ABSTRACT

Stroke is the UK's fourth highest cause of death and an estimated 300,000 people in England are living with stroke related disability. This paper explores the six-month review, a policy initiative that aimed to ameliorate unmet need. A multiple case study approach underpinned by critical realism was used to elicit the views of patients, carers, providers and commissioners across three sites using interviews, observations and documentation. Forty-six patients (age range 28-91 years), 30 carers and 28 professionals were interviewed between December 2015 and October 2016. Twenty-nine reviews were observed. Data was analysed thematically across sites.

Six-month reviews carried out by stroke nurse specialists were found to be more medically orientated than those completed by a Stroke Association co-ordinator who focused on social issues. Reviewers regarded reviews primarily as an opportunity to address unmet need and signpost to further services. Patients responded in three different ways: *proactive and engaged*, reflected an active orientation to recovery and self-management; *proactive and self-managing on their own terms*, encompassed patients who were striving for independence but took their own approach sometimes at odds with that of clinicians; and *passive orientation*, whereby patients did not engage in rehabilitation or self-management. Patients identified different priorities to those of reviewers, particularly those with other long-term conditions and this appeared to contribute to the dissatisfaction that some expressed.

In conclusion, there was little evidence that the six-month review played a key role in recovery. Locally defined outcomes for the six-month review reflecting national policy were not substantiated by the findings. Our findings suggest that the six-month review should review therapy goals and facilitate patient-led goals. Reviewers should be allowed the freedom to individualise the process rather than adhering to a rigid framework dictated by national policy and local protocols.

What is known about this topic

- Stroke can result in long-term limitations that affect all areas of daily life.

- Stroke survivors report feeling abandoned when statutory services withdraw.

- The UK National Stroke Strategy (2007) introduced the six-month review to identify unmet need but it lacks evidence of effectiveness.

What this paper adds

- The model of review informed the focus: stroke nurse specialists focused on medical management and Stroke Association co-ordinators were socially orientated.

- Clinicians were client centred but were constrained by the review's rigid format and other systemic constraints.

- Most patients and carers valued reviewers' professional expertise and trusted their advice. However, the most vulnerable people, struggling to manage co-morbidities and complex social circumstances found the review of limited help.

INTRODUCTION AND BACKGROUND

In the United Kingdom (UK), stroke is the fourth highest cause of death and an estimated 300,000 people in England are living with moderate to severe stroke related disability (Department of Health, 2007). It has been estimated that stroke costs the UK economy approximately £9 billion per year of which almost half is accounted for by direct care costs and the rest split between indirect costs and informal care (Saka, McGuire, & Wolfe, 2009).

In 2007, the National Stroke Strategy set out an ambitious plan to develop stroke services (Department of Health, 2007) which lead to the current constellation of hyper-acute and acute stroke units followed by further rehabilitation with emphasis on early supported discharge. The Strategy (2007) recommended reviewing patients at six weeks, six months and yearly thereafter. This was endorsed by subsequent clinical guidelines (NICE, 2013; Royal College of Physicians, 2012; Royal College of Physicians, 2016) based on the premise of unmet need, with one seminal study (McKevitt et al., 2011) and report (Stroke Association, 2012) cited as evidence.

While the review process is intended to identify unmet need, there is much variation in implementation and limited evaluation (Care Quality Commission, 2011; Goncalves-Bradley et al., 2015; Walker, Fisher, & Fletcher-Smith, 2014) or audit (Curtis & Gallifent, 2014; Gedge, France, & Jones, 2013; Jenkins, King, & Brigden, 2012). Although six-month reviews (6MRs) were mandated in England (NHS England, 2013), only 54% of commissioners in England, Wales and Northern Ireland were supporting them in 2015 (Royal College of Physicians, 2015) and this figure has not increased (Royal College of Physicians, 2017). There is no literature exploring process, outcomes or the patient experience of review. This paper reports findings from a qualitative study that explored the contribution of the 6MR to overall recovery for patients and carers. Carers were defined as whoever the patient regarded as their main source of practical and/or emotional support. The research questions were:

1. What is the purpose of the review process from the perspective of patient, carer, provider and commissioner?

2. What are the intended and/or unintended outcomes of the review process from the perspective of patient, carer, provider and commissioner?

3. By what mechanisms does the review process achieve the intended outcomes?

METHODS

A multiple case study design (Yin, 2014) underpinned by critical realism (Bhaskar, 1978) was used. Realism is well-matched to case study design where the objective is 'understanding why things are as they are' (Easton, 2010, p119) and is particularly suited to health services research (Clark, Lissel, & Davis, 2008; Proctor, 1998). Critical realism takes a middle road between the extremes of positivism and constructivism (Robson, 2011). A distinctive feature is the belief that the world is independent of our understanding of it and 'all knowledge is partial, incomplete and fallible' (Maxwell, 2012, p5). It proposes that social phenomena exist in an open system where structures and mechanisms interact at different 'layers' of reality and are in a constant state of flux (Clark et al., 2008). Particular structures give rise to certain causal powers referred to as 'generative mechanisms' (Bhaskar, 1978, p50). Depending on the context, a mechanism may not be 'fulfilled or actualised' or may be fulfilled without our perceiving it (Bhaskar, 1978, p50). There are different interpretations of context but this study has defined it as 'contextual influences that are hypothesised to have triggered the relevant mechanism' (Wong, Greenhalgh, Westhorp, Buckingham, & Pawson, 2013, p2) and context involves the interplay between structure and agency.

In tandem with a realist paradigm, explanatory case studies aim to elucidate causal mechanisms, or underlying factors, that mediate between cause and effect (Gerring, 2007). Yin's (2014, p17) case study approach is 'orientated' towards realism and allowed the collection of multiple sources of data across three sites to inform theory development. The focus, or unit of analysis, was the 6MR; the six-

week review occurs when most patients are still receiving therapy and the yearly review is currently not funded in most areas. The temporal boundaries were from discharge home to shortly after the 6MR, although where possible people were tracked up to one year, to include their annual review. The parameters of the case were all those directly (patients, carers, stroke nurse specialists, other clinicians including therapists and Stroke Association employees) or indirectly (managers, commissioners) involved in the 6MR. Stroke nurse specialists (SNSs) are employed by stroke services to advise patients on all aspects of their condition. The Stroke Association (SA), a voluntary organisation, is funded to provide support alongside statutory services and trains their own stroke support workers and co-ordinators; the latter carry out 6MRs.

