BMJ Open Is a novel digital system for arm and hand rehabilitation suitable for stroke survivors? A qualitative process evaluation of OnTrack

Elizabeth Taylor , ¹ Gianpaolo Fusari , ² Ara Darzi, ² Fiona Jones

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¹Centre for Allied Health, St George's University, London, UK ²Helix Centre, Imperial College London and the Royal College of Art London IIK ³Population Health Research

Institute, St George's University,

Correspondence to

London, UK

Dr Elizabeth Taylor; etaylor@sgul.ac.uk

ABSTRACT

Objectives and design National guidelines emphasise the need to enhance arm and hand recovery poststroke. OnTrack is a 12-week package aiming to address this need. Feasibility was evaluated in a single-arm feasibility study (reported separately). This paper presents findings from a nested process evaluation. The objectives were to explore users' experiences of OnTrack and fidelity of delivery, in order to inform a definitive trial of effectiveness and future delivery.

Setting Participants were interviewed in a range of settings in hospital, home or via telephone, at the end of their intervention cycle. Session observations for a selection of coaching sessions were carried out in person at home or remotely, post-COVID-19.

Participants Eleven participants who completed the intervention following a stroke were interviewed. Seven coaching sessions were observed.

Intervention This process evaluation was part of a larger feasibility study of OnTrack, which involves setting movement targets and monitoring activity using a tracker on the wrist, motivational messaging via a Smartphone and self-management coaching. Preliminary analysis of data collected was conducted with a public and patient involvement group formed of stroke survivors. This informed changes in intervention delivery.

Results Participants reported finding the OnTrack programme beneficial, with the coaching role seen as particularly important. Participants found activity tracking motivating, but some noted discrepancies between tracked movement and what they considered useful activity. Motivational messages were sometimes irritating. Most felt ready to sustain their own activity practice at the end of the programme.

Conclusions This process evaluation supported initial theoretical assumptions that OnTrack would enable activity practice through the use of remote monitoring. There was a strong emphasis on the coaching role as a mechanism of impact supporting the technological intervention. These findings will inform the next stages of delivery in a definitive trial.

Trial registration number NCT03944486.

INTRODUCTION

Globally, each year, over 15 people experience a stroke, with 5 million

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The combination of interviews and observations enabled researchers to evaluate the fidelity of the study delivery, that is, whether it was delivered as intended.
- ⇒ Members of the public and patient involvement group who had experienced a stroke were involved in interview and observation data analysis after the first phase of the study, this influenced changes made in coaching for the second phase.
- ⇒ Face-to-face coaching sessions were replaced with online or telephone sessions due to COVID-19 restrictions.
- ⇒ Learning about the skills required by coaches to support participant engagement and intervention delivery is an important factor for future research.
- ⇒ Participants with stroke were supported to increase levels of hand and arm activity through the use of OnTrack and this will add to theoretical assumptions necessary to evaluate the intervention in a larger definitive trial.

experiencing permanent disability as a result. The economic impact of stroke is high, with an estimated cost of £26 billion in the UK every year.² Of the 1.2 million people who have a stroke every year in the UK, 450 000 are affected by arm and hand weakness.²

Dose-intensive repetitive rehabilitation and functional task practice are recommended for regaining ability after stroke, but it can be challenging to provide this within usual rehabilitation, particularly if arm and hand weakness is secondary to other problems such as mobility or communication issues.³ However, arm recovery after stroke has consistently been identified as a national research priority and a clear unmet need expressed by stroke communities.4

It has been well established that individuals often feel abandoned after discharge from rehabilitation and unsure about how to support their continued progress, including



how to improve their arm function.^{5 6} Integrating self-management approaches into the delivery of rehabilitation can empower patients to monitor their own progress and develop new ways to sustain levels of activity.^{7–11} Self-tracking for health has become mainstream in the general population, and there is a growing interest in the use of dataveillance and gamification to support stroke rehabilitation.^{12 13} The purpose of this nested process evaluation is to assess the acceptability of the OnTrack intervention and evaluation design, as well as the fidelity of delivery.

METHODS

Study background and design

OnTrack is a 12-week package of support for people post stroke. A wearable tracker on the wrist tracks hand and arm activity and sends updates on individual progress. Motivational messages are sent to the user, and the device is supported by one-to-one coaching sessions. The assumptions behind the OnTrack package are that providing real-time feedback to individuals on their hand and arm activity and supporting them to self-manage their progress would lead to increased and sustained use of their affected arm and hand.

