

# **CO-DESIGN OF THE DRAFT NCS CHARTER OF RIGHTS AND RESPONSIBILITIES (THE DRAFT CHARTER)**

## **Summary**

The design and development of the NCS Charter of Rights and Responsibilities ('the Charter') is being driven by the outcomes of three core phases of co-design with people accessing and providing community health, social work and social care support. The first two phases of co-design on the Charter – the 'understanding' and 'sense-making' phases - have been completed resulting in an early draft of the Charter. This draft will undergo further co-design in a third 'agreeing' phase.

Over 500 people were involved in the first two phases of co-design. This included people accessing and delivering community health, social work and social care support, lived experience panels and stakeholder organisations and their members. Particular focus was applied to ensure that the Charter co-design was inclusive and captured the views of vulnerable or seldom heard groups so as to make sure that the Charter will deliver for everyone. Details on recruitment and methodologies are included at Annex A.

All aspects of the draft Charter are the product of the co-design process and refinement to ensure that the content is legally accurate. This paper provides an overview of the co-design process and links to further findings from each phase of co-design that have been published on the Scottish Government website.

The current draft will continue to be developed through co-design until close to the launch of the NCS to maximise opportunities for people with lived experience to improve the Charter and allow the content to be updated to reflect anticipated changes in the policy and legislative landscape.

## **Introduction**

We are co-designing the Charter of Rights and Responsibilities which will set out people's rights and responsibilities when accessing NCS support and provide clarity on the pathway for people to make a complaint if their rights are not met in relation to the NCS.

The NCS consultation demonstrated strong support for a NCS Charter of Rights and Responsibilities, so people know what they can expect. The design and development of the Charter is being driven by the outcomes of multiple phases of co-design with people with lived experience of accessing and providing community health, social work and social care support, including unpaid carers to ensure that it meets their needs. This is being complimented by desk research and stakeholder engagement.

The NCS Bill, as introduced, sets out that the Charter will include as a minimum:

- The rights and responsibilities of people accessing NCS support and those with an interest in their wellbeing such as a family member or carer and any

other category of person the Scottish Ministers consider appropriate to include; and

- Information on processes which will provide recourse if Charter rights are not met.

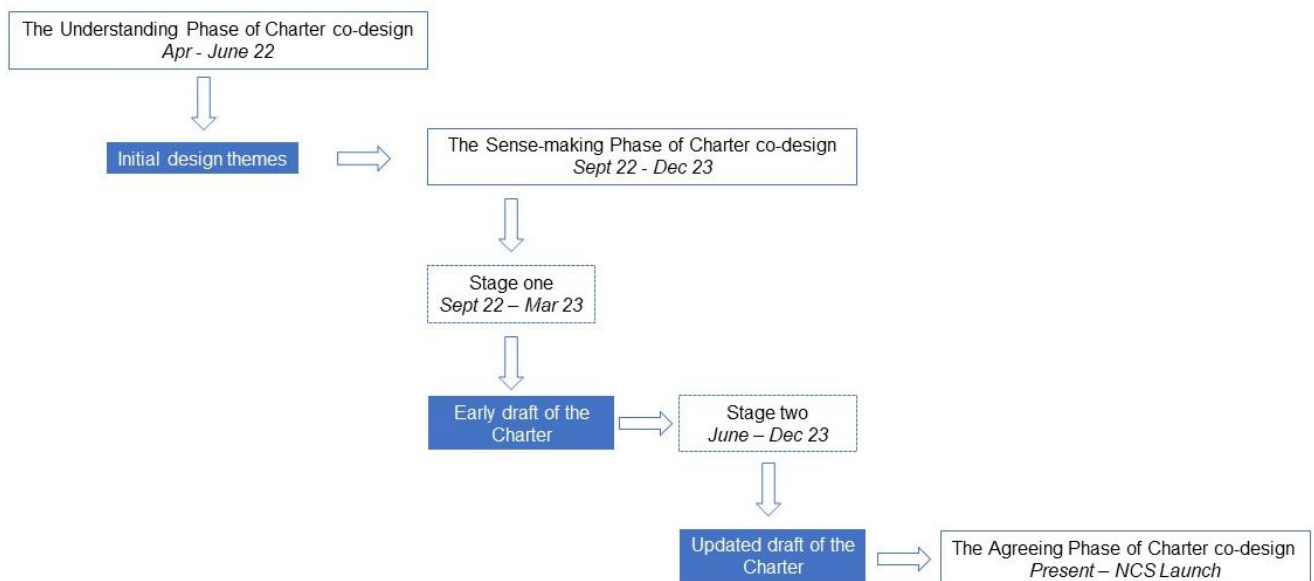
The Charter will support people accessing NCS support to better hold the system to account and receive the services they need to thrive. It is also intended that the Charter will be built into NCS continuous improvement processes to drive ongoing and sustainable progress in the delivery of supported people's rights across Scotland.

