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# POST-STROKE REVIEW PILOT PROJECT

EVALUATION REPORT LAUNCH

13<sup>TH</sup> OCTOBER 2010

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# Welcome

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**Chris Clark**

Director of Operations, UK

The Stroke Association

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# BACKGROUND

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**Professor Ruth Boaden**

Deputy Director and Implementation Lead

NIHR CLAHRC for Greater Manchester

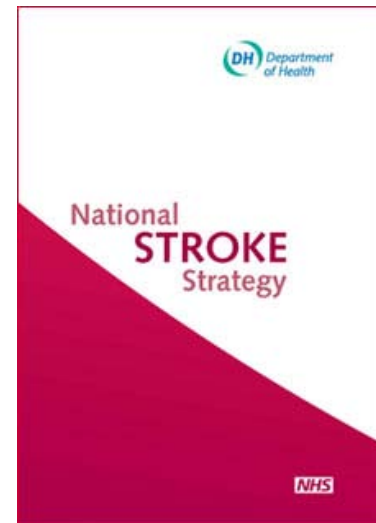
# Background

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- Stroke is the **leading cause of severe adult disability**.
- Many stroke survivors report a sense of **'abandonment'** in the months and years after stroke.
- Many have difficulty accessing the **help and support** they require to meet their needs.

# Background

- **Quality Marker 14 (QM14).**
- Six week, six month and annual reviews.
- **NAO Report (2010)** indicated that little progress had been made towards meeting QM14.
- Lack of clarity regarding the **content** of the review and **appropriate service models.**



# Background

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- NIHR CLAHRC for Greater Manchester: Collaboration for Leadership in Applied Health Research and Care.
- A collaboration between a leading university and its surrounding NHS trusts that will...
  - Conduct high quality health services research.
  - Ensure knowledge gained from the research is translated into improved health care in the NHS.
- Mission: to improve the health of the people of Greater Manchester by improving NHS quality of care and support for patient self-management.

*Focus on vascular conditions: Stroke, Diabetes, Chronic Kidney Disease, and Heart Disease.*

# Background

- Aimed to define the content of the six month review and support the development and implementation of local service models for delivering the review.
- **GM-SAT: the Greater Manchester Stroke Assessment Tool.**
- An evidence-based, standardised post-stroke assessment tool.



# Background

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- **The Stroke Association**
- Information, Advice and Support (**IAS**) coordinators.
- CLAHRC stakeholders (professionals and service users) thought that IAS coordinators were well placed to deliver the six month stroke review.
- An **important yet simple formalisation** of the work they were ordinarily doing.



# Background

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- In June 2010, the CLAHRC for Greater Manchester and The

Stroke Association established a pilot project:

**“To evaluate the appropriateness and acceptability of IAS**

**coordinators delivering the six month review”**

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# THE PILOT PROJECT

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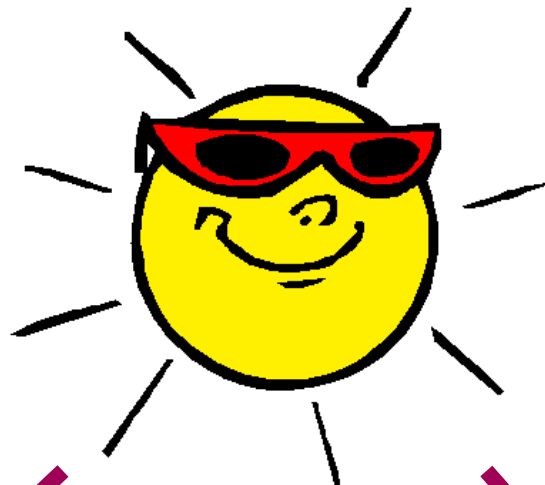
**Sue Fawcett**

Community Stroke Coordinator

The Stroke Association

# The Pilot Project

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**15 Stroke Association  
Coordinators**

**10 Regions**

# The Pilot Project



1. Hartlepool
2. Leeds
3. Wigan
4. Salford
5. Stockport
6. Chester
7. Shropshire
8. Bracknell Forest
9. East Dorset
10. Plymouth

