## Research

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# How primary care can help survivors of transient ischaemic attack and stroke return to work:

focus groups with stakeholders from a UK community

#### Abstract

Evidence about how primary care can best enable survivors of transient ischaemic attack (TIA)/stroke return to work is limited

This study explored the role of primary care in supporting survivors of transient ischaemic attack (TIA)/stroke return to work with stakeholders from a local UK community.

A qualitative study using framework analysis.

#### Method

Four focus groups were carried out in Cambridgeshire, UK, between September and November 2015. The 18 participants included survivors of TIA/stroke, carers, an employer representative, GPs, occupational therapists (OTs), and clinical commissioners.

There was a mismatch between patient and carer needs and what is provided by primary care. This included: lack of GP awareness of invisible impairments; uncertainty how primary care could help in time-limited consultations; and complexity of return-to-work issues. Primary care physicians were not aware of relevant services they could refer patients to, such as OT support. In addition, there was an overall lack of coordination between different stakeholders in the return-to-work process. Linking with other services was considered important but challenging because of ongoing changes in service structure and the commissioning model. Suggestions for improvement include: a central contact in primary care for signposting to available services; a rehabilitation assessment integrated with the electronic record; and a patient-held shared-care plan at discharge from stroke wards.

#### Conclusion

Improving the role for primary care in helping survivors of TIA/stroke return to work is challenging. However, primary care could play a central role in initiating/coordinating vocational rehabilitation. Through focus group discussions with stakeholders from a local community. patients, carers, and clinical commissioners were able to put forward concrete proposals to address the barriers identified.

employment; invisible impairments; primary health care; qualitative research; stroke.

#### INTRODUCTION

A quarter of all strokes happen in working age,1 and a general practice with a list size of 6000 patients contain on average 15 survivors of stroke aged 18-65 years.

Enabling people who have had a stroke to return to work has positive effects on health<sup>2-4</sup> and unemployment is associated with physical and mental health problems. 5,6 It is estimated that stroke costs the UK around 9 billion GBP a year as a society. This includes 1.3 billion GBP in lost income due to care, disability, and death, and over 800 million GBP in benefit payments.3

The 2007 UK stroke strategy<sup>7</sup> highlighted the need for survivors of stroke to be enabled to participate in paid, supported, and voluntary employment, identifying any obstacles to returning to work in order to develop interventions and build the health economic evidence that would support commissioning of these services.<sup>4,8</sup> The 2013 National Institute for Health and Care Excellence (NICE) guidelines on stroke rehabilitation recognise the value of returning to work and mention impairments including psychological difficulties and fatigue.8

A systematic review of 70 studies has shown that return-to-work rates in poststroke patients of working age varies from 0%-100%.2 The authors' previous study among a UK online community of survivors of transient ischaemic attack (TIA)/stroke and their relatives9 revealed that survivors of stroke, as well as those who suffered from TIA-only, experienced residual invisible impairments, which could affect staying in work. In addition, primary care has a limited role in helping survivors of TIA/ stroke who managed to return to work stay in employment. In particular, participants described primary healthcare professionals' difficulties recognising the effects of 'invisible' impairments such as fatigue, memory, and concentration problems, and their longlasting nature on the ability to work. 10,11

When brain injury problems persist longterm, quidelines suggest that patients should be able to self-refer to appropriate services, though awareness of this recommendation is limited. 11 Occupational health services vary greatly across the UK and between employers.<sup>12</sup> Although the introduction of GP fit notes in 2010 could potentially have had positive effects on staying in work by acknowledging specific limitations of survivors of stroke at the workplace, it seemed to have made little impact. One of the explanations for this was that it was perceived as the 'easiest' option for GPs to sign off survivors of stroke from work as being 'not fit'. 13 Therefore, there is a need to explore the current role of primary care in helping survivors of TIA/ stroke to return to work, and how primary

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#### How this fits in

Many people of working age who have a stroke want to return to work but encounter difficulties. Existing research does not provide clear-cut answers as to how primary care can best enable survivors of TIA/stroke to achieve this. The role of primary care with different stakeholders was explored. This identified: a limited current role for GPs; a mismatch between patient and carer needs and what is provided; and the limited awareness and integration of primary care with other services, in particular, neurorehabilitation services for survivors of stroke, whose capacity is limited. Clinical commissioners envisaged problems with commissioning neurorehabilitation services due to lack of evidence of cost-effectiveness. Suggestions for improvement included: a dedicated primary care clinician navigating patients through available services; a neurorehabilitation assessment integrated within the primary care electronic record, highlighting invisible impairments; and a patient-held shared-care plan at discharge from hospital.

care interfaces with other community stakeholders in order to better support employment after TIA/stroke.

