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RESEARCH ARTICLE

Stroke recovery—what are people talking about on Twitter? A content analysis

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ABSTRACT

Purpose: Prioritisation exercises seek out what matters to key stakeholders to inform the planning of research. Social media platforms are potentially useful data sources. The aim was to examine the content of tweets, short messages containing text and pictures, to ascertain the priorities of Twitter users regarding stroke recovery.

Materials and methods: Content analysis of Twitter was conducted. An electronic search used the identifiers: #strokesurvivor and #strokerecovery. Tweets spanning four weeks from January 2021 were analysed.

Results: There were 1361 tweets extracted and 486 analysed following exclusion of duplicates and unrelated material. Six themes were uncovered (n = number of tweets): maintaining motivation and positivity (153); sharing of resources (146); raising awareness of stroke (74); symptomatic aspects of recovery (39); experience of rehabilitation (63); and concerns about Covid-19 (17).

Conclusions: Despite the brevity of tweets, a rich picture arose. A key limitation was lack of biographical data about Twitter users. Recommendations about topics requiring attention from stroke researchers, clinicians and policy makers are: management of psychological problems; public perception of stroke; rehabilitation considerations including treatment burden, person-centred care and equality of care; symptom management including fatigue and aphasia. Findings can be used to supplement and validate other priority-setting exercises.

➢ IMPLICATIONS FOR REHABILITATION

- Priority setting exercises are integral to improving patient care.
- Twitter is a useful source of data alongside more traditional in-person methods.
- Key areas of stroke care requiring attention include: psychological support; information sharing; treatment burden; equity of access to rehabilitation services; management of fatigue and aphasia.

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Stroke; rehabilitation; research prioritisation; patient experience; qualitative; social media

Introduction

The planning of stroke services, policy and research should be guided by the people that have first-hand experience, i.e., stroke survivors and their caregivers. However, capturing the views of a diverse range of people with lived experience is challenging. The James Lind Alliance's Priority Setting Partnership (*PSP*) was conducted in 2021 [1] to prioritise research questions and address the unmet needs of stroke survivors through focus groups and surveys. Another potential method of gaining the thoughts and needs of key stakeholders is through social media platforms such as Twitter (www.twitter.com).

Twitter (now known as X) is a social networking website on which users communicate through short posts consisting of a maximum of 280 characters called tweets. As most tweets are available in the public domain, they are a readily available data source, unlike the data from other social media platforms such as Facebook and Instagram that have stricter privacy settings. Similar tweets are often grouped using a relevant *hashtag*—a word or short phrase related to the content of a tweet, denoted by a hashtag symbol (#). This allows tweets relating to a topic or community to be analysed collectively. There are advantages to analysing data from Twitter for priority setting. Social media provides access to a group of people that may not volunteer to take part in more traditional priority setting exercises such as interviews, focus groups and surveys. The method is low burden for participants and cost effective for researchers and funding bodies. Another advantage is that Twitter users can post at the time that a thought or feeling occurs to them, so recall bias is minimised. There are, however, likely to be limitations to the use of Twitter as a data source, for example Tweets are limited in length by the platform which may limit depth of understanding [2], and selection bias is likely with Twitter users being younger, more highly educated and wealthier than the general public [3], although representation of the sample population is rarely sought in qualitative research [4]. Twitter is becoming increasingly popular as a data source in healthcare research and has been used to research other long-term conditions such as diabetes and obesity [5]. The research aim was to examine the content of tweets relating to stroke recovery in order to ascertain

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topics of importance to stroke survivors and the general public, which may be useful in guiding future research and policy.

Materials and methods

Study methodology was developed with reference to the Association of Internet Researchers' ethical guidelines [6]. For studies utilising data available in the public domain, formal ethical approvals are not required, but typical procedure is to omit all directly identifying information to preserve the anonymity of participants [7]. While there is no universal ethical framework for social media research [8], guidance states that the use of Twitter data presents less ethical issues than data from private forums and recommends that Tweets not be quoted directly in the interest of users' privacy [9]. As tweets quoted directly without alteration are obtainable through Twitter's native search function [10], tweets presented in this paper were closely paraphrased, maintaining close allegiance to their original context and sentiment. Unless directly relevant to the interpretation of a tweet's meaning, hashtags were omitted from quotations featured in the results.

