Is localism working for people with neurological conditions?

Survey findings and recommendations

September 2014

Contents

Acknowledgements

This report was written by small group of individuals from neurological charities who are currently steering the Neurological Alliance's local influencing project:

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Introduction

Neurological conditions have historically been poorly prioritised in the health and social care system. Neurological conditions are unique compared to other long term conditions – they are often not preventable, fluctuate considerably, can deteriorate rapidly and they last a lifetime. Lack of understanding and prioritisation has resulted in neurological services which are neither efficient nor person-led, creating a system which does not serve budget-holders or people affected by neurological conditions.

National policy and public affairs work remains important for neurology (particularly in relation to the direct commissioning responsibilities of NHS England and the broader NHS improvement framework). Increasingly however, the policy and influencing levers available to bring about better services are at local level. On 1 April 2013, the Health and Social Care Act 2012 came into force, bringing with it many new structures and arrangements for the *NHS and social care* in England. It created 211 new Clinical Commissioning Groups (CCGs) which control around 60 per cent of the NHS budget and decide which services to fund according to local needs. Health and Wellbeing Boards (HWBs) in each local authority area bring together health, social care and public health leads to develop a local Health and Wellbeing Strategy (HWS) which informs commissioning plans across health and social care.

The new system also places greater emphasis on the role of people affected by neurological conditions in improving services. The most visible manifestation of this is local Healthwatch. This, along with other patient involvement mechanisms in the new structures, offers new opportunities for people affected by neurological conditions and their representatives to influence the health and social care system. People affected by neurological conditions need to be equipped with the knowledge and support to effectively engage in new local structures. Local structures need to be equipped to allow for engagement with a population that has specific needs, such as the cognitive issues experienced by many people with neurological conditions.

Another characteristic of the new system is that increasingly decision-makers (politicians and commissioners) want to engage with patient organisations on a platform that is wider than one individual condition. Individual charities have different strengths, structures, and objectives. However the overall aim, stripped right back, is the same: to improve services and quality of life for people affected by neurological conditions. Many of the challenges faced by people affected by neurological conditions in relation to health and care are similar.

This report is the first step in our response to the local influencing agenda. The recommendations outlined in this report show that we all have a part to play in understanding and engaging with the new health system, and ensuring people affected by neurological conditions are able to do so.

Summary of findings

- These findings derive from a survey of 160 staff, volunteers, people affected by neurological conditions and carers which was open to complete between 29th January and 25th February 2014.
- The majority of people surveyed take part in engaging and influencing activity, but overall they feel this has become more challenging since the changes to the health and social care system in April 2013.
- Staff members have a higher level of involvement in influencing activities within the new structures than volunteers, service-users and carers (with the exception of GP practices).
- The most widely-used forms of engagement include attending stakeholder events and receiving newsletters and updates.
- A considerable percentage of people, including staff, volunteers, people affected by neurological conditions and their carers are unaware of HWBs, local Healthwatch and Strategic Clinical Networks (SCNs) across the country.
- A significant percentage of people are engaged in local hospital influencing activity, in particular people affected by neurological conditions and carers.
- The majority of people surveyed work across neurological conditions because they find this to be very effective. It enables collaborative working and the ability to have a greater impact on services by representing a much larger group.
- People suggested there is a need for health professionals, particularly GPs, to have more training and education on the range and complexities of neurological conditions.
- Patient involvement was identified as key to achieving better neurological services locally, and patients need to be encouraged and supported to be proactive in these structures.
- Respondents suggested there is a need for a neurological conditions champion within GP practices and other structures.
- The barrier preventing the largest number of people from influencing locally is lack of knowledge about available opportunities for engaging with and influencing the new structures.
- Time constraints and limited resources also prevent many people from effectively engaging and influencing locally.
- The most common form of support that people require from the Neurological Alliance and other charities includes information resources on how the local structures operate and available routes for getting involved in their activities.

Conclusions and recommendations

Individual neurological charities, the Neurological Alliance, NHS England, local commissioners, local Healthwatch and politicians all have a role to play in responding and engaging with localism.

The vision of 'no decision about me, without me' – which we can all agree is desirable – will only be achieved with us each doing our part.[1] This includes committing time, effort and resource to equipping and supporting people affected by neurological conditions, and people who represent them, to engage in new local structures. Structures will also need to open up so they are ready and willing to hear and act on individual's views and ideas.

Neurological charities and their leaders should...

- Recognise the importance of influencing at the local level and build this into strategic planning and resource allocation. Consider the links and balance between national and local influencing.
- Inspire and invest in a new cohort of people affected by neurological conditions who are equipped, supported and confident to engage with local health and social care structures.
- Be clear on whose responsibility and role it is to 'do' local influencing in your organisation, including staff members and volunteers, and how these roles will be supported to influence effectively.
- Develop capacity to collect and use data to influence locally.
- Sign a pledge for working pan-neurologically at the local level.

The Neurological Alliance should...

- Develop a pledge for working pan-neurologically at the local level and support collective work on issues that affect different groupings of neurological conditions.
- Map what is already happening locally, such as members' existing assets, projects, and plans for the future.
- Help members to articulate their individual and collective offers to local commissioners and decision-makers, including by providing forums and opportunities to share good practice and develop joint approaches.
- Continue to develop neurological health and social care data and tools that support the use of data by members locally as well as nationally.
- Put together a taskforce to scope the patient leader role.
- Invite patient participation officers/managers within CCGs and managers of local Healthwatch to a roundtable to discuss the opportunities/barriers in participating in local decision-making.

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[1] Liberating the NHS: No decision about me, without me (December 2012) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf

NHS England should...

- Commit adequate resource to develop support, tools and resources to make the localism agenda work for people affected by neurological conditions, including through their representatives in the voluntary sector.
- Host a summit to consider the specific needs of the neurological community and barriers they face to engaging effectively in the localism agenda.
- Support the spread of good practice, including local partnerships leading to service change, through central communications and guidance.
- Review the involvement of people affected by neurological conditions at Strategic Clinical Network (SCN) level.
- Ensure the Compact (which set out the principles for partnership working between the voluntary and community sector and public sector bodies) is promoted across the new NHS landscape.

Public Health England

- Continue to develop the data available on neurological conditions, services and outcomes through the Neurology Intelligence Network and ensure this is linked to the activities of the Neurosciences Specialised Commissioning Clinical Reference Group and SCNs.
- Commit to additional funding to develop support, tools and resources to make the localism agenda work for people affected by neurological conditions and their representatives.

Local commissioners should...

- Commit to involving people affected by neurological conditions in their planning processes in a meaningful way.
- Commit to additional funding to develop support, tools and resources to ensure people affected by neurological conditions are able to engage effectively.
- Assign a neurological conditions lead to each CCG.
- Include an assessment of neurological needs in the Joint Strategic Needs Assessment (JSNA).
- Consider themes that are particularly pertinent to neurological conditions within their HWS, and work with the local neurological community to develop these further.

Local Healthwatch should...

- Commit to understanding the specific needs and barriers faced by people affected by neurological conditions and involve as many people as possible in wider activities in a range of meaningful ways.
- Convene regular meetings with people affected by neurological conditions and their representatives to consider key concerns in your local area and feed these back to the Department of Health, NHS England and Care Quality Commission (CQC) as appropriate.

Politicians (Members of Parliament and councillors) should...

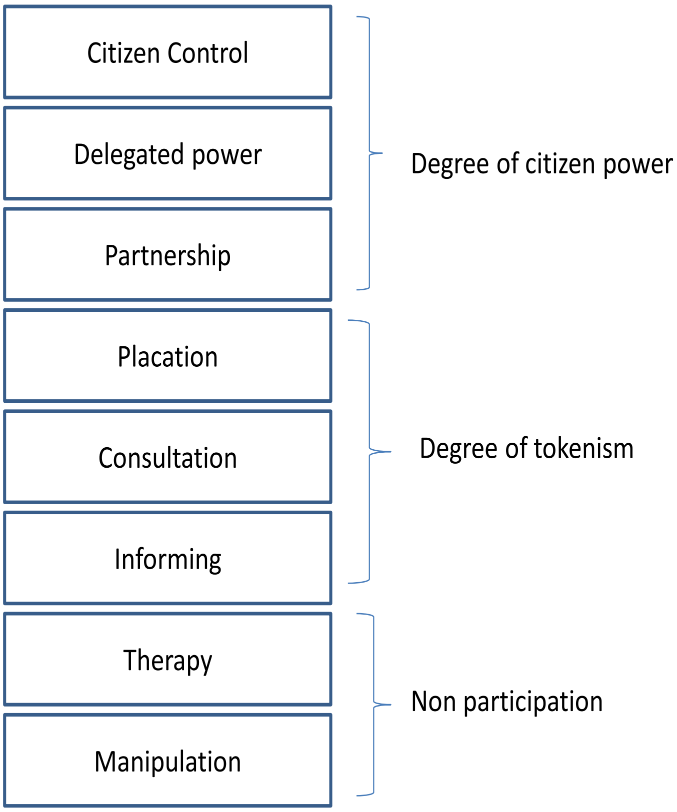
- Develop relationships with the neurological community in their local area, and draw on their understanding to guide their work on relevant policy issues.
- Develop relationships with local health and social care commissioners and facilitate opportunities for commissioners and the neurological community to work together to improve service provision.

