

BMJ Open

BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (<http://bmjopen.bmj.com>).

If you have any questions on BMJ Open's open peer review process please email info.bmjopen@bmj.com

BMJ Open

The Views of Public and Clinician Stakeholders on Risk Assessment Tools for Post-Stroke Dementia: A Qualitative Study

| | |
|-------------------------------|--|
| Journal: | <i>BMJ Open</i> |
| Manuscript ID | bmjopen-2018-025586 |
| Article Type: | Research |
| Date Submitted by the Author: | 23-Jul-2018 |
| Complete List of Authors: | Tang, Eugene; Newcastle University, Institute of Health and Society Exley, Catherine; Northumbria University, Faculty of Health and Life Sciences Price, Christopher; Newcastle University, Institute of Neuroscience, Stroke Research Group Stephan, Blossom; Newcastle University, Institute of Health and Society Robinson, Louise; Newcastle University, Institute of Health and Society |
| Keywords: | PRIMARY CARE, STROKE MEDICINE, QUALITATIVE RESEARCH, Dementia < NEUROLOGY |
| | |

SCHOLARONE™
Manuscripts

Peer Review Only

The Views of Public and Clinician Stakeholders on Risk Assessment Tools for Post-Stroke Dementia: A Qualitative Study

Dr. Eugene Yee Hing Tang^{1,2} e.y.h.tang@newcastle.ac.uk

Prof. Catherine Exley³ catherine.exley@northumbria.ac.uk

Dr. Christopher Price⁴ c.i.m.price@newcastle.ac.uk

Dr. Blossom CM Stephan^{1,2} blossom.stephan@newcastle.ac.uk

Prof. Louise Robinson^{1,2} a.l.robinson@newcastle.ac.uk

¹ Institute of Health and Society, Newcastle University, Baddiley-Clark, Richardson Road, Newcastle upon Tyne, UK, NE2 4AX

² Newcastle University Institute of Ageing, Newcastle University, Campus for Ageing and Vitality, Newcastle upon Tyne, UK, NE4 5PL

³ Faculty of Health & Life Sciences, Northumberland Building, Northumbria University, Newcastle upon Tyne, NE1 8ST

⁴ Institute of Neuroscience, Stroke Research Group, Newcastle University

Corresponding author: Dr. Eugene Yee Hing Tang, Institute of Health & Society, Newcastle University, Level 2, Newcastle Biomedical Research Building, Campus for Ageing and Vitality, Newcastle upon Tyne, NE4 5PL, T: 0191 208 8758,

E: e.y.h.tang@newcastle.ac.uk

Abstract

OBJECTIVE: Stroke-survivors are at increased risk of future dementia. Assessment to identify those at high risk of developing a disease using predictive scores has been utilised in different areas of medicine. A number of risk assessment tools for dementia have been developed but none has been recommended for use clinically. The aim of this qualitative study was to assess the acceptability and feasibility of using a risk model to predict post-stroke dementia.

DESIGN: Qualitative semi-structured interviews were conducted with thematic analysis. Patients and carers were also offered a follow-up interview at 12 months.

SETTING: The study was conducted in the North-East of England with stroke patients, family carers and healthcare professionals in primary and secondary care.

PARTICIPANTS: Thirty-nine (17 clinicians and 15 stroke patients and their carers at baseline. Twelve stroke patients and their carers were also seen at follow-up) interviews were conducted.

RESULTS: Barriers and facilitators to risk assessment were discussed by each group. For patients and carers the focus for facilitators were based on the outcomes of risk assessment i.e. an assessment could assist with preparation, diagnosis and for reassurance. For clinicians, facilitators were focused on the process i.e. familiarity in primary care, resource availability in secondary care and collaborative care. For barriers, both groups focussed on the outcome including for example the anxiety generated from a potential diagnosis of dementia. For patients and carers a further barrier included concerns about how it may affect their recovery. For clinicians there were concerns about limited interventions and how it would be different from standard care.

1
2
3 **CONCLUSIONS:** Risk assessment for dementia after stroke presents challenges
4 given the ramifications of a potential diagnosis of dementia. Attention needs to be
5 given to how information is communicated, and the strategies developed to support
6 patients and carers if risk assessment has taken place.
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Strengths and Limitations of the Study:

- To the best of our knowledge this is the first qualitative study to examine critically the views of stroke patients and their family carers and clinicians about the acceptability and feasibility of a risk assessment approach to assist in earlier identification of post-stroke dementia.
- Understanding stakeholder views on risk assessment for dementia can help inform future strategies if risk assessment for dementia is used to assist with earlier diagnosis.
- Patient participants came from one area of England who were able to attend hospital outpatient departments and so may not represent the views and experiences of those with more severe post-stroke sequelae.
- Clinician participants came from one area of England and so may not represent the views of other service models in other regions of the UK.
- It is recognized that clinicians tended to be more familiar with the process of risk assessment and could elaborate further on the process involved.

Introduction

There is currently no cure for dementia and it is estimated that the worldwide economic burden will rise to US\$2 trillion by 2030¹. It has been suggested that the most powerful way to affect costs is by reducing the numbers of people who develop the illness. This may be facilitated by prediction of individual risk for the disease. Stroke is associated with an increased risk of dementia and cognitive impairment²⁻⁴. A history of stroke doubles the risk of incident dementia in older populations, a risk that is independent of demographic and cardiovascular risk factors and prestroke cognitive decline². Stroke incidence and numbers of stroke-survivors are likely to increase due to simultaneous ageing populations and declining stroke mortality rates⁵. Given that the incidence of dementia increases exponentially with age^{1 6}, this will mean that post-stroke dementia will also become increasingly prevalent. It will therefore be important to identify those at greatest risk of developing dementia following stroke in order to implement strategies to reduce risk.

Risk prediction models for dementia to identify those at higher risk have been developed in whole populations^{7 8} with some models specifically developed to predict cognitive impairment and dementia in stroke populations⁹⁻¹². These stroke-specific models predict dementia or cognitive impairment over a relatively short time period. In spite of the expanding research in this field, none of the dementia risk prediction tools have been clinically implemented. Further, no studies have assessed the feasibility or acceptability of implementing such a strategy in a stroke population. Although risk models are currently used in everyday clinical practice in other branches of medicine, in particular prevention of cardiovascular¹³ and cerebrovascular¹⁴ disease, it is unclear how clinicians would feel about using a similar strategy to predict dementia. Further, no studies have evaluated whether

1
2
3 using risk assessment tools for dementia would be acceptable to stroke patients
4
5 themselves.

6
7
8 This paper presents findings from a qualitative study conducted with patients,
9
10 carers and clinicians, which sought to critically examine their views about the
11
12 acceptability and feasibility of using risk prediction models in post-stroke care to
13
14 identify those at greatest risk of future dementia.
15

16 17 18 19 **Methods**

20 21 22 *Patient and Public Involvement*

23
24
25 Patients and members of the public have been involved in the development of this study
26
27 from the beginning of the proposal. A participant advisory group also oversees the work
28
29 conducted and annual face-to-face meetings are held to inform them of the study findings.
30
31 The participant advisory group consists of members from a stroke research patient and carer
32
33 panel, an organisation aimed at capturing public views about research and from a dementia
34
35 and neurodegeneration specialty PPI group. The same group reviewed the study materials
36
37 to ensure suitability particularly for stroke-survivors and their family carers.
38

39 40 *Ethical Approval*

41
42
43 The study was conducted in the North East of England. Ethical Approval was
44
45 obtained from the London – Hampstead Research Ethics Committee (reference
46
47 16/LO/0133). Participants provided informed written consent prior to the interview.
48

49 50 *Data collection*

51
52
53 Interviews were conducted between April 2016 and July 2017 by one researcher
54
55 (EYHT). The topic guide was initially derived from relevant literature and expert
56
57
58
59
60

1
2
3 clinical views within the research team. It was designed to be iterative to enable any
4 topics, which had not been previously identified, to be pursued in subsequent
5 interviews. Face to face semi-structured interviews were conducted with all but one
6 participant (clinician) who had a telephone interview. The patient and family carer
7 were interviewed individually or in pairs as requested by participants. Clinicians were
8 interviewed individually. The interviews focussed on the benefits and challenges of
9 improving earlier diagnosis of dementia after stroke. This included specific questions
10 on the delivery of this assessment (e.g. who should carry it out), what variables could
11 be used and how best to manage the outcome. The interviews also sought the views
12 of stakeholders on the care experience of post-stroke individuals with memory
13 problems. The views of clinicians have been reported elsewhere¹⁵ and the views of
14 patients and carers will be reported separately. The process of risk assessment was
15 described to participants. This was further emphasised with examples of published
16 tools in order to highlight examples of variables used to ensure participant
17 understanding of the process. Informed written consent was obtained from all
18 participants prior to the interview commencing. All interviews were audio-recorded
19 and then transcribed verbatim. To protect participant anonymity, unique identifiers
20 were used throughout the process with identifiable personal data removed before
21 analysis was conducted.

Patient and Carer Sampling

22
23
24 Patients and carers were purposively sampled from stroke clinics. As part of routine
25 clinical practice in United Kingdom (UK) stroke services, all stroke-survivors are
26 invited to a specialist review at six months after the event which includes a general
27 enquiry about memory concerns¹⁶. If the patient reported any subjective memory
28 concerns at the clinic and was over the age of 60, the stroke specialist nurse would

1
2
3 provide further study information. Family carers were also recruited if they were
4 involved in the stroke-survivor's care, for example, if they attended the clinic
5 appointment with them. If potential participants were interested in taking part in the
6 study, their details were passed onto the research team. On receipt of this
7 information the patient or carer was contacted by one researcher (EYHT) to provide
8 detailed information and an opportunity to ask questions before agreeing to
9 participate. Participants were asked to take part in an interview immediately following
10 their six-month review and/or six months later.
11
12
13
14
15
16
17
18
19

20 *Clinician Sampling*

21
22
23 General Practitioners (GPs) and secondary care clinicians (stroke consultants and
24 specialist nurses) in the North East of England were contacted to participate in the
25 study. Participants were given an opportunity to ask further questions. Clinicians
26 were purposively sampled to ensure that a broad range of care professionals in both
27 primary and secondary care were recruited.
28
29
30
31
32
33
34

35 *Data analysis*

36
37 Interview data was analysed using thematic analysis¹⁷ following the principles of
38 constant comparative methods¹⁸. One researcher (EYHT) familiarised himself with
39 the dataset and subsequently coded the transcripts line-by-line. Initially, a small
40 subset of transcripts were analysed to identify initial themes and these were
41 discussed between CE and EYHT. Data collection and analysis was iterative and as
42 interviews progressed, further analysis led to new themes emerging and refinement
43 of existing themes and subthemes, which were subsequently grouped into broad
44 categories to facilitate interpretation¹⁹. The wider team (EYHT, CE, LR, BS and CP)
45 discussed and agreed on the final categories which are presented below. For patient
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 and carer interviews, where follow-up interview data was also obtained, these were
4
5 analysed as separate interviews to assess for any change in views over time. There
6
7 was particular focus to understand what was important to patients, carers and
8
9 clinicians. Data analysis was facilitated by a data software handling package (NVivo
10
11 version 11). The paper conforms to the Standards for Reporting Qualitative
12
13 Research checklist²⁰ (please see supplementary table 1).
14
15
16
17
18

19 **Results**

20
21
22 In total, 30 baseline interviews were conducted, analysed and compared including:
23
24 15 patient and carer interviews (see table 1) and 17 primary and secondary care
25
26 clinician interviews (see table 2). Eight stroke-survivors and four carers agreed to a
27
28 further follow-up interview six months later with nine interviews completed. The data
29
30 from this study suggest that in terms of risk assessment facilitators and barriers exist
31
32 to implementation. Whereas patient facilitators focussed on the outcome of the risk
33
34 assessment, clinicians focussed more on the process of risk assessment for
35
36 facilitators. Both groups discussed some potential barriers associated with risk
37
38 assessment focussing on the outcome.
39
40
41

42 ***Patient and Carer Views: Facilitators to Risk Assessment Focuses on the*** 43 44 ***Outcome of Assessment***

45
46
47 When stroke-survivors and carers discussed the concept of risk assessment, the
48
49 overarching theme was that an assessment outcome was what was important,
50
51 irrespective of the process and clinicians involved. Participants focussed on several
52
53 areas of why the outcome was important to them.
54
55

56 **For Preparation**

1
2
3 Some stroke-survivors were generally positive about receiving a risk assessment for
4 dementia. They acknowledged that a diagnosis was something that could enable
5 individuals to prepare themselves both at baseline and subsequently at follow-up
6 interview:
7
8
9

10
11
12 *“It’s the same as knowing and not knowing, if you know that something is*
13 *approaching. Not everybody is the same with the problem. You might be able to deal*
14 *with it in a different way or the person supporting you, the nurse or whoever, might*
15 *be able to find a different way or a more positive way of managing it.” (P6, male,*
16 *stroke-survivor at follow-up interview)*
17
18
19
20
21
22

23 Similarly, for carers, there was the emphasis on what could be done following the
24 assessment. One carer emphasized the importance of looking after the whole
25 person, and, how earlier recognition of a potential dementia diagnosis could ensure
26 strategies were in place to help the individual:
27
28
29
30
31

32
33 *“But I think, if you look at the whole thing of this care of this person, if we knew*
34 *earlier that you know the chances are that your memory is going to get bad and you*
35 *are going to go into dementia or whatever, then we can start thinking, “Right, well*
36 *let’s prop it up, let’s think of ways in helping your memory as it is, to maintain the*
37 *level it is before you’ve got no choice, it’s going to get worse.” You know, maintaining*
38 *what you’ve got and different ways of maintaining it, I think that would help.” (C5,*
39 *female carer (daughter) of stroke-survivor)*
40
41
42
43
44
45
46
47

48 For Timely Diagnosis

49

50
51 For some stroke-survivors it did not matter who was performing the risk assessment
52 for dementia or where it was undertaken. What was important was that the diagnosis
53 was reached at the right time:
54
55
56
57
58
59
60

1
2
3 *"I wouldn't say it matters, as long as it's diagnosed at the right time."* (P5, male
4 stroke-survivor)
5
6

7 To enable this, when discussing who should perform the risk assessment, carer
8 participants felt that primary care and the community were regarded as being optimal
9 because of the existing GP-patient relationship, with the GP having an overall view
10 of the individual's care, rather than the focus on the process of evaluation:
11
12
13

14 *"I think if you've got a good relationship with your GP I think it should be that, it
15 should be them. Yeah, because you know you trust them you build up a relationship
16 with them so I think that probably, for me that would be the one."* (C4, female carer of
17 stroke-survivor)
18
19
20
21
22
23
24

25 26 For Reassurance

27
28 When stroke-survivor participants were asked about a structured risk assessment
29 process, they reported that the outcome could also ensure some reassurance, either
30 that their symptoms were not related to a dementia diagnosis or that a diagnosis of
31 dementia would be accompanied by support information:
32
33
34
35
36

37 *"I think it's reassurance a lot of reassurance with people. You have to give them that
38 [they are at low risk] to tell them, that "We are there with you. We're going to be
39 helping you." And that's you know, I think that's a good thing."* (P2, female stroke-
40 survivor)
41
42
43
44
45
46

47 **Patient and Carer Views: Barriers to Risk Assessment Focuses on the**

48 **Outcome of Assessment**

49 Anxiety around a potential diagnosis of dementia

50
51
52
53
54
55
56
57
58
59
60

1
2
3 Some carers commented on how the outcome from risk assessment could generate
4 worry and anxiety because of the potential diagnosis of dementia:
5
6

7
8 *"To be honest, I don't know if it would help somebody saying, "You're like this, you're
9 upset because you're like this now, but we actually think you're going to get much
10 worse." Do you know what I mean?"* (C3, female carer (daughter) of stroke-survivor)
11
12

13
14 This person's opinion did not change when she was followed-up six months later.
15

16
17 The participant's focus was again on worrying about what could develop and how
18 ignorance and not knowing about one's risk would actually be more preferable:
19
20

21
22 *"If you could find out and then say, "Right, we've got this medication, or something,
23 that can help you," maybe. But if they're just going to tell you, and then you've got
24 this hanging over your head, and you're thinking, "When is it going to start?" and
25 then you'd be thinking you'd forget something and you'd think, "Oh, that's it, it's
26 coming", which it would be quite normal if you hadn't had that diagnosis, you'd think,
27 "Well I just forgot something, everybody does that."* (C3, female carer (daughter) of
28 stroke-survivor at follow-up interview)
29
30
31
32
33
34
35

36
37 However, one carer felt that despite the worry a potential diagnosis may generate,
38 the benefit of this would be to find strategies to maintain cognitive function:
39
40

41
42 *"I think if you had earlier diagnosis, then you would be sort of prepared before things
43 got difficult to handle, or before problems arise, that would be a very good thing. The
44 disadvantages as you say, alarming the carers or the patients themselves, "I'm going
45 to lose my mind." Because, particularly in the older generation, that's a big worry to
46 them. It is a big worry, it's a big worry to all of us, but to older people particularly."*
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Concerns about how it may affect their recovery

1
2
3 Not all stroke-survivors were as keen to engage in risk assessment, as there was
4 emphasis on how this may affect them psychologically particularly when their
5 physical deficits had recovered enough to allow them to return to a more usual
6 routine. Therefore, although diagnosis was felt to be important, whether an individual
7 would like to know was also dependent on their subsequent post-stroke recovery:
8
9
10
11
12

13
14 *“That’s difficult you know because I mean if you have an early diagnosis you know*
15 *and say, well “It’s going to happen” you know but at the moment now I seem to be*
16 *progressing through, I’m driving now, you know I’m going back to meetings and*
17 *whatever. I wonder whether an early diagnosis would restrict that.” (P4, male stroke-*
18 *survivor)*
19
20
21
22
23
24

25
26 This was particularly evident when patients were followed up six-months later. One
27 participant had actually changed her view over time. Although she had initially felt
28 positive about the process, she then changed her mind when questioned on the
29 same process at her follow-up interview:
30
31
32
33
34

35 *“I think my thinking has gone the other way for knowing about that. I think it’s sad. I*
36 *think it’s a sad thing. I really do, I think it’s really sad that for people to know that*
37 *they’re going to be at high risk, it’s a sad thing for it to happen to people, and I don’t*
38 *think I’d want to be one of the sad people. I think I’d just want to be, potter along and*
39 *that’s it.” (P2, female, stroke-survivor at follow-up interview)*
40
41
42
43
44
45

46
47 At follow-up interviews participants also felt that risk assessment should be an
48 individual choice because of the ramifications of the assessment outcome i.e. a
49 potential diagnosis of dementia. Although clinicians may deem it to be helpful, the
50 choice to undergo risk assessment needs to be a weighed up, which should negate
51 any calls for it to be made a universally applied process:
52
53
54
55
56
57
58
59
60

1
2
3 *"I think, medically speaking, yes. On the other hand, does it give people things to*
4 *worry about that they wouldn't have worried about if you hadn't done the tests? So, I*
5 *think it depends really on your personal point of view. Do you want to be, you see I*
6 *would look on the test as saying, well you're at a low, you've got a low risk so that's*
7 *great but then if it turned out you'd got a high risk are you going to be more worried*
8 *and less happy than you were before. It's hard to really balance it, isn't it? (P3,*
9 *female, stroke-survivor at follow-up interview)*

Clinician Views: Facilitators to Risk Assessment Focusses on the Process

21 Clinicians discussed facilitators to risk assessment in terms of how the process may
22 affect the individual and also how the process could be implemented in the future.

26 When discussing how to implement this process, both primary and secondary care
27 specialists discussed the advantages associated with hosting this process within
28 their own individual teams.

