Gathering Views Report on the Draft National Care Service Charter of Rights and Responsibilities

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Section 1: Executive summary

The Scottish Government is working with people and organisations across the country to improve community health, social work, and social care support in Scotland. It is introducing the National Care Service (NCS), which aims to make sure everyone has access to consistently high-quality local services across Scotland, whenever they might need them. The NCS is being shaped in collaboration with the organisations and people who have experience of accessing and delivering community health, social work, and social care support. One part of this work is developing the NCS Charter of Rights and Responsibilities ('the Charter'). The Charter will help people to better understand their rights and what they can expect from the NCS. The Charter will also provide a clear way to get further support and advice, and make clear how to make a complaint if rights are not met.

The Scottish Government commissioned Healthcare Improvement Scotland in August 2023 to undertake a Gathering Views exercise to help shape the Charter, with a particular focus to capture the views of people who frequently access Community Healthcare[1], from vulnerable or seldom heard groups. The engagement for this Gathering Views exercise represents one important strand of the Scottish Government's wider work to co-design the Charter. Over 500 people have been involved in the co-design of the Charter so far.
The findings from this work have already informed updates to the next draft of the Charter, to ensure that it meets the needs and expectations of those that are likely to use it, setting out people's rights and responsibilities clearly when accessing support through the NCS.

Targeted engagement took place in October 2023 through individual or group interviews, recruiting 20 participants overall who are frequent users of Community Healthcare[2] and also belong to one or more of the below groups:

- pregnant people and mothers of children up to 18 years old
- trans and non-binary individuals[3]
- people from minority ethnic backgrounds, and
- people from minority religious communities.

Equality monitoring information about the participants is provided in Appendix 4.

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[1] Community Healthcare describes care and support provided in the community and not in hospital.

[2] By "frequent users of Community Healthcare services" we mean people who have used Community Healthcare services two or more times in the last 12 months.

[3] Due to the voluntary nature of completing equality monitoring forms, our monitoring may not fully capture all protected characteristics, especially regarding gender identity. Our approach to engaging with trans and non-binary individuals involved outreach through relevant groups for participation.

Participants were provided with the latest version of the draft Charter at the time of the engagement[4] in advance, as well as the question set so they could reflect and prepare for the interview.

This report outlines the feedback from participants as well as key areas they highlighted for improvement. Key findings, outlined in detail in Section 4, include the following:

The Charter in the context of Community Healthcare: it was clear to most that the Charter applies to Community Healthcare, however, improvements were suggested, for example, in how Community Healthcare is defined in the Charter and what roles are included, explaining who the Charter is for, and how participants understand the different aspects of health and social care. Participants also wanted more specific information, such as around condition-specific challenges, charitable organisations, and the roles of carers and guardians.

Service user rights: the majority of the participants were happy with the section around users' rights, saying it is clear, easy to read and inclusive, covering what they would expect to see. Many discussed areas for improvement, however, such as having an exhaustive list of rights in one place, making the language clearer and easier to understand, and expecting to see what happens when user rights are not respected. Further rights that participants would like to see added were also discussed, for example around person-centredness, accessible formats and resources, and being able to access further and specialised support and care.

Service user responsibilities: participants identified a range of user responsibilities, and some said they would like this to be expanded on in the Charter to ensure these are clear and don't assume prior or implicit knowledge.

Further information needs: many said they would like further information included in the Charter, for example around the NCS, what it is, and how to access support through it, information about advocacy, and inclusive communication. Participants also highlighted that the implementation of the Charter must be accompanied by improved communication, including between staff and services to support the discussed rights and responsibilities, as well as a more person-centred and joined-up approach to care, with improved relationships.

Charter aims: The majority of the participants agreed that the Charter meets its aims. Some participants said it was good to know that the Charter defends users' rights and the value of feedback and complaints, however some would like the Charter aims to be referenced earlier in the document[5] and with more detail and easier to access language.

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[4] It should be noted that the draft Charter is being continually reviewed and updated following insights and recommendations from co-design. Participants in this work were shown the draft Charter used in co-design between June and December 2023. An updated version has since been developed. This updated draft includes some insights from this report as well as from wider co-design work in the most recent phase. The Charter will continue to be updated and refined until the launch of the NCS.

[5] It is important to note that participants' responses reflect their perception and understanding at the time of interview. In this case, the aims of the Charter are stated early in the document, however, this was not clear to some participants, therefore this suggests that further clarity is needed around this.

Relevance and use of the Charter for participants: Most participants agreed that the Charter applies to their experience of Community Healthcare. Some participants thought the Charter was not relevant to them personally or their experiences, but recognised that it would be for others. Most participants said they would use the Charter if they had issues with the care they, or people they support, were receiving, or if they wished to make a complaint. Participants discussed the Charter as a good resource to rely on and a useful reference, but some thought that the Charter wouldn't impact on their daily life. It was clear that most participants didn't think they would use the Charter unless they had issues with their care.

The 'Charter landscape': Most participants were not aware of the Health and Social Care Standards nor the NHS Charter of Patient Rights and Responsibilities, and for the few that were aware of these this was due to activities related to work or volunteering. Most participants said that these are good resources to have and that they would use these if they had issues with their care, or needed to make a complaint or advocate for themselves or others. However, participants highlighted that, while these are good to have, low public awareness limits their benefit. Some participants were unsure how these resources will work alongside the NCS Charter. Participants also discussed the need for further clarity around the remit of these resources, to make it easier for people to know which one to use.

Priorities and key areas for improvement around the NCS Charter of Rights and Responsibilities: Key priorities and areas for improvement focused on supporting access, inclusion, and equality aspects, and highlighted the importance of the Charter leading to improvement of health and care in practice, and to improved understanding and engagement in health and care.

Early findings from this work were shared with Scottish Government in December 2023, leading to early updates of the draft Charter, as outlined in Section 6. An updated draft NCS Charter is expected to be made available online in due course.

The recommendations below, outlined in detail in Section 5.2 including specific aspects that should be considered by the Scottish Government in the development of the NCS, and the NCS Charter specifically, working where appropriate with partner organisations, such as NHS Scotland, COSLA and others.

Recommendation 1: Consider implementing changes in the content, language, and structure of the NCS Charter based on these findings to increase clarity and understanding, and address information needs.

Recommendation 2: Ensure the NCS Charter helps users find the specialised information they need through appropriate signposting.

Recommendation 3: Work towards increased clarity within the 'Charter landscape'.

Recommendation 4: Ensure the appropriate implementation of the NCS Charter and that it is supported by relevant processes as needed.