The objective for this study was to explore the role of primary care in supporting survivors of TIA/stroke to return to work, gathering views from stakeholders in a local community.

#### **METHOD**

#### Design

This was a qualitative study using framework analysis of four focus groups held in Cambridgeshire, UK, with survivors of TIA/ stroke, carers, an employer representative, GPs, occupational therapists (OTs), and clinical commissioners. Focus groups were chosen to create discussion between stakeholders and create the opportunity to identify difficulties in the return-to-work

The composition of the focus groups was carefully chosen, and the first three groups included patients and carers as well as GPs and OTs. The fourth focus group included professionals involved in employment, return-to-work care, and commissioning of services. The authors were specifically interested in interaction between stakeholders; however, it was decided not to include patients together with employers in order to avoid difficult situations and inhibition of expression.

#### **Participants**

Survivors of TIA/stroke, caregivers, and GPs were recruited from two GP practices in Cambridgeshire (one inner city and one village practice), while two additional patients were recruited from the local community neurorehabilitation service. OTs were recruited from a local community neurorehabilitation service and a specialist neurorehabilitation centre (Oliver Zangwill Centre); clinical commissioners from the local clinical commissioning group; and the employer representative through the university. Invitation letters to the study were sent to patients aged 18-65 years on stroke registers. The letter included a freepost envelope and a reply slip to identify physical, communication, or cognitive impairments, and degree of returning to work: no return to work, work on voluntary basis, work part time, work full time. Caregivers were invited to attend through the patients. Due to the small sample size of eligible patients,14 convenience sampling was used.

#### Data collection

Four focus groups were conducted between September and November 2015. Topic guides were developed from a previous study by the authors<sup>11</sup> and with input from researchers with expertise in qualitative methods, primary care, and neurorehabilitation. An experienced researcher in qualitative methods and an experienced OT facilitated the focus groups, which included four to 12 participants per group. The topic guides were piloted with a patient group in a specialist neurorehabilitation centre (Oliver Zangwill Centre) before data collection.

Three focus groups were held in the practice premises, the first with survivors of TIA/stroke, caregivers, and OTs only, while the second and third were joined by the GP from each participating practice. The fourth focus group was attended by clinical commissioners, OTs, and an employer representative, and took place at university premises. All focus groups were audiorecorded and transcribed by the Typing Works (http://www.thetypingworks.com).

#### Data analysis

Following each focus group two authors met to discuss emerging findings and analytical questions. Although formal coding started after the four focus groups were completed, two authors discussed content and notes after each focus group in preparation of the subsequent one. Framework analysis was used to analyse the transcripts.15 An initial framework was developed based on data immersion and initial coding, and all

ID	Sex	Age, years	TIA and/or stroke	Time since TIA/stroke, years	Impairments		Employment before stroke		Employment after stroke		
					Physical (visible)	Non-physical (invisible)	Working time	Job type <sup>a</sup>	Working time	Job type <sup>a</sup>	
P1	М	Not disclosed	TIA	30	-	+	Full time	Small employers and own account workers	Full time	4. Small employers and own account workers	
P2	М	55	Stroke	2	+	+	Full time	Small employers and own account workers	Part time	Volunteer work	
P3	М	51	Stroke	1	-	+	Full time	3. National government administrative occupations	Not working	Not working	
P4	М	Not disclosed	TIA	7	-	+	Full time	2. Laboratory technicians	Full time	2. Laboratory technicians	
P5	F	65	TIA + stroke	8	+	+	Full time	3. National government administrative occupations	Part time	3. National government administrative occupations	
P6	М	50	TIA + stroke	0	+	+	Full time	5. Plumbers and heating and ventilating engineers	Not working	Not working	
P7	М	58	TIA	2	-	+	Full time	1.2 Chemical scientists	Full time	1.2 Chemical scientists	
P8	М	60	Stroke	4	-	+	Full time	2. Managers and proprietors in other services	Not working	Not working	
			Carer's relationship with stroke survivor								
C1	F		Wife of P1								
C2	F		Wife of P6								
	Sex		Professio	n	Work det	ails					
OT1	F		Occupatio	nal therapist	Specialised neurorehabilitation centre						
OT2	F		Occupational therapist Local community neuro				abilitation sen	vice			
GP1	М		GP		Practice of 11 000 patients						
GP2	М		GP			Practice of 8000 patients					
Е	М	Employer representative				>500 staff					
CC1	М		Clinical commissioner			Mental health					
CC2 CC3	M M		Clinical commissioner Clinical commissioner			Occupational health — stroke services  Heart and stroke medicine					