# The Pilot Project



# The Pilot Project

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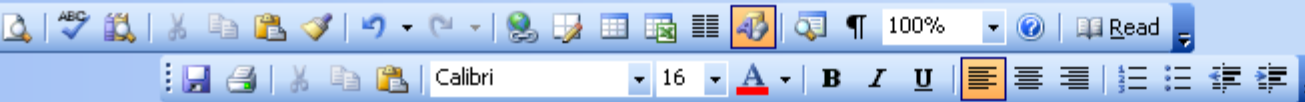




# The Pilot Project

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Registered Charity Number 211015



The University of Manchester



National Institute for  
Health Research

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

# Who should I review?

You should select clients on your caseload who:

- Have had a stroke. NOT a subarachnoid haemorrhage or a TIA.
- Are approximately 6 months post hospital discharge (NOT post stroke). It is acceptable for clients to be between 5 and 7 months post hospital discharge.



# The Pilot Process: Step-by Step

## 1. Identify service user who is suitable for review

*See sheet entitled 'Who should I review?'*

## 2. Book appointment with the service user

## 3. Review the service user using the stroke assessment tool

*You will be writing on the proforma and using the flow diagrams as a reference guide. Try to write down as much information as you can, including details of problems identified, any actions you take at the appointment (e.g. providing verbal advice or a leaflet) and any actions you need to take once you return to the office (e.g. making referrals, sending further information).*

## 4. Leave the service user with an evaluation questionnaire, flyer and pre-paid envelope

## 5. Return to office and complete the 'Review Summary Report'

*See sheet entitled 'Example Review Summary Report'. Try to be as detailed as you can when describing the problems identified and record all actions taken/to be taken, including any verbal advice and information provided. Try to avoid using jargon or complex terms to ensure the service user if able to understand what is written in the report. *n.b.* you may need to press on hard when writing the report to ensure that your writing reaches the 4<sup>th</sup> sheet!*

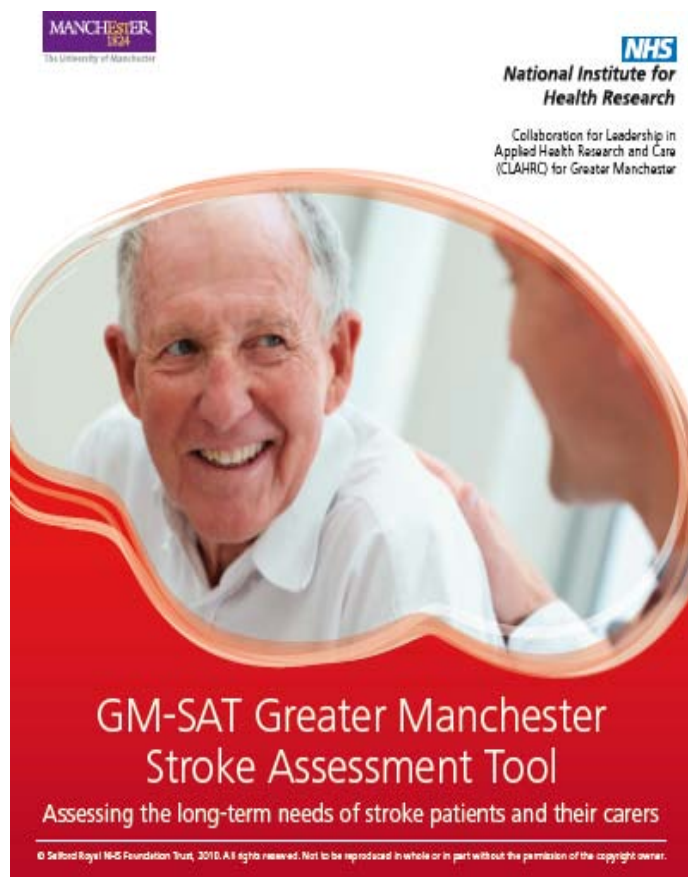
## 6. Send the Review Summary report ...:

White = Service user	Blue = GP (accompany this with the 'GP covering letter')
Yellow = Sue Fawcett	Pink/ Purple = Keep for your records

