



# Post-stroke Review Pilot Project The Evaluation Report

# Acknowledgements

**The pilot project reported here would not have been possible without the help and support of a great number of people.**

We would like to thank the Information, Advice and Support (IAS) coordinators involved for the enthusiasm, dedication and commitment they demonstrated throughout the project. The pilot project demanded a great deal from the coordinators and we are indebted to them for the time and efforts they gave so generously.

Our thanks also go to the commissioning organisations from across all 10 pilot sites for their vision and unfailing support for the project. We are additionally grateful to the service users, their families and carers who were involved in the pilot, particularly those who completed and returned the evaluation questionnaire, providing invaluable feedback and insight into the review process.

# Contents

Foreword .....	2
Executive summary .....	3
1. Background .....	4
2. The pilot project .....	6
2.1. The review process .....	6
2.2. Training and support .....	7
2.3. The evaluation strategy .....	7
2.3.1. Analysis of review summary reports .....	7
2.3.2. Service user questionnaire .....	7
2.3.3. IAS coordinator questionnaire .....	7
3. Results .....	8
3.1. Unmet needs and actions .....	8
3.2. Service user feedback .....	10
3.3. IAS coordinator feedback .....	11
4. Discussion .....	13
5. Appendices .....	15
5.1. Summary report .....	15
5.2. Service user questionnaire .....	17
5.3. IAS coordinator questionnaire .....	18

# Foreword



**People recovering from acute stroke in hospital are inevitably focused on getting home. Following discharge, they may receive treatment from community therapy and nursing teams, but this is often only provided in the short term, and being 'discharged' from therapy can be difficult. Clinical teams often fail to recognise the difficulties stroke survivors may have, adjusting back to 'normal' life, and how long this may take.**

The idea of a structured assessment of people six months after discharge from hospital was first suggested in the National Service Framework for Older People of 2001, and again in the National Stroke Strategy, but it was not clear what this assessment should consist of, or who should undertake it.

Our project in Greater Manchester has involved service users and clinicians in identifying the problems people have six months following stroke, putting together a simple, evidence based assessment tool which can be used to identify and address these problems, signposting people to appropriate local services. This tool is termed GM-SAT: the Greater Manchester Stroke Assessment Tool.

We are very pleased to have had the opportunity to work with The Stroke Association to test the acceptability of GM-SAT to service users across England and begin to understand how GM-SAT may be best implemented to ensure that everyone leaving hospital following a stroke can benefit from routine structured assessment. Understanding needs and signposting to local services will improve outcomes and quality of life for stroke survivors, their carers and families.

A handwritten signature in black ink that reads "Pippa Tyrrell". The signature is fluid and cursive.

Dr Pippa Tyrrell

Stroke Clinical Lead, NIHR CLAHRC for Greater Manchester  
Senior Lecturer/ Honorary Consultant Stroke Medicine  
University of Manchester and  
Salford Royal NHS Foundation Trust

**Stroke had for too many years been seen as a Cinderella illness, with people taking a fatalistic attitude to its prevention, treatment and recovery. We were therefore delighted by the publication in 2007 of the National Stroke Strategy, and also its emphasis on the whole care pathway.**

It was understandable that in implementing the Strategy much energy has gone into raising awareness through the FAST message, gearing up the emergency response and locating and staffing hyper acute and acute services. But we have not forgotten and neither have our colleagues in the NHS and social care that hospital is for most people the start of a long, long journey with many obstacles and setbacks to overcome.

The National Stroke Strategy established that people needed a review at six weeks, six months and annually after leaving hospital and made this one of only 20 Quality Markers for stroke care and support. We were excited when Dr Pippa Tyrrell approached The Stroke Association with a proposal that we would participate in a pilot programme of six month assessments. Not only did this fit with our vision, but it also seemed appropriate that the North West -the starting point of our Life After Stroke Services- should once again be in the vanguard.

It has been a delight to work with the NIHR CLAHRC for Greater Manchester team and the Primary and Acute Trusts, who have contributed to and supported this pilot. A model of collaboration. But more importantly this project has again demonstrated the challenges faced by stroke survivors and their families, and it has been humbling to be able to work with them on their journey.

A handwritten signature in black ink that reads "Jon Barrick". The signature is bold and cursive, with a long horizontal line underneath.