Introduction

What do we mean by engaging and influencing?

Local engagement can take on many different forms, ranging from simply receiving a newsletter to patients sitting as a member of the CCG board. Diagram 1 shows a ‘Ladder of Participation’, a concept first developed by social scientist Sherry Arnstein in 1969.[2] The nearer the top of the ladder, the more genuinely involved people are and the greater impact they are able to have on bringing about change. For the purposes of this report, all types of engagement have been considered ranging from informing through to citizen control.

Diagram 1



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[2] Originally published as Arnstein, Sherry R. "A Ladder of Citizen Participation," JAIP, Vol. 35, No. 4, July 1969, pp. 216-224

Are we influencing effectively at the local level?

A small group of Neurological Alliance members (see Acknowledgements) came together informally from January 2014 to discuss the response of the neurological community to the localised health and social care environment, and to explore ways of working collaboratively to improve local influencing efforts.

It was agreed that a survey would be developed to establish the extent to which people are engaging with and influencing locally (Appendix 1). This was open during February and was completed by voluntary and public sector staff, volunteers, service-users and carers.

A meeting was then held on 27th March in London with a range of participants (including survey participants) to reflect on the findings and to begin to shape the recommendations.

This report reports on the survey results and on the discussions and recommendations that emerged at the successive meeting. The final recommendations have been proposed by the central steering group.

Survey respondents

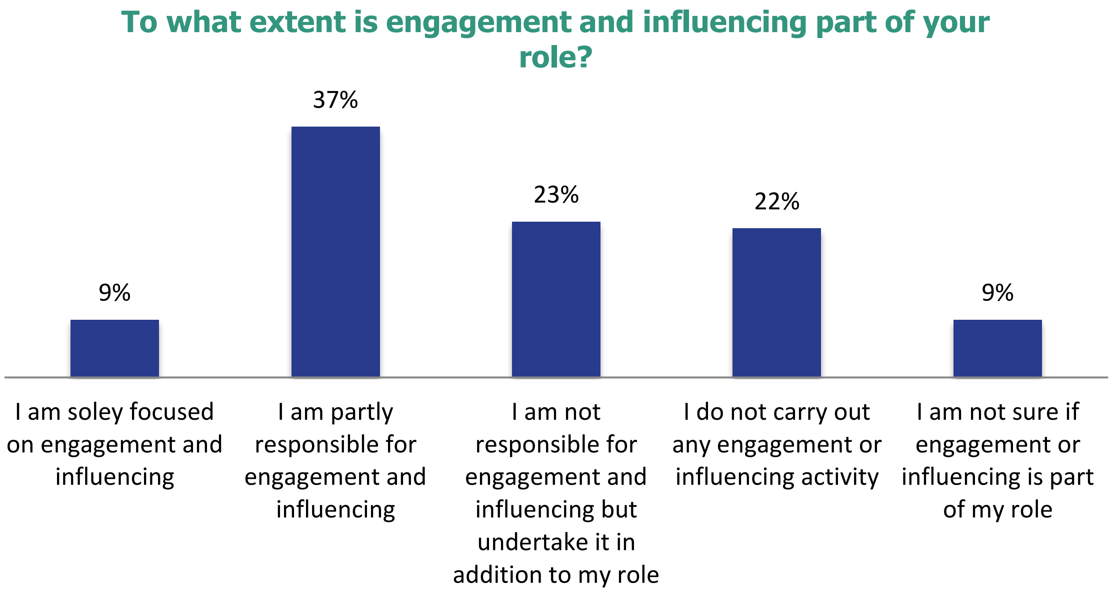
In total 160 people completed the survey, which was open to complete between 29th January and 25th February 2014. The responses were submitted by 59 members of staff, 66 volunteers and 35 others which included service-users and carers. Responses were received from all areas across England, the most being received from South East 20%, East of England 18% and West Midlands 16% (see Appendix 2).

91% of the responses were from voluntary sector staff, volunteers, service-users and carers; 3% from NHS staff and 6% unknown. (For full list of organisations see Appendix 3).

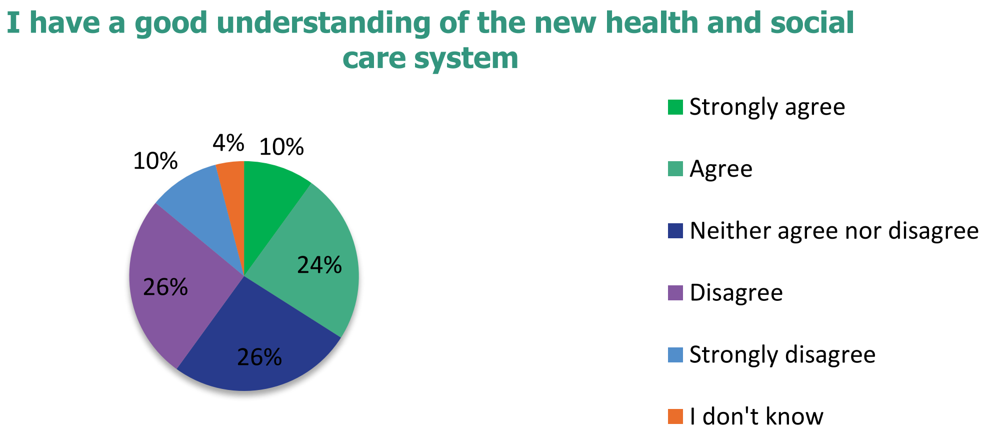
Survey Results

Role in engagement and influencing

Respondents were asked to describe to what extent engagement and influencing is part of their role. The results are presented in the chart below and clearly show that the majority (69%) undertake engagement and influencing work in some form as part of their role, in comparison to 22% who do not currently carry out any engagement or influencing activity. 9% of those surveyed are not sure if this is part of their role.



Respondents were also asked to rate their understanding of the new health and social care system since the changes were implemented from 1st April 2013 following the Health and Social Care Act 2012. A total of 34% stated they have a good understanding of the new system in comparison to 36% who stated they do not. 26% of respondents felt indifferent in their understanding of the new health and social care structures and 4% didn't know if their understanding was correct.



Overall, 47% of those surveyed stated that in their opinion engagement and influencing has become more challenging in the new health and social care structures in comparison to 9% who said it is now is easier. 19% believe it is the same as before the changes were implemented and a significant 25% are unsure if it is more challenging or easier to influence in the new system.

Engaging with and influencing GP practices

Respondents were asked to what degree they currently engage with and influence their local GP practice. 59% (94 people) stated 'not at all' in comparison to 2% (4 people) who do so to 'a great extent'. A further 39% are engaged and influence 'somewhat' or 'a little'. This shows the wide variation in levels of engagement with local GP practices across England, with the majority of those surveyed not engaged at all.

The chart below shows the forms of engagement and influencing opportunities that are available and the percentage of people surveyed who make use of these opportunities to engage with their local GP practice.

The most frequently used form of engagement with GP practices, used by 22% of respondents (33 people), is through receiving newsletters providing up-to-date information regarding the provision of GP services in their local area. Of these 33 people, 11 are staff members, 14 are volunteers and the remaining 8 are service-users and carers.

As few as 12% of those surveyed are engaged in GP patient reference groups and stakeholder events, both of which are designed to increase patient and public involvement in the commissioning and shaping of healthcare services in their local area. Only 2 members of staff are engaged in the GP reference group in comparison to 17 volunteers, service-users and carers. The results show that 10 staff members are involved in stakeholder events in comparison to 8 volunteers, service-users and carers.

