



Voices of Experience Scotland  
McLellan Works  
270 Sauchiehall Street  
Glasgow G2 3EH  
0141 226 9855  
[pfraser@mentalhealth.org.uk](mailto:pfraser@mentalhealth.org.uk)

Gillian Martin MSP  
Health, Social Care & Sport Committee  
The Scottish Parliament

7/12/2022

Dear Gillian,

Thanks to you and the committee for listening to VOX members' views during the evidence panel on the 22<sup>nd</sup> of November. Please see below for relevant answers on behalf of VOX members to additional questions the committee had. I have also attached our most recent report on the Members' responses to the National Care Service Bill, so that our Members' thoughts and quotes can be seen by members of the committee. Pages 11-14 relate to data sharing.

#### **Implementation risks**

- Do you recognise particular concerns about the impact on service users during the period of transition to new data systems and new approaches to information sharing as part of the Bill's implementation? What are those concerns and how might they be addressed?

VOX members have often expressed concerns about the inconsistency of record keeping and data systems in the current system, where often even within mental health services or within physical health services, data is not accurate or consistent. Members have voiced frustration and point to lack of communication and standardised record-keeping, but also the failure of IT and data systems. This already has an impact on services members receive.

While the need for improved data and IT systems is recognised by members, there are concerns that during the transition period this may worsen people's experiences of services, with potential impacts on security and loss of personal data, waiting lists, further reduction in communication, and the omission or overlooking of important information for an individual's physical and mental health treatment. Members would want to see a realistic and practical plan in place to ensure the security and integrity of data was maintained, and crucially for thorough training of staff in new IT and data systems to take place as quickly as possible to make the transition smoother.

In terms of changes to information sharing, it is important for our members that it is reiterated that many of them have deep concerns about mental health data being shared beyond mental health services at all and that members have worries about what the impact in terms of stigma and confidentiality will be both during a transition phase, and full implementation, if this is to include mental health records.

### Ownership and control of data

- To what extent do you believe Part 2 of the Bill as currently drafted reflects a human rights-based approach? What changes might be needed to ensure individuals' human rights are respected and protected in the implementation of this Part of the Bill?

While on the face of it Part 2 of the Bill demonstrates a human rights-based approach, members are sceptical about what this will mean in practice, how they will practically enact what they are entitled to and what onus will be on the service to provide what is needed. Members see it as their right to have ready access and ownership over their medical data, their right to challenge contents of records where they believe it is inaccurate or misrepresentative, and their right to confidentiality of sensitive mental health data, where they should be able to give informed consent for any data sharing that takes place.

- The Committee has heard evidence of an appetite among people who use services to own their own data, which Mydex CIC discussed in some detail in their written evidence to the Committee. During the meeting, you raised a range of issues about this concerning regulation, high level data capture and data protection. The Committee would be grateful if you could provide more detail about the nature of these concerns, whether there is an opportunity to create an abbreviated care record that an individual could use/own to prevent the repetition and re-traumatisation people currently experience when seeing different professionals or whether the shared care record scheme outlined in the Bill would be sufficient to address this issue?

As mentioned, many members do not agree with any sharing of mental health data beyond mental health services (where the records are currently closed) and are deeply concerned about the impact this sharing could have on how they receive services and their wider experiences. Re-traumatising effects of retelling people's stories have often been *within* mental health services. Other members who see the value of a more integrated communicative system still have concerns about confidentiality and stigma and have suggested limited sharing of mental health data beyond mental health services with informed consent for access to this. An abbreviated care record owned and used by an individual may be a helpful addition to the bill to give better ownership, access, and control over the sharing of data.

I hope these answers are helpful for the committee. Please also see our attached report from Members on the National Care Service Bill.

Yours sincerely,



Paula Fraser  
VOX Scotland Development Officer



**VOX Scotland Evidence relating to  
The Scottish Government's National Care Service Bill**

**1<sup>st</sup> of September 2022**



For further information contact: Paula Fraser, VOX Scotland Development Officer on [pfraser@mentalhealth.org.uk](mailto:pfraser@mentalhealth.org.uk)

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# National Care Service Bill

## VOX Members' Evidence

### Who we are

VOX Scotland is a national charity run by people with lived experience for people with lived experience. We represent our members' views to Scotland's politicians and health professionals to ensure our laws and mental health services reflect our members' needs and interests.

