

## **Consultation on the General Standards for Neurological Care and Support – ALLIANCE Neurological Involvement Network response**

### **Standard One**

#### **Statement and rationale**

- Organisational self-evaluation needs to be backed up with some form of independent review
- Organisations need to ensure that the information on services that they offer are continuously kept up to date and reflect each organisations delivery.
- There is a need for an implementation plan to be created immediately after the standards are signed off.
- There was general agreement that each organisation needs to have a nominated lead.
- Multi agency approach – needs to include 3<sup>rd</sup> sector
- The leadership standard lacks vision, inspiration and fails to encourage innovative practice.

#### **Criteria**

##### **1.2**

- ‘Multi-agency approach, where required....’, this should be changed to the assumption that a multi agency approach will always be required. Suggested this should be changed to ‘Multi-agency approach is expected unless there are clear reasons not to follow it.’
- On capturing feedback, this needs to include people how have communication difficulties and use AAC equipment.
- ‘ongoing and consistent quality monitoring..’, will this be standardised across the country or will it be set by each organisation? Feeling of the group is that it should be standardised across the country to ensure consistency.

##### **1.3**

- collaborative working, - specify who the collaborators are or provide examples
- ‘Continuous development of a knowledge...’, what does continuous development actually mean in practice? How often should development be undertaken?
- How will training needs be identified and how often? Every year, every three years every five years?
- There needs to be proof that any training undertaken is actually implemented.
- ‘minimising any barriers..’, how with this be supported? There needs to be a review to identify the barriers in the first place.

##### **1.4**

- Pathways – services need to demonstrate people are aware of them and that they are being followed and used.

- Feedback needs to be proactive – actively elicited from all involved.
- There needs to be a cultural change where negative feedback is viewed as service improvement rather than something to conceal or hide.
- Time should be taken to ensure correct diagnosis and treatment first time, with less focus on how quickly patients are dealt with or cost
- State who is responsible for measuring success and how
- More than one person from more than one field should be involved
- Support cooperation to ensure standards are implemented

## **Standard Two**

### **Statement and Rationale**

- Partnership working is essential to community care. Currently there is no continuation of service and people are left without things and have to buy things for themselves. There is a real need for ongoing social work support and ownership over this
- People don't want to be in hospital, and therefore other services need to be involved. Need to prevent hospital admissions not increase them
- In some places support exists and in some places it doesn't. Some places bring third sector and community healthcare together, but in partnership working there is a strong sense that healthcare 'owns' it
- In the rationale: use of the phrase 'evidence suggests'. Why not 'evidence strongly supports', why only suggest? Is there enough evidence? What is the state of the evidence? Remove passive wording throughout
- Concerns about the implementation: will this be achieved? What priority is this? Will resources be diverted?
- Rationale does not mention third sector, are there good examples we could showcase? Importance of third sector involvement—like to see standards reflecting a commitment or timeframe/way of demonstrating, If they are not all doable, what are the priorities?
- Comment that not much here to empower patients to feed back on how partnership working has worked for their care. Regarding the 'what it means for people' section – how would you measure this?
- As a third sector organisation, there is very little to suggest how the standards will support our work with the NHS with regard to partnership working as third sector are often the ones pushing for partnership working

### **Criteria**

#### **2.1**

- Feeling that anticipatory care plans should be happening already as a standard thing – this is not aspirational
- Comment about how they will meet anticipated needs when they struggle to meet current ones

- Step back a stage, locally-agreed well-coordinated care and support pathways and protocols do not exist yet! Who's going to develop them and who will fund it? There is still a lot to do there.
- Care plan---references health and social care, but not people or their families. What is important to people going in to an appointment. Need to work to engage patients about their role in the partnership.
- People feel powerless when not involved in their hospital discharges, and feel not listened to if they said they need to remain in hospital due to lack of support outside it
- 'Locally agreed' – but we also need to ensure equitability across Scotland with regards to implementation and provision
- There should be something around changing the mode of 'partnership' – it is often that at diagnosis there is signposting outwards from services, this can often lead to there being not much support for people in 'the middle of the journey' – therefore, the third sector and community services that see people regularly should be able to refer in and link better with clinical services so that people are not just forgotten