Jon Barrick

Chief Executive  
The Stroke Association

# Executive summary

- Stroke survivors, their carers and families report feeling abandoned in the months and years following a stroke, a time during which many experience significant changes, both positive and negative, in their health, social and emotional care needs and struggle to adjust to the often devastating impact the stroke has had on their lives.
- The National Stroke Strategy, under quality marker 14, requires all stroke survivors and their carers to receive regular reviews of their health and social care needs. However, nationally, little progress has been made towards the implementation of comprehensive post-stroke review services. This is due, in part, to the lack of evidence available to inform how such reviews should be delivered, including what the content of the reviews should be, who should undertake them and in what setting they should be delivered.
- In mid 2010, the NIHR CLAHRC for Greater Manchester and The Stroke Association established a pilot project to investigate the role The Stroke Association's Information, Advice and Support (IAS) coordinators could play in the delivery of the six month stroke review.
- The pilot involved 15 IAS coordinators from 10 pilot sites nationwide. A total of 137 reviews were delivered by the coordinators during the pilot period. All reviews were conducted in the home setting using GM-SAT: the Greater Manchester Stroke Assessment Tool, an evidence based, standardised post-stroke assessment tool.
- In total, 464 unmet needs were identified across 37 areas spanning health, social and emotional care domains. Service users presented with an average of three unmet needs, however, the number of unmet needs identified varied significantly from zero to 14 unmet needs per service user.
- Whilst half of the unmet needs identified could be addressed through the provision of information and advice, 20% and 9% of problems respectively required the service user to be signposted or referred to other services. Further, in response to 21% of the unmet needs identified, service users were advised to make an appointment with their primary care team.
- The review process was well received by all service users. They were confident that their coordinators knew how to help them and placed an extremely high value on the stroke specialist knowledge IAS coordinators demonstrated during the reviews and their understanding of and empathy for the impact a stroke has on people's lives in the long term. Many service users additionally indicated that they felt comfortable and at ease during their review, an atmosphere in which they felt able to talk openly about their problems and discuss sensitive issues.
- IAS coordinators were confident in their skills and ability to administer the six month review, with many feeling that the review was, to a great extent, a simple yet important formalisation of the work they were routinely doing prior to the pilot project.
- The pilot project results demonstrate that IAS coordinators are well placed to deliver post-stroke reviews, particularly those undertaken six months after leaving hospital. This provides a practical way of meeting the significant challenge presented by quality marker 14 of the National Stroke Strategy in a way that is appropriate, acceptable and highly valued by stroke survivors, their carers and families.

# 1. Background

## **Stroke is the leading cause of severe adult disability in the UK.**

There are currently 300,000 people in England alone living with moderate to severe disabilities as a result of stroke and, with an ageing population, this figure looks set to rise year on year<sup>1</sup>. The effects of stroke are often devastating, with far reaching consequences for the individuals, their families and carers. The problems they experience in the long term are often complex, numerous and diverse, spanning across health, social and psychological care domains. For many, the full impact of a stroke is only realised following discharge from hospital or community rehabilitation when they are left to suddenly adjust to the full impact of the stroke on their life at home or in a care home. It is at this stage that many report a sense of abandonment and have difficulty accessing the services they need to address their long term unmet needs.

The National Stroke Strategy<sup>2</sup>, under quality marker 14, requires all stroke survivors and their carers to receive regular reviews of their health and social care needs. These reviews can help ensure that stroke survivors and their carers feel supported in the long term and have access to the medical, social and emotional support they require as their needs change over time. The Strategy states that:


- People who have had strokes and their carers, either living at home or in care homes, are offered a review from primary care services of their health and social care status and secondary prevention needs, typically within six weeks of discharge home or to care home and again before six months after leaving hospital.
- This is followed by an annual health and social care check, which facilitates a clear pathway back to further specialist review, advice, information, support and rehabilitation where required.

Whilst the above recommendation is drawn from clinical consensus and there is, as yet, no formal evidence of the efficacy of post-stroke reviews, anecdotally, the benefits can be numerous and include the avoidance of hospital admissions, improved compliance with medication and increased quality of life<sup>3</sup>.

However, as detailed in the National Audit Office's 'Progress in Improving Stroke Care' Report<sup>1</sup>, nationally, little progress has been made towards implementation of comprehensive post-stroke review services. This is, in part, due to the lack of evidence available to inform how reviews should be delivered, including what the content of the reviews should be, who should undertake them and in what setting they should be delivered. Additionally, there are relatively few examples of cost effective service model options for the delivery of post-stroke reviews.

Over the past 18 months, the NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for Greater Manchester has been working on an innovative project which has looked to define the optimal content of the six month stroke review and support the development and implementation of local service models for review delivery. The first phase of this project, which is now complete, centred on development of an evidence based, standardised post-stroke assessment tool for use in the six month review. GM-SAT: the Greater Manchester Stroke Assessment Tool, as it is termed, is a simple assessment tool which can be used to identify and address individuals' long term, unmet post-stroke needs. It provides simple management algorithms that guide the reviewer through the assessment process, from the questions they need to ask to identify an individual's unmet needs through to the actions they need to take to address any needs identified. It covers a wide range of health, social and emotional care needs, from medication management to mood and fatigue.

For more information, visit  
<http://clahrc-gm.nihr.ac.uk/gmsat>.



Following completion of GM-SAT, the NIHR CLAHRC for Greater Manchester has been working with commissioning and provider organisations from across the health, social and voluntary care sector to identify appropriate service models for the delivery of the six month review.