VOX Scotland welcomes the opportunity to present evidence from our members on the National Care Service bill and we hope to positively influence the way in which the bill is taken forward with particular regard to the impact on mental health services and support, informed by a lived experience perspective.

### Who we engaged with

VOX Scotland's evidence is informed both by contributions our members made during the original consultation (August-October 2021, 41 participants) and the feedback members provided in August 2022 on the bill (17 participants). We engaged with 58 Members in total from different areas of Scotland, including Argyll & Bute, Lanarkshire, Greater Glasgow, Lothian and Highlands. The majority of the discussions were held online, while open question survey data was also collected.

Engagement with our VOX group members also took place in 2021, including:

- CAPS Advocacy
- Acumen
- Mental Health Network Greater Glasgow
- Time and Space
- Lanarkshire Links
- Advocard

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VOX also participated in the Scottish Government’s Consultation online events in 2021 and 2022. We sought clarification through questions to facilitators and contributed our members’ views and concerns on the bill.

### **Methods for engaging with our members**

Feedback we submitted from our members on the original consultation included the overwhelming view that it was difficult to engage with the consultation information and questions on both a practical (initial lack of easy-read options, lack of BSL) and content-based level. While the Scottish Government online events in 2022 improved on this in terms of BSL interpreters and powerpoint bullet points, which were welcome, members were still disappointed at the lack of an easy-read version of the bill. It was explained by facilitators that this was due to the formal legal terms which need to be used in the bill.

In the original consultation, to help members relate the questions to their own experiences of mental health, and of social care needs and experiences, we started discussions from a more approachable basis and explained the proposals and principles the Scottish Government had put forward. We then prompted discussion using open topic-based questions (see appendix A). In our more recent engagement with members on the bill, we focused on specific areas of the bill, most relevant to our members, giving background and explanation where needed (see appendix B).

## **Our Evidence**

### **1) Consultation process and the structure of the bill.**

As was the case in the initial phase of the consultation, members expressed the concern that mental health support and services did not seem to be given importance within the bill, with little detail on what, if any, impact the establishment of a National Care Service would have on mental health support and services.

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*“More detail of the basic scope would have been helpful at the initial stage. For example, is mental health in or out of scope? Or are parts in and parts out?”*  
(Member)

The majority of members expressed their frustration and dismay at the current state of mental health services and support but did not feel reassured by the bill, that the National Care Service would help to improve this. Some members felt the bill leaves too many important questions unanswered, and that it has been *“rushed through too quickly”* without enough detail.

- *“The Scottish Government is jumping from a plane with no parachute. It is not credible. It is like Brexit.”* (Member)
- *“It is not transparent... It shows disrespect and arrogance.”* (Member)

Another member had profound concerns about the basis of the bill and the balance of power its introduction would create, along with a wish to see rights for individuals and communities enhanced and protected to receive genuinely personalised care.

*“I believe it is a mistake to give power and responsibility to the Scottish Government rather than legislative moves to give more rights to people requiring social care and empowering local communities to deliver unique innovative and personalised care to their equally valued members. **People should be at the centre, not services or institutions.**”* (Member)

Some members did not understand why co-design work had not taken place to inform a fuller, more detailed bill to start off with, rather than going ahead with the bill and then using co-design to create the detail in the regulations afterward. They were also skeptical about the authenticity of the co-design phase, having the time and focus to meaningfully involve enough people, including those with lived experience of mental health problems.

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*“The proposal to co-design the NCS with people who use care services is welcome, but we should have been involved from day one, setting the agenda as well as responding to an agenda set by others. The Scottish Government rushed to appoint consultants to take forward their plans before setting up a structure or mechanisms to facilitate the participation of those with lived experience of social care services, and to be honest, this makes me skeptical of how genuine Co-design will be achieved rather than token involvement.”* (Member)

Another member liked the flexibility aspect of the bill framework, to be used to create a ‘from the bottom up’ structure, giving decision-making powers to people affected. Other members thought the framework could work with the right representation of people in the co-design phase.

- *“I’m glad that there is room for flexibility in the framework towards final decision making. A vital and a positive approach. Framing from the ground up hopefully will make more sense. Previous policies decided from **very top downward**, have **crushed service users and those trying to support us**. So, I welcome the flexibility of proposals.”* (Member)
- *“There are many positives to this approach with the correct mix of people contributing.”* (Member)

More detail on members’ thoughts on the co-design phase are in section 7.