Recommendation 5: Ensure the impact and use of the NCS Charter is monitored, evaluated, and communicated to the public.

Recommendation 6: Work towards increasing awareness and understanding of the NCS Charter, among public and staff.

Section 2: Background

Healthcare Improvement Scotland enables the people of Scotland to experience the best quality of health and social care. Healthcare Improvement Scotland – Community Engagement & System Redesign is committed to supporting the engagement of people and communities in the development and design of health and social care services.

The Scottish Government is working with people and organisations across the country to improve community health, social work, and social care support in Scotland. It is introducing the National Care Service (NCS), which aims to make sure everyone has access to consistently high-quality local services across Scotland, whenever they might need them. The NCS is being shaped in collaboration with the organisations and people who have experience of accessing and delivering community health, social work, and social care support. One part of this work is developing the NCS Charter of Rights and Responsibilities (‘the Charter’). The Charter will help people to better understand their rights and what they can expect from the NCS. The Charter will also provide a clear way to get further support and advice, and make clear how to make a complaint if rights are not met.

In August 2023, the Scottish Government commissioned us to undertake a Gathering Views exercise. The engagement for this Gathering Views exercise represents one important strand of the Scottish Government’s wider work to co-design the Charter. Over 500 people have been involved in the co-design of the Charter so far. Particular focus was applied to ensure that the Charter co-design was inclusive and captured the views of vulnerable or seldom heard groups, to make sure that the Charter will deliver for everyone.

The findings from this work have already helped inform updates to the next draft of the Charter, to ensure that it meets the needs and expectations of those that are likely to use it, setting out people’s rights and responsibilities clearly when accessing support through the NCS.

During the Gathering Views exercise which took place in October 2023, we held targeted engagement focusing on people who are frequent users of Community Healthcare, from vulnerable or seldom heard groups. These communities are often underrepresented in health research and more likely to experience health inequalities, and were highlighted by officials as requiring priority attention in this work and in the NCS EQIA.

- pregnant people and mothers of children up to 18 years old
- trans and non-binary individuals
- people from minority ethnic backgrounds, and
- people from minority religious communities.

By “frequent users of Community Healthcare services” we mean people who have used Community Healthcare services two or more times in the last 12 months.

We engaged with 20 people overall, through individual or group interviews, and targeted recruitment focusing on the characteristics mentioned above: six people were recruited due to their living experience of being pregnant or mothers, four trans or non-binary individuals, five people from minority ethnic backgrounds, and five people who have a minority religion[6]. Participants were provided with the latest version of the draft Charter at the time of the engagement[7] in advance, as well as the question set so they could reflect and prepare for the interview.

Among the people we engaged with, there was experience of both long-term and more general use of Community Healthcare services, as well as experience of extensive periods of time on a waiting list and using both in person and online services. Furthermore, beyond accessing services for themselves, some of the participants had used services for others, such as their family and children or supporting friends to access care. Some mentioned being unpaid carers or supporting others to access care, and during the interviews, they reflected on their personal experiences and their experience of others trying to get access to care as well.

The participants mentioned having a range of experiences within Community Healthcare, as well as experience of the wider health and care system, highlighting positive aspects and challenges and issues. The participants mentioned accessing the following services in the last 12 months:

- GP
- Optician
- Weight loss group
- Physiotherapy

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[6] Due to the voluntary nature of completing equality monitoring forms, our monitoring does not fully capture all protected characteristics. For example, the equality monitoring data does not reflect the number of trans and non-binary individuals we engaged with. Our approach to engaging with trans and non-binary individuals involved outreach through relevant groups for participation, so we know the number of trans and non-binary individuals we engaged with through this process, independently of whether these participants completed the voluntary equality monitoring form. Furthermore, as this was targeted engagement focusing on specific characteristics and groups, participants were recruited for one characteristic, for example, they may be a mother and focused on discussing their experience in that context, but individuals may have reflected other relevant characteristics in their equality monitoring response, which was not disclosed nor discussed during the interviews. In this section, we outline the number of participants as targeted to participate in this work according to the main characteristic they were recruited for, while recognising that individuals are multifaceted and may belong to more than one of the above groups. This is supported by the equality monitoring data in Appendix 4.

[7] It should be noted that the draft Charter is being continually reviewed and updated following insights and recommendations from co-design. Participants in this work were shown the draft Charter used in co-design between June and December 2023. An updated version has since been developed. This updated draft includes some insights from this report as well as from wider co-design work in the most recent phase. The Charter will continue to be updated and refined until the launch of the NCS.

- Dentist
- Pharmacy
- Midwifery services
- Advance Nurse Practitioners
- Health Visitors
- Vaccination
- Optometry
- District nurses
- NHS24 e.g. via phone call
- A&E
- “Keep well team” for health checks
- Audiology
- Psychiatry
- Adult mental health team/nurse
- Prescription service
- Support workers
- Link workers
- Support through charities
- Gender identity clinic
- Children and Adolescent Mental Health services
- Social work

Section 3: Approach

Healthcare Improvement Scotland – Community Engagement & System Redesign has developed an approach called Gathering Views[8]. This aims to gather lived experience views on specific subject areas to inform the development of health and care policy and services.

Gathering Views exercises are not undertaken as formal research, nor as formal public consultation. The engagement is intended to supplement work undertaken by Scottish Government or other commissioners, consider new or different ideas, and make recommendations based on the findings.

The question set (Appendix 1) developed to help us to gather people's views, insights, and experiences around the draft Charter and other similar Charters and Standards. A total of 18 questions, with supplementary questions, were presented.

An information sheet was provided for the participants as well as a consent form to take part in the work, and all participants provided written or verbal consent in advance of the interview (Appendix 2).

Equality monitoring questions were in the form of a questionnaire (Appendix 3). Participants could complete the survey either before or during the discussions, via email or paper copy. This achieved a 75% response rate and equality monitoring information is provided in Appendix 4.

Recruitment methods were agreed based on the scope and aims of this work. We engaged with 20 individuals through individual or group interviews over a 2-week period, collecting extensive and in-depth responses. Following a qualitative approach, and aligned with the objectives of this work, the aim was to collect rich and meaningful feedback from people who frequently access Community Healthcare services, with the particular targeted characteristics.

The questions covered the following areas:

- the Charter sections
- the Charter overall
- the wider Charter "landscape" – The NCS Charter and other Charters and Standards, and
- what matters to participants about the Charter.

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[8] On behalf of the Scottish Government and Healthcare Improvement Scotland, views are gathered from members of the public across a variety of health-related topics.