The Stroke Association is the UK's largest provider of specialist community support services for stroke survivors, their carers and families. Sitting at the heart of The Stroke Association's 'Life After Stroke' services are Information, Advice and Support (IAS) coordinators\* who work as part of the stroke multidisciplinary team, acting as key workers for their clients, helping them navigate the health and social care system, ensuring they remain supported and that they are able to access the services they need. They keep in regular contact with their clients, either face to face or over the telephone, continually reassessing their needs to make sure they are still receiving the support they require, signposting and referring, where necessary, to other service providers and members of the multidisciplinary team.

During an extensive period of stakeholder consultation undertaken by the CLAHRC, health and social care professionals and service users alike, voiced how they considered IAS coordinators to be well placed to administer the six month review, many feeling that this would, to a great extent, be a simple yet important formalisation of the work they were already doing. Therefore, in June 2010, the NIHR CLAHRC for Greater Manchester and The Stroke Association established a pilot project to evaluate the appropriateness and acceptability of this method of delivering the six month stroke review. This report presents the findings.

\* the job titles of several of the coordinators participating in the pilot differed from that of IAS coordinator e.g. community stroke coordinator. However, all coordinators had principally the same job description as that of an IAS coordinator.

- 1 Progress in Improving Stroke Care, National Audit Office, 2010.
- 2 National Stroke Strategy, Department of Health, 2007.
- 3 Stroke rehabilitation guide: supporting London commissioners to commission quality services in 2010/11, Healthcare for London, 2009.

## 2. The pilot project

**The pilot project was undertaken over a five week period between 17th July and 20th August 2010 and involved 15 IAS coordinators from 10 pilot sites nationwide (figure 1).**

Sites selected for inclusion in the pilot represented both urban and rural areas and had differing commissioning arrangements in place. The IAS service was commissioned by health (i.e. Primary Care Trusts) at four sites, by social care (i.e. Local Authorities) at five, with the service at a single site being jointly commissioned by both local health and social care organisations. Notably, the choice of pilot sites was restricted to those from which approval to participate in the project could be obtained from the relevant commissioning organisation in the short timescales involved.

All 15 IAS coordinators involved in the project had a minimum of one year's experience of working in their current role, with the vast majority having been in post upwards of 10 years. Additionally, these coordinators had diverse occupational backgrounds, few of them having previously worked in a clinical post, and were felt to be representative of IAS coordinators nationally.

### 2.1. The review process

For the pilot, each coordinator identified stroke survivors on their caseload who had been discharged home from hospital approximately six months previously (five to seven months post hospital discharge) and were therefore due a six month stroke review. Each service user identified was then contacted by their coordinator who explained the pilot and offered them the opportunity to receive a review. For those who accepted, a convenient appointment was then made for the coordinator to visit them at home.

At the allotted time, the coordinator visited the service user at home and completed their stroke review using GM-SAT. Stroke survivors were reviewed either alone or, where a carer was present and the stroke survivor consented, as a service user-carer 'unit'.

**Figure 1. Pilot sites**



At the conclusion of each review, the coordinator summarised any unmet needs identified and mutually agreed the way forward with the service user and, where appropriate, his or her carer.

After each review, the IAS coordinator followed up any actions required to address the unmet needs identified, including making onward referrals to other services and sending any outstanding information to the service user. A 'review summary report' (see appendices) was additionally completed and sent to the service user's primary care team informing them of any unmet needs identified at the review and the actions that had been or were to be consequently taken, including any actions required of members of the primary care team themselves. A copy of the report was also routinely sent to the service user unless they had requested otherwise.



## 2.2. Training and support

Prior to commencing the pilot project, all 15 IAS coordinators involved attended a full day training session led by the project leads. At this coordinators were introduced to GM-SAT and were given an opportunity to practice using it in a series of role play scenarios. In addition to the training, coordinators were each provided with a comprehensive resource pack containing a copy of GM-SAT and all the supporting materials required for the pilot (e.g. review proformas, evaluation questionnaires).

For the duration of the pilot, coordinators were additionally offered informal support from the project leads via telephone and email, with all queries being addressed on the same or following working day. Coordinators also received a weekly bulletin which kept them abreast of how the pilot was progressing nationally and provided a means of communicating essential information.

## 2.3. The evaluation strategy

A multi-faceted approach was employed for the evaluation to enable the appropriateness and acceptability of the new model of delivering the six month review to be examined from a variety of perspectives.

### 2.3.1. Analysis of review summary reports

An anonymised copy of each review summary report completed during the pilot was returned to the project leads, who reviewed it and, for each, recorded the number and nature of unmet needs identified at the review and the actions that had subsequently been taken. For the purposes of the pilot project, unmet need was defined as 'a problem that is not being addressed or one that is being addressed but insufficiently (i.e. undermet need)'.