Patient and public involvement informed project development through consultation with the Stroke Association, Different Strokes (for working age people) and Connect (for those with aphasia). One independent patient representative was involved for the duration of the study. Ethical approval was granted by the Research Ethics Committee London-Surrey Borders (reference 15/LO/0808) prior to gaining research governance approval from each NHS Trust involved in the study.

Setting and data collection

The three case studies were located in South East England. All had better than average outcomes for premature death from stroke with rates between 11-12.4 per 100,000, compared to the range across England of 7.7 to 28.2 per 100,000; all sites were within relatively less deprived areas based on the index of multiple deprivation, had urban and rural areas and lacked ethnic diversity (Public Health England, 2016a; Public Health England, 2016b; Public Health England, 2016c). The sites were selected based on their model of review. To structure the review, Sites 2 and 3 used the Greater Manchester Stroke Assessment Tool (GM-SAT) which consists of 38 items, with yes/no answers and algorithms, covering medical management, secondary prevention and activities of daily living (Rothwell, Boaden, Bamford, & Tyrrell, 2013). Site 1 used their own template, covering similar areas but categorised under the headings 'health promotion', 'mental well-being' and 'daily living'.

In case study site 1, the reviewers were three SNSs each attached to a community stroke team; site 2 had one SNS, working within a neuro-rehabilitation community service, and the SNS ran a 'life after stroke' group which consisted of two sessions of advice and education about stroke and secondary prevention; and in site 3, the Stroke Association was contracted to provide 6MRs and employed a stroke co-ordinator to do so. Only site 1 provided yearly reviews.

Forty-six patients were interviewed between December 2015 and October 2016, thirty with their carer. Most (n=24, 52%) were followed for 6-12 months; one-third (n=15, 33%) for 12-18 months; and the rest (n=7, 15%) for less than six-months. Patients were between 28-91 years old and eighteen (39%) were under 65 years old of whom eight were working pre-stroke but only four resumed work during the study period. Most people owned their own homes (n=38, 83%) and were married or co-habiting (n=31, 67%). Half (n=23, 50%) had one or more pre-existing long-term condition.

Twenty-eight professionals were interviewed within and across sites. Thirty-one reviews were observed, primarily 6MRs in sites 1-2. Table 1 summarises interviewees and observations per site. Two patients declined a 6MR and five did not receive one.

[insert Table 1]

Data was collected through semi-structured interviews, observations and documentary analysis. Interview guides addressing the research questions were developed iteratively using the literature and in discussion with patient representatives. All patients opted for interviews in their own home and were visited six weeks post-discharge, after their 6MR and where possible, after their annual review. Commissioners, managers and other professionals were interviewed once, mostly by telephone, whilst reviewers were interviewed at work over several months. All interviews were digitally recorded and transcribed verbatim.

Observations included reviews, inpatient multi-disciplinary meetings (site 1) and a 'life after stroke' group (site 2). Fieldnotes included observations, analytic notes and reflections (Emerson, Fretz, & Shaw, 2011).

Documentary sources included open access material on the internet; documents provided by the South East Coast Strategic Clinical Network Stroke work programme which reviewed local services (2012 onwards); Clinical Commissioning Groups (CCGs) that commission stroke services within specific geographical areas; and the Stroke Association.

Analysis

Analysis and theory development was informed by Yin's (2014) case study approach. Thematic analysis was used to analyse data, chosen for its clear account of coding and epistemologically neutral stance (Braun & Clarke, 2006). Rigor was addressed through a combination of approaches including prolonged engagement with the data and thick description (Guba & Lincoln, 1982); multiple sources of data (Mays & Pope, 2000); negative case analysis (Yin, 2014); establishing a chain of evidence and maintaining an audit trail (Yin, 2014); and reflexivity to maintaining vigilance for researcher bias (Finlay, 2002). Both authors independently coded a sample of transcripts and then cross checked to ensure consistency.

FINDINGS

We provide an overview of how the 6MR was conceptualised (its purpose); explore factors that shaped patient responses to it (mechanisms); and describe the outcomes.

6MR: purpose and paradigm

Managers and commissioners regarded identifying unmet need as the main attribute of the 6MR. However, they also held diverse views about the review's purpose ranging from global aspirations such as improved quality of life to signposting to other services. Commissioning decisions to fund the

6MR appeared to depend on prior arrangements. Views were mixed as to who was best placed to provide the review and this was reflected in commissioning decisions.

Only a few respondents questioned whether the review was worthwhile. However, concerns were raised about equity of service provision across all long-term conditions and whether resources could be better spent elsewhere:

> *Do I honestly believe that as a nation we should be spending however many millions of pounds implementing this service and is that the most important thing to stroke patients? My honest answer would be, "No." My honest answer would be, "Give them equitable service in their GPs and get the GPs to call them back in at six months to see how things are"* (Case study site 2, manager)

None of the managers or commissioners recognised the gap between therapy withdrawing and the 6MR as a period when patients felt particularly unsupported. Despite acknowledging that recovery occurred at different rates they still advocated a rigid timeframe, as did the Stroke Association, in-line with their recovery model (Stroke Association, 2016).

Clinicians' views were also mixed as to the exact purpose of the review. SNSs focused on medical investigations, medication, blood pressure monitoring and referral to other statutory services such falls clinics. One SNS regarded the review as 'a full MOT', for example, asking about breast and prostate screening. The review was an opportunity to answer questions, chase investigations, provide support and troubleshoot. The SNSs acknowledged that they were medically orientated but this stemmed from reviewing patients with urgent medical needs and having limited resources:

> *I have become more medical model orientated these day which I assume is because of the limited other resources we can offer these days to make the patient's life easier* (Case study 1, SNS)

The SA's co-ordinator was unable to chase medical investigations or make referrals, instead having to defer to the GP. Her approach reflected the Stroke Association's social paradigm:

> *I think very much it is a holistic review and I think it is vital that it is not just a medical review, it needs to be all encompassing* (Stroke Association Regional Director)

The review focused on social and emotional aspects of stroke, providing general information and signposting to other non-statutory services such as exercise groups.