## 2.2

- Organisations should proactively work to support patients and carers to engage in partnership working. Person-centred services are not just about being compassionate, but partnership with cultural and society as a whole so that people are involved.
- With regards to 'understanding partners role' – this needs to go further, there needs to be mutual respect with an understanding of the IMPACT of the third sector on people
- Statutory services need to take responsibility for making partnerships and should be actively seeking them
- 'Health and social care' might not be interpreted as including the third sector – language needs to change around this – for example, if a person wants to get back into employment, the 'health' to 'social care' route would be to refer to DWP but there is wider and better support than this in communities. Clinicians need to be aware of this
- Questions about who drafts the guidance around information sharing and whether this is local/national and already in place.
- Regarding having protocols and guidance for discharge – can this be articulated so that there is some sense of urgency behind that – e.g. people with MND for example struggle to get discharged (often due to social care related hold ups) while stuck in hospital their condition deteriorates further and needs increase – quicker discharge plans result in better quality of life at home and is more efficient/cost saving. Comment that we want to see protocols and guidance matched up against achievement/timescales.

## 2.3

- Consider coaching for patients to be assertive. There is a strong power differential in a consultation room and people feel unable to challenge specialists. Need to address ways to reduce this power differential e.g when people may be pressured to take medications they are unsure about.
- Use of the phrase 'where appropriate'—what are the criteria of 'appropriateness'? This should be an expectation and people are to demonstrate where it is not helpful
- How do we promote the idea that people are at the centre and are we really doing it? How are goals or treatment plans communicated? Most people would have never thought about challenging consultants of things that may need further discussion (e.g the recommendation to stop driving)

### **Standard Three**

#### **Statement and Rationale**

- There should be clarity that specific training relating to neurological conditions takes place in all roles where a staff member might come into contact with a person with a neurological condition, for example, social care staff, Local Authority employees
- Training for all staff on people centred approach
- More patient involvement in diagnostics
- Emphasis on communication
- Raise awareness of neurological conditions among all staff, including non-medical. Pyramid system for training from those working directly with patients experiencing neurological conditions to basic training for those least likely to encounter these patients.
- Emphasise that standards relate to all staff the patient comes into contact with – not just clinical staff
- Requires more guidance on how standards are achieved
- Clear definitions of what is meant in parts
- Use clear language
- Must ensure training is put into practise and provide evidence of this
- Make sure training is tailored to achieve required competences
- Approach is well described and thorough, but lacks information required to achieve standards in practise
- Set out processes and state competences required from staff
- In some areas, images and diagrams may better illustrate standards
- Standards can be repetitive

### **Standard Four**

#### **Statement and Rationale**

- Diagnosis is not a person-centred as it should be. It goes without saying that diagnosis should be accurate—that is the bare minimum that we should be

looking for. In some cases, neurological disorders are complex and difficult to diagnose, but there should be some preliminary diagnosis. When you get the diagnosis it should be accurate.

- How does an individual assess whether the standards are being met? There is too much onus on the patient and many people would not have this expectation, engagement or willingness
- How people are diagnosed affects how they feel about it and manage it
- View that the standards need to be more instructive and support boards to plan their services on a population-basis. Question on whether there should be a criterion that local neurology plans are produced (e.g. like the 3-yearly ones of old).
- Suggestion that HIS needs to take account of the current work of the Scottish Access Collaborative, where there is lots of reference to diagnosis.

## Criteria

### 4.1

- Importance of diagnosis for treatment but it is also important to recognise the difficulty of living in uncertainty for a long time
- Inconsistency in who is referred to and when. For example, people with neurological conditions experience visual/optic disturbances but might not be referred to neurology for years even when it is suspected. Ongoing communication is vital for diagnosis, especially if the person develops more than one condition. People need access to specialists to review all of this information
- There should be a genuine understanding from doctors to support early diagnosis. FND is completely misunderstood, and people have to find specialists who understand it and are interested. People feel that doctors do not understand neurological conditions and doctors feel they can't help at all—people feel dismissed. Stress and uncertainty when trying to get a diagnosis makes it worse
- Comments that there is still a need for condition-specific drivers of improvement
- Suggestion that there should be a criteria that organisations make publicly available their waiting times for access to diagnostic tests etc. – this would be a performance measurement. Also need to reference timescales. Doing these things would likely confirm that organisations are overwhelmed and that the resource is not there.
- Suggestion that it is not clear the extent to which this standard actually supports access to specialism. View that given the lack of guidance for implementation of this standard, and given orgs are not asked to evidence having done it, it is too open to interpretation.
- Having said that, general feeling that the criteria for this standard are good – there are a lot of good things in it!
- Something is added around *equity* of access. There is little acknowledgement of the postcode lottery of diagnostic care.