The themes from participants' responses can be found in Section 4 of this report, and conclusions and recommendations are outlined in Section 5. Where appropriate, we have used anonymised quotes from people who participated to illustrate what we heard. When participant quotes are provided in this report, no identifiable characteristics, such as location, are included.

The analysis process followed a qualitative approach. All participant responses were themed and categorised, identifying a number of key and overarching themes which are discussed in this report. The recommendations were developed to address key points in these findings and are directly linked to the views and experiences shared with us during this work.

Participants provided comprehensive feedback. To support the interviews and ensure clarity and understanding, an information briefing was shared with all participants before the interviews took place, alongside the latest version of the draft Charter used in co-design between June and December 2023 and interview questions, provided in Appendix 2.

3.1. Limitations and influencing factors

It is important to highlight certain limitations and influencing factors around this work, to provide context and inform the reader's understanding and interpretation of the findings outlined in the next sections.

Due to its aims and objectives, this was a highly focused piece of work with constrained timelines, aimed at gathering insights from individuals with particular characteristics which could then be incorporated into the Charter alongside insights gathered through wider co-design work from a breadth of other individuals and groups. As such, this work intentionally involved a limited number of participants and focused on collecting in-depth, rich feedback from people with specific characteristics. Focusing on people with frequent experience of accessing Community Healthcare services and with the four specific characteristics addressed the aims of this work, however, it may make it more challenging to get a broader perspective. This is important to consider when drawing conclusions from this work.

The limited number of participants could potentially lead to challenges in terms of maintaining anonymity, therefore any reference to characteristics or information that is deemed to not be essential in order to understand the findings has been omitted.

This work used a qualitative approach to best address the work objectives. Discussions during interviews, at times, relied on participants' memory, and these findings highlight the participants' perceptions. Individual participants' contexts and understanding may also have influenced their understanding of the interview questions. The findings are not a definitive or necessarily 'true' reflection, but rather they reflect the participants' "truths" during the time of interview, tightly linked with the individual participants' contexts, experiences and understanding. A further aspect of this is that participants' responses may, at times, seem contradictory, however they reflect their views and perceptions. For example, a participant may respond that they are satisfied about a particular aspect of the Charter, but then still suggest improvements, resulting in findings potentially reporting that most participants were happy with these aspects but many suggested improvements nonetheless.

Furthermore, this work focused on the NCS Charter, while acknowledging that the NCS is not in place yet. Therefore, beyond the information provided ahead of the interviews (see Appendix 2), it is likely that some participants may not have a clear understanding of what the NCS is due to them not having experienced this yet, and this may have influenced their responses.

These findings are intended to offer insight and direction for improvement and further exploration. However, caution should be exercised if these findings were to be generalised.

Section 4: Feedback

This section outlines key points and themes from all the feedback collected through this Gathering Views exercise. Conclusions and recommendations based on these findings are outlined in Section 5.

4.1 The Charter in the context of Community Healthcare

For half of the participants it was clear that this Charter applies to Community Healthcare, one saying “it is quite clear to me that it is about Community Healthcare and not hospital healthcare” and another saying “it's very clear what the Charter wants to achieve and who it wants to reach”.

When asked if there is anything else that should be added or changed to make the Charter more applicable to Community Healthcare, 14 out of 20 of the participants said no or they weren’t sure. One said: “it covers everything for Community Care”.

Areas for improvement on clarity and use of the Charter in the context of Community Healthcare

In contrast, the rest of the participants said it wasn’t clear to them that the Charter applies to Community Healthcare, with one saying “I wouldn’t have thought this”, and most suggested improvements in the following areas.

Defining Community Healthcare, and what services and roles are included

Most participants emphasised the importance of including a definition of what Community Healthcare is at the start of the Charter. They said they want to understand what services are included in Community Healthcare and which aspects are relevant to the Charter. Participants suggested including a description and clear list of services that are included, and wide range of examples, particularly key services and those that people may not readily think of, such as falls prevention. Participants highlighted that the list of services needs to be clear and to include more services rather than less, for example. Some participants highlighted specific services they would like to see referenced in the Charter, including NHS 24, Sexual Health clinics, Drug and Alcohol services, Dentistry, Audiology, and Speech and Language therapy. One participant said “for the sake of clarity I feel it’s important to include more rather than less so people can relate”. This suggests that having a comprehensive list of services, potentially as a separate online resource that is signposted in the Charter, could be helpful.

Participants also noted that they want to know who is involved in delivering these services, with short explanations of what the services and teams/roles are, and what they do, for example, Allied Health Professionals, along with examples of professions falling within that category. Some thought that it is important to explicitly include in the Charter all the roles who are involved in providing services, even if they are indirectly involved in providing care, especially when thinking of service users' rights and which staff members should be adhering to respecting these. This should be set out clearly in the Charter, as some participants weren't sure if this section on rights includes, or should include, non-clinical staff. For example, administrative staff, receptionists, or security staff, who are less directly involved with their care but can have an impact on processes and people's experience. One participant said:

"Those indirectly involved can make a difference to how a service is provided. Make it clear exactly who is included and involved directly or indirectly".

A participant noted that these rights should apply to every service and emphasised their experience of the lack of a holistic approach between services.

Understanding of the health and social care context

A participant noted that the differences between Community Healthcare, social services, and social care were not clear to them to begin with. They said they would like the Charter to include more information on the differences between them, and how these aspects of care are linked. A participant said that they thought the Charter "was NHS in general". They also said that they felt clearer about what Community Healthcare is after the discussion that took place during the interview, suggesting that clarity around this could be increased for the public and users of Community Healthcare through discussion, or even through more interactive mediums, such as an explanation of this via an animation or video. Another participant suggested that having someone, for example, a youth worker, to support people to understand the Charter and relevant resources, and navigate the complaint process, would be helpful.

Another participant noted that they found this challenging to understand due to their general perception of healthcare as one overall service and not separating different aspects, saying:

"I don't think it's because of the document, I think it's because in my mind there's just healthcare".

Another participant suggested that it would be helpful to know how the current Health and Social Care Standards fit in with this work and for this to be made clear in the Charter. This suggests that adding a brief explanation in the Charter about how it fits into the wider healthcare context could be helpful.

Including more specific information

Two participants mentioned wanting information in the Charter that recognises condition-specific challenges, such as individuals with certain conditions needing to frequently access different services. This could suggest that the specific needs and challenges that people with certain medical conditions may face in terms of accessing Community Healthcare services could be considered more extensively, or be referred to more explicitly, in the Charter.

Participants also mentioned that charitable organisations should also be mentioned in the Charter, as they often have a significant role in providing support, particularly in areas like mental health.