The study protocol has been published¹⁴ and quantitative feasibility outcomes will be reported separately. The feasibility study had a nested process evaluation to assess the acceptability of the intervention and evaluation design, as well as the fidelity of delivery. The design of the study was developed through a collaborative approach between the study researchers and stakeholders, including a public and patient involvement (PPI) steering group, and therapists working in stroke rehabilitation (occupational therapists, physiotherapists and speech and language therapists). An independent research panel (the Research Design Service at the National Institute for Health Research) reviewed the study design. This paper reports on the findings from the nested qualitative process evaluation. The findings will inform a definitive trial of effectiveness and future delivery across stroke pathways.

For the process evaluation, semistructured interviews were carried out with participants in the OnTrack programme, and a selection of coaching sessions was observed. An opportunity for refinement was built into the intervention phase, with preliminary analysis of interview data by a PPI group and sharing of feedback from session observations occurring midway through the study. ¹⁵ Further information about this is provided in the main results paper. The OnTrack logic model and interview topic guide are provided as online supplemental files 1 and 2, respectively.

Study setting and recruitment for the feasibility study

Study participants were adult stroke survivors with an arm impairment recruited from an inner-city National Health Service hospital Trust in London. Intervention could be commenced in hospital and continued at home after discharge. Participants received the standard care available to them alongside the OnTrack intervention, and

this varied—largely due to COVID-19 but also depending on whether they were in hospital or the community, and whether they were being seen by an Early Supported Discharge team for therapy.

RECRUITMENT

For the process evaluation, all participants were offered an interview after the intervention period had ended (week 14). All participant sessions were open to observation by the process evaluation researchers, who selected sessions based on the need to observe a range of session types with a range of participants. We aimed to interview all OnTrack participants for the process evaluation—and thus the sample size was determined by what was required for the feasibility study using guidelines that advocate a sample size between 12 and 30. ¹⁴

Between August 2019 and March 2020, hospital therapists were responsible for screening and identifying suitable patients, introducing the study to potential participants and taking informed consent. Therapists then shared patient information with the research team delivering the intervention (GF and EG). Recruitment for the study was suspended between March and August 2020 due to COVID-19 restrictions. A study suspension exemption was processed by the National Institute for Health Research (NIHR) following a protocol amendment. From September 2020 onwards, therapy teams continued to perform eligibility screens but instead shared patient information with GF and EG as soon as the patient was discharged home, so that the consent and recruitment process could be commenced by them in the community. GF and EG passed patient details on to the process evaluation researchers (ET and FI) in order that observations and post-intervention interviews could be arranged.

Inclusion criteria:

- ► Adults (18+).
- ► First or recurrent stroke diagnosis in the prior 6 months.
- ► Arm impairment of any type or level (including dense hemiplegia, neglect and sensory deficits).
- ▶ Ability to provide informed consent.
- ► Ability to communicate (verbally or non-verbally) and understand English.
- ▶ Ability to read a predefined short message.

Exclusion criteria:

- ▶ Unstable medical condition.
- ► Self-reported 'severe' pain in the arm affected either at rest or during movement.
- ► Severe oedema in the impaired arm, judged by the consenting therapist.
- ► Known discharge plans to a hospital other than the recruiting Trust or residential care.
- ➤ Participants who were unable to engage with the intervention for a period of more than seven consecutive days were reviewed by the intervention team to determine if study continuation was appropriate.



Patient and public involvement

A PPI group comprising three stroke survivors helped refine the intervention to the version used for this study. The group met four times over the duration of the study. Their time and travel were reimbursed according to INVOLVE guidelines. The PPI group was involved in the development of all patient-facing material to ensure its clarity and accessibility. Members were trained by experienced researchers to participate in qualitative data analysis at the study's halfway point. They helped to refine themes and key messages arising from qualitative interviews. The PPI involvement plan was shared with Imperial College London's PPI 'Research Partners Group' to ensure the needs of the steering group were accounted for. Results will be disseminated to study participants via email, and they also will be kept updated about the next phase of OnTrack development.

Participant characteristics

Characteristics of the 11 participants are outlined in table 1.