The main enablers of timely 6MRs were manageable caseloads, administrative support, integrated databases and good working relationships with other professionals and services. There were instances where communication was limited, for example, where patients had several services involved and it was unclear who was doing what. The key barrier was identifying needs but not having services to refer onto or knowing there were long waiting lists. It was difficult to track if referrals had been instigated and reviewers struggled to find time to check.

Patients and carers held similar views as to the purpose of the 6MR although many were unclear about this. Some thought it was their 'signing off', several regarded it as a tick-box exercise and others could not remember much, even shortly afterwards. Only two patients viewed it as an opportunity to assess their progress. Nonetheless the 6MR prompted many to ask questions about their condition, prognosis and unresolved symptoms. Their responses to the 6MR appeared influenced by their experiences of the stroke care pathway.

The stroke care pathway as a mechanism for patients' responses to the 6MR

Mixed experiences, particularly of inpatient stroke care, were reported by patients and carers with the same rehabilitation unit deemed 'soul destroying' and 'fantastic'. When inpatient care appeared clearly compromised, this seemed to stem from staff shortages and system constraints, lack of communication and rushed discharge.

Many concerns related to individual clinicians where patients disagreed with their approach but felt overruled. Patients identified gaps where they felt particularly unsupported which appeared related to systemic problems, particularly care co-ordination within and between services. These 'hotspots' occurred during transitions between units, discharge home, waiting for community rehabilitation to commence, and when services withdrew:

I felt they had a timeframe and then they had to leave you on your own to get on with it... it's when you

need them the most they are not there for you (Case study 1, female, 37yrs)

In site 3, the SA co-ordinator tried to time her initial visit or 6MR with therapy withdrawal but in other areas this co-ordination was not apparent. In addition, patients had a longer-term outlook than therapists who might withdraw services when patients felt they could still improve. Patients also had specific unmet needs for information, education and advice:

If somebody sat down and spoken to us about it, saying... what we could maybe expect... once you've had a

stroke all these things, selfishness, argumentative, get exaggerated in their heads... It would be nice to have

been told things like that (Case study 1, wife of 73yr old)

The data suggested three different approaches in the way patients negotiated the care pathway and 6MR from which a typology was developed. These approaches were underpinned by responses to inpatient experiences, relationships with clinicians and attitudes towards rehabilitation (Figure 1).

[Insert Figure 1]

Type 1: Proactive and engaged

The largest group, ('Type 1') had an active orientation to recovery and were determined to improve their functional abilities. Returning home was an important factor in regaining independence and they used pre-existing and/or new activities to further their recovery.

There was no obvious age differential but this group had all been active pre-stroke and were determined to build on their rehabilitation. All were motivated, challenged themselves and were not prepared to accept the status quo when therapy withdrew. They appeared to trust staff and followed advice, although not without seeking further clarification. They were focused on self-managing their condition and were well-informed. Most did not have severe residual impairment so were able to

exercise, were not housebound and were in a better position to self-manage than those in the next two groups.

Type 1 patients regarded the 6MR as a source of reassurance, information and advice. While some were unclear about the purpose, they capitalised on the opportunity to address ongoing issues and valued the reviewer's expertise. Many commented on the 6MRs comprehensive nature:

> *I don't think GPs have the time or probably the expertise… The fact that she's [SNS] working with people who've had strokes almost exclusively, and she allows time* (Case study 2, male, 63yrs)

Information and explanation tailored to individual need was compared favourably to generic (Stroke Association) leaflets previously provided:

> *We have a whole host of leaflets… some of the information was useful, but I don't think any of them helped me with… how much I can do* (Case study 1, male, 85yrs)

Many patients commented how helpful it was to discuss their medications with the SNS who was able to liaise directly with the GP or consultant:

> *The best thing for me was her knowledge on the drugs that I'm taking. She told me more about the drugs than I've been told by the doctor or anybody else…* (Case study 1, male, 77yrs)

Reassurance was related to feeling listened to and unrushed. There was a personal connection between patients and reviewer which appeared to relate to therapeutic use-of-self. It was this rapport that was remembered more than the review's content.

Type 2: Proactive and self-managing on their own terms

A smaller number of patients ('Type 2') were striving for independence but took their own approach to rehabilitation and self-management at odds with that of professional staff who some regarded as risk averse. This group appeared to be regarded by therapists and reviewers as lacking in varying degrees motivation, 'compliance' and insight. However, they were motivated to continue their rehabilitation independently, albeit in a way that conflicted with their therapist's approach. Some were motivated by external goals such as resuming a caring role and felt staff failed to appreciate this.

They expressed tensions about accepting constraints on their daily life versus fighting to recover which related to how they had re-framed the stroke:

> *The difficult thing really is getting your mind round the degree to which you should accept where you are but on the other hand you don't want to just accept it and not feel that there is any forward* (Case study 2, male, 63yrs)

Secondary prevention might be challenging due to co-morbidities, residual impairment and other issues:

> *I would like to be able to go to a group for exercise… but… there's nothing in this immediate area… the big problem I've got with my condition is lack of exercise and keeping my weight under control* (Case study 2, male, 76yrs)

Type 2 patients were more likely to question the reviewer's advice and less likely to concur, instead preferring their own approach. There were instances where patients found the review of limited benefit because it duplicated their GP's involvement:

> *There isn't anything… which I wouldn't have discussed with the doctor anyway* (Case study 1, female, 72yrs)

The SA co-ordinator's lack of medical advice left one patient dissatisfied. She had ongoing balance problems that appeared not to have been investigated. The SA co-ordinator was unable to address this and advised her to ask her GP, which had already proved unhelpful. Other patients deferred to their GP rather than trusting the SNS:

> *When she said something about some pills I shouldn't be having, I thought, well that's really… my doctor's responsibility… I just dismissed that [advice]* (Case study 1, female, 66yrs)

Type 3: Passive orientation

The smallest group of patients ('Type 3') adopted a passive orientation to rehabilitation and did not appear interested in self-management or secondary prevention. Most had complex social circumstances, pre-existing long-term conditions, rarely went out and had limited interests. They had

mostly negative relationships with staff and ignored, forgot or rejected advice. Patients felt that therapists did not understand, while therapists were frustrated by their passive approach. They tried to engage patients but the therapists' outlook was medically orientated, discharge driven and at odds with patients' priorities who appeared to have genuinely disengaged from rehabilitation. When patients did not 'comply' it was regarded as an indication that they had not adjusted to the stroke or were not motivated. For example, one patient had been inactive pre-stroke, had other long-term conditions and was later diagnosed with dementia. However, his partner and therapists were frustrated by his perceived passivity:

> *He'll sit in that chair from 12 o'clock to 2am… he's completely unmotivated… sometimes I think he's using it as an excuse to be lazy* (Case study 1, carer)

Type 3 patients considered the 6MR irrelevant or unhelpful. Wider concerns about their social circumstances and co-morbidities took priority and patients did not feel these were addressed. Distrust instilled during their inpatient stay carried over into the review. Two patients declined review because they distrusted staff and while one only trusted her stroke consultant the other distrusted all professionals.