data were then mapped onto the framework and summarised (indexed). Data were then interpreted in-depth by looking for patterns and relations, and by cross-case comparison of initial topics/themes.

#### **RESULTS**

Eighteen participants including survivors of TIA/stroke, carers, OTs, GPs, an employer representative, and clinical commissioners participated in this study (Table 1). Six survivors of TIA/stroke and two caregivers were recruited from two GP practices, while two additional patients were recruited from the local vocational rehabilitation service. The analysis resulted in two main themes:

 mismatch between patient and carer needs, and what is provided. This theme focuses on the relationship between survivors of TIA/stroke and primary care; and

 lack of coordination/communication between the different agencies involved and primary care. This theme focuses on the relationship between primary care and other agencies involved in aiding survivors of TIA/stroke to return to work.

For each of these themes, ways of addressing the highlighted issues were discussed in the focus groups.

#### Mismatch between patient and carer needs, and what is provided

Awareness of invisible impairments. Patients' and GPs' awareness of hidden TIA/ stroke impairments were different:

'What's very interesting for me listening to all of this [that is, patients' and carers' discussions] as a GP is that as a doctor we have this very sort of black and white view of a stroke I think which is shared I suspect by society and we all think the same way that the stroke is about loss of power and loss of vision and those sorts of things and yet everything that you're saying is about subtle changes, it's about memory, it's about concentration, it's about fatigue which are things that are really hard for other people to recognise and really hard to explain and then perhaps are ignored but seem to be in a sense much more important than the obvious signs of a stroke. (GP1)

Assessing invisible impairments such as fatigue was also challenging, even for an occupational health doctor, because of lack of a formal tool:

When I was working on patient medicine you would actually go off what the patient, what the client themselves was saying their ability was at that point. So they would say, "Oh well, so how long would you be able to say for instance do your work, up to the point where you would have to take a break?"... there's no formal assessment [for fatigue] ... it actually just goes off the patient, off the client's opinion.' (Clinical commissioner [CC]2]

Challenges during GP consultations. Although both survivors of TIA/stroke and clinicians felt that GP support is important, patients and carers felt that there were major barriers for GPs to play a role in aiding survivors of TIA/stroke to return to work. Time of consultations was limited. Further, there was the belief that GP consultations were primarily for medical issues, while job-related discussion topics were felt as less appropriate and they were unsure how the GP consultation could help in returning to work:

Well my experience of the GP is exactly the same, I go in, he'll take my blood pressure, look at a blood test, look at the drugs I was on, you know, any issues but I don't know what else I expected from him.' (Patient [P]3)

Return to work issues complicated. Planning return to work was considered a difficult task at times by GPs and clinical commissioners:

'It all depends upon stability of the situation to be honest with you and predictability as well because if you're trying to get a patient, trying to get a client back to work and you've not had a period of stability in their condition, it's very hard to actually sort of make any formal plan. (CC2)

GPs described filling sickness or fitness notes challenging and faced the issue of employers coming back to them asking for a sicknote instead of considering work adjustments:

... and when I, with most employers, when I attempt to write a fit note ... trying to make some suggestions about amended duties etc., and most employers I just get a note back usually via the patient going "What? Can you write him a sick note?" [CC1]