Data collection

The process evaluation was conducted by two researchers (ET and FI) independent of the main study team. Both researchers have clinical and research experience in stroke and qualitative methods. Semistructured interviews were carried out with participants at the end of their OnTrack programme. Non-participant observations were carried out for a selection of coaching sessions, to observe fidelity of delivery. In the first phase of the study, observations were carried out in face-to-face sessions, and in the second phase (due to COVID-19 restrictions), online sessions were observed. Halfway through the study, data analysis was conducted with lay members not participating in the trial. Results from this and observations from the first phase were shared with the intervention team, leading to subtle but important changes in the intervention delivery in the second phase. The study was required to move to a remote delivery format due to COVID-19 restrictions, with interviews and observed sessions taking place remotely. To protect their identities, participants are referred to by code and the intervention researchers delivering the intervention and coaching are referred to as 'coach 1' and 'coach 2' in the interview data.

Data analysis

All interviews were recorded and transcribed by an independent transcription service. As part of the planned opportunity for refinement, patient and public involvement (PPI) data analysis workshop was carried out midway through the study, with members of the PPI group reviewing three interview transcripts. This involved sending PPI group members a sample of interview transcripts to read in advance, then discussing their transcript summaries together and grouping outputs into themes. A summary of these themes and feedback from observed sessions was shared with the intervention team. This led

Table 1 Participant characteristics at baseline (n=11)	
Gender	5 female (45%)
Age (years); mean (SD); median (min, max)	63.7 (8.8); 60.5 (52.2 min, 74.5 max)
Ethnicity; n (%)	
White British	4 (36)
White other	2 (18)
Asian	2 (18)
Black	2 (18)
Prefer not to say	1 (9)
Impaired arm	6 right (55); 5 left (45)
Dominant arm	10 right (91); 1 left (8)
Was the impaired arm the dominant arm?	7 yes (64); 4 no (36)
Stroke onset (days); mean (SD); median (min, max)	30.7 (16.45); 30 (11 min, 71 max)
Type of stroke; n (%)	
Ischaemic	8 (73)
Haemorrhagic	1 (9)
Unknown*	2 (18)
Baseline clinical outcome measures: mean (SD)	
Fugl-Meyer Assessment for upper extremity†	37.7 (17.2)
Upper-Extremity Motor Activity Log-14 How much score; How well score	2.00 (1.4); 2.26 (1.5)
Gross level of disability: modified Rankin Scale	2.8 (1.1)
Arm pain: Visual Analogue Scale	0.8 (1.0)
Cognition: Montreal Cognitive	22.6 (6.9)‡
Assessment	17.8 (3.4)§
Quality of life: EQ-5D-5L	0.462 (0.3)
Patient activation/engagement: patient activation measure	69.7 (17.8)
First stroke	8 yes (73)
Smartphone user	8 yes (73)
WiFi at home	11 yes (100)

*The research team did not have access to participants' medical records, and for two participants this information was not available. †Only performed during phase 1 due to inability to administer remotely.

‡Full version applied before lockdown measures (scores out of 30). §Telephone version applied after lockdown measures (scores out of 22).

to changes including a move from prescriptive coaching session plans to an overarching guidance sheet with examples of language that could support self-management in a more individualised way. It also led to the team discussing more meaningful and functional goals with participants, alongside numerical activity targets.

After all interviews and observations had been completed, data were analysed together using an inductive thematic approach. Following detailed and close reading, all transcripts were systematically and manually coded. A large bank of codes was generated and collated into similar groupings, transcripts were read



again a number of times to gather examples of potential themes and thematic maps were compiled. Themes were refined several times and discussed between FJ and ET. Refinement continued as each theme was developed and depicted with illustrative quotes taken from across the full data set.

RESULTS

Semistructured interviews were carried out with 11 of the 12 participants who had completed the OnTrack programme. The participant not included finished participation the week lockdown started in the UK and could not be contacted. Non-participant observations were carried out for seven sessions, and these included 'on-boarding', check-in sessions with different focuses, and a halfway review.

Overall, when considering the different components of OnTrack, participants reported the value was not in one component alone but the 'whole package' including key components. The following themes focus on separate components of the package and are reported in detail below. These were (1) the human element—which relates to the value participants placed on the human aspects of the package, and what it was they found so important; (2) mixed views on motivational messages—which shows the different perspectives participants had on the messages they received as part of OnTrack; (3) the relationship between tracked movement and useful movement and (4) ending and moving on.

The human element

Despite participants stating the value of 'the whole package', the significance of the human factor was represented in all interview data. Participants acknowledged the critical role played by the coaches, which involved technical guidance and interactions on a weekly basis to encourage and support self-management. When pressed to explain what it was about them that they found valuable, participants tended to speak of their personal qualities: they were kind, approachable and they listened to challenges and successes (table 2, 1.1).