## **2) Principles of the National Care Service**

The majority of members who participated did agree with the principles laid out in the bill, but most of those members also had caveats to their agreement. The biggest concern expressed was how the principles would translate into practice, with members citing experience of ideas or principles in similar proposals ‘looking good’ in theory and then not making a positive difference in reality.

- *“I do agree but they also need to translate to practice and be accessible and not just being fancy words on paper.”* (Member)

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- *“Yes, I do but I’m not optimistic about delivery. These are aspirations which most of us are tired of reading, they do not match people’s experiences of services. Principles do not help people navigate inconsistent and complex structures, perhaps it would have been good to see a principle that states that **people will get the help they need when they need it.**” (Member)*

Another member felt that one desperate need in mental health services is for interventions to become readily available without long waiting lists and that the interventions need to be longer lasting to make a difference. It was felt that this could be one example of a tangible change needed to actually deliver on the principles of ‘realisation of people’s human rights’, ‘enables people and communities to thrive’ and ‘promoting early intervention’.

Other members were worried that, while the principles appeared to be laudable, finances would dictate a less than principled service in practice, again from experience of having much-needed services cut. Another member pointed out where they felt two of the principles contradict one another.

- *“These principles are easy to write down but do not exist in practice. If services are financially costly, then they will be cut.” (Member)*
- *“In principle it sounds alright however having ‘financially sustainable services’ and the service as ‘an investment in society’ are contradictory. An investment in society is something that you don't expect a financial return on, but instead **a societal return.** This defines the return as **promoting dignity, advancing equality and non-discrimination** - these are the returns for the investment.”*

Some members who agreed, on the whole, with the principles set out suggested additional principles:

- *“More recognition of the role carers and the third sector play in care.” (Member)*
- *“People should be paid fairly.” (Member)*
- *“I would add support for independent living as a principle.” (Member)*



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- *“...it would have been good to see a principle that states that people will get the help they need when they need it.”* (Member) [As aforementioned.]
  - *“We have a duty of care to look after people that need help with day to day living and that is the basis of good governance.”* (Member)

Though it is acknowledged that one of the standalone principles is the ‘Realisation of human rights’ there was concern expressed by some members that the principles the bill outlines are *“not based on human rights and are not genuine”* (Member) despite the Feeley review highlighting the importance of a human rights-based and person-centred approach.<sup>1</sup>

Other members felt the principles do not reflect what the majority of people in society would want, and that more citizen participation to arrive at the principles should have been prioritised.

*“They are not written by citizens or carers. They are not legitimate.”* (Member)

### **3) Transfer of some services from NHS or local authority to the NCS**

Members had questions and concerns over which services would be moved from NHS (or local authority) control to NCS control. Many felt there needed to be more clarity over this in the bill, and more information, so they would be able to see the potential impact on services and support they and their loved ones use. Questions were asked about occupational therapy, GP services, disability services, and others where it is not clearly either a ‘care service’ or ‘health service’.

Of particular interest to members, were questions over the possible remit of the National Care Service with regards to any mental health services. As quoted earlier, a member thought the initial stage should have made it clear whether mental health *“was in or out of scope”*. Members also expressed concern about communication, centralisation, lack of clinical governance, added complexity and

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<sup>1</sup> Scottish Government, Independent Review of Adult Social Care 2021

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potential worsening of services if any parts of mental health services came under the National Care Service.

- *“The ‘National Care Service’ is a misnomer - the scope seems to go beyond social care and into health. If Community Mental Health Teams were under the National Care Service and other elements of healthcare relating to physical health are under the NHS, there is a **barrier to person-centred and joined up services**. And, if Community Mental Health Teams are under the National Care Service while in-patient mental health services remained under the NHS, discharge planning may be more fragmented. And will children's services be in or out of scope? Children and Adolescent Mental Health Services to adult services is recognised as a difficult transition at present - the National Care Service could possibly add another layer of complexity.”* (Member)
- *“I have worries that the absence of clinical governance and regular review would lower standards.”* (Member)
  - *“The services will continue to get worse with NCS.”* (Member)
- *“Services would be as bad, if not worse than now. Probably worse, as it would be centralised and not caring.”* (Member)
- *“These services need to be localised to respond to local needs - so this may not be a good idea.”* (Member)

However, for some members a potential move of mental health services away from the NHS seems like a positive one, dependent on resources, communication and comprehensive training in personalised care.