The rest of this group attended the review but did not find it helpful. One patient found it pointless and his wife found it depressing in the context of ongoing impairment. He was articulate, motivated and desperate to improve his mobility but had been discharged by therapists because he had evidently plateaued. The 6MR emphasised his ongoing disability without providing any useful outcomes:

> *I thought it was awful… if you weren't depressed when you went in, after all of that lot, my gosh* (Case study 2, carer)

A few patients were notable because of the glaring disparity of agenda with the SNS, similar to differences in priorities that they described with therapists. Two patients were unsure who the SNS was and were unable to differentiate her from other professionals involved in their care. Both had co-morbidities and while one actively resisted advice the other passively ignored it and neither appeared

interested in self-management. Both were examples where a social orientation to review appeared better suited to their needs at that time, despite medical concerns.

Positioning the 6MR in the care pathway: intended and unintended outcomes

There was little evidence that the 6MR played a key role in recovery, rather it was one event along the care pathway that provided reassurance and supplemented information and advice that had already been provided. For a minority of patients, the 6MR identified significant medical need, was a marker of progress or a prompt to adjust their lifestyle. Site 3 timed the review to coincide with the hotspot of therapy services withdrawing which helped embed the process into the care pathway but elsewhere more arbitrary timing added to the sense that it was a stand-alone event.

Unintended outcomes were limited, but some respondents did not feel listened to which exacerbated pre-existing frustration and anxiety. Some were confused by inconsistent advice and whose advice they adhered to appeared to relate to who they trusted. An unintended outcome suggested by one manager, but difficult to substantiate, was that the review might encourage dependency. A few respondents attended a yearly review even though they found the 6MR unhelpful. Table 2 summarises the different models and outcomes.

[Insert Table 2]

Locally defined outcomes for the 6MR reflected national policy but were not substantiated by the findings. For example, there was no evidence to support arguably aspirational outcomes including 'less likely to have another stroke' and 'improved health and general well-being' (Hargroves, French, & Trickey, 2014). While some outcomes lent themselves to a quantitative approach, such as readmission rates and GP attendance, these were not possible to ascertain and even if they had been, could not be directly attributed to the 6MR. Where there was evidence that the 6MR achieved

outcomes it was often only for Type 1 patients who were more resourceful. While access to information was valued and could contribute *indirectly* to improvements in daily life, it cannot be assumed that information leads to accessing the service or meeting the need, as local policy (Hargroves et al., 2014) and the Stroke Association suggest (Stroke Association, 2016).

DISCUSSION

The aim of the study was to clarify the purpose, outcomes and underlying mechanisms of the 6MR. Patients and carers were unclear about the purpose but found it a useful space to ask questions and discuss concerns. The SNSs maintained a medical focus while the SA co-ordinator concentrated on daily life. Both considered self-management but had limited scope to address it. Outcomes could be divided into tangible actions such as referrals and requests for GPs/Consultants (SNS only); advice, information and signposting; and secondary prevention. The discussion considers tensions inherent in the 6MR.

Figure 2 presents a model of the 6MR's components drawn from the findings. Contextual factors included policy discourse and the personal circumstances of patients, in particular the burden of illness, both of which are discussed below. Socio-economic status, a key determinant of health (Marmot, 2004), incorporates education (and health literacy), income and ethnicity. It was not possible to draw conclusions based on these factors, given the qualitative nature of the study, but the personal circumstances of patients are likely to have been underpinned by socio-economic status. For example, those who could afford to employed private physiotherapists while those who did not were unable to ameliorate the shortcomings of statutory services.

[Insert Figure 2]

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The ideology of individual responsibility

Over the past two decades there have been a plethora of government policies promoting empowerment, self-management and expert patients who collaborate with professionals and promote their own 'health and wellbeing' (NHS England, 2016, p50). However, there has been insufficient appreciation of structural constraints or that patients are relatively powerless in comparison to healthcare providers who possess biomedical expertise (Tang & Anderson, 1999). Policies tend to side-step the complexity of living with chronic illness (Porter, Sanders, Richardson, Grime, & Ong, 2015), the difficulty of self-managing (Parke et al., 2015) and the wider social determinants of health (Banks, Marmot, Oldfield, & Smith, 2006).

More recent commissioning guidance for rehabilitation (NHS England, 2016) acknowledge that it involves a 'complex interaction between their [patients'] health conditions, the environments recipients live in, their values and beliefs, and their… motivations' (NHS England, 2016, p12). Yet the guidance itself makes little reference to these factors, does not address managing co-morbidities and assumes that patients are able and willing to self-manage in a one-size fits all approach.

Emphasis on self-management and individual responsibility is consistent with stroke-specific guidelines for the 6MR (NICE, 2013; Royal College of Physicians, 2016). Clinicians are charged with empowering patients, but again policy does not acknowledge systematic constraints, or the power of structure over agency. Further interventions can only be offered 'if goals for specific functions and activities can be identified… and the potential for change is likely' (Royal College of Physicians, 2016, p113), two qualifiers that were often at odds with patients' views. Many patients wanted further intervention but there was a tension between their expressed needs and what reviewers considered appropriate.

