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Development of the stroke patient concerns inventory: A modified Delphi study

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Objectives: Stroke survivors often have unmet physical, psychological and/or social concerns. Patient Concerns Inventories (PCIs) have been developed for other health conditions to address concerns. Our objective was to develop a PCI for stroke care. *Methods:* This was a development study, including Modified Delphi study design, with academic and healthcare professionals with stroke care expertise.

In Stage 1, a draft Stroke PCI (Version 1a) was created through identifying patient-reported concerns post-stroke from three previous studies and through expert panel discussions using Nominal Group Technique.

In Stage 2, Version 1a was sent to 92 academic and healthcare professionals with stroke care expertise. Participants ranked their top 20 Stroke PCI items in order of importance and provided feedback. Rankings were converted into scores, and, with the feedback, used to amend the Stroke PCI. Two further rounds of feedback followed until consensus was reached between participants. A final draft of the Stroke PCI was created. *Results:* In stage 1, 64 potential Stroke PCI items were generated.

In Stage 2, 38 participants (41.3%) responded to the request to rank Stroke PCI items. The three highest ranked items were ‘Risk of another stroke’, ‘Walking’, ‘Recovery’.

After three rounds of feedback and amendments, the final draft of the Stroke PCI consisted of 53 items. *Conclusions:* A Stroke PCI has been developed using patient-reported concerns in previous studies and input from academic and healthcare professionals. Future work will involve gathering further feedback on the tool and exploring its acceptability and usability in a pilot study.

Keywords: Stroke—Patient-centred care—Quality of life—Unmet need—Patient concerns inventory

Introduction

Globally, there are estimated to be almost 25.7 million stroke survivors, and stroke is the third most common cause of disability worldwide.[1] The impact of stroke is sudden, and can be devastating and life-changing.[2] A stroke can result in a range of short and long-term

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physical, psychological and social problems for survivors.[3–6] Stroke survivors' needs can present at different times post-stroke and differ between individuals. Evidence suggests that, long-term, stroke survivors' needs are often inadequately met.[7–9] This is particularly so for younger stroke survivors.[10,11]

The diversity and number of patient needs, expressed as concerns, can make identification and prioritisation a challenge for healthcare professionals in the limited clinic time available. At least half of stroke survivors experience difficulties in communicating their varied healthcare needs.[12] Additionally, factors such as pride or acceptance of changed circumstances,[13] and stigma associated with reporting of mental health problems,[14] can further impede the identification of concerns. However, it is imperative that survivors' concerns are identified and managed, as long-term unmet need post-stroke is associated with reduced quality of life[15] and greater burden on the caregiver.[8] Without a standardized way of identifying and managing survivors' longer-term concerns post-stroke, practice will vary across service providers and needs will continue to be unmet.

A 'Patient Concerns Inventory' (PCI), has been developed for people with head and neck cancer.[16] The PCI is an Item Prompt List, the concept and structure of which have been derived from 'Question Prompt Sheets' and 'Question Prompt Lists', which have been shown to help patients raise questions and concerns in a clinical consultation.[17–21] The PCI consists of a list of potential concerns, which act as an aide memoire for patients, who then highlight issues that they would like to discuss during their consultation. The PCI is effective in increasing patient satisfaction and drawing attention to issues not covered by standard cancer care assessments.[22–26] Use of the Head and Neck PCI increased consultation length by only one minute on average, with most patients stating it had improved their experience of the consultation.[16] A cluster randomized controlled trial showed the PCI to benefit patients by improving quality of life.[27]

Following the successful development and testing of the Head and Neck PCI, work has been undertaken to develop other condition-specific PCIs, including the Breast Cancer PCI,[28] the Neuro-oncology PCI,[29] the Rheumatology-specific PCI[30] and the PCI-Burns.[31] In this paper we describe the development of the stroke-specific PCI which has the potential to improve the identification and management of stroke survivors' concerns.

Aim

To develop a stroke-specific Patient Concerns Inventory.

Methods

Development work for a Stroke Patient Concerns Inventory (PCI) took part in two stages. In the first stage, an initial draft of the Stroke PCI (Version 1a) was developed with an expert panel by exploring the concerns reported by stroke survivors in our previous studies. In the second stage, items in Version 1a were rated by academic and healthcare professionals with expertise in stroke care.

