–C6	B	T	0.4	16
15	56	Male	C1–C6	D	NT	0.3	23
Mean	50.8 (± 12.7)	n/a	n/a	n/a	n/a	5.5 (± 8.9)	18.7 (± 4.2)

*These AIS grades are based on self-report.

Table 2 Summary of the responses

Privacy of information	1 Not Concerned	2	3	4	5 Very Concerned	Mean (S.D.)
Video stored for use by clinicians	8 (53.3%)	3 (20.0%)	2 (13.3%)	1 (6.7%)	1 (6.7%)	1.93 (± 1.28)
Video stored for use by researchers	8 (53.3%)	2 (13.3%)	3 (20.0%)	1 (6.7%)	1 (6.7%)	2.00 (± 1.31)
Extracted metrics only stored for use by clinicians	12 (80.0%)	2 (13.3%)	1 (6.7%)	0 (0%)	0 (0%)	1.27 (± 0.59)
Extracted metrics only stored for use by researchers	13 (86.7%)	1 (6.7%)	1 (6.7%)	0 (0%)	0 (0%)	1.20 (± 0.56)
Concern about wearing a first person camera in daily life (including in home and public)	6 (40%)	1 (6.7%)	4 (26.7%)	2 (13.3%)	2 (13.3%)	2.53 (± 1.51)
Usefulness of the information	**1 Strongly Disagree**	**2**	**3**	**4**	**5 Strongly Agree**	**Mean (S.D.)**
Usefulness of Information about hand usage at home	0 (0%)	0 (0%)	3 (20.0%)	3 (20.0%)	9 (60%)	4.40 (± 0.83)
Usefulness of providing information to clinicians	0 (0%)	0 (0%)	3 (20.0%)	2 (13.3%)	10 (66.7%)	4.47 (± 0.83)
Usefulness of providing information to researchers	0 (0%)	0 (0%)	1 (6.7%)	2 (13.3%)	12 (80.0%)	4.73 (± 0.59)
Usefulness of providing information to family members	0 (0%)	3 (20.0%)	3 (20.0%)	4 (26.7%)	5 (33.3%)	3.73 (± 1.16)
Usefulness for you of having summary of measure of hand use	0 (0%)	0 (0%)	4 (26.7%)	2 (13.3%)	9 (60.0%)	4.33 (± 0.90)
Usability of the technology	**1 Strongly Disagree**	**2**	**3**	**4**	**5 Strongly Agree**	**Mean (S.D.)**
Would like to use the system frequently	3 (20.0%)	3 (20.0%)	4 (26.7%)	3 (20.0%)	2 (13.3%)	2.87 (± 1.36)
System is comfortable	3 (20.0%)	1 (6.7%)	3 (20.0%)	5 (33.3%)	3 (20.0%)	3.27 (± 1.44)
Interested in wearable technology	1 (6.7%)	0 (0%)	1 (6.7%)	5 (33.3%)	8 (53.3%)	4.27 (+ 1.10)

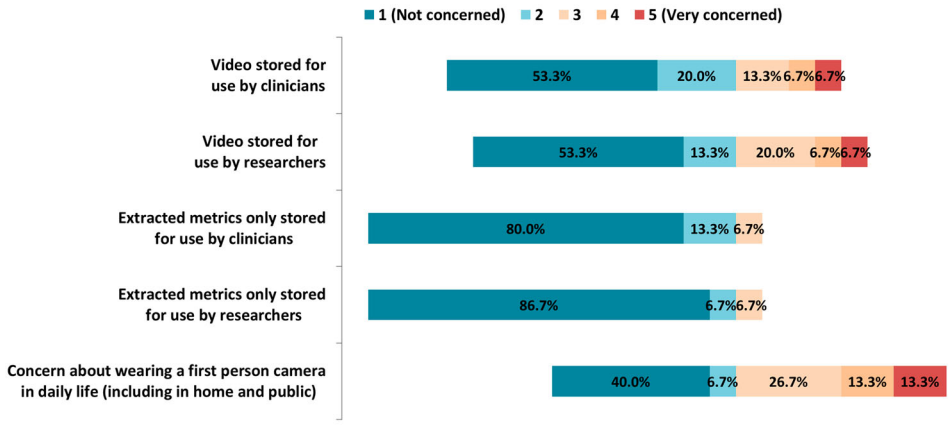

Figure 1 Distribution of answers to questions pertaining to privacy of information.

