



Helping you to have your say  
Working together to improve  
NHS Stroke Services

## Public Involvement Guidance for Health Professionals



## Acknowledgements

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[www.communicationforumscotland.org.uk](http://www.communicationforumscotland.org.uk)



## Table of Contents

<b>Stroke Voices Public Involvement Guidance .....</b>	<b>5</b>
<b>Executive Summary .....</b>	<b>7</b>
<b>1 Introduction .....</b>	<b>9</b>
1.1 Voices Scotland .....	9
<b>2 Principles and Models of Engagement .....</b>	<b>12</b>
2.1 Good practice in public engagement .....	12
2.2 Stroke Voices Principles of Engagement .....	13
2.3 The Mutual Managed Clinical Network (MCN) .....	13
2.3.1 <i>A Mutual MCN: Pathway to a mutual MCN</i> .....	14
2.3.2 <i>The Mutual MCN</i> .....	14
<b>3. Inviting Stroke Voices to a Managed Clinical Network (MCN) .....</b>	<b>16</b>
<b>Sections 4 – 7 Journey through the engagement process.....</b>	<b>17</b>
<b>4 Support .....</b>	<b>17</b>
4.1. Publicity .....	19
4.1.1 <i>Posters</i> .....	19
4.1.2 <i>Invitations</i> .....	20
4.2 Support before a meeting .....	21
4.3 Support during a meeting .....	22
4.3.1 <i>Stroke Voices Supporters’ Guidance</i> .....	24
4.3.2 <i>Preparing a “Case for Change”</i> .....	25
<b>5 Venues and other practical issues .....</b>	<b>28</b>
5.1 Choosing a venue .....	29
5.2 Directions to the venue .....	30
5.2 Venue Directions .....	30
5.3 Refreshments .....	31
5.4 Seating/room layout .....	32
5.5 Equipment .....	32
<b>6 Resources.....</b>	<b>33</b>
6.1 Agendas and papers .....	35
6.2 Minutes and handouts .....	37
<b>7 Running a meeting.....</b>	<b>39</b>

7.5 Timings and size of meetings .....	42
7.6 The representative's story and the Emotional Touchpoints Tool .....	43
7.7 Contributing to the meeting.....	45
7.7.1 Stop ✂ .....	47
7.7.2 Slow down ✂.....	48
7.8 Questions and Answers.....	49
7.9 Breaks .....	50
7.10 Ending the meeting.....	50
7.11 Paying expenses .....	50
7.12 Acknowledging the work of a patient and carer subgroup .....	50
<b>Appendix 1: Accessible guidelines for written material.....</b>	<b>52</b>
1. The words you use .....	53
2. Where to put words on the page.....	53
3. How to use pictures and symbols .....	54
4 Choosing the type of writing and the paper .....	55
5 Making it easier for everyone to understand.....	56
<b>Appendix 2 Stroke Voices Booking Form.....</b>	<b>56</b>
<b>Appendix 3: Overview of possible effects of a stroke.....</b>	<b>64</b>
<b>Appendix 4: “Making your Case for Change” template.....</b>	<b>68</b>
<b>Appendix 5: Communication Support Principles.....</b>	<b>69</b>
<b>Appendix 6: Inclusive communication.....</b>	<b>69</b>
<b>Appendix 7: Ground rules for meetings .....</b>	<b>72</b>
<b>Appendix 8: Adapting a topic for different levels of severity of aphasia.....</b>	<b>75</b>
<b>Appendix 9: Accessible PowerPoint Presentations .....</b>	<b>77</b>
<b>Appendix 10: Choosing a symbol set - picture communication symbols .....</b>	<b>78</b>

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## Stroke Voices Public Involvement Guidance

'Chest, Heart & Stroke Scotland aims to improve the quality of life for people in Scotland affected by chest, heart and stroke illness, through medical research, advice and information and support in the community.'

The Scottish Government funded the Stroke Voices project to develop a robust and sustainable patient/carer involvement training package, applicable to all patients/carers with experience of stroke. This will empower their voices in the development of stroke services across all 14 NHS Board areas in Scotland. The following guidance is based on the findings of this project and its pilots and is now recognised by the Scottish Government as best practice for starting a stroke representative's engagement journey with the NHS.

The purpose of this document is to give guidance to all who might be working within Patient Focus Public Involvement (PFPI); engaging with people who will be living with the effect of a stroke.

This guidance recommends that engagement starts with the Stroke Voices training and may then take the form of:

- Open days
- Information days
- Mailing lists
- Email lists
- Forums
- Discussion groups
- Representatives on committees\*
- Patient and carer subgroups\*

\*See Section 2 for a model for a Mutual MCN and a suggested pathway of engagement with the public to reach this goal.

This guidance will give tips and suggestions as to how to make this engagement more fruitful on both sides and signpost to recognised resources to facilitate this process. It includes information to consider prior to Stroke Voices training and goes on to suggest good practice suggestions for engaging with representatives living with the effects of a stroke at NHS meetings and other consultations.

**Bodies that benefit from this guidance will include:**

- Stroke Managed Clinical Networks (MCNs)
- Community Health Partnerships (CHPs)
- Public Partnership Forums (PPFs)
- NHS Bodies across Scotland
- Voluntary organisations with an interest in stroke
- Organisations and individuals with an interest in stroke across Scotland

## Executive Summary

- This document introduces Voices Scotland public involvement training and support programmes starting with Hearty Voices Scotland and Chest Voices and then focuses on **Stroke Voices**; in particular the guidance for managers and health professionals that will make this public engagement more fruitful.
- In order to embed public involvement into the structure of a Managed Clinical Network (MCN) for example, a **Model of a Mutual MCN** has been developed along with its pathway to achieve this aim. This is based on experience of working across Scotland with various MCNs of various disciplines in each NHS Board.
- A simple five step **Principles of Engagement** developed by the Voices Scotland team to summarise best practice when working with people living with the effects of stroke in public involvement.
- Each step of the **patient/carer representative's journey** has been evaluated in the light of the experience gained on the Stroke Voices pilots.
- Careful consideration is suggested to support the representative's engagement with the NHS right from the first contact, to the preparation of **"Making Case for Change"** (a key Voices Scotland tool) and the support needed before, during and after a meeting.
- Suggestions are offered on the practical issues of running a meeting in order to take a stroke user representative's needs into account.
- **Offering accessible documentation** is a key concept for Stroke Voices. If all documentation offered to a group is aphasia accessible, it will also be easier for all to use, including those with English as a second language, literacy issues, learning disabilities and other neurological conditions. Guidelines on writing accessible documentation and how to choose picture symbols are all included.

- When working with stroke user representatives Voices Scotland encourages everyone to be aware how the stroke has affected the individual; these effects are often hidden. A list of the **possible effects of stroke** has been included.
- Best practice principles are included in **communication techniques** for those with communication support needs.

Many suggestions in this document are relevant for **all engagement** with patient/carer representatives, not just those living with the effects of a stroke.



## 1 Introduction

### 1.1 Voices Scotland



#### Hearty Voices (HVS)

Chest, Heart & Stroke Scotland has committed to using our expertise, contacts and experience to promote and facilitate patient and carer involvement in chest, heart and stroke services across Scotland. We have contact with many thousands of patients and carers in every locality and utilise our opportunities to represent and empower their voices wherever possible.



CHSS formed a partnership with the British Heart Foundation (BHF) in 2005 to bring the Hearty Voices training programme to Scotland. Hearty Voices Scotland provides one day training sessions for patients and carers in order to empower them to become meaningfully involved in the delivery of healthcare and service planning. The project also provides a register of interested patients and carers and newsletter; these can be utilised in connecting patient/carers representatives and the organisations and bodies seeking consultation.

To date HVS achievements are:

- Over 350 heart patients/carers across Scotland completed the HVS Training Day (around 500 including Taster Sessions).
- HVS Training has been undertaken in 12 NHS Board areas.
- Over 350 heart patients/carers are listed on the HVS Register.
- HVS has an established Steering Group led by heart patients and carers providing direction and recommendations to the project.
- HVS supports and in some areas established, Managed Clinical Networks (MCNs) Patient/Carer Involvement Groups across Scotland.
- HVS is endorsed as an example of best practice by the Scottish Health Council.
- A HVS National Conference was held in November 2007 – in partnership with the BHF and supported by the Scottish Health Council.

- The issues gathered in the HVS database were shared with the Scottish Government “Better Together” programme.



### Chest Voices

Based on the successful Hearty Voices Scotland Programme, Chest Voices aims to encourage patients and carers to work with the NHS to influence change across the respiratory services in Scotland. To date Chest Voices has worked with around 70 patients and carers, working through the Respiratory MCNs, British Lung Foundation Breathe Easy Groups and pulmonary rehabilitation classes.



Hearty Voices Scotland and Chest Voices have been a success from the beginning and the positive benefits to patients, carers and professionals have exceeded expectations. Mindful of our responsibilities across chest, heart and stroke, we have now applied the lessons learned and success of the training programmes to the field of stroke care.



### Stroke Voices

The aim of Stroke Voices has been to develop a robust and sustainable patient/carers involvement training package, applicable to all patients/carers with experience of stroke, to empower their voices in the development of stroke services across all 14 NHS Board areas throughout Scotland. This has the potential to facilitate the effective user involvement on Stroke Managed Clinical Networks (MCNs), Community Health Partnerships (CHP), Public Partnership Forums (PPF) and other NHS Groups and Bodies.

An association was made with Different Strokes who were represented on the Project Steering Group for the development of Stroke Voices.



Stroke Voices is a series of sessions over three days, tailored to the needs of people living with the effects of stroke and gives them the confidence and skills to get involved and have their voices heard within the NHS.

Stroke Voices participants can then act as a potential source for establishing stroke patient and carer subgroups/forums e.g. within MCNs.

Participants will also be able to join a register of interested users of NHS services to allow consultation on issues arising in future.

A database of issues and concerns arising during the Stroke Voices training and taster sessions is being kept and used to feedback to the relevant stakeholders.

For more information on the Stroke Voices pilots and all available Voices Scotland training contact our Voices Scotland Lead:

[voicesscotland@chss.org.uk](mailto:voicesscotland@chss.org.uk)

## 2 Principles and Models of Engagement

### 2.1 Good practice in public engagement

These **Communication Support Principles** below from Communication Forum Scotland work alongside recognised good practice in community engagement. The Stroke Voices Project was based on these principles. Regularly review your participation methods and establish what works and what does not work.

#### **Involve people from the start of the process**

This encourages working in partnership. It means that participants will not feel the decision has already been made without their involvement.

#### **Work at a pace that suits both you and your participants**

You should allow enough time for participants to consider issues properly.

#### **Provide information that is clear, timely and accessible**

If you don't allow people enough time to take in the information, you are effectively excluding them from the participation process.

#### **Provide a range of ways to take part.**

Not everyone can or wants to get involved at the same level or in the same way. Provide a range of participation methods. By doing this, you will increase the opportunities for people to get involved in a way that suits them.

#### **Provide support to increase the opportunity of involvement**

As well as communication support needs, participants may require, for example, child care or help with transport.

#### **Always provide participants with feedback and outcomes**

It is very important that participants receive clear feedback. There is nothing worse than giving up your time, then not hearing what has happened. If people receive feedback they will be more motivated to get involved next time.