Process familiarity in Primary Care

36 For primary care, it was about the fact that risk assessment was already a familiar
37 process but that it needed to be individualised:

41 *"I think it's a good tool. We're quite good at using tools, aren't we, but there's always*
42 *going to be exceptions to the rules and you've got to individualise what you do with it*
43 *... But sometimes using a score or a tool is a way into a service."* (PC4, nurse
44 *practitioner in primary care)*

51 It was also recognised by one General Practitioner (GP) that although there is
52 familiarity with risk assessment in primary care, there needs to be caution that the
53 system is not overwhelmed with such tools:

1
2
3 *"I do quite like risk profiling. I think we went a little bit crazy with the risk profiling. And*
4 *there feels to be a lot of competing risk profiling tools, that we're getting a little bit*
5 *inundated with at the moment ... So I think anything like this, I love, if it can be*
6 *incorporated and brought on to an individual and needs level - so you can think*
7 *about caring, identifying risk and needs for an individual - would feel great for me"*
8
9
10
11
12
13
14 *(PC2, General Practitioner)*

Secondary care provides specialist input

15
16
17
18
19 Stroke care clinicians discussed the facilitators of risk assessment within a specialist
20 setting. This was based on the fact that they felt a responsibility to ensure that post-
21 stroke sequelae are followed up in their specialist services due to the
22
23 stroke sequelae are followed up in their specialist services due to the
24
25 multidisciplinary element of their standard practice and easier access to services.
26
27 This was particularly important to ensure information could also be given to patients
28
29 at a time when they may need it the most:
30
31

32
33 *"I think the six-month review tends to be a period of time when the patient's acute*
34 *side, acute phase of their care has kind of been established, and this is probably the*
35 *time when they start to recognise problems. And I think it should be within a stroke*
36 *MDT (multidisciplinary team), not so much focused on by GP's, as such."* (SC2,
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
Stroke specialist nurse)

44 *"Well, you need the right support. You need people that actually understand stroke.*
45
46 *So I think it would have to be delivered by stroke healthcare professionals. And I*
47 *think you get so much information when you're initially an inpatient, I think maybe*
48 *that's not the best place to do it ... Yeah, it's a big thing to be told that you might*
49 *develop dementia in a few years' time, so you need psychologists kind of available*
50
51
52
53
54
55
56
57
58
59
60

1
2
3 *for if someone needs counselling as a result of that finding. I think it's tricky.*" (SC6,
4
5 Stroke physiotherapist)

6 7 8 Collaborative Care 9

10 Primary care clinicians commented that there may be a place for both primary and
11
12 secondary care to work together in identifying those at risk.
13

14
15 *"I think primary care would be a completely reasonable place to do that. I guess it's*
16
17 *a conversation that could start at diagnosis, at discharge from hospital, like actually,*
18
19 *we know that people who have had a stroke are at higher risk of having dementia,*
20
21 *these are the things to be aware of, and you know to start that discussion"* (PC8,
22
23 General Practitioner)
24
25

26
27 Primary and secondary care clinicians felt that such a shared care pathway needed
28
29 to be formalized to reduce the risk of individuals falling into gaps in care:
30

31
32 *"... even if it was picked up in secondary care it's still going to be primary care where*
33
34 *most of the management is occurring. So I think it being identified at the six-month*
35
36 *follow-up, but then there being a formal sort of mechanism, in which primary care*
37
38 *pick it up and process it, would be fine.* (PC3, General Practitioner)
39

40
41 *"I don't mind where work is done, provided that it is done in a structured and*
42
43 *standardised way. If that be, if that can be in primary care that is really good,*
44
45 *because that is the long-term follow-up, long-term support, integrating the community*
46
47 *... just as long as it can be delivered in a systematic way, and people don't fall*
48
49 *through gaps or get inconsistent care."* (SC3, Stroke consultant)
50
51
52
53
54
55
56
57
58
59
60

1
2
3 Further, the process of communication between primary and secondary care could
4 also be used in the diagnostic process. It was felt that repeated assessments could
5 help facilitate diagnosis by identifying trends in symptoms:
6
7

8
9
10 *“You can measure a trend, can't you, if you're using something and measuring*
11 *something, you can look at a trend. So if its, depends on the type of tool, I guess. But*
12 *if you did it at you know at the six months review date and then we did it*
13 *subsequently a year later in primary care, you would see any changes or decline or*
14 *improvement. So it's a way of, it's a way of monitoring a trend on how they're doing, I*
15 *guess. So I don't, I don't see any reason why it couldn't be done in both and used*
16 *across both. I don't think we use enough across both.”* (PC4, nurse practitioner in
17
18
19
20
21
22
23
24
25 primary care)

26 27 28 **Clinician Views: Barriers to Risk Assessment Focusses on the Outcome**

29 30 31 Limited Interventions Available

32
33 Similar to the perspectives of carers, clinicians recognised the anxiety that a risk
34 assessment process might generate and felt that it should be a personal choice to
35 undertake an assessment because of the perceived lack of intervention:
36
37

38
39
40 *“Yeah, I think I would, I would have degree of anxiety, especially given that the*
41 *measures that we're putting in place are ... that we could put in place are largely*
42 *supportive rather than preventative ... I would be less confident that I could be giving*
43 *my patient advice to say, “Well, if we do this, and we do this, and if we do this and*
44 *you do that then that might move you into an even smaller risk group.”* (PC3,
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65
66
67
68
69
70
71
72
73
74
75
76
77
78
79
80
81
82
83
84
85
86
87
88
89
90
91
92
93
94
95
96
97
98
99
100
101
102
103
104
105
106
107
108
109
110
111
112
113
114
115
116
117
118
119
120
121
122
123
124
125
126
127
128
129
130
131
132
133
134
135
136
137
138
139
140
141
142
143
144
145
146
147
148
149
150
151
152
153
154
155
156
157
158
159
160
161
162
163
164
165
166
167
168
169
170
171
172
173
174
175
176
177
178
179
180
181
182
183
184
185
186
187
188
189
190
191
192
193
194
195
196
197
198
199
200
201
202
203
204
205
206
207
208
209
210
211
212
213
214
215
216
217
218
219
220
221
222
223
224
225
226
227
228
229
230
231
232
233
234
235
236
237
238
239
240
241
242
243
244
245
246
247
248
249
250
251
252
253
254
255
256
257
258
259
260
261
262
263
264
265
266
267
268
269
270
271
272
273
274
275
276
277
278
279
280
281
282
283
284
285
286
287
288
289
290
291
292
293
294
295
296
297
298
299
300
301
302
303
304
305
306
307
308
309
310
311
312
313
314
315
316
317
318
319
320
321
322
323
324
325
326
327
328
329
330
331
332
333
334
335
336
337
338
339
340
341
342
343
344
345
346
347
348
349
350
351
352
353
354
355
356
357
358
359
360
361
362
363
364
365
366
367
368
369
370
371
372
373
374
375
376
377
378
379
380
381
382
383
384
385
386
387
388
389
390
391
392
393
394
395
396
397
398
399
400
401
402
403
404
405
406
407
408
409
410
411
412
413
414
415
416
417
418
419
420
421
422
423
424
425
426
427
428
429
430
431
432
433
434
435
436
437
438
439
440
441
442
443
444
445
446
447
448
449
450
451
452
453
454
455
456
457
458
459
460
461
462
463
464
465
466
467
468
469
470
471
472
473
474
475
476
477
478
479
480
481
482
483
484
485
486
487
488
489
490
491
492
493
494
495
496
497
498
499
500
501
502
503
504
505
506
507
508
509
510
511
512
513
514
515
516
517
518
519
520
521
522
523
524
525
526
527
528
529
530
531
532
533
534
535
536
537
538
539
540
541
542
543
544
545
546
547
548
549
550
551
552
553
554
555
556
557
558
559
560
561
562
563
564
565
566
567
568
569
570
571
572
573
574
575
576
577
578
579
580
581
582
583
584
585
586
587
588
589
590
591
592
593
594
595
596
597
598
599
600
601
602
603
604
605
606
607
608
609
610
611
612
613
614
615
616
617
618
619
620
621
622
623
624
625
626
627
628
629
630
631
632
633
634
635
636
637
638
639
640
641
642
643
644
645
646
647
648
649
650
651
652
653
654
655
656
657
658
659
660
661
662
663
664
665
666
667
668
669
670
671
672
673
674
675
676
677
678
679
680
681
682
683
684
685
686
687
688
689
690
691
692
693
694
695
696
697
698
699
700
701
702
703
704
705
706
707
708
709
710
711
712
713
714
715
716
717
718
719
720
721
722
723
724
725
726
727
728
729
730
731
732
733
734
735
736
737
738
739
740
741
742
743
744
745
746
747
748
749
750
751
752
753
754
755
756
757
758
759
760
761
762
763
764
765
766
767
768
769
770
771
772
773
774
775
776
777
778
779
780
781
782
783
784
785
786
787
788
789
790
791
792
793
794
795
796
797
798
799
800
801
802
803
804
805
806
807
808
809
810
811
812
813
814
815
816
817
818
819
820
821
822
823
824
825
826
827
828
829
830
831
832
833
834
835
836
837
838
839
840
841
842
843
844
845
846
847
848
849
850
851
852
853
854
855
856
857
858
859
860
861
862
863
864
865
866
867
868
869
870
871
872
873
874
875
876
877
878
879
880
881
882
883
884
885
886
887
888
889
890
891
892
893
894
895
896
897
898
899
900
901
902
903
904
905
906
907
908
909
910
911
912
913
914
915
916
917
918
919
920
921
922
923
924
925
926
927
928
929
930
931
932
933
934
935
936
937
938
939
940
941
942
943
944
945
946
947
948
949
950
951
952
953
954
955
956
957
958
959
960
961
962
963
964
965
966
967
968
969
970
971
972
973
974
975
976
977
978
979
980
981
982
983
984
985
986
987
988
989
990
991
992
993
994
995
996
997
998
999
1000

1
2
3 *intervention so you know there's all the theory about blood pressure, and statins, and*
4 *all the rest of that, but my reading of the evidence on all of that at the moment is that*
5 *the jury is out whether it makes a difference to cognitive function. So yeah, I'm not*
6 *convinced that identifying risk, unless you've got a something you can do about it, is*
7 *actually sensible.” (SC4, Stroke consultant)*

14 Anxiety around a potential diagnosis of dementia

15
16
17 In recognising the anxiety that this process may generate, one clinician also
18 commented on the fact that patients may not be willing to engage in conversation
19 over the subject of dementia and care should be taken when discussing a potential
20 diagnosis of dementia.
21
22

23
24
25
26 *“I think it's good if we tell them that we're looking through and saying, “Look, you*
27 *know there could be a problem here.” But for every single patient, again, because it's*
28 *quite a still a – not a taboo subject – but it's still not something that people want to*
29 *talk about ... I don't know whether it would be used on every single 'per', you know*
30 *what I mean, like, everybody.” (SC5, Stroke specialist nurse)*

37 No Change from Standard Practice

38
39
40 The majority of clinical participants wanted to know, not only what the outcome of the
41 risk assessment would be, but also the resulting care the patient would receive. As
42 part of current routine clinical care, all stroke survivors are offered annual reviews in
43 order to ensure their vascular risk factors e.g. blood pressure and cholesterol are
44 well controlled. In terms of reducing risk, one primary care physician expressed
45 concerns as to what the benefit would to the individual if risk factor modification was
46 already in place anyway particularly with regards to the emotive side of a potential
47 dementia diagnosis. A secondary care specialist questioned the value when there
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 was seemingly limited interventions that could be implemented besides managing
4 their cardiovascular risk:
5

6
7
8 *“I guess you’ve got to be very clear about what it is that you’re going to be doing*
9 *differently for them. So I can see the value if you use a tool for kind of primary*
10 *prevention, then you’re kind of selecting a group of patients out to do something*
11 *particular with, but I just wonder what would be different about what you do with a*
12 *risk assessment tool for people who have already had a stroke, when really you*
13 *know already that it is all about managing their cardiovascular risk so I’m not sure*
14 *that you would be doing anything different for them.” (PC8, General Practitioner)*
15
16

17
18
19 *“Many people will not know of the association between dementia and stroke and*
20 *many people would not want to know if they were at risk of dementia and again, if*
21 *you’re identifying somebody at risk of a condition that you can’t do anything about,*
22 *what’s the right stage to, to do that? However, many of the things you need to do in*
23 *terms of people being at risk of dementia are the same of the general cardiovascular.*
24 *So, I’m not sure that there is anything additional that needs to be done about*
25 *reducing people’s risk for dementia over and above general cardiovascular risk.”*
26
27
28 (SC3, Stroke consultant)
29
30
31
32
33
34
35
36
37
38
39
40

41 **Discussion**

42 Main Findings

43
44
45
46
47 This is the first study to explore key stakeholders’ - stroke survivors, family
48 carers and primary and secondary care clinicians - views on the use of a risk
49 assessment process to predict future dementia in stroke-survivors. It is clear that
50 some of the participants interviewed believed that risk assessment could be of
51 clinical use but raised concerns about it being mandatory. Clinicians highlighted both
52
53
54
55
56
57
58
59
60

1
2
3 the benefits of collaborative and individual (i.e. primary or secondary) care if
4
5 dementia risk assessment for stroke survivors was to be implemented.
6
7

8 Clinician facilitators suggest benefits in either primary or secondary care
9
10 settings but also in a collaborative model of care between the two. This latter finding
11
12 echoes recommendations from the UK Intercollegiate Stroke Working Party for a
13
14 collaborative care model, linking community and specialist care, with the aim of
15
16 integrated long-term follow-up for those presenting neuropsychological problems¹⁶.
17
18 Although both primary and secondary care clinicians could see the benefits of
19
20 carrying this assessment in their own specialties, patients and carers in this study
21
22 valued their relationship with their GP. Further, primary care clinicians themselves
23
24 are familiar with the process of risk assessment. A recent survey of primary care
25
26 physicians found that they were also keen to implement a dementia risk assessment
27
28 strategy to assist in earlier identification²¹. However, potential barriers have been
29
30 identified in previous studies such as system-related factors (lack of support, time
31
32 constraints)^{22 23} and training in dementia²³, would need to be addressed. Risk
33
34 assessment is an objective process requiring specific individual variables e.g. age,
35
36 gender, education. Such data is readily available in primary care in many countries
37
38 where electronic medical record systems are in place. Further, GPs are already
39
40 asked to assess cardiovascular risk as part of routine clinical care²⁴. However, some
41
42 GPs themselves do not like using risk assessment tools particularly as the tools do
43
44 not provide the support needed in communication²⁵. Training in communicating the
45
46 risk assessment process particularly in the context of dementia would be required if
47
48 this were to be implemented in clinical practice.
49
50
51
52

53 Clinician participants were concerned about whether risk assessment would
54
55 actually change standard practice. In a stroke population, it is unclear whether
56
57
58
59
60

1
2
3 identifying those at risk would achieve any additional benefit from a risk factor
4 modification point of view. This is because stroke-survivors already receive annual
5 community follow-up with particular focus on vascular risk factor modification.
6
7 However, current evidence suggests that development of post-stroke dementia is
8 more than just about vascular risk and would require a different approach e.g.
9 psychological support, cognitive preservation strategies and additional resources.
10
11 Results from several trials, assessing whether vascular-based interventions can
12 reduce dementia risk, have been largely disappointing^{26 27}. These results suggest
13 that perhaps an individual's risk of post-stroke cognitive impairment and dementia
14 includes risk factors beyond vascular risk and/or that the disease has a different
15 mechanism such as inflammatory changes in the cerebral vasculature triggered by
16 stroke or related to small vessel disease.
17
18
19
20
21
22
23
24
25
26
27
28

29
30 Currently population screening for dementia is not recommended due to a
31 lack of evidence evaluating risks and benefits²⁸, despite positive views from older
32 adults²⁹. Risk assessment can target high-risk groups rather than the general
33 population. Recent evidence has found a decline in age-specific incidence of
34 dementia, particularly in high-income countries, suggesting that rising levels of
35 education and modifying cardiovascular risk may have driven a decline in dementia
36 risk^{30 31}. Indeed, the importance of modifiable risk factor reduction for dementia was
37 reported in the World Alzheimer Report (2014)³² and around a third of Alzheimer's
38 disease cases worldwide might be attributable to modifiable risk factors³³. Risk
39 assessment tools utilize these modifiable risk factors to predict risk. Similar to other
40 branches of medicine where risk assessment is utilized to predict risk of a future
41 illness, it would be hoped that this approach could reduce one's risk of future
42 dementia. Stroke affects more than 100,000 people in the UK per year³⁴, creating a
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 large population with cognitive deficits and/or at high risk of future decline who may
4 benefit from risk assessment for dementia. However, participant groups in this study,
5 particularly clinicians, reported that given the potential ramifications of risk
6 assessment, individuals should be given the choice of whether to undergo
7 assessment. Stroke-survivors were generally positive about such an approach but
8 agreed that it should be up to the individual and the family rather than applied
9 universally. Participants in this study recognised the anxiety this process could
10 generate particularly when the perceived possible interventions for dementia are
11 limited. The National Institute for Health and Care Excellence have recently updated
12 their guidance and have concluded that case finding should only be conducted as
13 part of a clinical trial, which also provides an intervention³⁵. Therefore, careful
14 discussion needs to be adopted with the patient and their carers before undertaking
15 such a process in any setting.

31 Clinical Implications

32
33
34 Case finding for dementia involves actively assessing individuals at risk of a future
35 dementia illness, which at present is only recommended in clinical trial settings due
36 to a lack of post-assessment intervention³⁶. Once a suitable intervention is found
37 however, the views of those conducting the assessment and the recipients of such
38 an assessment will need to be assessed. From this study we have identified the
39 priorities according to each stakeholder group which would need to be addressed
40 prior to clinical implementation in the future.

49 Limitations

50
51
52 The participants in this study came from one area of England and were Caucasian.
53 Patient participants were also well enough to attend outpatient assessment clinics.
54
55
56
57
58
59
60

1
2
3 Future studies could look to explore views in other populations including views from
4 minority ethnic groups, patients with more severe stroke-related impairments and
5 different service models. Due to familiarity, it is recognized that clinicians expanded
6 more around the risk assessment process. Despite this being the case, patients and
7 carers were given the opportunity to understand the concept of risk assessment as
8 part of the interview process but the emphasis on a need for a diagnosis and good
9 care was what was important for them. Participants were also aware that the
10 interviewer was also a primary care clinician, which may have the potential to
11 introduce bias into participant responses. This is because a clinician interviewer may
12 be viewed as an expert and judge in clinical decision making and moral judgements
13 made³⁷. On the other hand interviews tend to be broader in scope and richer in data
14 when conducted by a clinician researcher³⁷. Further, both clinical and non-clinical
15 members contributed to the analysis of the data to minimize the effect this may have
16 had.

33 Conclusions and Future Research

34
35
36 Timely recognition of those at risk of dementia is crucial to enable individuals
37 early access treatment and support. Although dementia screening after stroke is not
38 yet advocated on preventative grounds, assessing risk has some potential benefits
39 for individuals who make an informed choice to participate. There would need to be
40 better cohesiveness of communication between primary and secondary care, with
41 more support placed in the community. Further, it should be recognised that if risk
42 assessment were to be incorporated into clinical practice, this will potentially place
43 additional burdens on a dementia diagnostic service which is already overstretched.
44
45 Next steps are to identify which tool to use, how best to manage those who are
46 deemed high-risk individuals and whether there are any interventions, which can
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 reduce their risk. Future studies will need to look specifically at what factors put a
4 stroke-survivor at risk that could be potentially modified and also whether there are
5 specific interventions suitable to a post-stroke population to reduce risk.
6
7
8
9

10 **Acknowledgements:**

11 The authors would like to thank the participant advisory group for their advice on the
12 study materials used.
13
14

15 **List of Abbreviations**

16
17
18
19 **GP** General Practitioner

20
21
22 **UK** United Kingdom
23

24 **Declarations**

25 **Author Contributions:**

26
27
28 ET conceived the framework for this study. ET collected, analysed and interpreted
29 the data. ET prepared the manuscript for submission.
30
31

32
33
34
35 CE helped to conceive the framework for this study and assisted with the analysis of
36 the data and contributed to the drafting of the manuscript. CE also critically reviewed
37 and edited the manuscript.
38
39

40
41
42 CP helped to conceive the framework for this study, assisted with the analysis of the
43 data and critically reviewed and edited the manuscript.
44
45

46
47
48 BS helped to conceive the framework for this study, assisted with the analysis of the
49 data and critically reviewed and edited the manuscript.
50
51

52
53
54 LR helped to conceive the framework for this study, assisted with the analysis of the
55 data and critically reviewed and edited the manuscript.
56
57

Funding:

Eugene Tang is supported by a NIHR Doctoral Research Fellowship (DRF-2015-08-006).

Louise Robinson is supported by a National Institute for Health Research professorship (NIHR-RP-011-043) and a NIHR Senior Investigator award (NF-SI-0616-10054).

Consent for Publication:

All participants in the study have provided informed written consent. No identifiable personal information has been used.

Competing Interests:

LR reports grants from NIHR Professorship award, grants from NIHR Senior Investigator award, outside the submitted work. The remaining authors declare that they have no competing interests.

