**Manchester Disabled People’s Access Group response to the NHS Consultation on Making Health and Social Care Information Accessible**

**1. Introduction**

1. 1 This response represents the views of Manchester Disabled People’s Access Group (MDPAG), a voluntary organisation and registered charity, run and controlled by local disabled people. We primarily work with and involve disabled people, including people with mobility and sensory impairments, people with mental health or long-term health issues, people with learning difficulties and people who are neuro-diverse, including people with autism, dyspraxia or dyslexia.

1.2 We also work with older people and our work to encourage better access to buildings, the environment, housing, transport, information and services in the city also benefits children and families. We work with other voluntary sector, public and private organisations and work within the social model of disability. This model says that people are disabled by the way that society is organised and not because of a person’s impairment.

1.3 Our mission is to improve the lives of others by removing disabling barriers in Manchester. We do this by advising on and improving access around the city. More precisely we:

* Work with local disabled people to identify and remove access barriers in their communities and in the services they use;
* Train local disabled people to carry out access audits and surveys with the aspiration of making the buildings they use more accessible;
* Involve local disabled people in consultations and proposals relating to local and national policies, procedures and developments in the built environment;
* Support local people to understand their rights to access under equality legislation and planning and building regulations;
* Support disabled people to work together to campaign for improvements in access and facilities.
* We also provide a range of services to help organisations and businesses identify and remove disabling barriers. Typically this could include carrying out access audits and surveys, advising on policies and procedures and delivering staff training.

**2. Methodology we used to respond to this consultation**

2. 1 We welcome the consultation and the proposals to improve communication across NHS services. To gather views on this consultation, we circulated the surveys for patients, carers and service users and for organisations to all our members, our trustees and people who are involved with our lottery funded project. We also discussed the issues at three meetings. All these consultees are referred to as ‘our members’ below.

2.2 The views described below represent those expressed by our members when referring to the questions in the surveys and our final comments extend the questions in the patient survey, because our members were disappointed that the survey focuses on the use of accessible formats of written information, which is important, but doesn’t relate to other key communication issues.

2. 3 As a consequence of the point explained above, this narrative response to the consultation outlines our members’ views on the wider communication issues they believe are important in relation to improving access to health and social care services for disabled people. However, in doing this we also try to ensure that the questions asked in the consultation are answered properly ~~below.~~

**What are the key challenges faced by patients, carers and service users who have information or communication support needs when accessing NHS or social care services?**

**3. Impairments and medical issues**

3.1 A fundamentally important issue our members told us about was that they would like the NHS and providers of social care services to recognise the difference and make a clear distinction between a person’s access requirements that relate to their impairments and the reason why they may be receiving information and support from the NHS or social care. Not meeting a person’s access requirements can seriously affect the quality of care and the chances of recovery. These access requirements may include, for example, not having the right height of chair or toilet seat, not utilising an appropriate hoist, not having a wheelchair available on admission for daycare operations or not listening to a disabled person or their family when breathing equipment signals indicate a potential risk to life. All these situations have happened in recent years to members in hospital and, because they were not related to the medical condition they were admitted for, were ignored by staff. All of these situations seriously affected the person’s chance of recovery and, in some cases, made the medical condition much worse.

3.2 This issue can also apply to non-disabled people with temporary access requirements.

**3.3 We recommend that communication should include a commitment to, and understanding of, two way communication and collaboration with patients and their families, and should value the importance of up to date records on patients’ access requirements as well as listening to disabled people and their families and support workers.**

**4. Support**

4.1 A variety of our members told us that they never know who to talk to when they need to explain their requirements for accessible information or other facilities. This can be compounded when staff do not know how to provide information in alternative formats or how to put other access support into place.

4.2 **We believe it is vitally important and recommend that all staff receive training in knowing how to access information in alternative formats or other facilities or equipment which will support disabled people, particularly while in hospital as an inpatient and as an outpatient.**

**5. Communications**

5. 1 Our members told us that patients sometimes find that some NHS staff are not sufficiently able to explain in clear and simple language to disabled people what is happening, or what patients are required to do, and find it difficult to communicate with some disabled patients. This can create additionalcommunication difficulties for patients who have communication impairments themselves.

