

Working with Integrated Care Systems: issues for national charities

Background

On 17th October 2022, National Voices in partnership with NAVCA and supported by the NHS England Voluntary Partnerships team, convened a range of stakeholders to discuss how to better support national charities to work with Integrated Care Systems.

This note summarises key points raised by stakeholders in the meeting and the emerging priorities for action. A list of attendees, and the JamBoards used during discussions are included at the end of this paper.

Context

The meeting was informed by a survey and discussions with National Voices member charities. The findings were shared in the meeting, and in a paper which is appended to these notes.

Key points:

- The term “national charities” encompasses a wide range of organisations. It is sometimes used as shorthand for “large charities”, but many national charities among National Voices’ membership are small organisations that work on rare or under-recognised conditions, or with marginalised communities or sub-groups of the population whose needs can be overlooked (e.g. young people with arthritis).
- There is a strong rationale for devolution to Integrated Care Systems (ICSs) and most national charities are supportive of the change and want to make things work.
- The devolution of responsibility for both strategy and delivery to Integrated Care Systems presents practical challenges for national charities – many issues which would previously have been dealt with by engaging with one national figure or body will now require engagement with 42 separate bodies.
- There are also concerns that hard-won gains around providing more consistent and equitable access to treatment and support across the country may now be unpicked.
- There is a strong commitment in policy to involving VCSE organisations in ICSs and local VCSE Alliances are being developed to enable this work. However it is not clear how national charities (other than those with local branches) will be able to engage with these structures.

- We need to avoid pitting local vs national or small vs large charities. The diversity of the VCSE sector is its strength.

The NHS England Voluntary Partnerships Team outlined their work to support VCSE engagement in ICSs:

- The ICS design framework makes the role and value of the VCSE sector within ICSs explicit
- It recognises the need to enable the sector to have a role in strategic planning, service design and delivery
- Since 2019, NHS England has been supporting the development of VCSE Alliances which will have formal links to ICSs in every system. Independent capacity building and support has been provided through contracts with NCVO (2019-20) and NAVCA (2021-22).
- This discussion on national charities and ICSs is part of this NHSE-funded work

Key roles for national charities

Meeting participants discussed the key roles national charities could and should play within ICSs

Key roles included:

Providing services and resources

- Providing resources and services that can support people within long term conditions / improve outcomes / reduce pressures – these include commissioned services and free services such as peer support groups, information resources and helplines
- Providing resources and training to healthcare professionals

Building links and connections

- Supporting access to people with lived experience
- Providing links into communities
- Convening across different areas, and share good practice
- Convening and brokering across the VCSE sector
- Building capacity and capability within the VCSE sector and wider health system

Offering insight and expertise

- Providing specialist expertise
- Undertaking and sharing research, data and insight
- Offering expert advice around clinical pathways
- Translating policy into practice

Advocacy and campaigning

- Advocating for groups whose voices may not be heard
- Advocating for system improvements
- Advocating for the involvement of the wider VCSE sector

Key concerns were:

- That the move to ICSs may mean it becomes more difficult to make sure health system leaders are aware of the expertise and support available across the VCSE sector
- That charities which had historically struggled to make the case for action on their agenda may find it even more difficult with 42 separate bodies to influence
- That charities may find themselves having to make the case for their work from scratch – for example overcoming misconceptions of the sector – e.g. that the “voluntary” sector’s work is not robust / professional / evidence-based

A key focus of discussion was ensuring that the right mechanisms were put in place to enable ICSs to understand and access the full breadth and depth of the VCSE’s offer (national – local, big – small, health specialist – community-focused); and to help VCSE organisations understand where their input was most needed.

We identified three key areas of action:

- Making it easier for ICS leaders to find national charities with relevant expertise and resources
- Making sure that ICSs understand the full diversity of the VCSE sector and consider the full range of organisations as potential stakeholders – for example recognising national charities with specialist expertise as stakeholders in pathway redesign etc.

- Making it easier for VCSE organisations to get in touch with the right people in ICSs – potentially via VCSE Alliances

Participants shared information around ongoing initiatives and ideas for making progress:

- Sue Ryder shared a resource they had created based on enablers for ICSs working with end-of-life care providers, which may have wide application:
<https://www.sueryder.org/sites/default/files/2022-10/Key%20enablers%20for%20end-of-life%20care%20%282%29.pdf>
- The NHS Confederation held a recent webinar on ICP strategies - recording and slides are available here: <https://www.nhsconfed.org/events/watch-and-access-slides-making-sense-integrated-care-strategies>
- Larger national charities are considering how they can work with local areas to support them in engaging with ICSs – for example Barnado’s has been commissioned by one system to explore how their national team can support local delivery with capacity building etc.
- There are positive examples of national charities building collaborations locally – e.g. Rethink’s work in Somerset – but this took both a lot of work by the VCSE sector, and a shift in mindset and approach from commissioners (e.g. towards longer-term funding and supporting collaboration). ICSs may need guidance around how to engage differently with the VCSE sector to support these ways of working
- In many areas there are already strong partnerships between national and local organisations and referral pathways established between them – it will be important to ensure that commissioning processes, and pathway development enables these

A number of areas for potential collaboration were identified:

- It may be sensible for charities wishing to influence around the same issues – e.g. workforce – to come together to input collectively to ICSs rather than making multiple, fragmented approaches
- We may need a range of collaborations around different issues that ICSs might want support around – there won’t be one contact with ICSs for all of the issues around which national charities will want to engage.
- ICSs may need additional support in identifying trusted sources of advice and support among the voluntary sector – bringing information together could help to address gaps in understanding of the sectors work

