East Sussex Community Voice

Making health and social care information accessible

A response by third sector organisations in East Sussex

SpeakUp
Countywide Forum

November 2014

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ESCV delivers Healthwatch East Sussex, Young Inspectors, and commissions NHS Complaints Advocacy in East Sussex

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1) Introduction

This paper gives the view of a number of third sector organisations across East Sussex about NHS's England's 'Making health and social care information accessible' consultation and questionnaire. It has been compiled by Speakup Countywide Forum at the request of Healthwatch East Sussex.

It has been compiled from information provided by organisations which work in the following areas: mental health, autism, learning disabilities, brain injury, carers, visual impairment and dementia. Additional information has been taken from two documents, the first a document produced by 11 third sector organisations working with vulnerable and disabled people about their clients' experience of being in hospital.[1] The second, is the report of a 2013 survey of the barriers to black and minority ethnic communities accessing local third sector services.[2]

2) The standard's vision

All respondents agreed with the vision for the standard that disabled people should be given information that they can understand and communication support if they need it. They also agreed with the three things that the standard required of organisations, that they should find out people's communication needs, record them and give out information in a format that people can understand. All who participated in the survey thought that the impact of the standard would be very good or good.

3) The standard's scope

However, only four organisations in the survey felt that the scope of the information standards was right, with four believing that it is too small or is missing something.

> "We welcome the scope of the standard. In particular we welcome that both NHS and adults social care services are included, as people with dementia are core users of both services." (Alzheimer's Society)

The comments about what is missing are as follows:

a) Organisations required to comply with the standard

One organisation believed that the issue is so important it should be extended to all organisations, not just those funded by the government.

The Alzheimer's Society queried if it included services funded by local authorities.

b) People with mental health needs

How this standard is to be implemented for people with mental health needs which may

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[1] 3VA (2013). *Patients with additional needs in hospital. A Response to East Sussex Healthcare Trust's draft patient experience strategy*, Eastbourne, 3VA.

[2] Speakup (2013). *Transforming Infrastructure in East Sussex (TIES). Engagement with Black and Minority Ethnic Communities*, Eastbourne, Speakup.

vary from one appointment to another.

> "There needs to be a clearer focus on the needs of individuals with mental health problems." (SEAP)

c) People who are illiterate

Friends Families Travellers (FFT) submitted their own response to the pre-consultation in February 2014 and a separate response to the current consultation. However they expressed strong views on the subject of communication with people who have low literacy levels such as members of the Gypsy Traveller community and asked that their comments be included:

> "*The standard is very much focused on legal compliance of the Equality Act 2010 regarding disability as a protected characteristic, without much though as to how race (ethnicity and nationality) affect communication needs and wider equalities issues*." (Friends Families Travellers)

In terms of the Gypsy Traveller community, FFT consider it a missed opportunity that the new standard will not include identification of patients with low literacy levels and reasonable adjustments to meet their communication needs such as easy read, audio formats or text messages.

d) People who do not speak English

While understanding NHS's concentration on disability, several organisations in East Sussex feel that people whose first language is not English should be included in this standard. This view is partly based on their own experience within their organisations. However it is also based on a 2013 survey carried out by three organisations working with ethnic minority groups in the county.

They identified that BME groups were not accessing services and that this is due to a variety of factors, including language issues, lack of knowledge about services and unfriendly or inappropriate attitudes towards BME residents. They found that many BME individuals fail to use services because they are not adapting to their needs and that '*many BME individuals therefore fail to use these services or have negative experiences of them*'. In the same survey they found that, while accessing GP services is reasonably good, a significant proportion had difficulty in accessing hospital services. The provision of interpreters is patchy and family and friends are often called upon to interpret which is completely unacceptable.

Among nine recommendations for improving access to services, the report recommended that there should be greater and more consistent provision of interpreters.

> *"Language support to those whose first language is not English is vital because we otherwise disable individuals to access vital health and social care information." (JPK Project)*

e) People with cognitive impairments

While the document talks of disability, impairment or sensory loss and regularly mentions people with learning disabilities, it does not mention people with dementia.

> *"We recognise that the standards do not cover help for people to make decisions if they lack the capacity to do so, but it is important to remember that many people with dementia will be able to make decisions about their care if they have the information presented in an accessible way. Alzheimer's Society recommends adding cognitive impairment to the list to ensure that the information needs of people with dementia are included in this standard." (Alzheimer's Society)*

f) The process

Step 1 (assessment) is vitally important, particularly for those with autism. The person doing the assessment should have a good understanding of what to ask otherwise the following steps will not be appropriate.