indicated that they saw value in technology that could help them track their own improvements (n = 3), or get feedback from clinicians or researchers (n = 2). One participant expressed some doubt about the value to clinicians because they felt that doctors' observations were generally different from their own perceived experience. Others thought that the information would be primarily useful to clinicians and researchers, more so than to the participant (n = 2). Some participants (n = 2) expressed a concern that the system's usefulness was limited since it was not capturing all of the activities that they had difficulties with (e.g. buttons and zippers, shoelaces, door locks, certain light switches, dressing, wheeling, driving and emptying the bladder). The responses to the request for "other comments" generally re-iterated the points raised above. These included positive comments on the potential benefits of the technology (n = 2).

The responses to questions regarding usability are summarized in Fig. 3. Participants expressed an interest in wearable technology (4.27 ± 1.10), but found the system only moderately comfortable (3.27 ± 1.44) and were not unanimous in their desire to use such technology (2.87 ± 1.36). We further asked about glove use, which could have an impact on hand detection and segmentation algorithms in egocentric videos. Eight participants stated that they did not use gloves, 1 participant used gloves "all the time," 1 participant used gloves when out but not when at home, and the remaining 5 participants listed specific activities that they used gloves for, but estimated that these activities amounted to approximately 1 hour per day or less. In the open-ended comments for this section, several participants expressed dissatisfaction with the comfort of the current setup (n = 5). It is worth noting in interpreting these results that the participants were wearing 3 wearable cameras for the purposes of this study (2 over the ears and one on a headband), while a system ultimately deployed at home would consist of a single device. One participant again went back to some of the privacy considerations, including use in the washroom and in the presence of others. Another individual expressed concern about using the system in public, and drew a contrast in this respect with other wearable

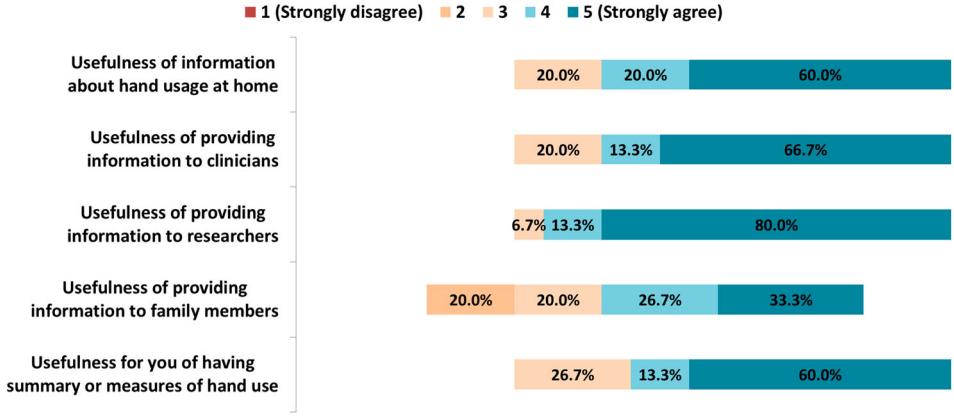

Figure 2 Distribution of answers to questions pertaining to the usefulness of the information.