- *“My initial reaction is **positive as the culture and operational environment of the NHS is so overwhelmingly driven by the medical model**, I don't believe it can ever deliver appropriate long-term care for people who experience mental and emotional distress.”* (Member)

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- *“It would make sense, as long as both are **properly funded and communicate well with each other.**” (Member)*
  - *“Does it really matter whether it is NHS or NCS if the funding for mental health support remains?” (Member)*
  - *“Anyone working in that service must be fully trained and capable of **taking the needs of service users fully into account.**” (Member)*

Others thought it may seem a positive step but were concerned about the financial viability and the information technology challenges such a change could create. They were also concerned about remedying the lack of flexibility in mental health services and the chronic lack of qualified staff particularly in more rural or remote areas.

- *“This would be okay in theory, but the IT access is badly set up at the moment and it will be costly to get it correct. It will be much more expensive than allowed for in Budget.” (Member)*
- *“**This shouldn't be used as a money saving exercise.** This service needs extra investment, not less. There is currently not enough support in the Highland region. We need greater flexibility of provision. There is a large issue of keeping staff (CPN's etc.) in Highland due to the cost of living here and lack of housing and childcare. **This must be taken into account before implementing any service change as these issues are not limited to NHS staff.**” (Member)*



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Several members were very unsure if a move of mental health services to the National Care Service would be positive or negative, due to the lack of information about how this could work and what it would mean for access and delivery. As in our initial consultation response, the overriding consideration for members was the detrimental impact the **current state of mental health services** is having on people's lives, with **key shortcomings** identified as:

- Lack of access to timely mental health services (at early and crisis points)
  - Lack of consistent longer-term services to keep people well (made worse by significant workforce issues, with high turnover or areas unable to recruit at all, particularly in rural areas)
  - Lack of flexibility in approach or patient choice and transparency in the mental health services and support they receive
- *"I work as a community link worker in a GP practice and see the difficulty first-hand that patients often have in trying to get support for their mental health difficulties. GPs often refer patients to us as mental health team waiting times are unacceptably long. I can only hope that some improvement can be made to the current situation because **I often see very vulnerable people left without the support they need, or given inadequate, short term support.**"*  
(Member)
- *"In my experience of NHS Community Mental Health Teams, resources within rural Scotland are sadly lacking in staff and replacement of staff, after leaving, are woefully dismal. This means existing services are unable to follow through on recommendations requested by Consultants within Psychiatry/Psychology, they often just do not happen."* (Member)

Many members were either unable to tell whether a transfer of services to the National Care Service (should that be proposed) would make a difference to these longstanding and harmful deficiencies, or they were of a view that these problems should be resolved now, before any thoughts of moving services out of the NHS.

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***“What would it mean? More people get help when they need it? Less clinical support and more social support? It’s impossible to give an opinion without knowing what the consequences for everyone involved would be. For most of us the issue is not structures, it is where can we get help when we need it, and just now there is no help, that’s all that matters.”*** (Member)



***“Mental Health services are in a mess at the moment so fix that first! The majority of people cannot get the help the way things are at the moment for Community Psychiatric Nurses, psychiatrists or psychologists in rural areas.”***

(Member)

#### **4) Integrated social care and health record**

Members conveyed varied views on the creation of a ‘nationally-consistent, integrated and accessible electronic social care and health record’. The integration of records for some members seems a positive move, so that they would not need to repeat themselves in different health board areas or different services, and in the hope that there would be a more joined-up approach throughout health and social care in general. Some members thought it should definitely go ahead, and would be for the good. Other members who saw it as a positive also recognised challenges that would need to be overcome around cost, IT systems and implementation.

- ***“Integrated records would enable better care, as anyone providing a service could see your history - very important in emergency situations or where***

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*capacity is reduced. It would also remove the need to retell experiences over and over.” (Member)*

- *“This is a crucial requirement otherwise the system will not work. THIS IS CURRENTLY A MAJOR ISSUE.” (Member)*

- *“In theory, yes, but COST. Also, protection of data from being sold, even anonymously as there is enough information out there to work out who is being mentioned.” (Member)*

- *“Often the buck lies with Social Work who may or may not implement or see as Critical therefore go unheeded. A more shared approach by NHS and Social Work is needed. Files from Social Work, Occupational Therapists etc. are kept under lock and key, information or assessments gathered by one service are not many times, accessible or willingly shared by another. I have often felt, that **as a Service User, I spend a lot of time repeating the same scenario again and again** and 'herding kittens' comes to mind. So, coherence IS essential.” (Member)*

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Members also considered whether inclusion of (currently closed) mental health records in such an integrated record would be an improvement, with some advantages recognised, but also risks around patient confidentiality, choice, control, judgements by staff, and safety identified. Almost two thirds of member participants supported the integration of records in principle, most with significant caveats. Some members also expressed support for more uniformity in the way in which notes are recorded across services.