Participants expressed how much they appreciated the regular check-in and chats to talk with coaches about their progress. Participants valued the encouragement to keep going and achieve goals, but it was also important that coaches showed understanding when participants felt discouraged (table 2, 1.2).

The human connection was also critical to support participants through challenges with the technology (table 2, 1.3).

Some participants had received their coaching sessions remotely due to pandemic restrictions and also found this acceptable (table 2, 1.4).

Mixed views on motivational messages

OnTrack messages included motivational greetings, links to sources of information such as the Stroke Association website, and updates on progress with tracked movement goals. Participants had a range of opinions about the messaging, with some finding it beneficial and others finding the messages irritating. Overall, it appeared that a more individualised approach to messaging that related to each person was needed to suit varying preferences (table 2, 2.1).

Personalised messages about progress were generally seen as more useful than general words of encouragement and acted as motivator to beat activity scores from previous days (table 2, 2.2).

Another valued aspect of messaging was the tips, links and stories shared with participants (table 2, 2.3).

Participants had different perspectives regarding how useful the messages were, suggesting this aspect of the package could benefit from further personalisation.

The relationship between tracked movement and useful activity

Participants all referred to the benefit of having a numerical target for increasing arm movement and being able to track their progress (table 2, 3.1).

OnTrack also gave the opportunity for participants to look back on their activity and be more aware of how they were doing, from week to week (table 2, 3.2).

However, participants valued the numerical targets alongside discussing their own meaningful goals, such as buttering toast, opening jars or fishing. They were consistent in wanting to discuss how they might use their hand or arm more in useful tasks. Earlier participants raised the need to bring more of a functional focus, and after this was suggested in the midway opportunity for refinement the coaches implemented this approach in their coaching sessions (table 2, 3.3).

Participants interviewed after these changes were made spoke positively of the way the coaches helped them focus on functional activities for which they wanted to be able to use their hand or arm for, as coaches made more conscious efforts to link the activity data with participants' functional goals.

Some participants noticed that having an active and busy day would not necessarily be reflected in their tracked activity, but generally they were able to make sense of this and distinguish between arm movement and overall activity (table 2, 3.4).

Just as tracked numbers could be seen as misrepresentative by being too low on a busy day, they could also be seen by some participants as too high when movement had not been perceived as 'useful' (table 2, 3.5).

Ending and moving on

All participants were asked how able they felt to continue their rehabilitation alone after the OnTrack programme had finished. Most participants expressed feeling confident and that although they had valued the programme, they did not feel dependent on it (table 2, 4.1).