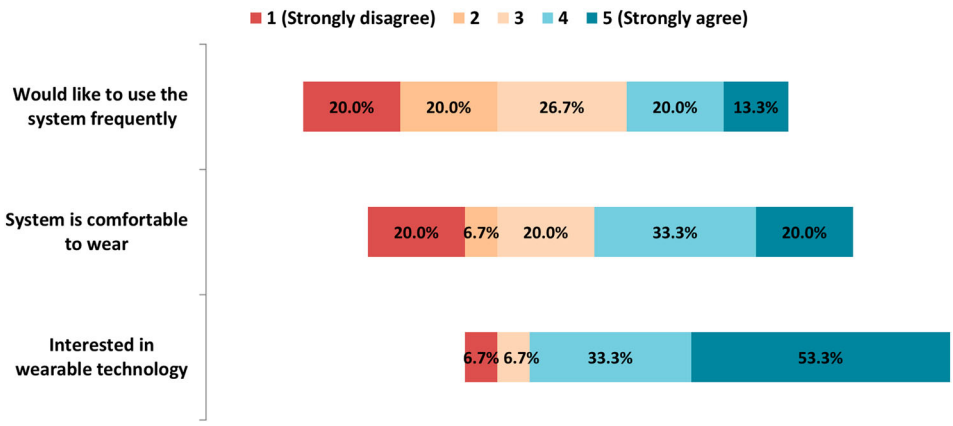

Figure 3 Distribution of answers to questions pertaining to the usability of the technology.

technology such as the Fitbit. Participants explained that while they would not necessarily wear the system over a long period of time, they would be willing to use it periodically or over a fixed time period for a few hours to get feedback (n = 2). Similarly, in "other comments," participants also express concerns that wearing a camera felt "weird" even when not recording, coupled with the observation that monitoring for an hour or two at a time would be acceptable (n = 1). A participant also suggested that the camera be incorporated into glasses or wardrobe to improve the usability and quality of the output (n = 1).

Discussion

Currently there is a need for a method to measure upper extremity function in individuals with cervical SCI at home or in the community. Unlike other wearable sensors, such as IMUs, a wearable camera system has the potential to capture more detailed information regarding functional hand usage. However, recording videos at home or in the community raises privacy issues. For this reason, understanding how individuals with SCI view this technology is crucial to adoption.

In this study, our questionnaire revealed that participants have minimal concerns regarding privacy for recordings of first-person video when intended for clinicians and researchers, and felt that the information would be of benefit to these groups as well as to themselves. The levels of concern were significantly reduced when the data stored is limited to automatically extracted metrics. This finding reveals the importance of real-time processing, in which an algorithm would extract the relevant metrics at the time of recording to avoid storing the full video footage. Nonetheless, certain scenarios were seen as problematic from a privacy point of view, with the majority of concerns stemming from recordings in private environments (e.g. in the washroom, during personal care activities, or with computers displaying private information), recording in areas where it is not permitted (e.g. workplaces or airports), and recordings of bystanders. These concerns are similar to those reported for other wearable camera studies.[22,24–26]

Depending on an individual's situation, these concerns can be addressed through strategic planning of when and where to record. In rehabilitation applications, it is likely that clinically useful information could be obtained by recording only a few hours a week of activity; continuous recordings at all times would not be necessary, making it easier to avoid problematic situations. This approach is in line with participants' responses in this study. They expressed an interest in wearable technology, but were not unanimous in their desire to use wearable camera technology frequently. This stance mostly stems from the aforementioned privacy concerns and the system's comfort. Participants reported that they are willing to use the system periodically or over a fixed time period for a few hours each day to get feedback on their hand usage. When using a wearable camera system in the context of rehabilitation, our results therefore suggest that researchers and clinicians should consult with participants or patients to determine when and where they will use the system. Since participants found the system only moderately comfortable and did not wish to wear it frequently, it is inadvisable to expect an individual to use the wearable camera all of the time. If possible, and if fully automated video processing is not feasible, then use should be avoided in the washroom, during personal care activities, in workplaces, or in front of a computer to respect the individual's privacy. The optimal details of use will vary depending on the study objective or the rehabilitation goals of a given patient.

Additional strategies to minimize privacy concerns include focusing recordings on the home environment, where the participant or patient could obtain permission for recording from individuals likely to appear in the video (e.g. caregivers or family members). A common theme across different wearable technologies where images or video are recorded is the ability of the wearer to stop recording.[13,22,26] The ability to control what is recorded addresses a number of privacy concerns (privacy of bystanders, privacy in private environments or areas where recording is not permitted) and is an important feature in wearable technology systems.

This study's main limitation is the constraints of the experimental setup (performance of a predetermined list of ADLs in a home simulation laboratory). Multiple participants raised concerns that not all activities that they find difficult were included. These comments may have been partially driven by which activities were included in the experimental session, rather than by what tasks the system could in fact monitor in the community. Additional qualitative research will be required in the future to capture the views of individuals with SCI who have had the opportunity to use the wearable cameras in more naturalistic settings in the home and community.

