

Health, Social Care and Sport Committee

Summary of digital public engagement on the National Care Service (Scotland) Bill

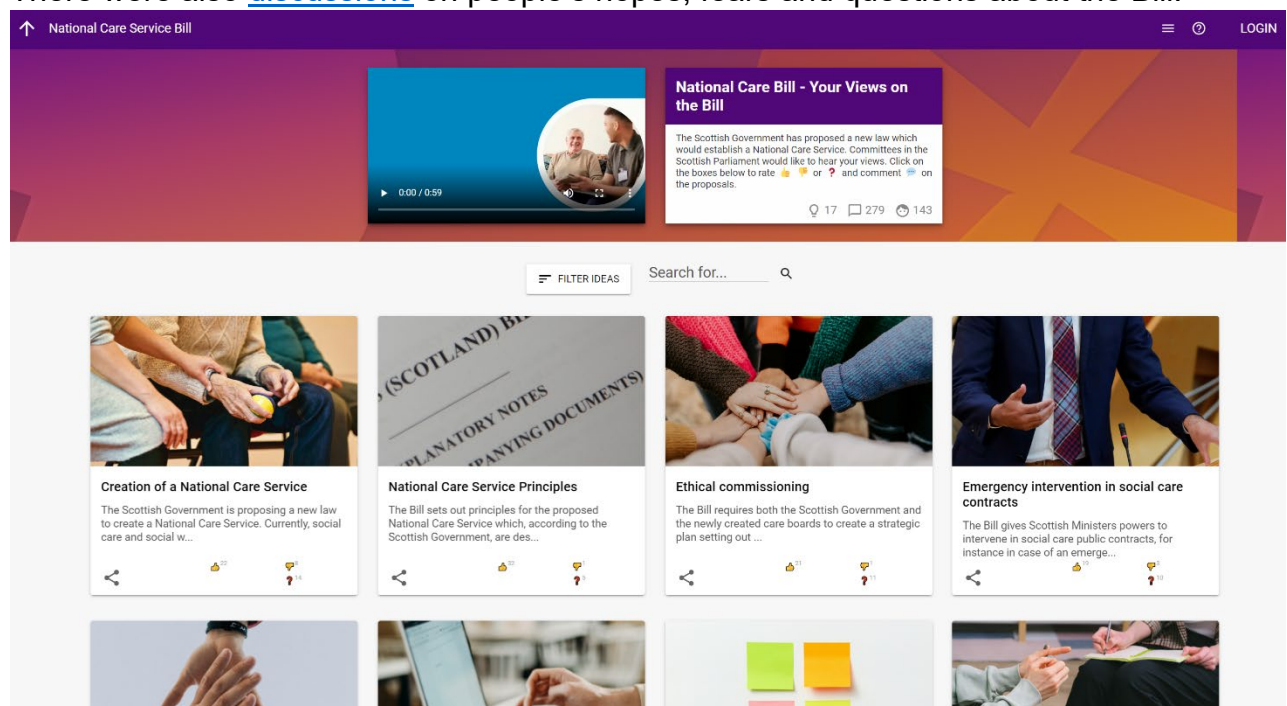
Digital Engagement

The Committee agreed to launch an online platform to gather the views and experiences of the public in relation to the National Care Service (Scotland) Bill, to support its Stage 1 scrutiny of the Bill.

The [online platform](#) was open for submissions from 8th July -9th September 2022.

The platform enabled participants to rate proposals using rating buttons indicating agreement (👍), disagreement (👎) or being unsure about the proposals and wanting to have more information (❓). Participants were also able to comment on seventeen individual provisions set out in the Bill.

There were also [discussions](#) on people's hopes, fears and questions about the Bill.



Who took part?

Over **150 users** took part in the online discussion providing **over 300 comments** on provisions in the Bill and **over 550 ratings**.

To counter potential digital exclusion, and to support diversity and equal access, the Participation and Communities Team (PACT) provided support and resources to partners in communities to gather a range of views. As a result, we received additional contributions from young people, people with additional support needs,

care service users, carers and care providers. We'd like to acknowledge and thank the following organisations for their support with this engagement process:

- Adoption UK
- Boleskin Community Care
- Buckie Buddies
- Children's Health Scotland
- Clackmannanshire Carers' Voice
- Coalition of Carers in Scotland
- Community Pharmacy Scotland
- Deafblind Scotland
- Edinburgh Health and Social Care Partnership
- Glasgow City Health and Social Care Partnership
- Inclusion Scotland
- Kinship Care Advice Service for Scotland
- Queensferry Care
- Royal Pharmaceutical Society
- Scottish Federation of Housing Associations
- Sense Scotland
- Stirling Council Children and Families
- The Thistle Foundation
- Unite the Union
- Voluntary Health Scotland
- Who Cares? Scotland

The views gathered in this manner were incorporated on to the site and are part of the summary of the key themes available below.

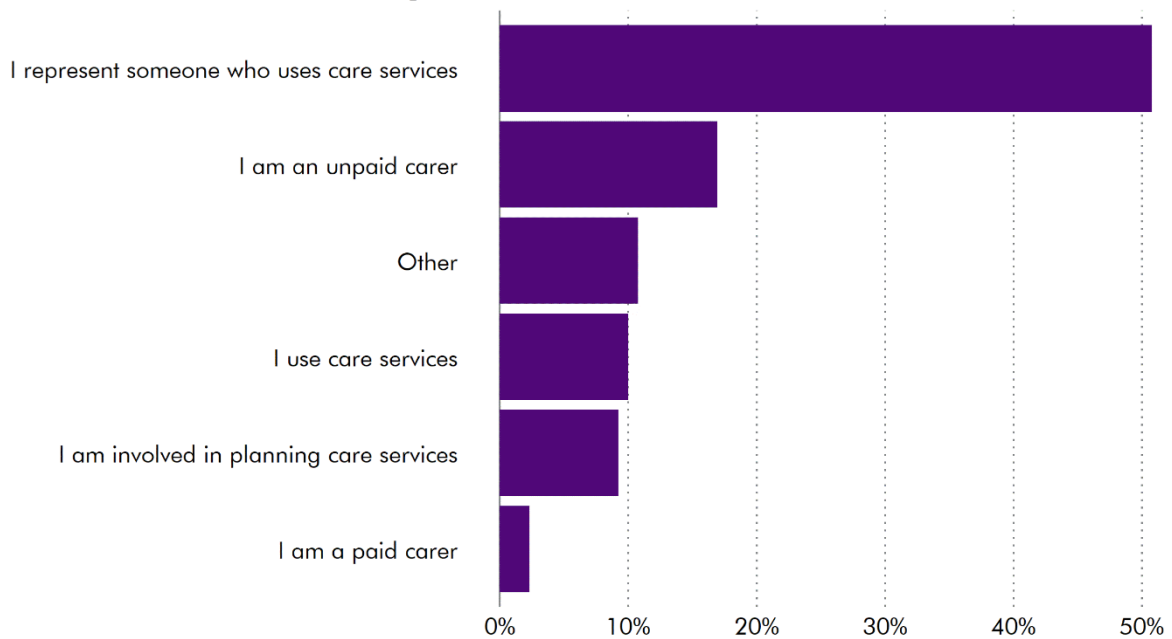
Users could choose to register to participate:

1. By registering an account on the platform with their email address, with the choice to provide additional demographic information
2. By linking their Facebook account

141 users provided some demographic information, which is illustrated below to provide a snapshot of participation levels. It is worth noting that some participants who provided data were submitting on behalf of a wider group, such as those listed above, so the demographic data should be used to provide a snapshot of participation, rather than used as a measure of all participants.

Connection to Care Services

Please tell us about your connection to care services

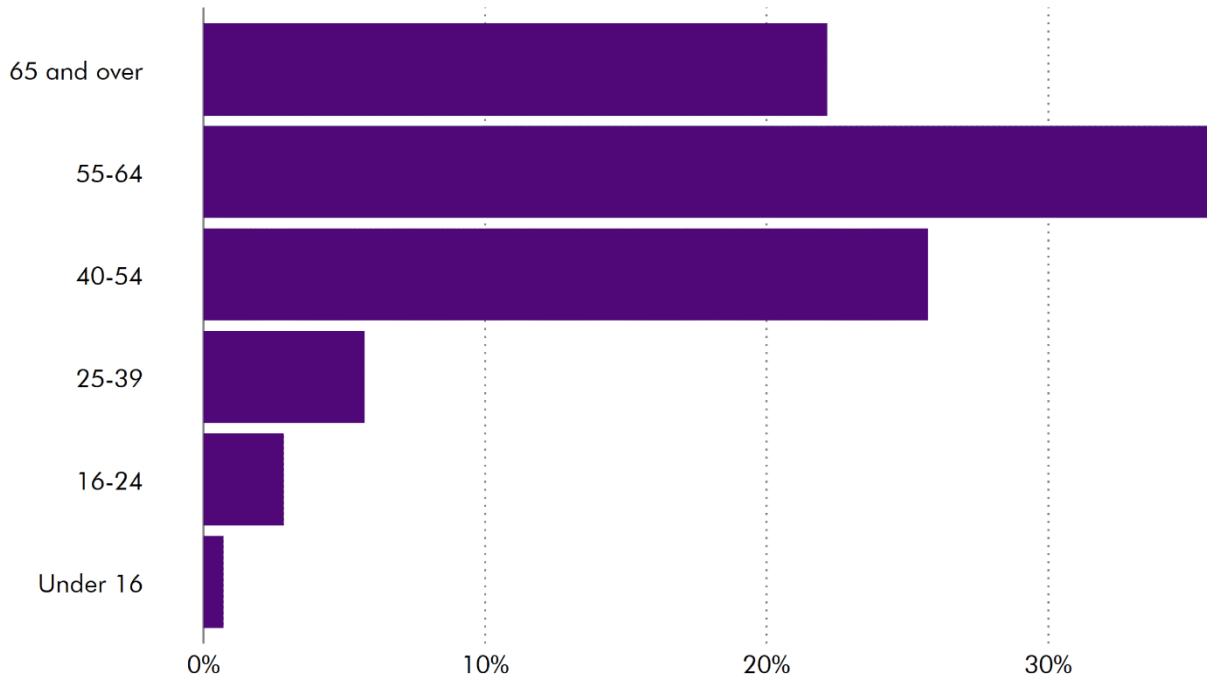


Around 51% of the 130 individuals who provided information on their connection to care services indicated they were someone who represented a care service user, such as a relative or support worker. 17% were unpaid carers; 10% were care service users; 9% were involved in planning care services; and 2% were paid carers. 11% of participants categorised their connection to care services as “other”. This included: previous care users, relatives or carers of previous care users, and those who had multiple connections to care services such as both receiving care services and providing unpaid care for another person.

Age

The data from the 130 people who provided details about their age is outlined below:

Age

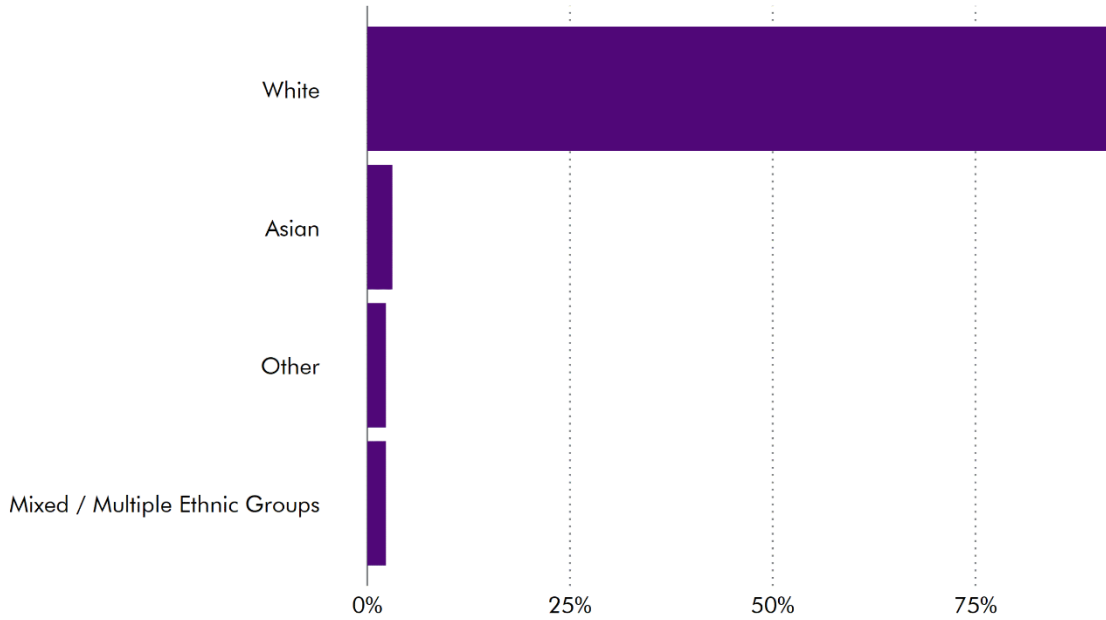


Although the data indicates that we engaged an older demographic, which perhaps relates to the subject matter and the core demographic of care service users, we also engaged organisations such as the Thistle Foundation and Who Cares? Scotland to ensure the views of younger carers and care service users were included in the discussion around the provisions in the Bill.

Ethnicity

The data from the 127 people who provided details about their ethnicity is outlined below:

Ethnicity

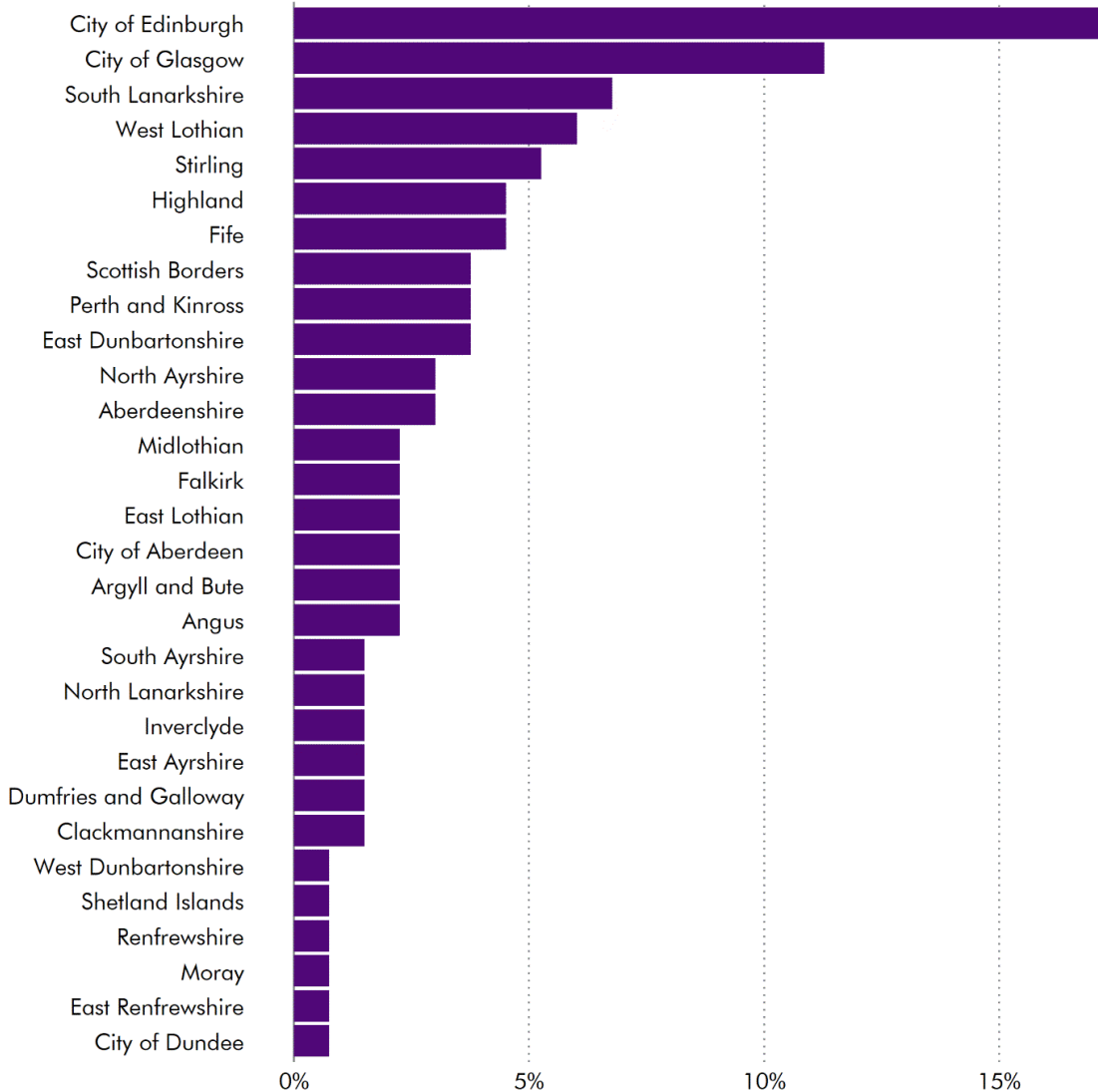


We recognise that those from minority ethnic groups are under-represented in the online discussion, especially those from Black communities in Scotland. We recommend that the Committee seeks further evidence on the Bill that takes into account the needs of minority ethnic groups in relation to the creation of the National Care Service.

Location

The engagement activity achieved participation by users from 30 of the 32 Scottish Local Authority areas, including all except the Orkney Islands and the Western Isles. Details of participation based on the 133 users who provided details of their location is outlined below:

Local authority



The data gathered from this exercise is not intended to be a representative sample of the population, but rather to give a snapshot of some of the experiences, questions and concerns the public have about the Bill.

contributors expressed the view that the Bill's "big ideas can be difficult to implement in practice".