- *“I can see how this would be useful in many ways, as one of the things many people say is that they find it difficult and traumatic having to repeat traumatic elements of their past history to multiple workers and wish records were shared. However, other people specifically ask about confidentiality and who sees their records and notes. **So informed consent and opting in or out of this would be very important.**” (Member)*

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- *“They **must include mental health records in a non-judgemental manner** so that people’s mental and physical health needs, which are often closely linked, can be fully attended to.” (Member)*
  - *“Only if there is **equal say in delivery of the service**. NHS and Social Work. Bullet points in relation to mental health history etc. could be accessed by Social Work. **More in-depth info could/should remain confidential**. I do believe that the stigma relating to mental ill Health is not helped by the absolute hiding of it. Shame breeds Shame.” (Member)*
  - *“It’s a good idea to have the record online as we have to deal with different people at various times and give permissions for records to be accessed currently. This is an issue that can be re-traumatising and triggering. There needs to be some form **of uniformity with records including standardised reporting across services**. There is some concern about having records kept online due to the potential for being hacked. **Having a service-only cloud storage that is secure would be more comforting**.” (Member)*

However, over a third of member participants had **deep reservations** about creating an integrated record, whether or not it was to include mental health records. Concerns were around patient choice, patient access to records, misuse of power, human rights, stigma, and issues of confidentiality.

- *“I have some concerns especially as our health records are controlled by clinicians and informed and shaped by the medical model and those with power over us. **We should have much more ownership and opportunities to shape our health and care recording including having the right to decide who can routinely access our records**.” (Member)*
- *“It will not be integrated as the individual does not control it - it is not helpful and should not happen.” (Member)*
- *“I think personal health information needs the **greatest level of security and protection**. The perspective here is for the ease of services not for the*

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*individual, you are taking away from people the ability to discuss their needs, which can vary in time, so there would at least need to be case by case assessment applied to individuals to understand what benefit it may be to them to have their information shared so widely.” (Member)*

- *“It is dangerous and only wanted by medical people. It does not suit families, individuals and carers. It is wrong.” (Member)*
- *“Despite efforts to the contrary **stigma still exists**. While this is the case it would be **unwise to widen the audience for mental health records**.”*
- *“It is not integrated or shared. It is held by the NHS or other organisations. Citizens and carers are denied human rights.” (Member)*
- *“I worry about confidentiality and also how to keep records up to date.” (Member)*

## **5) Anne’s Law**

The majority of member participants were **supportive of Anne’s Law** and the principles behind it. Many members also thought that the **same rights and protections regarding visitors and visiting should be afforded to patients in psychiatric wards**. Most members supporting Anne’s Law and the same principles for those in mental health units, also expressed the need to **balance those rights with ensuring the safety of patients and staff**.

- *“I support Anne's law and believe the equivalent should be implemented for people in psychiatric wards. The human rights of very vulnerable people should be protected and **human contact and connection with people important to them is essential to wellbeing for individuals**. Precautions can be taken to minimise risk of transmission of disease but the blanket banning of visitors is against their human rights.” (Member)*
- *“I think it is appropriate to extend this to mental health units.” (Member)*



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- *"It is disgusting that it does not cover **Psychiatric Wards** (FOI request confirmed this). Again, it **would help patients, and therefore staff, if mandatory.**" (Member)*
  - *"This is covered by the **human right to family life**. It is a right that all people should be afforded regardless of circumstance. There may need to be safety precautions but arrangements should always be made." (Member)*
  - *"I agree that people with a need to see their supportive people should be able to safely do so, while also protecting staff." (Member)*

Some members were more cautious about the idea of similar rights applying to psychiatric units if within a wider hospital setting, but also recognised the impact not allowing visitors could have on someone's already fragile mental health.