## 2.2 Stroke Voices Principles of Engagement

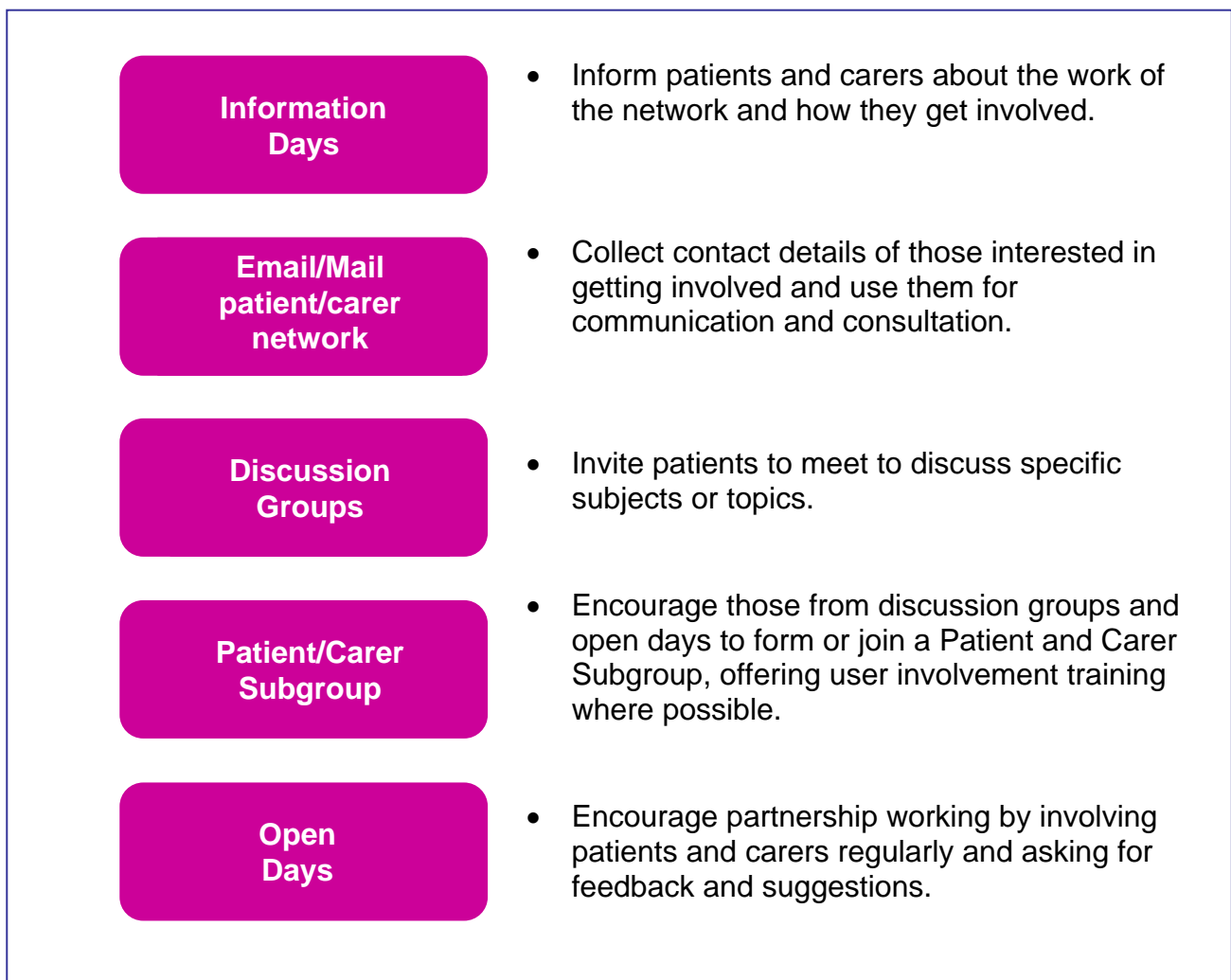
Throughout the Stroke Voices Project the Voices Scotland team learned valuable lessons through the pilots which led to the development of the full Stroke Voices programme. These have been summarised in the following Principles of Engagement.

1. **Understand** how the stroke has affected the individual representative.  
Remember that its effects may be hidden.
2. **Ask** the representative what is required for them to be effectively involved.
3. **Match** the representative's needs with accessible resources and support. If this does not succeed at first; keep trying!
4. **Support** the representative throughout their involvement; not just at meetings.
5. **Effective engagement** takes time – be prepared to take this time!

## 2.3 The Mutual Managed Clinical Network (MCN)

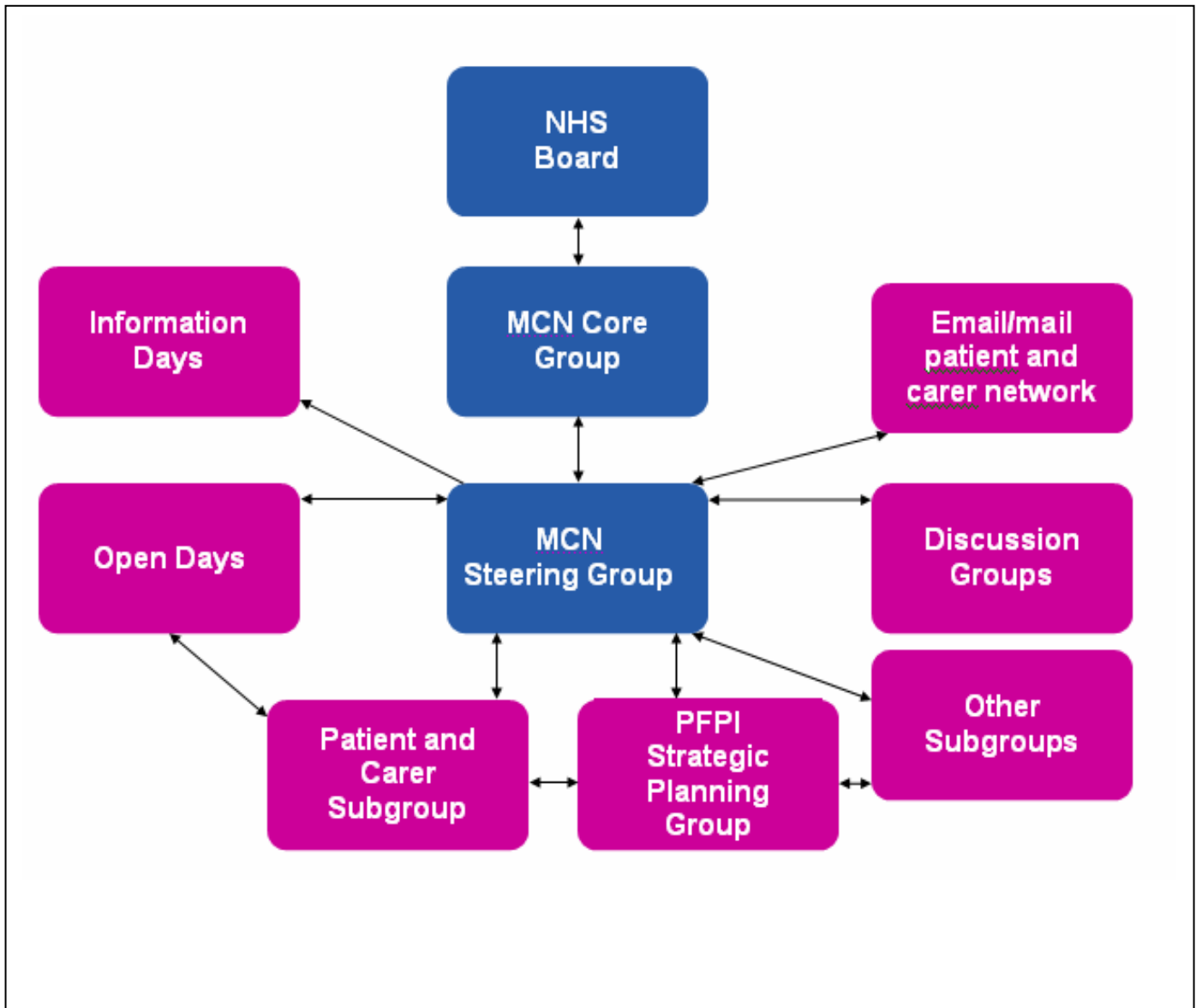
The Voices Scotland team has worked with MCNs across Scotland in respiratory, cardiac, stroke and paediatric services. This has allowed the team to observe various approaches to an MCN's public involvement. The following models have been developed to assist managers to develop their structure within the network to maximise the opportunities to involve the public. These models can be applied to other NHS bodies seeking to embed public involvement into their structure.

### 2.3.1 A Mutual MCN: Pathway to a mutual MCN



### 2.3.2 The Mutual MCN

*Developed by Chest Heart & Stroke Scotland in association with NHS Greater*

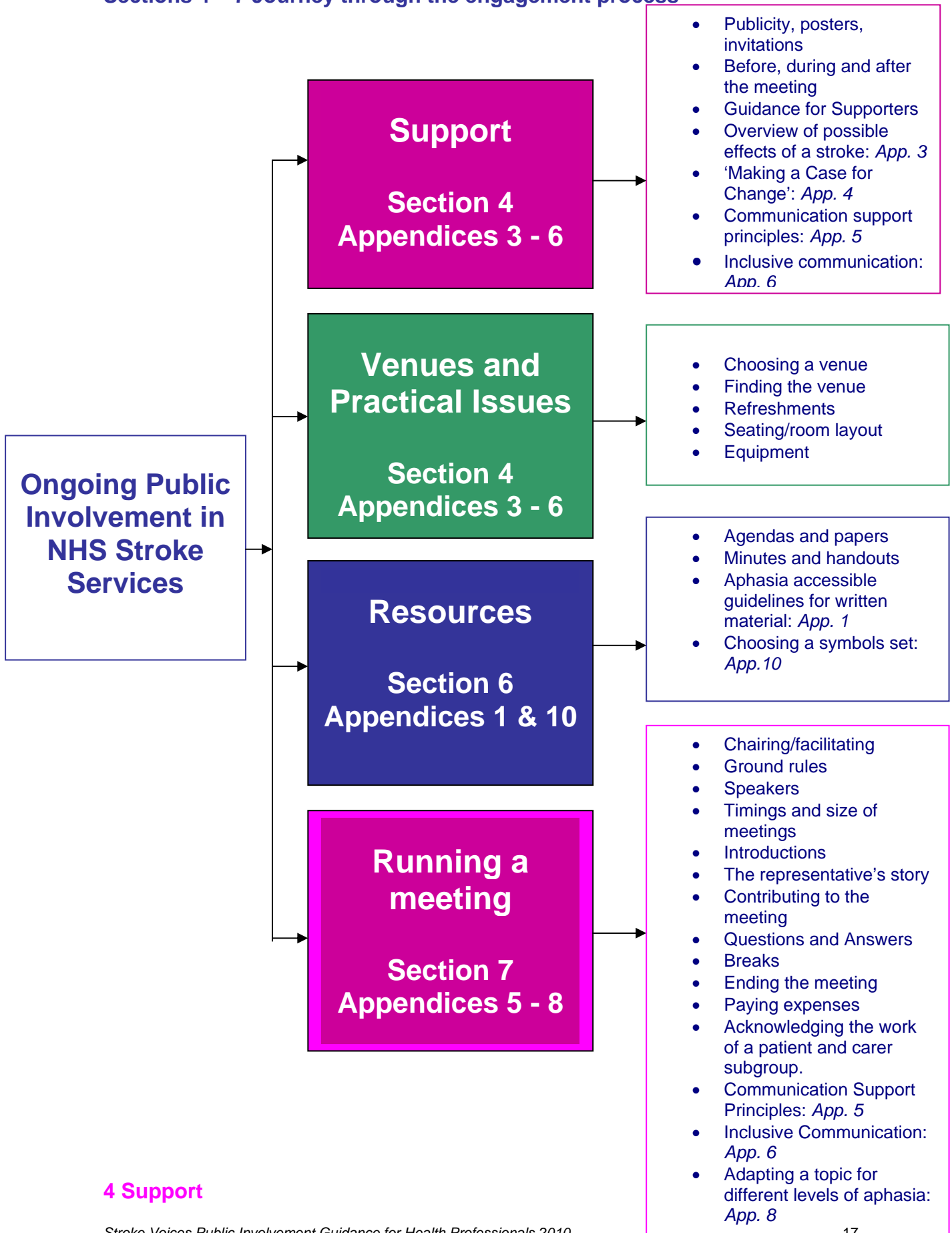


### 3. Inviting Stroke Voices to a Managed Clinical Network (MCN)

The best way to enhance your public involvement programme is to invite the Voices Scotland team to come to deliver the Stroke Voices workshops. All Voices Scotland training and resources are free, although the host is expected to cover venue and refreshment costs and participants' expenses. The following is a checklist for managers for tracking this process of setting up the workshops with the Voices Scotland team.