Only 5% of respondents (8 people, including one member of staff and 7 volunteers, people affected by neurological conditions and carers) have been involved in their local GP practice's consultations on plans and strategies. Overall, these findings suggest that engagement with GP practices is at a low level.

A number of respondents identified other ways in which they have engaged with their local GP practice. The most common method mentioned was through volunteering at their local practice, providing information on condition-specific organisations and making GPs aware of any problems they had encountered as a service-user. Other people used their GP appointment as an opportunity to highlight any concerns they had with their care or the services being provided. Some people also stated that they indirectly engage with and influence their GP practice through their involvement with CCGs. The comments below illustrate these findings:

"Being the point of contact for condition specific information/ information distributor."

"Write to individual GPs about problems encountered as a service user."

"Through GP appointment as a patient."

"Indirectly through CCG involvement."

Respondents were asked to comment on what more they think could be done to improve GPs' understanding of the needs of those with neurological conditions locally. There was a high response rate for this question and a number of themes emerged from the data.

Firstly, respondents emphasised the importance of GP training and education on neurological conditions and the specific needs of people affected by a neurological condition. Many stated that better training and awareness of could lead to better support for self-management and, in some cases, encourage faster diagnosis and quicker provision of appropriate treatment and support. Some respondents felt that this should be a compulsory part of GPs' training and continued professional development, while others recommended that GPs attend seminars or information events provided by voluntary sector organisations working with people affected by neurological conditions.

Respondents also called for better coordination of neurological information to make it readily available and accessible to GPs supporting people with these conditions.

Secondly, the responses illustrate the need for a neurological lead within GP practices. This should be someone with in-depth knowledge of the complexity of these conditions who can keep up-to-date with the latest information and treatments available.

Lastly, respondents noted the importance of joined-up working between GPs, people affected by neurological conditions and the voluntary sector to effectively influence neurological services at a local level. The importance of patient representatives attending regular meetings was highlighted to ensure that GPs are aware of the issues associated with living with a neurological condition and can provide appropriate care. Patient representatives can also help to 'signpost' people affected by neurological conditions to other organisations that can offer them support.

"Training on the specific needs of patients with neurological conditions and statutory neurological update every 3 years."

"It would be a huge benefit if they could be stringently encouraged to take up our offers of awareness and education events."

"More training for GPs to spot symptoms of conditions earlier and a better understanding of the mental health conditions that sometimes accompany neurological conditions."

"A better co-ordination of information of all neurological conditions as they already have so much on their plates, I feel they need one point of reference to boost their understanding."

"It would be helpful if each practice had a lead GP for neurological conditions, who could keep up to date on clinical issues and influence commissioning of services."

"They need to be made aware of local support available to patients from charities and voluntary groups."

"Recruit patient representatives and ensure they are invited to take part in regular meetings."

I think GPs should consult/attend events held by charities in their area in order to find a way to work together to inform each other and help those people with Motor Neurone Disease."

However some of those surveyed are satisfied with the care they have received from their GP and did not suggest any recommendations for improvement.

"My personal experience with my GP is satisfactory and provides plenty of evidence that Dr has sympathy and support for stroke survivors."

"Not sure anything is needed. In my experience the GP always responds to any issues I have raised."

Engaging with and influencing CCGs

Respondents were asked if they know what a CCG is, to which 82% (131 people) said yes and 18% (29 people) said no. They were then asked the amount of engagement and influencing they currently have with their local CCG. A plurality (48%, or 76 people) said 'none at all' in comparison to 8% (13 people) who said they are engaged 'to a great extent'. 22% of participants stated they were engaged either 'somewhat' or 'a little'.

The chart below presents the percentage of people who are engaged in each forum that is available to influence local CCGs.

The results presented in the table above indicate that levels of engagement and influencing are higher at CCG level than in GP practices. Of those participating in consultations on plans and strategies, 17 are members of staff, 12 are volunteers and 4 are service-users and carers. Unlike GP practices, staff members are more engaged in this area than any other group.

Stakeholder events have a higher level of engagement than any other forum for CCG involvement. A total of 26 members of staff have used these events to influence neurological services, in comparison to 12 volunteers and 9 service-users and carers.

Engagement with voluntary sector or patient representatives was equal among staff and volunteers surveyed (18 people each). However, only 8 service-users and carers are engaged with these representatives.

20 staff members and 15 volunteers receive CCG newsletters compared to only 6 service-users and carers, which suggests that the latter groups may be unaware of or unable to access these mechanisms.

Some respondents reported other methods by which they engage with their local CCG. The most common was to do so collectively through neurological networks, such as regional Neurological Alliances and other stakeholder groups. Some respondents saw this as the most effective way to influence neurological services in their area, as individual engagement at CCG level is often difficult to obtain. However, a few respondents have had direct contact with their commissioners to discuss specific issues. Others engaged with CCGs by regularly checking their local CCG website to read their board papers, and by contacting them via email.

This wide and varied level of engagement with CCGs demonstrates how different people's experiences are across England. The quotes below support these findings:

> *"Influencing through neuro networks, individual engagement is impossible."*
>
> *"Regularly checking their website & board papers."*
>
> *"Neuro stakeholder groups; contact with individual commissioners."*

Respondents were also asked to give their opinion on what more could be done to ensure CCGs better understand the needs of those with neurological conditions locally. The responses were similar to those given about GP practices. More training, awareness raising and a clinical lead for neurology were considered a priority by the majority of those surveyed. However a number of other recommendations were also discussed. These included the need to capture local neurological data on the numbers of people affected by these conditions, and the cost of their care and treatment. This was considered by a significant number of people as necessary to demonstrate the scale of the problem and to provide an evidence base for allocating the resources needed to treat neurological conditions effectively.

Stronger engagement networks between CCGs, health and social care professionals, the voluntary sector and service-users was considered by many to be essential to achieving better neurological care locally. The voluntary sector can demonstrate what effective services look like while also opening the communication between CCGs and service-users (either directly or by providing evidence such as case studies and patient testimonies). Furthermore, respondents noted that the voluntary sector has a key role to play in educating, signposting and encouraging their members and supporters to become engaged with CCGs.

It was noted that some people with complex neurological conditions have difficulty with physically attending stakeholder events and meetings with CCGs. Consequently, it was suggested that commissioners should be willing to attend local support groups to hear their views first-hand. These findings are demonstrated by the quotes below:

> *"Good up to date information that includes demographic information to demonstrate the incident of conditions locally- when budgets are tight it is important to help demonstrate the range of care & treatment options for neurological conditions and the effect on outcomes if they are to compete successfully for resources."*
>
> *"Present CCGs with incidence and prevalence figures for neurology and hospital admissions data particularly the length of stay which can be persuasive."*
>
> *"More engagement with the voluntary sector, which can demonstrate what effective services look like and where there are presently gaps. Working alongside the CCGs to innovatively bridge these gaps."*
>
> *"Often people with neurological conditions find it difficult to complete surveys or attend centralised meetings, CCGs could attend local support groups to hear views."*

Engaging with and influencing HWBs

When participants were asked if they knew what a HWB is, 62% (99 people) said yes and 38% (61 people) said no. This shows that people surveyed are more aware of CCGs than HWBs.

Respondents were then asked to state the level of involvement they currently have with their local HWB. 71% (114 people) answered that they were 'not at all' involved, while only 2% (3 people) stated 'to a great extent'. 11% (18 people) are engaged 'somewhat' with HWBs and 16% (25 people) 'a little'. In comparison to GPs and CCGs there is a significantly lower level of engagement with HWBs.

The chart below shows the types of engagement those surveyed are involved in with HWB.

The most common form of engagement is receiving information via Healthwatch, with 19 members of staff, 11 volunteers and 6 service-users and carers involved in this activity. However, only 23% of those surveyed are engaged in this way.

Similar numbers are engaged in stakeholder events and receiving newsletters, including 15 members of staff, 7 volunteers and 4 service-users and carers. This represents a much lower figure in comparison to GP practices and CCG engagement forums.

Involvement in consultations on plans and strategies and working with patient, public or voluntary sector representatives both have a very low engagement level overall, with only 8% reporting involvement in these forums. Members of staff are more active in these forums in comparison to volunteers, service-users and carers; however, only 8 out of the 59 staff members surveyed take part in these activities.