## 7. Complete the actions required of you e.g. make referrals, send the service user any extra information required

## 8. Fill in 'Information, Advice and Support Coordinators' Evaluation

# The Pilot Project



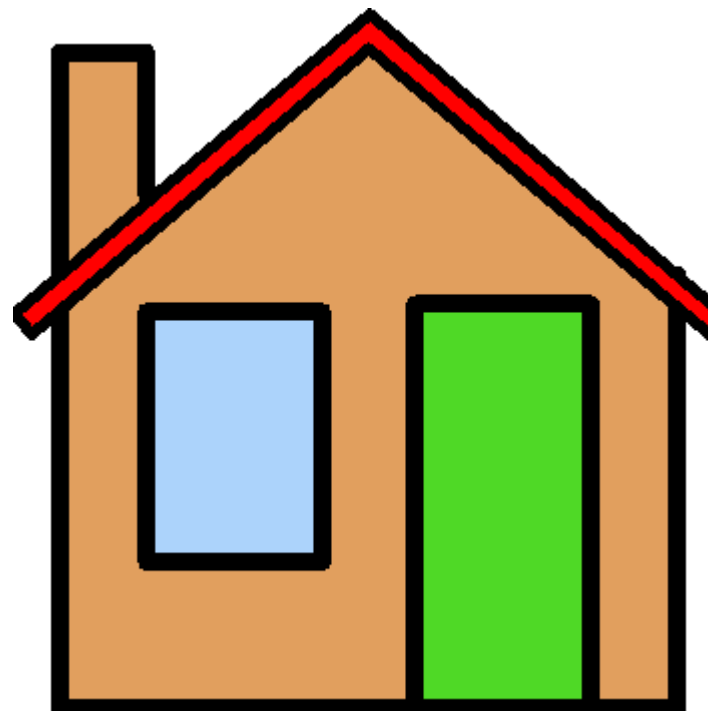
**MANCHESTER**  
The University of Manchester

**NHS**  
*National Institute for  
Health Research*

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

**GM-SAT Greater Manchester  
Stroke Assessment Tool**  
Assessing the long-term needs of stroke patients and their carers

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Forename	Martin	Surname	Thornton
NHS No.	999 999 9999	Review date	01/07/2010
Reviewed by	Jo Bloggs	Carers' Name (if applicable)	Mary

At your review we identified that you have some needs in relation to the following areas:

<input checked="" type="checkbox"/> +	<b>Meds Management</b>	<input type="checkbox"/>	<b>Communication</b>	<input type="checkbox"/>	<b>Mobility</b>	<input type="checkbox"/>	<b>Memory, Concentn, Attentn</b>	<input type="checkbox"/>
	<b>Meds Compliance</b>	<input type="checkbox"/>	<b>Dysphagia</b>	<input type="checkbox"/>	<b>Falls</b>	<input type="checkbox"/>	<b>Driving</b>	<input type="checkbox"/>
	<b>Secondary Prevention</b>	<input type="checkbox"/>	<b>Nutrition</b>	<input type="checkbox"/>	<b>Depression</b>	<input checked="" type="checkbox"/>	<b>Transport &amp; Travel</b>	<input type="checkbox"/>
	<b>Alcohol</b>	<input type="checkbox"/>	<b>Weight Management</b>	<input type="checkbox"/>	<b>Anxiety</b>	<input type="checkbox"/>	<b>Activities &amp; Hobbies</b>	<input type="checkbox"/>
	<b>Diet</b>	<input checked="" type="checkbox"/>	<b>Pain</b>	<input checked="" type="checkbox"/>	<b>Emotionalism</b>	<input type="checkbox"/>	<b>Employment</b>	<input type="checkbox"/>
	<b>Smoking</b>	<input type="checkbox"/>	<b>Headaches/ Migraines</b>	<input type="checkbox"/>	<b>Personality Changes</b>	<input type="checkbox"/>	<b>Benefits &amp; Finances</b>	<input checked="" type="checkbox"/>
	<b>Exercise</b>	<input type="checkbox"/>	<b>Seizures</b>	<input type="checkbox"/>	<b>Sexual Health</b>	<input type="checkbox"/>	<b>House &amp; Home</b>	<input type="checkbox"/>
	<b>Vision</b>	<input checked="" type="checkbox"/>	<b>Continenace</b>	<input type="checkbox"/>	<b>Fatigue</b>	<input type="checkbox"/>	<b>Carer/ Supporter Needs</b>	<input type="checkbox"/>
	<b>Hearing</b>	<input type="checkbox"/>	<b>ADLs</b>	<input type="checkbox"/>	<b>Sleep Pattern</b>	<input type="checkbox"/>		
	<b>Other:</b>							