Barriers and enablers for progress

Participants explored potential barriers to effective working between national charities and ICSs

Key barriers to national charity engagement identified included:

- Misconceptions of national charities role – e.g. as an alternative / in competition with local organisations rather than working alongside them
- Lack of capacity within charities to engage in 42 areas
- Lack of clarity around roles and responsibilities
- Lack of understanding and knowledge within ICSs around what support / expertise is out there
- No clear source of up-to-date information on ICS level priorities and performance

A specific concern was raised around a lack of clarity around the processes for multi-ICB commissioning and the future of specialist commissioning – which may leave charities which have historically influenced these processes with no clear way of supporting service improvement in future. There were also concerned about a loss of specialist knowledge within commissioning bodies in future.

However a range of enablers were identified – these included:

- National improvement programmes – e.g. GIRFT (getting it right first time)
- Strong relationships with medical specialists
- Regional structures within the NHS and some charities
- Existing alliances and collaborations
- Evidence around the impact of the VCSE sector
- Expertise and insight held within the VCSE sector
- National organisations' capacity to fill gaps in local provision and to offer capacity building support

Assurances were offered on a number of key points:

- Minimum standards, guidelines and directives will still be in place – while ICSs will have more autonomy they will still need to make provision in line with national standards
- A roadmap document has been published setting out plans for specialised services (https://www.england.nhs.uk/wp-content/uploads/2022/05/PAR1440-specialised-commissioning-roadmap-addendum-may-2022.pdf?dm_i=21A8,7VVXR,QZXL6D,W7GK7,1) there will be an assessment of system readiness before powers are delegated to multi-ICS-footprints and in many areas there will be joint commissioning with NHS England
- National level engagements around clinical standards and service specification will still be important, but there will be more flexibility to tailor things to the needs of local people
- Information on ICS structures and contacts will be available on the NHS England website: <https://www.england.nhs.uk/integratedcare/ics-leadership/>
- The NHS Futures Platform is an important space for sharing resources, insight and experiences from across the 42 VCSE Alliances and from ICS colleagues

Priorities for action

Our discussions identified some early priorities for action around sharing more information about emerging VCSE Alliances and sharing information about emerging ICS plans and priorities.

However to better support national organisations to engage with ICSs there is a need to do further work to improve coordination.

Specifically:

- There needs to be coordination to avoid hundreds of charities all contacting ICSs leaders or VCSE Alliances separately
- Equally we need to avoid VCSE organisations having to contact 42 ICSs separately
- It would be helpful if there could be work done to **support VCSE organisations with particular interests to prioritise those ICSs where their support is most needed** (there are some systems that are unlikely to engage in certain issues, and usually some front runners, but the focus for many charities needs to be on those who need some additional support to get things moving)
- National charities would benefit from access to a **single point of contact for information** around ICSs plans and priorities to help VCSE organisations identify where they should focus their work. This could be a role for National Voices or another umbrella body, but would require additional resource.

- It would also be helpful to support organisations working on similar themes to come together to **coordinate their input to ICSs**, to reduce the burdens on both sides

It will be important to identify ways **of creating an appropriate infrastructure to support interface between national charities, VCSE Alliances and the wider structures within ICSs**. This could include:

- An ongoing role in supporting two-way communication between ICSs and national charities – so both can share key priorities and concerns with one another
- An ongoing interface between local VCSE Alliances and national charities
- Ongoing support for national charities to collaborate around core priority areas identified across ICSs

Appendix 1: Attendees

Grace Adeyinka - Bedfordshire, Luton and Milton Keynes Integrated Care System

Rubina Ahmed - Associate Director for Systems Engagement, Stroke Association

Charlotte Augst – CEO, National Voices

Sue Brown – CEO, Arthritis and Musculoskeletal Alliance (ARMA)

Aimie Cole – Associate, National Voices

Leanne Creighton - Senior Influencing Manager, Sue Ryder

Amie Dobinson - Assistant Director of Health, Barnardo's

Louise Dooks - Regional Influencing Manager, Mind

Emma Easton - Voluntary Partnerships team, NHS England

Ceinwen Giles - Co-CEO, Shine Cancer Support

Paul Howard – CEO, LUPUS UK

Clare Jacklin – CEO, National Rheumatoid Arthritis Society (NRAS)

Carla Jones - CEO, Allergy UK

Kate Jopling – National Voices

Rachael Kitson – Senior Policy Advisor, Macmillan Cancer Support

Lubna Latif Curtis - Health Influencing Senior Officer, Prostate Cancer UK

Fiona Loud - Policy Director, Kidney Care UK

Ellis Michaels – Policy and Influencing, Stroke Association

Anne-Marie Morrison- Health and Wellbeing Manager, National Association of Voluntary and Community Action (NAVCA)

Sam Mountney - Policy & External Affairs Manager, The Neurological Alliance

Paul Munim - Health Inequalities Manager, Prostate Cancer UK

Frances Newell – Head of Partnership Development, System Transformation team, NHS England

Natalie Rogers - Founding Trustee, Long Covid Support

Gary Sainty - VCSE Programme Director, Humber and North Yorkshire Health and Care Partnership

Conor Smith - Projects Officer, NAVCA

Steven Towndrow - Patient and Community Involvement Manager, Prostate Cancer UK

Elizabeth Wade - System Transformation Team, NHS England

Caroline Winchurch - Harts Voluntary Action

Helen Wolstenholme - Assistant Director, NHS Confederation

Fraser Woodward - Head of Communications and Engagement, Specialised Commissioning Team, NHS England