A scan was conducted of prominent stroke-related Twitter accounts to identify commonly used words, phrases and hashtags. It is possible to search Twitter using either keywords or hashtags. A keyword search using "stroke" returned a large quantity of irrelevant material, therefore a hashtag-focused approach was implemented to increase specificity of the search. Following this scan, *#strokesurvivor* and *#strokerecovery* were deemed most appropriate as they are used predominantly by stroke survivors tweeting about life after stroke. Data were selected using the two hashtags and extracted from Twitter between 28 January and 25 February 2021 at seven-day intervals using NCapture (version 1.0.290.0, QSR International, US) a free web browser extension. Twitter's Application Programming Interface *(API)* limits extractions to the preceding week. Tweets were imported to qualitative analysis software *Nvivo (version 12,* QSR International, US). Inclusion and exclusion criteria are shown in Table 1. Tweets with no stroke-related content were excluded, for example those containing a stroke-related hashtag alone with no associated content or attached media. A "retweet" is the action of a Twitter user choosing to share another user's tweet. Retweets were included if not a duplicate of another included tweet. All duplicate tweets and retweets were excluded. Non-English tweets were excluded due to a lack of resources for translation. Tweets by organisations rather than individuals, for example healthcare providers, were excluded from analysis unless they directly quoted a stroke survivor.

Data were analysed using codebook thematic analysis [2,4]. Examined individually, tweets were assigned descriptive codes according to content, and codes then organised into overarching themes with subthemes. Within each theme, subthemes share an underlying meaning or concept, for example the subthemes "motivational comments," "functional improvements and milestones," and "accomplishments" were all deemed to share an underlying message of "motivation and positivity." Codes were formed inductively from the data by one researcher (DP) with coding decisions checked by a second researcher (KG) to minimise bias and ensure accuracy and consistency. An individual with lived experience of stroke and its recovery (PMcG) assisted in making sense of key themes found. In the case of Tweets lacking sufficient text to be analysed directly, embedded media and links to external sources were explored to determine their purpose and sentiment. Lastly, the themes were examined to create proposals about aspects of stroke recovery that require attention from researchers and policy makers. Only tweets in the public domain were utilised. Twitter users can choose to limit the audience of their posts to only those who have been approved. This provides the option of privacy, with non-private users implicitly consenting for their content to be available in the public domain by their agreement to Twitter's terms of service.

Table 1. Table of inclusion and exclusion criteria.

Included	Excluded
Tweets containing relevant #	No content related to stroke
Tweets posted during extraction period	Duplicate tweets or retweets
Tweets by individuals	Tweets by organisations e.g., charities or healthcare bodies
	Non-English content

Results

As shown in Figure 1, 1361 tweets were extracted and 486 analysed following the exclusion of duplicates and unrelated material. The themes and sub-themes uncovered from data analysis are presented in Table 2. The number of tweets within each theme is provided in the table.

The six broad themes were: motivation and positivity; raising awareness of stroke; experience of stroke rehabilitation; symptomatic aspects of recovery; sharing of stroke-related resources; and concerns about Covid-19. These themes are described below with subthemes and illustrative quotations. Where relevant, linked media content are described in brackets—*[]*—to preserve the context of accompanying text and convey the full meaning of a tweet.

Motivation and positivity

Motivational comments

Twitter users widely reported the benefits of a positive outlook in recovery and in life more broadly, offering encouragement to fellow survivors:

> Doesn't matter how slow you go, just don't stop. (Twitter user 6)

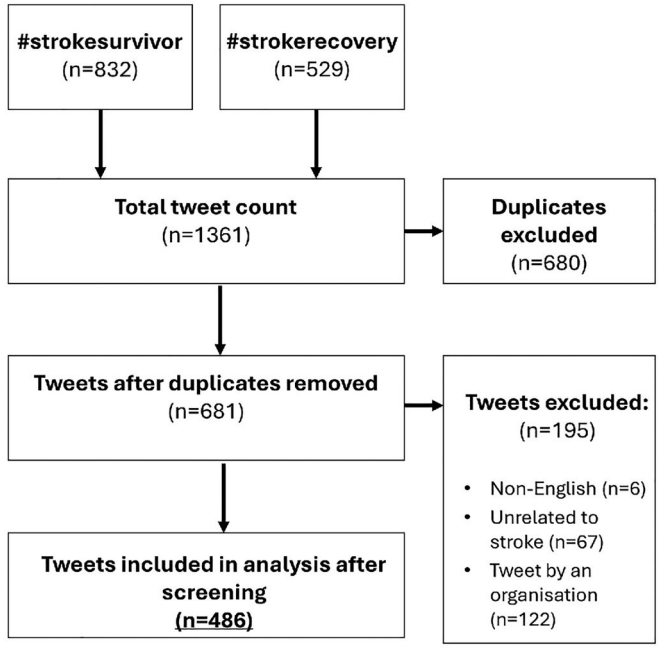

Figure 1. Flowchart of tweet screening process.