One participant, an unpaid carer, stated that:

"I believe there is a focus of government effort on creating strategies, or frameworks... but very little effort in considering how it will be implemented. It is drafted and 'thrown over fence' for local authorities or quasi new boards to deal with, without consideration or planning for what is involved... the aspiration is to be commended but the practicalities of how we move from the current system to deliver on these aspirations, whilst continuing to meet people's needs, requires more detailed planning and analysis."

Centralisation vs meeting local need

The other overarching theme was a debate over the ability of a centralised system to meet local needs.

Some participants hoped the creation of the National Care Service would "take away the postcode lottery of the level of care your council provides", ensuring that "it will provide the same policies and care for everyone" and "the same level of support when moving between Local Authorities".

Others also felt that "centralisation... might provide consistency, avoid overlap from different bodies (e.g. local authorities, Care Inspectorate, Scottish Care etc.) and create efficiencies."

However, other participants argued that centralisation could create an additional "layer of bureaucracy without service users seeing improvements..." and that the NCS "will not recognise local populations properly... (with) expertise likely to be diluted and lost".

Others felt that social care "services should remain with the local authority and with the local community" on the basis that "they are best placed to provide what is required."

Some participants had concerns "that services needed in rural areas with less population will not be looked at favourably, possibly the differing needs may be overlooked and be economically driven."

The Coalition of Carers in Scotland suggested that "a balance must be struck between centralisation and localism", arguing: "While national standards and accountability can drive improvements, decisions must be made as close to people and communities as possible."

Hopes and concerns about the NCS Bill

Participants were also given the opportunity to share additional hopes and concerns about the Bill:

Hopes

- “I hope the creation of a National Care Service will improve the status of Scotland's social care workforce and give them greater parity of esteem with NHS workers.”
- “I hope the creation of a National Care Service will improve respect for the expertise of carers and the people they care for by enacting the neglected policy 'Equal Partners in Care'. This attempts to address the extreme imbalance of power in decisions about health and social care by requiring all decision-makers to recognise such 'experts by experience', especially in the provision of care or self-care within the family, on a par with professionals such as doctors, nurses and social workers.”
- “I hope the Bill will be a good thing that will improve things in the care sector for staff, those embarking on a career in care.”
- “I hope the Bill will improve things for people in care, for my friends, my relatives, and even me if in future if require care.”
- “I hope that services will be available in local communities, and “those communities should be involved in the opening and running of the service.”
- “I hope there will be no ‘wrong door,’ any service you engage with should be able to triage it to the right place and offer interim support.”

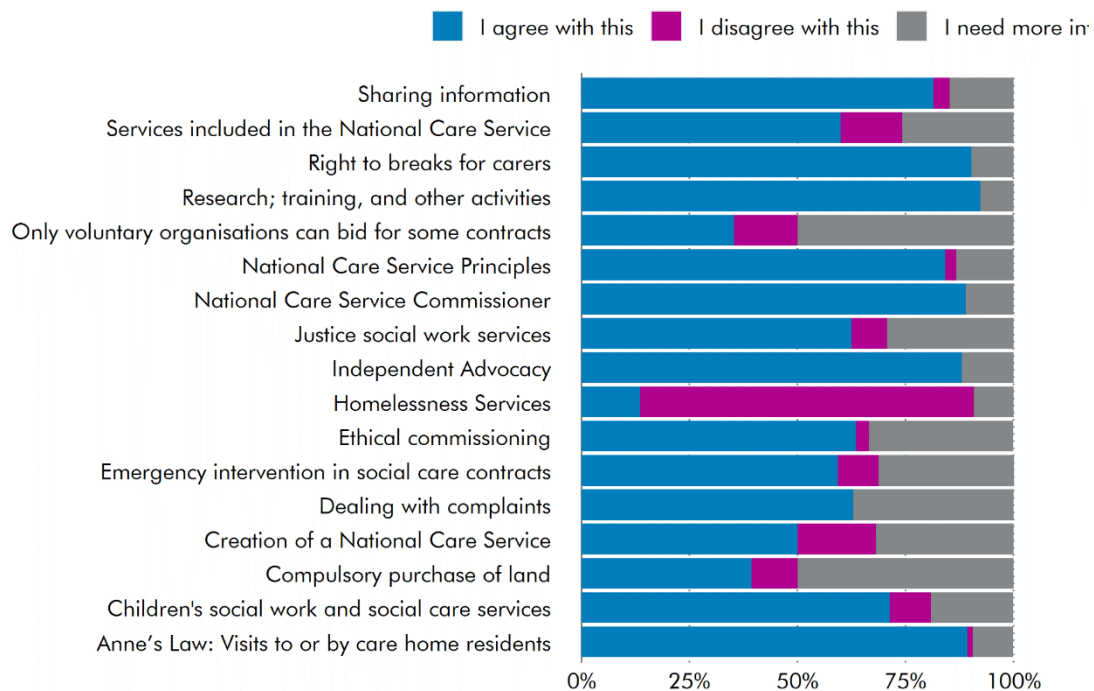
Concerns

- “I am concerned that the EQIA [Equalities Impact Assessment] also identified some potential negative impacts”. I would appreciate being able to read these "negative impacts" ... and have them available for discussion at the early stages to save everyone going around in circles, wasting precious time and money. Perhaps a short update could be included in the summary ensuring transparency.”
- “I am concerned that there is little evidence that a big machine like the NHS will solve the issues facing social care and also that social work will be swallowed in this big enterprise”
- “I am concerned that this will not be properly funded”
- “I am concerned that The Financial Memorandum is incorrect. Realistic estimates of the annual additional costs of the NCS and its impact are - (i) Disruption and friction, effort, risk and cost of NCS £ 550 million (ii) Additional costs borne by unpaid Carers £ 650 million (iii) Social infrastructure damage to employers, employees £ 400 million (iv) Direct costs of changes and additional staff £ 300 million”