5. 2 We also heard about problems for disabled people in trying to answer questions from nurses or other medical staff because they are not phrased clearly enough to ensure that patients understand them properly ~~and~~ so that they can give accurate answers. This is particularly relevant when patients are discharged because they need to ensure that their needs when they return home are understood and provided for.

5.3 From a wider perspective, members also said that significant problems can be caused, such as patients missing clinic appointments, if they receive incorrect or unclear information in the first place, for example about the location of clinics within a large hospital or accessible parking spaces. This is also a problem when accessible parking spaces near to the entrances or in the car parks are full. These more generous spaces are often required to enable wheelchair users, people with prosthetic limbs and people with other impairments to open the car doors sufficiently wide. It is also a particular problem for people attending community services such as GP surgeries, dentists and other community health facilities. Information about transport and accessible parking and drop-off arrangements are rarely made available to people when visiting as out-patients, for regular appointments, or as visitors.

5.4 Some hospitals have good services for providing interpreters for disabled people and in community languages but others do not have regular support procedures in place and this also makes communication very difficult.

**5.5 We recommend that all procedures for support including interpreters are widely available to staff and to patients and are regularly reviewed.**

5.6 Where patients are admitted in emergencies, or where patients have communication issues, it is important that people’s access requirements are easily available with their medical records to staff in hospitals and clinics. Where appointments are made in advance of attendance, there appears to be no procedures to identify any particular access requirements. This has been a particular problem when members have attended early in the morning for medical procedures and wheelchairs and porters are not available at this time of the day.

**5.7 We recommend that all appointments procedures include questions about patients’ access requirements and follow up procedures to ensure they are in place when patients arrive.**

**6. Signage and wayfinding**

6.1 Staying with the broader theme of receiving correct information about facilities, some of our members said that accessible signage and appropriate lighting is just as important in the design of buildings as written information in accessible formats. This is often an issue in smaller buildings such as GP surgeries, dentists and other community health facilities.

6.2 We say this because our members have encountered difficulties navigating around hospitals and clinics to find the correct departments, as address details may be unclear, maps are often not sent with appointment letters and directions within the hospital or clinic may be confusing. This can be particularly significant if people need different information about an accessible route rather than the standard one.

6.3 Signage to departments and facilities, the provision of guides and support staff, and information about wheelchair support and accessible toilets and how and where to claim travel expenses, is also variable in different NHS facilities. Access to and information about refreshment facilities is ~~also~~ vital for some patients, including those with diabetes, particularly as waiting times in Accident and Emergency departments can be many hours after initial arrival and examinations and food may not be made available to patients.

**What are the key challenges faced by NHS and social care organisations in meeting, or trying to meet, the needs of patients, service users or carers with information or communication support needs?**

**7. Training**

7. 1 Based on what our members told us, we believe that a key challenge of for staff from the NHS and social care organisations is a lack of appropriate training in communicating with disabled people.

7.2 This training should be available to all staff that people will come into contact with, not just clinical staff, and is particularly important for reception and admissions staff. It should include training where staff are encouraged not to make assumptions about the support needs of disabled people and to avoid appearing to be patronising. More specifically, our members also told us they thought there should be better training for staff on how to explain consent to people with learning difficulties.

**8. Lack of corporate policies and procedures and need for monitoring**

8.1 Staff are often unaware of who should be responsible for and where to find appropriate equipment or facilities, or appear not to have the time to ensure that this is available.

**8.2 We recommend that there are clear procedures for all staff about who is responsible for dealing with these issues and where to locate facilities, equipment and support.**

8.3 It appears from members’ experiences that many letters and other communications are produced by ~~many~~ different departments and ward staff. This leads to patients receiving different levels of information and staff are often unaware how easy it is to make information more accessible for everyone. This lack of corporate guidance can waste the time of staff as well as patients.