#### Summary of needs identified:

- Pain: you reported that, since the stroke, you have been experiencing severe, aching pain in your right shoulder which is not relieved when you take Paracetamol. This pain occurs on a daily basis and is usually at its worst first thing in the morning.
- Vision: you informed me that your vision has deteriorated since you last saw the orthoptist, 3 months ago, for your right-side visual problem (hemianopia).
- Diet: since learning that your cholesterol was a little high after your stroke, you mentioned that you have been unsure about what are the right things to eat to stop your cholesterol increasing.
- Depression: you mentioned that you were feeling a little low in mood at the moment.
- Benefits and Finances: you reported that you were unsure as to what benefits you were eligible to, since you had stopped working due to your stroke.

#### Actions for YOU (the Service User):

- Please book an appointment with your GP to discuss the pain you are experiencing in your shoulder.
- Read the 'Diet and Stroke' information leaflet I have left with you. This provides information on food that you can eat to maintain a low cholesterol level.
- Visit the local Citizens Advice Bureau who will be able to talk you through the benefits you are entitled to. I have left you their telephone number and address.

#### Actions for US ( REVIEWER AND STROKE TEAM):

- Refer you to the orthoptist to see you about your sight.
- Refer you to the stroke psychologist to see you about your low mood.
- Send you our 'Finance and Stroke' information leaflet- please find this enclosed.

## Service User Evaluation Questionnaire

### 1. 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I found it easy to talk about my needs and concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt comfortable answering all questions asked	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All my needs and concerns were addressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My Stroke Association Coordinator knew how to help me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was given all the information and advice I needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information and advice was given in a way that was easy to understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My carer/ relative/ friend was sufficiently involved <i>(if applicable)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The review was took too long to complete	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The review was valuable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### 2. As a result of receiving this review you are...

	Much Better	Better	Same Or Less	Not Applicable

# The Pilot Project



## Stroke Association Coordinator Evaluation Questionnaire

### 1. In relation to the review, please indicate to what extent you agree with the below statements

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
I felt comfortable undertaking the review	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had the skills required to complete the review	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Conversation focused on the needs and concerns expressed by the patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I knew how to address the needs and concerns expressed by the service user	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The assessment tool was easy to use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The assessment tool help me to discuss topics with the service user that I wouldn't have otherwise discussed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The assessment tool helped me explore sensitive issues with the service user	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was able to give the service user my full attention during the review	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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# THE RESULTS

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**Katy Rothwell**

Knowledge Transfer Associate

NIHR CLAHRC for Greater Manchester

# Needs and Actions

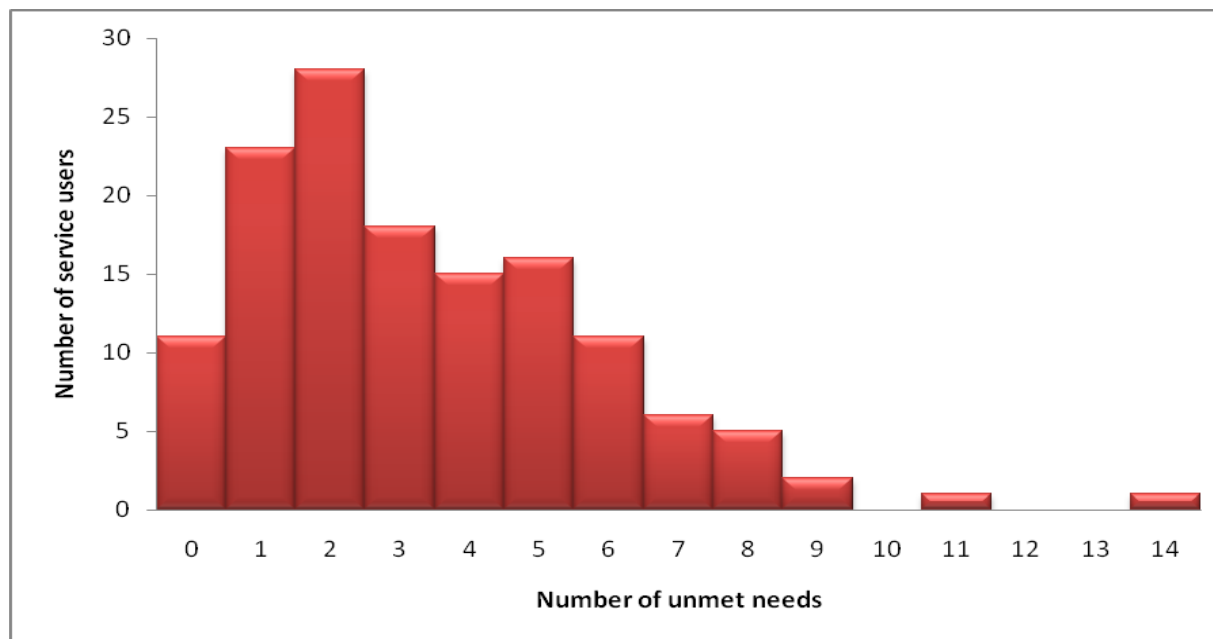
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- **137 reviews** were complete during the pilot period.
- Each IAS coordinator completed **between 6 and 11 reviews**.
- All service users have been discharged approximately **6 months** prior to the review.
- All reviews were delivered in the **home setting** using **GM-SAT**.