Disclaimer:

This paper presents independent research funded by the National Institute for Health Research (NIHR). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

Data Sharing Statement:

No further data will be made available.

References

1. Prince M, Wimo W, Guerchet M, et al. World Alzheimer Report 2015: The Global Impact of Dementia, An Analysis of Prevalence, Incidence, Cost and Trends. 2015.
2. Savva GM, Stephan BC, Alzheimer's Society Vascular Dementia Systematic Review G. Epidemiological studies of the effect of stroke on incident dementia: a systematic review. *Stroke; a journal of cerebral circulation* 2010;41(1):e41-6. doi: <http://dx.doi.org/10.1161/STROKEAHA.109.559880>
3. Pendlebury ST, Rothwell PM. Prevalence, incidence, and factors associated with pre-stroke and post-stroke dementia: a systematic review and meta-analysis. *The Lancet Neurology* 2009;8(11):1006 - 18.
4. Douiri A, Rudd AG, Wolfe CD. Prevalence of poststroke cognitive impairment: South London Stroke Register 1995-2010. *Stroke; a journal of cerebral circulation* 2013;44(1):138-45. doi: 10.1161/strokeaha.112.670844 [published Online First: 2012/11/15]
5. Feigin VL, Forouzanfar MH, Krishnamurthi R, et al. Global and regional burden of stroke during 1990-2010: findings from the Global Burden of Disease Study 2010. *Lancet* 2014;383(9913):245-54. [published Online First: 2014/01/23]
6. Prince M, Ali GC, Guerchet M, et al. Recent global trends in the prevalence and incidence of dementia, and survival with dementia. *Alzheimer's research & therapy* 2016;8(1):23. doi: 10.1186/s13195-016-0188-8 [published Online First: 2016/07/31]
7. Stephan BCM, Kurth T, Matthews FE, et al. Dementia risk prediction in the population: are screening models accurate? *Nat Rev Neurol* 2010;6(6):318 - 26.
8. Tang EY, Harrison SL, Errington L, et al. Current Developments in Dementia Risk Prediction Modelling: An Updated Systematic Review. *PloS one* 2015;10(9):e0136181. doi: 10.1371/journal.pone.0136181 [published Online First: 2015/09/04]
9. Kandiah N, Chander RJ, Lin X, et al. Cognitive Impairment after Mild Stroke: Development and Validation of the SIGNAL2 Risk Score. *Journal of Alzheimer's disease : JAD* 2016;49(4):1169-77. doi: 10.3233/jad-150736 [published Online First: 2015/11/26]
10. Lin JH, Lin RT, Tai CT, et al. Prediction of poststroke dementia. *Neurology* 2003;61(3):343-8. [published Online First: 2003/08/13]
11. Stephan BC, Minett T, Muniz Terrera G, et al. Dementia prediction for people with stroke in populations: is mild cognitive impairment a useful concept? *Age and ageing* 2014 doi: 10.1093/ageing/afu085 [published Online First: 2014/07/09]
12. Chander RJ, Lam BYK, Lin X, et al. Development and validation of a risk score (CHANGE) for cognitive impairment after ischemic stroke. *Scientific reports* 2017;7(1):12441. doi: 10.1038/s41598-017-12755-z [published Online First: 2017/10/01]
13. Siontis GC, Tzoulaki I, Siontis KC, et al. Comparisons of established risk prediction models for cardiovascular disease: systematic review. *BMJ (Clinical research ed)* 2012;344:e3318.
14. Johnston SC, Rothwell PM, Nguyen-Huynh MN, et al. Validation and refinement of scores to predict very early stroke risk after transient ischaemic attack. *Lancet* 2007;369(9558):283-92. doi: 10.1016/s0140-6736(07)60150-0 [published Online First: 2007/01/30]
15. Tang EYH, Price C, Stephan BCM, et al. Gaps in care for patients with memory deficits after stroke: views of healthcare providers. *BMC health services research* 2017;17(1):634. doi: 10.1186/s12913-017-2569-5 [published Online First: 2017/09/10]
16. Intercollegiate Stroke Working Party. National Clinical Guideline for Stroke. 2016 [published Online First: Fifth Edition]
17. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006;3(2):77-101. doi: 10.1191/1478088706qp063oa
18. Glaser B. The constant comparison method of qualitative analysis. *Soc Probl* 1965;12:436-45.

19. Ritchie J, Spencer L, O'Connor W. Carrying out qualitative analysis In: Ritchie J, Lewis J, editors. *Qualitative Research Practice: A guide for social science students and researchers*. London: SAGE 2003:219 - 262.
20. O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research: a synthesis of recommendations. *Academic medicine : journal of the Association of American Medical Colleges* 2014;89(9):1245-51. doi: 10.1097/acm.0000000000000388 [published Online First: 2014/07/01]
21. Tang EY, Birdi R, Robinson L. Attitudes to diagnosis and management in dementia care: views of future general practitioners. *International psychogeriatrics* 2016:1-6. doi: 10.1017/s1041610216001204 [published Online First: 2016/08/10]
22. Koch T, Iliffe S. Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: a systematic review. *BMC Fam Pract* 2010;11:52. doi: 10.1186/1471-2296-11-52 [published Online First: 2010/07/03]
23. Chithiramohan A, Iliffe S, Khattak I. Identifying barriers to diagnosing dementia following incentivisation and policy pressures: General practitioners' perspectives. *Dementia (London, England)* 2016 doi: 10.1177/1471301216682625 [published Online First: 2016/12/13]
24. Hippisley-Cox J, Coupland C, Brindle P. Development and validation of QRISK3 risk prediction algorithms to estimate future risk of cardiovascular disease: prospective cohort study. *BMJ (Clinical research ed)* 2017;357:j2099. doi: 10.1136/bmj.j2099 [published Online First: 2017/05/26]
25. Barfoed BL, Jarbol DE, Paulsen MS, et al. GPs' Perceptions of Cardiovascular Risk and Views on Patient Compliance: A Qualitative Interview Study. *International journal of family medicine* 2015;2015:214146. doi: 10.1155/2015/214146 [published Online First: 2015/10/27]
26. Matz K, Teuschl Y, Firlinger B, et al. Multidomain Lifestyle Interventions for the Prevention of Cognitive Decline After Ischemic Stroke: Randomized Trial. *Stroke; a journal of cerebral circulation* 2015;46(10):2874-80. doi: 10.1161/strokeaha.115.009992 [published Online First: 2015/09/17]
27. Bath PM, Scutt P, Blackburn DJ, et al. Intensive versus Guideline Blood Pressure and Lipid Lowering in Patients with Previous Stroke: Main Results from the Pilot 'Prevention of Decline in Cognition after Stroke Trial' (PODCAST) Randomised Controlled Trial. *PloS one* 2017;12(1):e0164608. doi: 10.1371/journal.pone.0164608 [published Online First: 2017/01/18]
28. Moyer VA. Screening for cognitive impairment in older adults: U.S. Preventive Services Task Force recommendation statement. *Annals of internal medicine* 2014;160(11):791-7. doi: 10.7326/m14-0496 [published Online First: 2014/03/26]
29. Justiss MD, Boustani M, Fox C, et al. Patients' attitudes of dementia screening across the Atlantic. *International journal of geriatric psychiatry* 2009;24(6):632-7. doi: 10.1002/gps.2173 [published Online First: 2008/12/31]
30. Langa KM. Is the risk of Alzheimer's disease and dementia declining? *Alzheimer's research & therapy* 2015;7(1):34. doi: 10.1186/s13195-015-0118-1 [published Online First: 2015/03/31]
31. Larson EB, Yaffe K, Langa KM. New insights into the dementia epidemic. *The New England journal of medicine* 2013;369(24):2275-7. doi: 10.1056/NEJMp1311405 [published Online First: 2013/11/29]
32. Prince M, Albanese E, Guerchet M, et al. *Dementia and Risk Reduction: An Analysis of Protective and Modifiable Factors*. 2014.
33. Norton S, Matthews FE, Barnes DE, et al. Potential for primary prevention of Alzheimer's disease: an analysis of population-based data. *The Lancet Neurology* 2014;13(8):788-94. doi: 10.1016/s1474-4422(14)70136-x [published Online First: 2014/07/18]
34. Stroke Association. State of the nation: stroke statistics. 2017. <https://www.stroke.org.uk/resources/state-nation-stroke-statistics> (accessed 14th August 2017).

- 1
2
3 35. Faircloth CA, Boylstein C, Rittman M, et al. Sudden illness and biographical flow in narratives of
4 stroke recovery. *Sociology of health & illness* 2004;26(2):242-61. doi: 10.1111/j.1467-
5 9566.2004.00388.x [published Online First: 2004/03/19]
6 36. National Institute for Health and Care Excellence. Dementia: assessment, management and
7 support for people living with dementia and their carers 2018.
8 <https://www.nice.org.uk/guidance/ng97>.
9 37. Chew-Graham CA, May CR, Perry MS. Qualitative research and the problem of judgement:
10 lessons from interviewing fellow professionals. *Fam Pract* 2002;19(3):285-9. [published
11 Online First: 2002/04/30]
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Table 1. Interview Participants (Patients and Carers)

| Unique Identifier (Patients and Carers) | Role | Gender | Age | Follow-up Interview Conducted |
|--|---------------------------|---------------|------------|--------------------------------------|
| P1 | Stroke-survivor | Female | 80 | No |
| P2 | Stroke-survivor | Female | 76 | Yes |
| P3 | Stroke-survivor | Female | 72 | Yes |
| P4 | Stroke-survivor | Male | 75 | Yes |
| P5 | Stroke-survivor | Male | 80 | Yes |
| P6 | Stroke-survivor | Male | 74 | Yes |
| P7 | Stroke-survivor | Female | 73 | Yes |
| P8 | Stroke-survivor | Female | 82 | Yes |
| P9 | Stroke-survivor | Male | 84 | No |
| P10 | Stroke-survivor | Male | 79 | Yes |
| C1 | Carer of P1 (Husband) | Male | 79 | No |
| C2 | Carer of P4 (Wife) | Female | 79 | Yes |
| C3 | Carer of P5 (Daughter) | Female | 57 | Yes |
| C4 | Carer of P6 (Wife) | Female | 71 | Yes |
| C5 | Carer of P8 | Female | 60 | |

| | | | | |
|--|------------|--|--|--|
| | (Daughter) | | | |
|--|------------|--|--|--|

For peer review only

Table 2. Interview Participants (Clinicians)

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

| Unique Identifier (Clinicians) | Role | Gender |
|-----------------------------------|---|--------|
| SC1 | Stroke Consultant | Female |
| SC2 | Stroke Specialist Nurse | Female |
| SC3 | Stroke Consultant | Female |
| SC4 | Stroke Consultant | Male |
| SC5 | Stroke Specialist Nurse | Female |
| SC6 | Stroke Physiotherapist (Rehabilitation) | Female |
| SC7 | Stroke Physiotherapist (Acute Care) | Female |
| SC8 | Stroke Occupational Therapist (Acute Care) | Male |
| SC9 | Stroke Occupational Therapist (Rehabilitation) | Female |
| PC1 | General Practitioner with Specialist Interest in Dementia | Male |
| PC2 | General Practitioner | Male |
| PC3 | General Practitioner | Female |
| PC4 | Nurse Practitioner in primary care | Female |
| PC5 | General Practitioner | Female |
| PC6 | Practice Nurse | Female |

| | | |
|-----|---------------------------------------|--------|
| PC7 | Nurse Practitioner in primary care | Female |
| PC8 | General Practitioner | Female |

For peer review only

Supplementary Table 1**Standards for Reporting Qualitative Research Checklist¹**

| No. | Topic | Item | Page(s) |
|---------------------------|--|--|---------|
| Title and abstract | | | |
| S1 | Title | Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended | 1 |
| S2 | Abstract | Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions | 2 - 3 |
| Introduction | | | |
| S3 | Problem formulation | Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement | 5 - 6 |
| S4 | Purpose or research question | Purpose of the study and specific objectives or questions | 6 |
| Methods | | | |
| S5 | Qualitative approach and research paradigm | Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale ^b | 8 |
| S6 | Researcher characteristics and reflexivity | Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability | N/A |
| S7 | Context | Setting/site and salient contextual factors; rationale ^b | 6 - 8 |
| S8 | Sampling strategy | How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale ^b | 7 - 8 |
| S9 | Ethical issues pertaining to human subjects | Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues | 6 |
| S10 | Data collection methods | Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale ^b | 6 - 7 |
| S11 | Data collection instruments and technologies | Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study | 7 |
| S12 | Units of study | Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results) | 29 - 32 |
| S13 | Data processing | Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts | 8 - 9 |
| S14 | Data analysis | Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale ^b | 8 - 9 |
| S15 | Techniques to enhance trustworthiness | Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale ^b | 8 - 9 |
| Results/findings | | | |
| S16 | Synthesis and interpretation | Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory | 9 - 19 |
| S17 | Links to empirical data | Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings | 9 - 19 |
| Discussion | | | |
| S18 | Integration with prior work, implications, transferability, and contribution(s) to the field | Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field | 19 - 22 |
| S19 | Limitations | Trustworthiness and limitations of findings | 22 - 23 |
| Other | | | |
| S20 | Conflicts of interest | Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed | 25 |
| S21 | Funding | Sources of funding and other support; role of funders in data collection, interpretation, and reporting | 25 |

Reference

- O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research: a synthesis of recommendations. *Academic medicine : journal of the Association of American Medical Colleges* 2014;89(9):1245-51. doi: 10.1097/acm.0000000000000388 [published Online First: 2014/07/01]

BMJ Open

The Views of Public and Clinician Stakeholders on Risk Assessment Tools for Post-Stroke Dementia: A Qualitative Study

| | |
|---------------------------------|---|
| Journal: | <i>BMJ Open</i> |
| Manuscript ID | bmjopen-2018-025586.R1 |
| Article Type: | Research |
| Date Submitted by the Author: | 08-Nov-2018 |
| Complete List of Authors: | Tang, Eugene; Newcastle University, Institute of Health and Society Exley, Catherine; Northumbria University, Faculty of Health and Life Sciences Price, Christopher; Newcastle University, Institute of Neuroscience, Stroke Research Group Stephan, Blossom; Newcastle University, Institute of Health and Society Robinson, Louise; Newcastle University, Institute of Health and Society |
| Primary Subject Heading: | Qualitative research |
| Secondary Subject Heading: | Mental health, Neurology, General practice / Family practice |
| Keywords: | PRIMARY CARE, STROKE MEDICINE, QUALITATIVE RESEARCH, Dementia < NEUROLOGY |
| | |

SCHOLARONE™
Manuscripts

1
2
3 **The Views of Public and Clinician Stakeholders on Risk Assessment Tools for**
4
5 **Post-Stroke Dementia: A Qualitative Study**
6
7

8 Dr. Eugene Yee Hing Tang^{1,2} e.y.h.tang@newcastle.ac.uk
9

10 Prof. Catherine Exley³ catherine.exley@northumbria.ac.uk
11
12

13 Dr. Christopher Price⁴ c.i.m.price@newcastle.ac.uk
14
15

16 Dr. Blossom CM Stephan^{1,2} blossom.stephan@newcastle.ac.uk
17
18

19 Prof. Louise Robinson^{1,2} a.l.robinson@newcastle.ac.uk
20
21
22
23
24
25

26 ¹ Institute of Health and Society, Newcastle University, Baddiley-Clark, Richardson
27 Road, Newcastle upon Tyne, UK, NE2 4AX
28

29 ² Newcastle University Institute of Ageing, Newcastle University, Campus for Ageing
30 and Vitality, Newcastle upon Tyne, UK, NE4 5PL
31
32

33 ³ Faculty of Health & Life Sciences, Northumberland Building, Northumbria
34 University, Newcastle upon Tyne, NE1 8ST
35
36

37 ⁴ Institute of Neuroscience, Stroke Research Group, Newcastle University
38
39
40
41
42
43
44
45

46 Corresponding author: Dr. Eugene Yee Hing Tang, Institute of Health & Society,
47 Newcastle University, Level 2, Newcastle Biomedical Research Building, Campus for
48 Ageing and Vitality, Newcastle upon Tyne, NE4 5PL, T: 0191 208 8758,
49
50

51 E: e.y.h.tang@newcastle.ac.uk
52
53
54
55
56
57
58
59
60

Abstract

OBJECTIVE: Stroke-survivors are at increased risk of future dementia. Assessment to identify those at high risk of developing a disease using predictive scores has been utilised in different areas of medicine. A number of risk assessment scores for dementia have been developed but none has been recommended for use clinically. The aim of this qualitative study was to assess the acceptability and feasibility of using a risk assessment tool to predict post-stroke dementia.

DESIGN: Qualitative semi-structured interviews were conducted and analysed thematically. Patients and carers were offered interviews at around 6 (baseline) and 12 (follow-up) months post-stroke; Clinicians were interviewed once.

SETTING: The study was conducted in the North-East of England with stroke patients, family carers and healthcare professionals in primary and secondary care.

PARTICIPANTS: Thirty-nine interviews were conducted (17 clinicians and 15 stroke patients and their carers at baseline. Twelve stroke patients and their carers were interviewed at follow-up).

RESULTS: Barriers and facilitators to risk assessment were discussed. For patients and carers the focus for facilitators were based on the outcomes of risk assessment i.e. an assessment could assist with preparation, diagnosis and for reassurance. For clinicians, facilitators were focused on the process i.e. familiarity in primary care, resource availability in secondary care and collaborative care. For barriers, both groups focussed on the outcome including e.g. the anxiety generated from a potential diagnosis of dementia. For patients and carers a further barrier included concerns about how it may affect their recovery. For clinicians there were concerns about limited interventions and how it would be different from standard care.

1
2
3 **CONCLUSIONS:** Risk assessment for dementia post-stroke presents challenges
4 given the ramifications of a potential diagnosis of dementia. Attention needs to be
5 given to how information is communicated, and strategies developed to support
6 patients and carers if risk assessment has taken place.
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

Strengths and Limitations of the Study:

- To the best of our knowledge this is the first qualitative study to examine critically the views of stroke patients and their family carers and clinicians about the acceptability and feasibility of a risk assessment approach to assist in earlier identification of post-stroke dementia.
- Understanding stakeholder views on risk assessment for dementia can help inform future strategies if risk assessment for dementia is used to assist with earlier diagnosis.
- Patient participants came from one area of England who were able to attend hospital outpatient departments and so may not represent the views and experiences of those with more severe post-stroke sequelae.
- Clinician participants came from one area of England and so may not represent the views of other service models in other regions of the UK.
- It is recognized that clinicians tended to be more familiar with the process of risk assessment and could elaborate further on the process involved.

Introduction

There is currently no cure for dementia and it is estimated that the worldwide economic burden will rise to US\$2 trillion by 2030¹. It has been suggested that the most powerful way to affect costs is by reducing the numbers of people who develop the illness. This may be facilitated by prediction of individual risk for the disease. Stroke is associated with an increased risk of dementia and cognitive impairment²⁻⁴. A recent meta-analysis found that both prevalent and incident strokes are strong independent risk factors for dementia⁵. Stroke incidence and numbers of stroke-survivors are likely to increase due to simultaneous ageing populations and declining stroke mortality rates⁶. Given that the incidence of dementia increases exponentially with age^{1 7}, this will mean that post-stroke dementia will also become increasingly prevalent. It will therefore be important to identify those at greatest risk of developing dementia following stroke in order to implement strategies to reduce risk. In general, strategies to reduce risk of dementia may include management of cardiovascular risk factors e.g. smoking, diabetes as well as regular physical activity⁸.