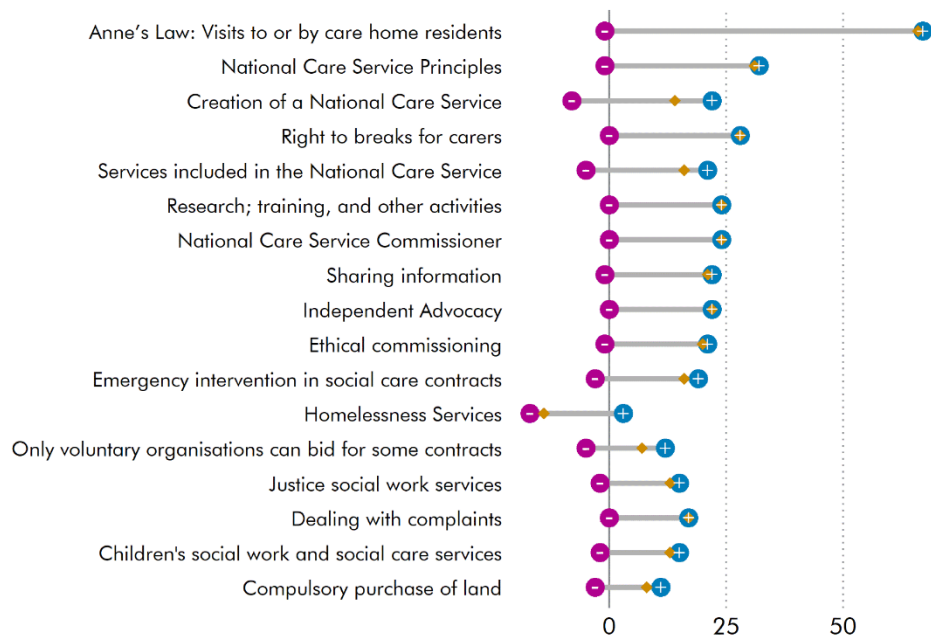
- “I am concerned that Clause 36 of the draft NCS Bill currently excludes citizens, carers and the Third Sector. Amend Clause 36 to read: Health & SC records - The Scottish Ministers may by regulations provide for a scheme that allows information and data to be shared, including the use of personal data stores with citizens, families and carers in order that services can be provided efficiently and effectively by and on behalf of— (a) the National Care Service, (b) the National Health Service and (c) the Third Sector.”
- “I am concerned that the Bill does not adequately address challenges created by increasing demand for social care services because of Scotland's ageing population.”
- “I am concerned we won't be able to measure success of the Bill. How will the general public know that the Bill is successful, if approved at Parliament? What measures of success will be used, from the outset to track performance, at a local and national level? We are great at coming with new 'grand schemes' but not great at implementing or assessing whether they were successful and rely on the subjective view of the minister who created the bill.”

Summary of ratings and comments

Each section on the engagement website focused on a particular provision in the Bill. The site enabled participants to rate each provision 'agree', 'disagree' or 'unsure' using rating buttons (👍👎 or ?). Below is an illustration of the overall ratings, in order of where the proposals appear in the Bill:



The chart below shows the spread of ratings for and against each provision, in order of levels of interaction. The gold diamond illustrates the net score in relation to positive comments vs negative comments. For example, the discussion on whether Anne’s Law should be enacted elicited the most ratings in favour.



The decision not to include homelessness services within the scope of the NCS was the most unpopular provision. While many of the provisions achieved overall approval, certain provisions also received significant “unsure” ratings, indicating that although participants tend to like the proposals in principle, more information is required for people to have confidence in the implementation and ultimate success of the NCS.

The remainder of this paper summarises the discussions outlined above and highlights comments in favour and against the Bill, and suggestions for improvement to the individual provisions.

Creation of a National Care Service

50% were in favour of this provision: 👍

18% were opposed: 👎

32% were unsure and required more information: ❓

“Not 100% convinced”

There were 15 out of 40 responses with a positive response to provisions within the Bill relating to the creation of a National Care Service. Within other responses there was variation between those clearly opposed and those with additional questions and requiring further clarification. One respondent described themselves as “not 100% convinced” while others highlighted specific areas where they had questions or felt the Bill provides insufficient detail to enable them to reach a view. These included:

- “How many boards there will be and where they’ll be located?”
- “Do all members have the right to vote on Boards? The Feely report said that all members of Care Boards should have a vote. This right has been omitted from the Bill when it is a significant point in respect to accountability of the Care Board.”
- “How the needs of unpaid carers would be managed – “There is a fundamental reliance on unpaid or family carers, which is not recognised and extremely undervalued.”
- Power dynamics – “There needs to be further discussion/ input to enable true co-production take place; i.e. help to non-professional people to gain the same meaningful influence as professionals; incl. providing additional support to unpaid carers and those with lived experience, and holding meetings in different formats.”
- Choosing board members – “Integrated Joint Boards (IJBs) already struggle to appoint unpaid carers, so making this a more challenging process will have an impact on unpaid carer involvement. ‘We presently lack proper representation of member of the public on boards. This may result in further problems as people won’t want to go through the process’.”
- Where housing sits with the NCS plans – “The lack of suitable housing is a huge barrier to independent living for many older and disabled people. If local care boards don’t work in partnership with housing, these issues will not be addressed”
- Geographical disparity – “concerned that services needed in rural areas with less population will not be looked at favourably”

Proposal lacks detail

The Carers Collaborate submission stated that 7 of their 10 Carers Centre staff and health and social care professionals were in favour of the proposal, with 2 against on the basis that the “proposal lacks detail, and it is impossible to articulate an informed response on their merits or deficits while they are in an amorphous state”.

The Carers Collaborate collated response raises the following questions about the Bill:

- “Will Care Boards be subject to independent monitoring instead of self-assessments?”
- “Will the responsibility for monitoring sit with Ministers?”
- “And will the codesign process have an ongoing role to play in independent monitoring?”

- “How will the new NCS help improve the integration agenda e.g. integration of digital records and moving towards shared assessments (involving statutory and voluntary sector).”

Equality of service

Positive responses to the proposal expressed a hope that the NCS would enable a more equal approach, remove the current “postcode lottery” approach to service provision, tackle variation in support provision across local authorities and “ensure equality of service quality”. One person also expressed support for Scottish Ministers having full responsibility, arguing that they would have “direct accountability”. Another comment expressed a hope that “as a result of its inception there is more consistency and improvement of provision and experiences”.