4) Confidentiality

There was quite a lot of concern about sharing information – both the importance of it being shared with all appropriate parties, but also about getting people's permission before doing so.

> *"There has always been a communication issue between Adult Social Care and Health (in East Sussex) when it comes to sharing information due to confidentiality. How will they overcome this?" (JPK Project)*
>
> *"From an advocacy point of view, there needs to be a choice! Will people be asked whether they want their information shared with other services?" (Headway)*

5) The types of communication support and information formats

a) Resource implications for organisations

Concern was expressed by several of the organisations consulted about the resource implications for organisations of implementing the standard and the need for such a diverse range of formats, although they felt they were generally well equipped to provide information in appropriate formats relating to the disability which they supported. One organisation, East Sussex Association for the Blind, pointed out that technological solutions can be good, but it is important to bear in mind that older members of the community often do not have access to technology or are unable to use it.

b) Communication support for people with dementia

The Alzheimer's Society requested that face-to-face contact should be included in the list:

> *"This is because some people with dementia will have difficulties using a telephone or understanding written communication, so face-to-face contact is necessary. We believe that advocates for people with dementia should be added to the list of communication professionals." (Alzheimer's Society)*

c) Interpreters – qualification requirement

There were mixed views about the need for qualifications for interpreters and the ban on using family and friends as interpreters. While in principle, several of the organisations agreed that qualified interpreters were preferable, they stressed that it should, in part, depend on the individual needs of the patient or service user.

> *"It all depends on what the individual needs. Words can be put into people's mouths if they have a learning disability. Parent carers are often the most knowledgeable about the needs of their child, but there might be an issue about whose needs they are advocating when speaking on behalf of a person with a learning disability." (JPK Project)*
>
> *"How does the Mental Capacity Act 2005 fit into this when individuals have been assessed under it as not having mental capacity to speak on their own behalf and have identified people to speak on their behalf?" (JPK Project)*
>
> *"Although the need for BSL interpreters is recognised in these standards, there is no mention of advocates having the necessary training. We believe that these standards must reflect the Care Act guidance and include a sentence stating that advocates must be highly trained to fulfil their role and that family or friends may not be suited to act as advocates." (Alzheimer's Society)*
>
> *"If some patients need a trusted person there, that they can rely on, this should be accepted." (Headway)*
>
> *"Generally this is very important to make sure the voice of the patient is heard, not the carer. However there has to be some leeway in some situations when, for example, an individual has formed a unique way to communicate and the carer is the only one to understand." (Care for the Carers)*
>
> *"There needs to be some mechanism to allow individual requests for those individuals who only want to be spoken to through family, friends or carers." (Mencap Eastbourne)*

6) Advice and support from the Department of Health

Most organisations which took part in the survey felt that the advice and support provided by the Department of Health is about right.

7) Ensuring organisations follow the standard

Concern was expressed about the impact of implementing the standard, particularly for smaller organisations. Another questioned who was going to monitor the CQC as in their view they currently do not provide easy read versions of reports or in other formats.

> *"The NHS will have to define what they are going to check and how, what will happen if an organisation doesn't follow the standard and how they will support smaller organisations to be able to follow the standard." (SEAP)*

> *"Clear and straightforward communication support is necessary when it comes to supporting organisations." (ESAB)*

> *"The concern that we have is that the standard makes no reference to monitoring of the standard. Without an obligation to do so, some organisations may not follow it. We believe it could be linked to the Information Standard self-audits and recertification audits." (Alzheimer's Society)*

8) Implementation

a) The cost of implementation

A number of contributing organisations expressed concern about the cost of implementing the standard, particularly for small organisations. Another contributor was concerned about the legal position regarding sharing information and sought clarification.

> *"Implementing the standard in small organisations will eat a lot of resources that will be taken away from service provision. Resources should be made available through the tendering processes to be able to meet standards." (SEAP)*

> *"Alzheimer's Society has concerns that the standard will have a financial impact on the organisation. We are currently working to get to a point where we will have our core set of information available in various formats, but if this new guidance becomes a legal requirement for us, the budget would need to be found."*

b) Training of staff

In 2013, a number of third sector organisations commented about the lack of awareness of additional communication needs for patients in local hospitals and the lack of communication between health care staff. However, they also noted that, not only were staff sometimes unaware of a disability or need, but that even when they were aware of it, they have not been trained in how to respond to that need. For example, staff call out the name of a patient in a clinic and then walk away, leaving a visually impaired patient or one with hearing loss, unable to follow. East Sussex Vision Care has numerous examples of visually impaired people who have not had their additional needs taken into account and who, as a result, have had difficulty in accessing services or have suffered a poor standard of care. It is important that any improvement in patient communication goes hand in hand with staff training, so that practice changes and services are delivered in appropriate ways for people with disabilities.