Additionally, one participant suggested that increased clarity on carer's roles and rights might be helpful to include in the Charter, specifically around guardianship and similar roles such as young carers, and how these may differ.

Defining who the Charter is for

A participant suggested improving the 'who' section of the Charter, by moving relevant information from later in the document to the beginning, as they noted that further down the document includes additional details on who it would apply to. They felt this would help people understand whether the Charter is relevant to them, saying:

"because you will have people that go in and look at that first section and straight away think it doesn't apply to them. If I had just read the introduction I would have thought 'oh it's a 9-page document and it doesn't apply to me' then I probably wouldn't have read any further".

Another participant suggested that it could be helpful to specify in the Charter whether it could be useful for someone who has not yet accessed support, wondering whether it may help individuals be aware of their rights in advance.

4.2 Thoughts about service users' rights when accessing services and support

When asked about the Charter section on service users' rights, the majority of the participants were happy with the section, one saying that it "makes sense". One participant said that the Charter will allow patients and staff to be on the same page about rights, with some participants mentioning that this section would be helpful specifically to highlight rights to staff. Some participants said that this section is clear, to the point, and easy to read. One participant said that "the list of rights seems to be based on general human rights and appears to be sufficient", and another felt that it covers aspects around protected characteristics well. A participant noted:

"I like how it mentions 'compassion and warmth' as important qualities. I haven't heard that discussed much before, but it's so important."

One of the participants felt that the Charter is inclusive, as it mentions the need to consider religion and translation needs. Someone else liked the statement about being entitled to services regardless of one's background. They said that it is important for this to be highlighted, as it may not necessarily be the case in other countries. They also noted people need assurance and encouragement to use services.

When asked whether they thought any rights that are mentioned in the Charter do not apply in the context of Community Healthcare, all participants answered that all the stated rights would apply in Community Healthcare[9]. One said that it's "all about respect and kindness" and another that they think "these are good rights and apply to everything".

Areas for improvement on service user's rights when accessing services and support

Understanding of service users' rights
A participant noted they are not aware what all their rights are, and another participant said that it would be useful to have an exhaustive list of rights in healthcare listed in one place, using language that is easier to understand and clearer. Another said that there is nothing in this section on what to do if rights haven't been met nor how to get support if that happened. Participants also highlighted the need for staff to also understand users' rights. A participant suggested that staff need to be trained on patients' rights and what they can expect to be asked for by patients.

Further service user rights
Some participants suggested particular rights that they thought should be added to this section of the Charter, including:

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[9] These responses may seem to contradict the finding on the Charter within the context of Community Healthcare, were many participants said it wasn't clear to them that the Charter applies to Community Healthcare. However, in this question around user rights, participants focused more on discussing the rights rather than whether these would be relevant within the Community Healthcare context. Furthermore, as explained in the section on limitations and influencing factors, the findings included in this report reflect the participants' understanding and views, therefore may reflect contradictions as expressed by the participants.

- the right to talk and be heard
- the right to ask for a referral to see a specialist
- the right to a second opinion
- the right for professionals to respect confidentiality
- the right to advocacy and to bring someone alongside to appointments, especially for patients struggling to voice concerns
- the right to a translator, if they don’t speak English, and including information on how to do this
- the right to what can be described as a more person-centred, realistic approach to medicine: participants mentioned, for example, the right to have an equal relationship with clinicians. They emphasised the importance of being taken seriously and not feeling dismissed, highlighting that there are instances where patients are at times made to feel lesser than the GP and dismissed, despite knowing their own body. Another participant mentioned the right to allow people to talk and make suggestions around their healthcare. Another said that patient knowledge of their own health and conditions should be respected by the professionals
- the right and responsibility to challenge whatever they feel is going against their will
- the right to get information and be fully informed about their patient journey, to enable personal agency and feel informed, saying: “if someone is asking questions they need to be informed about the whole time of their care. Not wee bits per appointment”
- the right to access well-trained and specialised professional staff. For example, a participant mentioned that they would expect staff to have basic knowledge of autism and that staff should work well together for effective autism diagnosis and support, whereas now it feels like there is no community of knowledge and support. Similarly, another participant said:

  “You have the right to a professional who knows what patients are requiring support with i.e. Autism disassociation disorders connected with trauma disorders, fawn, freeze fight or flight syndrome”.

4.3 Thoughts about service users’ responsibilities when accessing services and support

When discussing what responsibilities service users have when accessing services and support, all participants were able to think of some responsibilities they have as service users. Some participants mentioned having similar or equal rights to responsibilities, however some discussed that fulfilling their responsibilities, for example, being honest and giving correct information, would require them knowing that staff are respecting their rights as service users, for example, upholding confidentiality.

Many participants also said that it is their responsibility to inform staff about backgrounds and needs, to increase understanding, rather than expecting staff to know everything. For example, participants discussed that service users are responsible for making staff aware of their expectations and how they want things, to teach them about their community, or let them know if there are issues relating to their religion around a suggested treatment. One participant said:

“my religion and social structure is different from the UK, so if we want something we need to let them know how we want it to be and teach them about our community, rather than expecting them to know everything about our religion and community. It is our responsibility to tell them”.

Many mentioned that service users must be honest, provide correct information and not withhold information, including the reasons why they are using the service and their situation. Service users should be truthful, ensure good communication with staff and let them know about their needs in advance, and provide them with their history, to ensure they get the care they need. A participant said “if we want the best care for our children, we have to be honest” and another said “if I (…) wasn’t honest about how I was feeling and my situation, I wouldn’t have received the support that I got”. Participants also said that users should follow staff guidance, but also should ask if they don’t understand something.

Most emphasised that users must treat staff with kindness, dignity, respect, politeness, and fairness, regardless of backgrounds or characteristics, mirroring the service user’s rights discussed in the Charter. A participant said that service users are responsible for treating people the way they would expect to be treated, and another said they should give staff the benefit of the doubt.

Many participants also highlighted the service users’ responsibility to reach out and seek the help they need. Many also thought that service users are responsible for figuring out what the right service to go to is, what staff to speak to, and to be clear what their support and care needs are, one saying that users should “do their research”. However, another participant noted that service users don’t always know where to receive support. This highlights the need for service users to have access to helpful and clear tools and information that will support their decision-making at a first instance.

Others noted more practical responsibilities, such as attending appointments to not add pressure to the system, being on time, respecting the service, changing appointments and cancelling if needed, and engaging in good faith in the discussion of their care plan.