An additional limitation of the study is the low number of younger participants. This is particularly concerning as the demographics most at risk for SCI are adolescents (15–19 years), younger adults (20–29 years) and older adults (60+ years).[28] While this study captures the perspective of older adults, more input is needed from the younger population.

Another limitation is the cumbersome nature of the 3 wearable cameras. Ultimately, the system deployed at home would consist of a single device. The additional cameras were temporarily used to support development of automatic hand function detection algorithms. The form factor and placement of the camera may change when the system is deployed at home. The views on comfort recorded here may therefore not be applicable to the final system.

Conclusion

Wearable camera systems have the potential to capture functional hand usage of individuals with cervical SCI at home and in the community. However, these recordings may conceivably raise privacy concerns. This study revealed that participants do not have major concerns about privacy when the first-person video data is intended for use by clinicians and researchers, and that they see value in the technology. These findings suggest that individuals with SCI are open to the use of wearable camera as clinical and research tools. Nevertheless, concerns remain regarding recordings in sensitive environments or situations as well as about system comfort. Appropriate strategies will need to be developed to mitigate these concerns. Researchers and clinicians should allow the user to pause recordings while using the system, limit data storage, minimize the duration of recording, and optimize the system's comfort. Further research focusing on feedback after individuals use the wearable camera in their own homes and communities may provide more insight into these concerns.

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Appendix

The questions that were administered to the participants are transcribed below.

Privacy

Imagine that you are asked to use the wearable camera *at home* for a few hours each day, for a few days, for the purpose of evaluating your level of hand function. The following questions explore concerns regarding privacy and confidentiality for yourself and the people around you in your home or community. (For questions 1–5: 1: Not concerned; 5: Very concerned)

1 How concerned are you about first person video of your daily life being stored, if this data will be used only by a *clinician* (for example your doctor or physical or occupational therapist)?
2 How concerned are you about first person video of your daily life being stored, if this data will be used by *researchers* (for example during a research study to test a new therapy)?
3 How concerned are you about using a wearable camera system that does not store the recorded video, but uses a computer algorithm to analyze the video and only stores the output of that algorithm (for example, how many times today did you independently perform tasks using your hands)? Consider first the case where this data will be used only by a *clinician* (for example your doctor or physical or occupational therapist).
4 How concerned are you about using a wearable camera system that does not store the recorded video, but uses a computer algorithm to analyse the video and only stores the output of that algorithm, considering now the case where this data will be used by researchers?
5 In general, how concerned are you about wearing a first person camera in daily life (including in home and public)?
6 Please write any additional comments or concerns you may have regarding your privacy in terms of clinicians and researchers using the information from a wearable camera.

Value of access to information

Imagine that a wearable system capable of capturing information about hand use is developed. The following questions focus on how useful you think this information might be (For questions 1–5: 1: Strongly disagree; 5: Strongly agree).

1 I think it is useful to know information about hand usage at home
2 It would be useful to allow your *clinician* to access information regarding your hand usage at home

3 It would be useful to allow *researchers* to access information regarding your hand usage at home.
4 It would be useful to allow *family members* to access information regarding your hand usage at home.
5 It would be useful to you to have summaries or measures of your hand usage at home.
6 Please write any additional comments or concerns you may have regarding the usefulness of information about hand usage at home, and who could benefit from this information.

Usability

For the system that you wore in the experiment, imagine you were asked to wear the system for a week for up to 5 hours each day. The following questions explore the usability of the system (For questions 1–3: 1: Strongly disagree; 5: Strongly agree).

1 I think that I would like to use this system frequently.
2 I feel the system is comfortable to wear.
3 I am interested in wearable technology.
4 Do you wear gloves for assisting in upper limb activity at home and out in the community, and if so, how many hours a day to you wear gloves?
5 Please write any additional comments or concerns you may have regarding the usability of the system.

Other comments

Please use the space below for any other comments that you may have on the use of wearable cameras as a way to measure function and independence at home following rehabilitation.