Preparing for Stroke Voices (SV) workshops for MCN Managers			✓
1	First contact with SV team	<ul style="list-style-type: none"> <li>Do you have user involvement opportunities for SV participants to do after the course?</li> <li>Do you have someone who can deliver a presentation on your MCN at the last session?</li> <li>Do you plan to use an NHS Venue?</li> <li>Do you plan to use NHS catering? (see Section 5.3)</li> <li>Provide SV team with an accessible expenses form for participants to use (see Appendix 1: <i>Accessible Guidelines for written material</i>)</li> </ul>	
2	Practical considerations	<ul style="list-style-type: none"> <li>Do you have a venue in mind? Is it booked?</li> <li>Is it suitable for the course?</li> <li>Venue accessibility checklist (see Section 5.1)</li> </ul>	
3	Invitations	<ul style="list-style-type: none"> <li>Who do you want to invite to Stroke Voices?               <ul style="list-style-type: none"> <li>Give this information to the SV team who will send out invitations</li> <li>SV team will deliver Taster Sessions for any local groups of potential participants</li> </ul> </li> </ul>	
4	Support	<ul style="list-style-type: none"> <li>Work with the SV trainer to identify those participants who will need support on the training (see Section 4).</li> <li>Help identify sources of support (see Section 4)</li> </ul>	
5	Prepare local NHS presentation	<ul style="list-style-type: none"> <li>Obtain guidance from the SV team on the local perspective session.</li> </ul>	
6	Provide local NHS documents	<ul style="list-style-type: none"> <li>Provide SV team with any local documents relevant to stroke services</li> </ul>	
7	Ongoing involvement	<ul style="list-style-type: none"> <li>See Section 4 on how to continue to support those course participants who wish to become involved with your MCN</li> </ul>	

Sections 4 – 7 Journey through the engagement process



4 Support

## Support

Publicity, posters and invitations.....4.1

Support before a meeting .....4.2

Support during a meeting .....4.3

Support after a meeting.....4.4

**Appendix 3:** Overview of possible effects of a stroke

**Appendix 5 :** Communication Support Principles

**Appendix 6 :** Inclusive communication

## 4.1. Publicity

### 4.1.1 Posters

- Brief the design team on good practice for targeting an audience that may have communication support needs. (see Appendix 1: Accessible Guidelines for written material)
- Keep key information very clearly presented with a good contrast of background/foreground e.g. white or buff background and black writing
- Contact information should be clear and offer a variety of methods of communication e.g. email, phone, letter...
- All images should support communication especially:
  - Picture of venue
  - Time; present as a clock and in 12 hour format
  - Date; present as a calendar
  - Purpose of meeting; choose an appropriate symbol

This helps make the posters eye catching for all and not just those with communication support needs. Take care when using a design image that it is consistent with your intended message

An aphasia accessible poster template and symbol bank is available to download through the Communication Forum Scotland website at:

[www.communicationforumscotland.org.uk/2010/TK\\_Resources\\_Templates.php](http://www.communicationforumscotland.org.uk/2010/TK_Resources_Templates.php)

See also Appendix 1: Accessible guidelines for written material

## 4.1.2 Invitations

Invitations to the public to a meeting should include:

Top of the letter in bold

- **Time**
- **Day and date**
- **Location**
- **Name of meeting**

Body of the letter

- Options for transport to venue
- Offer of support to meeting
- Details of contact person for enquiries and confirmation; variety of communication methods available
- Details on claiming expenses
- What refreshments are provided
- Relevant papers enclosed
- How they would like to be contacted in the future.

Different people will prefer to be contacted in different ways e.g. telephone calls can be quick but not everyone finds them easy.

- Provide a checklist of options on how a stroke has affected the representative
- Ask how long it has been since the representative has been through the NHS stroke services.
- Template for this available on Appendix 2 as part of the Stroke Voices Booking Form

For format advice see Appendix 1: *Accessible guidelines for written material.*

## 4. 2 Support before a meeting

Effective and appropriate support before the meeting can eliminate many potential misunderstandings.

You may need to match the representative with a specific Supporter who can:

- Understand any specific impairments that the representative has following their stroke whether hidden or visible.  
(See Appendix 3: *Overview of possible effects of a stroke*)
- Before to getting involved with a particular committee you might like to ask the representative to observe the proceedings or shadow another representative to give them more confidence before they commit themselves to the role.
- Offer to contact the representative before the meeting (by their preferred method of contact).
- Go over the topics for discussion and offer any support required.
- Discuss with participants whether they want to attend whole meetings or just relevant sections; this may be helpful for people who suffer from fatigue after their stroke which is very common.
- Offer to escort the representative into the meeting if they would feel more comfortable with this support.
- Explain to the representative the NHS services locally if they are different from their experience. The representative may have different perceptions of services if they are from a rural area for example.
- Help the representative prepare their issue that they might want to bring up at a meeting.
- Encourage them to use the 'Making a Case for Change' Template  
(See 4.2.2 and Appendix 4: *'Making your Case for Change' Template*)
- Offer travel expenses for the person's Supporter of choice if they wish them to attend. Do not assume someone wishes to be accompanied.

### 4.3 Support during a meeting

#### Communication Support Needs

Communication Forum Scotland defines Communication Support Needs as any individual who requires support with one or more of the following:

- Understanding (verbal or written information)
- Expressing themselves
- Interacting with others

See also Appendix 3: *Overview of possible effects of a stroke*

People who have had a stroke may have communication support needs. They may or may not require specialist equipment or support. They may just need more time. When you decide to involve people think about what you can offer. Can you meet an individual's communication support needs should they have any? If you cannot, the meeting may not be a positive experience for a person who:

- needs extra time to understand what is said or to express themselves
- can only concentrate for short periods.

For an extensive list of the effect of stroke to understand why this might be necessary see Appendix 3: *Overview of possible effects of a stroke*.

To understand how aphasia can affect someone see the Stroke Training and Awareness Resources (**STARS**) website Communication section which includes video clips of patients explaining their experience of aphasia:

[www.strokecorecompetencies.org](http://www.strokecorecompetencies.org)

For representatives with communication support needs it is helpful if a

Supporter:

- is trained in supported communication techniques if required. Most Speech and Language Departments are able to provide training and advice in supported communication. CHSS also has expertise available in supported communication techniques.
- follows the Communication Support Principles of Communication Forum Scotland (see Appendix 5) and Inclusive Communication (Appendix 6)
- does not have their own agenda at the meeting
- is given a copy of **Stroke Voices Supporters' Guidance** (4.3.1) and handouts below
- finds out how the representative would best like to communicate generally and during the meeting
- invites them to fill out the Communication Support Checklist (Appendix 2: *Stroke Voices Booking Form*)
- sits beside the representative at the meeting
- has access to pen and paper

For handouts see the CHSS website: [www.chss.org.uk](http://www.chss.org.uk), Stroke Voices subsection of the Voices Scotland section

- Communication Breakdown
- Communication Support Strategies
- Helping Communication After A Stroke: Factsheet F5

### 4.3.1 Stroke Voices Supporters' Guidance

This template is used on Stroke Voices and offered to those who are going to support participants. It can be offered to those Supporters who will subsequently support these representatives at an NHS meeting.

## Stroke Voices Supporters' Guidance

Thank you for offering to help support the participants at NHS meetings. This will support them to have their say and their voices heard in the local NHS stroke services.

- **Your role is *vital* to help the participant follow the meeting. Your role can be compared to an interpreter.**
- The NHS will be able to provide you with information about how the stroke has affected the representative you have been asked to assist. You will be given information, about the person's strengths and weakness, in terms of their communication and will be told what communication strategies they find useful/use.
- Make the participant feel at ease so that they feel able to admit if they are not following what is going on and seek your help. Always be aware of the body language of your participants to pick up cues as to whether they are following the day. Feel free to clarify points during the meeting with the speakers yourself.

This might mean you need to:

- Recap after each session to cover the key points.
- Write down key words to support what you or a speaker is saying
- Tick or cross out subjects on the agenda to follow the meeting
- Write key words to summarise what is being said and get agreement
- Use drawings to illustrate the points being made in the discussion
- Make eye contact so the listener knows you are engaged
- Use clear, simple language
- Adjust the tone and rate of your voice
- Use gesture
- Be prepared to do some lateral thinking!

If you feel the person needs other props or larger print of the slides or handouts for other meetings, tell your NHS contact

The following handouts are available on the Chest Heart & Stroke website:

[www.chss.org.uk](http://www.chss.org.uk)

- Communication Breakdown
- Communication Support Strategies
- Helping Communication After A Stroke Factsheet F5

### 4.3.2 Preparing a “Case for Change”

Stroke Voices demonstrates how delegates can use the Case for Change template, first developed as part of the Hearty Voices Scotland training, to present their issues in evidence based, succinct format. Through completion of the template, representatives are encouraged to take a structured methodical approach, researching their chosen issue and quoting from relevant local and national NHS documents. They are then encouraged to present this to their local MCN/health professionals. As a result of the research undertaken and the evidence presented in the Case for Change, the local NHS management are more likely to take the issue forward on their behalf.

The questions are from Appendix 4: *‘Making your Case for Change’ Template.*

- What is the issue?
- How do you know the problem exists?  
What is your evidence?
- What has been the patient/carer experience?
- How has the problem affected NHS staff?
- What are the national guidelines saying on the subject?  
(Strategies, reports, recommendations)
- What are the local guidelines saying on the subject?  
(Strategies, reports, recommendations)
- How exactly do you want things to change?

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Additional resources available when 'Making a Case for Change':

- Access to **national NHS guidelines** is available from the CHSS website in the Voices Scotland section of the website: [www.chss.org.uk](http://www.chss.org.uk) under "Useful documents".
  - Accessible versions of documents are very often available from the Scottish Government.
  - **Local guidelines** are usually available on the NHS board's website.
  - Useful **Stroke Documents** are available from the CHSS website in the Education and Training/Study Resources section of the website: [www.chss.org.uk](http://www.chss.org.uk)
- The template for "Making your Case for Change" can be found in Appendix 4

#### 4.4 After a meeting

- Offer support or someone to support the representative to explain what went on at the meeting or if there is follow-up work from the meeting.
- Ask participants at the beginning how they want to be contacted e.g. email, phone, letter... Always use this means of contact.
- If you make an arrangement verbally, offer to confirm it in writing. For example not everyone will be able to write details down during a telephone conversation.
- Follow up those who have not arrived. This helps representatives feel included and lets you find out if there was anything else you could have done to enable their attendance.
- If someone wants to leave the group it is important to have an informal exit interview with them to find out how they found their experience and what necessary improvements could be made for others.
- When a representative leaves a group, send a letter of thanks for the time and work they have put in to the involvement process.
- It is often appropriate to have a time limit on how long representatives sit on the group and refresh the membership from time to time to keep issues current. This should be explained from the start.