Stage 1: creation of an initial draft Stroke PCI

Patient-reported needs and concerns were identified in three studies in which the authors had been involved. The first was the Stroke Association needs mapping review.[32–34] This was a systematic review which sought to identify stroke survivors' needs, experiences, prevalence of needs or problems, the degree of unmet need; and to prioritise needs and identify gaps. 27 studies where stroke survivors reported concerns were included in the systematic review, in total incorporating the concerns reported by 12,082 stroke survivor participants. The needs identified within the systematic review were then prioritised by several stroke service user groups, each with between 6 and 10 members, across England, Scotland, Wales and Northern Ireland. The service user groups also had the opportunity to add in any needs that they felt were missing from the review results. The second study was the Stroke Survivor Needs Survey,[9] which reported the needs and concerns of 1251 individuals who had experienced stroke. This survey built upon the previously described Stroke Association needs mapping review. The third study involved in-depth qualitative analysis of 60 transcripts from ten stroke survivor participants in a trial of Motivational Interviewing after stroke. Within the transcripts there were 257 expressions of stroke survivors' needs and concerns early after stroke.[3,35] Collating concerns from previous studies allowed a larger and more diverse range of participants (over 13,000) and concerns to be included than would have been possible within a single study.

Following the collation of stroke survivor-reported needs and concerns from a vast pool of participants, an 'expert panel' of individuals with extensive clinical and/or academic experience in stroke care was created from the clinical and professional networks of the research team members. Expert panel members were purposively selected to ensure diversity in role and professional background. The panel consisted of 15 members whose backgrounds included: Professor/Reader/Senior Lecturer, Consultant in Stroke Medicine, Stroke Specialist Nurse, Occupational Therapist and Clinical Psychologist. In addition to their clinical background, one of the panel members also had direct experience of caring for a close relative who had experienced a stroke.

Nominal Group techniques were used for panel discussions of the patient-reported needs and concerns identified from previous studies. The panel were asked two questions: "Which domains should be included in the

Stroke Patient Concerns inventory?" and "Which individual items should be included in the Stroke Patient Concerns inventory?" Panel members listed their individual ideas in silence (silent generation). The facilitator asked each panel member to state a single concern in turn, these were displayed for all members to see. Panel members could think of new concerns, but had to wait their turn before they could share with the group; this continued until ideas were exhausted. Panel members then had the ability to clarify and group similar concerns together. Each concern was discussed, and the final wording agreed by all panel members. The panel members were then provided with a ranking sheet and each member ranked the concerns anonymously. Votes were tabulated, and the items that received most votes were included. The results were shared with the group and discussed. This list of potential items was named Version 1a of the Stroke PCI (see Appendix 1).

Stage 2: rating of Stroke PCI items

Design: modified Delphi

Ethical review: Ethical approval for this work was received from the University of Central Lancashire's Science, Technology, Engineering, Medicine and Health Ethics Committee (reference number STEMH 534).

Procedure

A list of 92 academic and healthcare professionals working either full-time or part-time in the United Kingdom (UK), with expertise in stroke care, was created from our networks of professional contacts, knowledge of experts in the field and internet research to find other relevant experts whose professional contact details were publicly available.

These individuals were contacted via email and sent Version 1a of the Stroke PCI, a brief demographic questionnaire and a Participant Information Sheet. They were asked to complete the brief demographic questionnaire and to rate their top 20 Stroke PCI items in order of their perceived importance to stroke survivors. Explicit written consent was not sought – implied consent was assumed to have been given based upon participants returning the questionnaire and/or ratings.

After at least 1 month, any individuals who had not responded were sent the same email again. After this e-mail, any individuals who did not respond were deemed to be 'non-responders' and were not contacted again.

Results were collated, and each Stroke PCI item was given a score (based upon cumulative ratings) and placed in order of perceived importance. Free text comments made by raters were analysed qualitatively, using thematic analysis. A small working group [BC, CW, CL] modified the Stroke PCI Version 1a in light of the Stroke PCI item scores and free text comments. A second page was added to the Stroke PCI listing professionals a stroke survivor may wish to consult about their concerns. This is consistent with the structure of the original Head and Neck PCI.

A revised version (Version 1b) of the Stroke PCI was emailed to all participants who had rated the original items and who had indicated that they wished to continue their involvement. Feedback on Version 1b was used to make further changes, producing Version 1c. Version 1c was sent out for review to everyone who had responded on the previous occasion. Following feedback on Version 1c, further minor changes were made and the final draft (Version 1d) was produced and sent to participants. Consensus was reached between participants, in accordance with a Modified Delphi technique.[36]

Version 1d (see Appendix 2) will now be taken to the next phase of development (described in the discussion section).

Stroke survivor and carer involvement

Alongside the development work undertaken in Stages 1 and 2, two meetings were held over a 12-month period with different groups of stroke survivors and carers. The purpose of the meetings was to gather their feedback on the concept of a Patient Concerns Inventory, gather feedback on whether the draft Stroke PCI covered the main concerns they felt people might have after a stroke, and to seek their advice on plans for the next phase of research.