**8.4 We recommend that all information is audited from initial contact through to information on arrival and departure and during treatment or stay. This includes signage and posters and the use of electronic and digital information while patients are waiting. The audit should also include information available to visitors and families, as well as to emergency admissions, and out-patient services, and include all community health facilities as well as hospitals. Mental health services should be included in this audit also.**

**8.5 We also support the proposal that ~~the~~ all NHS facilities develop and monitor guidelines on communications across all media, including the use of “clear print guidelines” and procedures for clear communications by telephone including mobile phones and online~~,~~ and that staff are regularly trained in their use. We have added our clear print guidelines for further information.**

8.6 A lack of a corporate approach to communicating with disabled people is a particular problem where temporary or agency staff may be unaware of best practice.

**8.7 We therefore recommend that particular attention is given to supporting temporary and agency staff in communicating with disabled people. The proposed guidelines should assist in these situations, but training should also be made available.**

8.8 Staff may be unclear on whose responsibility it is to ensure that access requirements are met and how to ensure families and support staff/carers are consulted where appropriate.

**8.9 We recommend that guidelines are clear about the responsibilities of staff, not just on admission, but throughout a disabled person’s stay.**

8.10 Members are seriously concerned with the way in which DNR (Do Not Resuscitate) decisions are made, often without consultation with patients and their families.

**8.11 We recommend that clear guidelines are developed and consulted on and made available to patients and their families.**

8.12 In general, members often experience a lack of understanding about their impairments from staff at all levels who appear to focus mainly on the particular medical condition that the patient is admitted for. This would not be such a problem if staff were encouraged to communicate and consult patients about their impairments and access requirements. However, staff are not always trained and supported in how to consult effectively at a ward level, where appropriate, and at a corporate level.

8.13 We recommend that policies, procedures and training and support are made available to staff, to ensure that the issues affecting disabled people, including older people who have ongoing impairments, are regularly reviewed and taken into account.

**Do you have any suggestions as to how the experience of patients, carers and service users who have information or communication support needs could be improved, either generally or in particular settings? Please include any examples of good practice you are aware of.**

**9. Good practice**

9.1 Our members have participated in a small number of meetings with NHS staff and particularly good examples in the Manchester area include the Manchester Disablement Services and the Regional Lung Centre. However, many of the new organisations in the NHS, hospital trusts and the GP commissioning groups do not have a consistent policy about regularly consulting with disabled people’s organisations.

9.2 We therefore recommend there should be local advisory groups for all NHS organisations, which include representatives of disabled people’s organisations, and which review policies and practices and are able to provide support for staff dealing with these issues.

9.3 Similarly, we are aware that some limited opportunities exist for disabled people to have an input to communication training for medical staff and students by providing opportunities for them to speak directly with disabled people with different impairments. One of our visually impaired members regularly speaks with undergraduate medical students at South Manchester and Central Manchester Hospital Trusts and to all staff from consultants to office staff at Manchester Eye Hospital, about issues for visually impaired patients.

9.4 We recommend that this training, extended to cover a wide range of access barriers and communications issues, is made available to all staff in all NHS organisations.

9.5 Not all of the information we received, or the experiences we heard about, were negative, but where our members did have examples of good practice in sharing accessible information with disabled patients, they believed this was the exception to the rule and was not repeated within other departments.

9.6 We therefore recommend that where good practice does exist, there should be a system for sharing it with colleagues in other departments or related organisations.

9.7 In relation to meeting patients’ access requirements, we recommend that relevant information should be recorded and easily available to staff in a section at the front of every patient’s notes which are regularly referred to when staff have contact with patients.

9.8 We recommend that any communication guidelines should cover the size and design of standard communications and also large print, other alternative formats and easy read versions. All communications should be tested for their readability score as many patients may have a wide variety of communications skills and some patients will consider English as a Second Language. Alongside guidelines such as MDPAG’s clear print guidelines, the Patient Information Tools are also useful but are not used consistently across NHS services.