5 Venues and other practical issues

## Venues and Practical Issues

- Choosing a venue.....5.1
  - Venue Accessibility Checklist
- Venue Directions.....5.2
- Refreshments.....5.3
- Seating/room layout.....5.4
- Equipment .....5.5

## 5.1 Choosing a venue

Accessibility is about **more than physical accessibility**, it is also about having a venue accessible to those with communication support needs when required.

“Update” has an Access Guide giving details of the measurements and layout of building fixtures and fittings in order to make access easier for disabled people with mobility issues. This can be found at:

[www.update.org.uk/a/documents/TheAccessGuide.pdf](http://www.update.org.uk/a/documents/TheAccessGuide.pdf)

## Venue Accessibility Checklist

- **Transport:** Is the venue accessible via public transport?
- **Parking:** Is parking available? It is good practice to offer to reserve a disabled parking bay if the individual has a Blue Badge. Provide aphasia accessible directions to venue prior to meeting (see Appendix 1: Accessible guidelines for written material).
- **Access:** Provide a ground floor meeting room or check access via a lift.
- **Toilets:** Are the disabled toilets near the meeting room? Does the toilet have enough room for someone in a wheelchair to turn round and lock it from the inside independently?
- **Signage:** Is there good signage to the toilets and the meeting room? Use signs which have the word and visual image. Not only language based signs but signs should include images as well. This may need to be supplemented from what is already provided in the venue. Alternatively meet people at reception and bring them to meeting room. Advise those at reception that participants may be wheelchair users or have communication support needs which it would be helpful if they were aware of.
- **Lighting:** Is there good lighting in all areas of the room? This will allow those with some visual impairment to view presentations.
- **Acoustics:** Are there good acoustics? Check noise levels of activities in adjacent rooms at the times for your meeting. Choose a venue with a loop system or hire one in as is necessary.
- **Distractions:** Do the windows open? If so, will the outside noise be distracting?
- **Seating:** Do the chairs in the meeting rooms have arms? This allows people to remain independent in getting in and out of a chair if they have a one-sided weakness (hemiplegia).
- **Breakout Rooms:** Are there breakout rooms available if small group work is necessary in the meeting? This will allow people to discuss topics together without being distracted by other groups. These can also be offered as a rest room for “time out” if someone requires it.
- **Consistency:** Where possible, keep the venue and room consistent for future meetings.

### 5.2 Venue Directions

- Some people will find it helpful to have a reminder of the meeting arrangements near the time. Last minute changes of time or venue can be unsettling for transport planning. This may put some people off attending.
- Provide directions to your venue in the letter (including a photo of the venue if possible) which should be aphasia accessible (see guidelines in Appendix 1 *Aphasia accessible guidelines for written material*)
- If the representative is to be given a lift to the group, is the driver insured to do so? (Business Class insurance does not usually cost any more and just requires you to notify your insurance company that you will be using your car for 'business purposes')
- Brief reception staff to recognise any communication support/accessibility needs of your representatives.

### 5.3 Refreshments

Refreshments need to be easy to access for those with a one sided weakness (hemiplegia), in a wheelchair or using a stick.

- A coffee jar or sugar bowl and a spoon are easiest to cope with and allow the representative to keep their independence to serve themselves. Try and avoid the use of small packets as they are difficult to open with one hand.
- Help with the use of coffee machines as these are very difficult for those with only one functional arm to access.
- Serve lunch in a room with tables and chairs which have arms if possible. These chairs are easier for those with a one sided weakness to get out of themselves.

- Tactfully provide assistance to those who need it with their refreshments.
- External noise can be distracting to people with communication support needs. Brief caterers to reduce noise if they are preparing/laying out food whilst the meeting is going on.

#### 5.4 Seating/room layout

- Plan the seating arrangements for the meeting keeping the representative's disability in mind, with particular attention to those with visual, hearing and inattention problems.
- Sit representatives next to the person who is taking on the supporting role during the meeting and in clear view of the meeting Chair.
- Ensure clear path from the entrance to the allocated seat for representatives with mobility problems.

#### 5.5 Equipment

You should have the information on equipment required from the feedback to your initial invitations (see Appendix 6: *Inclusive Communication*).

Possible equipment required (not an exhaustive list)

- :Pen and paper
- Magnifiers for sight problems
- Portable hearing loops. These can be hired for one off events. There is no need to run a wire round a room if the loop is just needed for one individual. Portable loop systems can be worn round the neck of the individual and the speaker wears a microphone or it is placed on a table in the middle of a group of people.
- Pen holders for motor problems (e.g. Easy Grips)
- Page turners
- Card for using as a reading guide for someone to move down the page one line at a time.

**Make sure someone knows how to use any equipment and has tested it before the meeting starts.**

For those with communication support needs resources could be:

- Their own communication book
- Conversation Support Book: available from CHSS Health Information Department: 0131 225 2963 or from the Advice Line 0845 077 6000 or at [www.chss.org.uk](http://www.chss.org.uk)
- Diaries: to point at a date easily
- Maps: to point at an area of the country easily
- Pens and paper
- Flip chart

**Disabled Living Foundation**  
 can provide names of manufacturers and suppliers of all disability equipment. Some suppliers will hire out equipment on a one off basis.  
 Helpline: 0845 130 9177;  
[www.dlf.org.uk](http://www.dlf.org.uk);  
[helpline@dlf.org.uk](mailto:helpline@dlf.org.uk)

## 6 Resources

<h1>Resources</h1>	
• Agendas and paper.....	6.1
• Minutes and handouts.....	6.2



## 6.1 Agendas and papers

An **aphasia accessible template for agendas and information documents** to download is available through the Communication Forum Scotland website at:

[www.communicationforumscotland.org.uk/2010/TK\\_Resources\\_Templates.php](http://www.communicationforumscotland.org.uk/2010/TK_Resources_Templates.php)

- Follow basic good practice in all printed and electronic information (see Appendix 1: *Accessible guidelines for written material*). This will make it easier for everyone.
- You may like to develop your own templates. If you do, ask for feedback on their effectiveness.
- Explain abbreviations and any technical terms you use. If these are to be used regularly, put them in a suitable format that people can refer to easily, for example as an appendix to your papers. Accessible information is not just about the format but about the content as well.
- Know the needs of your representatives. Some people with a visual impairment may need a larger font – adapt their papers accordingly or provide a magnifying device.
- Circulate papers prior to meetings wherever possible. If any papers are circulated at the meeting, give people time to take in the information; a summary may be helpful. It is not always possible for everyone to take in information supplied at the last minute. This will affect the way they can take part in discussion.

Send out agendas and papers in plenty time.

- One or two weeks beforehand.

Use different colours of paper for different documents to allow those with aphasia to be able to differentiate quickly between papers:

- use light coloured paper
- 14 point black
- Arial font
- 1.5 line spacing

A **Glossary of Terms** (F28) is free to your representatives; ordered on line from CHSS: [www.chss.org.uk](http://www.chss.org.uk) or ordered from the CHSS Health Information Department by phone 0131 225 6963 or the Advice Line 0845 077 6000.

The complete Glossary is also available on line at: [www.chss.org.uk](http://www.chss.org.uk)

Topics covered are:

- General Medical
- Medical Abbreviations
- Chest Terms
- Heart Terms
- Stroke Terms
- Organisational Terms
- Financial Terms
- NHS Staff Terms

## 6.2 Minutes and handouts

**Accessible minutes and information document templates** are available to download on the Communication Forum Scotland website:

[www.communicationforumscotland.org.uk/2010/TK\\_Resources\\_Templates.php](http://www.communicationforumscotland.org.uk/2010/TK_Resources_Templates.php)

- Representatives need time to assimilate papers so avoid wherever possible bringing new papers along to the meeting.
- Colour coding different papers will help everyone to distinguish between the papers and allow quicker access to them during the meeting.
- Consider putting previous minutes up on an overhead projector or on PowerPoint.
- For written minutes, keep them in a consistent format (see Appendix 1: *Accessible guidelines for written material*). This makes it easier for people to understand and they can become familiar with what to look for.
- Send the minutes out promptly to help people remember what went on at the meeting and to plan for the next meeting. Clearly identify any questions and action point that are to be addressed at the next meeting and who is responsible for them.
- Remember that badly formatted documents in 24 point are no more accessible than 10 point  
(See Appendix 1: *Accessible guidelines for written material*)
  
- Minutes can be posted on the appropriate NHS website for easy public

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access; however remember that not everyone has internet access.

- Any NHS websites should comply with the Government's own guidelines on accessibility for public sector websites. The Central Office of Information (COI) has issued guidance on behalf of the government on web standards and guidelines. These are available at [www.coi.gov.uk/index.php](http://www.coi.gov.uk/index.php). The purpose of the COI web standards and guidelines is to ensure a high quality and consistent user experience of the public sector online. In particular for people that have a visual impairment, the guidelines will allow a website user to browse a website successfully with a screen reader which will read the site out aloud to the user. CHSS' own website complies with the Web Content Accessibility Guidelines (WCAG) from the Web Accessibility Initiative (WAI). It also has the facility to have the site read out to the reader without access to a screen reader.

7 Running a meeting

## Running a meeting

### Good practice points for *any meeting*

- Chairing/facilitating.....7.1
- Ground rules.....7.2
- Introductions.....7.3
- Speakers.....7.4
- Timings and size of meetings.....7.5
- The representative’s story.....7.6
- Contributing to the meeting.....7.7
  - “stop” and “slow down” cards.....7.7.1 - 2
- Questions and Answers.....7.8
- Breaks.....7.9
- Ending the meeting.....7.10
- Paying expenses.....7.11
- Acknowledging the work of a patient and carer subgroup .....7.12

Appendix 5: Communication Support Principles

Appendix 6: Inclusive Communication

Appendix 7: Ground rules for meetings

Appendix 8: Adapting a topic for different levels of aphasia

Appendix 9: Accessible PowerPoint presentations

## 7.1 Chairing and facilitating

Listen to Lindsay who has aphasia on the Communication Forum Scotland website.

She explains what makes a meeting easier to follow for those with aphasia.

[www.communicationforumscotland.org.uk/2010/TK\\_Needs\\_Audio\\_Lindsay.php](http://www.communicationforumscotland.org.uk/2010/TK_Needs_Audio_Lindsay.php)

- Coordinating, chairing and facilitating good engagement at a patient and carers' subgroup or professional meeting involving stroke representatives **takes time**. The more members of the public involved, the more time this will take. It helps if this is understood from the start by the Chair and not taken on in haste for those who do not have the time to do it well. Some NHS boards offer training in chairing meetings.
- A friendly welcome is important before the meeting starts, to set representatives at ease.
- Create a slower and welcoming atmosphere to allow the representative to feel like an equal participant. It may be appropriate to offer to chair a patient sub group jointly with a representative. This role can rotate round the group. Use the Communication Forum Scotland's Communication Support Principles (see Appendix 5).
- Adopt Ground rules for the meetings  
(See Section 7.2 and Appendix 7: *Ground Rules for Meetings*).
- Agree how everyone is going to show they want to make a point from the start. (see Section 7.7: Contributing to a meeting)
- It is important to understand any specific challenges that the

representative has following their stroke whether hidden or visible (see Appendix 3: *Overview of possible effects of a stroke*) and for those with communication needs refer to Appendix 8: *Adapting a topic for different levels of severity of aphasia*. This will enable everyone to communicate to the best of their abilities.

- Be concrete in your language; avoid sarcasm, metaphors and abstract humour as this may not be understood.
- Keep distractions to a minimum e.g. interruptions, conversations off side, activities outside the room.

## 7.2 Ground Rules

Agreeing ground rules for meetings is good practice. For someone with communication support needs adopting and implementing them can make the difference between being able to participate or being excluded.

