

Integrated Care System (ICS) consultation: BHIVA response

08/01/2021

Document leads: Laura Waters & Nicola Mackie

Contributors via email/BMM request to all members: Roy Trelvelion, Sarah Barber, Tristan Barber, Iain Reeves

1	What is your name?	Laura Waters
2	In what capacity are you responding?	Professional Society British HIV Association
3	Are you responding on behalf of an organisation?	Yes
4	Do you agree that giving ICSs a statutory footing from 2022, alongside other legislative proposals, provides the right foundation for the NHS over the next decade?	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input checked="" type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree
<p>Any comments/information to support your answer:</p> <p>As a general comment it is not obvious from the paper who is leading this consultation, how consultation responses will be shared, how we will receive a response to our input and how our input will shape the final proposals. Access to responses across the health sector is essential.</p> <p>We support any endeavour to improve collaboration and integrate different elements of the health and care systems, particularly for conditions like HIV, associated with disproportionate of physical health, mental health and social challenges</p> <p>We similarly support a focus on population health outcomes, especially considering the health inequalities that have been magnified by the COVID-19 pandemic.</p> <p>While the paper assures us that ICSs have the potential to reduce bureaucracy there is also a risk of increased bureaucracy given the multiple agencies involved. What work has been undertaken to ensure ICSs will indeed be 'leaner'?</p> <p>Devolution of functions and resource to local level was also the goal of the Health and Social Care Act. What has been learned since then and how will integrating care' better achieve those outcomes? If the benefits of local care co-ordination are clear, why are many places yet to achieve true partnership working?</p> <p>Despite mention of workforce skills and agility, acknowledgement that cost of living and accommodation is one of the main barriers to recruitment and retention in cities, particularly London, is lacking.</p> <p>Whilst the statement that ICSs have provided clear improvement in health and care may be true, we request evidence to support this. What data confirms that ICSs have "improved health", have "developed better and more seamless services" and, crucially, have led to public resources being used "where they can have the greatest impact"? The strong assertion of ICSs success forms the foundation for much of the document so must be backed up with supportive data and evidence.</p>		
5	Do you agree that option 2 offers a model that provides greater incentive for collaboration alongside clarity of	<input type="checkbox"/> Strongly agree <input checked="" type="checkbox"/> Agree <input type="checkbox"/> Neutral

	<p>accountability across systems, to Parliament and most importantly, to patients?</p>	<input type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree
<p>Any comments/information to support your answer:</p> <ul style="list-style-type: none"> • The paper, and this question, are clearly structured to express a preference for option 2 so it is hard to answer objectively. However, based on the information provided, option 2 provides greater incentive for collaboration. However, for such a significant change a more detailed impact assessment would be welcomed. The exception is a real lack of commitment to patient engagement throughout the paper which must be addressed. • For some services, particularly high-volume services managing common conditions, ICS-based commissioning will undoubtedly reduce variation. However, for services currently commissioned across footprints larger than ICSs, including those commissioned nationally, how will NHS England & NHS improvement ensure devolution does not widen inequalities? If ICSs are accountable for minimising variation within ICSs, who will be held accountable for variation between ICSs? Or between regions? • If national standards remain central to specialised care, what power do national bodies have to ensure ICSs, or groups of ICSs, meet those standards? • As the challenges of caring for an ageing population, multi-morbidity and polypharmacy grow, how will the needs of people living with uncommon conditions <i>and</i> common co-morbidities be met? And how can the outcomes for those different conditions be monitored in a unified manner? • The use of ‘digital and data’ to drive system working is crucial, and to embed a culture of shared data is an ambition we share. However, many people living with HIV have understandable concerns based on stigma and fears related to confidentiality and careful consultation and communication will be central to the success of this endeavour. • It is not clear who will lead ICSs? Will it be based on contracts open to tender? Will the independent sector be able to bid to run ICSs? Will that process be transparent and who will make those decisions? Option 2 involves the creation of several, senior roles – presumably, this is based on a detailed financial impact assessment? 		
6	<p>Do you agree that, other than mandatory participation of NHS bodies and Local Authorities, membership should be sufficiently permissive to allow systems to shape their own governance arrangements to best suit their populations needs?</p>	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input checked="" type="checkbox"/> Disagree <input type="checkbox"/> Strongly disagree
<p>Any comments/information to support your answer:</p> <ul style="list-style-type: none"> • We support local control of governance arrangements to best suit local population needs but limiting mandatory participation to NHS Bodies and Local Authorities risks under-representation of key stakeholders: <ul style="list-style-type: none"> ○ Are existing specialised service commissioners and leads included in the ‘NHS bodies’ considered mandatory? How do HIV care providers ensure their voice is heard at ICS level? Particularly if our priorities do not align with those of the ICS? ○ How will this structure ensure patient and public involvement? And what levers will ensure their concerns are acted on? ○ Where will third sector organisations, so essential to HIV care, fit in? 		