Results

Stage 1

Within the three studies, 372 concerns reported by stroke survivors were identified. Following the Nominal Group Technique, and subsequent review and discussion by the expert panel, 64 discrete items relating to potential concerns of stroke survivors were generated. Version 1a of the Stroke PCI is shown in Appendix 1.

Stage 2

Of the 92 individuals who were sent Version 1a of the Stroke PCI, 38 responded with feedback, equating to a response rate of 41.3%. Respondents' clinical backgrounds varied; these are shown in Table 1. The 'other' category includes those from backgrounds of Clinical Psychology, Neuropsychology, Speech and Language Therapy and Therapy Management.

68.4% of respondents (n = 26) were aged between 31 and 50 years, and 31.6% (n = 12) were aged between 51 and 65 years. Most participants (n = 21, 55.3%) were Senior Clinicians (Band 8 or above or Medical Consultant/GP), with other participants being Clinicians (n = 10, 26.3%), Senior Academics (Senior Lecturer, Reader and Professor) (n = 6, 15.8%) or Junior Academics (n = 1,

Table 1. *Response rates for each Stroke PCI version, according to clinical background.*

CLINICAL BACKGROUND	Request for feedback on Version 1a (including ratings)		Request for feedback on Version 1b		Request for feedback on Version 1c	
	No. approached	No. responded *(%)*	No. approached	No. responded *(%)*	No. approached	No. responded *(%)*
Medical doctor	15	7 *(46.7)*	5	2 *(40.0)*	2	2 *(100)*
Nurse	33	13 *(39.4)*	12	7 *(58.3)*	7	4 *(57.1)*
Physiotherapist	10	4 *(40.0)*	4	1 *(25.0)*	1	1 *(100)*
Occupational Therapist	10	4 *(40.0)*	4	0 *(0.0)*	0	0 *(0.0)*
Other	20	10 *(50.0)*	9	6 *(66.7)*	6	4 *(66.7)*
Unknown	4	0 *(0.0)*	0	—	0	—
TOTAL	**92**	**38** ***(41.3)***	**34***	**16** ***(47.1)***	**16**	**11** ***(68.8)***

*4 individuals who provided feedback on Version 1a did not wish to continue their involvement in the Stroke PCI development work and were therefore not approached to give feedback on Version 1b.

2.6%). Most participants (n = 30, 79.0%) worked either within secondary care or within the community. Some of these individuals also held a post within a Higher Education Institute. A minority of participants (n = 8, 21.0%) were based solely within a Higher Education Institute or within another setting (non-specified).

Of the 38 participants who responded with feedback to Version 1a, 34 were then sent Version 1b (4 individuals did not wish to continue their involvement in the development of the Stroke PCI and were therefore not approached again). 16 participants provided feedback on Version 1b. These 16 participants were subsequently sent Version 1c and 11 responded with feedback. These response rates are shown in Table 1 and Fig. 1.

The top five items, in terms of ratings of perceived importance, were 'Risk of another stroke', 'Walking', 'Recovery', 'Mood' and 'Tiredness' (see Table 2).

Qualitative feedback was provided by participants during each round of review. Feedback about the PCI was generally positive in terms of its perceived usefulness to stroke survivors and applicability to the stroke outpatient clinic setting. Participants felt that the Stroke PCI was "looking really good", was a "great project" and was "very concise. . .[with]...all avenues covered". Participants commented on the tool's layout and formatting, emphasizing the importance of ensuring that the tool was accessible to stroke survivors with a range of disabilities including aphasia and vison/neglect problems. Participants pointed out that stroke survivors' concerns may vary across time, and that the nature of their concerns may be influenced by the availability of resources within their local community.

There were differing suggestions as to which items could be combined, such as:

- anxiety / depression / mood / fear / confidence
- eating / drinking / swallowing / weight / diet
- tiredness / sleep / energy

For some items, such as 'Relationships', participants differed in opinions of how best to further define the concept. Participants had the opportunity to comment on changes with each version circulated.

In addition to commenting on the items themselves, participants were also asked to provide feedback on the suitability of the domains to which items were allocated. Generally, there was agreement about the domain allocations, but there was debate concerning the allocation of the items 'Talking/Communication', 'Reading/Writing', 'Personal care' and 'Hearing' in terms of whether they would be more appropriately allocated to the 'Physical and functional wellbeing' domain or to the 'Social care and social wellbeing' domain. Ultimately, these items were allocated to the Social domain: although these problems may be physical in origin, they have a significant impact on a stroke survivor's social functioning and wellbeing.