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## 4.2

- Agree with the Standard rationale. For MS, only the consultation neurologist can make the diagnosis. GPs don't see enough neurological disorders to be able to assess what is happening and make a diagnosis. Emphasis should be on specialists. They need access to and knowledge of full diagnostic tools. Specialists make a more accurate diagnosis. Research suggests that earlier diagnosis is better.

## 4.3

- For certain things, the patient isn't given information. People are not aware of their care plan or what is happening, and this plus unsure of diagnosis can lead to stress

## 4.4

- GP in some cases has nobody to refer to. You need a two-way dialogue—patient to educate the GP about their condition in order to have support managing it
- Where you live, you might not get anybody who knows anything. This is not such a problem in the central belt but might be elsewhere

## 4.5

- Nothing about recording. No recorded incidents of MS diagnosis and although there is a register, there is no sanction for a Health Board or individual consultants who do not use or comply with the register
- Face to face diagnosis is important and the service needs to provide this, and be funded to do this—not write diagnosis letters and have a long time between the letter and the next appointment. This does not have to be with a

consultant, but with a specialist nurse who can deal with the emotional impact. MS nurses and epilepsy nurses are in short supply

- Everyone needs different levels of information about different things. This should happen but there are no repercussions if it doesn't and no resources
- Neurological disorders happen to families—carers/spouse/parents might need to know more than the person or need to be able to manage day to day. We should learn from oncology—need longer appointments for diagnosis which includes the whole family and other people for support

#### 4.6

- If the neuro condition does not respond to therapy – what is the trigger to reinvestigate the diagnosis? For example, misdiagnosis rate for epilepsy is between 21-30%. Can there be a criterion around where diagnosis is not confirmed/if there is uncertainty or no diagnosis made/where diagnosed condition does not respond to therapy that it should be explored with the individual and further/repeat investigations considered at some point?
- People opt out of the NHS and go private in order to get a diagnosis because it takes such a long time. Sometimes people are not then referred back into the NHS for wider holistic support

### Standard Five

#### Statement and Rationale

- Need to revisit the standard statement: opportunities of review by whom? For progressive MS, there is no drug therapy to help and so people are not reviewed by neurologists. There is no active medical treatment so people drop away from health service. People may be unable to get to appointments and are dependent on consultants/health board to actually use Attend Anywhere.
- People are passed from doctor to doctor, some consultants hardly know people. People need to feel believed and listened to.
- Is there mention made explicitly to third sector referrals?
- Suggestion that this needs to be part of diagnosis – there is a separate standard for diagnosis and one for assessment of needs, whereas these need to be dovetailed together in practice.
- There are no timescales alluded to in standard 5 – we need a more robust document with timeframes attached to some of these points
- Saying 'timely reviews' is not specific enough – obviously timescale is defined by each condition however could say something like: 'there is a flexible approach in how reviews are undertaken, timescales should be in accordance with any best practice guidelines for that person's condition.'

#### Criteria

## 5.1

- People struggle to get appointments and are seen less than once a year for a short amount of time. How is this conducive to a holistic assessment? What does holistic mean?
- Question over how well needs assessment is integrated with other care settings. Feeling that there is often a time lag between the clinical input and the other inputs – e.g. the ‘OT’ assessments may be some months after the diagnosis. Feeling that a comprehensive needs assessment can take forever in rural areas due to lack of access to the required parties. There is no timescale related to the standard to drive this.