Some participants mentioned respecting how difficult it is for staff, rather than being demanding, with one saying: “I think community care staff, probably all NHS staff and support staff, take the brunt of it sometimes”. A participant mentioned service users needing to understand that some expectations cannot be met and that service users should do what they can on their end, with one saying it’s helpful to have “an understanding that what I want might not always be possible, because I think there are limited resources available”. Another said that service users should manage their expectations, even bearing in mind that they might need to go down the private route, as “it’s just the way that things are now”.

Areas for improvement on service user’s responsibilities when accessing services and support

Standards of behaviour and clarity on service user responsibilities

A participant suggested that the section on responsibilities could be expanded, as there isn’t a lot of information there and these are not always obvious for people. A participant suggested adding to the Charter a section on service user standards of behaviour, to clarify responsibilities and set out service providers’ expectations. A participant mentioned this potentially being understood more as a transactional exchange, with consequences for when people are rude, saying “it’s a transactional exchange. As consumers we are asking for a service”.

4.4 Further information needs when accessing Community Healthcare services and support

Some participants could not think of any further information they would need to know that isn’t already included in the Charter. One said that all information is there in the Charter.

Areas for improvement and further information needs

Improved communication

Participants also noted improvements needed in the broader area of communication, to ensure that the rights outlined by the Charter are implemented in practice. For example, a participant highlighted that service users can’t contact services in advance, as there are no contact details on letters, and this doesn’t allow them to explain their care requirements in advance in order to get the support they need. This, for example, could mean that service users can’t request alternative formats, or a translator or support worker to accompany them to an appointment. As participants highlighted that it is a service user responsibility to let services know about their needs and requirements, the fact that there is often no way of doing that in practice is seen by participants as a significant barrier.

Some participants also highlighted the need for more person-centred, joined-up and integrated care, with good working relationships between staff and services. They said there is a need to build patient and staff relationships and that, in their experience, Community Healthcare services lack engagement, empathy, and communication and there is disconnect between different staff and services. A participant characteristically said that “professionals lack connection with each other, they are not talking to each other”. This means, in the participant’s experience, that it falls to the service user to inform staff and pass on any necessary information from scratch, but this is on top of their health concerns and challenges, and they don’t always have enough energy or time for this. One participant said:

“The patient informs the different professionals. The patient’s role is essential at the moment in terms of updating professionals, but they are not allowed or have enough time to express their concerns about their own health. If you are accessing health services, you don’t necessarily have a lot of spare energy to support the connections between professionals. This takes up all of your appointment and you don’t have time to speak about your concerns”.

Another participant said they would like staff to take time to ask about the service user’s wellbeing, and another mentioned the need for relationships between service users and service providers to be governed by mutual respect.

Further information service users would like to be included in the Charter

Further information that participants discussed they would like to be included in the Charter:

- information about the National Care Service to support understanding.
- how to access support and what is meant by “support”, as it is not always clear who to go to for support.
- limitations to the support, to help set expectations.
- how to access alternative help, where to go, and what those alternatives might be. For example, one participant discussed how, when needing mental health support, many can’t get it through the NHS. They emphasised that there are other ways to get support, and these alternatives should be mentioned to increase awareness.
- practical information, for example, when it is better to go to A&E rather than contact a health centre by telephone.
- information on independent advocacy services in a more visible and effective manner within GP practices, to support effective implementation, and
- information about inclusive communication practices and how these can be accessed, such as interpreter services available as an option at healthcare reception areas.

4.5 Thoughts on whether the Charter meets its aims

When asked whether they feel the Charter has met its aims and objectives, as outlined in Appendix 1, the majority of the participants were positive about this.

Some participants discussed aspects that they liked and found positive. One participant said that it was good to see clear mention of what counts as a community, and another noted the value of including a section on giving feedback and making complaints. They said it is good to know that service users are encouraged to give feedback or make complaints, and they said they are:

“happy to see this section included, as people’s opinion can really help shape services. I personally didn’t know I can do this and that this is something that is encouraged”.

Another said that it’s good that there is a Charter that defends service users’ rights and that there is a route to follow if there is a problem. They also said:

“in general, you just want the healthcare, and you want it to be effective and to get the advice about where to go when you need it. Being able to provide the care is the most important thing”.

A participant also noted that the sections ‘Involve a member or support network in your assessment planning’ and ‘Assessment is not a test’ are really good to see included in the Charter, as “having an assessment can be very anxiety-inducing”.

However, one participant said they don’t agree with the statement around the aims of the Charter, saying: “I don't agree with the statement. How and where would people access the Charter? It doesn't tell me anything”.

Areas for improvement for the Charter to meet its aims

Many participants also discussed what else they’d like to see changed for the Charter to meet its aims.

The Charter’s aims and objectives

Someone said that the aims are covered, but that they should be referenced earlier in the document. A participant said that “it (the Charter) is clear against the aims”, but doesn’t have much detail, and others said it meets the aims “as long as they are adhered to” and that “it needs to be user friendly and in plain English for people to understand”. Two participants said that they’d have to see the final Charter to confirm this.

Clarity around assessment processes

A participant also said that the section ‘Assessment to find out what support you need’ should include more information on who would be invited to the assessment and the timelines, so service users know who can provide assessment for each service. And about the section ‘Involve a member of a support network in your assessment planning’, they said it would help if it was clearer that carers may need to provide consent on behalf of the person they care for.

4.6 The Charter in the context of service users’ experience of Community Healthcare

Most participants said that the Charter relates to their experience and were positive about this. A participant said this was clear to them, and another said:

“it’s good to know my opinion is important, that I have certain rights, that I will be listened to and that I’m encouraged to put forward my suggestions. Not everyone knows this, so raising awareness of this is important!”

One participant said, “I now know there is an obligation of care for me and will insist on that care being provided”. Other participants were also positive, saying “I think it reflects what actually happens when you go to your GP. It’s a good representation of what happens” and that “it applies to overall care”.

Areas for improvement for the Charter to apply to Community Healthcare

Relevance of the Charter to individuals

One participant said that they thought the Charter was not relevant to them personally. Another said that certain sections, for example, around advocacy or language barriers, don’t apply to them, but they recognised that they do apply to others. One participant understood that they “need the Charter to cover as many people as possible”.

4.7 How service users may use the Charter and when

When asked how and when they would use the Charter, most participants said they would use it if they had issues with the care they, or the people they support, were receiving, or if they wished to make a complaint. One participant said the Charter is good to have, and that “it is keeping me informed and giving me choices”. Some said that it would be a good resource to rely on and a useful reference, and another thought that it won’t impact them day-to-day, but “it’s good to know it’s being looked at”.