A very small percentage of people surveyed engage in some other form of activity with HWBs. One person stated they have contacted leads for neurology in some areas and another said they are involved with their local council support group.

Respondents were asked to comment on what more they think could be done to ensure HWBs better understand the needs of those with neurological conditions locally. Again, respondents prioritised better education and understanding of neurological conditions and their impact on individuals, as well as the need for a ‘champion’ of neurology to steer the agenda.

A large proportion of people also said that there needed to be better promotion of HWBs locally, because many people in the community are unaware of their existence and their integral role in the new health and social care structures. This restricts the level of patient engagement with the new system and limits neurology representation.

In addition, the importance of neurology being a part of the JSNA locally was discussed by a significant number of participants. Some stated that this would encourage local prioritisation of neurology services, but would only be realistic if there was data available to demonstrate the incidence and prevalence of neurological conditions in the community.

One other strong theme to emerge is the need to provide HWBs with factsheets to identify key issues in neurological services locally, and to encourage GPs, CCGs and HWBs to discuss these regularly in order to make neurological conditions a priority. The quotes below illustrate these findings:

> *“More publicity is needed around HWBs existence and role and real efforts to reach out to all sections of the community and get them to engage.”*
>
> *“They need to inform the public about what they do and how they can be contacted. Currently most people and many relevant organisations don't know of their existence. This is not good enough given that HWBs have a crucial role to play in the new NHS.”*
>
> *“Neurology has to be in the JSNA so there is better understanding of neurology, collection of data by condition.”*
>
> *“Provide some factsheets and some quick wins, identify some key issues and provide data. Gather GPs, CCGs and HWB together on a regular basis.”*

Engaging with and influencing local Healthwatch

60% (96 people) surveyed replied yes when asked if they knew what a local Healthwatch is and 40% (64 people) said no, similar to the results for HWBs. The majority (62%) have no engagement at all with their local Healthwatch, in comparison to 4% who engage and influence to 'a great extent'. 21% are engaged 'a little' and 13% 'somewhat'.

The chart below displays the level of engagement in local Healthwatch structures of those surveyed.

The most prevalent form of engagement with local Healthwatch is through receiving their newsletters (received by 21 members of staff, 17 volunteers and 10 service-users and carers). However, they are received overall by only 30% of those surveyed.

Stakeholder events are attended by 20% of people surveyed (16 members of staff, 13 volunteers and 3 service-users and carers). This represents a very small amount of service-user involvement in influencing local Healthwatch, considering its purpose is to increase patient input into the design and implementation of local health and social care services.

Similarly to GPs, CCGs and HWBs, engagement with consultations on plans and strategies is very low. Only 8% of respondents (13 people) are involved in this process, none of whom is a service-user or carer.

Only one other form of engagement with local Healthwatch was identified by respondents. This involved organising an event so that their local Healthwatch could gain feedback on their local social care services from consumers.

When asked how local Healthwatch could improve their understanding of the needs of those with neurological conditions, respondents mentioned the same points that were expressed regarding GPs, CCGs and HWBs. The consensus of those surveyed is that there is a lack of awareness of local Healthwatch's existence and the role it plays in developing health and social care services locally.

Some respondents also called for an increase in the number of stakeholder events better promotion of these within the community (for example in GP surgeries) with the relevant professionals in attendance. A few also stated that local Healthwatch should have a role in running or supporting specific campaigns, and that local Healthwatch organisations could set up and lobbying groups or sub committees. These findings are illustrated by the following quotes:

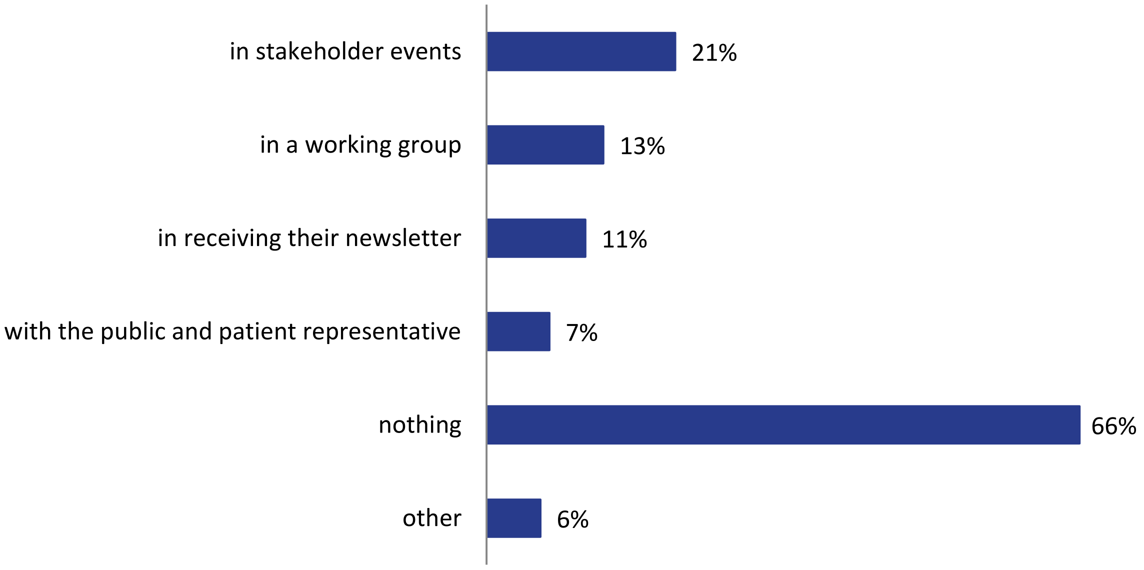
> *"More stakeholder events, with a specific focus, ensuring the invitation to participate is distributed via relevant voluntary organisations, PPGs, GP surgeries and specialist nurse etc."*
>
> *"Set up a lobbying group or a sub-committee of Health Watch."*
>
> *"Local Healthwatch could help with campaigning for our service."*

Engaging with and influencing SCNs

Respondents were asked if they know what a strategic clinical network for dementia, mental health and neurological conditions is. 58% (93 people) said yes and 42% (67 people) said no. This demonstrates SCNs are the least well-recognised of all the new health and social care structures included in this survey. It is not surprising therefore that when asked to state their level of engagement with SCNs, a substantial 66% replied 'none at all,' in comparison to 4% who said 'to a great extent'. Only 13% stated they are engaged 'a little' and 15% 'somewhat'. Overall, this represents a low level of engagement with SCNs among members of staff, volunteers, service-users and carers.

The chart below shows the types of engagement those surveyed are involved in with SCNs.

In my local SCN I am engaged in…



Overall, engagement and influencing with SCNs is low. Unlike the other structures covered previously in this report, stakeholder events are the most used forum for engaging with SCNs. Once again however service-user and carer involvement is minimal with only 2% (1 person) surveyed having been to one of these events, in comparison to 24 members of staff and 8 volunteers.

SCN working groups largely consist of staff engagement; 15 members of staff are involved with them in comparison to only 2 volunteers and 3 service-users and carers. This suggests that staff members may have better access to these forums. Unlike the other structures, newsletters are not obtained by a significant number of people surveyed but, of those who do receive them, members of staff are the majority.

In total only 11 out of the 160 people surveyed are engaged with the public and patient representative at SCN level and there is very little difference between staff and volunteers.

2 people stated that they are currently engaged with an SCN as a member of its steering group. However, it is unclear what this activity involves and if any actions have been taken as a result of this group.

Respondents were asked to give their opinion on what more could be done to ensure SCNs better understand the needs of those with neurological conditions locally. A significantly smaller number of responses were received for this question than others. However, most responses discussed points already raised in connection with GPs, CCGs, HWB and local Healthwatch, such as the need for better awareness of SCNs, higher awareness of neurological conditions and related issues among SCNs, and increased patient involvement.