Table 2 Participant quotes from semistructured interviews Theme Participant quote 1. The human 1.1 'I found(coach 1)very good. She was approachable, motivating. At one point, I thought, "I'm fed up with the OnTrack element because it looks like I'm being monitored all the time." She said, "I'll give you the time to think about it," and she gave me the time. She could advise me... She was a, sort of, person who was, like, nice, approachable, and she could listen well and she could give appropriate advice, to be honest.' PF006 1.2 'There was one day that I was in tears with(coach 1), and she said, "Do you know what? Just don't do anything today." I said, "I can't be bothered to put the watch on. I don't care, I'm having a bad day, my walking's not going well, everything I try is going wrong." She said, "Right, just watch the TV, have a day off and just binge watch TV or something." I said, "But if I don't wear my watch, I feel like I'm letting you down and I'm letting myself down." But she was able to pick up on my mood.' PF015 1.3 'He was always very helpful and encouraging. And also, whenever I had this problem with the technology side of it and all, and the way he explained it to me and the way we, you know, got over the problem, it was good. I didn't... Because I have a fear of technology because my age and because of the generation we are born in, that's why, which he made it guite okay, things were alright, and it made me feel, "Okay, I can handle this technology part". PF020 1.4 'The human element is very important. I think even in somebody who's totally au fait with the technology they still benefit from some sort of human interaction(...)I would say that - obviously this depends on Covid being defeated, but definitely at the beginning there should be a face-to-face thing. I think, well, most of it can be done on video or whatever.' 2. Mixed views 2.1 'The daily messages that you get on the app every day, like, "Good morning. Today's going to be a good day," I found myself talking back to it and saying, "What makes you think that it's going to be a good day?" I found the messages that on motivational messages came up on the phone. I found them sometimes a little bit childish.' PF015 2.2 'The [useful] ones that told me how well I'd done the day before... 'Let's see if we can beat it.'... And it would make you think, 'Yeah I'm going to beat you, I'm going to beat the *** out of you now.' PF015 2.3 'In the beginning I would just look at those(...)because it's asking me very useful information; for example, they would tell me information from the Australian Stroke Association. So, I would go there which was amazing... He'd send me messages every morning and then around midday I would get another reminder that, "You're doing a good job", or "You reached very close to your target; try and get your target". PF001 3. The 3.1 'That's what I was talking about with the motivation... Like, the numbers going up, so yesterday if I did 20, then the next relationship day, I'd do 30, 40, then I'm able to do 100, 120, 150, 200. That's motivation. Or go for a long walk, come back. Sort of, it's a between tracked motivation, you know, okay, although I'm down, then the next day you feel a little bit better. It motivates you'. PF006 3.2 'I could look at the stats of the previous week, compare the stats on the days, and then I would find out why these days movement and useful movement had a little less activity. So, it was making me conscious of meeting my goals, tracking myself.' PF001 3.3 'I'm the one who said, "Okay, I have a cup here; I've been trying to..." So, they need to send a message reminding me every day, "Try and hold a cup once".(...)Functional because the functional goals will increase the targets without you knowina, PF001 3.4 'Because, you know, the watch is on your arm, and it tends to do arm movement... You know, when you use your arm a tremendous amount, you'd find the minutes really shoot up. If, for instance... I started the watch at eight o'clock and I was really busy all day and it didn't look as if I'd done very much so, although I was really busy with the rest of my body, my arm was not used probably as much as it could've been. When I was chopping vegetables up and cutting onions... I found that that was really increasing the minutes. So, the comparison between the two, although I'd had a really busy day... didn't show as if I'd had as busy a day as when I was chopping onions. ... I knew in my mind that I'd had a really busy time and also it had been explained that the movement was mainly on my right arm, so I wasn't demoralised.' PF007 3.5 'So, for instance, you get 90 minutes you could exceed your target. And it shouts at you, "Well done, you've done really well". And I have. But it's not necessarily useful movement.' PF021 4. Ending, and 4.1 'I think it helped me to see what's going on and helped me to find out more information and how to help myself. It's not moving on like it has stopped there, but it's continuing, it's still continuing to help me to improve... I'm not saying I'm okay, no, I'm still struggling with the stroke, and I'm trying to come to terms with it, so it has helped motivate me to work my way, although I'm under, sort of, like, difficult circumstances, but it has helped me.' PF006 4.2 'I'm talking to you now, pushing my arm out and in, you know. That's what I tend to do. I do that when I'm on the phone and waiting for the kettle to boil. I do some arm exercises, or I walk up and down the room, making sure that I use my

arms as well. So yeah, and then I look at my wrists and I'm like, "Oh yeah, there's no phone, there's no watch, there's no

4.3 'I know I've got to if I want to stay enthusiastic, with all my limbs....I think I need guidance, I want guidance, you know, I need it, that's always me, always, always. I can do an awful lot by myself, but actually, I always like that... It's a bit like

4.4 'I'd still like to be using it now, even now. Even when I'm hoping to go back to work in September. ... I'd like to be able

to have the OnTrack back for a little while, or maybe forever really. I didn't want to give it up.' PF015

There were also examples of how participants were building activity into everyday tasks, almost as if their activities were still being tracked (table 2, 4.2).

having the schoolteacher slapping your wrist.' PF013

nothing.'PF023

However, one participant said that they were a person who depended on guidance from others and was more concerned about how they would stay motivated after the programme (table 2, 4.3).

Some participants would have liked to continue with tracking long term, and many described strategies they were going to try and use to maintain and increase their progress including buying a smartwatch with activity tracking and using the information they had learnt through the trial (table 2, 4.4).

Some participants told us they would have liked more attention to be paid to ending the programme, including being informed what would happen next in the research and development of OnTrack. Many people said they would value a follow-up to check on their progress sometime after the programme had ended. Although they felt able to manage without the programme, they would prefer to have some ongoing contact with the coaches both for updates on the project (as research participants) and as a motivator to keep going with their progress.