Some participants had clear thoughts on how they will use it. One participant said they will take the final draft to their own appointments and their mother’s, to encourage staff to be aware of it and to ensure that their needs are met as set out in the Charter. Others said they would share it with people in their local communities.

Areas for consideration and improvement around the use of the Charter

Relevance of the Charter

Many said they wouldn’t use the Charter unless they had issues in their care, as they wouldn’t feel the need for it otherwise. One participant said they wouldn’t use it at all, as they take what is in the Charter as a given and know their rights. Another wasn’t sure, as they haven’t experienced anything that would call for using the Charter. Another said that they don’t think people would look out for the Charter naturally.

Use of the Charter in communities

One participant said that people in their community sometimes don’t know their rights or where to go, for example, when they want to make a complaint or need to explain things to staff. They felt that it would be important for them to know there is a document that protects their rights[10] and that outlines a route to follow. Another participant highlighted that people in their community, and from different countries, go to them due to their existing relationships to get information, highlighting the importance of existing relationships and established trust that enables raising awareness informally through word of mouth. Another participant noted that they would tell people in their community about the Charter, and that “I would ask them to raise their voice because I believe everyone in Scotland is equal and every voice should be heard”. Another said:

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[10] While this is the participants’ understanding, it is important to note that the NCS Charter does not protect user rights per se, but rather summarises rights and provides direction to hold the system to account in the case that they are not upheld.

“I didn’t know all this when I came to the UK for the first time years ago and I wish someone had explained it to me”.

4.8 The ‘Charter landscape’

Questions regarding the Health and Social Care Standards and the NHS Charter of Patient Rights and Responsibilities were also included in this work. The NCS Charter of Rights and Responsibilities is intended to complement existing Charters and Standards. So, by asking about the Health and Social Care Standards and the NHS Charter of Patient Rights and Responsibilities, we sought to gather the views of people with experience of accessing Community Healthcare services to understand how people envision using these documents together. This will help to develop a coherent approach to presenting and sharing these documents to deliver a ‘no wrong door’ approach and enable people to get to the information that they need as effectively as possible.

Awareness of the Health and Social Care Standards and the NHS Charter of Patient Rights and Responsibilities

As shown in the chart below, most participants were not aware of the Health and Social Care Standards nor the NHS Charter of Patient Rights and Responsibilities (12 out of 20 participants). Two participants were aware only of the Health and Social Care Standards, and one was only aware of the NHS Charter of Patient Rights and Responsibilities, saying that “it’s used for patients in hospitals”. Five participants were aware of both.

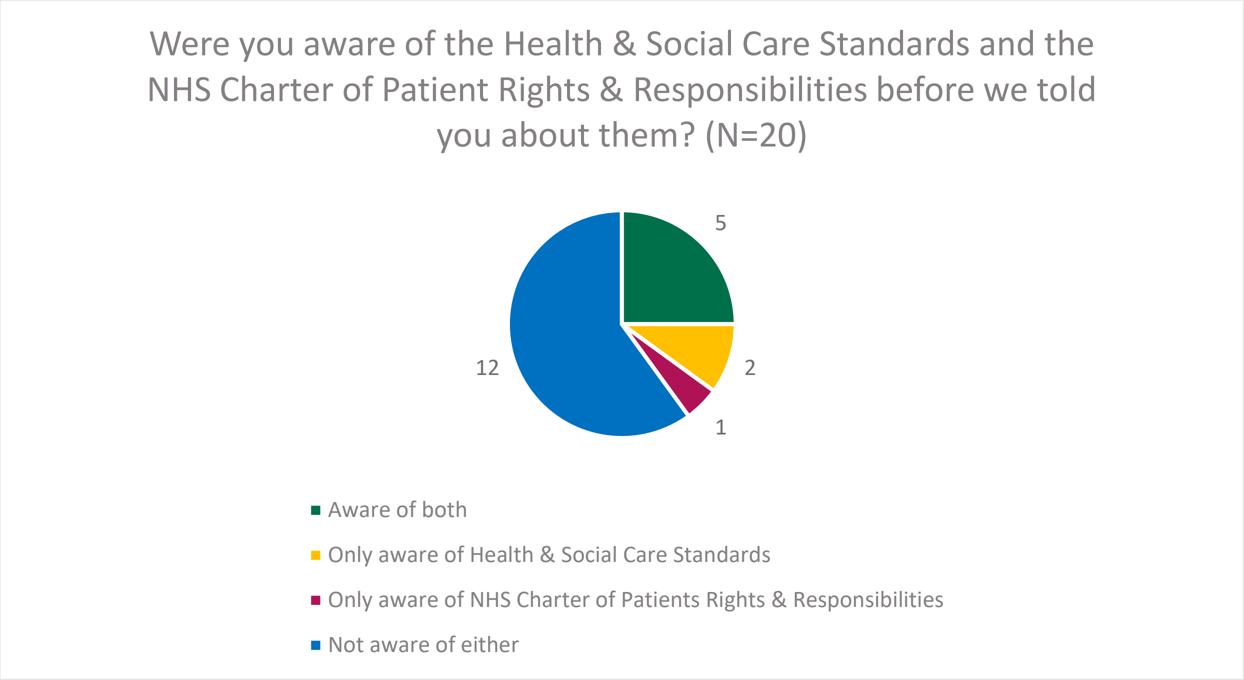

Figure 1. Awareness of NHS Charter of Patient Rights and Responsibilities and Health and Social Care Standards

How service users found out about the Health and Social Care Standards and the NHS Charter of Patient Rights and Responsibilities

Not many participants responded to this question (7 out of 20 participants), as most were unaware of these resources. One participant said they weren't aware of the resources but knew they had some rights. One participant said they found them online via Google, but all others who responded came across these resources through work, formal or informal/voluntary roles. For example, for one participant it was when they were translating local NHS and social work documents, another when advocating for others and supporting them through a complaint process, and one participant when they started working as a support worker. For another, it was when they worked with services and organisations such as the Trans Rights Commission, and for another when they did a breastfeeding peer support volunteer course. A participant said that they found out about both through their own research, saying it was:

"when I was trying to get my GP to cover my blood tests (…), maximum wait times for Sandyford is 4.5 years. I used these Standards to persuade my GP to cover my blood tests".

How service users use the Health and Social Care Standards and the NHS Charter of Patient Rights and Responsibilities

When asked whether they've used these resources, only four participants said that they used one or both of them. One participant has used the NHS Charter to communicate with relevant departments for their care. Another has used them as a reflective exercise at work and another is currently working with these resources. A participant said that they used them:

"two days ago when the prison service left a Traveller without medical support for 48 hours. They were suicidal. The (NHS) Charter was very useful in informing of the rights that the person could expect to receive".