Improving the role of primary care: a point of contact for work-related issues. As GPs were considered very busy and mainly focused on the clinical aspects of TIA/stroke recovery, having a designated point of contact in primary care clinician to contact for post-TIA/stroke work-related issues was suggested and was felt important by patients and carers, as well as GPs:

Yeah. I mean you could train a nurse, it doesn't necessarily have to be a GP does it? Nowadays they have specialist asthma nurses who know more about asthma than the GP. So you don't necessarily have to skill up to the extent that you need to know all of the neuro implications but you need somebody who can facilitate the questions and finding the answer and say "OK, I don't know that but I know where to go to." (Carer [C]1)

However, a concern would be that services are duplicated and even more complex:

'It's an interesting point isn't it, whether by doing that you just duplicate and make things more complicated or whether it actually simplifies things because there are clearly all these other agencies, Citizens Advice, occupational health, all these other people doing similar sorts of things and whether if you provide something within GP practices you're just providing another layer of complexity that's not communicating with anyone else. (GP1)

Clinical commissioners mentioned a pilot, ongoing at the time, of a software tool aimed at helping the process of navigating and signposting to current services:

"... a decision management software tool which has been purchased ... we purchased a licence for a pilot number of practices, about twenty odd practices and this is meant to be something that sits on the patients, on the GP's desktop and it gives,

and if you put in say stroke it will ping up saying, "Here are the local services for stroke." (CC2)

#### Lack of coordination/communication between the different agencies involved and primary care

Awareness of services. Despite recognising that work is good for patient health, in terms of suggesting community services for helping with return to work and staying in employment, GPs described difficulties with knowing about all services available and pointing survivors of TIA/stroke to the right ones. GPs and clinical commissioners were also unaware of the option of direct referral between primary care and community occupational services, which was thought to be only through secondary care:

'So can GPs refer to your service, that's really ...?' (CC3)

'Yes certainly, absolutely yeah.' (occupational therapist [OT]2)

'That's interesting. Why don't we know about it?' (CC3)

The lack of a structured organisation of services meant that a large number of referrals to neurorehabilitation teams came from a small group of practices who knew about the service.

Lack of organisation. There was confusion about the role of different stakeholders in the process of returning to work after a TIA/stroke. Participants were unaware of differences between the role of an occupational health department and an occupational therapist. Moreover, stakeholders, including the employer representative and the GPs, were not aware of what sort of role an OT could have, such as issuing Health and Work Reports that patients could use to claim employer's sick pay for short-term absences and to support GPs filling in sick notes;<sup>17</sup> liaising with family members, occupational health, and work managers; and giving recommendations about work.

In addition, only a few patients had experience of the OT services ongoing at the time of the study:

'I think you're right. Yeah, ensure a patient has occupational health review and I must say I don't know what else to do from an employer's side and I don't fully understand actually where occupational health and you guys [OT] come in in a way ... does that

mean I should be referring them so they are having occupational health, but can you see them as well, or is that a waste of NHS resources. '(GP2)

As neurorehabilitation services are not centrally organised and need referral from primary or secondary care, it is not available to all patients, especially patients suffering from invisible impairments such as fatigue or memory and concentration problems:

... however, there are sometimes people being missed as well, I don't know why that happens though, I had a patient a while ago [...] was properly mobile and I think that's when they decided he didn't need community services at home, but it turned out that he was really struggling and got through the GP and physio direct back to us, so it still happens that people get lost in the system somehow.' (OT2)

The importance of OT support. Patients who suffered from stroke more recently and had access to the local OT service (the neurorehabilitation team) highlighted their important role in facilitating successful return to work:

'I keep singing their praises, the neuro health rehab team and Remploy, she [OT from the neurorehabilitation team] brought Remploy in and somebody else, I can't remember who they were, basically a contractor saying "Right, this is the chair he needs, this is the software he needs, this is the computer keyboard he needs, make sure he's got a parking space within a reasonable bit of the building" ... if I'd actually gone back to work, that would have been the absolute very solid concrete help. (P3)

Survivors of stroke described that an important role of the neurorehabilitation service was to connect people who suffered from a stroke and enable peer support:

'I got discharged from hospital and then really you're not dealing with anybody else in your predicament ... and it wasn't until again the neuro rehab team last summer set up a returning to work, there was like eight sessions over eight weeks ... well I met other people in the same boat and that was quite an eye-opener and also it's very, very encouraging. (P3)