Ground Rules template examples are available in Appendix 7

## 7.3 Introductions

- Putting representatives at their ease when they arrive is most important. It can be quite daunting arriving at a meeting with professionals especially for the first time.
- People often lack confidence because of their disability so you might offer an escort from the front door if they would prefer this.
- Name cards propped in front of each member reinforces the names for those that only meet up occasionally and do not see members of the

group in between meetings. Put the names on *both sides* of the card to allow people that are sitting beside each other and those opposite each other to read the cards.

- Consider different ways of people introducing themselves. A verbal introduction is not easy for those with communication support needs. You might need to use the name cards to point to or a map to point to say where they have come from. This may only be needed in the first instance until people relax. Some people may need to prepare before introducing themselves.
- If people arrive late to the meeting, introduce them to everyone. This should include the role that each person is representing on the group.
- Using first name terms for everyone will put people more at their ease.

#### 7.4 Speakers

It may be helpful to brief speakers on the following good communication practice for their verbal and PowerPoint presentations:

- Appendix 9: *Accessible PowerPoint presentations*
- Appendix 1: *Accessible guidelines for written material*
- Appendix 5: *Communication Support Principles*

Speakers should be asked in advance to avoid jargon and abbreviations; if they are used the Chair should ask them to explain any or technical terms.

#### 7.5 Timings and size of meetings

Be aware how far the representative has had to travel to the meeting and how tired they may be because of the travelling time.

- Keep meetings fairly short.

- 
- Aim for meetings to last ideally one hour with one break and no longer than an hour and a half with two breaks. During Stroke Voices workshops a break was offered every 20 – 30 minutes.
  - Keep the agenda short; it is better to meet more frequently for a shorter time.
  - Meet in the mornings if possible; people who have had a stroke could be tired by the afternoon and not able to follow the meeting as well.
  - Keep to the time allocated for the meeting.
  - Keep the group size as small as is appropriate. In our experience, around 10 members are enough if the group has people with communication support needs. Some people find a large group more intimidating and find it more difficult to follow and contribute.

## 7.6 The representative's story and the Emotional Touchpoints Tool

It is most important to give the representative the chance for others to hear their story. The following technique is particularly effective as it:

- gets to the heart of the issue that the representative is concerned with

quickly

- the representative feels heard

### Emotional Touchpoints Technique

Representatives are invited to engage with the NHS because they have a valuable personal experience to contribute.

To help them share their experience, ask them to identify their overriding emotion about their story when a group is brought together first.

Invite them to offer a brief phrase or two about what event was behind this emotion; this can quickly get to the issue that is most important to the representative and subsequently they feel heard.

It is when representatives do not feel heard that they may keep going back to their story during a meeting.

For more information on this technique contact the Voices Scotland team: [voicesscotland@chss.org.uk](mailto:voicesscotland@chss.org.uk)

## 7.7 Contributing to the meeting

Agree how everyone is going to show they want to make a point from the start.

Different people will be comfortable with different methods. Here are some suggested methods:

- Ask people to hold up their hands to slow or stop the meeting
- Give participants access to a red card to hold up to stop the chair or another speaker.
- Offer the use of a yellow card to slow someone down.

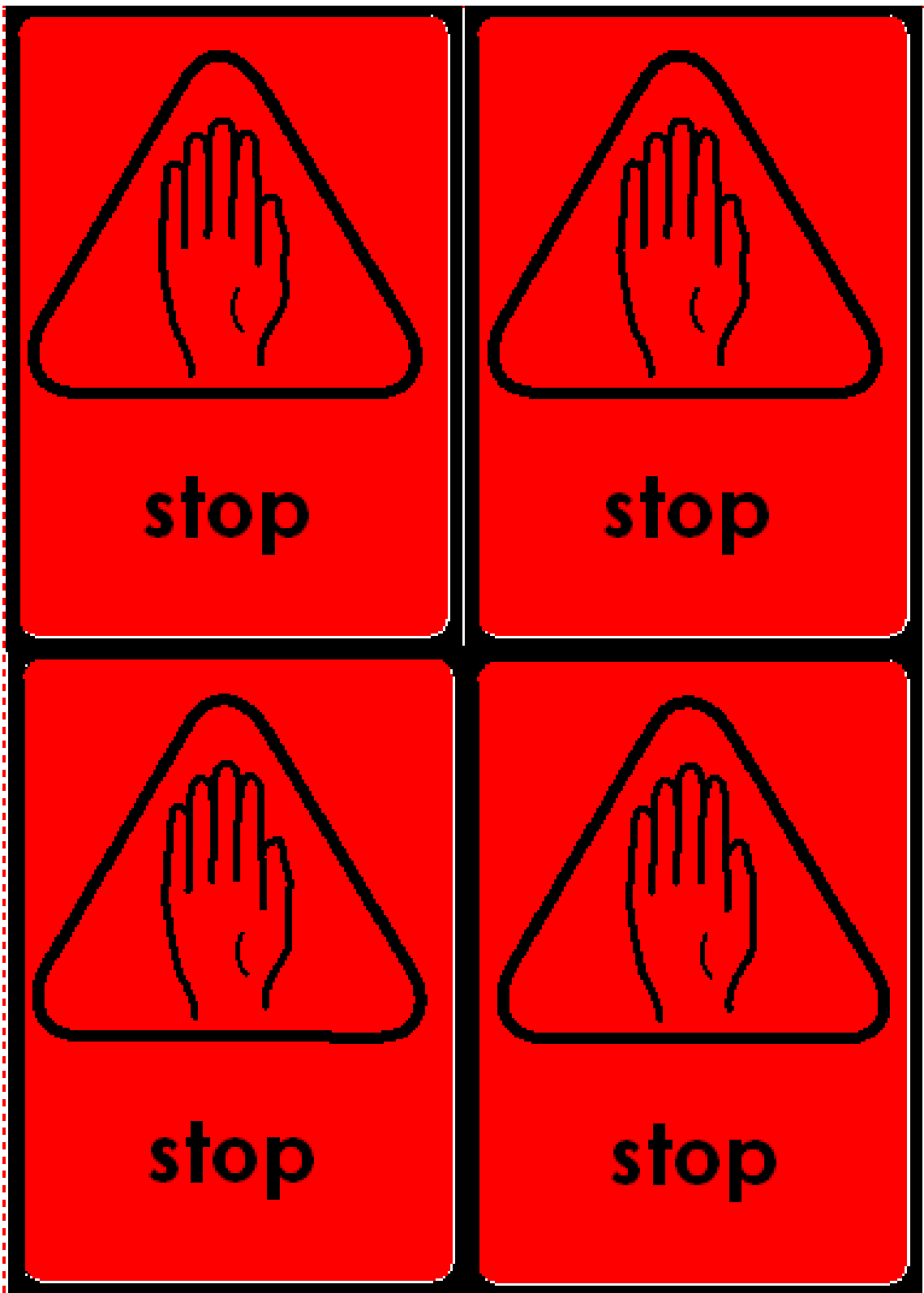
(Templates available in section 7.7.1 and 7.7.2 to copy, cut and laminate)

- Make a clear distinction between topics and recap after each topic.
- Give people “thinking time” and don’t interrupt or finish their sentences for them. You may need to repeat your points to them. If problems arise with someone not following the meeting they may not come back to the group.
- Giving the representative someone to sit beside them to help them follow what is going on will give them more confidence. The Supporter may need to write down key words or phrases during the meeting to assist the person to follow the meeting better and therefore contribute more and appropriately See Section 4.3: Stroke Voices Supporters’ Guidance.
- Try to adapt the style of the meeting to help them as much as possible to feel included. Representatives have a great deal to offer to contribute to the meeting so it is important that they feel heard in the most effective manner.
- **Politely stopping someone.** Occasionally some people have difficulty

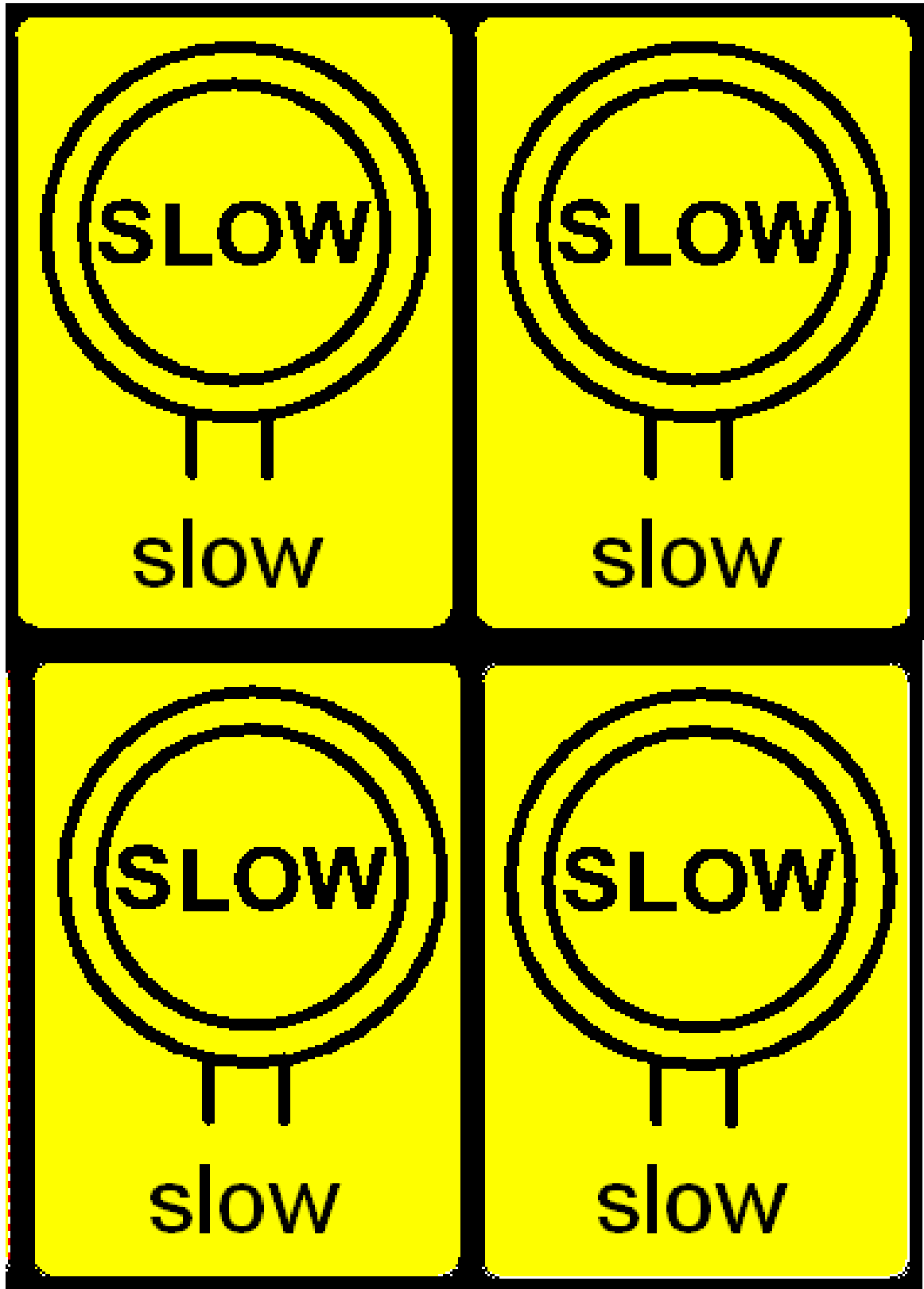
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with their ability to know when to stop talking (a communication problem where it affects a person's ability to take turns in conversation and/or realise when they have spoken at length on topic), see Appendix 3: *Overview of possible effects of a stroke*). If you already know this, you can agree with the person beforehand that you will hold up your hand or hold up a red card to ask them to stop when they have already made their point.