Participants also suggested more professionals to add to the list in the Stroke PCI Version 1b, most notably 'Audiologist' and 'Orthoptist/Optician' were added. It was apparent from participants' responses that access to a local Stroke Association adviser depends on whether the service is commissioned within the local area. We retained the term 'Stroke Association' on the Stroke PCI, in order

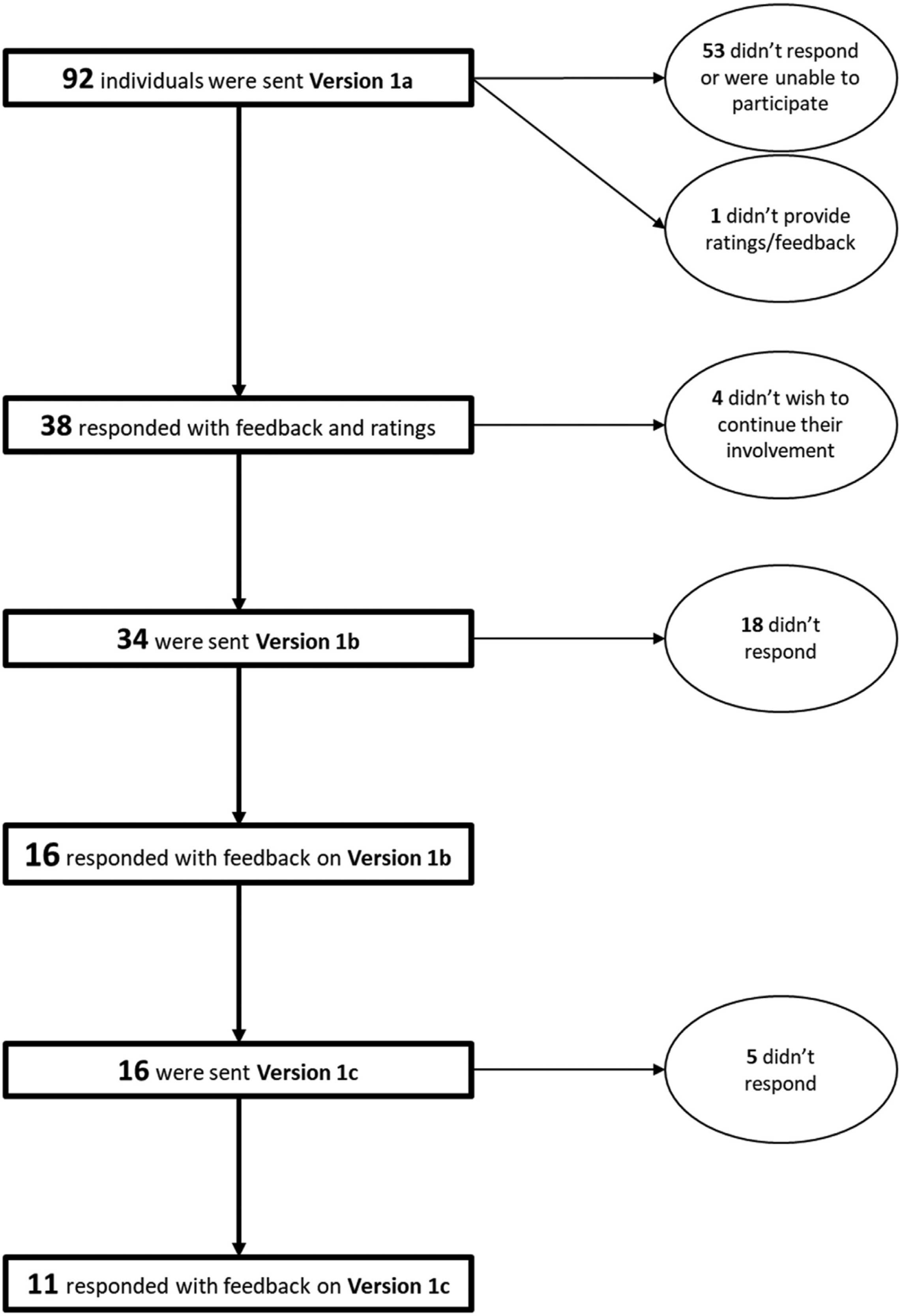

Fig. 1. *Response of participants to each Stroke PCI version.*

Table 2. *Total scores and rankings for Version 1a Stroke PCI items*

ITEM	TOTAL SCORE	RANK
Risk of another stroke	417.0	**1**
Walking	414.5	**2**
Recovery	306.5	**3**
Mood	301.0	**4**
Tiredness	274.5	**5**
Talking	264.0	**6**
Pain	258.5	**7**
Driving	245.5	**8=**
Memory	245.5	**8=**
Therapy	235.0	**10**
Medication	233.5	**11**
Independence	229.0	**12**
Continence	218.5	**13**
Confidence	206.0	**14**
Emotions (anger, crying, laughing inappropriately)	193.0	**15**
Arm movement	192.0	**16**
Help and Support	188.5	**17**
Swallowing	184.5	**18**
Test results	170.5	**19**
Hand movement	169.5	**20**
Coping	149.0	**21**
Concentration	140.0	**22=**
Understanding	140.0	**22=**
Depression	139.0	**24**
Lifestyle (Smoking and alcohol)	138.0	**25**
Return to work	136.0	**26**
Anxiety	134.0	**27**
Balance	125.5	**28**
Energy	112.0	**29**
Financial and benefit advice	109.0	**30**
Drinking	104.0	**31**
Behaviour or personality	102.0	**32**
Vison	97.5	**33**
Loneliness / Isolation	92.0	**34**
Aids & adaptations	88.0	**35**
Eating	87.5	**36**
Falls and accidents	84.0	**37=**
Relationships	84.0	**37=**
Sleep	77.0	**39**
Personal care (washing & dressing)	73.0	**40**
Exercise	64.0	**41**
Headaches	62.0	**42**
Fear	60.5	**43**
Fits/seizures	57.0	**44**
Travel	46.0	**45**
Other tests	44.0	**46**
Return to hobbies	39.5	**47**
Accommodation	39.0	**48**
Spasms / stiffness	38.5	**49**
Dizziness	34.5	**50**
Diet	32.0	**51**
Sensation	26.0	**52**
Sex	25.5	**53**
Children	22.0	**54**
Transport	10.0	**55**
Reading	5.0	**56**
Shopping	3.0	**57**
Weight	2.0	**58**
Mouth care	1.0	**59**
Hearing	0.0	**60=**
Housework	0.0	**60=**
Numbers	0.0	**60=**
Pregnancy	0.0	**60=**
Writing	0.0	**60=**

to cover both local advisers and the national Stroke Association organisation in the case of a local service being unavailable. For some terms, such as 'Speech and Language Therapist (for communication/swallowing problems)' and 'Stroke Doctor', discussion ensued regarding the most appropriate term to ensure stroke survivors' understanding. The terms decided upon will be presented to stroke survivors and carers in the next phase of work and their feedback sought.