The Bill provides that nothing in the Charter is to give rise to any new rights, impose any new responsibilities or alter in any way any existing right or responsibility. The rights set out in the Charter will be underpinned by domestic law and will therefore have a legal basis in Scotland. The Charter will summarise existing care specific rights to support wider awareness and make them accessible.

It is intended that the Charter will be a foundational document in the development and delivery of the NCS, providing direction for the realisation of equality and human rights in the NCS.

### The draft Charter co-design process

The Charter and the wider NCS programme is being co-designed in three core phases – the 'understanding' phase, the 'sense-making' phase and the 'agreeing' phase. These phases have been planned, designed and delivered in close collaboration with the Office of the Chief Designer to ensure consistency, quality, ethicality and efficiency.



**Figure 1.** Diagram depicting the co-design process for the NCS Charter of Rights and Responsibilities.

### The understanding phase

The understanding phase took place between April and June 2022. This phase gathered preliminary information on: people's knowledge of their care-specific rights; how people wanted to use the Charter and how it could help them; previous experience of using Charters; and thoughts on what would help make the Charter as accessible as possible.

Analysis of the understanding phase provided initial themes for how the Charter could be designed to support people to understand their rights and provide a pathway to uphold those rights. These initial themes were taken into the sense-making phase for further exploration.

### The sense-making phase

The sense-making phase ran between September 2022 and December 2023 and was completed in two stages.

The first stage of sense-making co-design took place between September 2022 and March 2023. This focussed on further developing the initial themes identified in the understanding phase with people with wider and more diverse experiences of community health, social work and social care, including people providing care and support. The output from this stage was the preliminary structure and content for an early draft of the Charter.

The second stage of sense-making co-design took place between June 2023 and December 2023. During this stage the early draft of the Charter was further co-designed to ensure that the content accurately reflected what people had told us previously and to further develop the draft content.

The key output of the sense-making phase is the draft Charter, provided separately.

### The agreeing phase

The agreeing phase is planned for 2024/25 and will involve:

- Updating the placeholders to reflect the outcome of co-design of the wider NCS programme such as the NCS complaints process and the definition of community health.
- Updating the draft Charter to include information specific to certain Children and Family services or Justice services once a final decision has been taken regarding their inclusion in the NCS.
- Revising aspects of the current draft in response to legislative and policy changes.
- Further testing the current draft to improve usability, language, structure and format including design and visual appeal.
- Developing alternative versions and routes to access the Charter.

The draft Charter will continue to be updated and refined until close to the launch of the NCS. This will maximise opportunities for people with lived experience to improve the Charter and ensure that it is updated dynamically as the co-design of the NCS and the wider policy landscape develops.

## **Methodology**

A range of methodologies were used across the understanding and sense-making phases of co-design including individual and group interviews, feedback from existing lived experience panels, official-led and stakeholder-led workshops and the 2023 NCS regional forums. In addition, Healthcare Improvement Scotland (HIS) undertook a 'Gathering Views' exercise on the draft Charter. Detailed information on these methodologies is included at Annex A.

## **Recruitment**

Consistent with the human rights based approach being taken in developing the NCS, Charter co-design has deliberately sought to recruit people with diverse views and ensure that seldom heard voices were involved throughout.

Protected characteristics, as defined in the Equality Act 2010, were used as an initial basis on which to target recruitment over the understanding and sense-making phases. In addition, given inequality of access has impacts beyond protected characteristics, further work was done to identify and include other marginalised or stigmatised groups including: people who have experienced homelessness; people who have experience of substance use; people who have been the victims of crime; and people who have experience of mental ill health.