Limitations of the 6MR: a system problem

Differences between stakeholders concerning the 6MR was a central finding as professional groups drew on their own specific discourse. The rhetoric of frontline professionals differed to that of

managers, commissioners and the Stroke Association. Similarly, the discourse of all professional groups did not necessarily match that of patients. The 6MR did not adequately address important areas of patients' experience and furthermore did not address all the 'lines of work' (Corbin & Strauss, 1985, p224) undertaken when managing a long-term condition, conceptualised as illness work, everyday life work, and biographical work. Biographical work can be regarded as a response to biographical disruption which encompasses the many ways that chronic illness interrupts 'the structures of everyday life' (Bury, 1982, p169-70). Whilst this acknowledges the multiple demands on patients and families, it does not incorporate wider systemic issues.

The concept of treatment burden incorporates similar notions of the patient workload but sets this against capacity to mobilise and co-ordinate resources and acknowledges the system as adding burden (May, Montori, Montori, & Mair, 2009). Capacity denotes the ability to manage this work and includes socio-economic and psychological resources, literacy, language and social support (Shippee, Shah, May, Mair, & Montori, 2012). When demand exceeds capacity, treatment becomes burdensome and is likely to result in reduced adherence and poorer outcomes (May et al., 2014) as illustrated with our 'Type 3' patients.

The 6MR did not ascertain treatment burden and its one-off nature provided little, if any, opportunity to help patients develop their capacity to manage daily life. Self-management and secondary prevention were perceived as an embedded component of the 6MR, but neither were integrated into the care pathway or part of a wider approach. Patients were expected to continue to self-manage without ongoing support to address problems as they arose and overtime.

The SA co-ordinator wanted to focus on patient and carer priorities but was constrained by systemic requirements to complete the GM-SAT and various questionnaires. There was a tension between a desire to remain client-centred and socially orientated, and the pseudo-medical approach dictated by the 6MR. The rhetoric of SA co-ordinators having extensive knowledge of stroke, being able to take blood pressure, identify atrial fibrillation, liaise with GPs, improve medication adherence, target

lifestyle choices and promote self-management (Stroke Association, 2016) suggests professional training. This may be intended to appeal to commissioners, many of whom are GPs, but is at odds with the social orientation of the staff interviewed, which was their key asset.

Sadler et al.'s (2014) systematic review compared lay and healthcare professional understandings of self-management for various long-term conditions, including stroke. Understanding self-management appeared to encompass traditional/paternalistic models of the professional-patient relationship based on compliance rather than empowerment: a striking dissonance (Wilson, 2001; Wilson, Kendall, & Brooks, 2007).

Another systematic review also highlighted the dominance of a traditional model of care and an emphasis on personal responsibility (Franklin, Lewis, Willis, Bourke-Taylor, & Smith, 2017). Didactic delivery of information, similar to the 6MR, was intended to increase knowledge and promote behaviour change. While some patients were satisfied, others wanted help to apply knowledge to their situation and expressed a preference for tailored advice with specific strategies to make information relevant and practical.

A stronger criticism suggests that the discourse around self-management has been dominated by policymakers who regard it as a means to reduce the financial impact of chronic illness on statutory services (Kendall, Ehrlich, Sunderland, Muenchberger, & Rushton, 2011). The notion of individual responsibility, for the greater good of society, implies that those who do not comply with professional interpretations of self-management are likely to be deemed 'difficult', as was the case with some 6MRs.

The study has limitations: it was not possible to recruit a site where therapists carried out 6MRs; delays in gaining approval from site three limited data collection; commissioners were difficult to engage; and patients discharged to care homes were not included.

CONCLUSION

While information and advice provided by the 6MR was valued by many patients, a single review is unlikely to facilitate self-management or behaviour change (Forster et al., 2012). The six-month review needs to be embedded into the care pathway and strategies for secondary prevention reviewed and consolidated at each stage. Reviewers should be allowed the freedom to individualise the process on a needs-led basis rather than adhering to a rigid framework dictated by policy. Our findings suggest that the 6MR should review therapy goals and facilitate patient-led goals to encourage participation in valued activities, including return to work.

References

Banks, J., Marmot, M., Oldfield, Z., & Smith, J. P. (2006). Disease and Disadvantage in the United States and in England. *Jama, 295*(17), 2037-2045.

Bhaskar, R. (1978). *A Realist Theory of Science*. Hassocks, Sussex: Harvester Press.

Braun, V., & Clarke, V. (2006). Using Thematic Analysis in Psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Bury, M. (1982). Chronic Illness as Biographical Disruption. *Sociology of Health & Illness, 4*(2), 167-182.

Care Quality Commission. (2011). *Supporting Life After Stroke. A Review of Services for People Who have had a Stroke and their Carers.* Retrieved from http://www.cqc.org.uk/sites/default/files/documents/supporting_life_after_stroke_national_report.pdf

Clark, A. M., Lissel, S. L., & Davis, C. (2008). Complex Critical Realism: Tenets and Application in Nursing Research. *Advances in Nursing Science, 31*(4), E67-79. 10.1097/01.ANS.0000341421.34457.2a [doi]

Corbin, J., & Strauss, A. (1985). Managing Chronic Illness at Home: Three Lines of Work. *Qualitative Sociology, 8*(3), 224-247.

Curtis, A., & Gallifent, R. (2014). *Long Term Reviews for Stroke Patients in SW & NW Surrey. Pilot Project Report.* (No. N/A). Surrey: Virgin Care/NHS.

Department of Health. (2007). *National Stroke Strategy.* Retrieved from

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Healthcare/Longtermconditio

ns/Vascular/Stroke/DH_099065

Easton, G. (2010). Critical Realism in Case Study Research. *Industrial Marketing Management, 39*(1),

118-128. 10.1016/j.indmarman.2008.06.004

Emerson, R. M., Fretz, R. I., & Shaw, L. L. (2011). *Writing Ethnographic Fieldnotes* (Second ed.).

Chicago: The University of Chicago Press.

Finlay, L. (2002). "Outing" the Researcher: The Provenance, Process, and Practice of Reflexivity.

Qualitative Health Research, 12(4), 531-545. 10.1177/104973202129120052

Forster, A., Brown, L., Smith, J., House, A., Knapp, P., Wright, J. J., & Young, J. (2012). Information

Provision for Stroke Patients and their Caregivers (Review). *Cochrane Database of Systematic*

Reviews, (11)- 10.1002/14651858.CD001919.pub3

Franklin, M., Lewis, S., Willis, K., Bourke-Taylor, H., & Smith, L. (2017). Patients' and Healthcare

Professionals' Perceptions of Self-Management Support Interactions: Systematic Review and

Qualitative Synthesis. *Chronic Illness,*

Gedge, C., France, T., & Jones, L. (2013). *Stroke Reviews Project.* (No. N/A). Medway: Medway

Community Healthcare.