Focus on the Frontline

One contributor in response to the proposed National Care Service highlighted concerns on not reaching those working on the frontline and stated that “I do worry we will spend the next decade and a shedload of money on a restructure that will result in lots of experienced people leaving the service (no doubt on packages) and won't result in an extra penny going to the frontline of care where it's really needed.”

A 79 year old father, unpaid carer, who has a lifetime of caring experience for his severely disabled 51 year old daughter states “There are lots of questions, where are the staff and the buildings?”.

Another respondent asks “How will Scottish Ministers be trained so they know what standard good person centred care looks like? Will they have the time to oversee training and employment standards?”.

Tackling underfunding

It was suggested by one person that “we should be improving the current system we have” while another contributor emphasised their hope that the proposed National Care Service is “properly funded”. Another contributor raised concerns that the creation of a National Care Service could divert resources from frontline care provision.

One person stated “I fundamentally oppose removing these services from local authorities. Many of the problems with delivering quality services has been due to chronic underfunding for many years.... Most councils know their health and education colleagues well and can deliver quality services if funded properly.”

One person was concerned that the creation of a NCS could result in “billions of extra cost(s) in a decade.”

National Care Service Principles

84% were in favour of this provision: 👍

3% were opposed: 👎

13% were unsure and required more information: ?

Lived experience voices

Across the 15 responses there are multiple references to ensuring, in the development of a National Care Service, there is “much more direct contact with those with lived and living experiences.” to ensure services are “relevant” to those involved in the care system.

Aspirational versus practicality

A number of comments focused on highlighting key considerations in implementing the National Care Service principles in practice. These include:

- Effective communication
- Specific reference to role of unpaid carers and where they fit in the principles
- Training needs
- Defining how the principles were arrived at – “principles require proper organisation, planning, communication with people, understanding of rights and resourcing to deliver”
- Financial sustainability reference – “who determines the amount social care finance...to base a decision on sustainability”

One contributor commented that: “the aspiration is to be commended but the practicalities of how we move from the current system to deliver on these aspirations, whilst continuing to meet people’s needs, requires more detailed planning and analysis.”

Ethical commissioning

64% were in favour of this provision: 👍

3% were opposed: 👎

33% were unsure and required more information: ?

Requests for further detail

Many of the 16 comments under this section were requests for further detail with one person concluding: “What exactly is entailed by ethical commissioning needs to be spelled out!”. Another person disagrees with this provision, arguing that a “national commissioning structure” is not necessary. While one person expressed themselves as being “in favour of ethical commissioning”, they also commented: “Why can’t this be delivered currently by local authorities/ collaboration amongst councils to the same ethical standards?”.


Some contributors argued that a lack of information made it difficult for them to “make an informed decision” and also raised questions about “how this would be done and who would decide the budget for the area and how the funding would work?”.

Flexible procurement

One of the responses to the provision on ethical commissioning stated: “Experience by some on the board who have worked in social work suggest procurement needs to be flexible to ensure quality and value for money can be sought locally, rather than from large corporate businesses who are more able to reduce prices but not always deliver quality.”

As well as providing comments on procurement processes and flexibility, contributors also raised questions about how to ensure community-based services “offer both formal and informal support, with a focus on relationship-based practices, building consistent and trusting relationships with individuals, families and communities.”

Emergency intervention in social care contracts

59% were in favour of this provision: 

9% were opposed: 

31% were unsure and required more information: 

Lack of clarity


The majority of comments on this provision raised questions and called for further detail on how emergency interventions could impact on services in circumstances where, in the view of those contributors, “users or people with lived experience have no voice”. Contributors also questioned how this provision would improve the current system, how an emergency or service failure would be defined and what would be done to ensure best practice and quality care.


One person argued: “There is no detail as to when an inquiry may be invoked, nor the members, or terms of reference, or powers/authority, and most importantly, that it will be fully independent of Government.”.

Challenges of centralisation

A comment in support of this provision highlighted the need for “swift action...if things start to go wrong” and suggested the provision could encourage “continuity of care”. However, other contributors expressed concerns around the impact the transfer of decision-making to Ministers could have on services in circumstances where, in their view, these decisions would be made without “lived experience” and “local knowledge and good relationships with other providers.”.

Only voluntary organisations can bid for some contracts

35% were in favour of this provision: 

15% were opposed: 

50% were unsure and required more information: 

Two out of the 16 responses expressed support for this provision, arguing that the focus should be on quality, high standards and that “restricting some procurement to voluntary orgs” could be beneficial in improving the financial security of third sector organisations in the process of rebuilding their capacity after the negative impacts of the Covid pandemic.

Conflict of interest

There were several comments expressing concerns over a potential conflict of interest for the Scottish Government in restricting access to procurement of certain contracts, namely: “I have concerns about both government interference, preferential treatment of certain suppliers and thus conflicts of interest. More clarity is needed, with clear definitions and examples”.

Lack of clarity

There were several comments calling for more clarity on this provision while flagging potential challenges voluntary organisations could face with financing, governing and managing contracts. One person responded in support of the provision but added: “there needs to (be) a high level of scrutiny on how services are being delivered by voluntary organisations”.

One key question asked by many contributors was: How will this Bill impact on existing voluntary organisations/charities?

Dealing with complaints

63% were in favour of this provision: 👍

0% were opposed: 👎

37% were unsure and required more information: ❓

Calls for greater clarity

Of the 16 responses to this provision, two expressed support while emphasising the benefits of using the process of co-design to develop alternative systems for dealing with complaints. However, there were a number of contributors who responded with further questions around:

- how those complaining would be supported
- how there will be a “local understanding of complaints”
- whether this system would be additional to current processes, and
- the status of Kinship families under this provision.