Table 2. Table of themes and sub-themes.

Themes (n = number of tweets)	Sub-themes
Motivation and positivity ($n = 153$)	Motivational comments
	Functional improvements & milestones
	Accomplishments
Raising awareness of stroke ($n = 74$)	Risk at all ages
	Risk factors and prevention
	Perception and treatment of stroke survivors
	Advocacy and campaigning
Experience of stroke rehabilitation ($n = 63$)	Treatment burden
	Rehabilitation services
	Importance of community
	Person-centred care and individuality
	Financial burden
	Coping mechanisms and aids
Symptomatic aspects of recovery ($n = 39$)	General function & mobility
	Neurological
	Psychological
	Fatigue
	Aphasia
Sharing of stroke-related resources ($n = 146$)	Educational & informative
	Rehabilitation & self-management
Concerns about Covid-19 ($n = 17$)	Increased risk to stroke survivors
	Vaccine access

There were also motivational posts about accepting and embracing one's circumstances to aid rehabilitation:

> …a stroke journey can be a positive experience…I'm enjoying learning how to do things again and seeing what I can achieve every day. (Twitter user 11)

Functional improvements and milestones

Some users shared specific milestones in their recovery, typically physical feats or functional tasks previously beyond their capacity:

> 4 months ago I was paralysed on my right side. Today I walked up 3 flights of stairs. (Twitter user 3)

Accomplishments

Users often framed their non-stroke accomplishments in life with reference to their identity as a stroke survivor to convey added significance:

> I guess I shouldn't be worried about taking the bar exam and practising [law] after surviving a stroke… (Twitter user 12)

Raising awareness of stroke

Risk at all ages

Stroke survivors drew attention to the risk of stroke in people of all ages to address the widely held perception that stroke is a disease solely of old age:

> it can happen to ANYONE at any age! I know I am lucky to be alive, I know I shouldn't stop living just because of #aphasia…. Lots of living to do. (Twitter user 18)

Risk factors and prevention

Survivors discussed concerns about stroke recurrence, and shared advice aimed at reducing the risk of this:

> Adjusting your diet can help manage stroke risk factors and aid in your #strokerecovery. (Twitter user 8)

Perception and treatment of stroke survivors

Stroke survivors discussed their experience of mistreatment by members of the public and their desire not to be wholly defined by their stroke survivorship:

> I was pitied to start with. People would look at me differently, like I wasn't as capable as I was before I had my stroke… (Twitter user 5)

Survivors also described perceived stigmatisation by healthcare professionals and frustration at people's lack of understanding, suggesting that this might be addressed by better education:

> I am sometimes called brave for my #strokerecovery history but this morning suffered unprofessionalism by some incredibly ignorant medical staff. There are so many misconceptions…as if people have no books, Google, or education… (Twitter user 2)

Advocacy and campaigning

Some participants directly advocated for changes in clinical practice and care provision, using hashtags to identify themselves as stroke survivors and lend weight to their opinions:

> All we need is a clear picture…make CT/MRI scans affordable now!! #strokesurvivor. (Twitter user 17)

Experience of stroke rehabilitation

Treatment burden

A common topic of discussion was stroke survivors' experience of treatment burden. Users referenced complex referral processes, difficulties faced when navigating the stroke care pathway, and shared images of large quantities of medication, implying difficulty in adhering to treatment regimens:

> The handful of medication I've had to take since my #stroke, and this is the FEWEST it's been… [attached picture of large handful of tablets]. (Twitter user 16)

Rehabilitation services

There were tweets relating to rehabilitation services, in particular expressing thanks to care providers and sharing positive aspects of their experience:

> Massive thanks to [name] from @User(CareAgency) for their help over the past few days. Sometimes a person comes through for you when you need them most. #angel #carer. (Twitter user 19)