## 5.3

- All fine, but again comes back to how this type of care plan is meaningfully implemented. Patients have no copy of the care plan and can't tell when things are not followed up. Everybody should see it, so it should be developed *and shared* with people/their carers. People should not have to ask to see it
- If somebody goes to hospital following a fall or infection (or a seizure), because they don't have a care plan with them medication might not be taken as and when required, leading to worsening of the condition. This might not be picked up because of lack of knowledge among general staff at the hospital—a person with Parkinson's might be treated as end of life when in fact they would not be had they taken their medication.
- Need a commitment from all agencies to share and share in a respectful way. There is no uniform approach to sharing information—who is accountable?

## 5.4

How does this get triggered? Do you allow self-referral, is it flexible for individuals or the service? People should not have to be flexible to make up for service capacity

## Standard Six

### Statement and Rationale

- ‘What is already there’ – there is very little in this standard about improvement of services and is more about rearranging the services we already have
- Issue with access around functional symptoms – this standard seems to assume that there are well developed services – in many areas this is not the case
- For example – there is a real lack of specialist support for adults with cerebral palsy – ‘it assumes the availability of care and support but there isn't’
- Transitions need referencing – what happens when moving between child and adult services?
- The term ‘treatment’ is vague – is this drugs, clinical treatment, physio?
- The notion of ‘ongoing management’ is also difficult as what does this entail? Medication reviews? Pathways?



- There needs to be more robust language around what 'ongoing treatment' means – with many non-degenerative conditions people are diagnosed, assessed and left to it – but 'ongoing' support would entail regular equipment reviews and needs assessments – condition might not change but people do
- Very interaction based – not much recognition of this as a journey
- Where is the accountability for failing to meet the standard? There are no clear requirements – it says it would be good to have care plans – well there should be more robust language around **NEEDING** to have them
- 'Treatment and management' – this is an odd heading for a non-condition specific document
- 'Right care and support at the right time' – 'right care' is a signposting issue and 'right time' is a waiting time issue – this needs to be made more explicit
- Criteria

## **Criteria**

### **6.1**

- 'Accessible treatment' needs clarifying – access is not just about the ability to access services that are there but in ensuring that the right treatment options are available – if a treatment is available in the Highlands and not the Borders then this needs to be treated as an 'access issue' – including with regard to treatments and support offered by the third sector

### **6.3**

- Too much qualification – 'specialist services, where necessary' – who decides what is necessary? Needs to be stronger
- Language around 'timely' access – timely according to who?
- 'Have access to...self management support' – this needs to be funded
- Holistic care plans shouldn't be separate from clinical care plans – it is all the same person

## **Standard Seven**

### **Statement and Rationale**

- The starting point should be to ensure that there is an individualised care plan which can be monitored, measured and accessed by all.
- This needs investment – financial and time
- Person centred care should be central throughout the whole document rather than having a particular standards. It should be a principle, not a standard.

## **Criteria**

### **7.1**

- Contradiction with 6.1 'Right to access right services at the right time but 7.1 is just signposting available services.
- 'Supporting local available services' leads to differences in what is available where ie postcode lotteries. There should be a baseline of services across all geographic areas.

## 7.2

- Need for clear and appropriate access to specialist nurses and services where they exist.

## 7.4

- Introduce a single point of contact to help manage a patients journey throughout their disease progression.

## 7.6

- For person centred care to work there needs to be improved communications between all services involved, with a central portal that all organisations can access.

## Other comments

This response is the output from a discussion event hosted by the ALLIANCE. In the room was a mix of people from third sector organisations and those living with a neurological condition. There was consensus within the room that while these standards seemed positive and aspirational, they remained meaningless as there is no explanation around how they will be monitored, scrutinised and linked to quality improvement.

It is understood that the monitoring etc is to take place at a local level and therefore not within the remit of these standards. There was concern that such an approach will lead to further increasing variation in services across Scotland which is very acute in neurological services. Similarly, with no guidelines or compulsion within the standards to meet the standards, there was scepticism as to whether local decision makers would adhere to them.

Within the context of central standard setting and local planning for implementation there was concern that, while engagement in developing the standards has been good, this would not carry on through to the decision making around implementation at a local level.

Therefore, with regard to completing these standards, there needs to be clarity over the process of implementing these standards. There should also be clarity over the role of Healthcare Improvement Scotland beyond the development of the standards in ensuring that there are improvements as a result of them.