### 2.3.2. Service user questionnaire

At the conclusion of each review, service users were given a structured questionnaire (see appendices). This comprised of both open and closed ended questions which aimed to examine what service users and their carers thought of the review process and whether they deemed the service model being used to deliver the six month review appropriate and acceptable. Whilst the majority of this questionnaire was purposely constructed for use in the pilot project, part of it employed an adapted version of the consultation quality index (CQI)<sup>4</sup>, a validated tool ordinarily used in general practice to measure the holism and patient-centeredness of a service user consultation.

### 2.3.3. IAS coordinator questionnaire

The 15 IAS coordinators were also asked to complete a structured questionnaire after each review (see appendices). This contained open and close ended questions designed to elicit views on the usefulness of GM-SAT, the overall review process, any difficulties encountered, any areas in which they felt they would benefit from additional training and the time taken to undertake the review.

4 Howie, J.G.R. et al., 2000. Developing a 'consultation quality index' (CQI) for use in general practice, 19, Family Practice.

# 3. Results

**A total of 137 reviews were completed by IAS coordinators during the pilot period, each coordinator completing between six and 11 reviews.**

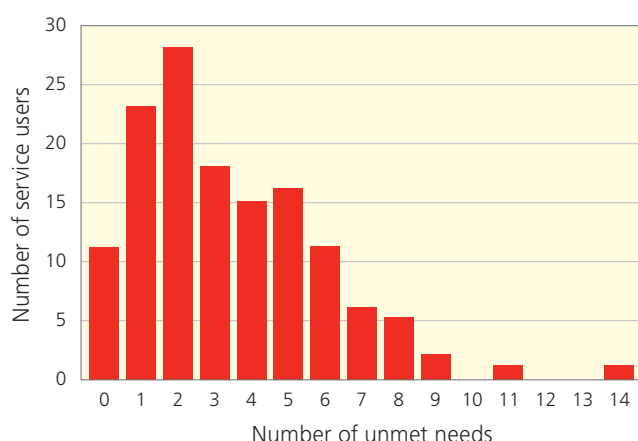
All service users reviewed had been discharged from hospital approximately six months prior to their review and all reviews were delivered in the home setting using GM-SAT.

### 3.1. Unmet needs and actions

In total, 464 unmet needs were identified during the pilot. Service users presented with an average of three unmet needs. However, the number of unmet needs identified at each review varied significantly from zero to 14 unmet needs per service user (figure 2).

Unmet needs were identified across 34 of the 35 areas covered by GM-SAT (table 1). Over one third of service users presented with unmet needs relating to fatigue (n=47; 34%), whilst around a quarter had unmet needs in the areas of memory, concentration and attention (n=35; 26%), secondary prevention (non lifestyle) (n=30; 22%) and depression (n=26; 19%). The areas of fatigue, memory, concentration and attention, secondary prevention (non lifestyle), depression and benefits and finances accounted for over one third of all unmet needs identified [163 out of 464 (35%)]. There were only two areas not covered by GM-SAT in which unmet needs were identified, will making (n=1; 1%) and foot care (n=2; 1%). Service users presented with no unmet needs relating to seizures.

**Figure 2. Number of unmet needs identified**



**Table 1. Number of unmet needs identified and percentage of individuals presenting with unmet needs**

	Number (n) of unmet needs identified	% of individuals presenting with unmet need
Medication management	4	3
Medication compliance	18	13
Secondary prevention (non lifestyle)	30	22
Alcohol	7	5
Diet	9	7
Smoking	10	7
Exercise	18	13
Vision	8	6
Hearing	8	6
Communication	13	9
Swallowing	7	5
Nutrition	6	4
Weight management	8	6
Pain	12	9
Headaches/ Migraines	9	7
Seizures	0	0
Continence	13	9
Activities of daily living	13	9
Mobility	9	7
Falls	10	7
Depression	26	19
Anxiety	20	15
Emotionalism	4	3
Personality changes	16	12
Sexual health	4	3
Fatigue	47	34
Sleep pattern	11	8
Memory, concentration and attention	35	26
Driving	13	9
Transport and travel	7	5
Activities and hobbies	11	8
Employment	9	7
Benefits and finances	25	18
House and home	10	7
Carer/ Supporter needs	11	8
Other	3	2
<b>TOTAL</b>	<b>464</b>	

To address the unmet needs identified, a total of 464 actions were undertaken during the pilot (figure 3). The most common of these was the provision of verbal and/or written information and advice by the IAS coordinator which accounted for half of all actions undertaken (n=234; 50%).

In order to address 92 (20%) of the unmet needs identified, IAS coordinators signposted service users to other services. The most frequent of these were signposts to services providing advice on benefits (e.g. Citizens Advice Bureau) and to local exercise opportunities to which 14% (n=19) and 7% (n=10) of service users respectively were signposted. Other services to which service users were signposted include carers' centres, opticians, smoking cessation services and providers of aids and adaptations.