7.7.1 Stop ✂



7.7.2 Slow down ✂



## 7.8 Questions and Answers

- Agree in advance how people will ask questions.
- Make sure everyone can take part.
- Give people enough time to ask questions and respond. If the meeting feels rushed someone with communication support needs may be reluctant to ask a question.
- Encourage the use of red cards to stop or yellow cards to slow the meeting down (or raising a hand) as available at 7.7.1 and 7.7.2
- If someone has not been contributing, offer them a chance to comment by bringing them into the conversation. This should be done sensitively as some people with communication support needs may feel put on the spot.
- For some people with communication support needs, closed questions may be simpler. These are questions which only require a yes/no answer.
- Make eye contact and speak slowly if necessary in shorter sentences. Facial expressions are very important to make sure the representative is able to see everyone (See Appendix 6: *Inclusive Communication*). Again this needs to be done sensitively or this might come over as being patronising.

## 7.9 Breaks

Representatives often find that they have difficulty concentrating and get easily tired.

- Allow time for frequent breaks and encourage the participants to go for their own breaks if they need to.
- Try not to go more than half an hour without offering a break.
- If the right atmosphere is created, the representatives will feel free to take their own breaks when they need them.

## 7.10 Ending the meeting

- Give participants the opportunity to raise further points before closing. End on a positive note and thank people for coming, making it clear that the meeting has ended.
- Speak to the representatives after the meeting to find out what their experience was and how things could be improved (if at all) for the next time.

## 7.11 Paying expenses

Develop an accessible expenses form; this will be easier for everyone to complete.

For advice see Appendix 1: *Aphasia accessible guidelines for written material*.

## 7.12 Acknowledging the work of a patient and carer subgroup

If appropriate to the remit of the group, you can acknowledge a specific achievement to the group as a whole. Submitting the group's achievements and a photo of the members together to the local NHS newsletter or website can be a way of valuing the group's work and promoting it to a wider audience.

**Communication Forum Scotland** has a step by step guide for how to engage people with diverse communication support needs in public engagement activities such as:

- Regular special interest group meeting
- Information campaign
- Consultation survey
- Focus group
- Conference

[www.communicationforumscotland.org.uk/2010/TK\\_Engagement\\_Examples.php](http://www.communicationforumscotland.org.uk/2010/TK_Engagement_Examples.php)

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## Appendices

- Appendix 1 Accessible guidelines for written material
- Appendix 2 Stroke Voices Booking Form
- Appendix 3 Overview of possible effects of stroke
- Appendix 4 “Making your case for change” template
- Appendix 5 Communication Support Principles
- Appendix 6 Inclusive communication
- Appendix 7 Ground rules for meetings
- Appendix 8 Adapting a topic for different levels of severity of aphasia
- Appendix 9 Accessible PowerPoint
- Appendix 10 Choosing a symbol set: Picture communication symbols (PCS)

### **Appendix 1: Accessible guidelines for written material**

*This appendix is written in the format recommended by Mencap as a demonstration*

We have adapted (with permission) the principles for used in Mencap's "Make it clear" guidelines for easy read information for this project. They have been adapted to suit those who need aphasia accessible written materials. It is basic good practice to just have one version of your written material to be accessible to everyone.

## 1. The words you use

- Use common words that we use all the time.
- Use numerals for numbers not words. 23 instead of twenty three.
- Write in short, clear sentences. Just have 1 idea in every sentence.
- Use active verbs. Verbs are doing words. They describe what someone does.

For example:

John **loves** Mary, not Mary *is loved* by John

- Use full stops. Try not to use other punctuation.
- Use bullet points for examples and instructions.
- Do not use abbreviations. Use for example and do not, not e.g. and don't.

## 2. Where to put words on the page

- Keep everything about a subject on the same page.
- If you have to use more than 1 page for a subject, start each new page with more about whatever the subject is.
- Do not split words over 2 lines.
- Do not split sentences over 2 pages. If you can not finish a sentence on a page move the whole sentence to the next page.
- Use page numbers.
- Avoid columns they are confusing. It is easier to read straight across the page.
- On forms leave a lot of room for people to fill in their name, address and so on. It often helps people to have a box to write in rather than lines to write on.

### 3. How to use pictures and symbols

Visual images help everyone but the image must support the text and not just be a design tool. One picture should support one idea not each word.

- Be consistent. Use the same picture or symbols to mean the same thing in your document.
- Pictures/symbols on the left, words on the right because we read English from left to right.
- Do not float text on top of or across a picture/symbol.
- Show times with clocks. Times should be in 12 hour format.
- Maps are difficult to understand. Use pictures of places that people will recognise.
- Explain how to find the place in words as well as pictures/symbols.
- Charts are often difficult to understand. Try not to use them.
- Using a pretty picture on a poster or leaflet will not help if it does not make it clear what the information is about.

- There are different symbols systems available; see Appendix 10: *Choosing a Symbol Set* for the advantages and disadvantage of each system reviewed by the project. The project used mostly Widgit symbols with the occasional use of Boardmaker, clip art and photos. Symbols should be used consistently throughout your material and organisation.

#### 4 Choosing the type of writing and the paper

- Use a typeface that is clear like Arial.
- Text should be at least 14 point or bigger.
- Do not use underlining.
- Do not use UPPER CASE text should always be in lower case.
- Italics and block capitals change the shape of words and can make them harder to read for some people.
- Use **bold** to highlight important words or phrases. To check that this has been done correctly, read back the highlighted phrases, is the meaning correctly conveyed?
- Make sure headings are clear.
- Use 1.5 line spacing between lines.
- Make sure the writing stands out against the colour of the paper Buff paper with black writing is the clearest but pastel coloured papers with black text can help with distinguishing different papers without words.
- Green is not a good colour for paper. Words in white (reversed out text) on a coloured background can be much harder to read.
- If you are writing something with a lot of pages, think about using colour coding to make the different sections clear.
- Use the same colours in the index and the contents page, but remember not everyone can recognise colours.
- Shiny paper makes it harder to see the words and pictures because it reflects light. Use matt (uncoated) rather than shiny paper and use matt laminating pouches.


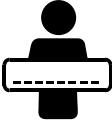

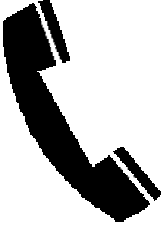



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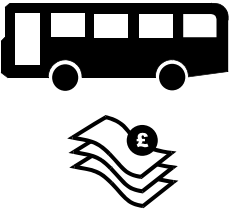

## 5 Making it easier for everyone to understand

- Information that you can read like a book is easier to follow than lots of sheets. Make your book A5 size or larger so it is easy to hold and turn the pages.

### **What would you rather read?**





- Something that is full of jargon jumps about from one topic to another and makes you work hard to find out what you really need to know or something that is clear, well structured with all the key points and information?



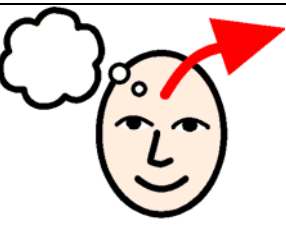


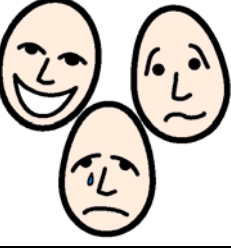
	<p><b>Chest Heart &amp; Stroke Scotland</b>  <b>Stroke Voices Booking Form</b></p>
	<p>Name</p>
	<p>Address:</p>
	<p>Home Telephone</p> <p>Mobile</p>
	<p>E-mail address:</p>
	<p>How do you <b>prefer</b> to be contacted?</p> <p>Post <input type="checkbox"/></p> <p>Phone <input type="checkbox"/></p> <p>Email <input type="checkbox"/></p>
	<p>I would like to <b>attend</b> the Stroke Voices workshops <input type="checkbox"/></p>
















	<p>How old are you? Please ✓</p> <p>20-30 <input type="checkbox"/> 30-40 <input type="checkbox"/> 40-50 <input type="checkbox"/></p> <p>50- 60 <input type="checkbox"/> 60-70 <input type="checkbox"/> 70-80 <input type="checkbox"/></p> <p>over 80 <input type="checkbox"/></p>
	<p>✓ The venue is accessible to wheelchair users <input type="checkbox"/></p> <p>Do you use one? <input type="checkbox"/></p>
	<p>✓ The lunch will be provided</p> <p>Do you have any <b>special diet needs</b>? <input type="checkbox"/></p>
	<p>Do you need a <b>loop system</b>? <input type="checkbox"/></p>
	<p>Details of <b>how to get to the venue will be forwarded on to you.</b></p> <p>You will be <b>reimbursed</b> for your travel by the NHS</p>
	<p><b>How long</b> is it since your <b>last stroke</b>?</p> <p>1 - 3 years <input type="checkbox"/></p> <p>3 - 5 years <input type="checkbox"/></p>








	More than 5 years <input type="checkbox"/>
--	--

Please put a tick in the boxes below if you have any additional requirements. ✓

	<p><b>Communication Support Needs</b></p> <p>I have communication support needs <input type="checkbox"/></p> <p>Please fill in the form below</p>
	<p><b>Parking</b></p> <p>I am a blue badge holder <input type="checkbox"/></p>
 <p>Support</p>	<p><b>Support Person</b></p> <p>I would like <b>support provided</b> <input type="checkbox"/></p> <p>I will be accompanied by</p> <p>Person's name:</p> <p>Contact phone number: </p>

 <b>How has the stroke affected you?</b>	
	Mobility How? <input type="checkbox"/>
	Memory/thinking How? <input type="checkbox"/>
	Sight How? <input type="checkbox"/>
	Communication How? <input type="checkbox"/>
	Emotions How? <input type="checkbox"/>
	Other – please state

<b>Communication Check List: It helps my understanding if.</b> ✓	
	use <b>every day words</b> and short sentences
	give me <b>time to understand</b>
	use <b>gestures</b> such as pointing
	<b>look at me</b> when they are talking to me
	use <b>pictures</b> , photographs or drawings of the things they are talking about
	use <b>written information</b> with pictures or photos
	record information
Aa	use <b>large print</b>
	Other – please list:
<b>It helps me to tell my views/story if people:</b> ✓	
	<b>give me time</b> and don't interrupt
	observe my <b>gestures</b> , facial expression and body language
	<b>ask questions</b> / make suggestions about what they think I am saying
	remember I can use <b>pictures</b> or photographs or <b>drawings</b>
	write down <b>key words</b> for me or I have a pen/paper
	remember I use my <b>communication board</b> , book or machine / aid
	Other – please list:

	<p>What do you feel you want to <b>get from these workshops?</b></p>
   	<p>An understanding of <b>how to get your views heard</b> in the NHS. <input type="checkbox"/></p> <p>An understanding of the effects of a <b>stroke</b>. <input type="checkbox"/></p> <p>An understanding of the <b>NHS structure</b>. <input type="checkbox"/></p> <p>Knowledge of what <b>resources to use to back up your argument</b>. <input type="checkbox"/></p> <p>Other: please state <input type="checkbox"/></p>
	<p>Please return in the <b>stamped address envelope:</b>          Voices Scotland          Chest Heart and Stroke Scotland          Third Floor          Rosebery House          9 Haymarket Terrace          Edinburgh EH12 5EZ</p> <p>0131 225 6963 </p>

## Appendix 3: Overview of possible effects of a stroke.

Remember the disability may well be hidden.