Appendix 2: JamBoards

Discussion 1: What are the roles national charities can play in ICSs? (page 1)



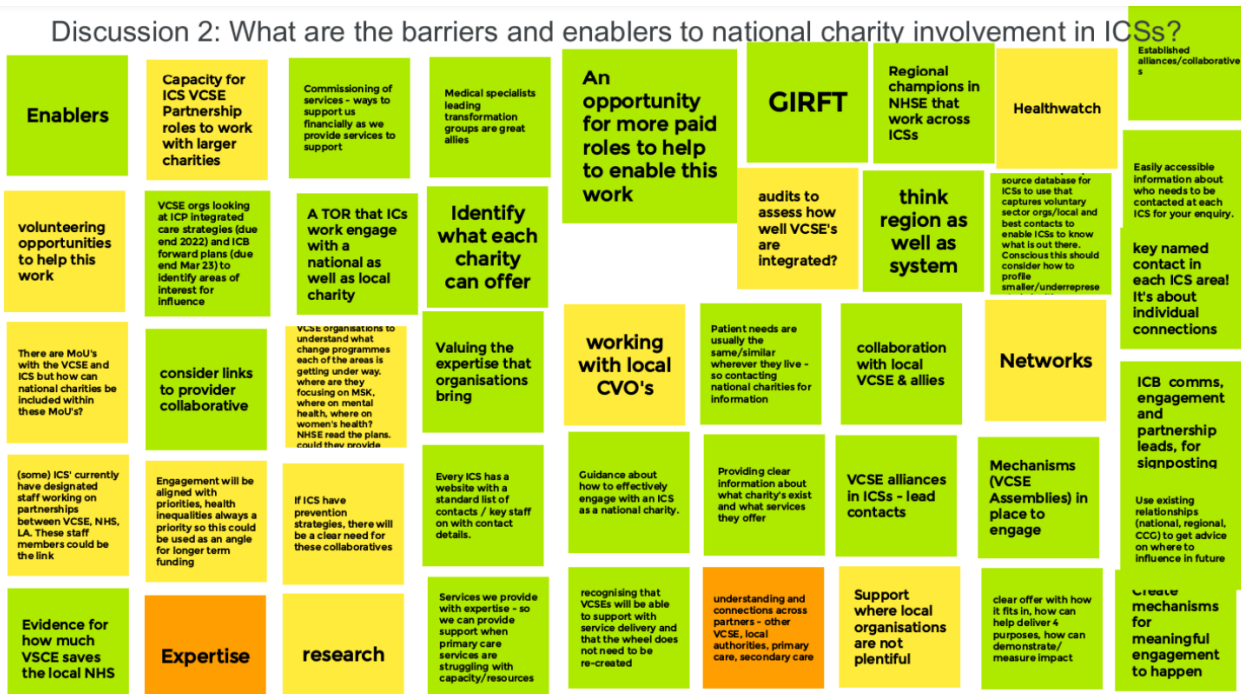
Discussion 1: What are the roles national charities can play in ICSs? (cont)



Discussion 2: What are the barriers and enablers to national charity involvement in ICSs?



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Actions to move this forward

Sharing basic information - Leaders web page to be shared

Sharing details of specialist commissioning processes

Ally with the VCSE Alliances - to help them benefit from members' expertise etc

Identify who's job this is / make it someone's job

Share information with ICS VCSE lead networks

NHS Futures platform...

VP team working to look at where VCSE appearing in plans

Sharing of ICS priorities through local and national VCSE networks

Clarify understanding of how commissioning works

Acknowledge where we are in ICS development... and reassure that there is no conspiracy to exclude

Make it easier for both the NHS and VCSE to see each other - at every level

200 charities emailing CEO... Go to ICS VCSE lead...

What people don't know - how to get priorities / issues on the agenda

ICSs only 2-3 months old... some of this might need a bit of time. ICSs might not yet know what they want

Appendix 3: Briefing paper

Working with Integrated Care Systems: issues for national charities

Summary

- National policy recognises the Voluntary, Community and Social Enterprise (VCSE) sector as a key partner in the design and delivery of health and care services. To put this into practice local VCSE alliances are in the processes of developing formal partnership agreements with the 42 integrated care systems (ICSs) across England.
- These will create mechanisms for health and care leaders to engage with VCSE organisations as strategic leaders and partners, embedding them into the decision making and governance of the system, which is vital for improved population health and tackling health inequalities.
- This work is at different stages of development in different ICSs, but overall there is positive engagement with the local VCSE sector to ensure they have a seat around the table as ICSs are forming.
- However, while this enhanced role for the VCSE and focus on local communities is very welcome, there are concerns about how citizens and local health and care leaders access the insight / expertise / services of national VCSE organisations within these new local structures.
- It is not realistic for most national charities with expertise or delivery capacity to engage with 42 separate VCSE strategic alliances or ICSs.
- But it is vital that national organisations, who have different expertise (e.g. in specific rare conditions) and capacity (e.g. in delivery at scale, with national helplines etc) are able, on an ongoing basis to provide their expertise and insight to, the NHS.
- There is a lack of clarity around how national bodies will participate in the new structures being proposed. While some local VCSE alliances include local arms/ reps/ branches of national organisations, this is the exception rather than the rule, and it is usually only the largest national organisations that have capacity for this, and then only in some areas.
- This problem is also present in the move of specialised commissioning to the ICS level. Most voluntary groups who have insight into experience of rarer conditions and issues do not have the capacity to influence 42 local commissioning processes.
- There are real concerns that national organisations will be left out of the loop, which is a missed opportunity and failure to deliver on the ambition to harness the full potential of the VCSE sector to improve health outcomes. This is a particular problem around rarer conditions and health inclusion issues, where most work is done at a national level.
- The VCSE sector is diverse. If it is to play its full part in improving population health and reducing health inequalities, it is important that the full breadth and depth of the sector is involved – small to big, local to national, across diverse communities, geographies and thematic issues.