When asked how they think they might use them, most participants said they'd use these if they had issues and a bad experience with a service and if they needed to make a complaint, or they needed to advocate for themselves and their friends in terms of rights, similarly to what most said about when they may use the NCS Charter. Participants said they would cross-check their rights and responsibilities and where to go from there. One participant said that they hoped to never have to use these, as this in all likelihood would be linked with a negative experience, while some participants said that it is positive to have these to give users a voice. One participant said it gave them "peace of mind". A couple of other participants discussed using these for different reasons, for example, to educate themselves and to help others understand their rights.

Participants were then asked what they thought now that they know there are other Charters and Standards covering rights and responsibilities. Nearly all participants said that it is good to have these in place to be used by everyone at any given time, and that they would use them to advocate for their rights and the rights of others, such as family and friends, to know what to expect, and also to educate themselves about their rights and responsibilities. One participant said that having these is a:

"sign of being in a very fortunate country to have that as part of the law of the land so that you are protected by law".

When asked how they would like the Health and Social Care Standards, the NHS Charter of Patient Rights and Responsibilities, and the NCS Charter of Rights and Responsibilities to work together, some were unsure. For others it was clear that these work together and should do, for "the betterment of everyone".

Areas for consideration and improvement around the ‘Charter landscape’

Awareness of the Health and Social Care Standards and the NHS Charter of Patient Rights and Responsibilities

A few participants discussed the need for users to know more about these resources. One said:

“I think I would have benefited from knowing about them before, for example when I had my first baby, I didn’t understand my rights and what I’m entitled to. I thought I just had to follow procedures, I didn’t know I had a voice. I also didn’t know I could make a complaint”.

A participant said that it is good to have them in place, “but (it’s) unfortunate that people are unaware of them”. Some participants noted that these need to be more accessible and clearly visible, with one suggesting that a Health Visitor could provide more information about these and that they could be included in the Red Book[11]. In fact, one participant discussed how they had not known any of this before the interview, and now they would seek out these documents to learn more and use them. They also said:

“before this conversation my view was that there were regulations in place but I didn’t realise it was quite as in depth as to ways of behaving etc. It has been an eye opener for me to find out that patients and carers have more rights than we probably realised we had”.

Another said they felt:

“it’s important to know they (the Charter and Standards) exist and to share these with people in advance so they know what to expect, particularly people with protected characteristics, as it’s important to set out expectations at the start as a lot of problems occur because these aren’t set out”.

Another participant said that they are:

“roughly aware of Standards. There are working groups that are trying to make things better but I couldn’t say where they are. It is not clear what they do or why they exist. The Health and Social Care Standards don’t feel as though they are there for patients, it appears they are more for clinicians”.

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[11] The Personal Child Health Record, also known as the PCHR or 'red book', is a national standard health and development record given to parents/carers at a child's birth.

One participant noted that they find “the other Standards more interesting than the Charter”.

One participant said it would be good to have these when registering with a GP as “having come from Tokyo, there was a lot of information that was overwhelming, so something more simple and collated on how it all works would be good”.

Clarity of remit

One participant said that “it’s a bit confusing having them all over, but from what I’ve heard aiming for the same things” and another said that it can be intimidating if there’s too much information if people were needing to figure out which applies to them, as well as being time-consuming to do so. One said that the language and purpose is the same across these, so they should be merged into one, as there is not much difference between them and this would make it standard and accessible for everyone. One participant said that they all should be based on the same values and rules substantively.

Other participants, however, said they prefer having these separate, so that if one has a specific problem they can go to a specific document, and that “when combining things there are always loopholes and things are missed”, so it is good to have separate and more focused documents. The difficulty would be, however, to figure out how to find them and which one to use, one participant saying: “it’s about how they are organised so that people can find what they need”. Another said that it “should be made easy for them (users) to find the information they needed without having to trawl through loads of information or go through the full document”. One participant said that presenting all these together may initially feel like information overload, and suggested providing the NCS Charter to begin with and then the Standards that support it, as “informing people of their rights is the most important thing here”.

One participant said that, if they had a bad experience, they would check to see if there is a Charter relating to the relevant service, implying a lack of clarity about which document applies to which services, and that service users may need to figure out which one to use, which could be an issue and barrier.

Implementation in practice

Some participants focused not on the documents themselves, but how they should be used. One noted that these are good as long as they lead to behaviours and experiences that reflect what is in these resources, saying:

“I think they work together in the sense that they are there and have been produced, but it’s just a piece of paper, a policy, it needs to show that it has triggered change because I think some change is needed.”

Another was positive about these, “as long as they benefit the public and are followed”.

4.9 Priorities and key areas for improvement around the National Care Service Charter of Rights and Responsibilities

When participants were asked what matters most to them about the NCS Charter of Rights and Responsibilities, the following key areas were discussed:

Access, inclusion, and equalities aspects

Equalities aspects

Legislation context: Some participants suggested that the Charter should include more information around the Human Rights Act and the Equality Act 2010. Having a clear mention of the legal status of the Charter at the start was also suggested, to set the tone and increase clarity. This should state that the Charter is in line with these acts, and that any changes made thereafter to those would apply to the Charter as well.

Inclusion, exclusion, and discrimination: Participants highlighted that all the important aspects must be covered in the Charter, such as rights and responsibilities, social boundaries linked to particular characteristics or groups, for example, religion, customs and traditions. They said that the Charter needs to cover everybody, and rights, responsibilities, and respect must be prioritised.

Some participants also mentioned wanting the Charter to delve a bit deeper and be clearer in terms of equality and discrimination, including information specifically around unlawful discrimination under this section on rights, with a brief and clear explanation of what is meant by that. One participant suggested that explaining terminology around discrimination will help people understand the later section on complaints. Other participants highlighted the need to be mindful of attitudes towards minorities, and that further aspects should be added that could be linked to discrimination, such as referring to immigration status, HIV status, weight (BMI), or the language that one speaks. One participant mentioned having experienced instances of misogyny from clinicians. A participant mentioned that Travellers are “excluded” from the Charter. To note, many communities and characteristics are not explicitly mentioned in the Charter and this is not to say that those not mentioned explicitly are not included in the Charter. However, this feedback suggests that there could be further clarity around this. A participant succinctly said “conditions and cultures and identities should be respected”.