Some users expressed dissatisfaction with rehabilitation services, in particular the perceived lack of adequate care provision in some regions:

> It's a real shame that provision of care packages for a stroke survivor in [UK Region] is a postcode lottery. Apparently [location] is "too rural" for us to get any carers…. (Twitter user 19)

Importance of community

The benefits of peer-support and community amongst stroke survivors were referenced widely, with participants expressing the value they place on the sharing of lived experiences and in maintaining social connections with fellow stroke survivors:

> I feel blessed to have a fantastic family and a great group of friends… brain injury brought us all much closer together… (Twitter user 21)

Social events for stroke survivors were promoted, aiming to promote communication and socialisation to aid recovery:

> Come and join us tomorrow morning for a cuppa and virtual chat with fellow younger stroke survivors… #peersupport. (Twitter user 23)

Person-centred care and individuality

Many users expressed their desire to be recognised as individuals; not to be treated based on preconceived notions of stroke survivorship:

> People shouldn't be shoe-horned into expectations…. Everyone has their own pace and goals, and we should be proud when they meet them!! (Twitter user 7)

Financial burden

Some participants disclosed difficulties in funding stroke treatment, either because of reduced work capacity during recovery or the expense of stroke treatment itself. Some tweets were direct appeals for financial assistance, with others describing problems accessing government benefits:

> He's home but we still have a long way to go with his recovery [shares link to fundraising page to cover rent while husband recuperates post-stroke].

Coping mechanisms and aids

Users discussed the hobbies and interests they have found useful in their stroke recovery:

> [Name] explains wonderfully how art has helped him: "there is no cure for aphasia, you really have to learn to adapt to the lack of coordination"… (Twitter user 22)

With reference to Covid-19 restrictions on socialisation, users expressed eagerness to return to hobbies which were unfeasible at the time:

> I miss singing so much! Singing allows us to escape and forget the reality we live in for a while… (Twitter user18)

Symptomatic aspects of recovery

General function and mobility

Stroke survivors reported their current state of function and physical wellbeing. Many users documented the gradual improvement in their motor function and the strategies they've employed in overcoming and adapting to physical symptoms:

> Learning to re-walk is exhausting. I've trained myself to walk again by watching other people's legs and feet… (Twitter user 4)

Neurological

Users discussed neurological symptoms, including seizures and sensory abnormalities:

> Pins and needles in the soles of my feet. Yuck! (Twitter user 22)

Psychological

The psychological impact of stroke was frequently referenced. Distinct from their physical complaints, users commented on the difficulty in adapting to their new circumstances, and the associated strain on their mental wellbeing:

> Take care of yourselves today. Our emotional and mental health is just as important as our physical recovery… remember to be kind to yourselves. (Twitter user 13)

Fatigue

Users also referenced the severe fatigue associated with stroke, with some commenting that it eased gradually over time:

> …the "crushing fatigue" that [Name] feels sometimes faded after the first year. (Twitter user 10)

Aphasia

Users sought to dispel misconceptions about aphasia and associated communicative difficulties which could make them feel misunderstood:

> not being able to speak is NOT the same as having nothing to say!. (Twitter user 18)

Sharing of stroke-related resources

Educational and informative

Links to educational resources were shared, such as those reporting advancements in treatment. These took the form of journal articles and seminars amongst others, and predominantly catered to stroke survivors.

> Amazing!! A study is underway at [Hospital] looking to help stroke survivors regain lost function in their bodies… this is HUGE!!—[shares link to article outlining the study] (Twitter user 14)

Rehabilitation and self-management

Others shared links to practical resources aimed at improving self-management and general wellbeing in stroke survivors:

> Stroke Survivors please check out [Instagram Account]… just added some stroke exercises I was given after my stroke in 2020. My hand has recovered well. (Twitter user 9)

Concerns about Covid-19

Increased risk to stroke survivors

Users referenced the specific risk posed to stroke survivors by Covid-19, encouraging others to accept vaccinations and expressing their own eagerness to receive them. Others commented on the potential risk of stroke posed by Covid-19 infection in otherwise healthy people:

> Covid-19 is dangerous—1/3 of Covid survivors have serious complications like stroke… (Twitter user 20)

Vaccine access

Some expressed eagerness to be vaccinated against Covid-19, while those who had received a vaccination expressed gratitude and relief:

> Uuuuurrgh—I really want that vaccine, y'all. (Twitter user 15)

Discussion

Summary of results

The research objectives have been met. This analysis of Twitter using codebook thematic analysis enabled the production of a rich picture of key topics in relation to stroke recovery of importance to stroke survivors and the general public. Twitter was utilised as a method of peer support, a platform for raising awareness and a source of information. The discussions about stroke recovery on Twitter were diverse, with several prominent themes arising (Table 2).