A total of 40 (9%) problems required a referral to other services. However, as, on several occasions, service users were referred to the same service for more than one problem (e.g. referred to speech and language therapy for problems relating to both communication and swallowing), this amounted to 37 actual referrals. Table 2 details the referrals made. The majority of these were to social services (n=5; 14%), speech and language therapy (n=5; 14%), continence advisory services (n=5; 14%) and occupational therapy (n=4; 11%).

In response to 98 (21%) of the unmet needs identified, service users were advised to make an appointment with their primary care team. The service users' GPs were also informed of these problems via the review summary report completed by the IAS coordinators after each review. As with

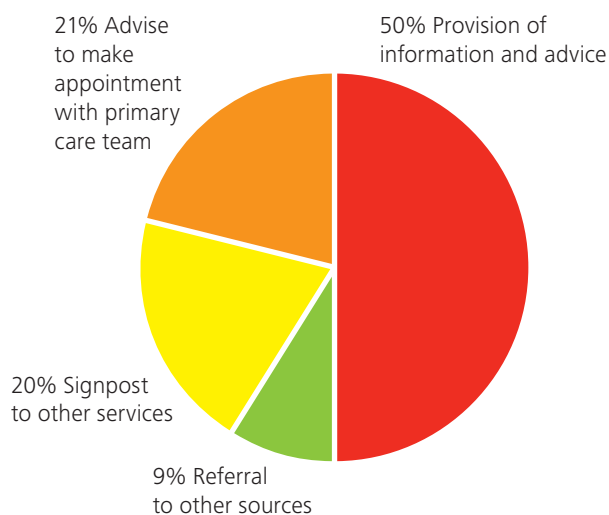
the referrals made to other services, service users were often advised to make an appointment with their primary care team to discuss more than one of the problems identified and therefore only 61 (45%) service users were advised to make an appointment.

Sixteen percent (n=27) of all service users reviewed were advised to make an appointment with their primary care team to have their blood pressure checked as they indicated at their review that this was not being done on a regular basis\*.

Additionally, 10% (n=14) were advised to make an appointment to discuss the side effects they were getting from their medication, whilst a further 9% (n=12) were directed to make an appointment to discuss the pain they were experiencing, both neuropathic and musculoskeletal. Other problems service users were directed to discuss with their primary care team included depression (n=5; 4%), falls (n=4; 3%) and problems with memory, concentration and attention (n=4; 3%).

On two occasions, with the service user's consent, the IAS coordinator made this appointment on the service user's behalf during the review visit.

**Figure 3.**  
**Actions taken to address unmet needs identified**



**Table 2. Referrals made to other services**

	Number of referrals
Audiology	3
Communication support service	3
Continence advisory service	5
Counselling service	2
Dietetics	1
Falls clinic	2
Falls prevention service	1
Occupational therapy	4
Physiotherapy	3
Psychology	2
Social services	5
Speech and language therapy	5
Visual impairment service	1
<b>TOTAL</b>	<b>37</b>

\* regular is defined as the service user having their blood pressure checked approximately every six weeks unless they had been advised otherwise.

### 3.2. Service user feedback

Of the 137 questionnaires distributed to service users, 101 were completed and returned giving an overall response rate of 74%. All responders rated the review they had received as good or better, with 31% (n=31) rating it very good and a further 49% (n=49) rating it excellent (figure 4).

When asked to what extent they agreed with the statement 'All my needs and concerns were addressed (at my review)' 46% (n=46) of responders strongly agreed, with a further 49% (n=49) agreeing. A similar response was obtained in response to the statement 'My Stroke Association coordinator knew how to help me' with 59% (n=58) and 39% (n=39) strongly agreeing and agreeing with this statement respectively. Further, 98% strongly agreed or agreed that they had been given all the information and advice they needed.

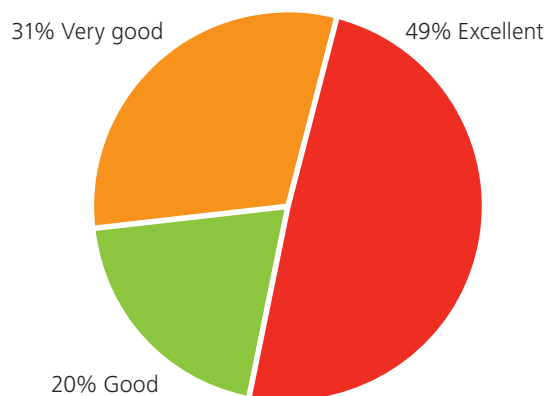
As a result of receiving their six month review from the IAS coordinator, 55% (n=55) of responders indicated that they were able to cope much better (n=19; 19%) or better (n=36; 36%) with their condition. Additionally, 60% reported that they were able to understand their condition better (n=37; 37%) or much better (n=23; 23%) than before their review.