- We are keen to work with members / NHSE to explore solutions that ensure people and communities, and the professionals that support them, benefit from both the local and national insight / expertise / infrastructure / services that the VCSE sector brings to health and care.

Background

The shift towards Integrated Care Systems

In July 2022, 42 integrated care boards (ICB) and integrated care partnerships (ICP) took on statutory responsibilities for the design, commissioning and delivery of health and care services across England – taking on a range of responsibilities from Clinical Commissioning Groups as well as assuming newly delegated powers from NHS England.

This move marked a significant shift in the locus of control over what happens within hospitals and across secondary care to the ICS level, with strategy, planning and delivery becoming wholly local. While the GP contract continues to be set nationally, Primary Care Networks are expected to have greater autonomy over time.

The ICPs and ICBs which together make up ICSs have a big job to do. They are tasked with bringing together strategic leaders and providers in statutory health and care, local government, VCSE sector and all other organisations with a stake in health, to work together to improve population health outcomes for people in their local communities and reduce health inequalities. With the challenging context of the Covid-19 pandemic as backdrop, this is no small task.

For the VCSE it is also no small task to work strategically with ICSs. Few VCSE organisations or networks operate across ICS footprints. Recognising this, NHS England is supporting the building or strengthening of local VCSE alliances to act as a representative body within ICSs – with formal agreements embedding the VCSE in governance.

However how these plans will work for national VCSE organisations specifically remain less clear.

The role of national charities

VCSE organisations and groups working in health and care whether at national or local level share a desire to improve the lives of people in our communities so they can live as well as possible, for as long as possible.

National VCSE organisations and bodies, like local VCSE organisations and groups, do this in different ways. Some are significant providers of information, advice and support for people with particular health conditions, or for people with particular characteristics. Some engage significantly in advocacy, building and making the case for change across the system. Others invest in research to identify new treatments and ways of supporting people with different conditions. These are all vital roles that need to inform and influence local systems.

Many national charities in health and care work on rarer conditions or for smaller communities where the numbers in any given ICS areas are few – by collectivising expertise and voice across areas they can achieve more for people. Some are small organisations, such as the Myasthenia Gravis Association, others that work in this way include nationally recognised brands such as the MS Society.

One of the key roles national bodies play is in arguing for equity of access to support and for improving standards of care across different systems. Many national organisations have run, and continue to run, campaigns highlighting variations in standards of care and support, and in access to services for people with specific conditions.

While some national organisations work through federated structures, or have local or regional branches or staff, the majority work across England (or the UK), often with only a handful (or no) staff. However over the years they have played a key role in influencing NHS policy, planning and delivery for the groups with and for whom they work – often by working through national structures. And there is a lot more that they could contribute to the future health and care system, as it seeks to shift away from treating illness and towards promoting health.

The Issue

As work continues to build and strengthen local VCSE alliances to partner ICSs, a gap remains around how national organisations which do not work through a local branch structure, and do not have local or regional officers, can be involved.

Lack of information

Our members told us that they lacked information about how they could feed into the emerging ICS-level structures, and struggled to identify basic information such as who was leading on which areas of work within ICSs structures.

One member summarised this issue in this way:

“Although we currently work at a national level the programme we engage with is moving more strongly to a local implementation phase so we need to work locally. This is going to be a challenge due to our size but also because ICS are new and forming so it is hard to know who to talk to. We don't have the resource to track down the right people locally. Also not sure ICS is the right level to engage at as a lot of service improvements will happen at place level which is even less clear and more varied in structure and arrangements locally.”

Another member said:

“Our focus has historically been on national influencing with contacts and structures in place to deliver this. Significant challenges around capacity to influence 42 footprints and to compete with other specialties for bandwidth. Challenges around poor data, particularly regional data and a lack of clarity around ICS contacts and structures compound this.”

Some members were clear that they would never have the capacity to engage with all 42 structures. One member said:

“All 42 directly is far too much for us. A select few is all we can hope for.”

This is a common perspective. It is not going to be practical for most national groups to engage directly with all ICSs. With almost ALL NHS decision-making being delegated to this level, national specialist health charities face real challenges and solutions need to be found. This is particularly the case as many national organisations' touchpoints with the system are around diagnosis and during treatment in secondary care,

and they have previously worked with specialist teams within NHSE and with other national bodies. In future their work to influence policy and practice so that it better meets the needs of their communities will be extremely challenging without further thought to creating national mechanisms to support them in doing this.

One member told us:

“Significant delegation of commissioning responsibilities from NHS England and Improvement to individual ICSs will be a challenge for influencing and engaging on these issues - shifting from a single body to 42 separate bodies.”

Challenges bringing attention to neglected issues

We are concerned that there is a risk that the ability of national charities to collectivise voices across geographically-dispersed communities and to represented neglected issues may be weakened.