Ref: [www.pifonline.org.uk/topics-index/evaluating/readability-tools/](http://www.pifonline.org.uk/topics-index/evaluating/readability-tools/)

9.9 We recommend that corporate and NHS guidelines and checklists should be easily available to staff in every department.

9.10 We are aware of many situations where confidentiality issues are breached during communications with disabled people and with other patients, particularly at admissions desks.

9.10 It is recommended that areas are made available where patients and staff who need support in communicating confidential matters can do this in private.

9.11 There are specific communication issues for deaf and hard of hearing people which we have not identified in great detail but there are particular difficulties in community health facilities where staff are not experienced in supporting deaf and hard of hearing people or there are no induction loops, no interpreters and a lack of awareness around confidentiality where the use of induction loops can “leak sound” into the surrounding areas to other users.

9.12 Communication barriers also exist for people who may be stressed as a result of their situation and may exhibit challenging behaviour. People with mental health issues or are neuro-diverse, for example people with autism, dyslexia and dyspraxia, also experience difficulties in communicating with staff.

**9.13 It is recommended that any guidelines and training for staff supports best practice in communicating with disabled people who may communicate in a variety of different ways.**

9.14 We welcome the increasing use of text messages and recommend extending use of the internet and mobile phones to allow patients to record their access requirements online and to find out about accessible parking, wheelchair access and other facilities and to get confirmation that support facilities and services have been booked and arranged for arrival.

9.15 Communications from doctors’ surgeries are often inconsistent and where, for example, prescriptions have not been signed within the usual five days, it is recommended that surgeries inform disabled people so that they do not have an expensive wasted journey where they may have arranged specialist transport arrangements to collect medication. Other communications from surgeries should also be clear and meet the specific requirements of disabled people where they have requested this.

9.15 Members have reported that where they are admitted to hospitals as emergencies, the ambulance services are often very good at identifying access requirements, although members have also experienced less effective support where the ambulance service has been carried out by private companies commissioned by the NHS. The information gathered initially is also not always passed on to ward staff once members have been admitted.

**9.16 It is recommended that procedures for collection of access requirements for emergency admissions are reviewed and best practice guidelines developed and made available to all NHS staff.**

**Do you have any other comments about accessible information and communication support?**

**10. Other issues**

10.1 Our members were concerned that we stress the point that there is no point in having very good policies for the use of accessible information if these policies are not implemented effectively.

10.2 Members also told us that information seems to be provided in alternative formats inconsistently, and that information in appropriate formats is not always available when required by patients.

**10.3 Communication between different organisations and departments**

10.3.1 On a broader theme, our members made a variety of comments related to a lack of communication between different NHS and social care departments and organisations about the access and support needs of disabled patients and service users. These comments included:

* + 1. There is a lack of co-ordination between different organisations and departments about the access requirements of patients. This means that it can be very ‘hit and miss’ whether a patient’s needs are met or not, particularly if their treatment means needing to receive services from more than one department organisation. One example of this is where a patient moving to an x-ray department in one hospital was told he could get out of a temporary wheelchair himself and was dragged out by a member of staff, although he was in great pain.
    2. Members have experienced notes not being scanned onto computer systems effectively. This can result in other departments having out of date records.
    3. Also, members had a variety of concerns about how information about how their access needs is shared between different departments or organisations. These include~~d~~:

1. A plea for better explanations of how information being received from a patient will be shared between different departments.
2. Accompanying information with this and other NHS surveys and information, including recent information which currently contains vague information about data protection and other regulations on sharing information, should be made more open and transparent and described in clear and simple language.

**11. Conclusion**

11.1 MDPAG would be happy to be consulted further on any of these issues or to provide additional information for the proposed guidelines.