As decisions on whether the scope of the NCS will include certain children and young people's social care and social work and justice social work have yet to be made, officials ensured that the perspectives of people accessing these services were included from the beginning so that the Charter can meet their needs.

Officials worked with organisations representing people from these groups to ensure that their preferences for engagement, as well as trauma informed practice guidelines, were followed. Detailed information on recruitment is included at Annex A.

## **Findings and outcomes**

Some of the key insights from co-design so far are included below.

### Co-design findings that apply throughout the draft Charter

- The Charter should be short, simple and accessible.
- Technical information should be included in separate documents for people that want further detail.

- The Charter must be in plain English and available in different languages and formats. It should be available in GP surgeries, libraries, schools or included in an induction pack.
- The Charter should be used to positively influence staff and societal views of supported people.
- The rights and expectations in the draft Charter do not always reflect people's experience of support as it currently exists.

### The introduction

- The Charter should clearly describe what the NCS is and what it does, what the purpose of the Charter is and who the Charter is for. This should include a list of example services to help people understand if their support is covered by the Charter.
- The Charter should emulate aspects of the Social Security Charter including the 'This Charter was created by' section.
- The Charter should clarify the difference between rights and expectations.
- The 'who is this Charter for?' section should be as inclusive as possible.
- A child-friendly version of the Charter should be made available and clearly signposted to.

### Your rights

- Rights should be clearly listed in one place to help people see what their rights are at a glance and emphasise the importance of their rights.
- Some people thought that this section might cause duplication and it should be clearer that it is also a contents page. This will be further addressed in the agreeing phase.

### Equality, dignity and respect

- The Charter must be inclusive and promote the dignity of supported people. It should introduce rights to equal opportunities set out in the Equality Act (2010).
- The NCS should go further than simply treating people equally and should treat people with dignity, respect, warmth and compassion.
- The Charter should include examples to help people identify with the rights and expectations.
- Groups that are not protected by the Equality Act also face inequality, discrimination and stigma. These include rural and island communities, people with experience of trauma or of drug and alcohol use.
- Good support is based on good relationships between supported people and support providers that are built on mutual respect.
- Staff, and organisations that represent them, sometimes shared experience of being exposed to violent and aggressive behaviour. However, many said that these behaviours often stem from traumatic experiences, medical conditions or emotional stress.
- Some staff and supported people raised concerns that some supported people may not be able to adhere to any responsibilities and that the inclusion of responsibilities in the Charter could be a barrier to much needed care and support.

- Staff sometimes feel undervalued for the highly skilled support they provide. The Charter should recognise the importance of staff and provide information on how supported people should work with them.

#### Your support network, community and independent advocacy

- Support networks are important in making sure that people's rights are upheld and that they receive the care they need.
- Care support is essential to the realisation of the right to Independent Living in Article 19 of the UNCRPD<sup>1</sup>.
- Community is important to different people in different ways.
- People told us that care homes are people's homes and people must be able to have visitors, if they want, in the same way that they would if they were receiving care in a non-residential setting.
- Support for people accessing care at home needs to respect the needs of other people in the home as well as the privacy of the supported person.
- Unpaid carers and young carers said that the Charter should explicitly state that it applies to them and should include reference to rights that are specific to them.
- Independent advocacy is very important and different types of advocacy can help in different situations.
- Some people were unsure about what independent advocacy support was, and some called for a right to independent advocacy for everyone to be included<sup>2</sup>.
- People want the Charter to include information on how to access independent advocacy.

#### Involvement, participation and choice

- Many people want to be more involved in decisions on their care support and some don't feel they have enough control, so the Charter should help with this.
- People spoke about care being done *to* them rather than *with* them and how they want to work in partnership with people providing care.
- Social care assessments can be intimidating and the Charter should provide information to make the process less so.
- Staff told us that they are sometimes legally obligated to limit the choices of some people. This includes where people pose a danger to themselves or others.
- The Charter should include information on supported decision making and explanations of what guardianship and power of attorney are.
- Many people do not always get the information they need to make the best choices about their care.
- Some information is not accessible and it must be provided in a way that people can understand.