Risk prediction models for dementia to identify those at higher risk have been developed in whole populations^{9 10} with some models specifically developed to predict cognitive impairment and dementia in stroke populations¹¹⁻¹⁴. These stroke-specific models predict dementia or cognitive impairment over a relatively short time period (up to 18 months¹⁴). In spite of the expanding research in this field, none of the dementia risk prediction tools have been clinically implemented. Further, no studies have assessed the feasibility or acceptability of implementing such a strategy in a stroke population. Although risk models are currently used in everyday clinical practice in other branches of medicine, in particular prevention of cardiovascular¹⁵ and cerebrovascular¹⁶ disease, it is unclear how clinicians would feel about using a

1
2
3 similar strategy to predict dementia, particularly given the stigma surrounding the
4 diagnosis and perceived limited interventions and increased awareness of cognitive
5 difficulties that patients and carers may have following stroke. Further, no studies
6 have evaluated whether using risk assessment tools for dementia would be
7 acceptable to stroke patients themselves.
8
9
10
11
12
13
14

15 This paper presents findings from a qualitative study conducted with patients,
16 carers and clinicians, which sought to critically examine their views about the
17 acceptability and feasibility of using risk prediction models in post-stroke care to
18 identify those at greatest risk of future dementia.
19
20
21
22
23
24
25
26
27

28 **Methods**

29 *Patient and Public Involvement (PPI)*

30
31 Patients and members of the public have been involved in the development of this
32 study from the beginning of the proposal. A participant advisory group also oversees
33 the work conducted and annual face-to-face meetings are held to inform them of the
34 study findings. The participant advisory group consists of members from a stroke
35 research patient and carer panel, an organisation aimed at capturing public views
36 about research and from a dementia and neurodegeneration specialty PPI group.
37
38 The same group reviewed the study materials to ensure suitability particularly for
39 stroke-survivors and their family carers.
40
41
42
43
44
45
46
47
48
49
50
51
52

53 *Ethical Approval*

1
2
3 The study was conducted in the North East of England. Ethical Approval was
4
5 obtained from the London – Hampstead Research Ethics Committee (reference
6
7 16/LO/0133). Participants provided informed written consent prior to the interview.
8
9

10 *Patient and Carer Sampling*

11
12
13 Patients and carers were purposively sampled from stroke clinics i.e. to ensure a mix
14
15 of genders and a range carers were recruited. As part of routine clinical practice in
16
17 United Kingdom (UK) stroke services, all stroke-survivors are invited to a specialist
18
19 review at six months after the event which includes a general enquiry about memory
20
21 concerns¹⁷. If the patient reported any subjective memory concerns at the clinic and
22
23 was over the age of 60, the stroke specialist nurse would provide further study
24
25 information. Family carers were also recruited if they were involved in the stroke-
26
27 survivor's care, for example, if they attended the clinic appointment with them. If
28
29 potential participants were interested in taking part in the study, their details were
30
31 passed onto the research team. On receipt of this information one researcher
32
33 (EYHT) would make contact with the patient or carer. He would provide detailed
34
35 information and an opportunity to ask questions about the study. Following their
36
37 agreement to participate in the study, participants were asked to take part in an
38
39 interview immediately following their six-month review and/or around six months
40
41 later.
42
43
44
45
46
47
48

49 *Clinician Sampling*

50
51
52 General Practitioners (GPs) and secondary care clinicians (stroke consultants and
53
54 specialist nurses) in the North East of England were contacted to participate in the
55
56 study. Participants were given an opportunity to ask further questions. Clinicians
57
58
59
60

1
2
3 were purposively sampled to ensure that a broad range of care professionals in both
4
5 primary and secondary care were recruited.
6
7

8 *Data collection*

9

10
11 Interviews were conducted between April 2016 and August 2017 by one researcher
12
13 (EYHT) who is a medical doctor. The topic guide was initially derived from relevant
14
15 literature and expert clinical views within the research team. It was designed to be
16
17 iterative to enable any topics, which had not been previously identified, to be
18
19 pursued in subsequent interviews. Face to face semi-structured interviews were
20
21 conducted with all but one participant (clinician) who had a telephone interview. The
22
23 patient and family carer were interviewed individually or in pairs as requested by
24
25 participants. Clinicians were interviewed individually. The interviews focussed on the
26
27 benefits and challenges of improving earlier diagnosis of dementia after stroke. This
28
29 included specific questions on the delivery of this assessment (e.g. who should carry
30
31 it out), what variables could be used and how best to manage the outcome.
32
33

34
35 Alongside this, the interviews also sought the views of stakeholders on the care
36
37 experience of post-stroke individuals with memory problems from clinicians, patients
38
39 and carers. The interviews also looked to understand the impact of post-stroke
40
41 memory problems on patients and carers. These views on care experience from
42
43 clinicians¹⁸, patients and carers¹⁹ have been reported elsewhere. The impact of post-
44
45 stroke memory problems on patients and carers will be reported separately. This
46
47 paper reports the views of clinicians, patients and carers on risk assessment only.
48
49

50
51 The process of risk assessment was described to participants. This was further
52
53 emphasised with examples of published tools in order to highlight examples of
54
55 variables used to ensure participant understanding of the process. Informed written
56
57 consent was obtained from all participants prior to the interview commencing. All
58
59
60

1
2
3 interviews were audio-recorded and then transcribed verbatim. To protect participant
4
5 anonymity, unique identifiers were used throughout the process with identifiable
6
7 personal data removed.
8
9

10 *Data analysis*

11
12
13 Interview data was analysed using thematic analysis²⁰ following the principles of
14
15 constant comparative methods²¹. We ceased data collection when the researcher felt
16
17 that data saturation occurred. This was defined as being when a full understanding
18
19 of the participant's perspective²² and also "informational redundancy" had been
20
21 reached²³. One researcher (EYHT) familiarised himself with the dataset and
22
23 subsequently coded the transcripts line-by-line. Initially, a small subset of transcripts
24
25 were analysed to identify initial themes and these were discussed between CE and
26
27 EYHT. Data collection and analysis was iterative and as interviews progressed,
28
29 further analysis led to new themes emerging and refinement of existing themes and
30
31 subthemes, which were subsequently grouped into broad categories to facilitate
32
33 interpretation. The wider team (EYHT, CE, LR, BS and CP) discussed and agreed
34
35 on the final categories which are presented below. For patient and carer interviews,
36
37 where follow-up interview data was also obtained, these were analysed as separate
38
39 interviews to assess for any change in views over time. Data analysis continued after
40
41 fieldwork had ceased. There was particular focus to understand what was important
42
43 to patients, carers and clinicians. Data analysis was facilitated by a data software
44
45 handing package (NVivo version 11). The paper conforms to the Standards for
46
47 Reporting Qualitative Research checklist²⁴ (please see supplementary table 1).
48
49
50
51
52
53
54
55
56
57

58 **Results**

59
60

1
2
3 In total, 30 baseline (6 month) interviews were conducted, analysed and compared
4 including: 15 patient and carer interviews (see table 1) and 17 primary and
5
6 secondary care clinician interviews (see table 2). Two pairs of participants were
7
8 interviewed together at baseline. Eight stroke-survivors and four carers agreed to a
9
10 further follow-up interview six months later with nine interviews completed. Three
11
12 pairs of participants were interviewed together at follow-up. One stroke-survivor
13
14 declined further follow-up, another stroke-survivor and carer were not followed up
15
16 due to medical reasons. The data from this study suggest that in terms of risk
17
18 assessment facilitators and barriers exist to implementation. Whereas patient
19
20 facilitators focussed on the outcome of the risk assessment, clinicians focussed
21
22 more on the process of risk assessment for facilitators. Both groups discussed some
23
24 potential barriers associated with risk assessment focussing on the outcome.
25
26
27
28
29

30
31 ***Patient and Carer Views: Facilitators to Risk Assessment Focuses on the***
32
33 ***Outcome of Assessment***
34

35
36 When stroke-survivors and carers discussed the concept of risk assessment, the
37
38 overarching theme was that an assessment outcome was what was important,
39
40 irrespective of the process and clinicians involved. Participants focussed on several
41
42 areas of why the outcome was important to them.
43
44

45
46 ***For Preparation***
47

48
49 Some stroke-survivors were generally positive about receiving a risk assessment for
50
51 dementia. One stroke-survivor acknowledged that a diagnosis was something that
52
53 could enable individuals to prepare themselves both at baseline and subsequently at
54
55 follow-up interview:
56
57
58
59
60

1
2
3 *“It's the same as knowing and not knowing, if you know that something is*
4 *approaching. Not everybody is the same with the problem. You might be able to deal*
5 *with it in a different way or the person supporting you, the nurse or whoever, might*
6 *be able to find a different way or a more positive way of managing it.” (P6, male,*
7 *stroke-survivor at follow-up interview)*

14
15 Similarly, for carers, there was the emphasis on what could be done following the
16 assessment. One carer emphasized the importance of looking after the whole
17 person, and, how earlier recognition of a potential dementia diagnosis could ensure
18 strategies were in place to help the individual:

25 *“But I think, if you look at the whole thing of this care of this person, if we knew*
26 *earlier that you know the chances are that your memory is going to get bad and you*
27 *are going to go into dementia or whatever, then we can start thinking, “Right, well*
28 *let's prop it up, let's think of ways in helping your memory as it is, to maintain the*
29 *level it is before you've got no choice, it's going to get worse.” You know, maintaining*
30 *what you've got and different ways of maintaining it, I think that would help.” (C5,*
31 *female carer (daughter) of stroke-survivor)*

42 For Timely Diagnosis

45 For some stroke-survivors it did not matter who was performing the risk assessment
46 for dementia or where it was undertaken. What was important was that the diagnosis
47 was reached at the right time:

52 *“I wouldn't say it matters, as long as it's diagnosed at the right time.” (P5, male*
53 *stroke-survivor)*

57 To enable this, when discussing who should perform the risk assessment, carer
58 participants felt that primary care and the community were regarded as being optimal
59
60

1
2
3 because of the existing GP-patient relationship. This is because the GP has an
4 overall view of the individual's care:
5
6
7

8 *"I think if you've got a good relationship with your GP I think it should be that, it*
9 *should be them. Yeah, because you know you trust them you build up a relationship*
10 *with them so I think that probably, for me that would be the one."* (C4, female carer of
11 stroke-survivor)
12
13
14
15
16

17 For Reassurance

18
19
20
21 When stroke-survivor participants were asked about a structured risk assessment
22 process, a further participant reported that the outcome could also ensure some
23 reassurance, either that their symptoms were not related to a dementia diagnosis or
24 that a diagnosis of dementia would be accompanied by support information:
25
26
27
28
29

30
31 *"I think it's reassurance a lot of reassurance with people. You have to give them that*
32 *to tell them, that "We are there with you. We're going to be helping you." And thats*
33 *you know, I think that's a good thing."* (P2, female stroke-survivor)
34
35
36
37

38 **Patient and Carer Views: Barriers to Risk Assessment Focuses on the**

39 **Outcome of Assessment**

40 Anxiety around a potential diagnosis of dementia

41
42
43
44
45
46
47 Some carers commented on how the outcome from risk assessment could generate
48 worry and anxiety because of the potential diagnosis of dementia:
49
50

51
52 *"To be honest, I don't know if it would help somebody saying, "You're like this, you're*
53 *upset because you're like this now, but we actually think you're going to get much*
54 *worse." Do you know what I mean?"* (C3, female carer (daughter) of stroke-survivor)
55
56
57
58
59
60

1
2
3 This person's opinion did not change when she was followed-up six months later.

4
5 The participant's focus was again on worrying about what could develop and how not
6
7 knowing about one's risk would actually be more preferable:
8

9
10 *"If you could find out and then say, "Right, we've got this medication, or something,*
11 *that can help you," maybe. But if they're just going to tell you, and then you've got*
12 *this hanging over your head, and you're thinking, "When is it going to start?" and*
13 *then you'd be thinking you'd forget something and you'd think, "Oh, that's it, it's*
14 *coming", which it would be quite normal if you hadn't had that diagnosis, you'd think,*
15 *"Well I just forgot something, everybody does that."* (C3, female carer (daughter) of
16
17 stroke-survivor at follow-up interview)
18
19
20
21
22
23
24
25

26
27 However, one carer felt that despite the worry a potential diagnosis may generate,
28
29 the benefit of this would be to find strategies to maintain cognitive function:
30

31
32 *"I think if you had earlier diagnosis, then you would be sort of prepared before things*
33 *got difficult to handle, or before problems arise, that would be a very good thing. The*
34 *disadvantages as you say, alarming the carers or the patients themselves, "I'm going*
35 *to lose my mind." Because, particularly in the older generation, that's a big worry to*
36 *them. It is a big worry, it's a big worry to all of us, but to older people particularly."*
37
38 (C5, female carer (daughter) of stroke-survivor)
39
40
41
42
43
44
45

46 47 Concerns about how it may affect their recovery

48

49
50 Not all stroke-survivors were as keen to engage in risk assessment, as there was
51
52 emphasis on how this may affect them psychologically particularly when their
53
54 physical deficits had recovered enough to allow them to return to a more usual
55
56 routine. Therefore, although diagnosis was felt to be important, whether an individual
57
58 would like to know was also dependent on their subsequent post-stroke recovery:
59
60

1
2
3 *“That’s difficult you know because I mean if you have an early diagnosis you know*
4 *and say, well “It’s going to happen” you know but at the moment now I seem to be*
5 *progressing through, I’m driving now, you know I’m going back to meetings and*
6 *whatever. I wonder whether an early diagnosis would restrict that.” (P4, male stroke-*
7 *survivor)*

8
9
10
11
12
13
14
15 This was particularly evident when patients were followed up six-months later. One
16 participant had actually changed her view over time. Although she had initially felt
17 positive about the process, she then changed her mind when questioned on the
18 same process at her follow-up interview:

19
20
21
22 *“I think my thinking has gone the other way for knowing about that. I think it’s sad. I*
23 *think it’s a sad thing. I really do, I think it’s really sad that for people to know that*
24 *they’re going to be at high risk, it’s a sad thing for it to happen to people, and I don’t*
25 *think I’d want to be one of the sad people. I think I’d just want to be, potter along and*
26 *that’s it.” (P2, female, stroke-survivor at follow-up interview)*

27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
At follow-up interviews participants also felt that risk assessment should be an individual choice because of the ramifications of the assessment outcome i.e. a potential diagnosis of dementia. Although clinicians may deem it to be helpful, the choice to undergo risk assessment needs to be a weighed up, which should negate any calls for it to be made a universally applied process:

61
62
63
64
65
66
67
68
69
70
“I think, medically speaking, yes. On the other hand, does it give people things to
worry about that they wouldn’t have worried about if you hadn’t done the tests? So, I
think it depends really on your personal point of view. Do you want to be, you see I
would look on the test as saying, well you’re at a low, you’ve got a low risk so that’s
great but then if it turned out you’d got a high risk are you going to be more worried

1
2
3 *and less happy than you were before. It's hard to really balance it, isn't it? (P3,*
4
5 *female, stroke-survivor at follow-up interview)*
6
7

8 ***Clinician Views: Facilitators to Risk Assessment Focusses on the Process***

9

10
11 Clinicians discussed facilitators to risk assessment in terms of how the process may
12
13 affect the individual and also how the process could be implemented in the future.
14

15
16 When discussing how to implement this process, both primary and secondary care
17
18 specialists discussed the advantages associated with hosting this process within
19
20 their own individual teams.
21
22

23 *Process familiarity in Primary Care*

24

25
26 For primary care, it was about the fact that risk assessment was already a familiar
27
28 process but that it needed to be individualised:
29
30

31
32 *"I think it's a good tool. We're quite good at using tools, aren't we, but there's always*
33
34 *going to be exceptions to the rules and you've got to individualise what you do with it*
35
36 *... But sometimes using a score or a tool is a way into a service."* (PC4, nurse
37
38 *practitioner in primary care)*
39
40

41
42 It was also recognised by one General Practitioner (GP) that although there is
43
44 familiarity with risk assessment in primary care, there needs to be caution that the
45
46 system is not overwhelmed with such tools:
47
48

49
50 *"I do quite like risk profiling. I think we went a little bit crazy with the risk profiling. And*
51
52 *there feels to be a lot of competing risk profiling tools, that we're getting a little bit*
53
54 *inundated with at the moment ... So I think anything like this, I love, if it can be*
55
56 *incorporated and brought on to an individual and needs level - so you can think*
57
58
59
60

1
2
3 *about caring, identifying risk and needs for an individual - would feel great for me”*

4
5
6 *(PC2, General Practitioner)*

7
8
9 *Secondary care provides specialist input*

10
11 Stroke care clinicians discussed the facilitators of risk assessment within a specialist
12 setting. This was based on the fact that they felt a responsibility to ensure that post-
13 stroke sequelae are followed up in their specialist services due to the
14 multidisciplinary element of their standard practice and easier access to services.
15 This was particularly important to ensure information could also be given to patients
16 at a time when they may need it the most:
17
18

19
20
21
22
23
24
25
26 *“I think the six-month review tends to be a period of time when the patient’s acute*
27 *side, acute phase of their care has kind of been established, and this is probably the*
28 *time when they start to recognise problems. And I think it should be within a stroke*
29 *MDT (multidisciplinary team), not so much focused on by GP’s, as such.” (SC2,*
30 *Stroke specialist nurse)*

31
32
33
34
35
36
37
38 *“Well, you need the right support. You need people that actually understand stroke.*
39 *So I think it would have to be delivered by stroke healthcare professionals. And I*
40 *think you get so much information when you’re initially an inpatient, I think maybe*
41 *that’s not the best place to do it ... Yeah, it’s a big thing to be told that you might*
42 *develop dementia in a few years’ time, so you need psychologists kind of available*
43 *for if someone needs counselling as a result of that finding. I think it’s tricky.” (SC6,*
44 *Stroke physiotherapist)*

45
46
47
48
49
50
51
52 *Collaborative Care*

53
54
55
56
57
58 Primary care clinicians commented that there may be a place for both primary and
59 secondary care to work together in identifying those at risk.
60

1
2
3 *"I think primary care would be a completely reasonable place to do that. I guess it's*
4 *a conversation that could start at diagnosis, at discharge from hospital, like actually,*
5 *we know that people who have had a stroke are at higher risk of having dementia,*
6 *these are the things to be aware of, and you know to start that discussion"* (PC8,
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
General Practitioner)

Primary and secondary care clinicians felt that such a shared care pathway needed to be formalized to reduce the risk of individuals falling into gaps in care:

"... even if it was picked up in secondary care it's still going to be primary care where most of the management is occurring. So I think it being identified at the six-month follow-up, but then there being a formal sort of mechanism, in which primary care pick it up and process it, would be fine. (PC3, General Practitioner)

"I don't mind where work is done, provided that it is done in a structured and standardised way. If that be, if that can be in primary care that is really good, because that is the long-term follow-up, long-term support, integrating the community ... just as long as it can be delivered in a systematic way, and people don't fall through gaps or get inconsistent care." (SC3, Stroke consultant)

Further, the process of communication between primary and secondary care could also be used in the diagnostic process. It was felt that repeated assessments could help facilitate diagnosis by identifying trends in symptoms:

"You can measure a trend, can't you, if you're using something and measuring something, you can look at a trend. So if its, depends on the type of tool, I guess. But if you did it at you know at the six months review date and then we did it subsequently a year later in primary care, you would see any changes or decline or improvement. So it's a way of, it's a way of monitoring a trend on how they're doing, I

1
2
3 *guess. So I don't, I don't see any reason why it couldn't be done in both and used*
4 *across both. I don't think we use enough across both.” (PC4, nurse practitioner in*
5
6 *primary care)*
7
8
9

10 ***Clinician Views: Barriers to Risk Assessment Focusses on the Outcome***

11 *Limited Interventions Available*

12
13
14
15
16
17 Similar to the perspectives of carers, clinicians recognised the anxiety that a risk
18 assessment process might generate and felt that it should be a personal choice to
19 undertake an assessment because of the perceived lack of intervention:
20
21
22

23
24 *“Yeah, I think I would, I would have degree of anxiety, especially given that the*
25 *measures that we're putting in place are ... that we could put in place are largely*
26 *supportive rather than preventative ... I would be less confident that I could be giving*
27 *my patient advice to say, “Well, if we do this, and we do this, and if we do this and*
28 *you do that then that might move you into an even smaller risk group.” (PC3,*
29
30
31
32
33

34 *General Practitioner)*

35
36
37
38
39 *“Outside research trials, I'm not convinced that there is a definitive value in doing that*
40 *yet. You know if we get really overwhelming evidence that it's amenable to*
41 *intervention so you know there's all the theory about blood pressure, and statins, and*
42 *all the rest of that, but my reading of the evidence on all of that at the moment is that*
43 *the jury is out whether it makes a difference to cognitive function. So yeah, I'm not*
44 *convinced that identifying risk, unless you've got a something you can do about it, is*
45 *actually sensible.” (SC4, Stroke consultant)*
46
47
48
49
50
51
52

53 *Anxiety around a potential diagnosis of dementia*

1
2
3 In recognising the anxiety that this process may generate, one clinician also
4
5 commented on the fact that patients may not be willing to engage in conversation
6
7 over the subject of dementia and care should be taken when discussing a potential
8
9 diagnosis of dementia.
10