DISCUSSION Principal findings

OnTrack is a package that has been designed to address unmet needs reported by stroke survivors, boosting their hand and arm activity through a combination of tracking and self-management coaching. Although self-tracking of health and physical activity in the general population is not new, ¹⁶ its use in stroke rehabilitation is relatively novel. The aims of this qualitative process evaluation were to understand the acceptability and usability of OnTrack by stroke survivors, and to explore the fidelity of the way it was delivered, in order to inform future delivery. We were curious about whether one aspect of the programme would stand out to participants more than others. We found that most participants valued 'the whole package', that is, movement tracking, coaching and messaging, but it was striking how frequently and consistently people discussed the value they placed on the human interactions they had with the coaches. We noted that session plans for coaching devised in advance of the programme were not helpful. Following discussion these were replaced with a guiding principles document to support the coaches in taking a self-management approach throughout the sessions. Participants appreciated it when the coaches had a flexible, open approach did not put pressure on them, and helped them to identify tasks and activities that they could work on to improve their arm movement and independence This is in line with existing evidence illustrating the importance of tailoring self-management information to the individual¹⁷ and that a more open style of communication which explores and supports existing strategies to target everyday activities can change an individual's confidence in their ability to self-manage. 18

Strengths and weaknesses of the study and in relation to other studies

A potential limitation is that only participants who completed the programme were interviewed, although those who did not complete it were asked for their reasons for leaving the study. Two of the researchers in the study enacted the role of coaches in the study, and it is possible that their enthusiasm for the programme contributed to the positivity expressed by participants, which would be a consideration for scale up across more sites. The process evaluation was completed by researchers outside the research team, and this made it possible to observe

delivery of the sessions at a distance, with objectivity. Findings from the process evaluation were not shared continuously but were shared midway through the study, as an opportunity for refinement, and at the end of the study. A strength of the study was the meaningful involvement of stroke survivors and carers in the design of the intervention and study and in analysing interview data. It has been noted that much of the discourse around self-tracking for health has been theoretical, and concerns about how individuals may feel are often not realised when participants discuss their experiences. 19 It was, therefore, a strength that this was a practice-based study with participants' views at the centre.

Discussion of important differences in the results

Mostly, we found similarities among participants in their views about the OnTrack programme, but there were some notable differences in the results, such as in the mixed feelings about motivational messages. While the coaches could be sensitive to the various moods and experiences of participants and tailor their responses in the moment, the remote messaging was less personal. A single discrepancy in responses was that one participant expressed concern about the extent to which the watch might be 'listening in', particularly in meetings at work. Although only one participant expressed these concerns, it suggests that giving clear information to participants about what will and will not be surveilled, and how tracking data will be used, is important. Critical discussion of dataveillance practices has tended to emphasise concerns regarding use of data and being monitored or surveilled, but there has been a more recent call to recognise the benefits people may experience, such as learning more about themselves and achieving better health, well-being and a feeling of control over their lives.²⁰

One further discrepancy was that one participant was fairly ambivalent about the programme and stated that as she had already been through stroke rehabilitation in the past it did not really help her. When discussing this with her it seemed that she had already learnt how to selfmanage her condition and motivate herself and did not find additional benefits from OnTrack. Her main concern was her risk of having a further stroke. This is consistent with theory underpinning self-management and supports the link to self-efficacy and the need for different levels of support. 18 21 Other studies have found that automated digital interventions can be used to increase self-efficacy,²² which appeared to be the case for the majority of the participants in this study.

The meaning of the study

The underlying assumptions underpinning the study outlined in the logic model were that by providing realtime feedback and coaching sessions participants would be motivated and empowered to include their arm more in everyday tasks and be empowered to participate in valued activities. 12 23 24 Our findings suggest that the coaching support is an essential and highly valuable factor in increasing participants' activity and self-management skills. This aligns with recent results from a web-based physical activity intervention for people with multiple sclerosis which also found the development of supportive coaching roles to be important.²⁵ We have found that feedback on arm movement is valued, but participants want to focus on activities that matter to them as well as numerical movement targets. It has been noted that in some cases of self-tracking, individuals come to trust the numerical data more than their own bodily feelings.¹⁹ Conversely, Lupton²⁰ has claimed that a 'less than human' digitised profile, however detailed, will never encapsulate the 'fleshly, sensate body, replete with thoughts and affective forces'. In this study, participants perceived the numerical data in the context of the whole package and made sense of it in relation to their felt experiences, for example, of having a more active day. This supports claims made by Lupton and others, that individuals do not simply accept the accuracy or validity of their numerical data at face value, but actively interpret and appraise it. 20 $^{26-30}$ In our study, age or familiarity with smart devices were not barriers to engaging and benefitting from the programme, but it may be less useful to people who have already experienced previous strokes and learnt to selfmanage their condition following previous episodes of rehabilitation.