One organisation in the mental health field told us:

“We have a strong relationship with the NHSEI mental health team, so our concern is how much leverage they will have with ICS on investment, workforce and delivering LTP commitments.”

We need to arrive at a more nuanced understanding of communities, and the groups they set up for themselves: Not all communities are local. If you have child born with a heart defect, or are diagnosed with a rare condition, or are living with stigma and discrimination, you might well consider ‘your community’ to be other people who share your problem or ambition – and who might live nowhere near you. These communities of interest and practice organise themselves into groups and organisations, just like local communities do. And they need a place at the table.

Work on national standards

A particular concern for members was that long-standing work to drive up standards of support offered to people with specific (often rare) conditions through work on national standards with national teams would be unpicked:

Colleagues working on allergy issues told us:

“It is great that it is about local services to reduce health inequalities at a local level, but It is not clear how local structures (where there will be differences in my understanding) will link in effectively to the overall national approach and I fear our services and allergy as a whole will be lost, especially as the ICS integration seems very unsettled/unorganized and as would be expected ensuring the top health needs will be addressed first.”

Another member summarised their concerns in this way:

“More uncertainty, lack of detail about how it is going to work. Concern about lack of national standards.”

Colleagues working on MSK issues told us:

“There is a tension between the need to give local autonomy so that services can develop in line with local needs and the need to ensure national consistency to avoid further exacerbating the post code lottery in care. If ICS based their priorities on population need then they would all make MSK a massive priority. Without pressure from above, none of them will.”

One of our members working on mental health told us:

“Our sense is that the national levers that have been crucial to driving the improvement of mental health services are likely to become weaker and there is a risk of exacerbating the existing post code lottery in access to and quality of services. We are not currently set up to influence 42 systems from the national team”

Another member told us:

“Currently CCGs have differing interpretations of the NICE guidelines so it's not clear yet as to how procurement and sequential use of medicines pathways are going to be adopted by the ICSs. My concern is, will the ICS adopt the path of least resistance and opt for the 'cheapest' pathway adopted by one of their regions CCGs or will do the right thing and follow the NICE guidance as it was intended?”

These are important concerns and thought is needed as to how they can be addressed. At present, the mechanisms for enabling charities to continue to play these vital roles are unclear.

Engaging with ICSs

While some national charity brand names are represented in emerging VCSE Alliances, these are generally charities which operate federated structures (e.g. Mind) or which have local branches or officers. Our member, Rethink Mental Illness, has invested significant resource in building relationships at ICS level and is taking a role in some Alliances. They are taking this work forward in a spirit of generous leadership:

“We hope to be involved with some but not all [ICSs] - as part of a VCSE alliance we will lead in some areas and other organizations will lead elsewhere (we are happy to run VCSE alliances with 'generous leadership' but we don't expect or hope to dominate that leadership)”

However other members were clear that this is not a role they can realistically play. It is only possible for the very largest charities with resource to devote at system level to offer generous leadership in this way.

Organisations told us that they were interested in understanding more about how to engage with the new processes, but most lacked the information they needed. Members told us they were struggling to find even basic information.

A member in the MSK field said:

“We very much want to be but currently have not found the best mechanism to link with each of the 42 ICS as there is not very clear information as to how 'national' organisations can link with them if they don't have 'local' representation.”

As well as concerns about the practicalities of engaging with ICS level organisations, our national members told us about significant concerns around change of personnel and loss of continuity as staff change. These are also issues for local charities, but it can be particularly hard to keep track of local change when organisations are not embedded in the wider local VCSE infrastructure but are instead providing highly

specialised input to (say) one hospital trust in an area. Members are concerned that they will not have capacity to rebuild their connections and that as a result issues may once again be left off the agenda.

One member told us:

“The amount of information we have varies from ICS to ICS - all are at different stages of development and the general view coming out of ICSs (or CCGs moving into ICSs) is that little will change immediately and that impacts of ICSs won't be felt, commissioning wise, for some time yet. We do not know whether local commissioners will change, but this could impact influencing activity in terms of stakeholder relationships and organisational memory

As is typical of our sector, we heard that organisations were already doing their best to find ways through – including developing volunteer roles to engage with local structures – and were optimistic about the potential of delegation of powers.

Members working in the MSK field told us:

“As each ICS will have an appointed MSK lead we are hoping this will give us a more direct link to embedding our services into patient pathways in the treatment of inflammatory arthritis.”

Another member told us:

“I have given this consideration but do not yet have sufficient understanding of the potential issues. It is presently unclear as to how we will work with the 42 separate regional organisations or to what extent. There is the potential for this to be a barrier as to how we influence policy and practice with regards to decisions around this emerging condition, depending on to what degree policy decisions continue to be taken at national level and what mechanisms are put in place to operationalise them at regional level. Potentially the move from around 130 CCG's to 42 ICS could simplify things as there will be less commissioners involved.”

Another said:

“There will be more work engaging in many places rather than just nationally but ultimately it will be service delivery better.”

However ad hoc arrangements cannot be a long-term solution and will not be a practical way to address the gap across the sector.

It may be that there is good practice to draw on from other fields. For example one member working in the cancer field told us that their fears were somewhat allayed by the recognition of an ongoing role for Cancer Alliances.

“We know from a recent publication that Cancer Alliances will still exist and will be the main drivers of cancer activity within ICSs. ICBs are being encouraged to work closely with Cancer Alliances to achieve cancer targets. As this guidance has only just been published, we won't know the full impact but we continue to engage with Cancer Alliances to help us understand.”