11
12
13 *“I think it’s good if we tell them that we’re looking through and saying, “Look, you
14
15 know there could be a problem here.” But for every single patient, again, because it’s
16
17 quite a still a – not a taboo subject – but it’s still not something that people want to
18
19 talk about ... I don’t know whether it would be used on every single ‘per’, you know
20
21 what I mean, like, everybody.” (SC5, Stroke specialist nurse)*
22
23

24 25 No Change from Standard Practice 26

27
28 The majority of clinical participants wanted to know, not only what the outcome of the
29
30 risk assessment would be, but also the resulting care the patient would receive. As
31
32 part of current routine clinical care, all stroke survivors are offered annual reviews in
33
34 order to ensure their vascular risk factors e.g. blood pressure and cholesterol are
35
36 well controlled. In terms of reducing risk, one primary care physician expressed
37
38 concerns as to what the benefit would to the individual if risk factor modification was
39
40 already in place anyway particularly with regards to the emotive side of a potential
41
42 dementia diagnosis. A secondary care specialist questioned the value when there
43
44 was seemingly limited interventions that could be implemented besides managing
45
46 their cardiovascular risk:
47
48
49

50
51
52 *“I guess you’ve got to be very clear about what it is that you’re going to be doing
53
54 differently for them. So I can see the value if you use a tool for kind of primary
55
56 prevention, then you’re kind of selecting a group of patients out to do something
57
58 particular with, but I just wonder what would be different about what you do with a
59
60*

1
2
3 *risk assessment tool for people who have already had a stroke, when really you*
4 *know already that it is all about managing their cardiovascular risk so I'm not sure*
5 *that you would be doing anything different for them.” (PC8, General Practitioner)*
6
7

8
9
10
11 *“Many people will not know of the association between dementia and stroke and*
12 *many people would not want to know if they were at risk of dementia and again, if*
13 *you're identifying somebody at risk of a condition that you can't do anything about,*
14 *what's the right stage to, to do that? However, many of the things you need to do in*
15 *terms of people being at risk of dementia are the same of the general cardiovascular.*
16 *So, I'm not sure that there is anything additional that needs to be done about*
17 *reducing people's risk for dementia over and above general cardiovascular risk.”*
18
19

20
21
22
23
24
25
26
27 *(SC3, Stroke consultant)*
28

29 **Discussion**

30 Main Findings

31
32
33
34
35
36 This is the first study to explore key stakeholders' - stroke survivors, family
37 carers and primary and secondary care clinicians - views on the use of a risk
38 assessment process to predict future dementia in stroke-survivors. It is clear that
39 some of the participants interviewed believed that risk assessment could be of
40 clinical use but raised concerns about it being mandatory. Clinicians highlighted both
41 the benefits of collaborative and individual (i.e. primary or secondary) care if
42 dementia risk assessment for stroke survivors was to be implemented.
43
44
45
46
47
48
49
50

51
52
53 Clinician facilitators suggest benefits in either primary or secondary care
54 settings but also in a collaborative model of care between the two. This latter finding
55 echoes recommendations from the UK Intercollegiate Stroke Working Party for a
56 collaborative care model, linking community and specialist care, with the aim of
57
58
59
60

1
2
3 integrated long-term follow-up for those presenting neuropsychological problems¹⁷.
4
5 Although both primary and secondary care clinicians could see the benefits of
6
7 carrying this assessment in their own specialties, patients and carers in this study
8
9 valued their relationship with their GP. Further, primary care clinicians themselves
10
11 are familiar with the process of risk assessment. A recent survey of primary care
12
13 physicians trainees found that they were also keen to implement a dementia risk
14
15 assessment strategy to assist in earlier identification²⁵. However, potential barriers
16
17 have been identified in previous studies, such as system-related factors (lack of
18
19 support, time constraints)^{26 27} and training in dementia²⁷, which would need to be
20
21 addressed. Risk assessment is an objective process requiring specific individual
22
23 variables e.g. age, gender, education. Such data is readily available in primary care
24
25 in many countries where electronic medical record systems are in place. Further,
26
27 GPs are already asked to assess cardiovascular risk as part of routine clinical care²⁸.
28
29 However, some GPs themselves do not like using risk assessment tools particularly
30
31 as the tools do not provide the support needed in communication²⁹. Training in
32
33 communicating the risk assessment process, particularly in the context of dementia,
34
35 would be required if this were to be implemented in clinical practice. Further, some
36
37 models, particularly those developed in stroke populations¹¹ may also include
38
39 variables such as complex imaging data, which will only be available in secondary
40
41 care and may be difficult to obtain even in specialist settings. If risk assessment were
42
43 to be conducted in primary care, then the risk assessment models utilising data
44
45 which can be accessed in primary care, needs to be externally validated in stroke
46
47 populations to assess their accuracy.
48
49
50
51
52
53
54

55
56 Clinician participants were concerned about whether risk assessment would
57
58 actually change standard practice. In a stroke population, it is unclear whether
59
60

1
2
3 identifying those at risk would achieve any additional benefit from a risk factor
4
5 modification point of view. This is because stroke-survivors already receive annual
6
7 community follow-up with particular focus on vascular risk factor modification.
8
9
10 However, current evidence suggests that development of post-stroke dementia is
11
12 more than just about vascular risk and would require a different approach e.g.
13
14 psychological support, cognitive preservation strategies and additional resources.
15
16 Results from several trials, assessing whether vascular-based interventions can
17
18 reduce dementia risk, have been largely disappointing^{30 31}. These results suggest
19
20 that perhaps an individual's risk of post-stroke cognitive impairment and dementia
21
22 includes risk factors beyond vascular risk and/or that the disease has a different
23
24 mechanism such as inflammatory changes in the cerebral vasculature triggered by
25
26 stroke or related to small vessel disease.
27
28
29

30
31
32 Currently population screening for dementia is not recommended due to a
33
34 lack of evidence evaluating risks and benefits³², despite positive views from older
35
36 adults³³. Risk assessment can target high-risk groups rather than the general
37
38 population. Recent evidence has found a decline in age-specific incidence of
39
40 dementia, particularly in high-income countries, suggesting that rising levels of
41
42 education and modifying cardiovascular risk may have driven a decline in dementia
43
44 risk^{34 35}. Indeed, the importance of modifiable risk factor reduction for dementia was
45
46 reported in the World Alzheimer Report (2014)³⁶ and around a third of Alzheimer's
47
48 disease cases worldwide might be attributable to modifiable risk factors³⁷. Risk
49
50 assessment tools utilize these modifiable risk factors to predict risk. Similar to other
51
52 branches of medicine where risk assessment is utilized to predict risk of a future
53
54 illness, it would be hoped that this approach could reduce one's risk of future
55
56 dementia. Stroke affects more than 100,000 people in the UK per year³⁸, creating a
57
58
59
60

1
2
3 large population with cognitive deficits and/or at high risk of future decline who may
4 benefit from risk assessment for dementia. However, participant groups in this study,
5 particularly clinicians, reported that given the potential ramifications of risk
6 assessment, individuals should be given the choice of whether to undergo
7 assessment. Stroke-survivors were generally positive about such an approach but
8 agreed that it should be up to the individual and the family rather than applied
9 universally. Participants in this study recognised the anxiety this process could
10 generate particularly when the perceived possible interventions for dementia are
11 limited. The National Institute for Health and Care Excellence have recently updated
12 their guidance and have concluded that case finding should only be conducted as part
13 of a clinical trial, which also provides an intervention³⁹. Therefore, careful discussion needs
14 to be adopted with the patient and their carers before undertaking such a process in any
15 setting. In the context of the dementia diagnostic journey, transition from living with
16 an undiagnosed memory problem to being diagnosed with a dementia illness is
17 underpinned by uncertainty⁴⁰. Although risk assessment certainly does not provide any
18 certainty for a dementia illness, the discussions and objective evaluation using the tools may
19 help the individual's process their current condition and assist in the preparation for a
20 potential diagnosis of dementia. Preparation was mentioned by participants in this study as a
21 facilitator for risk assessment.

22 Clinical Implications

23
24 Case finding for dementia involves actively assessing individuals at risk of a future
25 dementia illness, which at present is only recommended in clinical trial settings due
26 to a lack of post-assessment intervention⁴¹. Once a suitable intervention is found
27 however, the views of those conducting the assessment and the recipients of such
28 an assessment will need to be assessed. Similarly there will be challenges with
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 regards to assessment of capacity when performing risk assessment for this at-risk
4 population. It is also important to note that GPs find communicating the diagnosis of
5 dementia difficult⁴². Although risk assessment is not providing a diagnosis of
6 dementia, careful consideration will be required in training health professionals in
7 communicating the concept of risk for a disease such as dementia. From this study
8 we have identified the priorities according to each stakeholder group which would
9 need to be addressed prior to clinical implementation in the future.
10
11
12
13
14
15
16
17
18
19

20 Limitations

21
22 The participants in this study came from one area of England and were Caucasian.
23 Patient participants were also well enough to attend outpatient assessment clinics.
24 Future studies could look to explore views in other populations including views from
25 minority ethnic groups, patients with more severe stroke-related impairments and
26 different service models. Due to familiarity, it is recognized that clinicians expanded
27 more around the risk assessment process. Despite this being the case, patients and
28 carers were given the opportunity to understand the concept of risk assessment as
29 part of the interview process but the emphasis on a need for a diagnosis and good
30 care was what was important for them. Participants were also aware that the
31 interviewer was also a primary care clinician, which may have the potential to
32 introduce bias into participant responses. This is because a clinician interviewer may
33 be viewed as an expert and judge in clinical decision making and moral judgements
34 made⁴³. On the other hand interviews tend to be broader in scope and richer in data
35 when conducted by a clinician researcher⁴³. Further, both clinical and non-clinical
36 members contributed to the analysis of the data to minimize the effect this may have
37 had.
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Conclusions and Future Research

Timely recognition of those at risk of dementia is crucial to enable individuals early access treatment and support. Although dementia screening after stroke is not yet advocated on preventative grounds, assessing risk has some potential benefits for individuals who make an informed choice to participate. There would need to be better cohesiveness of communication between primary and secondary care, with more support placed in the community. Further, it should be recognised that if risk assessment were to be incorporated into clinical practice, this will potentially place additional burdens on a dementia diagnostic service which is already overstretched. Next steps are to identify which tool to use, how best to manage those who are deemed high-risk individuals and whether there are any interventions, which can reduce their risk. Future studies will need to look specifically at what factors put a stroke-survivor at risk that could be potentially modified and also whether there are specific interventions suitable to a post-stroke population to reduce risk.

Acknowledgements:

The authors would like to thank the participant advisory group for their advice on the study materials used.

List of Abbreviations

GP General Practitioner

UK United Kingdom

Declarations

Author Contributions:

1
2
3 ET conceived the framework for this study. ET collected, analysed and interpreted
4 the data. ET prepared the manuscript for submission.
5
6
7

8 CE helped to conceive the framework for this study and assisted with the analysis of
9 the data and contributed to the drafting of the manuscript. CE also critically reviewed
10 and edited the manuscript.
11
12
13

14 CP helped to conceive the framework for this study, assisted with the analysis of the
15 data and critically reviewed and edited the manuscript.
16
17
18

19 BS helped to conceive the framework for this study, assisted with the analysis of the
20 data and critically reviewed and edited the manuscript.
21
22
23

24 LR helped to conceive the framework for this study, assisted with the analysis of the
25 data and critically reviewed and edited the manuscript.
26
27
28

29 30 31 **Funding:**

32 Eugene Tang is supported by a NIHR Doctoral Research Fellowship (DRF-2015-08-
33 006).
34
35
36
37
38

39 Louise Robinson is supported by a National Institute for Health Research
40 professorship (NIHR-RP-011-043) and a NIHR Senior Investigator award (NF-SI-
41 0616-10054).
42
43
44
45
46

47 **Consent for Publication:**

48 All participants in the study have provided informed written consent. No identifiable
49 personal information has been used.
50
51
52
53

54 **Competing Interests:**

1
2
3 LR reports grants from NIHR Professorship award, grants from NIHR Senior
4
5 Investigator award, outside the submitted work. The remaining authors declare that
6
7 they have no competing interests.
8
9

10
11 **Disclaimer:**
12

13
14 This paper presents independent research funded by the National Institute for Health
15
16 Research (NIHR). The views expressed are those of the author(s) and not
17
18 necessarily those of the NHS, the NIHR or the Department of Health.
19

20
21 **Data Sharing Statement:**
22

23
24 No further data will be made available.
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

References

1. Prince M, Wimo W, Guerchet M, et al. World Alzheimer Report 2015: The Global Impact of Dementia, An Analysis of Prevalence, Incidence, Cost and Trends. 2015.
2. Savva GM, Stephan BC, Alzheimer's Society Vascular Dementia Systematic Review G. Epidemiological studies of the effect of stroke on incident dementia: a systematic review. *Stroke* 2010;41(1):e41-6. doi: <http://dx.doi.org/10.1161/STROKEAHA.109.559880>
3. Pendlebury ST, Rothwell PM. Prevalence, incidence, and factors associated with pre-stroke and post-stroke dementia: a systematic review and meta-analysis. *Lancet Neurol* 2009;8(11):1006 - 18.
4. Douiri A, Rudd AG, Wolfe CD. Prevalence of poststroke cognitive impairment: South London Stroke Register 1995-2010. *Stroke* 2013;44(1):138-45. doi: <http://dx.doi.org/10.1161/STROKEAHA.112.670844>
5. Kuzma E, Lourida I, Moore SF, et al. Stroke and dementia risk: A systematic review and meta-analysis. *Alzheimer's & dementia : the journal of the Alzheimer's Association* 2018 doi: 10.1016/j.jalz.2018.06.3061 [published Online First: 2018/09/05]
6. Feigin VL, Forouzanfar MH, Krishnamurthi R, et al. Global and regional burden of stroke during 1990-2010: findings from the Global Burden of Disease Study 2010. *Lancet* 2014;383(9913):245-54. [published Online First: 2014/01/23]
7. Prince M, Ali GC, Guerchet M, et al. Recent global trends in the prevalence and incidence of dementia, and survival with dementia. *Alzheimer's research & therapy* 2016;8(1):23. doi: 10.1186/s13195-016-0188-8 [published Online First: 2016/07/31]
8. Baumgart M, Snyder HM, Carrillo MC, et al. Summary of the evidence on modifiable risk factors for cognitive decline and dementia: A population-based perspective. *Alzheimer's & dementia : the journal of the Alzheimer's Association* 2015;11(6):718-26. doi: 10.1016/j.jalz.2015.05.016 [published Online First: 2015/06/06]
9. Stephan BCM, Kurth T, Matthews FE, et al. Dementia risk prediction in the population: are screening models accurate? *Nat Rev Neurol* 2010;6(6):318 - 26.
10. Tang EY, Harrison SL, Errington L, et al. Current Developments in Dementia Risk Prediction Modelling: An Updated Systematic Review. *PloS one* 2015;10(9):e0136181. doi: 10.1371/journal.pone.0136181 [published Online First: 2015/09/04]
11. Kandiah N, Chander RJ, Lin X, et al. Cognitive Impairment after Mild Stroke: Development and Validation of the SIGNAL2 Risk Score. *Journal of Alzheimer's disease : JAD* 2016;49(4):1169-77. doi: 10.3233/jad-150736 [published Online First: 2015/11/26]
12. Lin JH, Lin RT, Tai CT, et al. Prediction of poststroke dementia. *Neurology* 2003;61(3):343-8. [published Online First: 2003/08/13]
13. Stephan BC, Minett T, Muniz Terrera G, et al. Dementia prediction for people with stroke in populations: is mild cognitive impairment a useful concept? *Age and ageing* 2014 doi: 10.1093/ageing/afu085 [published Online First: 2014/07/09]
14. Chander RJ, Lam BYK, Lin X, et al. Development and validation of a risk score (CHANGE) for cognitive impairment after ischemic stroke. *Scientific reports* 2017;7(1):12441. doi: 10.1038/s41598-017-12755-z [published Online First: 2017/10/01]
15. Siontis GC, Tzoulaki I, Siontis KC, et al. Comparisons of established risk prediction models for cardiovascular disease: systematic review. *BMJ (Clinical research ed)* 2012;344:e3318.
16. Johnston SC, Rothwell PM, Nguyen-Huynh MN, et al. Validation and refinement of scores to predict very early stroke risk after transient ischaemic attack. *Lancet* 2007;369(9558):283-92. doi: 10.1016/s0140-6736(07)60150-0 [published Online First: 2007/01/30]
17. Intercollegiate Stroke Working Party. National Clinical Guideline for Stroke. 2016 [published Online First: Fifth Edition]

18. Tang EYH, Price C, Stephan BCM, et al. Gaps in care for patients with memory deficits after stroke: views of healthcare providers. *BMC health services research* 2017;17(1):634. doi: 10.1186/s12913-017-2569-5 [published Online First: 2017/09/10]
19. Tang EYH, Price C, Stephan BCM, et al. Post-stroke memory deficits and barriers to seeking help: views of patients and carers. *Fam Pract* 2018(In Publication)
20. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006;3(2):77-101. doi: 10.1191/1478088706qp063oa
21. Glaser B. The constant comparison method of qualitative analysis. *Soc Probl* 1965;12:436-45.
22. Legard R, Keegan J, Ward K. In-depth interviews. In: Ritchie J, Lewis J, editors. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage 2003:pp. 139–169.
23. Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & quantity* 2018;52(4):1893-907. doi: 10.1007/s11135-017-0574-8 [published Online First: 2018/06/26]
24. O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research: a synthesis of recommendations. *Academic medicine : journal of the Association of American Medical Colleges* 2014;89(9):1245-51. doi: 10.1097/acm.0000000000000388 [published Online First: 2014/07/01]
25. Tang EY, Birdi R, Robinson L. Attitudes to diagnosis and management in dementia care: views of future general practitioners. *International psychogeriatrics* 2016;1-6. doi: 10.1017/s1041610216001204 [published Online First: 2016/08/10]
26. Koch T, Iliffe S. Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: a systematic review. *BMC family practice* 2010;11:52. doi: 10.1186/1471-2296-11-52 [published Online First: 2010/07/03]
27. Chithiramohan A, Iliffe S, Khattak I. Identifying barriers to diagnosing dementia following incentivisation and policy pressures: General practitioners' perspectives. *Dementia (London, England)* 2016 doi: 10.1177/1471301216682625 [published Online First: 2016/12/13]
28. Hippisley-Cox J, Coupland C, Brindle P. Development and validation of QRISK3 risk prediction algorithms to estimate future risk of cardiovascular disease: prospective cohort study. *BMJ (Clinical research ed)* 2017;357:j2099. doi: 10.1136/bmj.j2099 [published Online First: 2017/05/26]
29. Barfoed BL, Jarbol DE, Paulsen MS, et al. GPs' Perceptions of Cardiovascular Risk and Views on Patient Compliance: A Qualitative Interview Study. *International journal of family medicine* 2015;2015:214146. doi: 10.1155/2015/214146 [published Online First: 2015/10/27]
30. Matz K, Teuschl Y, Firlinger B, et al. Multidomain Lifestyle Interventions for the Prevention of Cognitive Decline After Ischemic Stroke: Randomized Trial. *Stroke* 2015;46(10):2874-80. doi: 10.1161/strokeaha.115.009992 [published Online First: 2015/09/17]
31. Bath PM, Scutt P, Blackburn DJ, et al. Intensive versus Guideline Blood Pressure and Lipid Lowering in Patients with Previous Stroke: Main Results from the Pilot 'Prevention of Decline in Cognition after Stroke Trial' (PODCAST) Randomised Controlled Trial. *PLoS one* 2017;12(1):e0164608. doi: 10.1371/journal.pone.0164608 [published Online First: 2017/01/18]
32. Moyer VA. Screening for cognitive impairment in older adults: U.S. Preventive Services Task Force recommendation statement. *Annals of internal medicine* 2014;160(11):791-7. doi: 10.7326/m14-0496 [published Online First: 2014/03/26]
33. Justiss MD, Boustani M, Fox C, et al. Patients' attitudes of dementia screening across the Atlantic. *International journal of geriatric psychiatry* 2009;24(6):632-7. doi: 10.1002/gps.2173 [published Online First: 2008/12/31]
34. Langa KM. Is the risk of Alzheimer's disease and dementia declining? *Alzheimer's research & therapy* 2015;7(1):34. doi: 10.1186/s13195-015-0118-1 [published Online First: 2015/03/31]