Many of the service users returning the questionnaire used the free text space to express how the process of receiving a review had made them feel supported.

Service users additionally remarked on how useful they had found the review. They indicated that they had found the opportunity to talk about their needs and work with the coordinator to address these highly beneficial. They also voiced how the structured and comprehensive nature of the review had given them an opportunity to discuss issues that they would not have otherwise raised (e.g. those relating to sexual health).

Additionally, service users expressed how they felt comfortable being reviewed by their IAS coordinator and remarked on how they appreciated the opportunity to talk to someone who understood stroke and the way it impacts on people's lives.

Figure 4. Service user review ratings



*"What was good about the review? The fact that at last somebody was concerned about how I was going on after leaving hospital."*

*"I think it is an excellent tool for covering all areas as it is so comprehensive. It brought up issues that the service user may have otherwise dismissed."*

*"I was able to explore areas of concern in more detail. It prompted the client to reflect on several occasions and recognise some improvements that he had not yet acknowledged."*

*"It enabled me to cover all areas systematically within a framework."*

*"It's nice to know people care."*

*"My coordinator always made me feel relaxed when discussing any issues I had and used language I could easily understand. She was friendly, light hearted and very professional."*

*"The gentleman was very helpful with all my questions. You could not have had a better person doing the review."*

### 3.3. IAS coordinator feedback

The 15 IAS coordinators completed and returned a total of 132 questionnaires (one coordinator compiled their feedback from several reviews on a single questionnaire).

When asked to what extent they agreed with the statement 'I felt comfortable undertaking the review' all coordinators strongly agreed (66%) or agreed (34%) and exactly the same response was obtained when coordinators were posed with the statement 'I knew how to address the needs and concerns expressed by the service user'. A number of coordinators did, however, express a need to receive some additional training to help them to better respond to service users' concerns and worries relating to their sexual health after stroke.

In relation to GM-SAT, 96% of coordinators agreed (27%) or strongly agreed (69%) that it was easy to use and with 71% agreeing (39%) or strongly agreeing (32%) that it helped them to explore sensitive issues with the service user.

95% of responders indicated that they felt the service user benefited from having the review, whilst the remaining 5% neither agreed nor disagreed with this statement.

The review, in the service user's home, took coordinators on average 74 minutes to complete. However this ranged significantly from 20 to 195 minutes. Coordinators additionally spent an average of 33 minutes outside the review completing the appropriate paperwork to coordinate the actions required (e.g. making referrals to other services).

The IAS coordinators were also asked to indicate how the amount of time they spent completing the review differed from that they would normally spend on a routine home visit. This included both the home visit itself and the additional related tasks that followed. On average, coordinators indicated that the structured post-stroke review took an additional 33 minutes to complete, although this too ranged significantly from zero to 150 minutes.

*"What was good about the review? Being able to discuss things with someone who understands how the stroke affects and changes a person and could help and advise on all these points."*

*"It is a comprehensive tool which helps focus clients' thoughts on their issues."*

*"This review and its format give the service user 'permission' to express their concerns and feelings."*

*"An excellent tool. The more I use it the more I can see its value."*

*"I had no difficulties whatsoever undertaking the review. It was extremely useful for me to have the tool."*

*"I felt confident with the process and had no problems. The questions and topics discussed are those that I discuss routinely at the initial assessment and other home visits."*

*"I think I would benefit from some training around post-stroke sexual health issues."*

*"It is good to know that there is someone I can ask when I have a question. I don't like to bother my GP."*

*"Do you do this for every patient? It has been really helpful and we are very grateful indeed."*

*"We felt very at ease with our coordinator."*

*"Very thorough and thought provoking. It covered a very broad range of subjects about my life after stroke. Very thoughtfully and professionally undertaken."*

*"It helped me identify one or two issues that needed to be resolved to enable me to improve my quality of life."*

*"The review gave me an opportunity to take stock of myself and how much I have changed and improved since I left hospital. As an individual I tend to lose sight of these things as they are around me all day and in some respects taken for granted. This review helped me to channel my thoughts as to where to go from here, prompting some good ideas as to how to move forwards."*

*"Can we go back to that question about relationships? I think I would really like an opportunity to talk about that." (comment made by service user during their review, reported by IAS coordinator)*

*"The service user and his wife seemed appreciative of the time I spent with them. They both said that they felt lucky in some ways that the stroke had not caused more disability. The questions I asked made them realise how many problems they could have been facing."*

*"I felt this review was very much needed and helped support the service user and their family with their concerns."*

*"Open, honest forum, identified needs and some solutions. Chance for stroke survivor and wife to broach sensitive issues."*

*"It was good to be able to discuss the effect that the stroke has had on my everyday life with someone impartial and willing to give me help and advice regarding things that were bothering me. The best thing about the review was being able to talk about anything I wished to and be believed. Most people tend to think that everything is just OK."*