Linking with other services. A lack of communication between GP surgeries and other services, as well as agencies such

as job centres and occupational health departments, was pointed out. OTs and clinical commissioners mentioned the importance of linking with other services, getting to know what is on offer, and how they could be linked together for survivors of TIA/stroke of working age, though the ongoing changes in the service structure were making the process challenging:

"... we're beginning to have conversations with the whole mental health team really because we've now joined together so I think in six months' time I'd hope to be able to sit round a table and say we've actually made some movements there to link the two services together. Because obviously they've got Recovery College, they've got all sorts of things there and we're now in the same organisation but as professionals we're not yet getting together and we need to begin to make those contacts. (OT2)

Amajor problem for the neurore habilitation team being able to offer their care to the local stroke population was their limited capacity, and that the service is paid a fixed amount/ year, rather than being commissioned based on demand:

'The other problem of course is how much capacity you've got because if all GPs suddenly think, "Ah I've got three patients ... for you" ... you consider the number of practices just in City itself that you deal with, you could be swamped. (CC3)

Commissioning such a neurorehabilitation service, though, was considered challenging without a strong financial argument for cost-benefits:

... Yeah, and then have to be a financial argument for doing that as well, I mean that's the biggest thing.' (CC2)

Another barrier to linking the services together could be the commissioning model. In the case of mental health, commissioning is separated from non-mental health, making the linking services challenging:

... low motivation, depressive symptoms go up and that then makes it, you know, that is non-synergistic with doing anything else like getting back into work and, you know, mental health services are quite separately commissioned etcetera, than physical health ... we can't necessarily suddenly transfer loads of funding to one organisation to do it because the other organisations will complain but you could find a way

of integrating these psychological support programmes better with stroke. (CC1)

Improving communication: a rehabilitation assessment integrated with the electronic record. Through the topic guide, participants were prompted to discuss a potential online rehabilitation assessment tool to provide a post-stroke picture over time of patient needs and functional impairments, which survivors of TIA/stroke and their carers could access and share with interested parties.

Survivors of TIA/stroke and carers liked the idea of an objective assessment tool they could fill in and help them to become aware of impairments and problems, considering some patients may lack insight:

... a tool to actually try and figure out where you actually really are, and what actually the picture of where you might be, as opposed to as I say my own very subjective position."

Other stakeholders were also positive about the possibilities of an online tool. GPs were particularly interested in quick access to a patient's up-to-date functioning:

"... I think that's perfectly reasonable actually, so especially if it were, I think in a template form so I can actually just tick on a certain area and then I get a kind of functional status of the patient which is the most recent ... I think that is a bit like the End of Life care, it's something that should be very easily ... that would reduce our time. (GP2)

The sharing aspect of such a tool was also recognised as important by stakeholders:

... a lot of places are looking to readonly access to other people's systems ... SystmOne can get overloaded if everyone is writing into it, but offer practices that want to, anyone who wants a widget where they can see what the psychologist is doing." (CC1)

Another major concern is the privacy of patients and appropriate access to shared personal data:

... I would be very careful about who else has access to all this data ... you might not necessarily want people to have access to some of that.' (P8)

A potential solution that was mentioned by patients is the idea of a compartmentalised

online record, so each party could access information that is only relevant to them.

Improving communication: a patient-held shared-care plan. Survivors of stroke discussed the problem of remembering the plan communicated to them by healthcare professionals and that a written report might greatly help:

'Yeah. I think the written record is a very important, I mean I sometimes when I go to see a specialist nurse or something like that and my daughter asks me when I get home "What did he say?" and I've lost half of it. '(P1)

Other stakeholders mentioned the missed opportunities in discharge documents/a shared-care plan. For example, GP and clinical commissioners commented that meaningful cognitive screens, management plans, and information about community services are not always included in hospital discharge letters:

"... that's a real lost opportunity not just to send a simple letter at the point of discharge to the patient, the GP saying, "Here are the long-term services available and here's how you get back into them if you're having problems." Why are we not doing that?'(CC1)

'Yeah. It's about empowering the patients actually and signposting them, kind of making them aware of what's there. (CC2)

### **DISCUSSION**

#### Summary

This study explores the role of primary care in supporting survivors of TIA/stroke in returning to work including perspectives of a range of stakeholders. There was a mismatch between patient and carer needs and what was provided by primary care, and a lack of coordination between primary care and other services.