However it is urgent that work to think through the mechanisms for other conditions and patient groups now moves forward. Otherwise we will not only see risk of loss of vital input to the policy making process,

but also a risk that we see an increasing lack of equity of access to the support offered by national VCSE organisations.

The risks

Without action to address these gaps we see a risk that:

- The voice of people with rarer conditions / from smaller or marginalised communities will simply not be heard in the development of NHS policy / priorities / delivery
- Local people, and the organisations and systems that support them, will lack access to existing national support and services (like helplines and peer support groups) as well as the insights and sharing of good practice that can happen across national bodies
- There will not be a route for national organisations to offer their expertise and provision to the local system and to be commissioned to provide support, nor easy routes for local communities to commission support out of area when gaps are identified.

Current situation

The challenges for local systems in tapping into nationally based support have already been recognised – for example the Innovation Accelerator programme within NASP has been established to address just this issue. However, we are concerned that other system leaders have yet to recognise that this issue may get worse.

Messages from NHS England are mixed. Some leaders appear to assume that national organisations will be able to participate in local VCSE Alliances, and others are working on the basis that national charities will still play a role through influencing national policy and / or engaging in specialist commissioning processes (although the extent of either of these is currently following the creation of ICSs is not clear). The latter position, in particular, fails to take account of the work national charities already do in supporting local delivery, and creates no space for national charities to make a greater contribution to delivery or to contribute their insights or outreach to local systems which may be grappling with particular challenges without access to local sources of advice.

There is work to be done within the VCSE sector to understand our own mechanisms for removing the barriers between national and local organisations working together to improve health and care in our communities, but it is vital that we avoid unintended consequence and do not create more barriers.

What we want to see

Ultimately, we want to avoid a situation in which either national or local organisations are side-lined in key decisions. Instead we want to develop clear and realistic mechanisms that support both national and local VCSE organisations to play to their strengths as part of effective health and care systems up and down the country.

We want leaders within NHS England to bring together their discussions about the future role of the whole VCSE in the system reform agenda.

We want to engage constructively with colleagues across NHS England and in local VCSE alliances to define the future role of national organisations, and how structures for supporting their engagement will be aligned alongside new local structures.

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- These will create mechanisms for health and care leaders to engage with VCSE organisations as strategic leaders and partners, embedding them into the decision making and governance of the system, which is vital for improved population health and tackling health inequalities.
- This work is at different stages of development in different ICSs, but overall there is positive engagement with the local VCSE sector to ensure they have a seat around the table as ICSs are forming.
- However, while this enhanced role for the VCSE and focus on local communities is very welcome, there are concerns about how citizens and local health and care leaders access the insight / expertise / services of national VCSE organisations within these new local structures.
- It is not realistic for most national charities with expertise or delivery capacity to engage with 42 separate VCSE strategic alliances or ICSs.
- But it is vital that national organisations, who have different expertise (e.g. in specific rare conditions) and capacity (e.g. in delivery at scale, with national helplines etc) are able, on an ongoing basis to provide their expertise and insight to, the NHS.
- There is a lack of clarity around how national bodies will participate in the new structures being proposed. While some local VCSE alliances include local arms/ reps/ branches of national organisations, this is the exception rather than the rule, and it is usually only the largest national organisations that have capacity for this, and then only in some areas.
- This problem is also present in the move of specialised commissioning to the ICS level. Most voluntary groups who have insight into experience of rarer conditions and issues do not have the capacity to influence 42 local commissioning processes.
- There are real concerns that national organisations will be left out of the loop, which is a missed opportunity and failure to deliver on the ambition to harness the full potential of the VCSE sector to improve health outcomes. This is a particular problem around rarer conditions and health inclusion issues, where most work is done at a national level.

- The VCSE sector is diverse. If it is to play its full part in improving population health and reducing health inequalities, it is important that the full breadth and depth of the sector is involved – small to big, local to national, across diverse communities, geographies and thematic issues.
- We are keen to work with members / NHSEI to explore solutions that ensure people and communities, and the professionals that support them, benefit from both the local and national insight / expertise / infrastructure / services that the VCSE sector brings to health and care.

Background

The shift towards Integrated Care Systems

In July 2022, 42 integrated care boards (ICB) and integrated care partnerships (ICP) took on statutory responsibilities for the design, commissioning and delivery of health and care services across England – taking on a range of responsibilities from Clinical Commissioning Groups as well as assuming newly delegated powers from NHS England.

This move marked a significant shift in the locus of control over what happens within hospitals and across secondary care to the ICS level, with strategy, planning and delivery becoming wholly local. While the GP contract continues to be set nationally, Primary Care Networks are expected to have greater autonomy over time.

The ICPs and ICBs which together make up ICSs have a big job to do. They are tasked with bringing together strategic leaders and providers in statutory health and care, local government, VCSE sector and all other organisations with a stake in health, to work together to improve population health outcomes for people in their local communities and reduce health inequalities. With the challenging context of the Covid-19 pandemic as backdrop, this is no small task.

For the VCSE it is also no small task to work strategically with ICSs. Few VCSE organisations or networks operate across ICS footprints. Recognising this, NHS England and Improvement is supporting the building or strengthening of local VCSE alliances to act as a representative body within ICSs – with formal agreements embedding the VCSE in governance.

However how these plans will work for national VCSE organisations specifically remain less clear.

The role of national charities

VCSE organisations and groups working in health and care whether at national or local level share a desire to improve the lives of people in our communities so they can live as well as possible, for as long as possible.