# Needs and Actions

- Total of **464 unmet needs** identified
- **Average of 3 unmet needs** (range= 0-14)



# Needs and Actions

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- Unmet needs identified in **36 different areas**.
- Needs were identified in **34 of the 35 areas covered by GM-SAT**.

# Needs and Actions

	Number (n) of unmet needs identified	Percentage (%) of individuals presenting with unmet need
Medication management	4	3
Medication compliance	18	13
<b>Secondary prevention (non lifestyle)</b>	<b>30</b>	<b>22</b>
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

	Number (n) of unmet needs identified	Percentage (%) of individuals presenting with unmet need
Falls	10	7
<b>Depression</b>	<b>26</b>	<b>19</b>
Anxiety	20	15
Emotionalism	4	3
Personality changes	16	12
Sexual health	4	3
<b>Fatigue</b>	<b>47</b>	<b>34</b>
Sleep pattern	11	8
<b>Memory, concentration and attention</b>	<b>35</b>	<b>26</b>
Driving	13	9
Transport and travel	7	5
Activities and hobbies	11	8
Employment	9	7
<b>Benefits and finances</b>	<b>25</b>	<b>18</b>
House and home	10	7
Carer/ Supporter needs	11	8
Other	3	2
<b>TOTAL</b>	<b>464</b>	

# Needs and Actions

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- Actions fell into **4 categories:**