- 1
2
3 35. Larson EB, Yaffe K, Langa KM. New insights into the dementia epidemic. *The New England journal*
4 *of medicine* 2013;369(24):2275-7. doi: 10.1056/NEJMp1311405 [published Online First:
5 2013/11/29]
6
7 36. Prince M, Albanese E, Guerchet M, et al. Dementia and Risk Reduction: An Analysis of Protective
8 and Modifiable Factors. 2014.
9 37. Norton S, Matthews FE, Barnes DE, et al. Potential for primary prevention of Alzheimer's disease:
10 an analysis of population-based data. *Lancet Neurol* 2014;13(8):788-94. doi: 10.1016/s1474-
11 4422(14)70136-x [published Online First: 2014/07/18]
12 38. Stroke Association. State of the nation: stroke statistics. 2017.
13 <https://www.stroke.org.uk/resources/state-nation-stroke-statistics> (accessed 14th August
14 2017).
15 39. Faircloth CA, Boylstein C, Rittman M, et al. Sudden illness and biographical flow in narratives of
16 stroke recovery. *Sociology of health & illness* 2004;26(2):242-61. doi: 10.1111/j.1467-
17 9566.2004.00388.x [published Online First: 2004/03/19]
18 40. Campbell S, Manthorpe J, Samsi K, et al. Living with uncertainty: Mapping the transition from
19 pre-diagnosis to a diagnosis of dementia. *Journal of aging studies* 2016;37:40-7. doi:
20 10.1016/j.jaging.2016.03.001 [published Online First: 2016/05/01]
21 41. National Institute for Health and Care Excellence. Dementia: assessment, management and
22 support for people living with dementia and their carers 2018.
23 <https://www.nice.org.uk/guidance/ng97>.
24 42. Phillips J, Pond CD, Paterson NE, et al. Difficulties in disclosing the diagnosis of dementia: a
25 qualitative study in general practice. *The British journal of general practice : the journal of*
26 *the Royal College of General Practitioners* 2012;62(601):e546-53. doi:
27 10.3399/bjgp12X653598 [published Online First: 2012/08/08]
28 43. Chew-Graham CA, May CR, Perry MS. Qualitative research and the problem of judgement:
29 lessons from interviewing fellow professionals. *Fam Pract* 2002;19(3):285-9. [published
30 Online First: 2002/04/30]
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Table 1. Interview Participants (Patients and Carers)

| Unique Identifier (Patients and Carers) | Role | Gender | Age | Follow-up Interview Conducted |
|--|---------------------------|---------------|------------|--------------------------------------|
| P1 | Stroke-survivor | Female | 80 | No |
| P2 | Stroke-survivor | Female | 76 | Yes |
| P3 | Stroke-survivor | Female | 72 | Yes |
| P4 | Stroke-survivor | Male | 75 | Yes |
| P5 | Stroke-survivor | Male | 80 | Yes |
| P6 | Stroke-survivor | Male | 74 | Yes |
| P7 | Stroke-survivor | Female | 73 | Yes |
| P8 | Stroke-survivor | Female | 82 | Yes |
| P9 | Stroke-survivor | Male | 84 | No |
| P10 | Stroke-survivor | Male | 79 | Yes |
| C1 | Carer of P1 (Husband) | Male | 79 | No |
| C2 | Carer of P4 (Wife) | Female | 79 | Yes |
| C3 | Carer of P5 (Daughter) | Female | 57 | Yes |
| C4 | Carer of P6 (Wife) | Female | 71 | Yes |

| | | | | |
|----|---------------------------|--------|----|-----|
| C5 | Carer of P8 (Daughter) | Female | 60 | Yes |
|----|---------------------------|--------|----|-----|

For peer review only

Table 2. Interview Participants (Clinicians)

| Unique Identifier (Clinicians) | Role | Gender |
|---|---|---------------|
| SC1 | Stroke Consultant | Female |
| SC2 | Stroke Specialist Nurse | Female |
| SC3 | Stroke Consultant | Female |
| SC4 | Stroke Consultant | Male |
| SC5 | Stroke Specialist Nurse | Female |
| SC6 | Stroke Physiotherapist (Rehabilitation) | Female |
| SC7 | Stroke Physiotherapist (Acute Care) | Female |
| SC8 | Stroke Occupational Therapist (Acute Care) | Male |
| SC9 | Stroke Occupational Therapist (Rehabilitation) | Female |
| PC1 | General Practitioner with Specialist Interest in Dementia | Male |
| PC2 | General Practitioner | Male |
| PC3 | General Practitioner | Female |
| PC4 | Nurse Practitioner in primary care | Female |
| PC5 | General Practitioner | Female |

| | | |
|-----|---------------------------------------|--------|
| PC6 | Practice Nurse | Female |
| PC7 | Nurse Practitioner in primary care | Female |
| PC8 | General Practitioner | Female |

For peer review only

Supplementary Table 1*Standards for Reporting Qualitative Research Checklist¹*

| No. | Topic | Item | Page(s) |
|---------------------------|--|--|---------|
| Title and abstract | | | |
| S1 | Title | Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended | 1 |
| S2 | Abstract | Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions | 2 - 3 |
| Introduction | | | |
| S3 | Problem formulation | Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement | 5 - 6 |
| S4 | Purpose or research question | Purpose of the study and specific objectives or questions | 6 |
| Methods | | | |
| S5 | Qualitative approach and research paradigm | Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale ^b | 8 - 9 |
| S6 | Researcher characteristics and reflexivity | Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability | 7 |
| S7 | Context | Setting/site and salient contextual factors; rationale ^b | 6 - 9 |
| S8 | Sampling strategy | How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale ^b | 7 - 9 |
| S9 | Ethical issues pertaining to human subjects | Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues | 6 - 7 |
| S10 | Data collection methods | Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale ^b | 8 |
| S11 | Data collection instruments and technologies | Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study | 8 - 9 |
| S12 | Units of study | Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results) | 31 - 34 |
| S13 | Data processing | Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts | 8 - 9 |
| S14 | Data analysis | Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale ^b | 9 |
| S15 | Techniques to enhance trustworthiness | Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale ^b | 9 |
| Results/findings | | | |
| S16 | Synthesis and interpretation | Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory | 9 - 20 |
| S17 | Links to empirical data | Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings | 9 - 20 |
| Discussion | | | |
| S18 | Integration with prior work, implications, transferability, and contribution(s) to the field | Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field | 20 - 24 |
| S19 | Limitations | Trustworthiness and limitations of findings | 24 |
| Other | | | |
| S20 | Conflicts of interest | Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed | 26 - 27 |
| S21 | Funding | Sources of funding and other support; role of funders in data collection, interpretation, and reporting | 26 |

Reference

- O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research: a synthesis of recommendations. *Academic medicine : journal of the Association of American Medical Colleges* 2014;89(9):1245-51. doi: 10.1097/acm.0000000000000388 [published Online First: 2014/07/01]

BMJ Open

The Views of Public and Clinician Stakeholders on Risk Assessment Tools for Post-Stroke Dementia: A Qualitative Study

| | |
|---------------------------------|---|
| Journal: | <i>BMJ Open</i> |
| Manuscript ID | bmjopen-2018-025586.R2 |
| Article Type: | Research |
| Date Submitted by the Author: | 25-Jan-2019 |
| Complete List of Authors: | Tang, Eugene; Newcastle University, Institute of Health and Society Exley, Catherine; Newcastle University, Institute of Health and Society Price, Christopher; Newcastle University, Institute of Neuroscience, Stroke Research Group Stephan, Blossom; Newcastle University, Institute of Health and Society Robinson, Louise; Newcastle University, Institute of Health and Society |
| Primary Subject Heading: | Qualitative research |
| Secondary Subject Heading: | Mental health, Neurology, General practice / Family practice |
| Keywords: | PRIMARY CARE, STROKE MEDICINE, QUALITATIVE RESEARCH, Dementia < NEUROLOGY |
| | |

SCHOLARONE™
Manuscripts

1
2
3 **The Views of Public and Clinician Stakeholders on Risk Assessment Tools for**
4
5 **Post-Stroke Dementia: A Qualitative Study**
6
7

8 Dr. Eugene Yee Hing Tang^{1,2} e.y.h.tang@newcastle.ac.uk
9

10 Prof. Catherine Exley¹ catherine.exley@newcastle.ac.uk
11
12

13 Dr. Christopher Price³ c.i.m.price@newcastle.ac.uk
14
15

16 Dr. Blossom CM Stephan^{1,2} blossom.stephan@newcastle.ac.uk
17
18

19 Prof. Louise Robinson^{1,2} a.l.robinson@newcastle.ac.uk
20
21
22
23
24
25

26 ¹ Institute of Health and Society, Newcastle University, Baddiley-Clark, Richardson
27 Road, Newcastle upon Tyne, UK, NE2 4AX
28

29 ² Newcastle University Institute of Ageing, Newcastle University, Campus for Ageing
30 and Vitality, Newcastle upon Tyne, UK, NE4 5PL
31
32
33

34 ³ Institute of Neuroscience, Stroke Research Group, Newcastle University.
35 Newcastle upon Tyne, UK
36
37
38
39
40
41
42

43 Corresponding author: Dr. Eugene Yee Hing Tang, Institute of Health & Society,
44 Newcastle University, Level 2, Newcastle Biomedical Research Building, Campus for
45 Ageing and Vitality, Newcastle upon Tyne, NE4 5PL, T: 0191 208 8758,
46
47
48

49 E: e.y.h.tang@newcastle.ac.uk
50
51
52
53
54
55
56
57
58
59
60

Abstract

OBJECTIVE: Stroke-survivors are at increased risk of future dementia. Assessment to identify those at high risk of developing a disease using predictive scores has been utilised in different areas of medicine. A number of risk assessment scores for dementia have been developed but none has been recommended for use clinically. The aim of this qualitative study was to assess the acceptability and feasibility of using a risk assessment tool to predict post-stroke dementia.

DESIGN: Qualitative semi-structured interviews were conducted and analysed thematically. Patients and carers were offered interviews at around 6 (baseline) and 12 (follow-up) months post-stroke; Clinicians were interviewed once.

SETTING: The study was conducted in the North-East of England with stroke patients, family carers and healthcare professionals in primary and secondary care.

PARTICIPANTS: Thirty-nine interviews were conducted (17 clinicians and 15 stroke patients and their carers at baseline. Twelve stroke patients and their carers were interviewed at follow-up; some interviews were conducted in pairs).

RESULTS: Barriers and facilitators to risk assessment were discussed. For patients and carers the focus for facilitators were based on the outcomes of risk assessment e.g. assistance with preparation, diagnosis and for reassurance. For clinicians, facilitators were focused on the process i.e. familiarity in primary care, resource availability in secondary care and collaborative care. For barriers, both groups focussed on the outcome including e.g. the anxiety generated from a potential diagnosis of dementia. For patients/carers a further barrier included concerns about how it may affect their recovery. For clinicians there were concerns about limited interventions and how it would be different from standard care.

1
2
3 **CONCLUSIONS:** Risk assessment for dementia post-stroke presents challenges
4 given the ramifications of a potential diagnosis of dementia. Attention needs to be
5 given to how information is communicated, and strategies developed to support
6 patients and carers if risk assessment is used.
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

Strengths and Limitations of the Study:

- To the best of our knowledge this is the first qualitative study to examine critically the views of stroke patients and their family carers and clinicians about the acceptability and feasibility of a risk assessment approach to assist in earlier identification of post-stroke dementia.
- Understanding stakeholder views on risk assessment for dementia can help inform future strategies if risk assessment for dementia is used to assist with earlier diagnosis.
- Patient participants came from one area of England who were able to attend hospital outpatient departments and so may not represent the views and experiences of those with more severe post-stroke sequelae.
- Clinician participants came from one area of England and so may not represent the views of other service models in other regions of the UK.
- It is recognized that clinicians tended to be more familiar with the process of risk assessment and could elaborate further on the process involved.

Introduction

There is currently no cure for dementia and it is estimated that the worldwide economic burden will rise to US\$2 trillion by 2030¹. It has been suggested that the most powerful way to affect costs is by reducing the numbers of people who develop the illness. This may be facilitated by prediction of individual risk for the disease.

Stroke is associated with an increased risk of dementia and cognitive impairment²⁻⁴.

A recent meta-analysis found that stroke is a strong independent risk factor for dementia⁵. Stroke incidence and numbers of stroke-survivors are likely to increase due to simultaneous ageing populations and declining stroke mortality rates⁶. Given that the incidence of dementia increases exponentially with age^{1 7}, this will mean that post-stroke dementia will also become increasingly prevalent. It will therefore be important to identify those at greatest risk of developing dementia following stroke in order to implement strategies to reduce risk. In general, strategies to reduce risk of dementia may include management of cardiovascular risk factors e.g. smoking, diabetes as well as regular physical activity⁸.

Risk prediction models for dementia to identify those at higher risk have been developed in whole populations^{9 10} with some models specifically developed to predict cognitive impairment and dementia in stroke populations¹¹⁻¹⁴. These stroke-specific models predict dementia or cognitive impairment over a relatively short time period (up to 18 months¹⁴). In spite of the expanding research in this field, none of the dementia risk prediction tools have been clinically implemented. Further, no studies have assessed the feasibility or acceptability of implementing such a strategy in a stroke population. Although risk models are currently used in everyday clinical practice in other branches of medicine, in particular prevention of cardiovascular¹⁵ and cerebrovascular¹⁶ disease, it is unclear how clinicians would feel about using a

1
2
3 similar strategy to predict dementia, particularly given the stigma surrounding the
4 diagnosis and perceived limited interventions and increased awareness of cognitive
5 difficulties that patients and carers may have following stroke. Further, no studies
6 have evaluated whether using risk assessment tools for dementia would be
7 acceptable to stroke patients themselves.
8
9
10
11
12
13
14

15 This paper presents findings from a qualitative study conducted with patients,
16 carers and clinicians, which sought to critically examine their views about the
17 acceptability and feasibility of using risk prediction models in post-stroke care to
18 identify those at greatest risk of future dementia.
19
20
21
22
23
24
25
26
27

28 **Methods**

29 *Patient and Public Involvement (PPI)*

30
31 Patients and members of the public have been involved in the development of this
32 study from the beginning of the proposal. A participant advisory group also oversees
33 the work conducted and annual face-to-face meetings are held to inform them of the
34 study findings. The participant advisory group consists of members from a stroke
35 research patient and carer panel, an organisation aimed at capturing public views
36 about research and from a dementia and neurodegeneration specialty PPI group.
37
38 The same group reviewed the study materials to ensure suitability particularly for
39 stroke-survivors and their family carers.
40
41
42
43
44
45
46
47
48
49
50
51
52

53 *Ethical Approval*

1
2
3 The study was conducted in the North East of England. Ethical Approval was
4
5 obtained from the London – Hampstead Research Ethics Committee (reference
6
7 16/LO/0133). Participants provided informed written consent prior to the interview.
8
9

10 *Patient and Carer Sampling*

11
12 Patients and carers were purposively sampled from stroke clinics i.e. to ensure a mix
13
14 of genders and a range carers were recruited. As part of routine clinical practice in
15
16 United Kingdom (UK) stroke services, all stroke-survivors are invited to a specialist
17
18 review at six months after the event which includes a general enquiry about memory
19
20 concerns¹⁷. If the patient reported any subjective memory concerns at the clinic and
21
22 was over the age of 60 and were able to communicate effectively in English, the
23
24 stroke specialist nurse would provide further study information. Family carers were
25
26 also recruited if they were involved in the stroke-survivor's care, for example, if they
27
28 attended the clinic appointment with them. If potential participants were interested in
29
30 taking part in the study, their details were passed onto the research team. On receipt
31
32 of this information one researcher (EYHT) would make contact with the patient or
33
34 carer. He would provide detailed information and an opportunity to ask questions
35
36 about the study. Following their agreement to participate in the study, participants
37
38 were asked to take part in an interview immediately following their six-month review
39
40 and/or around six months later.
41
42
43
44
45
46
47

48 *Clinician Sampling*

49
50 General Practitioners (GPs) and secondary care clinicians (e.g. stroke consultants,
51
52 specialist nurses, physiotherapists and occupational therapists) in the North East of
53
54 England were contacted to participate in the study. Participants were given an
55
56 opportunity to ask further questions. Clinicians were purposively sampled to ensure
57
58
59
60

1
2
3 that a broad range of care professionals in both primary and secondary care were
4
5 recruited.
6
7

8 *Data collection* 9

10
11 Interviews were conducted between April 2016 and August 2017 by one researcher
12
13 (EYHT) who is a medical doctor. The topic guide was initially derived from relevant
14
15 literature and expert clinical views within the research team. It was designed to be
16
17 iterative to enable any topics, which had not been previously identified, to be
18
19 pursued in subsequent interviews. Face to face semi-structured interviews were
20
21 conducted with all but one participant (clinician) who had a telephone interview. The
22
23 patient and family carer were interviewed individually or in pairs as requested by
24
25 participants. Clinicians were interviewed individually. The part of the interviews
26
27 focussing on risk assessment asked participants for their views on using risk
28
29 assessment to help identify stroke-survivors who are most at risk of dementia in the
30
31 future. They were also asked about the benefits and problems associated with the
32
33 delivery of this assessment (e.g. who and where it should be carried out), what
34
35 variables could be used and how best to manage the outcome if individuals were
36
37 found to be at high or low risk. At follow-up interviews, patient and carer participants
38
39 were asked to elaborate again on their views of a risk assessment process.
40
41

42
43 Alongside this, the interviews also sought the views of stakeholders on the care
44
45 experience of post-stroke individuals with memory problems from clinicians, patients
46
47 and carers. The interviews also looked to understand the impact of post-stroke
48
49 memory problems on patients and carers. These views on care experience from
50
51 clinicians¹⁸ and patients and carers¹⁹ have been reported elsewhere. The impact of
52
53 post-stroke memory problems on patients and carers will be reported separately.
54
55

56
57 This paper reports the views of clinicians, patients and carers on risk assessment
58
59
60

1
2
3 only. The process of risk assessment was described to participants. This was further
4 emphasised with examples of published tools in order to highlight examples of
5 variables used to ensure participant understanding of the process. Informed written
6 consent was obtained from all participants prior to the interview commencing. All
7 interviews were audio-recorded and then transcribed verbatim. To protect participant
8 anonymity, unique identifiers were used throughout the process with identifiable
9 personal data removed.
10
11
12
13
14
15
16
17
18
19

20 *Data analysis*

21
22 Interview data was analysed using thematic analysis²⁰ following the principles of the
23 constant comparative method²¹, an iterative approach which allows for issues raised
24 in earlier interviews to be explored subsequently. Data analysis was both deductive
25 and inductive in that we applied learning from previous research and compared with
26 our own data as well as inductively deriving new themes from our data. We ceased
27 data collection when the researcher felt that data saturation occurred. This was
28 defined as being when a full understanding of the participant's perspective²² and also
29 "informational redundancy" had been reached²³. One researcher (EYHT) familiarised
30 himself with the dataset and subsequently coded the transcripts line-by-line. Initially,
31 a small subset of transcripts were analysed to identify initial themes and these were
32 discussed between CE and EYHT. Data collection and analysis was iterative and as
33 interviews progressed, further analysis led to new themes emerging and refinement
34 of existing themes and subthemes, which were subsequently grouped into broad
35 categories to facilitate interpretation. The wider team (EYHT, CE, LR, BS and CP)
36 discussed and agreed on the final categories which are presented below. For patient
37 and carer interviews, where follow-up interview data was also obtained, these were
38 analysed as separate interviews to assess for any change in views over time. Data
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 analysis continued after fieldwork had ceased. There was particular focus to
4 understand what was important to patients, carers and clinicians. Data analysis was
5 facilitated by a data software handling package (NVivo version 11). The paper
6 conforms to the Standards for Reporting Qualitative Research checklist²⁴ (please
7 see supplementary table 1).
8
9
10
11
12
13
14
15
16
17

18 **Results**

19
20
21 In total, 30 baseline (6 month) interviews were conducted, analysed and compared
22 including: 15 patient and carer interviews (see table 1) and 17 primary and
23 secondary care clinician interviews (see table 2). Two pairs of participants were
24 interviewed together at baseline. Eight stroke-survivors and four carers agreed to a
25 further follow-up interview six months later with nine interviews completed. Three
26 pairs of participants were interviewed together at follow-up. One stroke-survivor
27 declined further follow-up, another stroke-survivor and carer were not followed up
28 due to medical reasons. The data from this study suggest that in terms of risk
29 assessment facilitators and barriers exist to implementation. Whereas patient
30 facilitators focussed on the outcome of the risk assessment, clinicians focussed
31 more on the process of risk assessment for facilitators. Both groups discussed some
32 potential barriers associated with risk assessment focussing on the outcome.
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48