- *"There is a difference between visiting someone's home and visiting a hospital. Careful consideration is required to balance the needs of all, including the patient or resident. Safety and physical health is a key consideration, but the impacts of decisions on mental health should also be part of decision making." (Member)*

Some members felt on balance that **safeguarding from virulent diseases can sometimes be more of a priority**, and therefore Anne's Law and the idea of similar rights for psychiatric patients may not be the right course of action. Members had suggestions about how fair decisions could be made in these circumstances.

- *"I think public health considerations should possibly hold sway here - there is no point in the above approach if it is going to spread disease - especially as there is a lot of unknowns about diseases at the start of pandemics." (Member)*

- *“This is not the way forward, but rather an **independent body should be set up to advise and oversee such decisions** including an appeals process which is accessible to all parties effected by decisions” (Member)*
- *“This is a hugely complex issue which cannot be addressed in a normative manner. Issues around access during a time of virulent disease is, in my view, quite different to those for people undergoing psychiatric care when virulent disease is not present. The matters of safeguarding are different and therefore they need to be, and should be capable of being, treated differently.”  
(Member)*

## 6) Mental Health Considerations in relation to the National Care Service

Members considered what would be important elements around mental health services and support, should they come under the remit of the National Care Service. This included:

- representation from local third sector organisations on local care boards
- the principle of consensual care
- recognition of the value of peer-led support
- free peer-led local community recovery centres with clinical and support services integrated
- person-centred care



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- *“If mental health is within scope for the NCS then **representation from local mental health organisations should be included on local Care Boards**. This is important to ensure that mental health secures sufficient priority, resources, staffing, etc.” (Member)*
  - *If we are to get a National Care Service it needs to be based on the **premise of consensual care rather than the coercion under which so much mental health care is delivered by NHS services**. Also, recognition of the importance of peer-led services for people experiencing mental and emotional distress.” (Member)*
  - *“**Integration between clinical and care services**. Diagnosis should be more accurate and need to take more time investigating people's experiences and where necessary investigate them with people rather than forcing a diagnosis based on assumptions. (Person-centred approach). Peer Supporting should be recognised and taken seriously as a positive factor in recovery. **Peer-led recovery centres integrated with both clinical and support services in areas where people can access them, not hours away**. These should be free to develop in a way that suits the local community.” (Member)*
  - *“More budget, less medical and more community. The National Care Service has forgotten there are **social determinants of health**. It puts bureaucracy and profit before services. It will fail.” (Member)*
  - *“**Increased and consistent support to the third sector in combination with stricter scrutiny and standardisation**.” (Member)*

Some also expressed concern about what the National Care Service could mean for the mental health system.

- *“The health of a person is a part of the person. **This Bill centralises and adds more bureaucracy and waste to a system that is already broken**. Ministers*

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*and the civil service are about to destroy health, support, care, wellbeing by taking everything to a central and unaccountable black hole.” (Member)*

## **7) Next Steps - Thoughts on the Co-design phase of the process**

Some members felt that co-design would take a *“long time to complete”* (Member) and that it could *“cause delay and make it impossible to know what is happening”*. (Member) However, most members were **in favour of the co-design** process as part of the establishment of the National Care Service. As mentioned earlier though, some members would have preferred a much longer consultation process, with co-design taking place before the bill was written and put to the Scottish Parliament. Other members were positive about the prospect of co-design and input on decision-making at the next stage, but were skeptical about this taking place meaningfully.

*“It depends on reality of ‘co-design’.” (Member)*

Members put forward their ideas for making the co-design phase as authentic, representative, and powerful as possible.

- *“I’m positive about this, BUT ONLY IF this co-design is overarching and involves EVERYONE and EVERY SECTOR and the findings apply to the WHOLE OF SCOTLAND with special reference to REMOTE AND RURAL requirements.” (Member)*
- *“This should be a collaborative process with service user voices consulted at every stage to inform decisions.” (Member)*

*“Generally positive, depending on how the consultation is carried out. This should be done by **engaging the most amount of people possible**, for example, if this is done online only a large group of people would be excluded. **Reaching out to small remote communities with meetings in their areas is a must**. This cannot be a one size fits all solution and must be flexible depending on people’s circumstances and locations.” (Member)*

- *“It sounds okay but **please do as much as possible to go to people for information and not expect them to come to you, most people needing support could not complete this process or participate in meetings**. I kind of*

despair when I read this because **we already know what people need in many ways, we just don't seem to be able to provide it for economic reasons, and keep trying to fit needs into budgets.**"

- **"People with Lived experience should be included at every phase of design and decisions, and those should be weighted as most valuable. Example of scale of opinion - People with Lived Experience, Carers, CPNs/Professionals, Clinical."**
- **"This approach remains the most practical, valued, inclusive, accessible, respectable, and appreciated option on the table!"**

Members remained concerned that decisions taken would truly reflect all those who take part in the co-design, and not just be "lip service" or to "tick the co-design box" (Members).