National VCSE organisations and bodies, like local VCSE organisations and groups, do this in different ways. Some are significant providers of information, advice and support for people with particular health conditions, or for people with particular characteristics. Some engage significantly

in advocacy, building and making the case for change across the system. Others invest in research to identify new treatments and ways of supporting people with different conditions. These are all vital roles that need to inform and influence local systems.

Many national charities in health and care work on rarer conditions or for smaller communities where the numbers in any given ICS areas are few – by collectivising expertise and voice across areas they can achieve more for people. Some are small organisations, such as the Myasthenia Gravis Association, others that work in this way include nationally recognised brands such as the MS Society.

One of the key roles national bodies play is in arguing for equity of access to support and for improving standards of care across different systems. Many national organisations have run, and continue to run, campaigns highlighting variations in standards of care and support, and in access to services for people with specific conditions.

While some national organisations work through federated structures, or have local or regional branches or staff, the majority work across England (or the UK), often with only a handful (or no) staff. However over the years they have played a key role in influencing NHS policy, planning and delivery for the groups with and for whom they work – often by working through national structures. And there is a lot more that they could contribute to the future health and care system, as it seeks to shift away from treating illness and towards promoting health.

The Issue

As work continues to build and strengthen local VCSE alliances to partner ICSs, a gap remains around how national organisations which do not work through a local branch structure, and do not have local or regional officers, can be involved.

Lack of information

Our members told us that they lacked information about how they could feed into the emerging ICS-level structures, and struggled to identify basic information such as who was leading on which areas of work within ICSs structures.

One member summarised this issue in this way:

“Although we currently work at a national level the programme we engage with is moving more strongly to a local implementation phase so we need to work locally. This is going to be a challenge due to our size but also because ICS are new and forming so it is hard to know who to talk to. We don't have the resource to track down the right people locally. Also not sure ICS is the right level to engage at as a lot of service improvements will happen at place level which is even less clear and more varied in structure and arrangements locally.”

Another member said:

“Our focus has historically been on national influencing with contacts and structures in place to deliver this. Significant challenges around capacity to influence 42 footprints and to compete with other specialties for bandwidth. Challenges around poor data, particularly regional data and a lack of clarity around ICS contacts and structures compound this.”

Some members were clear that they would never have the capacity to engage with all 42 structures. One member said:

“All 42 directly is far too much for us. A select few is all we can hope for.”

This is a common perspective. It is not going to be practical for most national groups to engage directly with all ICSs. With almost ALL NHS decision-making being delegated to this level, national specialist health charities face real challenges and solutions need to be found. This is particularly the case as many national organisations’ touchpoints with the system are around diagnosis and during treatment in secondary care, and they have previously worked with specialist teams within NHSE & I and with other national bodies. In future their work to influence policy and practice so that it better meets the needs of their communities will be extremely challenging without further thought to creating national mechanisms to support them in doing this.

One member told us:

“Significant delegation of commissioning responsibilities from NHS England and Improvement to individual ICSs will be a challenge for influencing and engaging on these issues - shifting from a single body to 42 separate bodies.”

Challenges bringing attention to neglected issues

We are concerned that there is a risk that the ability of national charities to collectivise voices across geographically-dispersed communities and to represented neglected issues may be weakened.

One organisation in the mental health field told us:

“We have a strong relationship with the NHSEI mental health team, so our concern is how much leverage they will have with ICS on investment, workforce and delivering LTP commitments.”

We need to arrive at a more nuanced understanding of communities, and the groups they set up for themselves: Not all communities are local. If you have child born with a heart defect, or are diagnosed with a rare condition, or are living with stigma and discrimination, you might well consider ‘your community’ to be other people who share your problem or ambition – and who might live nowhere near you. These communities of interest and practice organise themselves into groups and organisations, just like local communities do. And they need a place at the table.

Work on national standards

A particular concern for members was that long-standing work to drive up standards of support offered to people with specific (often rare) conditions through work on national standards with national teams would be unpicked:

Colleagues working on allergy issues told us:

“It is great that it is about local services to reduce health inequalities at a local level, but It is not clear how local structures (where there will be differences in my understanding) will link in effectively to the overall national approach and I fear our services and allergy as a whole will be lost, especially as the ICS integration seems very unsettled/unorganized and as would be expected ensuring the top health needs will be addressed first.”

Another member summarised their concerns in this way:

“More uncertainty, lack of detail about how it is going to work. Concern about lack of national standards.”

Colleagues working on MSK issues told us:

“There is a tension between the need to give local autonomy so that services can develop in line with local needs and the need to ensure national consistency to avoid further exacerbating the post code lottery in care. If ICS based their priorities on population need then they would all make MSK a massive priority. Without pressure from above, none of them will.”

One of our members working on mental health told us:

“Our sense is that the national levers that have been crucial to driving the improvement of mental health services are likely to become weaker and there is a risk of exacerbating the existing post code lottery in access to and quality of services. We are not currently set up to influence 42 systems from the national team”

Another member told us:

“Currently CCGs have differing interpretations of the NICE guidelines so it's not clear yet as to how procurement and sequential use of medicines pathways are going to be adopted by the ICSs. My concern is, will the ICS adopt the path of least resistance and opt for the 'cheapest' pathway adopted by one of their regions CCGs or will do the right thing and follow the NICE guidance as it was intended?”

These are important concerns and thought is needed as to how they can be addressed. At present, the mechanisms for enabling charities to continue to play these vital roles are unclear.