*"Nice to talk to someone who understands my condition and worries."*

*"What was good about the review? The opportunity to talk with a well informed and nice person who understands the basis of what I was asking."*

*"What was good about the review? The time and effort that was taken to ensure that I was at ease, enabling me to answer the questions fully giving me an insight into my condition."*

*"The review was very good. The coordinator was very easy to get on with and she put us both at ease. She was very helpful and informative and helped us talk through any problems we may have come across. To know that we will be supported in the long term is a big relief."*

# 4. Discussion

**Stroke survivors, their carers and families report feeling unsupported in the months and years following a stroke, a time during which many experience changes, both positive and negative, in their needs and struggle to adjust to the often devastating impact the stroke has had on their lives. Through its recommendation of regular reviews, the National Stroke Strategy had aimed to address this, yet offered little by way of suggestions as to how such reviews could be delivered. This pilot project, however, has served to identify an innovative solution to this problem, demonstrating that The Stroke Association's IAS coordinators provide an appropriate, acceptable and potentially cost effective means of delivering post-stroke reviews.**

As the results of the pilot project demonstrate, the needs experienced by stroke survivors in the long term are diverse, and in some cases numerous, spanning across health and psychosocial care domains. This indicates that it would be unrealistic and unfeasible for any one individual, regardless of their professional background, to be able to address all of these needs 'on the spot' at a stroke review. Rather, it suggests a need for emphasis to be placed on using the review to identify stroke survivors' needs and helping them access any medical, social and psychological help and support they require to address these.

As demonstrated during the pilot, coordinators were able to effectively use GM-SAT and work with service users to identify their unmet needs and, whilst a significant proportion of these could be addressed through the provision of information and advice, where specialist input was required, coordinators were able to exploit their established referral pathways and vast knowledge of local services to address these needs.

Coordinators participating in the project were confident in their skills and ability to administer the six month review. Many voiced that the review was a formalisation of the work they were routinely undertaking prior to the pilot, with GM-SAT purely providing a structured framework they could use when reviewing service users' needs.

Furthermore, service users were confident that their coordinator knew how to help them and placed an extremely high value on the stroke specialist knowledge they demonstrated within the reviews and their understanding of and empathy for the impact a stroke has on people's lives in the long term. Whilst coordinators did indicate that they would benefit from some additional training relating to areas such as sexual health after stroke, this is a training need that is not unique to the coordinators and is, on the whole, applicable to professionals working right across the stroke pathway.

The overwhelmingly high response rate received from service users in response to the evaluation questionnaire reflects service users' satisfaction with the reviews they received. A great number of service users expressed how they felt comfortable and at ease during the review, an atmosphere which offered an open, honest forum in which stroke survivors, their carers and families were able to talk candidly about the problems they were experiencing. Whilst this may be a consequence of the review taking place in the home setting, it is more likely to reflect the fact that coordinators had already established relationships with many of the service users reviewed. The IAS service offers continuity of care, with the coordinator being one of the only mainstays in a service user's life from the day of their stroke, into the months and years that follow, giving the coordinator time to build strong relationships of trust and openness with the service user.

The structured post-stroke review, on the whole, took coordinators longer to complete than a routine home visit. However, as coordinators were new to GM-SAT and the review process, the figures presented here are likely to overestimate the time it would take coordinators to deliver the review in the long term. Additionally, the significant variation that was observed in the time it took coordinators to complete the review and associated paperwork, reflects the varying number and complexity of unmet needs with which the service users presented.

It is possible that the evaluation results presented within this report understate the benefits which may be derived from The Stroke Association's coordinators undertaking post-stroke reviews as part of the wider IAS services. The continuity of care provided by IAS coordinators means that the review would not take place in isolation. Through their ongoing contact with the service user, coordinators would be able to ensure that problems identified at the review had been resolved by the actions put in place and could additionally align review outcomes and subsequent actions to the service user's long and short term goals, which the coordinator would be able to monitor on a regular basis. Further, in complex cases, where multiple unmet needs were identified at a review, coordinators would be able to work with the service user to prioritise these, ascertaining their key areas of concern and identifying the problems which, if resolved, would have the largest positive impact on the service user's quality of life. The coordinator could monitor the other unmet needs, ensuring they were addressed at a more appropriate time.

The results presented here serve to demonstrate that The Stroke Association's IAS coordinators are well placed to deliver post-stroke reviews, particularly those undertaken six months after leaving hospital. Whilst several key cross organisational challenges will need to be addressed to operationalise this as part of the wider IAS services and realise the benefits presented here, the exciting findings from this project demonstrate a practical way of meeting the significant challenge presented by quality marker 14 of the National Stroke Strategy in a way that is both acceptable and highly valued by stroke survivors, their carers and families.