- **"Co-design sounds great but will power really be shared or will the government take the final decisions?"**



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## ***References***

Scottish Government, Feeley, S. (2021) *Independent Review of Adult Social Care*

## ***Acknowledgements***

Graphics by Graham Ogilvie, Ogilvie Design Ltd.

Our sincere thanks to all our VOX members and participants, and to CAPS Advocacy, Time and Space, Acumen, Lanarkshire Links, Mental Health Network Greater Glasgow and Advocard, for their time and contributions in the first consultation stage.

For further information please contact: Paula Fraser, VOX Development Officer on [pfraser@mentalhealth.org.uk](mailto:pfraser@mentalhealth.org.uk)

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## Appendix A) Prompt questions in discussions with members August, September and October 2021

- Whether people with mental health problems currently have their needs met (physical, emotional and social support).
- What needs to be focused on to ensure people have the social care they need to live independently, be active citizens, participate and contribute to society and maintain their dignity and human rights.
- What sort of service is required to address the needs of people with mental health problems.
- Whether they thought a National Care Service could help to make this work.
- What pros and cons could be identified about a National Care Service.

## Appendix B) Questions for members August 2022

National Care Service Bill Information given-

"The Scottish Government wants to ensure:

- consistent delivery of high-quality social care support to every single person who needs it across Scotland, including better support for unpaid carers; and
- That care workers are respected and valued.

To achieve this, we will create a National Care Service, making Scottish Ministers accountable for social work and social care support, as they already are for health.

Local care boards will plan, commission and procure community health and social care services, to standards set and monitored by Ministers."

" We want to work with people who access support and those who provide it, including unpaid carers, to co-design the detail of how the National Care Service will work.

- To allow for that, the Bill creates a framework for the National Care Service but leaves space for more decisions to be made at later stages.
- This also provides flexibility for the service to develop over time.
- Co-design work will develop the policy of what should be in the regulations and directions over the next year or so. "

1) These are the National Care Service Principles:

- NCS services are an investment in society
- Realisation of human rights

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- Enables people and communities to thrive
  - Services are financially sustainable
  - Promote early intervention
  - Services designed collaboratively
  - Continuous improvement
  - Promoting dignity, advancing equality and non-discrimination
  - Inclusive communication
  - Promoting Fair Work

Do you agree with these principles? Why or why not and if you have any additional suggestions.

2) The bill to go to the Scottish Parliament has been designed in skeleton/framework form purposefully, with most of the detail to be filled in during the 'co-design phase' over the coming year to allow flexibility and decisions to be made in partnership. What are your views on this approach (positives or negatives)?

3) The bill anticipates some services may move from the NHS (or local authority) to the National Care Service. What would be your view on any services moving to the National Care Service, and in particular, what would be your view on community mental health teams or mental health support coming under the remit of the National Care Service, should that be proposed?

4) "Part 2 of the Bill supports the creation of a nationally-consistent, integrated and accessible electronic social care and health record.

This will avoid people needing to repeat information to different services, and provide statistics to support planning and reporting."

It also supports creating a standard way of inputting notes into the record across the services.

Do you have any views on an integrated social care and health record?

Currently, mental health records are closed records and therefore not shared beyond mental health services. Do you have any thoughts on any future potential inclusion of mental health records within an integrated social care and health record?

5) Is there anything relating to mental health or mental illness that you think should be included or considered in the National Care Service Bill?



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6) Do you have any views on the 'co-design' phase where those affected should be able to help make decisions?

7) "Anne's Law" is intended to make sure people living in care homes can see people who are important to them even during disease outbreaks. Section 40 of the Bill allows Scottish Ministers to give Directions to care homes about visits to residents, or visits by residents to other places."

What do you think of 'Anne's Law' regarding care homes? Members have brought up visitation issues to psychiatric wards during the pandemic. Do you have any thoughts on seeking similar sorts of rights/protections with visits for individuals in psychiatric wards?