Possible explanations and implications

In the growing body of literature relating to dataveillance and self-tracking for health, 16 19 31 our participants were unusual in that as well as valuing self-surveillance, it mattered that the intervention team were monitoring them too. Other self-tracking approaches incorporate a social or competitive element, such as fitness trackers where progress is shared with other users who can also compete for awards. This is often named gamification and has been used in other stroke rehabilitation programmes. 14 15 Although OnTrack did not have that element, participants were aware of the gaze of others as well as their own, and they found this motivating. Sharon ¹⁹ has discussed the relationship of empowerment vs surveillance and has suggested the importance of placing values at the heart of discussions about tracking. OnTrack combined technological monitoring with human monitoring and coaching, and participants felt that the combination of the personalised support and the technology was crucial. Empowerment was central to the values of the programme, and the coaches had a vital role in empowering and encouraging participants. Early participants in the study reported that they would like to discuss their functional goals as well as focusing on movements. After discussing this with the intervention coaches and designing new self-management guidance together, both intervention coaches became skilled at guiding activity and linking tracked movement with personalised goals. Adapting the study to a remote model of coaching due to COVID-19 restrictions enabled us to discover that participants felt this was an acceptable

and effective option, although they would like to meet coaches in person at the start and end of intervention. This has implications for future delivery and suggests that remote coaching could be an effective model even post-COVID-19.

Unanswered questions

We recommend that any further research is carried out with stroke survivors to codesign the messaging function of the programme. This should explore the purpose, content and frequency of messages. The role of the coach also requires further consideration. In our study, the coaches were highly valued by participants, and they were able to address technical issues as well as supporting a selfmanagement approach. There were only two coaches, and they were also researchers in the study so had an excellent understanding of the technical side as well as the aims and the theories underpinning the study. Further exploration is needed to determine what training, support or background experience is needed for others to coach on the OnTrack programme. There are further questions to be explored about how OnTrack might become embedded in existing rehabilitation services. Our participants noted that tracked movement did not always represent what they considered to be useful movement, and further work could explore whether tracking could be refined to distinguish functional movement. We did not identify barriers to suitability based on factors such as age, previous technology use or Wi-Fi connection, and our findings suggest that any stroke patient with a need for arm rehabilitation could potentially benefit from OnTrack. However, this is based on a small sample and further research may identify factors influencing suitability. All of these questions will be important to research for OnTrack (or similar programmes) to be evaluated and available more widely across stroke services.

Twitter Elizabeth Taylor @ElizaTay1 and Fiona Jones @JonesFio

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Patient consent for publication Not applicable.



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ORCID iDs

Elizabeth Taylor http://orcid.org/0000-0002-4596-823X Gianpaolo Fusari http://orcid.org/0000-0002-7263-3398

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On-Track Participant post-study interview guide

Setting the scene

- This interview is to find out about your experiences of using OnTrack. I am here to evaluate the process and let the team know if there are things that could be improved.
- Tell me a bit about your story. What happened to you, and how did you come to use Ontrack?
- How were you feeling about your arm and / or your activity levels at that point?
- How would you explain what OnTrack is to someone else that hadn't heard of it?
- What were your feelings about OnTrack when you were first told about it? Did you believed it would be helpful for you? (Why? / Why not?)

Overall impressions of OnTrack

- When I talk about OnTrack I am referring to the watch, the tracking app, and the coaching and consultation sessions you received from the OnTrack team (e.g. Ella). We are interested in your experiences (good or bad) of all these aspects of the OnTrack package. What would you like to tell me about it?
- What were you most impressed by?
- What could improve?

Specific aspects of OnTrack

- Can you say a bit about how OnTrack was explained to you? Is there anything that could have been better about that?
- Can you describe how you used OnTrack, from how you started the morning to how you used it throughout the day?
 - Use of watch v phone
 - Checking progress through the day
 - Receiving messages
- What are your thoughts (positive and negative) regarding tracking your arm activity?
- You received messages to alert you to move and do activities. What are your thoughts (positive and negative) regarding the messages you received?
 - Owere there too many, or too few?
 - O What about the way the messages were worded?
- What are your thoughts (positive and negative) regarding the OnTrack therapist consultations?
- Is there anything about the way the On-track team worked with you that you think made a difference?
- Thinking about all those things, what was helpful / unhelpful?
 - Was the OnTrack programme what you expected it to be?
 - Did it fail to meet your expectations in any way?
 - Can you give an example of when this worked something did or didn't work for you?