	<ul style="list-style-type: none"> • How will local population needs be assessed, prioritised and monitored? There is a risk that marginalised populations, disproportionately affected by HIV, will be under-represented in those assessments • Shaping governance arrangements locally may be appropriate but specialised care providers and patients must be involved in setting the relevant standards Overall, we feel more direction and broader mandatory participation is crucial to ensure speciality providers, under-represented populations, and third sector organisations are heard. 	
7	<p>Do you agree, subject to appropriate safeguards and where appropriate, that services currently commissioned by NHSE should be either transferred or delegated to ICS bodies?</p>	<input type="checkbox"/> Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neutral <input type="checkbox"/> Disagree <input checked="" type="checkbox"/> Strongly disagree
<p>Any comments/information to support your answer:</p> <ul style="list-style-type: none"> • The range of services currently commissioned by NHSE vary significantly so it is impossible to conflate them into a single question. Each will have their own challenges, requirements and views of patients and third sector organisations; we risk a disservice to complex specialised services by lumping them together • More detail on the precise meaning of “appropriate safeguards” and “where appropriate” is essential to answer this question. <ul style="list-style-type: none"> ○ Are these to be determined by existing specialised services, in collaboration with ICSs? ○ Will specialised services have a say in which elements (if any) of their services are transferred or delegated? ○ If agreed outcomes are not met what levers exist to revise ICS roles and responsibilities? • In terms of HIV care there are elements we believe must remain national, based on BHIVA guidelines and standards, with the HIV Clinical Reference Group (CRG) continuing to provide oversight and leadership for the foreseeable future: <ul style="list-style-type: none"> ○ As already committed to in ‘Principle One’, national service specification remains key, but despite an agreement for ICSs to meet locally agreed priorities, information on how ICSs would be held accountable for meeting national standards is lacking. ○ ‘Principle One’ also commits ICSs to standardised eligibility for specific treatments (as is currently determined by NHSE, and more recently, NICE HIV drug policies within the framework of BHIVA treatment guidelines). However, national drug procurement and prescribing targets are also key. We are in a transition from regional to national procurement currently, with an aim of driving efficiency while reducing inter-regional inequity in access to novel HIV therapies; we need to honour this commitment in order to assess the impact of this major change. Moving drug budgets into an ICS ‘single pot’ risks more geographical variation and dilution of competition-driven efficiencies. ○ ‘Principle two’ offers reassurance that the degree to which any speciality is organised at local, regional, or national level will be individualised, but it is not clear how this is decided or by whom. ○ National data collection, analysis and sharing of HIV data by PHE, and their collaboration with multiple stakeholders, has been central to the excellent HIV outcomes achieved in the UK. Although that data collection could be devolved to regional, or even ICS level, at some point in the future, to 		

change the way we monitor care at the same time we change how we deliver care would be an unacceptable risk so national data management should be preserved until we are confident that any change in care delivery has not negatively impacted outcomes for people living with HIV

- 'Principle three' rightly champions clinical networks, which are already a key element of HIV services, and we welcome the commitment to support network-driven and delivered improvement. However, we suggest those clinical networks, many of which have suffered cuts to administrative support, are empowered to deliver change, should be adequately supported first to maximise their role, and utilise their experience and expertise, in any re-design of HIV service delivery
- 'Principle four' commits to shifting funding from provider-based to population-based (which we read as place-based) budgets which is a significant concern for HIV services. Any move to place-based care requires community engagement and thorough impact assessment. Many people living with HIV access care outside their ICS of residence for numerous reasons including stigma, convenience and a need or desire to access specific support, expertise or engagement with their peers who may not reside in the same geographical footprint. We believe this is a driver of England's excellent rates of engagement in care. A move to place-based HIV care may be in the best interests of the NHS, and most importantly patients, but it must be undertaken gradually and within a carefully monitored standards framework. Community consultation and engagement should address the drivers for people to access out of area care and this, alongside evidence that place-based care reduces, rather than exacerbates, inequalities may then drive a desire to access care locally. The 'agreed pace of change' mentioned, must be agreed by current service providers and users. However, flexibility to offer choice, to provide care to mobile populations and to people with insecure place of residence, must be preserved and supported by seamless cross-charging where necessary.
- A shared workforce to improve collaboration and improve efficiency is welcomed. Some elements of HIV care that would be ideal for ICS-based delivery, such as HIV testing and HIV community nursing. Community HIV nurse specialists are already accustomed to collaborative working across organisations to support the most vulnerable and improve their health outcomes but suffer from erratic commissioning and service co-ordination. We strongly support ICS commissioning of these, and other agreed elements of service provision such as monitoring non-complex patients or specialist outreach, in an initial phase. That experience could then guide broadening the future portfolio of ICS-based HIV care as appropriate.
- A 'single pot' financial framework will offer some advantages (e.g. commissioning the services highlighted in the previous point) but also risks, particularly if financial decisions are led by systems with a lack of understanding of specialised care; stepwise, monitored progression towards financial integration would help mitigate these risks.
- Of note, optimal care models for people with HIV will differ according to the complexity of their HIV care needs and systems will need to permit seamless movement between models of care as required.
- Access to mental health care is a well-established area of concern, and one that disproportionately impacts people living with HIV. The NHS long term plan focusses on increased access to IAPT, and more serious mental illness necessitating suicide prevention and inpatient care but many people with HIV (and undoubtedly other long-term conditions) have chronic mental health issues, which in turn impact adherence to treatment, that are too complex for IAPT but not 'serious' enough for secondary care. How will ICSs address the needs of these people who currently fall

	<p>through the gaps in provision? Who will co-ordinate their care? HIV patients often have mental health needs along with substance misuse problems. Joined up commissioning for these individuals will require collaborative commissioning and a major uplift in funding to provide the necessary access to care.</p> <ul style="list-style-type: none">• Ultimately, the Integrating Care paper/consultation addresses two vastly different issues. The first is strengthening and empowering ICSs through reconfiguration and legislation; the second is the devolution of appropriate specialised services. We suggest that providing ICSs with a statutory footing, then carefully monitoring the impact on services already commissioned at local and sub-regional level must be undertaken before any large-scale transfer or delegation of nationally commissioned services. Undertaking both simultaneously, based on a consultation undertaken over the festive period, during a major COVID peak, that some key stakeholders were not aware of, is perhaps rash. Patient-centred care necessitates patient-centred decision-making and to rush through such a major change risks disengagement, destabilisation and harm.