Recommendations for research and policy prioritisation

Table 3 shows our recommendations about topics that require attention from researchers, clinicians and policy makers, based on the six themes and 22 subthemes uncovered.

Results in context of previous research

The recent priority setting partnership (PSP) exercise conducted in the UK used surveys and workshops involving stroke survivors, carers and stroke health professionals to ascertain key topics of research for prioritisation [1]. Both our study and the PSP found the psychological impact of stroke to be a key theme. The sudden adjustment after stroke has vast psychological implications [11], yet research in this area is lacking. A previous UK study identified the provision of psychological rehabilitation as a primary concern amongst stroke clinicians [12]. A recent global systematic review showed that this aspect of stroke recovery is valued highly by key stakeholders in high-income countries [13]. Improving motivation was a key finding in both PSP and our study, Twitter users did this by sharing their own stories of success.

A key theme that arose from the Twitter data was that of increasing public awareness of the personal burden of stroke.

Table 3. Recommendations for research and policy prioritisation for stroke according to Twitter users.

Psychological support	Improve the detection and management of psychological problems post stroke.
• Support the maintenance of motivation during recovery and beyond. • Aid the development of coping mechanisms to build psychological resilience. • Foster a sense of community for stroke survivors and carers. • Improve management of low mood, negative feelings and anxiety after stroke.	
Raising awareness	Enhance the public perception of stroke survivors and awareness within the stroke survivor population.
• Raise awareness of risk factors for stroke. • Raise awareness of atypical presentations e.g., stroke in younger people. • Reduce stigma faced by stroke survivors. • Improve access to reliable information e.g., enhance information sharing.	
Rehabilitation experience	Improve the experience of rehabilitation and foster equality.
• Reduce healthcare workload and treatment burden after stroke. • Improve aid with financial difficulties after stroke. • Improve equitable access to rehabilitative services following stroke. • Provide person-centred, individualised care.	
Symptom improvement	Improved management of symptoms following stroke.
• Enhance treatments for physical symptoms e.g., limb weakness, numbness, seizures. • Improve the management and prevention of reduced mobility. • Improve recognition and management of fatigue. • Better support those with aphasia and improve treatments.	

Raising awareness of stroke symptoms has featured in other stroke priority-setting exercises [13]. Twitter users expressed a strong desire for public recognition as individuals, and a reduction in stigma faced. These findings were not reported from other priority-setting exercises, although the need to individualise care was recognised in the PSP as was the improvement of public understanding about hidden disabilities [1].

Twitter was used to promote a sense of community amongst stroke survivors, aid positivity, impart information, and share coping mechanisms. These aspects of stroke recovery were not detailed in other priority-setting exercises [1,13]. Communication with other stroke survivors is likely to be particularly important for people with less well-established social networks, and those who wish to connect with others going through a similar experience. One benefit of using social media is the ability to join and withdraw from a conversation at any point in time, which may be beneficial for those with post-stroke issues such as fatigue and emotional lability.

Mobility issues were reported as a major hurdle in recovery by Twitter users and similarly the PSP and a recent Swedish questionnaire study found this to be a central concern for stroke survivors [1,14]. Twitter users reported fatigue as being very impactful on quality of life and other studies have reported similar [1,14,15] yet this remains poorly understood and treated [16]. Another similarity between our findings and other priority-setting exercises was the need for better management of communication issues such as aphasia [1,14], an important yet under researched sequalae of stroke. To address this, a large collaboration of aphasia trialists have recently conducted an individual participant data meta-analysis of systematically sourced aphasia datasets that provides important insights into the trajectory of aphasia after stroke and the effectiveness of aphasia interventions [17].