Version 1d consists of 53 items on one page, categorised according to the original Head and Neck PCI domains of 'Physical and functional wellbeing', 'Treatment related', 'Psychological, emotional and spiritual wellbeing' and 'Social care and social wellbeing'. Twenty professionals are listed on the second page, grouped under the same categories.

Stroke survivor and carer involvement

Two separate groups, each with 7 individuals, met over a 12-month period. The groups comprised stroke survivors and carers, with a mix of genders across a range of ages and ethnicities, and included individuals with communication impairments. Both groups felt strongly that needs and concerns are often not adequately addressed within clinic appointments and agreed that the research is very important.

When the first group were shown the existing Head and Neck Cancer Patient Concerns Inventory, the stroke survivors and carers were very supportive of its concept and potential use as a tool within the stroke clinic. They thought it would be very useful and would help them raise concerns. They discussed ways in which to make the PCI user-friendly, such as ensuring plain English is used and considering the best colours and formatting to use. They also considered different accessibility options, e.g. online, on a tablet and in paper form. When the second group were shown the draft Stroke PCI they felt it covered all the main concerns they had or that they felt people might have after a stroke, that there were no omissions, and that the organisation of concerns within each category was appropriate. The group thought the format was clear and easy to use and felt it was a good prompt for discussing concerns. It was deemed important to factor in time for clinic staff to help stroke survivors/carers complete the PCI if needed, and to allow opportunities for completion at numerous time points post-stroke, e.g. at discharge and at home before a clinic appointment, as well as in the outpatient waiting room.

The stroke survivors and carers also gave advice on aspects of the next phase of research, in which the usability and acceptability of the Stroke PCI will be explored within a clinic setting. They emphasized the importance of giving potential participants ample time and space to consider taking part, by providing the study information to them well in advance of the clinic appointment. They also advised that, whilst some stroke survivors may initially decline to take part, their wishes may change over time and therefore it is worth (with consent) sending them the study information again, at a later date post-stroke. Stroke survivors discussed the possibility of audio recording clinical consultations as a means of data collection, and it was clear that some individuals would not consent to this and therefore an alternative method of data collection would need to be agreed.