Management of current and new systems

Two responses included several focused questions around the spectrum of complaints and variations on how these are dealt with, highlighting the need to give complainers agency and choice in how their complaints are dealt with, including:

- What will the Bill do to improve the way complaints about social care are handled and to ensure they are resolved more quickly?
- If someone raised a complaint whether they would still have access to support whilst the complaint is being investigated or whether their support would be paused?
- Would the proposed centralised complaints system protect service users so the level of care they receive remains unaffected?
- How would the system deal with false accusations?
- Would this complaint system replace all existing processes or systems covering complaints about registered services, overall care delivery (health and social care for a person), the process of assessment and procurement of care etc.
- The approach an individual would need to go through when making a complaint (i.e. individual to complain to service provider first before taking complaint to NCS)?

- Will all local authority areas be required to provide the same level of explicit support to Kinship families and what will the process be for local processing and resolution of issues and complaints?
- Would this not be just another obstacle or additional bureaucracy for people who need complaints resolved quickly?

National Care Service Commissioner

89% were in favour of this provision: 👍

0% were opposed: 👎

11% were unsure and required more information: ❓

“Avoid top heavy management”

Across the 8 comments on this provision, half agreed “in principle” with proposals to co-design the role of the Commissioner. However, there were questions around the management of the role and where and how local knowledge would be incorporated into their work. A user specifically commented: “They cannot be biased” and posed questions around recruitment, appointment and the kind of powers they would hold.

Another user highlighted a lack of clarity over the purpose of the role, asking “What is the point of this position?”.

Another specific question raised was: Will the NCS Commissioner be responsible for investigating individual/ group complaints?

Unheard voices

One contributor highlighted the risk that those who “speak the loudest” would have the greatest influence on decisions while: “Many carers with lived experience lose confidence because of caring role, and become invisible.”.

Independent Advocacy

88% were in favour of this provision: 👍

0% were opposed: 👎

12% were unsure and required more information: ❓

Necessary

The comments on this provision suggested general agreement on the need for independent, sustainably funded advocacy, describing it as “indispensable” with a particular emphasis on the need for advocacy for young people.

Funding and provision

Contributors raised queries around where funding will come from with one comment arguing: “We have four advocacy workers for the whole of one city! It isn’t enough and people aren’t being heard, so how will centralising everything help the people we support”.

Another frequently asked question was: How will Independent Advocacy across Scotland be protected in this process and will it be adequately funded?

Management

One user emphasised the importance of giving people access to independent advocacy services throughout their lifetime and that this support needs to be “tailored to specific groups, including Care Experienced people.”.

Research; training, and other activities

92% were in favour of this provision: 👍

0% were opposed: 👎

8% were unsure and required more information: ❓

Conditions to implement proposal

Most comments agreed with this provision albeit with some conditions attached to its implementation. These conditions included ensuring “those with lived experience are centrally included in such provision”, and “oversight of provision is key, with challenges over conflicts of interest, ensuring it provides Best Value for money”.

Standards of training

One contributor commented specifically on standards of training and the practical application of the proposed changes, stating: “There are many different levels of training out there and not all of them (are) good enough or adequate enough to meet the standards I and my colleagues in social care for Learning disabilities would and do expect.”.

Compulsory purchase of land

39% were in favour of this provision: 👍

11% were opposed: 👎

50% were unsure about the provision and required more information: **?**

Potential with further clarity required

Responses to this provision of the Bill largely highlighted the need for further information. These included many queries around the impact of centralised services on local people alongside the following additional questions:

- Why can't (compulsory purchase of land) be done locally to meet local needs?
- How easy(ily) accessible will (the services on the acquired land) be for people that are going to use it?
- What impact will (this) have on local people?
- As long as it is not going to intrude on protected areas?
- Are they going to use compulsory purchase for repurposing land, and could they ask people to leave their homes?
- Who will hold (the) central body to account (around decisions made to compulsorily purchase land)?

One user argued: "Regeneration of local areas is a potential positive of this part of the Bill". There was some support for the provision although many also highlighted the need to further clarify how it would work in practice. This request for further detail included:

- whether land is owned by individuals or property developers
- who makes decisions on what happens to local spaces and places, and,
- who will scrutinise decisions.

Services included in the National Care Service

60% were in favour of this provision: 👍

14% were opposed: 👎

26% were unsure about the provision and required more information: ❓

Two comments had a positive response, with one contributor stating they had “mixed feelings” about this provision, and a majority of comments asking additional questions around the changes including:

- What would be the relationship between health services and the NCS?
- Who governs this integration, what counts as health care and social care?
- Some people that are non verbal, they want to express themselves, but they may not be able to, how does it work for them?
- Will all Kinship families have access to therapeutic support?

Challenges with “centralised services”

Some contributors expressed scepticism about the prospect of enabling Ministers to “draw even more powers centrally” with one comment arguing that, while “IJB’s are apolitical and patient-oriented, there is nothing to prevent short-term political opportunism, especially in an election year” in the event that powers were transferred from IJBs to a centralised NCS under the control of Ministers. Another contributor expressed similar views, concluding: “I do not have any more faith in politicians to deliver”.

One contributor queried: “we have a SSSC (Scottish Social Services Council) for reg(ulation) ...Why an NCS as well?”. Meanwhile, another contributor expressed concerns that “centralised services will not recognise local populations properly.”.

Dementia and Alzheimer's

A number of contributors highlighted the disparity in treatment of those in receipt of care with dementia compared to patients with Alzheimer’s with one arguing: “there should be no “Dementia Tax”.

One contributor elaborated on these concerns, asking: “Does the Scottish Government recognise dementia (100 different types) and Alzheimers as the physical disease which it is, and therefore should sufferers benefit from the same medical care (paid for by the nhs) as someone with a brain injury or tumour? Or do they intend to charge dementia patients and their families for their care as happens at the moment?”

Not including Homelessness Services

14% were in favour of this provision: 👍

77% were opposed: 👎

9% were unsure about the provision and required more information: ❓

Most participants disagreed with this provision. The reasons for opposing the exclusion of homelessness services from the scope of the National Care Service included:

- a need to recognise “access to social care and homelessness are related”,
- homelessness is caused when social care functions do not provide adequate support, and,
- that many homeless people have “physical and psychiatric impairments.”.