> *"It would help if there were a staff member in each service who could take on advocacy work on behalf of the patient and know how to access and respond*

> *to the needs of patients". (Southdown Housing Association)*
> *"The challenge will be to make sure all staff members are knowledgeable and will be able to use tools and are aware of a range of needs." (Southdown Housing)*

9) How will your organisation be affected?

a) Resource implications

Contributing organisations said that, while they felt the standard was important, they are concerned about the resource implications, particularly for smaller organisations. A number of the organisations already do provide information in accessible ways, particularly where they work with people with specific disabilities. However, there was widespread concern that the requirement to provide information in an expanded range of formats, would be costly.

> *"We are big enough, but for some of our smaller recovery partners, this will definitely take them away from working on the frontline. While this standard is very important, smaller organisations should be provided with consultancy and advice or work together to use tools and create information." (Southdown Housing Association)*

> *"We use quite a few tools already to help clients to access information or refer back to information as our clients suffer from memory loss." (Headway)*
> *"If we needed to convert information into different formats or access interpreters, we would need funding for these. How will organisations pay for services? Where is the funding? What is the role of the CVS to make support available?" (SEAP)*

b) Need for shared resources

Several organisations suggested that joint partnership or a network for organisations would be useful and joint training for support would be helpful, a place where good practice could be shared. Another suggestion was that a one-stop shop for communication support resources should be created.

> *"We take equal access very seriously at Care for the Carers and have a lot of knowledge about how to make information accessible and how to do it cost-effectively." (Care for the Carers)*

> *"We have all the tools available at the moment [to help make information accessible for those with visual impairments]. We are happy to help other organisations cope with changes and support". (ESAB)*

(See next sheet for conclusion)

10) Conclusion

> *"If it is implemented in the way it needs to be rather than being done quickly, and if it is done seriously, then it is very good." ((SEAP).*

In general terms, the principles of improving the accessibility of NHS and care services is applauded and approved of by those organisations which responded.

However the organisations involved in the survey felt that important groups had been left out of the scope of the standard, in particular Black and Ethnic minority groups, those who were illiterate and those with dementia.

There were also concerns around the emphasis on the use of trained interpreters, particularly for those with learning disabilities or other special needs. For such groups it was felt that it is important that there is some flexibility so that the wishes of the patient are not over-ridden. Parallel lack of standards for advocates was a glaring omission for one organisation.

There was also great concern about how third sector organisations, particularly small ones, will be able to implement the standard properly without additional resources and funding. Finally, many organisations felt that standards in communication need to be linked to staff training and work practices in order for them to be completely effective in enabling people with particular or special needs to access services.

Prepared by Speak Up and Healthwatch East Sussex
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CONTRIBUTORS TO THE REPORT

Alzheimer's Society
Provide information, advice and support for people with dementia and their carers across East Sussex.

Care for the Carers
An independent charity which supports unpaid carers in East Sussex who look after a relative, friend or neighbour who is frail, disabled, and/or has a long term illness.

East Sussex Association of the Blind and Partially Sighted
Whilst aiming to increase the independence, confidence and wellbeing of blind and partially sighted people, we also work to promote the understanding of sight loss in local communities. We work with 17,000 members annually.

Friends Families Travellers
Seeks to end racism and discrimination against Gypsies, Travellers and Roma, whatever their ethnicity, culture or background, whether settled or mobile, and to protect the right to pursue a nomadic way of life.

Headway Hurstwood Park
Provide day services for people with brain injuries and a community outreach service, and information and support groups for carers.

JPK Project
A Sussex-wide supported living centre for people with learning disabilities. They help 30 people at a time plus their parents/carers.

Mencap Eastbourne
Provides a range of services from 24 hour residential care to day opportunities and family services. They have more than 100 members who include people with learning disabilities, their families and those dedicated to supporting and improving the lives of people with learning disabilities.

SEAP
Provides mental health advocacy support across East Sussex for 286 individuals.

Southdown Housing Association
Help individuals with autism (and others) access services, employment and activities through their Community Links service. They help 500 people in total annually, 70 of them with autism.