Discussion

The aim of this study was to develop a stroke-specific PCI. The first stage of work involved an exploration of concerns reported by stroke survivors in previous studies, followed by an expert panel using Nominal Group Technique to generate PCI items based upon the identified concerns. The second stage involved a range of clinical and academic professionals with expertise in stroke care reviewing the PCI items. Through this work we have produced a 53-item Stroke PCI which was then reviewed by stroke survivors and carers. The tool has reproduced the domains used in the original Head and Neck PCI[16] and also lists twenty different professionals that a stroke survivor may wish to see. Whilst developed within a UK setting, it is anticipated that the Stroke PCI could subsequently be adapted for use in other global health settings in which services and clinicians may be named differently. The next phase of work will entail an exploration of the acceptability of the Stroke PCI followed by further amendment, and the feasibility of its use tested in a pilot study.

One could question the premise of adapting a tool developed in Head and Neck Cancer for use in stroke care. However, it is the concept and approach used within Head and Neck Cancer, i.e. that of an Item Prompt List, which has been used, and not the content itself. The approach of using an Item Prompt List to better elicit the problems and concerns of patients has clearly been feasible and successful for Head and Neck Cancer patients, Rheumatology patients, Breast Cancer patients and for Neuro-Oncology patients.[16,26,28–30] Given the level of unmet need following a stroke,[9] it seems imperative to explore whether this same approach could also greatly benefit stroke survivors by enabling their concerns to be better heard, understood and ultimately resolved. In developing the Stroke PCI, the concept and structure of the tool have been maintained, but the content (i.e. the items themselves and the professionals listed) has been specifically developed to reflect the perceived needs and concerns of stroke survivors.

The Stroke PCI will be complementary to existing questionnaires, such as the Greater Manchester Stroke Assessment Tool,[37] Longer-term Unmet Needs after Stroke questionnaire[38] and Post Stroke Checklist,[39,40] which seek to evaluate level of need in a number of key areas post-stroke. Questionnaires such as these create a standardised approach for evaluating need after a stroke, whereas the PCI seeks to create a nuanced, individualised approach in which a stroke survivor is able to tailor a consultation to address their individual concerns where possible. Compared to existing questionnaires, the Stroke PCI will also be much quicker to complete and cognitively less demanding, attributes which are especially important within a noisy, busy and time-pressured outpatient clinic environment. The Stroke PCI can therefore also be used at various points along the stroke care pathway; whilst an individual's concerns might change over time, the design of the Stroke PCI means that it can act as a prompt enabling them to express their concerns at any timepoint. Within the next phase of work, stroke survivor and carer input will be sought to ensure that the final version of the Stroke PCI is as user-friendly, acceptable and readable as possible. This will optimize its potential as an aid for stroke survivors within a busy clinic environment.

It is clear from professional feedback on the Stroke PCI and from our own clinical knowledge that the local services available to stroke survivors may differ substantially across geographical areas[41] in part due to differences in commissioning arrangements. One could argue that a Stroke PCI could raise a stroke survivor's expectations inappropriately if a concern is identified but no local service is available to address this concern. Whilst a valid consideration, it is our belief that the varying availability of local services is not a reason to discourage a stroke survivor from raising a concern that is important to them. Rather, training in the use of the tool should help clinicians develop suitable strategies to address stroke survivors' concerns when the relevant services are not directly available. Additionally, use of the Stroke PCI may highlight the need for expansion of services for areas that are neglected and could thus drive service development. Within the future feasibility study, we will explore with stroke survivors and clinicians the degree to which the Stroke PCI could be locally adapted by individual

National Health Service Trusts and/or local areas in order to better reflect the services available locally. It will be necessary to agree which components and/or principles of the Stroke PCI are the core ingredients that cannot be changed and which aspects could be amenable to local adaptation.[42] Reassuringly, evidence from the development of the Head and Neck PCI, the Neuro-Oncology PCI and the Rheumatology-specific PCI demonstrates very high levels of patient and staff satisfaction with the tools,[16,26,29,30] thus suggesting that inappropriate raising of expectations is not a significant concern.

Study limitations

Firstly, the participants who rated the Stroke PCI items and provided qualitative feedback on the tool were selected using a purposive sampling strategy, based upon the authors' professional networks and information publicly available on the internet. Ideally participants would have been randomly selected from an existing list/framework, but, given that no such list exists for academic and healthcare professionals with expertise in stroke care, this was not possible. The sampling strategy was pragmatic and felt to be sufficiently robust for this development phase.

Secondly, the number of participants who responded to the first round of feedback was only 38 (response rate of 41.3%). However, the diversity of respondents, in terms of professional background, seniority and clinical exposure, strengthens the relevance of their feedback.