One of the things the researchers wondered about was whether OnTrack users would tend
to focus on arm activity, or whether it would have benefits more generally about increasing
the things you felt able to do for yourself. What are your thoughts on this?

Usability

These questions are about how easy you found it to use the technology. I'll ask about the watch and phone separately.

<u>Watch</u>

- Wearing the watch (putting it on and off, comfort)
- Using it daily (remembering)
- Starting OnTrack (finding the app, starting, stopping)
- o Charging (remembering, did you ever run out of battery, etc.)
- Screens (clarity, usefulness, etc)
- o Any problems?

Phone

- Carrying the phone indoors/outdoors
- Using it daily (remembering)
- OnTrack (finding the app, navigating, etc)
- Charging (remembering, did you ever run out of battery, etc.)
- Screens (clarity, usefulness, etc)
- o Any problems?
- Any adverse symptoms (pain, swelling, overuse)/events?

Impact of OnTrack

- What impact do you think Ontrack had on you? You might want to consider your affected arm, your general activity levels, your motivation or anything else.
- Do you think it affected your awareness of any progress you were making? (If so, how?)
- Did it affect your motivation, confident or belief that you could do things to manage your own progress?
- Was there any impact on your participation in things like groups or activities? (Why / why not?)
- And if Ontrack didn't help you, can you explain why that was?
- How able to do you feel to continue your rehabilitation journey alone, without OnTrack?

Imagining future possibilities

- What else would you like to tell the team about OnTrack, is there anything that could be improved or might help others to use it?
- Imagine we are 30 years into the future, and it is standard for people who have had a stroke to use technology such as the tracker to help with their rehabilitation.
 - O Would that be a good thing?
 - o How would you imagine that working? What would make it work really well?
 - o Is there anything you would want to be different from your experience?

Need

Arm disability after stroke affects 450,000 people in the UK and can lead to loss of independence. Repetitive activity is critical for recovery but research shows that people can struggle with knowing what or how much to do, and keeping track of their progress, especially after discharge from therapy services.

Intervention

OnTrack consists of smart-devices (smartphone and smartwatch) and coaching support. Smart-devices are used to track arm movement, receive motivational messages and provide a real-time display of completed arm activity. Coaching support is provided through periodical consultations.

Inputs

Staff

OnTrack team NHS staff

Time

12-14 week intervention

Research Base

OnTrack Theory of Change IMB model Background research / evidence base

Materials / equipment / technology

Apple devices OnTrack app

Support docs

Links to resources

Outputs

Activities

Deliver

Coaching sessions Assessment sessions Motivational messages

Self-management information Stroke services information

Provide

Real-time arm tracking Daily and weekly arm activity summaries

Conduct

Consultations with therapists

Maintain

OnTrack software

Stroke survivors

Participation

Relatives / carers

Therapists & nurses

Outcomes

Short-term

Increased awareness of Increased arm involvement / function progress and ability (analytics, interviews) (MAL)

Increased arm activity Increased QOL

(EQ 5D)

Increased activation (PAM)

(analytics)

Increased knowledge of self-management (metric TBD)

Increased participation (interview)

Reduced impairment (FM, neglect)

Long-term

Stroke survivor reduced dependency on therapists BMJ Open

Reduced incidence of further stroke

Increased return to work

Reduced care needs

Reduced use of NHS resources (due to secondary problems)

Evidence

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Assumptions

By providing real time feedback on arm movement and coaching sessions patients will be motivated and empowered to include their arm more in every day tasks and be empowered to participate in activities they

Providing stroke survivors with a real-time indication of their arm activity throughout the day will encourage more activity.

Providing stroke survivors with coaching support will increase their activation level and self-management skills.

External factors

Level of disability

Level of family support

Discharge package / plans / location

Ability to access local facilities and services (once discharged)

Ownership of phone contributing to low interaction with OnTrack phone app / messages

Clinician influence

Project has found big support from ICHT staff

Feasibility outcomes

OnTrack acceptable to patients (SUS, interview)

OnTrack acceptable to therapists (interview, questionnaires)

Funding applications for RCT (# submitted, # pitched)

PPIE continued involvement in R&D / RCT prep

Ease of recruitment (interviews)

Therapists increased interest in research / R&D / innovation (interviews, questionnaires)

Acceptability of study procedures (interview, questionnaires)