# 5. Appendices

## 5.1 Summary Report: Six Month Post-Stroke Review

Forename		Surname	
NHS number		Review date	
Reviewed by		Carer's name (if applicable)	

Medication Management <input type="checkbox"/>	Communication <input type="checkbox"/>	Mobility <input type="checkbox"/>	Memory, Attention Concentration <input type="checkbox"/>
Medication Compliance <input type="checkbox"/>	Swallowing <input type="checkbox"/>	Falls <input type="checkbox"/>	Driving <input type="checkbox"/>
Secondary Prevention <input type="checkbox"/>	Nutrition <input type="checkbox"/>	Depression <input type="checkbox"/>	Transport and Travel <input type="checkbox"/>
Alcohol <input type="checkbox"/>	Weight Management <input type="checkbox"/>	Anxiety <input type="checkbox"/>	Activities and Hobbies <input type="checkbox"/>
Diet <input type="checkbox"/>	Pain <input type="checkbox"/>	Emotionalism <input type="checkbox"/>	Employment <input type="checkbox"/>
Smoking <input type="checkbox"/>	Headaches/ Migraines <input type="checkbox"/>	Personality Changes <input type="checkbox"/>	Benefits and Finances <input type="checkbox"/>
Exercise <input type="checkbox"/>	Seizures <input type="checkbox"/>	Sexual Health <input type="checkbox"/>	House and Home <input type="checkbox"/>
Vision <input type="checkbox"/>	Continence <input type="checkbox"/>	Fatigue <input type="checkbox"/>	Carer/ Supporter Needs <input type="checkbox"/>
Hearing <input type="checkbox"/>	ADLs <input type="checkbox"/>	Sleep Pattern <input type="checkbox"/>	
Other:			

Summary of needs identified:

Actions for you (the service user):

Actions for us (reviewer and stroke team):

Actions for your GP practice:

A copy of this summary has been automatically sent to your GP (unless you stated otherwise at your review).

For further information see [www.nhs.uk](http://www.nhs.uk) and enter a search term relating to your health condition e.g. stroke.

Reviewer's signature:

For further information please contact:

## 5.2 Service User Evaluation Questionnaire

In relation to your review, please indicate to what extent you agree with the below statements					
	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
I appreciated the opportunity to discuss my needs and concerns					
I found it easy to talk about my needs and concerns					
I felt comfortable answering all the questions asked					
All my needs and concerns were addressed					
My Stroke Association coordinator knew how to help me					
I was given all the information and advice I needed					
Information and advice was given in a way that was easy to understand					
My carer/ relative/ friend was sufficiently involved (if applicable)					
The review took too long to complete					
The review was valuable					

As a result of receiving this review you are...				
	Much Better	Better	Same Or Less	Not Applicable
Able to cope with life				
Able to understand your condition				
Able to cope with your condition				
Able to keep yourself healthy				
	Much More	More	Same or Less	Not Applicable
Confident about your health				
Able to help yourself				

What was good about the review?

How could the review be improved?

Any other general comments?

Overall, how would you rate today's review?

Excellent       Very good       Good       Poor       Very poor

Please return this questionnaire in the prepaid envelope provided.

Thank you for completing this questionnaire. Your views and opinions are very important to us.

### 5.3 IAS Coordinator Evaluation Questionnaire

In relation to the review, please indicate to what extent you agree with the statements below					
	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
I felt comfortable undertaking the review					
I had the skills required to complete the review					
Conversation focused on the needs and concerns expressed by the service user					
I knew how to address the needs and concerns expressed by the service user					
The assessment tool was easy to use					
The assessment tool helped me to discuss topics with the service user that I would not have otherwise discussed					
The assessment tool helped me explore sensitive issues with the service user					
I was able to give the service user my full attention during the review					
I felt the service user benefited from having the review					
I would like to offer this service to all my service users					

Please indicate the amount of time required to undertake the review.	
Direct time (i.e. time with the service user):	mins
Indirect time (i.e. completing paperwork, making referrals):	mins
In total (direct and indirect time), how much longer did it take to complete the review process in comparison to a normal home visit?	mins

Please describe any difficulties you encountered during the review

Please describe any areas in which, following the review, you think you would benefit from extra training

What was good about the review?

How could the review have been improved?

Any other general comments?







Collaboration for Leadership in  
Applied Health Research and Care  
(CLAHRC) for Greater Manchester

© NIHR CLAHRC for Greater Manchester and The Stroke Association 2010

**The Collaboration for Leadership in Applied Health Research and Care** is a partnership between the Greater Manchester NHS Trusts and the University of Manchester and is part of the National Institute for Health Research.

**The Stroke Association** is a Company Limited by Guarantee, registered in England and Wales (No 61274)

**Registered office:** Stroke House, 240 City Road, London EC1V 2PR

Registered as a Charity in England and Wales (No 211015) and in Scotland (SC037789)

Also registered in Isle of Man (No 945) Jersey (NPO 369) and in Northern Ireland