Finally, it is possible that there are important post-stroke concerns that have not been identified within the studies reviewed and the discussions held with professionals. However, the next phase of work, in which stroke survivors and carers will be approached to provide further feedback on the Stroke PCI, will provide an essential opportunity to identify any additional concerns that may be missing from the tool. Additionally, the Stroke PCI is not designed to evaluate every possible problem or concern a stroke survivor may have, but rather simply to act as a prompt to empower stroke survivors to raise concerns for which they may receive reassurance or support as appropriate. Hence there is a space within the tool for a stroke survivor to write about any other problem or concern that is important to them, and this therefore provides scope for items not already listed to be raised.

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.jstrokecerebrovasdis.2023.107053.

References

1. Feigin VL, Norrving B, Mensah GA. Global burden of stroke. Circ Res 2017;120:439-448. https://doi.org/10.1161/CIRCRESAHA.116.308413.
2. Salter K., Hellings C. Foley N., Teasell R. The experience of living with stroke: a qualitative meta-synthesis. J Rehabil Med. 2008;40:595−602.
3. Auton MF, Patel K, Carter B, et al. Motivational Interviewing post-stroke: An analysis of stroke survivors' concerns and adjustment. Qual Health Res 2016;26:264-272.
4. Walsh ME, Galvin R, Loughnane C, et al. Community re-integration and long-term need in the first five years after stroke: results from a national survey. Disabil Rehabil 2015;37:1834-1838.
5. Murray J, Ashworth R, Forster A, Young J. Developing a primary care-based stroke service: a review of the qualitative literature. Br J Gen Pract 2003;53:137-142.
6. Murray J, Young J, Forster A, Ashworth R. Developing a primary care-based stroke model: the prevalence of longer-term problems experienced by patients and carers. Br J Gen Pract 2003;53:803-807.
7. Andrew NE, Kilkenny M, Naylor R, et al. on behalf of the National Stroke Foundation. Understanding long-term unmet needs in Australian survivors of stroke. Int J Stroke 2014;9:106-112.
8. Ekstam L, Johansson U, Guidetti S, et al. The combined perceptions of people with stroke and their carers regarding rehabilitation needs 1 year after stroke: a mixed methods study. BMJ Open 2015;5:e006784.
9. McKevitt C, Fudge N, Redfern J, et al. Self-reported long-term needs after stroke. Stroke 2011;42:1398-1403.
10. Kersten P, Low JTS, Ashburn A, et al. The unmet needs of young people who have had a stroke: results of a national UK survey. Disabil Rehabil 2002;24:860-866.
11. Low JTS, Kersten P, Ashburn A, et al. A study to evaluate the met and unmet needs of members belonging to Young Stroke groups affiliated with the Stroke Association. Disabil Rehabil 2003;25:1052-1056.
12. O'Halloran R, Worrall L, Hickson L. Stroke patients communicating their healthcare needs in hospital: a study within the ICF framework. Int J Lang Commun Disord 2012;47:130-143.
13. Shannon RL, Forster A, Hawkins RJ. A qualitative exploration of self-reported unmet need one year after stroke. Disabil Rehabil 2016;38:2000-2007.
14. Corrigan P. How stigma interferes with mental health care. Am Psychol 2004;59:614-625.