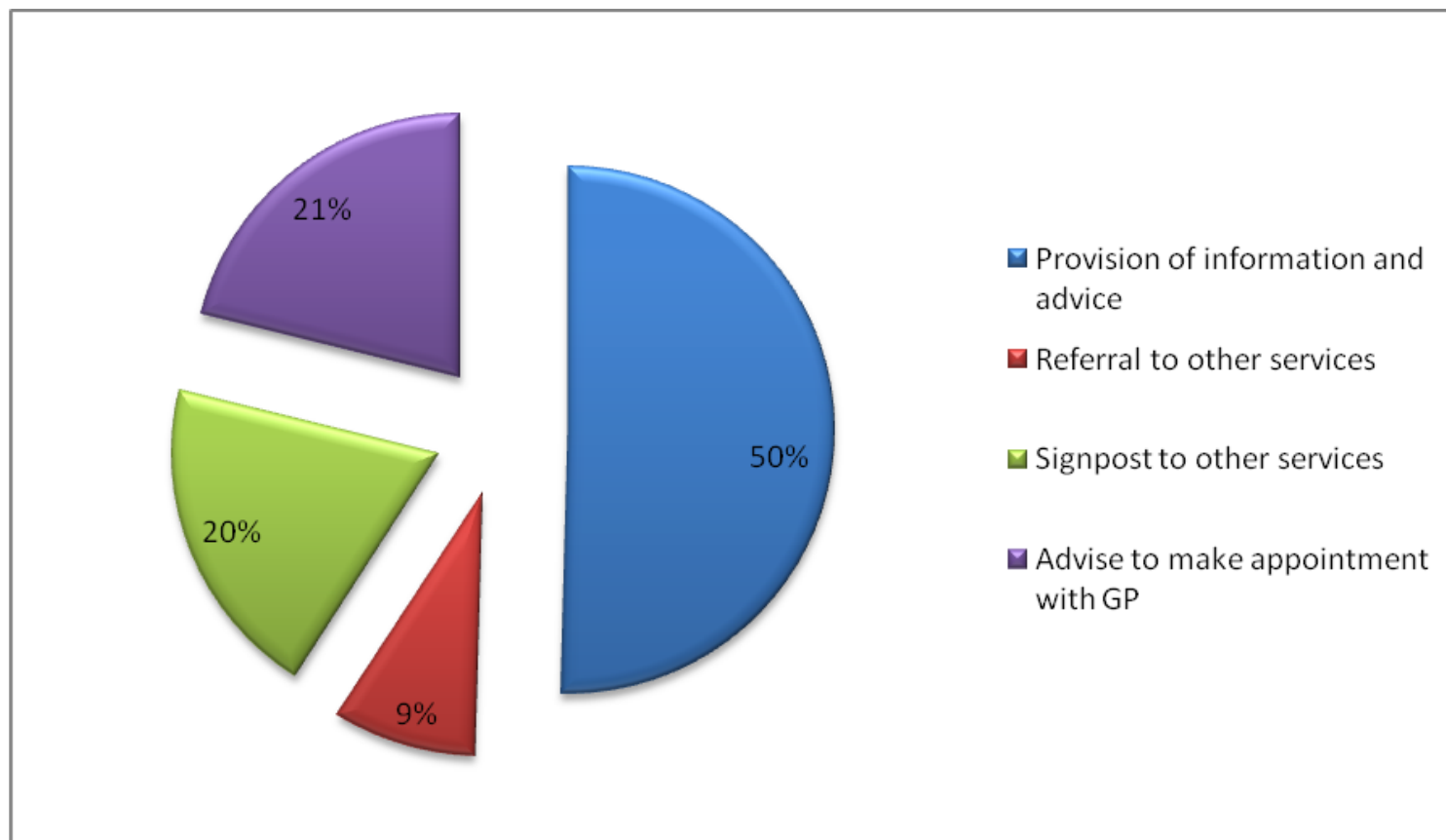
1. provision of **information and advice.**

2. **refer** to other services.

3. **signpost** to other services.

4. advise to make an appointment with **primary care team.**

# Needs and Actions



# Needs and Actions

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- **92 (20%)** of the unmet needs identified were **addressed by signposting**.
- **14% benefits services** (e.g. CAB); **7% local exercise opportunities**.
- **Others:** carers' centres, opticians, smoking cessation services, providers of aids and adaptations.

# Needs and Actions

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

- **14% of all referrals were made to each of the following services:**

  - Social services
  - Speech and language therapy
  - Continence advisory services
- **11% of all referrals were made to:**

  - Occupational therapy

# Needs and Actions

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- To address **98 (21%)** of the unmet needs identified service users were advised to **make an appointment with their primary care team.**
- Primary reason was that the service user's **blood pressure was not being checked on a 'regular basis'.**