Gerring, J. (2007). *Case Study Research: Principles and Practices*. Cambridge: Cambridge University

Press.

Goncalves-Bradley, D. C., Boylan, A. M., Koshiaris, C., Vazquez Montes, M., Ford, G. A., & Lasserson,

D. S. (2015). GPs' Adherence to Guidelines for Structured Assessments of Stroke Survivors in the

Community and Care Homes. *Family Practice, 32*(6), 659-663. 10.1093/fampra/cmv074 [doi]

Guba, E., & Lincoln, Y. (1982). Epistemological and Methodological Bases of Naturalistic Inquiry. *Educational Technology Research and Development, 30*(4), 233-252. 10.1007/BF02765185

Hargroves, D., French, E. & Trickey, M. (2014). *Stroke Six Month Reviews.* Retrieved from http://www.secscn.nhs.uk/our-networks/cardiovascular/stroke-clinical-advisory-group/

Jenkins, L., King, A., & Brigden, C. (2012). *Evaluation of the Stroke Association's 'Life After Stroke' Services in Eastern and Coastal Kent.* (No. TSA FF 2009/01). University of Kent: Centre for Health Service Studies.

Kendall, E., Ehrlich, C., Sunderland, N., Muenchberger, H., & Rushton, C. (2011). Self-Managing Versus Self-Management: Reinvigorating the Socio-Political Dimensions of Self-Management. *Chronic Illness, 7*(1), 87-98. 10.1177/1742395310380281 [doi]

Marmot, M. (2004). Tackling Health Inequalities since the Acheson Inquiry. *J Epidemiol Community Health, 58*, 263-264.

Maxwell, J. A. (2012). *A Realist Approach for Qualitative Research*. Thousands Oaks, CA: SAGE Publications.

May, C., Eton, D. T., Boehmer, K., Gallacher, K., Hunt, K., MacDonald, S., Mair, F. S., May, C. M., Montori, V. M., & Richardson, A. (2014). Rethinking the Patient: Using Burden of Treatment Theory to Understand the Changing Dynamics of Illness. *BMC Health Services Research, 14*, 281. 10.1186/1472-6963-14-281

May, C., Montori, V. M., Montori, V., & Mair, F. S. (2009). Analysis: We Need Minimally Disruptive Medicine. *BMJ: British Medical Journal (Online), 339*, b2803.

Mays, N., & Pope, C. (2000). Qualitative Research in Health Care. Assessing Quality in Qualitative Research. *BMJ (Clinical Research Ed.), 320*(7226), 50-52.

McKevitt, C., Fudge, N., Redfern, J., Sheldenkar, A., Crichton, S., Rudd, A. R., Forster, A., Young, J., Nazareth, I., Silver, L. E., Rothwell, P. M., & Wolfe, C. D. (2011). Self-Reported Long-Term Needs After Stroke. *Stroke, 42*(5), 1398-1403.

NHS England. (2013). *CCG Outcomes Indicator Set 2014/15. Technical Guidance.* Retrieved from https://www.england.nhs.uk/resources/resources-for-ccgs/ccg-out-tool/ccg-ois/

NHS England. (2016). *Commissioning Guidance for Rehabilitation. Publications Gateway Ref no. 04919.* Retrieved from https://www.england.nhs.uk/wp-content/uploads/2016/04/rehabilitation-comms-guid-16-17.pdf

NICE. (2013). *Stroke Rehabilitation: Long-Term Rehabilitation After Stroke (Clinical Guideline CG162).* Retrieved from http://www.nice.org.uk/guidance/CG162

Parke, H. L., Epiphaniou, E., Pearce, G., Taylor, S. J., Sheikh, A., Griffiths, C. J., Greenhalgh, T., & Pinnock, H. (2015). Self-Management Support Interventions for Stroke Survivors: A Systematic Meta-Review. *PloS One, 10*(7), e0131448.

Porter, T., Sanders, T., Richardson, J., Grime, J., & Ong, B. N. (2015). Living with Multimorbidity: Medical and Lay Healthcare Approaches. *International Journal of Clinical Rheumatology, 10*(2), 111-119.

Proctor, S. (1998). Linking Philosophy and Method in the Research Process: The Case for Realism. *Nurse Researcher, 5*(4), 73-90.

Public Health England. (2016a). *East Sussex County Health Profile 2016.* Retrieved from http://fingertipsreports.phe.org.uk/health-profiles/2016/e10000011.pdf

Public Health England. (2016b). *Kent County. Health Profile 2016.* Retrieved from http://fingertips.phe.org.uk/profile/health-profiles

Public Health England. (2016c). *Surrey County Health Profile 2016.* Retrieved from

   http://fingertipsreports.phe.org.uk/health-profiles/2016/e10000030.pdf

Robson, C. (2011). *Real World Research: A Resource for Users of Social Research Methods in Applied*

   Settings (Third ed.). Chichester: Wiley.

Rothwell, K., Boaden, R., Bamford, D., & Tyrrell, P. J. (2013). Feasibility of Assessing the Needs of

   Stroke Patients After Six Months using the GM-SAT. *Clinical Rehabilitation, 27*(3), 264-271.