### Communication issues (aphasia/dysphasia)

- Dysarthria (difficulty in communicating due to weakness of the muscles used in speaking, speech is often slurred and unclear)
- Reading problems
- Writing problems
- Spelling problems
- Understanding problems
- Expressing problems
- Inability to pick up facial expressions and interpret them appropriately
- Gesture and interpretation of gesture – the inability to do this correctly
- Intonation; difficulty interpreting correctly
- Need time to think before speaking
- Difficulty with abstract humour and non literal expressions
- Difficulties with money and numbers

### Dyspraxia of speech

- Controlling speech organs
- Making speech sounds
- Word finding
- Forming words
- Breath control difficulties
- Feeding difficulties

### Ability to contribute to conversation or tell a story (discourse)

- Verbosity, over elaborate input
- Limited input
- Inability to stick to the topic
- Difficulty initiating conversation
- Poor turn taking
- Reduced sensitivity to the listener
- Poor eye contact
- Inability to pick up non verbal cues in conversations
- Reduced affect during conversations
- Missing the central point of a conversation

### Cognitive issues

- Poor problem solving ability
- Short and long term memory problems
- Concentration difficulties
- Short attention span
- Easily confused
- Poor orientation abilities (topographical orientation) – especially around a new area e.g. meeting room
- Inability to understand a subject as a whole - only able to concentrate on the details.
- May lack insight into own disabilities
- Pragmatics – literal thinkers
- Cognition – the person’s processing skills can be intact but dramatically reduced so patient will require longer and more repetition to grasp a concept

### Perceptual problems; poor ability to recognise

- Faces e.g. not recognising friends or spouse
- Depth and distance - inability to judge these correctly
- Textures - the inability to identify these correctly
- Temperature of objects - the inability to identify this correctly

There are many more perceptual problems that are not included in this document.

### Mobility problems

- Apraxia/dyspraxia (difficulty in coordinating movement (e.g. getting dressed))
- Poor fine motor coordination
- Poor timing
- Difficulty combining movements into a controlled sequence
- Problems with spatial awareness
- Poor muscle tone
- Difficulty determining left from right
- Determination of distance
- Inattention to one side
- Balance problems/dizziness
- Dysphonia (Voice disorder in which the quality and / or volume of the voice is changed)
- Swallowing difficulties, people may need special diets (dysphagia)
- Drooling
- Seizures/epilepsy after stroke
- Contractures of a limb
- Post stroke pain
- Difficulty in maintaining high levels of alertness
- Longer time to get out in the morning

### Visual Impairment

- Visual field loss: most common is loss of half of visual field in EACH

eye (hemianopia) or quadrant of the visual field (quadrantopia)

- Double vision (diplopia)
- Visual inattention/neglect from visual field loss OR/AND inattention of one side of the body

#### Sensory challenges

- Sight e.g. not seeing a white paper on a white table
- Touch e.g. feeling like insects crawling on a person's face, a person would have to check in the mirror to orientate themselves
- Hearing e.g. a man walking onto a quiet road thinking it was clear but did not recognise the sound of a car approaching and nearly had an accident – auditory agnosia
- Smell and taste e.g. food tasting and smelling like sewage
- Loss of feeling in part of the body

#### Affective and mood issues

- Depression and anxiety
- Low self esteem, lack of confidence
- Uncontrolled emotions
- Very easily tired, subsequently making any disabilities more apparent
- Increased apathy

#### Other

- Inability to drive, so travelling to a meeting may be a problem
- Financial hardship as a result of stroke, (people might prefer expenses up front)
- Role reversal with partner/spouse to cope with

For more information on the effects of stroke you can download our Stroke Publications from [www.chss.org.uk](http://www.chss.org.uk) or order free from our Health Information Department: 0131 225 6936 or phone the Advice Line 0845 077 6000.

**Appendix 4: “Making your Case for Change” template**

<p><b>What is the issue?</b></p>
<p><b>How do you know the problem exists?</b> <i>What is your evidence?</i></p>
<p><b>What has been the patient/carer experience?</b></p>
<p><b>How has the problem affected NHS staff?</b></p>
<p><b>What are the national guidelines saying on the subject? (Strategies, reports, recommendations)</b></p>
<p><b>What are the local guidelines saying on the subject? (Strategies, reports, recommendations)</b></p>
<p><b>How exactly do you want things to change?</b></p>

## Appendix 5: Communication Support Principles

Communication Forum Scotland



### Principle 1:

- Recognise that every community or group may include people with communication support needs.



### Principle 2:

- Find out what support is required.



### Principle 3:

- Match the way you communicate to the ways people understand.



### Principle 4:

- Respond sensitively to all the ways an individual uses to express themselves.



### Principle 5:

- Give people the opportunity to communicate to the best of their abilities.



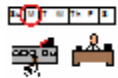





### Principle 6:





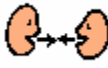
- Keep trying.

## Appendix 6: Inclusive communication

Using a range of methods to help people get messages in and out.

We use a limited number of methods, both to understand and to express ourselves. Inclusive communication makes use of the broadest range of methods to help people get messages in and out. Here are some examples of what you can do.

To assist understanding	Communication method	To assist expression
Use familiar venues and familiar contact people	<b>Routines</b> 	Ensure people have their communication aids to hand
Reduce noise and distractions at meetings	<b>Environmental sounds</b> 	Recognise electronic sounds used, for example, to attract attention
Match the emotion in your voice to your message	<b>Human sounds</b> 	Recognise sounds used, for example, to gain attention or express feelings
Point at pictures or objects during your presentation	<b>Gesture</b> 	Recognise gestures used to express opinions or when making a request
Make eye contact so the listener knows you are engaged	<b>Eye-to-eye contact</b> 	Recognise use of eye contact to get attention
Use objects to support the issue being discussed	<b>Objects</b> 	Have objects available, for example to help people make choices

<p>Use photographs to illustrate places or people</p>	<p><b>Photographs</b></p> 	<p>Use photographs, for example, to help people make choices</p>
<p>Use drawings to illustrate the points being made in the discussion</p>	<p><b>Drawings</b></p> 	<p>Recognise the use of drawings to make a point</p>
<p>Use symbols to supplement written advice and information</p>	<p><b>Symbols</b></p> 	<p>Recognise the use of supplied symbols to express opinions and give consent</p>
<p>Use clear, simple language in all written documents</p> <p>Write down key words to support what you are saying</p>	<p><b>Reading/writing</b></p> 	<p>Recognise the use of written answers during discussion, and allow sufficient time for this</p>
<p>Use clear, simple language</p> <p>Adjust the tone and rate of your voice</p>	<p><b>Verbal language and speech</b></p> 	<p>Give people time to answer questions and express their points of view</p>

Mayer Johnson PCS symbols (c) Mayer Johnson LLC Contact Widgit Software  
[www.widgit.com](http://www.widgit.com)

Appendix 7: Ground rules for meetings

	<p><b>Ground rules</b></p> <p>Turn mobile phones off</p>
	<p>Keep to the agenda</p> <p>Finish on time</p> <p>Give everybody time to express their views</p>
	<p>One person to speak at a time</p>
	<p>Speak slowly. Use simple language</p>
	<p>Raise hand if you do not understand</p>
	<p>Listen and respect the views of other people</p>
	<p>Keep confidential information in room</p>

[www.communicationforumsotland.org.uk/2010/TK\\_Resources](http://www.communicationforumsotland.org.uk/2010/TK_Resources)

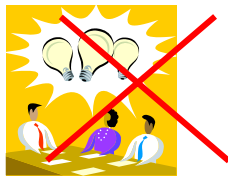


Chair controls the meeting



Raise hand if want to speak

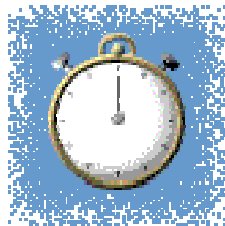
Raise hand if want to slow pace down



One person speaking at a time



Don't pounce with a question



Allow time to contribute/think

Short discussions



Breaks when needed

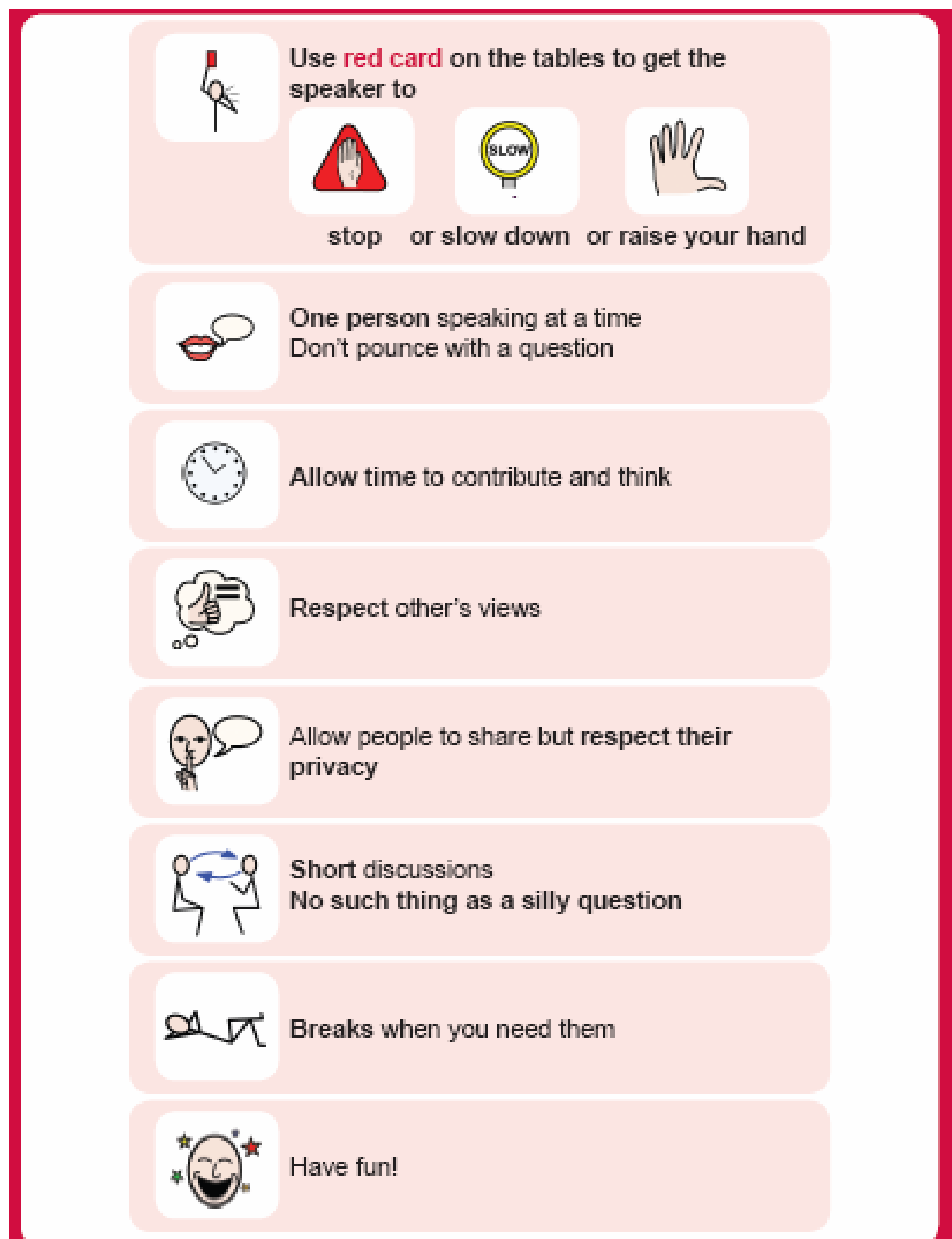


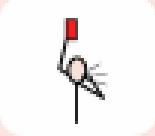
Have fun!