#### Strengths and limitations

The strength of this study lies in the participation of a range of different stakeholders from a local community. The key limitation is that the small sample of participants was from a single geographical area.

### Comparison with existing literature

Patients and carers discussed a range of issues with TIA/stroke-related impairments and their assessment, especially in relation to invisible impairments, is consistent

with what has previously been reported by participants of an online forum. 11,18 In agreement with a previous study by Sinclair et al, 19 it was found that access to services relied on brokered provision and tacit knowledge. The timing of vocational rehabilitation interventions was complex and there was a substantial degree of unmet needs. Investment in non-acute stroke services was seen as 'non-essential' because of competing commissioning priorities. Primary care providers lacked training and cross-sector partnerships were weak.19 Results are consistent with and partly explain the variability in the rate of return to work post-stroke previously reported.<sup>2</sup> Effective use of the GP fit note scheme is hampered by difficulties with assessing TIA/stroke-related impairments and their effect on return to work, in particular in respect to fatigue and cognitive issues. Rather than GPs opting for the easiest option of signing survivors of stroke off work, 15 evidence was found of employers asking clinicians for sick notes rather than undertaking work adaptations, suggesting they face similar difficulties with assessment of post-stroke impairments and work adaptations.

### Implications for research and practice

The results of this study have several practice implications for improving the success rate of return to work after TIA/ stroke, while taking into account the current pressure on GP workforce and budget constraints of clinical commissioners.

Although findings showed that primary care currently has a limited role, there is a need to increase awareness of the potential key role of primary care in vocational rehabilitation after TIA/stroke. This includes addressing unmet needs in case patients have fallen through the net, and coordinating care and communication among the different services involved. As fatigue and cognitive impacts on return to work extend well beyond 2 years poststroke, services need to be responsive to the changing needs of the survivor of stroke throughout their recovery process and have better mechanisms to ensure re-entry into stroke vocational rehabilitation.<sup>19</sup> Three solutions have been put forward to help patients return to work after TIA/stroke. These proposals are integrated within GP consultations and primary care to minimise workload while addressing unmet needs: a rehabilitation assessment that is part of the electronic health record to assess 'where they actually are' in terms of rehabilitation and functioning abilities related to their

work; a designated nurse within the GP practice dedicated to issues of post-TIA/ stroke employment, with knowledge of local services including community and specialist neurorehabilitation services; and the enhancement of the opportune sharing of the electronic medical record with parties involved in the return-to-work process.

Patients and their families face rigid rules about sick pay and often have to make a decision whether going back to work at 28 weeks (6 months) and by 1 year post-stroke, when their recovery might still be ongoing. The Equality Act 2010 obliges employers to consider whether 'reasonable adjustments' could help survivors of stroke return to work, provided there is an assessment of their impairments/ disabilities. This is more straightforward for physical impairments and primary care might be the only source of help for patients whose invisible impairments have not been highlighted and are exacerbated by returning to work, and for survivors of TIA/stroke who are self-employed or

business owners. Primary care is in a crucial position to support survivors of TIA/ stroke to successfully return to work and address inequalities in access to vocational rehabilitation support. This aligns with the United Kingdom Acquired Brain Injury Forum campaign to raise awareness of the rehabilitation prescription.<sup>20</sup> Research is needed to develop the three suggestions emerging from this study into interventions, addressing potential problems together with their evaluation in terms of costbenefit. Commissioning investments into non-acute stroke services, such as stroke vocational rehabilitation, is challenging without the evidence to support their costeffectiveness.

There is a need to gather evidence around the cost associated with the current suboptimal lack of rehabilitation support in the community and balance it against reduced health and social care resource use and the wider health benefits of maintaining employment.

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#### **Ethical approval**

This study has received ethical approval from Cambridge Central Research Ethics Committee (REC reference: 15/EE/0133), IRAS project ID: 171328.

#### **Provenance**

Freely submitted; externally peer reviewed.

#### **Competing interests**

The authors have declared no competing interests.

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