   10.1177/0269215512457403

Royal College of Physicians. (2012). *National Clinical Guidelines for Stroke. Intercollegiate Stroke*

   Working Party. Fourth Edition. Retrieved from https://www.rcplondon.ac.uk/resources/stroke-

   guidelines

Royal College of Physicians. (2015). *Post-Acute Organisational Audit 2015. Phase 2: Organisation*

   Audit of Post-Acute Stroke Service Providers. Prepared by the Clinical Effectiveness and

   Evaluation Unit on Behalf of the Intercollegiate Stroke Working Party. Retrieved from

   https://www.strokeaudit.org/results/PostAcute/National.aspx

Royal College of Physicians. (2016). *National Clinical Guidelines for Stroke. Intercollegiate Stroke*

   Working Party. Fifth Edition. Retrieved from https://www.rcplondon.ac.uk/guidelines-

   policy/stroke-guidelines

Royal College of Physicians. (2017). *Rising to the Challenge. the Fourth SSNAP Annual Report. Stroke*

   Care Received between April 2016 to March 2017. Retrieved from

   https://www.strokeaudit.org/Documents/AnnualReport/2016-17-SSNAP-Annual-Report.aspx

Sadler, E., Wolfe, C. D., & McKevitt, C. (2014). Lay and Health Care Professional Understandings of

Self-Management: A Systematic Review and Narrative Synthesis. *SAGE Open Medicine, 2*

Retrieved from http://journals.sagepub.com/doi/full/10.1177/2050312114544493

Saka, O., McGuire, A., & Wolfe, C. (2009). Cost of Stroke in the United Kingdom. *Age and Ageing,*

38(1), 27-32. 10.1093/ageing/afn281 [doi]

Shippee, N. D., Shah, N. D., May, C. R., Mair, F. S., & Montori, V. M. (2012). Cumulative Complexity: A

Functional, Patient-Centered Model of Patient Complexity can Improve Research and Practice.

Journal of Clinical Epidemiology, 65(10), 1041-1051.

Stroke Association. (2012). *Struggling to Recover.* Retrieved from

http://www.stroke.org.uk/involved/struggling-recover

Stroke Association. (2016). *Post-Stroke Review.* Retrieved from https://www.stroke.org.uk/finding-

support/our-life-after-stroke-services/post-stroke-review

Tang, S., & Anderson, J. M. (1999). Human Agency and the Process of Healing: Lessons Learned from

Women Living with a Chronic Illness - 're-writing the Expert'. *Nursing Inquiry, 6*(2), 83-93.

Walker, M., Fisher, R. & Fletcher-Smith, J. (2014). *Stroke Six Month Reviews: A National Audit of*

Service Provision. Retrieved from http://www.nottingham.ac.uk/emahsn/documents/summary-

report---national-audit-of-6-month-reviews-after-strokefinal.pdf

Wilson, P. M. (2001). A Policy Analysis of the Expert Patient in the United Kingdom: Self-care as an

Expression of Pastoral Power? *Health & Social Care in the Community, 9*(3), 134-142.

Wilson, P. M., Kendall, S., & Brooks, F. (2007). The Expert Patients Programme: A Paradox of Patient

Empowerment and Medical Dominance. *Health & Social Care in the Community, 15*(5), 426-438.

Wong, G., Greenhalgh, T., Westhorp, G., Buckingham, J., & Pawson, R. (2013). RAMESES Publication

Standards: Realist Syntheses. *BMC Medicine, 11*(1), 21. 10.1186/1741-7015-11-21 [doi]

Yin, R. K. (2014). *Case Study Research: Design and Methods* (Fifth ed.). London: SAGE Publications.

Table 1: Interviewees and observations per site

	Case study 1	Case study 2	Case study 3
Interviews:			
Patients (carers)	26(14)	15(11)	5(5)
Stroke nurse specialists	3	3	-
Stroke Association support worker*	1	1	-
Stroke Association co-ordinator*	-	-	1
Physio- or occupational therapist	1	3	-
Service manager, General Practitioner and CCG	5	2	2
Across site interviews[+]	6		
Observations:			
Initial visit	1	-	1
Six-month review	10	9	4
One-year review (only available in site 1)	6	-	-
Multi-disciplinary meetings (site 1 only)	11	-	-
'Life after stroke' group (site 2 only)	-	5	-

*SA workers did not carry out reviews whereas SA co-ordinators only carried out reviews

[+]Royal College Physicians Stroke Working Party, Strategic Clinical Network for the South East, Stroke Association regional directors, clinical/academic orthoptist

Table 2: Summary of SNS and SA review: process and outcomes

	Stroke nurse specialist review	Stroke Association review
MEDICAL	In-depth knowledge of stroke, able to review medication and make recommendations; able to liaise with consultants and GPs; access to inpatient and GP databases; understanding of co-morbidities; able to screen for sleep apnoea and refer as appropriate.	Medical management could not be addressed by co-ordinators.
Outcomes:	Patients/carers (particularly 'Type 1s') felt reassured by tailored explanations and medical followed-up.	Some dissatisfaction with limited answers to medical queries.
OBSERVATIONS	Able to make meaningful observations including blood pressure (using sphygmomanometer), heart rate and blood glucose level; able to interpret observations and act accordingly.	Ascertained blood pressure using digital monitor; used an algorithm to advise follow-up. Unable to diagnose atrial fibrillation.
Outcomes:	Timely and appropriate medical follow-up provided further reassurance to most patients and carers (largely 'Type 1s').	Many patients already had a blood pressure monitor which made measurement appear perfunctory.
EDUCATION, INFORMATION AND ADVICE	Provided in-depth and tailored explanation around stroke, medication and secondary prevention.	Some patients and carers appreciated generic Stroke Association leaflets but others did not find them helpful, feeling overwhelmed by too much information and/or wanting it tailored to their needs.