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<sup>1</sup> The UNCRPD is an international human rights treaty which is not currently in domestic law so the Charter cannot include the explicit right to independent living at this time. The draft Charter does however include domestic legal rights intended to reflect the tenets of Article 19.

<sup>2</sup> The Charter cannot create new rights but the draft does summarise existing legal rights, including the rights of some people to access independent advocacy in specific situations.

- People want to know more about how their information will be used and processed by the NCS and its support providers, and how they can request personal information held about them.

#### Upholding your rights: feedback and complaints

- People often don't know how to complain or who to go to if things go wrong, and they are sometimes scared to make a complaint for fear of repercussions.
- People want to be able to give positive feedback as well as complaints.
- The Charter should include information in the form of a visual diagram on the complaints process.
- Some people thought the Charter should set out the option to apply for judicial review in some circumstances where domestic legal rights are not upheld.
- Some, however, expressed concern that judicial review can be complex, time consuming and costly making it an inaccessible route to recourse for many.

Further findings from different phases and aspects of the Charter co-design have been published on the SG website:

- Findings from the understanding phase of Charter co-design – [How we are embedding human rights into the National Care Service](#)
- Findings from the first stage of sense-making phase of charter co-design – [An update on how we are designing the Charter of Rights and Responsibilities](#)
- Findings from the 2023 NCS Regional Forums – [Realising rights and responsibilities: Summary of findings from regional forums](#)
- Findings from the Health Improvement Scotland 'Gathering Views' exercise – TBC
- Findings from the second stage of sense-making co-design – TBC

#### **Next steps in the development of the Charter**

The development of the Charter will now move into the agreeing phase of co-design. This will extend until close to the launch of the NCS to maximise opportunities for people with lived experience to influence and improve the draft Charter and enable the draft Charter to be updated in response to progress in the co-design of the NCS and changes in the legislative landscape.

The agreeing phase of Charter co-design will run in parallel to the co-design of the NCS and support a greater focus on delivering on people's rights. This will include consideration of the co-design evidence provided in the Charter co-design to date relating to delivering on people's rights.

## **UNDERSTANDING AND SENSE-MAKING PHASE OF CHARTER CO-DESIGN - METHODOLOGIES AND BREADTH OF RECRUITMENT**

### Understanding phase methodologies

In the understanding phase, 24 people took part in a series of one-to-one co-design interviews. People were invited back to workshops to reflect on what was heard through the interviews, discuss and agree key findings and to further explore people's experiences and expectations for the Charter.

Many of the people involved in this phase were accessing care at home, or care in a residential setting from a broad geographical spread across Scotland, including people from rural Aberdeenshire, the Borders and people from island communities. Several of those involved identified as being from LGBTQI+ communities, while some had learning impairments or identified as neurodiverse. The majority of people involved were women under the age of 65.

### Sense-making methodologies

#### *The first stage of sense-making co-design - September 2022 – March 2023*

The first stage of sense-making co-design built on the initial themes identified in the understanding phase and included:

- Interviews and group discussions with 71 people - 42 people with experience of accessing support and 29 people with experience of providing support including unpaid carers.
- Workshops and written responses from eight existing lived experience panels with experience of dementia, disability, being LGBTQI+, substance use and recovery, mental health services, providing social work support and other diverse experiences.
- Extensive stakeholder engagement including a Minister-led deep-dive with around 50 equality and human rights stakeholders.

The 42 people accessing support involved in the co-design interviews included people living in residential care and people living in rural areas, with good representation from older people and people from minority ethnic communities. Some people were disabled or had additional support needs, sensory impairments/loss, dementia or experience of palliative/end of life care.

The 29 people providing support involved in this stage of co-design included paid and unpaid carers as well as nurses, social workers, representatives from community brokerage organisations, young carers and young carer workers. Many more people with lived experience of accessing support and members of the



workforce were involved in co-design through the methods outlined in the rest of this section.