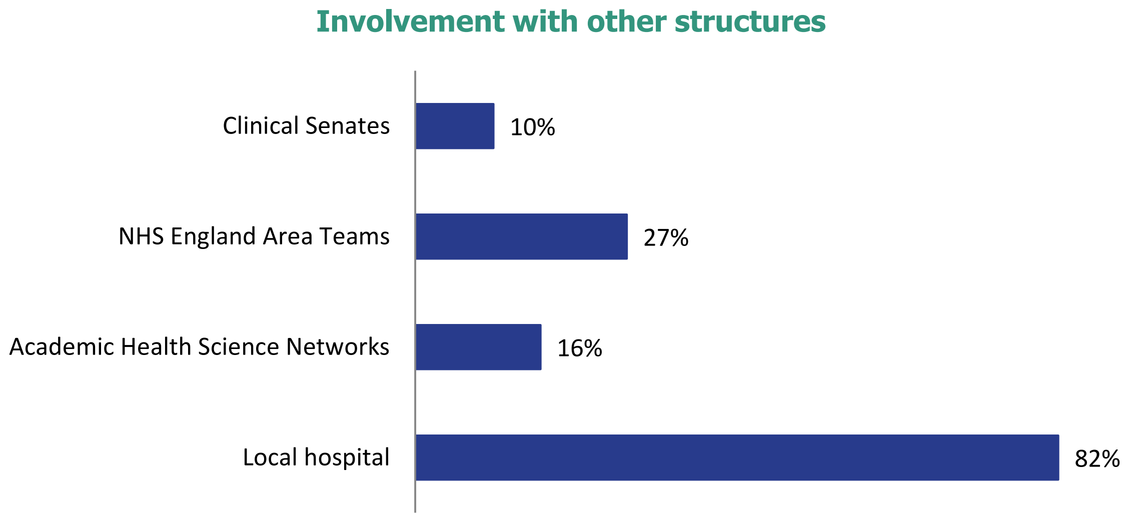
Furthermore, a number of respondents highlighted the need to share information and best practice around patient pathways among all stakeholders. This links to other discussions around better communication between all groups in the SCN and across the country, working together to improve neurological care locally and highlighting any disparities between SCNs. However, one respondent noted that the current method of 'mapping services' was too time consuming and another more effective approach needed to be taken.

A small number of people surveyed said that due to the complex nature of neurological conditions, they should be separated out from mental health and dementia to have a higher level of priority and recognition. The quotes below illustrate these findings:

> *"To make sure information is passed/ shared with all those involved. To look at good practice going on across the country and to ensure this is shared with everyone so that people no longer work in silos. That time is not wasted trying to work out how to do things that are already happening."*
>
> *"The initial agenda is to 'map existing services', which is taking too much time and has all been done several times before, then filed and forgotten."*
>
> *"Neurological conditions should be separate from mental health and dementia."*

Other structures

There are a number of other structures that have mechanisms to engage with and influence locally. A total of 65% of respondents (104 people) indicated that they had involvement with one or more of the structures displayed in the chart below.



26 staff, 23 volunteers and 14 service-users and carers engage with their local hospital, making it the most widely engaged with of the structures listed in the above chart. This is a significant finding as it demonstrates a much higher proportion of service-user and carer engagement than any other of the structures included in this survey. Involvement with local hospitals varies from participation in stakeholder and patient groups, discussions with hospital managers, clinical leads and nursing staff to volunteering activities including ensuring that relevant condition-specific information is available on information stands.

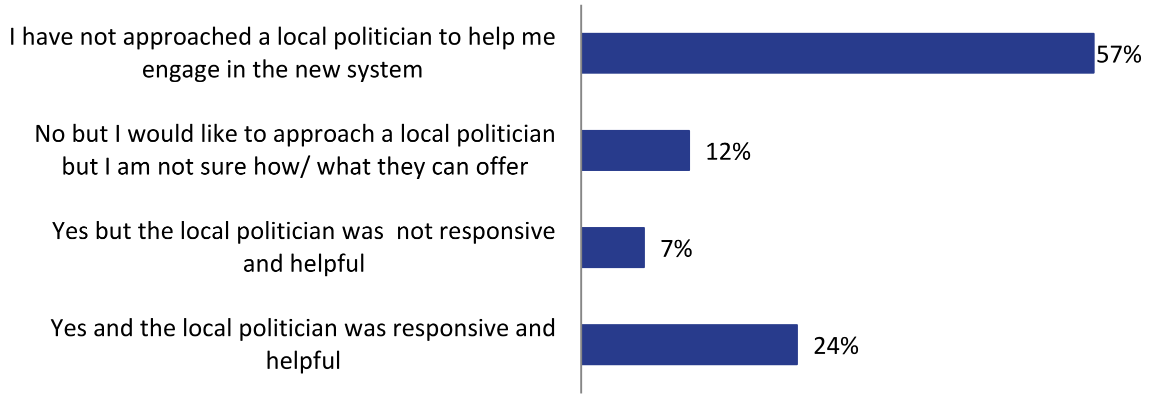
The findings indicate that it is predominately staff (14 people) who engage with NHS England Area Teams, in comparison to 5 volunteers and no service-users or carers. This is not surprising considering the role of Area Teams in contract management. Similarly, Academic Health Science Networks have a very low level of engagement overall with only 7 members of staff and 4 volunteers involved with their work. This is perhaps surprising considering their role is to translate research into practice to deliver integrated health care services through building networks and sharing best practice.

Clinical Senates have minimal engagement with those surveyed (5 staff and 3 service-users and carers). This is also a notable finding considering the role of Clinical Senates is to link clinical expertise with local knowledge of the kind provided by charity organisations and patient groups. This low level of engagement may reflect the difficulty and complexity of engaging with the wide range of structures involved in the new system.

Engaging with local politicians

91% of people answered this question, of which 57% have not approached a local politician to help them with engaging in the new system. 24% (35 people) who have contacted their local politician found them to be responsive and helpful. This demonstrates that this type of approach can potentially help to make engaging and influencing more effective in the new health and social care system.

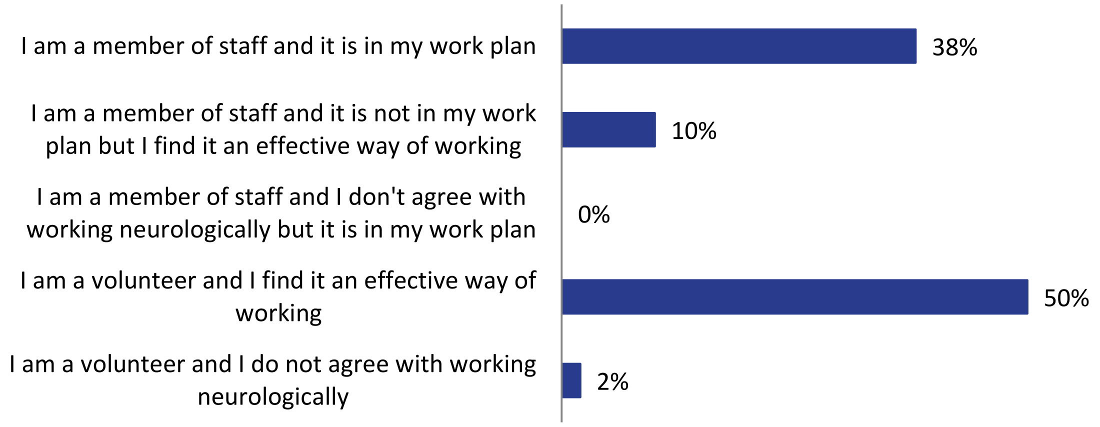
Have you approached a local politician?



Working neurologically

64% of those surveyed work in collaboration with other neurological organisations and 36% do not. The chart below shows why people work across neurological conditions either in their capacity as a member of staff, volunteer, service-user or carer.

Why do you work across neurological conditions?



The majority of staff members surveyed said they work across neurological conditions because it is in their work plan, compared to 10% who do this even though it is not part of their work plan but do so because it is an effective way of working. No member of staff surveyed disagreed with working in this way to improve neurological services at a local level. 50% of volunteers find this approach, effective compared to 2% who do not agree with working in this way.

In addition to this, many people offered further explanations as to the benefits of working across neurological conditions rather than taking a condition-specific approach at all times.

Firstly, a large number of people discussed the importance of collaborative working in order to have a greater impact on influencing services locally. They highlighted the commonality of many neurological conditions with regards to symptoms and impact on the individual and their carer. Working across neurological conditions enables neurology to have a stronger voice and a greater impact when engaging with and influencing at CCG level as commissioners do not focus on specific conditions when planning local services. Furthermore, it was stated that focusing on common aspects of neurological conditions results in better implementation of effective services. A pan-neurological approach is able to represent a larger group of the population, with potential for more widespread improvement in wellbeing outcomes and larger efficiency savings. These are factors that appeal to commissioners.