Potentially including Justice social work services

63% were in favour of this provision: 👍

8% were opposed: 👎

29% were unsure about the provision and required more information: ❓

The comments submitted largely expressed concerns or opposition to the provision including emphasis on the need for a cautious approach and views that, in relation to including justice social work within the scope of the NCS, the “scale of the project must not be underestimated”.

One contribution raised a specific query around why this category of service is being considered for potential inclusion in the new NCS when homelessness services are not? It also raised the question of whether the provision “ allows for additional resources at a local level to capture the volume of additional information that will be required to be collated?”.

Potentially including children’s social work and care services

71% were in favour of this provision: 👍

10% were opposed: 👎

19% were unsure about the provision and required more information: ❓

There was some consensus in favour of the principle of including children’s services but with some “concern” around the practicalities. A number of contributions highlighted the need for “further consultation” with those who would be impacted by the changes (children, young people, carers, service providers) and for further evidence to justify why this potential change should take place.

Diversity and inclusivity

The majority of comments highlighted specific challenges related to this proposal including; the need to “be mindful of the diverse range of children (and services) that this includes”, and, for some contributors, the lack of a compelling “case to remove local authorities” in favour of a national service.

Kinship care

Contributors also made comments specifically around the complex needs of young people in Kinship Care and their carers and posed the following direct question: “Will all care experienced children under the new service receive the same levels of support and will needs be actively explored for all Kinship children?”.

Sharing Information

81% were in favour of this provision: 👍

4% were opposed: 👎

15% were unsure about the provision and required more information: ❓

Potential of sharing information to tackle inefficiencies

The majority of comments supported the need for information sharing and defined this provision as a “sensible” approach to enable “professionals (to) get the information that helps safeguard people at risk”. One contributor stated: “Experience of some of our members of our board with social work backgrounds have witnessed poor service delivery when sharing information is absent.”.

Secure information

While generally supportive of the provision, some contributors also highlighted the need for safe and secure processes to be part of what will be a “very complex system to design and implement” and called for clarity on how security systems that hold personal data would be implemented.

Inclusivity

Some contributors expressed concern that the current drafting is “organisation centred and denies human rights” with some suggesting it “needs amending to include citizens, carers, families and the Third Sector”. One contributor commented specifically on the human rights of Care Experienced people and the need for better communications and information sharing between services.

Right to breaks for carers

90% were in favour of this provision: 👍

0% were opposed: 👎

10% were unsure about the provision and required more information: ❓

Essential need but unanswered questions

Across the comments, including an collated submission from an organisation that had consulted its membership, comprising a range of services and carers, there was a consensus in support of the need for respite care for carers. However, some expressed doubts whether the provisions in the Bill would be far-reaching enough to address the current challenges carers face. Contributors raised a number of questions including:

- How would short breaks be calculated?
- Would breaks be longer for those who had not had a break for a long time?
- Will there be a LEGAL right to a short break?
- Will carers have immediate access to breaks or could it take months to access their rights?
- Will the provision include financial support to enable the unpaid Carer to be able to take advantage of the break on offer, “since for me to take a break my sister needs to pay to fly over to Scotland?”
- Would this be means tested?
- Will Kinship Carers be entitled to respite if there is a need identified?

Complexity of range of different carers and those they are caring for

Several contributors highlighted potential challenges with taking a blanket approach to respite care when “not all cared for can be put in a home to give their carer a break.”. There was a question directly focused on the needs of Kinship Carers and the inclusion of their right to a break, currently not provided for.

One specific question was: How would short breaks be calculated? Would breaks be longer for those who had not had a break for a long time?

Limited resources

Some contributors raised concerns about the implementation of what they considered to be an “essential” provision due to the limited resources available to practically apply it.

One contributor asked: “how this would work?” Other comments reflected concerns over the “shortage in social care staff”, “limited services for carers to access a short break”, and that “respite is under provisioned”. Certain contributors placed a particular emphasis on a current lack of provision for respite carers with one contributor highlighting their “difficulty in accessing a break due to the lack of suitable replacement care.”.

Those with lived experience of being unpaid carers highlighted challenges with sourcing “professional replacement care”, even when funding is available for this. For example, one contributor commented: “I have the money from our short breaks fund here but my daughter needs medical as well as social care and we have found nowhere to spend the money”.

Anne’s Law: Visits to or by care home residents

89% were in favour of this provision: 👍

1% were opposed: 👎

9% were unsure about the provision and required more information: ❓

Why Anne’s Law is “essential”

Contributors submitting comments on the introduction of Anne’s Law demonstrated a strong consensus on the importance of introducing Anne’s Law as a “fundamental human right”, that should be considered “absolutely essential”, and needed to be “implemented immediately”.

Frustration over implementation time

Contributors expressed frustration with the time taken to reach this point, which was described as disappointing for relatives and families detrimentally impacted by Covid restrictions. One contributor stated: “The basic human rights of our fragile family members have to be protected and we should not have to wait any longer for this to be implemented.”

Grief and trauma of families impacted by Covid restrictions and separation from loved ones

Those commenting on this provision reflected a sense of grief and frustration with reference to their experiences during lockdown, when they were separated from their loved ones, which they described as “traumatic”.

Concerns over the wording of the Bill

Multiple comments highlighted a degree of “ambiguity” in the Bill as currently drafted and called for “more clarity over wording”.

One contributor stated: *“The provisions in the Bill will make no difference to visitation rights. It fails to understand, grasp or highlighting the essential nature of family and relative contact for residents and service users well being.”*

Some contributors made direct reference to elements of the proposed changes being “too vague” with particular emphasis on the text in the Bill that reads: *“visiting will always be supported in line with discussions by the Scottish Ministers”* which was felt to be insufficiently clear to ensure families and loved ones of those in care are not hindered from visiting under any circumstances.

Anne’s Law needs to widen focus

Some contributors argued that the focus of Anne’s Law should be widened to include “acute psychiatric units for the elderly” and to ensure those in care are guaranteed access to other services such as physiotherapy. One contributor commented: “Access for physiotherapy was also denied resulting in loved one now bed bound.”