In addition, questions were shared with lived experience panels representing diverse groups, including:

- Older people from a minority ethnic background
- Older people that identify as LGBTQI+
- People with experiences of a wide range of social care support, both as supported people and unpaid carers
- People with lived experience of recovery from drug and alcohol use
- People with living or lived experience of mental ill health
- People with lived experience of dementia
- Front line social workers

### *The second stage of sense-making co-design - June 2023 – December 2023*

The second round of sense-making co-design tested and further developed the early draft Charter and included:

- NCS regional forum events where 116 people took part and interrogated the early draft sections of the Charter in sessions in Glasgow, Stranraer, Skye, Shetland, Hawick and online.
- Additional interviews with six people: four disabled people with lived experience of community health, social care and social work and two independent advocates.
- Workshops and written responses from 13 existing lived experience panels with diverse experiences of accessing and providing different services, including seldom heard groups.
- Independent research conducted by Health Improvement Scotland (HIS) into the views of 20 people with experience of community health services on the early draft Charter.
- Extensive stakeholder engagement including stakeholders representing people accessing and delivering a range of community health, social work and social care services, as well as seldom heard groups.

The early draft of the Charter was shared with participants ahead of the NCS regional forum events. The 116 people that took part represented a mix of people with experience of accessing and providing social care, social work and community health services and provided rich and often detailed feedback on the early draft sections of the Charter.

Following early findings from the NCS regional forums, officials worked with a content designer to lead co-design to improve the early draft of the Charter where people had expressed that the content was confusing or unhelpful. Four disabled people with experience of accessing community health, social work and social care support were involved in this process to improve language and structure. Further content design is intended in the agreeing phase.

One-to-one interviews with two independent advocates were also carried out to explore how the Charter could be improved to ensure it is effective for them and those they support.

Similar to the first stage of the sense-making phase, in this stage further engagement was undertaken with lived experience panels representing diverse groups. Questions were shared with these panels along with a copy of the draft Charter for review. Some ran workshops with their members, some invited officials to lead workshops, while others gathered written responses. A summary of the types of groups who participated and/or provided responses is included below:

- Justice Social Workers
- People with experience of accessing domestic abuse support
- Young carers and people who work alongside them
- People with experience of homelessness
- Disabled people with experience of accessing social care support
- Women from minority ethnic backgrounds
- People with a wide range of experiences of adult social care support, both as supported people and unpaid carers.
- Independent Advocates
- People with experience of having loved ones in nursing and residential homes
- Individuals accessing and delivering support through charities created to help vulnerable children, young people and their families.

In addition, HIS undertook a series of engagement activities to gather insights from people with experience of accessing community health services and asked them about how they envisage using the NCS Charter alongside the NHS Charter of Patient Rights and Responsibilities and the Health and Social Care Standards, as part of their 'Gathering Views' work. Twenty people were involved through either one-to-one or group interviews.

In line with other Charter co-design, HIS engaged with underrepresented communities more likely to experience health inequalities. People that took part had one or more of the following characteristics:

- Pregnant women and mothers of children up to 18 years old
- Trans people, including non-binary people
- People from minority ethnic backgrounds
- People from minority religious communities.

Those who took part highlighted that they had accessed a range of services over the last 12 months, including:

- GP
- Optician
- Dentist
- Pharmacy
- Midwifery services
- Advance Nurse Practitioners
- Weight loss group
- Physiotherapy
- Audiology
- Psychiatry
- Adult mental health team/nurse
- Prescription service

- Health Visitors
- Vaccination
- Optometry
- District nurses
- NHS24 e.g. via phone call
- A&E
- “Keep well team” for health checks
- Support workers
- Link workers
- Support through charities
- Gender identity clinic
- Children and Adolescent Mental Health services
- Social work

Stakeholder engagement in the second stage of the sense-making phase involved sharing draft content directly with over 25 stakeholder organisations with an interest in the Charter, and inviting views and feedback to enable iterative updates to be made. This included organisations which represent or have expertise in:

- Equality and human rights
- Substance misuse
- Certain Children’s services
- Palliative/end of life care
- Minority ethnic communities
- Minority religious communities
- Individuals with disabilities and additional support needs
- Oversight bodies
- Mental health and neurodivergence
- Social work and justice social work
- Justice services including victim support
- Carers, including young carers
- Health services
- Island communities.

As in the ‘understanding’ phase and in the first round of the sense-making phase, people were invited back to workshops to reflect on what was heard through the interviews and group discussions and agree key findings, particularly where there was a lack of consensus.