**12. Appendix**

**Manchester Disabled People’s Access Group (MDPAG)**

**Clear Print Guidelines**

1. **Introduction**

* 1. These are the current recommendations for producing clear standard formats for all materials and media. They ensure that information is presented in a way that is accessible to a wide range of people and does not present additional barriers for people with visual impairments, have cognitive impairments or are learning disabled people. It also makes it easier for people to transcribe the information into other formats including Braille, large print, audio and websites.
  2. When producing large print documents, it is not acceptable to photocopy documents in A3 format as this is difficult to manage and to read. All documents should be formatted to read easily in the larger print.
  3. Ensure that all documents are produced in a person’s preferred format. This can include large print, Braille, audio tape, email, memory disks, CD Roms, Word format or Rich Text Format (RTF). PDF files are still difficult for many people to access, as they are produced as images. Adobe’s software for making PDF documents “accessible” currently takes away all formatting, making it very difficult to read.
  4. These guidelines apply to all media, including print, websites, and presentations.

**2. Quick summary**

2.1 Use Arial (or other sans serif) font, using 14pt standard for all documents.

2.2. No underlines, italics, fancy fonts or whole words in capital letters.

2.3 Text should be left justified not centre justified.

2.4 Avoid columns if providing alternative formats.

2.5 Coloured text should be highly contrasted with its background.

2.6 Don’t use text over graphics or images.

2.7 Avoid bullet points, using numbering and headings for sections.

**3. The Guidelines**

3.1 Use a sans serif font such as Arial, like this document or similar fonts such as Helvetica and Verdana. MDPAG’s visually impaired members prefer Arial.

3.2 Disabled people’s organisations recommend using a minimum of size 14pt print size as a standard for every document.

3.3 Use text justified on the left, with ragged right margins, not centre justified text, which creates extra spaces between words in the sentences.

3.4 Where columns are used, redesign the text for alternative formats without the use of columns, so information can be followed line by line. This is also important for large print documents as it is easier to read.

3.5 Don’t use whole words in capital letters, for example, in headings. Many people recognise words by their shape, and words made up of capitals create a block, which is more difficult to read.

3.6 Don’t use italics or underline words and phrases, as this also makes words more difficult to read. Use Bold and/or larger print instead, for emphasis at all times.

3.7 Don’t use fancy fonts in print, on flip charts or on Powerpoint.

3.8 Ensure that there is maximum contrast between the text and its background, avoiding pale colours on a pale background. Dark blue and black are preferred colours. Red and green can be difficult for some people to identify. Use of beige, cream or yellow coloured paper is preferred by some disabled people, as it reduces glare. Avoid placing text in shaded boxes.

3.9 Avoid printing over background graphics or images, including “draft” text, which may confuse the eye and reduce contrast between text and background.

3.10 Avoid the use of bullet points, using numbering instead, as someone following a document in Braille, large print or in an audio version, will not be able to identify each section. This is also important as page numbering in documents will be different for people using alternative formats.

3.11 Identify sections or paragraphs by name or number, and refer to them in the text in this way, rather than by page number.

3.12 Use single spacing between lines, as it makes it easier to read in sequence.

3.13 Avoid abbreviations and symbols or public documents where you are not sure of the users, for example, use the word “equal” rather than =, “plus” not +, “and” not &.

3.14 Diagrams, charts and images should be described for alternative formats.

3.15 Use summaries and indexes at the beginning and between sections of reports and minutes for all audio versions, so that someone can identify where on the tape they may want to listen.

3.16 When using Powerpoint, use large print and avoid using too many words on each screen.

3.17 Use matt rather than glossy or laminated paper, which reflects the light. This applies also to signage and notices, where the use of a glossy cover will reflect any light and reduce readability.

3.18 Avoid putting documents in PDF or in image format such as GIF or JPG/JPEG, as text browsers, used by many visually impaired people, cannot identify any text in an image. Where an image or PDF is provided for some people, a text alternative version in Word or Rich Text Format should also be produced and made available at the same time, for example, on a website for people to download.

3.19 Easy Read documents should also be made available, especially for consultations, but require additional clear print guidelines. Please contact Manchester People First or MDPAG for more details.

3.12 For accessible website design, please contact MDPAG for specialist information and guidance. The main international reference is at: **www.w3.org/WAI/**

3.13 For more information on providing alternative formats, including large print, Braille, Easy Read, audio versions etc. please contact MDPAG

**Manchester Disabled People’s Access Group**

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