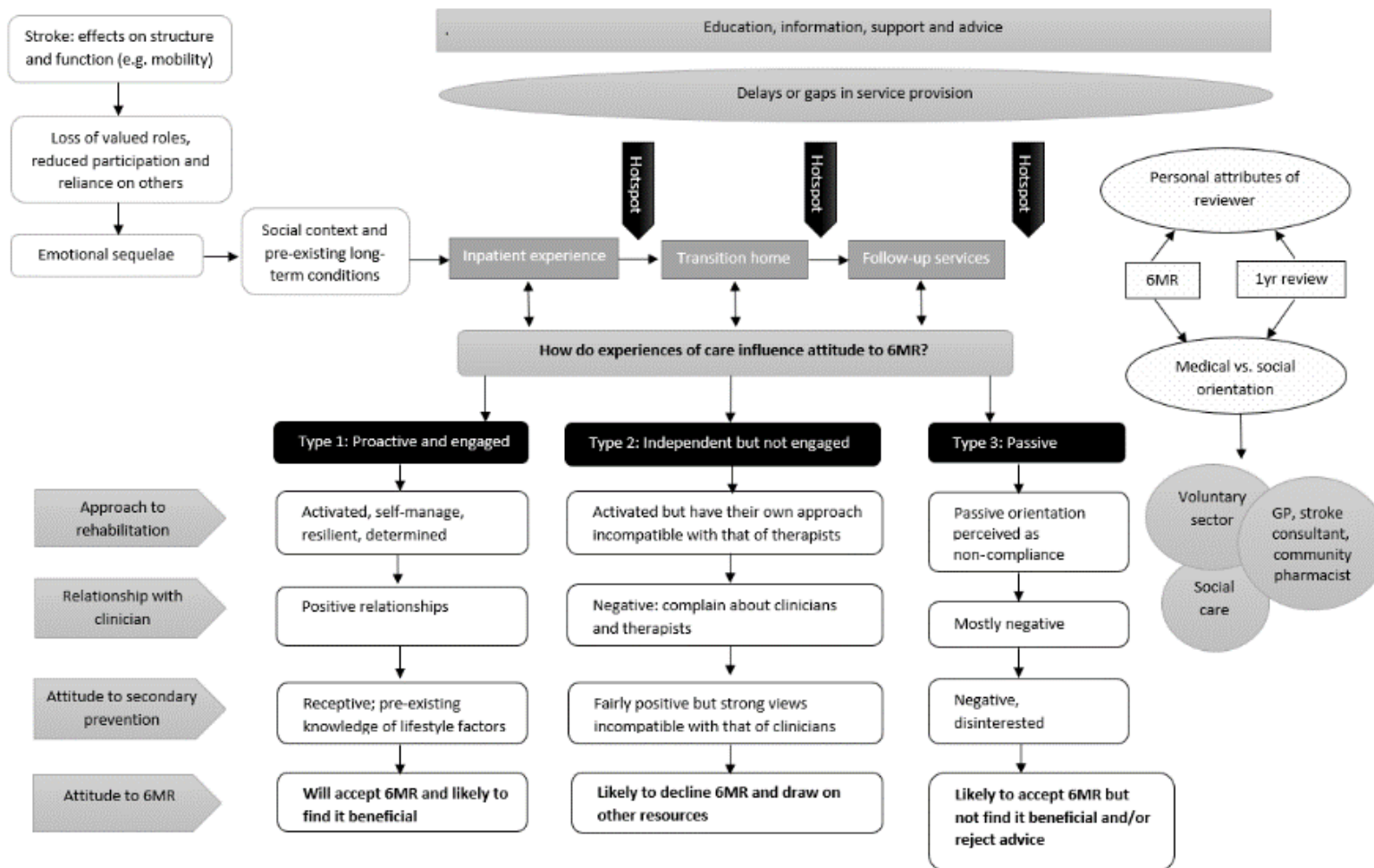|		
	Signposting to non-statutory/community services was limited but patients were referred to the Stroke Association for this information.	Comprehensive knowledge of local services including exercise classes, aphasia cafés, financial advice and carer support.
Outcomes:	Patients/carers reassured by tailored medical advice (mostly 'Type 1s') but complained when identified need remained unmet (often 'Type 2s' who wanted exercise classes and/or further rehabilitation).	Some dissatisfaction with generic information. Signposting to community services was appreciated and indirectly could have improved community participation.
PATIENT-REVIEWER RELATIONSHIP	Patients and carers trusted SNSs' medical expertise and in-depth explanation that the relatively long appointment allowed (compared to those with GPs/ consultants).	Focused on developing rapport and prioritising patient and carers' concerns which often included filling gaps in statutory services. Not time limited.
Outcomes:	Patients/carers ('Type 1s') felt reassured by SNSs' expertise.	Patients/carers felt listened to and not rushed (all Types).
BOTH MODELS LACKED FOCUS ON:	• Identification of therapy needs and/or goals. • Return to work. • Unresolved vestibular and visuo-perceptual symptoms. • Opportunity to consolidate information discussed during the review, particularly secondary prevention (medical and lifestyle).	
Outcomes:	Lack of follow-up for specific therapy and vocational needs resulting in dissatisfaction, frustration and/or anxiety.	

Figure 1: The journey from stroke to 6MR

Figure 2: Context, mechanisms, purpose and outcomes of the 6MR

CONTEXT:

➤ **Policy discourse**
- Patients are responsible for their health and should be encouraged to self-manage
- Identifying unmet needs will lead to their amelioration
- Provision of information and/or education will lead to behaviour change

➤ **Social determinants of health**
- Demographics: age, income, occupation, education, ethnicity
- Socio-economic status
- Health literacy

➤ **Personal circumstances**
- Illness burden: stroke related impairment and co-morbidities
- Ability to participate in valued activities
- Environmental facilitators and barriers (in- and outside)
- Level of independence pre- and post-stroke
- Social network and support

PURPOSE:
- Identify unmet (expressed) need
- Self-management support
- Some patients/carers unclear

PATIENT RESPONSE (TYPOLOGY)

Type 1: Proactive and engaged

Type 2: Proactive and self-managing on their own terms

Type 3: Passive orientation

IMPLEMENTATION:
- One-off review of needs structured by a standard template
- Takes place in clinical setting or patient's home
- Provision of information and education
- Majority of eligible patients receive 6MR (in areas that commission it)
- Limited tailoring appropriate to stroke-related deficits (communication and cognitive impairment) but not according to other contextual issues

MECHANISM

Type 1: Patients trust the reviewer's expertise; reviewer's therapeutic use-of-self facilitates trust

Type 2: Patients distrust clinicians and have mismatched beliefs and priorities

Type 3: Patients distrust clinicians and have disengaged from rehabilitation

OUTCOMES (INTENDED & UNINTENDED)

Type 1 patients:
- Feel reassured
- Are signposted to other services, where available
- Appreciate follow-up of medical investigations &/or appointments
- Engage with information including that on secondary prevention

Type 2 patients:
- Do not feel listened to or reassured
- Are signposted to other services but maybe dissatisfied with the service
- Mostly appreciate follow-up of medical investigations &/or appointments
- Disregard information and advice and pursue their own ideas/alternative advice

Type 3 patients:
- Do not feel listened to or reassured
- Are signposted to other services but seldom attend
- Are ambivalent about medical follow-up
- Disregard or reject information and advice
- Have needs which reflect priorities beyond the 6MR's remit, remain unaddressed or cannot be met