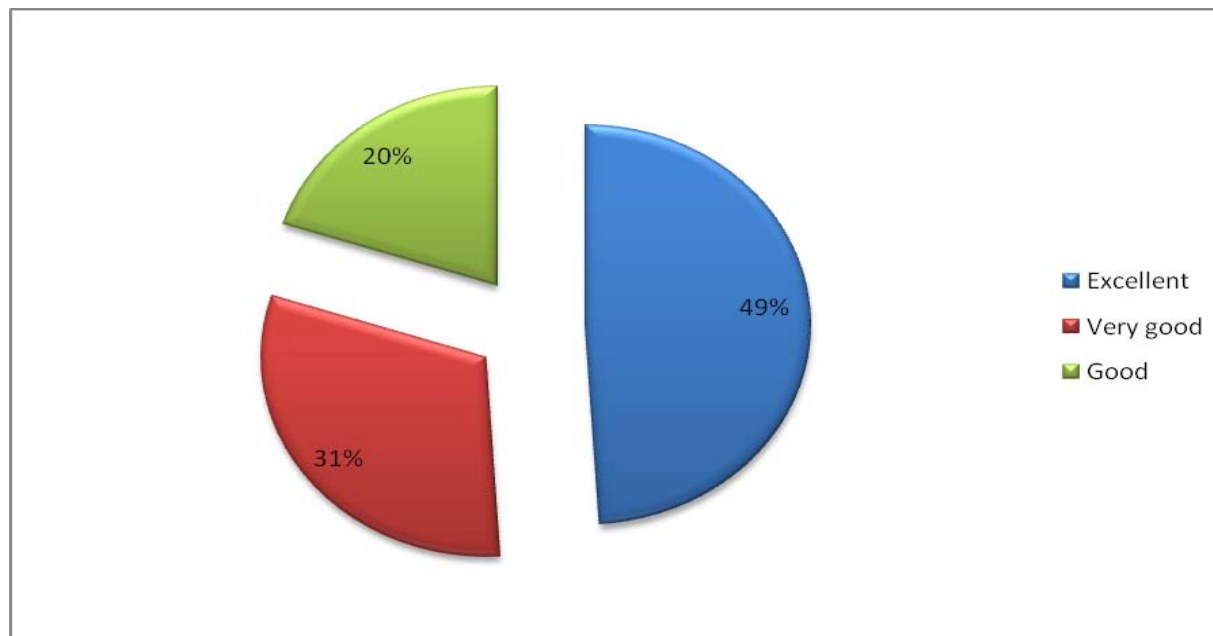
# Needs and Actions

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- Of all service users reviews:
  - **10%** directed to discuss **side effects** from their medication;
  - **9%** to discuss their **pain**;
  - **4% depression; 3% falls; 3%** problems with their **memory, concentration and attention.**

# Service User Feedback

- **74% response rate** [101/137 completed questionnaires returned]
- **Service user review ratings:**



# Service User Feedback

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- **“All my needs and concerns were addressed (*at my review*)”**
  - 46% strongly agreed; 49% agreed.
  
- **“ My Stroke Association Coordinator knew how to help me”**
  - 59% strongly agreed; 39% agreed.
  
- **“ I was given all the information and advice I needed”**
  - 98% strongly agreed or agreed.

# Service User Feedback

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- Service users indicated that the review made them feel **supported**
- They found the reviews **useful** and said that the **comprehensive** nature of the review prompted them to **discuss issues they wouldn't have otherwise discussed** (e.g. those relating to sexual health)

# Service User Feedback

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- Service users felt **comfortable** and **at ease** during their reviews.
- They appreciated the opportunity to talk to **someone who understood stroke and the impact that it has on people's lives.**



# IAS Coordinator Feedback

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- **132** questionnaires completed and returned.
  
- **“I felt comfortable undertaking the review” and “I knew how to address the needs and concerns expressed by the service user”**
  - 66% strongly agreed; 34% agreed.
  
- **“I found the assessment tool easy to use”**
  - 96% strongly agreed or agreed.

# IAS Coordinator Feedback

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**Jim Brown**

**Information, Advice and Support coordinator, Wigan.**



# IAS Coordinator Feedback

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- **Direct time** with service user= **average 74 minutes** (range 20-195)
- **Indirect time**= **average 33 minutes**
- **Additional time** needed to undertake review compared to a routine home visit= **33 minutes** (range 0-150 minutes)



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# DISCUSSION

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# Discussion

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- Problems experienced by stroke survivors in the long term are **diverse** and, in some cases, **numerous**.
- Span **health** and **psychosocial domains**.
- Emphasis needs to be placed on **identification** and **helping** **people access any specialist help or advice they require**.

# Discussion

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- Coordinators were confident in their **skills** and **abilities**.
- **GM-SAT** provided a structured, standardised framework.
- **Service users** were had **confidence in their coordinators abilities**.
- **Stroke specialist knowledge** and understanding highly valued.
- Service users felt **comfortable** and **at ease**. Probably due to the **continuity of care** offered by the IAS service.

# Discussion

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- The review took **longer to complete** but varied significantly.
  
- Additional benefits:
  - actions could be **aligned to long term goals**.
  
  - needs could be **monitored**.
  
  - in complex cases, **actions could be prioritised**.

# Discussion

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- IAS Coordinators are **well placed** to deliver post-stroke reviews, using **GM-SAT**.
- Several **key cross organisational challenges** will need to be addressed if the benefits reported here are to be realised.

# Discussion

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This project has demonstrated that The Stroke Association's IAS coordinators provide a **practical, appropriate, acceptable** and **potentially cost-effective** means of delivering the six month review in a way that is **highly valued** by stroke survivors, their carers and families.