Previous studies and our own findings indicate a need for reduced inequality in rehabilitation service provision [1,13]. Treatment burden was an issue highlighted by Twitter users, yet this was not reported in the PSP or other priority-setting studies [1,13]. Previous research has shown treatment burden to be a topic of high importance to stroke survivors [18]. The PSP did emphasise a need to improve the patient experience and provide person-centred care [1]. Echoing previous priority-setting exercises [1,13], some Twitter users reported financial challenges after stroke. A pressing need for improved services for young stroke survivors was reported by both our study and the PSP [1], similar to findings by recent studies conducted in Australia [19] and the US [20].

Twitter users did not discuss cognitive difficulties online, yet the PSP and other studies have found this to be a topic of concern [1,21]. This may be due to selection bias in our study, as those with cognitive difficulties may be less likely to engage with online platforms. Similarly, the PSP and other priority-setting exercises have placed an emphasis on the need to acknowledge carer burden and provide support for carers of stroke survivors [1,13], yet this was not a theme that arose in our analysis. This is likely to be because the hashtags chosen in our study were more likely to be utilised by stroke survivors than carers, rather than an indication that the topic is unimportant to Twitter users. Lastly, Twitter users reported concerns about Covid-19, and although not reported in the PSP, this was likely due to the timing of data collection, and because the PSP did not focus on the pandemic [1].

Strengths and limitations

The aim was to explore a small sample of tweets rather than conduct an exhaustive search or obtain a representative sample, which aligns with our qualitative research paradigm and thematic analysis

methods [2]. The recommendations made are not intended to be exhaustive but valuable alongside other priority setting exercises. Check coding of a subset of data by a second researcher enhanced rigour. The researcher conducting data analysis was a medical student and the second coder was an academic general practitioner so both had experience and knowledge of stroke treatments and recovery, which could have influenced results. An individual with lived experience of stroke and its recovery helped to analyse findings and make sense of the key themes found. This is an important strength.

The word count limit on tweets could have restricted depth of meaning. There was no communication with participants, so clarification of tweets or further discussion was not possible. However, a rich picture was built using the data available. Only tweets containing relevant hashtags over a four-week period were included and therefore tweets may not be representative of all tweets on this topic. The decision to use a four-week period was made following our scoping search that revealed a high yield of relevant tweets using the two identifiers selected (#strokesurvivor and #strokerecovery). Tweets examined were posted during the Covid-19 pandemic and this may have influenced results.

The lack of biographical information on Twitter meant that it was not always possible to know if the person tweeting was a stroke survivor or carer or interested member of the public, but their use of the relevant hashtags suggested that they were interested in stroke recovery. Additionally, the wording of most tweets did suggest that the user was a stroke survivor, but we were unable to verify this, and the length of time since stroke was unknown. The lack of biographical information was a notable limitation. It is unlikely that Twitter users are representative of all stroke survivors, for example, post-stroke sequalae such as aphasia or visual changes may make the use of digital devices difficult. However use of this novel method allows access to a different population from in-person methods. Examination of representativeness was not possible due to the lack of biographical information. The anonymous nature of Twitter therefore resulted in clear limitations, however it is possible that being able to post concerns anonymously encourages individuals to express opinions that they would not typically voice to a researcher or health professional.

Tweets by accounts that had chosen private settings were not accessible and this may have resulted in certain aspects of stroke survivorship being underrepresented in the dataset. Selection bias may have arisen not only from the exclusion of those unable to use social media but also those who chose not to, for example those who wished to avoid information about stroke recovery or feared accessing unreliable information.

Future research

Further research using social media for priority setting exercises could consider using public platforms like Twitter (now known as X) to ask users about what they think are important research topics or to gain feedback on the importance of difference research topics in relation to one another. Analysis of data from private chatrooms for stroke survivors and carers would be very useful however informed consent would be required from participants.

Conclusion

In summary, this study demonstrates the utility of Twitter in assessing the views of stroke survivors and the general public about stroke recovery. Twitter served both as a facilitator of discussion amongst users and a useful intermediary between stroke survivors and the general public. Lack of biographical information about participants was a key limitation. The findings will serve to complement those of the PSP and other priority-setting exercises [1,13] in guiding the apportionment of stroke funding to the areas of greatest need.

Consent form

No informed consent required as data available in public domain.

Guarantor

KG.

Author contributions

KG, TQ, and DRM researched literature and conceived the study. DP collected and analysed the data with input from KG and PM. KG and DP wrote the first draft of the manuscript. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

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