15. Andrew NE, Kilkenny MF, Lannin NA, Cadilhac DA. Is health-related quality of life between 90 and 180 days following stroke associated with long-term unmet needs? Qual Life Res 2016;25:2053-2062.
16. Rogers SN, El-Sheikha J, Lowe D. The development of a Patients Concerns Inventory (PCI) to help reveal patients concerns in the head and neck clinic. Oral Oncol 2009;45:555-561.
17. Butow PN, Dunn SM, Tattersall MH, Jones QJ. Patient participation in the cancer consultation: evaluation of a question prompt sheet. Ann Oncol 1994;5:199-204.
18. Brown R, Butow PN, Boyer MJ, Tattersall MHN. Promoting patient participation in the cancer consultation: evaluation of a prompt sheet and coaching in question-asking. Br J Cancer 1999;80:242-248.
19. Brown RF, Butow PN, Dunn SM, Tattersall MHN. Promoting patient participation and shortening cancer consultations: a randomised trial. Br J Cancer 2001;85:1273-1279.
20. Clayton J, Butow PN, Tattersall M, Chye R, et al. Asking questions can help: development and preliminary evaluation of a question prompt list for palliative care patients. Br J Cancer 2003;89:2069-2077.
21. Rogers SN, Thomson F, Lowe D. The Patient Concerns Inventory integrated as part of routine head and neck cancer follow-up consultations: frequency, case-mix, and items initiated by the patient. Ann R Coll Surg Engl 2018;100:209-215.
22. Rogers SN, Cleator AJ, Lowe D, Ghazali N. Identifying pain-related concerns in routine follow-up clinics following oral and oropharyngeal cancer. World J Clin Oncol 2012;3:116-125.
23. Ghazali N, Kanatas A, Langley DJR, et al. Treatment referral before and after the introduction of the Liverpool Patient Concerns Inventory (PCI) into routine head and neck oncology outpatient clinics. Support Care Cancer 2011;19:1879-1886.
24. Ghazali N, Lowe D, Rogers SN. Enhanced patient reported outcome measurement suitable for head and neck cancer follow-up clinics. Head Neck Oncol 2012;4:32 .
25. Kanatas A, Ghazali N, Lowe D, Rogers SN. The identification of mood and anxiety concerns using the patients concerns inventory following head and neck cancer. Int J Oral Maxillofac Surg 2012;41:429-436.
26. Rogers SN Lowe D. An evaluation of the head and neck cancer patient concerns inventory across the merseyside and cheshire network. Br J Oral Maxillofac Surg 2014;52:615-623.
27. Rogers SN, Allmark C, Bekiroglu F, et al. Improving quality of life through the routine use of the patient concerns inventory for head and neck cancer patients: main results of a cluster preference randomised controlled trial. Eur Arch Otorhinolaryngol 2020;278:3435-3449.
28. Kanatas A, Lowe D, Velikova G, et al. Issues patients would like to discuss at their review consultation in breast cancer clinics – a cross-sectional survey. Tumori 2014;100:568-579.
29. Rooney AG, Netten A, McNamara S, et al. Assessment of a brain-tumour-specific Patient Concerns Inventory in the neuro-oncology clinic. Support Care Cancer 2014;22:1059-1069.
30. Ahmed AE, Lowe D, Kirton JA, et al. Development of a Rheumatology-specific Patient Concerns Inventory and its use in the Rheumatology outpatient clinic setting. J Rheumatol 2016;43:779-787.
31. Gibson JAG, Spencer S, Rogers SN, Shokrollahi K. Formulating a Patient Concerns Inventory specific to adult burns patients: learning from the PCI concept in other specialties. Scars, Burns Heal 2018;4. https://doi.org/10.1177/2059513117763382.
32. French B, Leathley M, Radford K, et al. UK Stroke Survivor Needs Survey Information Mapping Exercise. Final report for the Stroke Association. London, UK: Stroke Association; 2008.
33. French B., Burton C., Dey P., et al. Needs after stroke rehabilitation: an information mapping review. UK. 3rd UK Stroke Forum Conference Harrogate. 2008:39. 3rd UK Stroke Forum Conference Book of Abstracts.
34. Radford K., Burton C., Dey P., et al. Needs after stroke rehabilitation: stroke service users' views. UK. 3rd UK Stroke Forum Conference Harrogate. 2008:57. 3rd UK Stroke Forum Conference Book of Abstracts.
35. Watkins CL, Auton MFA, Deans CF, et al. Motivational Interviewing early after acute stroke: a randomised controlled trial. Stroke 2007;38:1004-1009.
36. Dalkey N, Helmer O. An experimental application of the Delphi method to the use of experts. Manage Sci 1963;9:458-467.
37. Rothwell K, Boaden R, Bamford D, Tyrrell PJ. Feasibility of assessing the needs of stroke patients after 6 months using the GM-SAT. Clin Rehabil 2013;27:264-271.
38. LoTS care LUNS study team. Validation of the Longer-term Unmet Needs after Stroke (LUNS) monitoring tool: a multicentre study. Clin Rehabil 2013;27:1020-1028.
39. Philp I, Brainin M, Walker MF, et al. on behalf of the Global Stroke Community Advisory Panel. Development of a Poststroke Checklist to standardize follow-up care for stroke survivors. J Stroke Cerebrovasc Dis 2013;22:e173-e180.
40. Ward AB, Chen C, Norrving B, et al. on behalf of the Global Stroke Community Advisory Panel (GSCAP). Evaluation of the post stroke checklist: a pilot study in the United Kingdom and Singapore. Int J Stroke 2014;9:76-84.
41. Sentinel Stroke National Audit Programme (2019). Results - Post-Acute Audit., https://www.strokeaudit.org/results/PostAcute.aspx [accessed 19.06.19].
42. Dusenbury L, Brannigan R, Falco M, Hansen WB. A review of research on fidelity of implementation: implications for drug abuse prevention in school settings. Health Educ Res 2003;18:237-256.