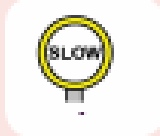

Produced by members of Chest, Heart & Stroke Scotland (CHSS) as part of  
the Civic Participation Network Project October 2007

[www.communicationforumscotland.org.uk/2010/TK\\_Resources](http://www.communicationforumscotland.org.uk/2010/TK_Resources)


## Ground rules used on Stroke Voices training





 Use **red card** on the tables to get the speaker to


  


stop or slow down or raise your hand


 One person speaking at a time  
Don't pounce with a question


 Allow time to contribute and think

 Respect other's views

 Allow people to share but respect their privacy

 Short discussions  
No such thing as a silly question

 Breaks when you need them

 Have fun!

## Appendix 8: Adapting a topic for different levels of severity of aphasia

### Mild difficulties

People may have a mild comprehension or expressive problems, though they may not see their own difficulties as mild. They may have more trouble in a group than one to one. Some people have good comprehension but are still very frustrated by word finding difficulties and inability to talk as they used to. Generally these people are able to be understood with words or another strategy. The speed of conversation within a group will be nearer a normal pace however help and support needs to be available especially for those more abstract concepts.

### Moderate difficulties

Defined here as people who have moderate comprehension or expressive problems. They will understand more complex instructions and perhaps need visual support to follow a conversation but they will need various strategies to assist their comprehension especially in a group setting. They may be able to say some phrases and short sentences but they will have word finding difficulties and may resort to writing, drawing or gesture. They will need props, pens and paper on the table.

They may be less reliant on others pointing to pictures or words for their responses. This does not mean that the issues that you talk about will be any different for those in the group with severe difficulties but they will be less structured and perhaps in more detail. You can use open questions; if they get stuck you can adapt the question to make it easier to respond.

### Most severe difficulties

In general people in this group have significant comprehension and expressive problems. They may only understand a few words at a time or very simple directions. They may be unable to talk at all or may manage only a few words, perhaps needing cues or prompting from a facilitator. They may be helped to follow the conversation if they see key words written down as they talk and they need to have props on their table to point to. Sometimes they may try to use writing, drawing or gesture to get their message across.

When working with this group, the session should be structured. Even if you discuss something complex, try to use supportive strategies that allow the participants to get involved. You can point to pictures on your subject as you talk. Use pen and paper and write down key words as the conversation develops. Give them choices in your questions and give them the key words/drawings to point to on the paper. Use yes/no questions not open questions. Always give them plenty time to respond by what ever method is easiest for them.

Hersh, D., 1998. *Making Conversations a Handbook for Running Groups for Chronic Aphasia*. South Australia: Queen Elizabeth Hospital Research Foundation Inc.

## Appendix 9: Accessible PowerPoint Presentations

- Use the Slide Master to create the basic layout, repeated elements and backgrounds.
- Avoid changing the layout, adding textboxes and text or other elements to the slide section. Use a different Slide Master to create a new slide.
- Format the title and text boxes in the Slide Master. Ensure the text is a minimum 24 point and in a non-serif font such as Arial or Verdana.
- Use a plain background which contrasts well with the text.
- Use bullet points and short statements in jargon-free plain English.
- Keep the text background clear and avoid overlaying graphics with text.
- Avoid any kind of flickering or sound effects..
- Back up each idea with an image if there are to be representatives with aphasia present.
- Bring one concept onto the screen at a time, using the “appear” custom animation only.
- Do not elaborate much on the text on the screen – keep your language simple that accompanies the slides. Some audiences may only need the slides read out to them.
- Make the presentation slowly and give time for feedback to check the message is understood.

Adapted from Scottish Accessible Information Forum (SAIF):  
[www.saifscotland.org.uk](http://www.saifscotland.org.uk)

## Appendix 10: Choosing a symbol set - picture communication symbols (PCS)

**The Stroke Voices Stroke Symbol** (below) was developed for Stroke Voices the project and used on all the relevant Stroke Voices literature. The Voices Scotland team felt that the symbols for a “stroke” that were available as part of the various symbol systems below, were ambiguous and inadequate.

Various CHSS stroke groups were offered a range of different options representing a stroke and this helped the Project Steering Group to choose the final version. It has been drawn in various colour options. While the symbol is copyright to CHSS, it is available on request from the Voices Scotland team.



The following Picture Communication Systems (PCS) have been reviewed during the Stroke Voices Project:

1. Boardmaker
2. Widgit
3. Widgit Visual Impairment Symbols
4. **Communicate In Print 2: Widgit and Boardmaker together**  
(used for Stroke Voices)
5. Photosymbols
6. Bonningtons
7. Clip Art

## 1. Boardmaker



### Used for

- Most widely used symbol set in the field of augmentative and alternative communication (AAC);
- Favoured by Speech and Language Therapy
- Very popular in Scotland

### Distinguishing features

- Symbols are pictorial, coloured
- 4.500 symbols
- Customising appearance possible

### Disadvantages

- Not very good for abstract concepts, limited health related symbols
- Can be seen as childish drawings
- Often second person in image is a child

### Available from both

<http://uk.mayer-johnson.com/products/default.aspx>

[www.widgit.com/products/mayer-johnson/boardmaker.htm](http://www.widgit.com/products/mayer-johnson/boardmaker.htm)

Boardmaker Symbols © Copyright Dynavox Mayer-Johnson Software2010

[www.mayer-johnson.com](http://www.mayer-johnson.com)

## 2. Widgeit



### Used for

- Adult learners
- Supporting literacy skills
- Software can add symbols as you type automatically
- Used extensively in Stroke Voices Project

### Distinguishing features

- Colour or black and white
- Can customise appearance
- Can import other symbol systems
- Schematic structure facilitating independent vocabulary development.

### Disadvantages

- Education based not health based

### Available from

[www.widgeit.com/symbols/index.htm](http://www.widgeit.com/symbols/index.htm)

Widgeit Symbols © Copyright Widgeit Software [www.widgeit.com](http://www.widgeit.com)

### 3 Widgit Visual impairment Symbols

Used for

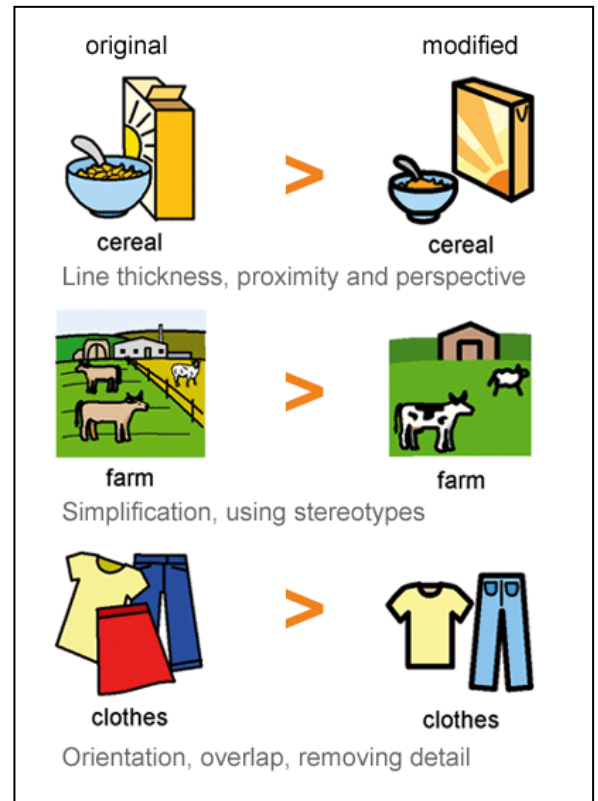
For those with sight problems, otherwise as above

#### Distinguishing features

- Modifications: 2,400
- Line thickness
- Less cluttered symbol
- The proximity of multiple images within a symbol reduced
- The colour contrast and use of colour to contextualise the symbol
- Visual perception of an image and the 'readability' of the symbol improved

#### Disadvantages

- Education based not health based



Available from [www.widgit.com/symbols/index.htm](http://www.widgit.com/symbols/index.htm)

Widgit Symbols © Copyright Widgit Software [www.widgit.com](http://www.widgit.com)

## 4. Communicate In Print 2; Widgit and Boardmaker Together

Used for the Stroke Voices Project



Used for

Communicate In Print 2 is a flexible symbol-supported desktop publishing package for creating books, worksheets, newsletters and posters.



### Distinguishing features

- Lay out in grids for timetables and activity sheets Add speech bubbles and frames
- Print in any size; as books ready to fold or as single sheets
- Use the 1500 coloured pictures to build up your own illustrations
- Fully flexible layout, with guides rulers and templates
- It's easy to insert your own digital images and scanned pictures
- A really professional finish can be achieved with all the functionality you would expect in a DTP and smart printing.
- Extra free downloads available
- The more licences bought the cheaper the price

### Disadvantages

- Copyright regulations state that only 100 symbols can be used per organisation free for external printing purposes regardless of how many licences an organisation. There is a charge for all symbols after the initial 100 symbols are used. However this does not apply for use within an organisation. All copyright enquiries for Widgit software directed to [copyright@widgit.com](mailto:copyright@widgit.com)

Used for the Stroke Voices project Communicate and Print 2 (Widgit) with the PCS Addendum Library add on (Boardmaker)

Available from : [www.widgit.com/symbols/index.htm](http://www.widgit.com/symbols/index.htm)

Widgit Symbols © Copyright Widgit Software [www.widgit.com](http://www.widgit.com)

## 5. Photosymbols



### Used for

- Aimed at learning disabilities
- Most of the characters are acted by models with learning disabilities and there is a strong emphasis on equality and diversity

### Distinguishing features

- Photos use people with learning disabilities and therefore may not be seen by the representative of the group you are communicating with

### Disadvantages

- Photos use people with learning disabilities
- Quite expensive

### Available from

[www.photosymbols.com](http://www.photosymbols.com)



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## 6. Bonningtons

### Used for

- Aimed at learning disabilities
- Community signs
- Adopted by Communication Forum Scotland

### Distinguishing features

- Symbols not childlike
- Based on British Sign Language
- Mostly black and white
- Basic symbols very clear

### Disadvantages

- Can be very abstract
- Lothian based system
- Learned system – some symbols can be quite obscure
- Project no longer funded, contact Tom Orr [www.tomorraccessibility.co.uk](http://www.tomorraccessibility.co.uk) for further information.

## 7. Clip Art



### Used for and by

- Anyone

### Distinguishing features

- Highly specific to topic
- Freely available

### Disadvantages

- Can be too busy for visual impairments
- Can be seen as too “cartoony” and not always appropriate
- Not adaptable

Grateful thanks go to the BRITE Centre in Edinburgh [www.brite.ac.uk](http://www.brite.ac.uk) which provides information, advice and training on inclusive education, assessment and enabling technologies. They were most helpful in guiding the project to ultimately use the software “**Communicate In Print 2**” in the addition of the PCS Addendum (Boardmaker) – a package that is able to give options on the use of both Widgit and Boardmaker at the same time.

For further information about this document or to organise Stroke Voices training for your area contact:

**Voices Scotland**

Chest Heart & Stroke Scotland  
3rd Floor West  
Rosebery House  
9 Haymarket Terrace  
Edinburgh  
EH12 5EZ

0131 225 6963

[www.chss.org.uk](http://www.chss.org.uk)

[voicesscotland@chss.org.uk](mailto:voicesscotland@chss.org.uk)

Advice Line 0845 077 6000  
9.30am - 4pm

Stroke Voices is part of the CHSS Voices Scotland Network



Chest, Heart & Stroke Scotland and CHSS are operating names of The Chest, Heart & Stroke Association Scotland, a registered Scottish Charity. Registration No SCO18761