49 ***Patient and Carer Views: Facilitators to Risk Assessment Focuses on the*** 50 51 ***Outcome of Assessment***

52
53
54 When stroke-survivors and carers discussed the concept of risk assessment, the
55 overarching theme was that an assessment outcome was what was important,
56
57
58
59
60

1
2
3 irrespective of the process and clinicians involved. Participants focussed on several
4
5 areas of why the outcome was important to them.
6
7

8 For Preparation

9
10
11 Some stroke-survivors were generally positive about receiving a risk assessment for
12
13 dementia. One stroke-survivor acknowledged that a diagnosis was something that
14
15 could enable individuals to prepare themselves both at baseline and subsequently at
16
17 follow-up interview:
18
19

20
21 *“It's the same as knowing and not knowing, if you know that something is*
22
23 *approaching. Not everybody is the same with the problem. You might be able to deal*
24
25 *with it in a different way or the person supporting you, the nurse or whoever, might*
26
27 *be able to find a different way or a more positive way of managing it.” (P6, male,*
28
29 *stroke-survivor at follow-up interview)*
30
31

32
33 Similarly, for carers, there was the emphasis on what could be done following the
34
35 assessment. One carer emphasized the importance of looking after the whole
36
37 person, and, how earlier recognition of a potential dementia diagnosis could ensure
38
39 strategies were in place to help the individual:
40
41

42
43 *“But I think, if you look at the whole thing of this care of this person, if we knew*
44
45 *earlier that you know the chances are that your memory is going to get bad and you*
46
47 *are going to go into dementia or whatever, then we can start thinking, “Right, well*
48
49 *let's prop it up, let's think of ways in helping your memory as it is, to maintain the*
50
51 *level it is before you've got no choice, it's going to get worse.” You know, maintaining*
52
53 *what you've got and different ways of maintaining it, I think that would help.” (C5,*
54
55 *female carer (daughter) of stroke-survivor)*
56
57
58
59

60 For Timely Diagnosis

1
2
3 For some stroke-survivors it did not matter who was performing the risk assessment
4 for dementia or where it was undertaken. What was important was that the diagnosis
5 was reached at the right time:
6
7
8
9

10
11 *“I wouldn’t say it matters, as long as it’s diagnosed at the right time.”* (P5, male
12 stroke-survivor)
13
14

15
16 When discussing who should perform the risk assessment, carer participants felt that
17 primary care and the community were regarded as being optimal because of the
18 existing GP-patient relationship. This is because the GP has an overall view of the
19 individual’s care:
20
21
22
23

24
25
26 *“I think if you’ve got a good relationship with your GP I think it should be that, it
27 should be them. Yeah, because you know you trust them you build up a relationship
28 with them so I think that probably, for me that would be the one.”* (C4, female carer of
29 stroke-survivor)
30
31
32
33

34 35 For Reassurance 36

37
38 When stroke-survivor participants were asked about a structured risk assessment
39 process, a further participant reported that the outcome could also ensure some
40 reassurance, either that their symptoms were not related to a dementia diagnosis or
41 that a diagnosis of dementia would be accompanied by support information:
42
43
44
45
46

47
48 *“I think it’s reassurance a lot of reassurance with people. You have to give them that
49 to tell them, that “We are there with you. We’re going to be helping you.” And thats
50 you know, I think that’s a good thing.”* (P2, female stroke-survivor)
51
52
53
54

55 56 **Patient and Carer Views: Barriers to Risk Assessment Focuses on the** 57 58 **Outcome of Assessment** 59 60

Anxiety around a potential diagnosis of dementia

Some carers commented on how the outcome from risk assessment could generate worry and anxiety because of the potential diagnosis of dementia:

"To be honest, I don't know if it would help somebody saying, "You're like this, you're upset because you're like this now, but we actually think you're going to get much worse." Do you know what I mean?" (C3, female carer (daughter) of stroke-survivor)

This person's opinion did not change when she was followed-up six months later.

The participant's focus was again on worrying about what could develop and how not knowing about one's risk would actually be more preferable:

"If you could find out and then say, "Right, we've got this medication, or something, that can help you," maybe. But if they're just going to tell you, and then you've got this hanging over your head, and you're thinking, "When is it going to start?" and then you'd be thinking you'd forget something and you'd think, "Oh, that's it, it's coming", which it would be quite normal if you hadn't had that diagnosis, you'd think, "Well I just forgot something, everybody does that."" (C3, female carer (daughter) of stroke-survivor at follow-up interview)

However, one carer felt that despite the worry a potential diagnosis may generate, the benefit of this would be to find strategies to maintain cognitive function:

"I think if you had earlier diagnosis, then you would be sort of prepared before things got difficult to handle, or before problems arise, that would be a very good thing. The disadvantages as you say, alarming the carers or the patients themselves, "I'm going to lose my mind." Because, particularly in the older generation, that's a big worry to them. It is a big worry, it's a big worry to all of us, but to older people particularly." (C5, female carer (daughter) of stroke-survivor)

Concerns about how it may affect their recovery

Not all stroke-survivors were as keen to engage in risk assessment, as there was emphasis on how this may affect them psychologically particularly when their physical deficits had recovered enough to allow them to return to a more usual routine. Therefore, although diagnosis was felt to be important, whether an individual would like to know was also dependent on their subsequent post-stroke recovery:

“That’s difficult you know because I mean if you have an early diagnosis you know and say, well “It’s going to happen” you know but at the moment now I seem to be progressing through, I’m driving now, you know I’m going back to meetings and whatever. I wonder whether an early diagnosis would restrict that.” (P4, male stroke-survivor)

This was particularly evident when patients were followed up six-months later. One participant had actually changed her view over time. Although she had initially felt positive about the process, she then changed her mind when questioned on the same process at her follow-up interview:

“I think my thinking has gone the other way for knowing about that. I think it’s sad. I think it’s a sad thing. I really do, I think it’s really sad that for people to know that they’re going to be at high risk, it’s a sad thing for it to happen to people, and I don’t think I’d want to be one of the sad people. I think I’d just want to be, potter along and that’s it.” (P2, female, stroke-survivor at follow-up interview)

At follow-up interviews participants also felt that risk assessment should be an individual choice because of the ramifications of the assessment outcome i.e. a potential diagnosis of dementia. Although clinicians may deem it to be helpful, the

1
2
3 choice to undergo risk assessment needs to be a weighed up, which should negate
4 any calls for it to be made a universally applied process:
5
6
7

8 *“I think, medically speaking, yes. On the other hand, does it give people things to*
9 *worry about that they wouldn't have worried about if you hadn't done the tests? So, I*
10 *think it depends really on your personal point of view. Do you want to be, you see I*
11 *would look on the test as saying, well you're at a low, you've got a low risk so that's*
12 *great but then if it turned out you'd got a high risk are you going to be more worried*
13 *and less happy than you were before. It's hard to really balance it, isn't it? (P3,*
14 *female, stroke-survivor at follow-up interview)*
15
16
17
18
19
20
21
22
23
24

25 ***Clinician Views: Facilitators to Risk Assessment Focusses on the Process***

26
27
28 Clinicians discussed facilitators to risk assessment in terms of how the process may
29 affect the individual and also how the process could be implemented in the future.
30
31

32
33 When discussing how to implement this process, both primary and secondary care
34 specialists discussed the advantages associated with hosting this process within
35 their own individual teams.
36
37
38
39
40

41 *Process familiarity in Primary Care*

42
43
44 For primary care, it was about the fact that risk assessment was already a familiar
45 process but that it needed to be individualised:
46
47

48
49 *“I think it's a good tool. We're quite good at using tools, aren't we, but there's always*
50 *going to be exceptions to the rules and you've got to individualise what you do with it*
51 *... But sometimes using a score or a tool is a way into a service.” (PC4, nurse*
52 *practitioner in primary care)*
53
54
55
56
57
58
59
60

1
2
3 It was also recognised by one General Practitioner (GP) that although there is
4 familiarity with risk assessment in primary care, there needs to be caution that the
5 system is not overwhelmed with such tools:
6
7
8

9
10
11 *“I do quite like risk profiling. I think we went a little bit crazy with the risk profiling. And*
12 *there feels to be a lot of competing risk profiling tools, that we’re getting a little bit*
13 *inundated with at the moment ... So I think anything like this, I love, if it can be*
14 *incorporated and brought on to an individual and needs level - so you can think*
15 *about caring, identifying risk and needs for an individual - would feel great for me”*
16
17
18
19
20
21
22 *(PC2, General Practitioner)*

Secondary care provides specialist input

23
24
25
26
27
28 Stroke care clinicians discussed the facilitators of risk assessment within a specialist
29 setting. This was based on the fact that they felt a responsibility to ensure that post-
30 stroke sequelae are followed up in their specialist services due to the
31 multidisciplinary element of their standard practice and easier access to services.
32
33
34
35
36
37 This was particularly important to ensure information could also be given to patients
38 at a time when they may need it the most:
39
40
41

42
43 *“I think the six-month review tends to be a period of time when the patient’s acute*
44 *side, acute phase of their care has kind of been established, and this is probably the*
45 *time when they start to recognise problems. And I think it should be within a stroke*
46 *MDT (multidisciplinary team), not so much focused on by GP’s, as such.” (SC2,*
47
48
49
50
51
52 *Stroke specialist nurse)*

53
54
55 *“Well, you need the right support. You need people that actually understand stroke.*
56
57 *So I think it would have to be delivered by stroke healthcare professionals. And I*
58 *think you get so much information when you’re initially an inpatient, I think maybe*
59
60

1
2
3 *that's not the best place to do it ... Yeah, it's a big thing to be told that you might*
4
5 *develop dementia in a few years' time, so you need psychologists kind of available*
6
7 *for if someone needs counselling as a result of that finding. I think it's tricky.” (SC6,*
8
9
10 *Stroke physiotherapist)*

11 12 13 Collaborative Care

14
15
16 Primary care clinicians commented that there may be a place for both primary and
17
18 secondary care to work together in identifying those at risk.

19
20
21 *“I think primary care would be a completely reasonable place to do that. I guess it's*
22
23 *a conversation that could start at diagnosis, at discharge from hospital, like actually,*
24
25 *we know that people who have had a stroke are at higher risk of having dementia,*
26
27 *these are the things to be aware of, and you know to start that discussion” (PC8,*
28
29
30 *General Practitioner)*

31
32
33 Primary and secondary care clinicians felt that such a shared care pathway needed
34
35 to be formalized to reduce the risk of individuals falling into gaps in care:

36
37
38 *“... even if it was picked up in secondary care it's still going to be primary care where*
39
40 *most of the management is occurring. So I think it being identified at the six-month*
41
42 *follow-up, but then there being a formal sort of mechanism, in which primary care*
43
44 *pick it up and process it, would be fine. (PC3, General Practitioner)*

45
46
47
48 *“I don't mind where work is done, provided that it is done in a structured and*
49
50 *standardised way. If that be, if that can be in primary care that is really good,*
51
52 *because that is the long-term follow-up, long-term support, integrating the community*
53
54 *... just as long as it can be delivered in a systematic way, and people don't fall*
55
56 *through gaps or get inconsistent care.” (SC3, Stroke consultant)*
57
58
59
60

1
2
3 Further, the process of communication between primary and secondary care could
4 also be used in the diagnostic process. It was felt that repeated assessments could
5 help facilitate diagnosis by identifying trends in symptoms:
6
7

8
9
10 *“You can measure a trend, can't you, if you're using something and measuring*
11 *something, you can look at a trend. So if its, depends on the type of tool, I guess. But*
12 *if you did it at you know at the six months review date and then we did it*
13 *subsequently a year later in primary care, you would see any changes or decline or*
14 *improvement. So it's a way of, it's a way of monitoring a trend on how they're doing, I*
15 *guess. So I don't, I don't see any reason why it couldn't be done in both and used*
16 *across both. I don't think we use enough across both.”* (PC4, nurse practitioner in
17 primary care)
18
19
20
21
22
23
24
25
26
27
28
29

30 ***Clinician Views: Barriers to Risk Assessment Focusses on the Outcome***

31 *Limited Interventions Available*

32
33
34
35
36 Similar to the perspectives of carers, clinicians recognised the anxiety that a risk
37 assessment process might generate and felt that it should be a personal choice to
38 undertake an assessment because of the perceived lack of intervention:
39
40
41

42
43 *“Yeah, I think I would, I would have degree of anxiety, especially given that the*
44 *measures that we're putting in place are ... that we could put in place are largely*
45 *supportive rather than preventative ... I would be less confident that I could be giving*
46 *my patient advice to say, “Well, if we do this, and we do this, and if we do this and*
47 *you do that then that might move you into an even smaller risk group.”* (PC3,
48
49
50
51
52
53
54

55 *General Practitioner*

56
57 *“Outside research trials, I'm not convinced that there is a definitive value in doing that*
58 *yet. You know if we get really overwhelming evidence that it's amenable to*
59
60

1
2
3 *intervention so you know there's all the theory about blood pressure, and statins, and*
4 *all the rest of that, but my reading of the evidence on all of that at the moment is that*
5 *the jury is out whether it makes a difference to cognitive function. So yeah, I'm not*
6 *convinced that identifying risk, unless you've got a something you can do about it, is*
7 *actually sensible.” (SC4, Stroke consultant)*

15 Anxiety around a potential diagnosis of dementia

18 In recognising the anxiety that this process may generate, one clinician also
19 commented on the fact that patients may not be willing to engage in conversation
20 over the subject of dementia and care should be taken when discussing a potential
21 diagnosis of dementia.
22
23
24
25
26

27
28 *“I think it's good if we tell them that we're looking through and saying, “Look, you*
29 *know there could be a problem here.” But for every single patient, again, because it's*
30 *quite a still a – not a taboo subject – but it's still not something that people want to*
31 *talk about ... I don't know whether it would be used on every single 'per', you know*
32 *what I mean, like, everybody.” (SC5, Stroke specialist nurse)*

40 No Change from Standard Practice

43 The majority of clinical participants wanted to know, not only what the outcome of the
44 risk assessment would be, but also the resulting care the patient would receive. As
45 part of current routine clinical care, all stroke survivors are offered annual reviews in
46 order to ensure their vascular risk factors e.g. blood pressure and cholesterol are
47 well controlled. In terms of reducing risk, one primary care physician expressed
48 concerns as to what the benefit would to the individual if risk factor modification was
49 already in place anyway particularly with regards to the emotive side of a potential
50 dementia diagnosis. A secondary care specialist questioned the value when there
51
52
53
54
55
56
57
58
59
60

1
2
3 was seemingly limited interventions that could be implemented besides managing
4 their cardiovascular risk:
5
6

7
8 *“I guess you’ve got to be very clear about what it is that you’re going to be doing*
9 *differently for them. So I can see the value if you use a tool for kind of primary*
10 *prevention, then you’re kind of selecting a group of patients out to do something*
11 *particular with, but I just wonder what would be different about what you do with a*
12 *risk assessment tool for people who have already had a stroke, when really you*
13 *know already that it is all about managing their cardiovascular risk so I’m not sure*
14 *that you would be doing anything different for them.” (PC8, General Practitioner)*
15
16

17
18 *“Many people will not know of the association between dementia and stroke and*
19 *many people would not want to know if they were at risk of dementia and again, if*
20 *you’re identifying somebody at risk of a condition that you can’t do anything about,*
21 *what’s the right stage to, to do that? However, many of the things you need to do in*
22 *terms of people being at risk of dementia are the same of the general cardiovascular.*
23 *So, I’m not sure that there is anything additional that needs to be done about*
24 *reducing people’s risk for dementia over and above general cardiovascular risk.”*
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41 (SC3, Stroke consultant)
42
43

44 **Discussion**

45 Main Findings

46
47 This is the first study to explore key stakeholders’ - stroke survivors, family
48 carers and primary and secondary care clinicians - views on the use of a risk
49 assessment process to predict future dementia in stroke-survivors. It is clear that
50 some of the participants interviewed believed that risk assessment could be of
51 clinical use but raised concerns about it being mandatory. Clinicians highlighted both
52
53
54
55
56
57
58
59
60

1
2
3 the benefits of collaborative and individual (i.e. primary or secondary) care if
4
5 dementia risk assessment for stroke survivors was to be implemented.
6
7

8
9 Clinician facilitators suggest benefits in either primary or secondary care
10 settings but also in a collaborative model of care between the two. This latter finding
11 echoes recommendations from the UK Intercollegiate Stroke Working Party for a
12 collaborative care model, linking community and specialist care, with the aim of
13 integrated long-term follow-up for those presenting neuropsychological problems¹⁷.
14
15 Although both primary and secondary care clinicians could see the benefits of
16 carrying this assessment in their own specialties, patients and carers in this study
17 valued their relationship with their GP. Further, primary care clinicians themselves
18 are familiar with the process of risk assessment. A survey of primary care physician
19 trainees found that they were also keen to implement a dementia risk assessment
20 strategy to assist in earlier identification²⁵. However, potential barriers have been
21 identified in previous studies, such as system-related factors (lack of support, time
22 constraints)^{26 27} and training in dementia²⁷, which would need to be addressed. Risk
23 assessment is an objective process requiring specific individual variables e.g. age,
24 gender, education. Such data is readily available in primary care in many countries
25 where electronic medical record systems are in place. Further, GPs are already
26 asked to assess cardiovascular risk as part of routine clinical care²⁸. However, some
27 GPs themselves do not like using risk assessment tools particularly as the tools do
28 not provide the support needed in communication²⁹. Training in communicating the
29 risk assessment process, particularly in the context of dementia, would be required if
30 this were to be implemented in clinical practice. Further, some models, particularly
31 those developed in stroke populations¹¹ may also include variables such as complex
32 imaging data, which will only be available in secondary care and may be difficult to
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 obtain even in specialist settings. If risk assessment were to be conducted in primary
4 care, then the risk assessment models utilising data which can be accessed in
5 primary care, needs to be externally validated in stroke populations to assess their
6 accuracy.
7
8
9
10
11
12

13 Clinician participants were concerned about whether risk assessment would
14 actually change standard practice. In a stroke population, it is unclear whether
15 identifying those at risk would achieve any additional benefit from a risk factor
16 modification point of view. This is because stroke-survivors already receive annual
17 community follow-up with particular focus on vascular risk factor modification.
18 However, current evidence suggests that development of post-stroke dementia is
19 more than just about vascular risk and would require a different approach e.g.
20 psychological support, cognitive preservation strategies and additional resources.
21 Results from several trials, assessing whether vascular-based interventions can
22 reduce dementia risk, have been largely disappointing^{30 31}. These results suggest
23 that perhaps an individual's risk of post-stroke cognitive impairment and dementia
24 includes risk factors beyond vascular risk. Inflammation following a stroke seems to
25 have both positive and negative effects and whether lowering inflammation can
26 prevent post-stroke dementia will need to be addressed in future trials³².
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45

46 Currently population screening for dementia is not recommended due to a
47 lack of evidence evaluating risks and benefits³³, despite positive views from older
48 adults³⁴. Risk assessment can target high-risk groups rather than the general
49 population. Recent evidence has found a decline in age-specific incidence of
50 dementia, particularly in high-income countries, suggesting that rising levels of
51 education and modifying cardiovascular risk may have driven a decline in dementia
52 risk^{35 36}. Indeed, the importance of modifiable risk factor reduction for dementia was
53
54
55
56
57
58
59
60