Secondly, a significant number of people highlighted the cost effectiveness of working across neurological conditions. In particular, this enables smaller charities, often representing rare neurological conditions, to use their limited resources more efficiently. It also enables them to have greater powers of influence and to reach a wider audience.

Thirdly, the importance of sharing best practice and local knowledge emerged as a strong theme. Emphasis was placed on the value of joint working on projects, such as defending specialist nurse posts or developing commissioning tools to influence effectively at local level. Many people referenced the benefits of being a member of the Neurological Alliance, which can campaign on their behalf and has access to specialists that can influence neurological services.

Lastly, the majority of volunteers, service-users and carers take this approach because of personal or family experiences of living with a neurological condition. They want to offer help and support to others who are affected in this way and believe that speaking as a neurological patient representative is helping to improve services. Some respondents felt that their perspective added more value when supported by that of others with different condition-specific experiences.

It is important to note that not everyone agreed that working pan-neurologically is effective. Some respondents observed that not all issues are the same for all neurological conditions and there are times when specialist input is required to avoid diluting key messages.

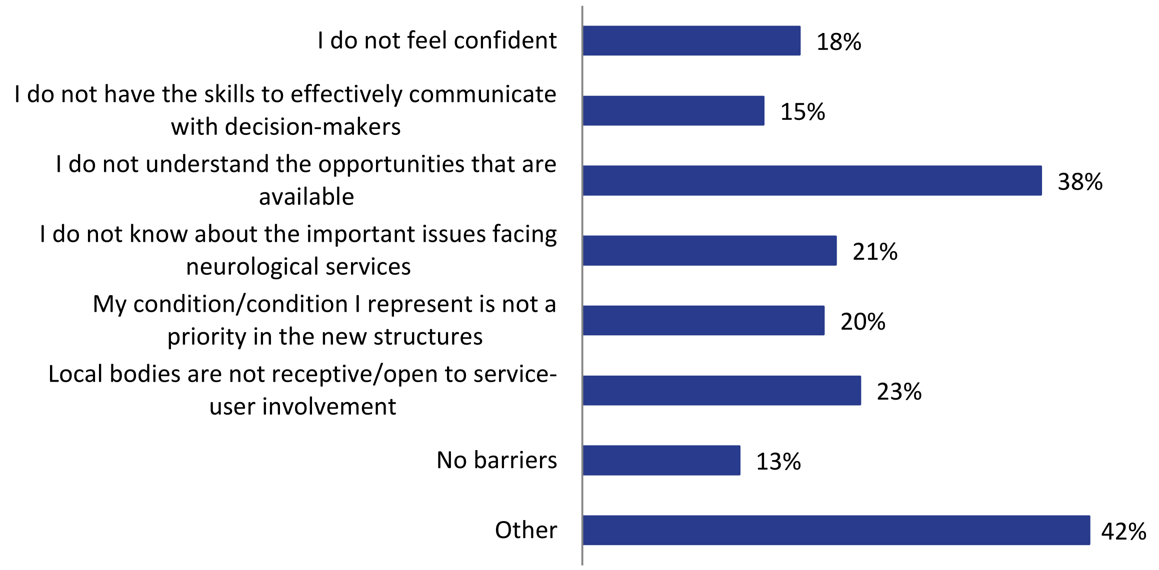
> *"Absolutely, collaborative working has become the main approach for my work. We are more appealing to commissioners as a collective voice, and the consultations we engage in can be reflective of a united voice if we work together, strength is definitely in numbers."*
>
> *"Local incidence of many neurological conditions is small so joint working widens influencing power and access to resources; sharing good practices."*
>
> *"By taking a more generic approach, we can improve equity of access, establish more holistic care pathways and more importantly, encourage people to self-manage in a better capacity if they are better informed."*
>
> *"The Neurological Alliance, in particular, gives us a voice and supports smaller organisations such as ours."*

> *"Being an MS patient, as such I have found that my perspective and experience is of value when added to that of health professionals and others from different condition specific experience."*
>
> *"Yes and no. Some patient issues are the same - others are not generic and require specialist input."*
>
> *"I'm saying yes, I agree that a united front is better, but as neuro conditions are so diverse, it can sometimes dilute the message."*

Barriers to influencing locally

The chart below demonstrates the barriers people are facing in effectively engaging with and influencing neurological services locally.

Barriers to effectively engaging and influencing locally



The most common barrier, faced by 38% of respondents (60 people), is lack of knowledge about available opportunities to engage with and influence the new structures. A further 23% (37 people) feel that local bodies are not receptive to service-user involvement, while 20% (32 people) believe their condition/the condition they represent is not a priority within the new system. The results also indicate that a significant number of people do not feel able to engage as they are representing a single neurological condition.

18% of respondents (28 people) do not feel confident in engaging with the new structures and a further 15% (24 people) believe that they do not have the skills to effectively engage with decision-makers. In addition, 21% (33 people) are unsure about the important issues affecting neurological services locally. This lack of understanding and confidence could potentially impact on an individual's ability to work with these structures to improve neurological services at a local level. The quotes below demonstrate these findings:

> *"My biggest barrier is finding the right person within the new structures with whom to meet."*
>
> *"More needs to be done to 'open up' the opportunities to influence the new NHS - there's still a lack of knowledge and awareness. The whole system can feel very complex and hard to understand - a minefield really."*
>
> *"I do not have the authority to engage with decision makers at a local level."*
>
> *"Involvement would mean education and confidence. You can only achieve these through experience and information, and achieve a voice."*
>
> *"Neurological conditions can fall between gaps because they are 'low volume' in CCG local population terms - not enough for CCG to prioritise them."*

41% (66 people) of respondents identified 'other' barriers that prevent them from effectively engaging and influencing at a local level. Firstly, time and resource constraints were identified as problematic. The findings suggest that these issues are common with smaller charities, many of whom have part-time staff that are unable to dedicate large amounts of time to influencing locally. Some respondents stated that the lengthy process of engagement with the new structures means that it is not always an effective use of their time and resources and could mean they would have to drop something else (such as providing information or care) in order to prioritise local influencing work.

It is clear that volunteers play a key role within these smaller organisations, but there is a lack of sufficient resources to support them in this capacity. Some respondents suggested that we could maximise our resources as a sector by focusing on where opportunities to influence present themselves (bodies being willing to engage easily) and where the care issues are the most problematic. There was also recognition of a need for strategic direction from Chief Executives of charities within the Alliance, affirming that focusing on local influencing is important and should be prioritised.

In addition, a number of people highlighted the difficulty service-users and carers have in engaging with the new structures. The nature of neurological conditions can have a great impact on everyday life, affecting energy levels, motivation and ability to travel. This makes it increasingly difficult to be able to attend events organised by CCGs, HWBs and local Healthwatch.

Furthermore, carers experience similar issues with tiredness, stress, working and time constraints. Carers often have a great deal of responsibility, and the need to manage these issues on a daily basis often makes it extremely hard to effectively engage and influence at a local level. Some suggested that organisations could provide funding to support these groups to participate. The responses below illustrate these findings:

> *"The greatest barriers to engagement for me are time and access - this engagement is a lengthy time consuming process when covering a number of CCGs and reluctance on their part just means leaving it and moving on those that are receptive."*
>
> *"I do not have time in the current contract of hours to take on more work."*
>
> *"Mainly resource issues with us being a relatively small charity. Though we do continue to communicate news about the new system to members."*

> *"My medical condition makes it difficult for me to become active in these matters. I work to my limit in my capacity as a volunteer."*
>
> *"It is important to recognise that the barriers to attendance could be access, cost of travel etc......so it is important that funding is available to enable engagement."*
>
> *"As a parent carer of a child with neurological conditions, I am exhausted by the daily difficulties and stresses which come as a result of the conditions combined with trying to work part time, ensure that my daughters educational needs are being met, which leaves me under- resourced and lacking in motivation to effectively engage with additional structures."*

Additional support

Respondents were asked what support they needed from the Neurological Alliance and other charities to ensure they are effectively engaging with and influencing the new health and social care structures. The strongest theme to emerge was support in the form of information resources on how to become involved in local influencing. The emphasis was on the need for concise, easy-to-navigate information either in booklet, leaflet or map format, clearly demonstrating who to contact within the structures and identifying the opportunities that are available to engage and influence.