Engaging with ICSs

While some national charity brand names are represented in emerging VCSE Alliances, these are generally charities which operate federated structures (e.g. Mind) or which have local branches or officers. Our member, Rethink Mental Illness, has invested significant resource in building relationships at ICS level and is taking a role in some Alliances. They are taking this work forward in a spirit of generous leadership:

“We hope to be involved with some but not all [ICSs] - as part of a VCSE alliance we will lead in some areas and other organizations will lead elsewhere (we are happy to run VCSE alliances with 'generous leadership' but we don't expect or hope to dominate that leadership)”

However other members were clear that this is not a role they can realistically play. It is only possible for the very largest charities with resource to devote at system level to offer generous leadership in this way.

Organisations told us that they were interested in understanding more about how to engage with the new processes, but most lacked the information they needed. Members told us they were struggling to find even basic information.

A member in the MSK field said:

“We very much want to be but currently have not found the best mechanism to link with each of the 42 ICS as there is not very clear information as to how 'national' organisations can link with them if they don't have 'local' representation.”

As well as concerns about the practicalities of engaging with ICS level organisations, our national members told us about significant concerns around change of personnel and loss of continuity as staff change. These are also issues for local charities, but it can be particularly hard to keep track of local change when organisations are not embedded in the wider local VCSE infrastructure but are instead providing highly specialised input to (say) one hospital trust in an area. Members are concerned that they will not have capacity to rebuild their connections and that as a result issues may once again be left off the agenda.

One member told us:

“The amount of information we have varies from ICS to ICS - all are at different stages of development and the general view coming out of ICSs (or CCGs moving into ICSs) is that little will change immediately and that impacts of ICSs won't be felt, commissioning wise, for some time yet. We do not know whether local commissioners will change, but this could impact influencing activity in terms of stakeholder relationships and organisational memory

As is typical of our sector, we heard that organisations were already doing their best to find ways through – including developing volunteer roles to engage with local structures – and were optimistic about the potential of delegation of powers.

Members working in the MSK field told us:

“As each ICS will have an appointed MSK lead we are hoping this will give us a more direct link to embedding our services into patient pathways in the treatment of inflammatory arthritis.”

Another member told us:

“I have given this consideration but do not yet have sufficient understanding of the potential issues. It is presently unclear as to how we will work with the 42 separate regional organisations or to what extent. There is the potential for this to be a barrier as to how we influence policy and practice with

regards to decisions around this emerging condition, depending on to what degree policy decisions continue to be taken at national level and what mechanisms are put in place to operationalise them at regional level. Potentially the move from around 130 CCG's to 42 ICS could simplify things as there will be less commissioners involved."

Another said:

"There will be more work engaging in many places rather than just nationally but ultimately it will be service delivery better."

However ad hoc arrangements cannot be a long-term solution and will not be a practical way to address the gap across the sector.

It may be that there is good practice to draw on from other fields. For example one member working in the cancer field told us that their fears were somewhat allayed by the recognition of an ongoing role for Cancer Alliances.

"We know from a recent publication that Cancer Alliances will still exist and will be the main drivers of cancer activity within ICSs. ICBs are being encouraged to work closely with Cancer Alliances to achieve cancer targets. As this guidance has only just been published, we won't know the full impact but we continue to engage with Cancer Alliances to help us understand."

However it is urgent that work to think through the mechanisms for other conditions and patient groups now moves forward. Otherwise we will not only see risk of loss of vital input to the policy making process, but also a risk that we see an increasing lack of equity of access to the support offered by national VCSE organisations.

The risks

Without action to address these gaps we see a risk that:

- The voice of people with rarer conditions / from smaller or marginalised communities will simply not be heard in the development of NHS policy / priorities / delivery
- Local people, and the organisations and systems that support them, will lack access to existing national support and services (like helplines and peer support groups) as well as the insights and sharing of good practice that can happen across national bodies
- There will not be a route for national organisations to offer their expertise and provision to the local system and to be commissioned to provide support, nor easy routes for local communities to commission support out of area when gaps are identified.

Current situation

The challenges for local systems in tapping into nationally based support have already been recognised – for example the Innovation Accelerator programme within NASP has been established to address just this issue. However, we are concerned that other system leaders have yet to recognise that this issue may get worse.

Messages from NHS England are mixed. Some leaders appear to assume that national organisations will be able to participate in local VCSE Alliances, and others are working on the basis that national charities will still play a role through influencing national policy and / or engaging in specialist commissioning processes (although the extent of either of these is currently following the creation of ICSs is not clear). The latter position, in particular, fails to take account of the work national charities already do in supporting local delivery, and creates no space for national charities to make a greater contribution to delivery or to contribute their insights or outreach to local systems which may be grappling with particular challenges without access to local sources of advice.

There is work to be done within the VCSE sector to understand our own mechanisms for removing the barriers between national and local organisations working together to improve health and care in our communities, but it is vital that we avoid unintended consequence and do not create more barriers.

What we want to see

Ultimately, we want to avoid a situation in which either national or local organisations are sidelined in key decisions. Instead we want to develop clear and realistic mechanisms that support both national and local VCSE organisations to play to their strengths as part of effective health and care systems up and down the country.

We want leaders within NHS England to bring together their discussions about the future role of the whole VCSE in the system reform agenda.

We want to engage constructively with colleagues across NHS England and in local VCSE alliances to define the future role of national organisations, and how structures for supporting their engagement will be aligned alongside new local structures.