1
2
3 reported in the World Alzheimer Report (2014)³⁷ and around a third of Alzheimer's
4 disease cases worldwide might be attributable to modifiable risk factors³⁸. Risk
5 assessment tools utilize these modifiable risk factors to predict risk. Similar to other
6 branches of medicine where risk assessment is utilized to predict risk of a future
7 illness, it would be hoped that this approach could reduce one's risk of future
8 dementia. Stroke affects more than 100,000 people in the UK per year³⁹, creating a
9 large population with cognitive deficits and/or at high risk of future decline who may
10 benefit from risk assessment for dementia. However, participant groups in this study,
11 particularly clinicians, reported that given the potential ramifications of risk
12 assessment, individuals should be given the choice of whether to undergo
13 assessment. Stroke-survivors were generally positive about such an approach but
14 agreed that it should be up to the individual and the family rather than applied
15 universally. Participants in this study recognised the anxiety this process could
16 generate particularly when the perceived possible interventions for dementia are
17 limited. The National Institute for Health and Care Excellence have recently updated
18 their guidance and have concluded that case finding should only be conducted as
19 part of a clinical trial, which also provides an intervention⁴⁰. Therefore, careful
20 discussion needs to be adopted with the patient and their carers before undertaking
21 such a process in any setting. In the context of the dementia diagnostic journey,
22 transition from living with an undiagnosed memory problem to being diagnosed with
23 a dementia illness is underpinned by uncertainty⁴¹. Although risk assessment
24 certainly does not provide any certainty for a dementia illness, the discussions and
25 objective evaluation using the tools may help the individual's process their current
26 condition and assist in the preparation for a potential diagnosis of dementia.
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 Preparation was mentioned by participants in this study as a facilitator for risk
4
5 assessment.
6
7

8 Clinical Implications 9

10
11 Case finding for dementia involves actively assessing individuals at risk of a future
12
13 dementia illness, which at present is only recommended in clinical trial settings due
14
15 to a lack of post-assessment intervention⁴². Once a suitable intervention is found
16
17 however, the views of those conducting the assessment and the recipients of such
18
19 an assessment will need to be assessed. Similarly there will be challenges with
20
21 regards to assessment of capacity when performing risk assessment for this at-risk
22
23 population. It is also important to note that GPs find communicating the diagnosis of
24
25 dementia difficult⁴³. Although risk assessment is not providing a diagnosis of
26
27 dementia, careful consideration will be required in training health professionals in
28
29 communicating the concept of risk for a disease such as dementia. From this study
30
31 we have identified the priorities according to each stakeholder group which would
32
33 need to be addressed prior to clinical implementation in the future.
34
35
36
37
38

39 Limitations 40

41
42 The participants in this study came from one area of England and were Caucasian.
43
44 Patient participants were also well enough to attend outpatient assessment clinics.
45
46 Future studies could look to explore views in other populations including views from
47
48 minority ethnic groups, patients with more severe stroke-related impairments and
49
50 different service models. Due to familiarity, it is recognized that clinicians expanded
51
52 more around the risk assessment process. Despite this being the case, patients and
53
54 carers were given the opportunity to understand the concept of risk assessment as
55
56 part of the interview process but the emphasis on a need for a diagnosis and good
57
58
59
60

1
2
3 care was what was important for them. Participants were also aware that the
4 interviewer was also a primary care clinician, which may have the potential to
5 introduce bias into participant responses. This is because a clinician interviewer may
6 be viewed as an expert and judge in clinical decision making and moral judgements
7 made⁴⁴. On the other hand interviews tend to be broader in scope and richer in data
8 when conducted by a clinician researcher ⁴⁴. Further, both clinical and non-clinical
9 members contributed to the analysis of the data to minimize the effect this may have
10 had.
11
12
13
14
15
16
17
18
19
20
21

22 Conclusions and Future Research

23
24
25 Timely recognition of those at risk of dementia is crucial to enable individuals
26 early access treatment and support. Although dementia screening after stroke is not
27 yet advocated on preventative grounds, assessing risk has some potential benefits
28 for individuals who make an informed choice to participate. There would need to be
29 better cohesiveness of communication between primary and secondary care, with
30 more support placed in the community. Further, it should be recognised that if risk
31 assessment were to be incorporated into clinical practice, this will potentially place
32 additional burdens on a dementia diagnostic service which is already overstretched.
33
34 Next steps are to identify which tool to use, how best to manage those who are
35 deemed high-risk individuals and whether there are any interventions, which can
36 reduce their risk. Future studies will need to look specifically at what factors put a
37 stroke-survivor at risk that could be potentially modified and also whether there are
38 specific interventions suitable to a post-stroke population to reduce risk.
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Acknowledgements:

The authors would like to thank the participant advisory group for their advice on the study materials used.

List of Abbreviations

GP General Practitioner

UK United Kingdom

Declarations

Author Contributions:

ET conceived the framework for this study. ET collected, analysed and interpreted the data. ET prepared the manuscript for submission.

CE helped to conceive the framework for this study and assisted with the analysis of the data and contributed to the drafting of the manuscript. CE also critically reviewed and edited the manuscript.

CP helped to conceive the framework for this study, assisted with the analysis of the data and critically reviewed and edited the manuscript.

BS helped to conceive the framework for this study, assisted with the analysis of the data and critically reviewed and edited the manuscript.

LR helped to conceive the framework for this study, assisted with the analysis of the data and critically reviewed and edited the manuscript.

Funding:

Eugene Tang is supported by a NIHR Doctoral Research Fellowship (DRF-2015-08-006).

1
2
3 Louise Robinson is supported by a National Institute for Health Research
4
5 professorship (NIHR-RP-011-043) and a NIHR Senior Investigator award (NF-SI-
6
7 0616-10054).
8
9

10 **Consent for Publication:**

11
12
13 All participants in the study have provided informed written consent. No identifiable
14
15 personal information has been used.
16
17

18 **Competing Interests:**

19
20
21 LR reports grants from NIHR Professorship award, grants from NIHR Senior
22
23 Investigator award, outside the submitted work. The remaining authors declare that
24
25 they have no competing interests.
26
27
28

29 **Disclaimer:**

30
31
32 This paper presents independent research funded by the National Institute for Health
33
34 Research (NIHR). The views expressed are those of the author(s) and not
35
36 necessarily those of the NHS, the NIHR or the Department of Health.
37
38

39 **Data Sharing Statement:**

40
41
42 No further data will be made available.
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

References

1. Prince M, Wimo W, Guerchet M, et al. World Alzheimer Report 2015: The Global Impact of Dementia, An Analysis of Prevalence, Incidence, Cost and Trends. 2015.
2. Savva GM, Stephan BC, Alzheimer's Society Vascular Dementia Systematic Review G. Epidemiological studies of the effect of stroke on incident dementia: a systematic review. *Stroke; a journal of cerebral circulation* 2010;41(1):e41-6. doi: <http://dx.doi.org/10.1161/STROKEAHA.109.559880>
3. Pendlebury ST, Rothwell PM. Prevalence, incidence, and factors associated with pre-stroke and post-stroke dementia: a systematic review and meta-analysis. *The Lancet Neurology* 2009;8(11):1006 - 18.
4. Douiri A, Rudd AG, Wolfe CD. Prevalence of poststroke cognitive impairment: South London Stroke Register 1995-2010. *Stroke; a journal of cerebral circulation* 2013;44(1):138-45. doi: 10.1161/strokeaha.112.670844 [published Online First: 2012/11/15]
5. Kuzma E, Lourida I, Moore SF, et al. Stroke and dementia risk: A systematic review and meta-analysis. *Alzheimer's & dementia : the journal of the Alzheimer's Association* 2018 doi: 10.1016/j.jalz.2018.06.3061 [published Online First: 2018/09/05]
6. Feigin VL, Forouzanfar MH, Krishnamurthi R, et al. Global and regional burden of stroke during 1990-2010: findings from the Global Burden of Disease Study 2010. *Lancet* 2014;383(9913):245-54. [published Online First: 2014/01/23]
7. Prince M, Ali GC, Guerchet M, et al. Recent global trends in the prevalence and incidence of dementia, and survival with dementia. *Alzheimer's research & therapy* 2016;8(1):23. doi: 10.1186/s13195-016-0188-8 [published Online First: 2016/07/31]
8. Baumgart M, Snyder HM, Carrillo MC, et al. Summary of the evidence on modifiable risk factors for cognitive decline and dementia: A population-based perspective. *Alzheimer's & dementia : the journal of the Alzheimer's Association* 2015;11(6):718-26. doi: 10.1016/j.jalz.2015.05.016 [published Online First: 2015/06/06]
9. Stephan BCM, Kurth T, Matthews FE, et al. Dementia risk prediction in the population: are screening models accurate? *Nat Rev Neurol* 2010;6(6):318 - 26.
10. Tang EY, Harrison SL, Errington L, et al. Current Developments in Dementia Risk Prediction Modelling: An Updated Systematic Review. *PLoS one* 2015;10(9):e0136181. doi: 10.1371/journal.pone.0136181 [published Online First: 2015/09/04]
11. Kandiah N, Chander RJ, Lin X, et al. Cognitive Impairment after Mild Stroke: Development and Validation of the SIGNAL2 Risk Score. *Journal of Alzheimer's disease : JAD* 2016;49(4):1169-77. doi: 10.3233/jad-150736 [published Online First: 2015/11/26]
12. Lin JH, Lin RT, Tai CT, et al. Prediction of poststroke dementia. *Neurology* 2003;61(3):343-8. [published Online First: 2003/08/13]
13. Stephan BC, Minett T, Muniz Terrera G, et al. Dementia prediction for people with stroke in populations: is mild cognitive impairment a useful concept? *Age and ageing* 2014 doi: 10.1093/ageing/afu085 [published Online First: 2014/07/09]
14. Chander RJ, Lam BYK, Lin X, et al. Development and validation of a risk score (CHANGE) for cognitive impairment after ischemic stroke. *Scientific reports* 2017;7(1):12441. doi: 10.1038/s41598-017-12755-z [published Online First: 2017/10/01]
15. Siontis GC, Tzoulaki I, Siontis KC, et al. Comparisons of established risk prediction models for cardiovascular disease: systematic review. *BMJ (Clinical research ed)* 2012;344:e3318.
16. Johnston SC, Rothwell PM, Nguyen-Huynh MN, et al. Validation and refinement of scores to predict very early stroke risk after transient ischaemic attack. *Lancet* 2007;369(9558):283-92. doi: 10.1016/s0140-6736(07)60150-0 [published Online First: 2007/01/30]
17. Intercollegiate Stroke Working Party. National Clinical Guideline for Stroke. 2016 [published Online First: Fifth Edition]

18. Tang EYH, Price C, Stephan BCM, et al. Gaps in care for patients with memory deficits after stroke: views of healthcare providers. *BMC health services research* 2017;17(1):634. doi: 10.1186/s12913-017-2569-5 [published Online First: 2017/09/10]
19. Tang EYH, Price C, Stephan BCM, et al. Post-stroke memory deficits and barriers to seeking help: views of patients and carers. *Fam Pract* 2018(In Publication)
20. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006;3(2):77-101. doi: 10.1191/1478088706qp063oa
21. Glaser B. The constant comparison method of qualitative analysis. *Soc Probl* 1965;12:436-45.
22. Legard R, Keegan J, Ward K. In-depth interviews. In: Ritchie J, Lewis J, editors. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage 2003:pp. 139–169.
23. Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & quantity* 2018;52(4):1893-907. doi: 10.1007/s11135-017-0574-8 [published Online First: 2018/06/26]
24. O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research: a synthesis of recommendations. *Academic medicine : journal of the Association of American Medical Colleges* 2014;89(9):1245-51. doi: 10.1097/acm.0000000000000388 [published Online First: 2014/07/01]
25. Tang EY, Birdi R, Robinson L. Attitudes to diagnosis and management in dementia care: views of future general practitioners. *International psychogeriatrics* 2016;1-6. doi: 10.1017/s1041610216001204 [published Online First: 2016/08/10]
26. Koch T, Iliffe S. Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: a systematic review. *BMC Fam Pract* 2010;11:52. doi: 10.1186/1471-2296-11-52 [published Online First: 2010/07/03]
27. Chithiramohan A, Iliffe S, Khattak I. Identifying barriers to diagnosing dementia following incentivisation and policy pressures: General practitioners' perspectives. *Dementia (London, England)* 2016 doi: 10.1177/1471301216682625 [published Online First: 2016/12/13]
28. Hippisley-Cox J, Coupland C, Brindle P. Development and validation of QRISK3 risk prediction algorithms to estimate future risk of cardiovascular disease: prospective cohort study. *BMJ (Clinical research ed)* 2017;357:j2099. doi: 10.1136/bmj.j2099 [published Online First: 2017/05/26]
29. Barfoed BL, Jarbol DE, Paulsen MS, et al. GPs' Perceptions of Cardiovascular Risk and Views on Patient Compliance: A Qualitative Interview Study. *International journal of family medicine* 2015;2015:214146. doi: 10.1155/2015/214146 [published Online First: 2015/10/27]
30. Matz K, Teuschl Y, Firlinger B, et al. Multidomain Lifestyle Interventions for the Prevention of Cognitive Decline After Ischemic Stroke: Randomized Trial. *Stroke; a journal of cerebral circulation* 2015;46(10):2874-80. doi: 10.1161/strokeaha.115.009992 [published Online First: 2015/09/17]
31. Bath PM, Scutt P, Blackburn DJ, et al. Intensive versus Guideline Blood Pressure and Lipid Lowering in Patients with Previous Stroke: Main Results from the Pilot 'Prevention of Decline in Cognition after Stroke Trial' (PODCAST) Randomised Controlled Trial. *PloS one* 2017;12(1):e0164608. doi: 10.1371/journal.pone.0164608 [published Online First: 2017/01/18]
32. Mijajlovic MD, Pavlovic A, Brainin M, et al. Post-stroke dementia - a comprehensive review. *BMC medicine* 2017;15(1):11. doi: 10.1186/s12916-017-0779-7 [published Online First: 2017/01/18]
33. Moyer VA. Screening for cognitive impairment in older adults: U.S. Preventive Services Task Force recommendation statement. *Annals of internal medicine* 2014;160(11):791-7. doi: 10.7326/m14-0496 [published Online First: 2014/03/26]

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
34. Justiss MD, Boustani M, Fox C, et al. Patients' attitudes of dementia screening across the Atlantic. *International journal of geriatric psychiatry* 2009;24(6):632-7. doi: 10.1002/gps.2173 [published Online First: 2008/12/31]
 35. Langa KM. Is the risk of Alzheimer's disease and dementia declining? *Alzheimer's research & therapy* 2015;7(1):34. doi: 10.1186/s13195-015-0118-1 [published Online First: 2015/03/31]
 36. Larson EB, Yaffe K, Langa KM. New insights into the dementia epidemic. *The New England journal of medicine* 2013;369(24):2275-7. doi: 10.1056/NEJMp1311405 [published Online First: 2013/11/29]
 37. Prince M, Albanese E, Guerchet M, et al. Dementia and Risk Reduction: An Analysis of Protective and Modifiable Factors. 2014.
 38. Norton S, Matthews FE, Barnes DE, et al. Potential for primary prevention of Alzheimer's disease: an analysis of population-based data. *The Lancet Neurology* 2014;13(8):788-94. doi: 10.1016/s1474-4422(14)70136-x [published Online First: 2014/07/18]
 39. Stroke Association. State of the nation: stroke statistics. 2017. <https://www.stroke.org.uk/resources/state-nation-stroke-statistics> (accessed 14th August 2017).
 40. Faircloth CA, Boylstein C, Rittman M, et al. Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of health & illness* 2004;26(2):242-61. doi: 10.1111/j.1467-9566.2004.00388.x [published Online First: 2004/03/19]
 41. Campbell S, Manthorpe J, Samsi K, et al. Living with uncertainty: Mapping the transition from pre-diagnosis to a diagnosis of dementia. *Journal of aging studies* 2016;37:40-7. doi: 10.1016/j.jaging.2016.03.001 [published Online First: 2016/05/01]
 42. National Institute for Health and Care Excellence. Dementia: assessment, management and support for people living with dementia and their carers 2018. <https://www.nice.org.uk/guidance/ng97>.
 43. Phillips J, Pond CD, Paterson NE, et al. Difficulties in disclosing the diagnosis of dementia: a qualitative study in general practice. *The British journal of general practice : the journal of the Royal College of General Practitioners* 2012;62(601):e546-53. doi: 10.3399/bjgp12X653598 [published Online First: 2012/08/08]
 44. Chew-Graham CA, May CR, Perry MS. Qualitative research and the problem of judgement: lessons from interviewing fellow professionals. *Fam Pract* 2002;19(3):285-9. [published Online First: 2002/04/30]

Table 1. Interview Participants (Patients and Carers)

| Unique Identifier (Patients and Carers) | Role | Gender | Age | Follow-up Interview Conducted |
|--|---------------------------|---------------|------------|--------------------------------------|
| P1 | Stroke-survivor | Female | 80 | No |
| P2 | Stroke-survivor | Female | 76 | Yes |
| P3 | Stroke-survivor | Female | 72 | Yes |
| P4 | Stroke-survivor | Male | 75 | Yes |
| P5 | Stroke-survivor | Male | 80 | Yes |
| P6 | Stroke-survivor | Male | 74 | Yes |
| P7 | Stroke-survivor | Female | 73 | Yes |
| P8 | Stroke-survivor | Female | 82 | Yes |
| P9 | Stroke-survivor | Male | 84 | No |
| P10 | Stroke-survivor | Male | 79 | Yes |
| C1 | Carer of P1 (Husband) | Male | 79 | No |
| C2 | Carer of P4 (Wife) | Female | 79 | Yes |
| C3 | Carer of P5 (Daughter) | Female | 57 | Yes |
| C4 | Carer of P6 (Wife) | Female | 71 | Yes |

| | | | | |
|----|---------------------------|--------|----|-----|
| C5 | Carer of P8 (Daughter) | Female | 60 | Yes |
|----|---------------------------|--------|----|-----|

For peer review only

Table 2. Interview Participants (Clinicians)

| Unique Identifier (Clinicians) | Role | Gender |
|---|---|---------------|
| SC1 | Stroke Consultant | Female |
| SC2 | Stroke Specialist Nurse | Female |
| SC3 | Stroke Consultant | Female |
| SC4 | Stroke Consultant | Male |
| SC5 | Stroke Specialist Nurse | Female |
| SC6 | Stroke Physiotherapist (Rehabilitation) | Female |
| SC7 | Stroke Physiotherapist (Acute Care) | Female |
| SC8 | Stroke Occupational Therapist (Acute Care) | Male |
| SC9 | Stroke Occupational Therapist (Rehabilitation) | Female |
| PC1 | General Practitioner with Specialist Interest in Dementia | Male |
| PC2 | General Practitioner | Male |
| PC3 | General Practitioner | Female |
| PC4 | Nurse Practitioner in primary care | Female |
| PC5 | General Practitioner | Female |

| | | |
|-----|---------------------------------------|--------|
| PC6 | Practice Nurse | Female |
| PC7 | Nurse Practitioner in primary care | Female |
| PC8 | General Practitioner | Female |

For peer review only

Supplementary Table 1*Standards for Reporting Qualitative Research Checklist¹*

| No. | Topic | Item | Page(s) |
|---------------------------|--|--|---------|
| Title and abstract | | | |
| S1 | Title | Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended | 1 |
| S2 | Abstract | Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions | 2 - 3 |
| Introduction | | | |
| S3 | Problem formulation | Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement | 5 - 6 |
| S4 | Purpose or research question | Purpose of the study and specific objectives or questions | 6 |
| Methods | | | |
| S5 | Qualitative approach and research paradigm | Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale ^b | 8 - 9 |
| S6 | Researcher characteristics and reflexivity | Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability | 8 |
| S7 | Context | Setting/site and salient contextual factors; rationale ^b | 7 - 9 |
| S8 | Sampling strategy | How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale ^b | 7 - 10 |
| S9 | Ethical issues pertaining to human subjects | Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues | 6 - 7 |
| S10 | Data collection methods | Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale ^b | 8 - 9 |
| S11 | Data collection instruments and technologies | Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study | 8 - 9 |
| S12 | Units of study | Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results) | 31 - 34 |
| S13 | Data processing | Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts | 8 - 10 |
| S14 | Data analysis | Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale ^b | 9 - 10 |
| S15 | Techniques to enhance trustworthiness | Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale ^b | 9 - 10 |
| Results/findings | | | |
| S16 | Synthesis and interpretation | Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory | 10 - 20 |
| S17 | Links to empirical data | Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings | 10 - 20 |
| Discussion | | | |
| S18 | Integration with prior work, implications, transferability, and contribution(s) to the field | Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field | 20 - 24 |
| S19 | Limitations | Trustworthiness and limitations of findings | 24 - 25 |
| Other | | | |
| S20 | Conflicts of interest | Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed | 27 |
| S21 | Funding | Sources of funding and other support; role of funders in data collection, interpretation, and reporting | 26 - 27 |

Reference

- O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research: a synthesis of recommendations. *Academic medicine : journal of the Association of American Medical Colleges* 2014;89(9):1245-51. doi: 10.1097/acm.0000000000000388 [published Online First: 2014/07/01]