Many people stated that the current system is complex and they are unaware how all the new structures work together and asked for briefing materials on this. Some people highlighted that a step-by-step guide to engaging and influencing locally would be beneficial to volunteers within their organisations.

In addition to this, some felt it would be useful if the information regarding the new structures could be provided by locality, identifying key people in each area to approach to influence neurological services. Also, a number of respondents expressed an interest in attending a training day on local influencing where they could gain practical information on the most effective way to work within the new health and social care structures.

A significant proportion of people surveyed discussed the need to share best practice and the value of case-studies demonstrating when local influencing has been effective. Many felt that this information would be useful when developing their organisational plans to support local influencing.

Alongside these points, respondents highlighted the need to be informed regularly about what other charities are doing to influence commissioners and support their members to undertake these activities. The following quotes demonstrate these findings:

> *"I need a 'map' of the new framework and some suggestions as to how to access it."*
>
> *"Provision of relevant information, contacts and 'door opening' opportunities."*
>
> *"Network charts, so we can easily understand where each bit of the health service fits."*
>
> *"A guide to places in the structures where there are opportunities to engage."*
>
> *"Information on who are the best people to engage with in specific areas."*

"Perhaps a day's training and suggestions of where it is time effective."

"I think a comprehensive but step by step guide would be useful for us to share with our audiences especially our volunteers."

"Simple guide to who does what in each area, and how they link together."

"Easily accessible and digestible information, particularly info that be accessed and acted on remotely (for example, links to websites to contact people/organisations remotely, links to templates to lobby people)."

"Info and updates on changes. Examples of where things have worked well - case studies etc."

"Reports on success and failure of influencing to date."

"Update on what other charities or influencers are planning to do so that we can act together at every opportunity. And consider how our service users can mutually benefit from the requests."

Conclusion

In conclusion, the majority of people surveyed take part in engaging and influencing in one form or another. However, most feel that this has become more challenging since the introduction of the new health and social care structures in April 2013.

The survey findings clearly demonstrate that staff members have a higher level of involvement in influencing activities within the new structures than volunteers, people affected by neurological conditions and carers (with the exception of GP practices). The most widely-used engagement forum varies between structures, but receiving newsletters and other information as well as attending stakeholder events are the most common forms overall.

A considerable percentage of people, including staff, volunteers, service-users and carers are unaware of HWBs, local Healthwatch and SCNs across the country. This provides an explanation for the relatively low level of engagement within these structures, in particular for service-users and carers. A significant percentage of people are engaged in local hospital influencing activity, especially service-users and carers. This suggests that this is an accessible structure to those in the local community and that forums to undertake this activity are well promoted and publicised in appropriate settings.

The smallest level of engagement is with Academic Health Science Networks, Clinical Senates and Area Teams, and the findings indicate that this is a result of a lack of awareness of these structures. A small number of respondents have approached local politicians to seek their support in engagement and influencing activity, and overall this form of engagement is viewed positively.

The majority of people surveyed work across neurological conditions because they find this to be very effective. It enables them to work collaboratively to use their resources efficiently and to plan activities to improve local influencing activity within their organisations. It allows them to have a greater impact to influence services as together they represent a much larger group of people, giving them more influence with commissioners and other stakeholders.

In terms of how the new health and social care structures can better understand the needs of neurological conditions locally, a number of common themes emerged from the data:

- Better awareness of neurological conditions and the impact on individuals and their carers is considered a priority by most of the people surveyed. Respondents emphasised the need for health professionals (particularly GPs) to have more training and education on the range and complexities of neurological conditions. Many considered patient involvement as key to achieving this and called for people affected by neurological conditions to be encouraged and supported to be proactive in these structures. Similarly, a neurological conditions lead or champion within GP practices and other structures emerged as a strong theme.
- Data collection was mentioned by a large volume of people as essential to keeping neurological conditions on the health agenda and making them a higher priority to commissioners and health and social care professionals. Some stated this information would be appealing to commissioners who could then be fully informed on the size and scale of neurological conditions locally. This also links to the recommendation of including neurological conditions in the JSNA.

A number of barriers to effectively engaging with and influencing locally were highlighted.

- The barrier affecting the greatest number of people is a lack of knowledge about the new structures and the mechanisms by which staff, volunteers, service-users and carers can engage with them. Many people are unsure how to approach these organisations to be involved in their activity. In addition, respondents reported a lack of confidence and negotiation skills to interact with decision-makers.
- A key finding is that engaging and influencing activity is made substantially harder by representing one specific neurological condition and many people feel that their condition or the condition they represent is not a priority within the new structures. This reinforces the need to work across neurological conditions in order to have a greater impact on improving neurology services locally.
- Time constraints and limited resources are issues many people face when engaging and influencing locally. In particular, smaller charities are unable to dedicate sufficient amount of time to this activity, which is often a lengthy process, as many staff members work on a part-time basis and already have heavy workloads. Furthermore, they struggle to offer the necessary support to their volunteers to enable them to be involved in this work.
- People affected by neurological conditions have difficulty in being involved in local influencing work as a result of the impact their condition has on their everyday life and their ability to physically attend events as a patient representative. Similarly, carers are finding it hard to balance local engagement with their caring responsibilities.

The most common form of support required from the Neurological Alliance and other charities includes information resources on how the local structures operate and the available routes to get involved in their activities. Many people want this information in the form of booklets, a map or a step-by-step guide that could be useful to staff, volunteers, service-users and carers. Furthermore, training days appealed to people across all sectors as a way to improve their knowledge base and increase their confidence to get involved in influencing activities.

Importantly, the survey results suggest that staff and volunteers, as well as service-users and carers, find the new health and social care structures difficult to engage with on a condition-specific level. Collaborative working across neurological conditions is therefore an essential tool for improving neurological care and support locally. The voluntary sector will have a key role to play in supporting cross-condition working and raising awareness of the common issues affecting neurological conditions in the health and social care system.

In addition, there is a clear need to improve understanding and awareness of available routes to engage with and influence the system at the local level. It is vital that key stakeholders both within the system and outside it work together to support people affected by neurological conditions, carers, staff and volunteers to engage effectively with the restructured system. Only by drawing on their experience and expertise can we ensure that the health and care system understands the complex needs of people affected by neurological conditions and meets them effectively.

Appendix 1 – the survey questions

Neurological Alliance - Engaging and influencing locally

The changes to the health and care system mean that many services accessed by people with neurological conditions are being planned locally rather than by national decision makers. The new system also emphasises the importance of involving patients and the public in developing services. The Neurological Alliance would like to understand more about the extent to which local staff, volunteers and people with neurological conditions are able to influence improvements to neurology services locally. We also want to hear about what support you might want to develop this activity in the future.

The new health and care system introduced many new bodies and organisations – including clinical commissioning groups, Health and Wellbeing Boards, Healthwatch and strategic clinical networks. We refer to many of the new bodies in this survey. We want to know about areas where engagement and influencing is working well. Equally however, we know the new system can be confusing. We want to hear where people need support to understand the different roles of the new organisations and how to engage and influence.

(We want to assure you that your responses to the questions in this survey are completely anonymous. No personally identifiable information is captured unless you voluntarily offer personal or contact information in any of the comment fields. Additionally, your responses are combined with those of many others and summarized in a report to further protect your anonymity. We therefore ask that you provide honest answers to the questions in this survey).

Thank you for your time in completing this survey.

1) Organisation/charity affiliation

2) Your role

☐ Staff
☐ Volunteer
☐ Other (please specify):

What do we mean by engagement and influencing?

Engagement and influencing encompasses a wide range of different activities including:

- being on a mailing list and receiving information from health and care decision makers
- being invited to comment on plans through formal written consultations or one off stakeholder events
- attending groups for people affected by neurological conditions and organisations to

talk directly to decision makers

- being a patient representative as a partner on formal decision making bodies

We want to hear about any engagement and influencing activities across the range outlined above. This will allow us to assess whether the new structures are effective in enabling patient and public involvement. It will also help us to develop appropriate support to help local staff and patients to influence locally.

3) To what extent is engagement and influencing part of your role? (Please tick the most appropriate)

☐ I am solely focused on engagement and influencing
☐ I am partly responsible for engagement and influencing
☐ I am not responsible for engagement and influencing but undertake it as an addition to my role
☐ I do not currently carry out any engagement or influencing activity
☐ I am not sure if engagement or influencing is part of my role

4) What geographical region (s) does your influencing work cover? (Please tick all that apply, even if your work only covers part of a geographical region).

☐ East Midlands
☐ East of England
☐ London
☐ Manchester, Lancashire and Cumbria
☐ Northern England
☐ South East
☐ South West Coast
☐ Thames Valley
☐ West Midlands
☐ Yorkshire and Humber
☐ Cheshire and Merseyside
☐ Wessex

5) Overall, since the changes from 1st April 2013 (following the Health and Social Care Act 2012) to what extent do you agree or disagree with the following statement

I have a good understanding of the new health and social care system

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	I don't know
☐	☐	☐	☐	☐	☐

6) Since the changes have been implemented, I think engaging and influencing has become:

☐ more challenging
☐ remained the same
☐ Easier
☐ I don't know

Engaging with and influencing GP practices

7) I currently engage with and influence my local GP practice...
☐ to a great extent
☐ Somewhat
☐ a little
☐ not at all

8) In my GP practice I am engaged in...(Please tick all that apply)

☐ consultations on their plans and strategies
☐ the GP patient reference group
☐ stakeholder events
☐ receiving their newsletters
☐ nothing
☐ Other (please specify):

9) In your opinion, what more could be done to ensure GPs better understand the needs of those with neurological conditions locally?

Engaging with and influencing clinical commissioning groups

10) I know what a clinical commissioning group (CCG) is...
☐ yes
☐ no

11) I currently engage with and influence my local CCG...
☐ to a great extent
☐ somewhat
☐ a little
☐ not at all

12) In my local CCG I am engaged in…. (Please tick all that apply)
☐ in consultations on their plans and strategies

☐ with the voluntary sector or patient representative
☐ in stakeholder events
☐ in receiving their newsletters
☐ in nothing
☐ Other (please specify):

13) In your opinion, what more could be done to ensure CCGs better understand the needs of those with neurological conditions locally?

Engaging with and influencing Health and Wellbeing Boards

14) I know what a Health and Wellbeing Board (HWB) is...
☐ Yes
☐ No

15) I currently engage with and influence my local HWB...
☐ to a great extent
☐ somewhat
☐ a little
☐ not at all

16) In my local HWB I am engaged in... (Please tick all that apply)
☐ consultations on their plans and strategies
☐ working with a patient, public or voluntary representative
☐ stakeholder events
☐ receiving their newsletters
☐ receiving information via Healthwatch
☐ nothing
☐ other (please specify):

17) If you have engaged with your local HWB, please indicate which member(s) this has been with. (Please tick all that apply)
☐ CCG representative
☐ Healthwatch representative
☐ Voluntary sector representative
☐ Councillor (leader or cabinet member)
☐ Public health officer
☐ Other (please specify):

18) In your opinion, what more could be done to ensure HWBs better understand the needs of those with neurological conditions locally?

Engaging with and influencing local Healthwatch

19) I know what a local Healthwatch is...

☐ yes

☐ No

20) I currently engage with and influence my local Healthwatch...

☐ to a great extent

☐ Somewhat

☐ a little

☐ not at all

21) In my local Healthwatch I am engaged in... (Please tick all that apply)

☐ consultations on their plans and strategies

☐ stakeholder events

☐ receiving their newsletters

☐ Nothing

☐ Other (please specify):

22) In your opinion, what more could be done to ensure that your local Healthwatch better understand the needs of those with neurological conditions locally?

Strategic clinical networks

23) I know what a strategic clinical network (SCN) for dementia, mental health and neurological conditions is... *

☐ yes

☐ no

24) I currently engage with and influence my SCN...

☐ to a great extent

☐ somewhat

☐ a little

☐ not at all

25) In my local SCN I am engaged.... (Please tick all that apply)

☐ in stakeholder events

☐ in a working group

☐ in receiving their newsletter

☐ with the public and patient representative

☐ nothing

☐ Other (please specify):

26) In your opinion, what more could be done to ensure that your SCN better understands the needs of those with neurological conditions locally?

Other structures

27) There are other structures that have mechanisms to engage with and influence locally. Please can you indicate if you have had any involvement with those listed below and provide a brief description of what this entailed. (Please tick all that apply)

☐ Clinical Senates

☐ NHS England Area Teams

☐ Academic Health Science Networks

☐ Local hospital

Engaging with local politicians

28) Have you approached a local politician (elected councillors and MPs) to help you engage with the new system? (If yes, please state their name.)

☐ Yes and the local politician was responsive and helpful

☐ Yes but the local politician was not responsive and helpful

☐ No but I would like to approach a local politician but I am not sure how/ what they can offer

☐ I have not approached a local politician to help me engage in the new system

Working neurologically

29) Do you work in collaboration with any other neurological organisations?

☐ No
☐ Yes (please state which organisations below)

30) Why do you work across neurological conditions?

☐ I am a member of staff and it is in my work plan
☐ I am a member of staff and it is not in my work plan but it is an effective way of working
☐ I am a member of staff and I don't agree with working neurologically but it is in my work plan
☐ I am a volunteer and I find it an effective way of working
☐ I am a volunteer and I do not agree with working neurologically

31) In your opinion, can more be achieved by working across neurological conditions? Please explain

☐ Yes
☐ No

Barriers to engaging and influencing locally

32) Overall, are there any barriers that prevent you from effectively engaging with and influencing any structures in the new health and social care system? (Please tick all that apply)

☐ I do not feel confident
☐ I do not have the skills to communicate effectively with decision-makers
☐ I do not understand the opportunities that are available to engage and influence in the new system
☐ I do not know about the important issues affecting neurological services
☐ My condition/ condition I represent is not a priority within the new structures
☐ Local bodies are not receptive/open to service user involvement
☐ No barriers
☐ Other (please specify):

Support and other comments

33) What assistance or guidance do you need from the Neurological Alliance and other charities to support you to effectively engage with and influence local decision-makers?

34) If possible, please provide an example of where you think local influencing has been successful and has had a positive impact.
35) Finally, please provide an example of when you think local influencing has not been successful and describe any negative impact this might have had.

36) If you would like to be contacted to discuss any of the topics covered in this survey or to know the result of the survey and hear about any future initiatives being planned by the Alliance members to support patient engagement and influence, please leave an email address or contact telephone number and a member of the organisation will be in touch.

Appendix 2- Geographical region of respondents

Geographical region	Response Percent (%)	Response Total
East Midlands	12%	19
East of England	17.5%	28
London	15%	24
Manchester, Lancashire and Cumbria	11%	17
Northern England	14%	22
South East	20%	32
South West Coast	15%	24
Thames Valley	10%	16
West Midlands	16%	25
Yorkshire and Humber	15%	24
Cheshire and Merseyside	12%	19
Wessex	11%	17

Appendix 3 - Organisation responses

Organisation	Total number of responses
Bedfordshire CCG public engagement forum	1
Black Country Neurological Alliance	4
Brain Injury Social Work Group (BISWG)	1
Carers UK	1
Different Strokes	5
Dystonia Society	3
Encephalitis Society	1
Epilepsy Action	21
Epilepsy Society	9
Gain	3
Gloucestershire Neurological Alliance	2
Hampshire Neurological Alliance	1
Hounslow & Richmond Neurological Partnership	1
MND Association	31
MS Society	21
Nene Commissioning stakeholder group	1
NHS Trust Staffordshire	1
Northern Neurological Alliance	1
Parkinson’s UK	24
PSP Association	1
Staffordshire Neurological Alliance	1
Stroke Association	1
Sue Ryder	3
Transverse Myelitis Society	3
Trigeminal Neuralgia Association	1
TVDNY	2
UHCW NHS Trust	1
Unknown	10
U3A	1
West Berkshire Neurological Alliance	1
West Midland Neurological Project	2
Young Epilepsy	1

About us

The Neurological Alliance is the collective voice of more than 80 national and regional organisations working together to make life better for the millions of people in England with a neurological condition. We campaign for access to high quality, joined up services and information for every person diagnosed with a neurological condition, throughout their life.

The Neurological Alliance is a charity registered by the Charity Commission for England and Wales (registration number 1039034) and a company limited by guarantee registered in England (registration number 2939840).

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