One participant, furthermore, felt that people from less fortunate backgrounds are excluded from services and aren’t heard as much as others. For example, they feel that asylum seekers are always treated differently, and they thought that there should be more in the Charter to support asylum seekers and refugees. For example, a participant said that services should be more inclusive of asylum seekers and refugees, and that rules for asylum seekers should be implemented in practice and in a more positive way, also saying that:

“most of them are battling mental health and not being treated equally makes it worse, which in turn costs more to the NHS to treat them”.

Another participant said that the Charter needs to address racism to allow ethnic minorities to access services with confidence.

Gender identity: Two participants mentioned improving the language in the Charter around gender identity. One participant said that the Charter could use better language around gender reassignment, though they recognised that the language used is due to the language used in the Equality Act 2010. The participant suggested that gender identity should be added as a characteristic to the bullet point list included in the Charter, alongside gender reassignment. A participant recommended a more inclusive approach by suggesting the addition of gender expression and gender identity, while being included in the same section referencing sex, sexual orientation, and gender reassignment. While the draft Charter circulated to participants for these interviews does mention gender expression, it was not included in the bullet point list of characteristics, and where mentioned it was alongside sexual orientation.

Access and ease of use

Language and barriers to understanding: The Charter needs to be written in simple, plain, and concise language. A participant noted that the layout could be clearer, that the text should provide context, and that the introduction is too wordy. One commented that the Charter is very wordy, even though they’ve lived in Scotland for over 10 years and their English is very good. Another participant noted the need for the Charter to use “more laymen’s terms”. A participant said that it’s a lot to take in for someone with no experience of the national care services. A participant said that they read the document five times before the interview to increase their understanding, though they highlighted that this could be due to English not being their first language. Another participant said that they understood the Charter and its remit, but mainly due to other documentation and explanations during and before the interview, and not from the Charter text itself. This suggests that there may be room for improvement around clarity and to increase accessibility, especially, but not exhaustively, for people whose first language is not English. Overall, it was clear that many of the participants made significant efforts to read and understand the Charter and accompanying materials. However, the remaining lack of clarity expressed at times, the participants’ questions about terminology used, and the fact that such significant efforts, as, for example, reading the Charter five times was needed for this exercise, suggests that considering how to simplify the Charter would be helpful. It was also highlighted that the language used in the Charter should enable readers to see something they recognise and relate to, one participant saying: “people don’t always know the terminology but they could relate to the document if they saw a specific healthcare professional mentioned there that maybe they have seen before”. This links in with comments earlier in this report around needing increased clarity on who the Charter is for. Plain English and understandable terminology should be used, and bullet points could be used to relay information more effectively in some places.

For example, when discussing the Charter section on user rights, some participants said that it is vague and needs more clarity. This is supported by another participant who said they’d want more time to digest the content. One participant said that language barriers should be considered when discussing user rights, suggesting that the language used in this section could be easier to understand, or that there should be a more accessible version to address any potential barriers in understanding.

Furthermore, one participant also discussed that they represent only one community and emphasised that there are many communities and diverse subgroups within what may be perceived by external observers as one community, and that this should be taken into consideration when thinking about people’s needs and preferences, as they may differ. Participants also discussed the need to enhance future engagement activities by making the Charter accessible in various languages, specifically if groups were being asked to shape a future publication.

Translation needs: Participants said that the Charter and any related documents and resources should be translated into different languages and made simple and understandable for people. For example, one participant said:

“a lot of patients just take the brochures and leaflets from the GP or anywhere and then just say OK, we will ask our children to help us out with this, but they don’t. For example, if my mother gives me a leaflet to read out for her, I won’t read it word for word to her I would just read a few lines and sum it up for her.”

One participant mentioned needing to have more readily translated information, especially in terms of standard NHS information and consent forms, etc. They suggested having these translated into a range of languages, made available across all services, and also online, so staff don’t have to hold printed copies but can download and print the information in the required language when needed. One participant said:

“If the patient needed it, then you could simply print it out and give them it in a language that they understand.”

A participant highlighted that many people come from other countries and don't know how the health and care system works, so ensuring this information is translated and easily accessible in printed copies and online would help people understand. They also said that, in their experience, many older people may not be able to speak or read English "properly" and will often say "it's ok" but then take information home and ask their family to translate it, which is not always possible. A participant suggested that services should employ people who speak a range of languages and encourage them to be deployed to services to help, for example, to accompany people to appointments within GPs, dentists, or any community services. A participant discussed the need to make interpreter services available as an option at healthcare reception areas. One participant mentioned not being worried about support due to having integrated with other non-English speaking communities, as a supporting factor.

Access needs: The resources should be readily available, and people need to be able to use it as soon as they need it. It needs to be easily readable and eye-catching, using visuals and not only blocks of text. One participant suggested that use of the Charter would require it being in a range of formats to enable access, such as audio, braille, large print, British Sign Language (BSL) video, easy read, and translation in other languages.

Another participant said that information should be available in appropriate formats for those with literacy or visual difficulties, and that services should take people's needs into account when deciding how to contact people and provide information. For example, their spouse gets letters from services to arrange appointments, which is a challenge to do, when a phone call would be a better option for them. The importance of services using preferred ways of communication was also highlighted when collecting feedback from the public around Waiting Times Guidance.

Charter format: To ensure the Charter and related documents are accessible to all, they should be available in a wide range of formats. There should be printed copies, as well as digital versions, and shorter versions highlighting key points. One participant suggested having one resource where all the documents are summarised with relevant links provided. Another suggested that there should be a summary of the Charter, with an option to look at a more detailed version, which would help clarity. Another participant emphasised that the needs of users who don't have access to a computer must be considered. The documents' structure and navigation should be simple and support people to understand them, and everything must be optimised for web searches so they are easy to find.

Charter awareness and dissemination: Participants noted that the Charter must be communicated to people appropriately and effectively to increase awareness. For this purpose, participants were clear that a wide range of methods and channels must be used to ensure high visibility and the wide reach needed, as everyone prefers and uses different sources. Another participant wondered about how the Charter will be available to the public and how it will be accessed. People won't know it exists if it's not easily accessible.

Participants said it is important that it is clear that these resources are relevant to people whether they are using services for the first time or not. Many participants recognised that this would be challenging to do. Some participants thought that it is the services' responsibility to ensure service users know about these documents and that the onus is on them to make people aware. Some participants highlighted using local groups for this; local groups they know their audience and what they are looking for and can encourage people to bring friends along. A participant noted how important it is to involve as many people and groups as possible. You "need to hear from wider audiences, not just the loudest". It is important to reach out to people, it "will help people in their ability to say to professionals that you can't treat me like this, you shouldn't do it and I don't like it".

In terms of media and different tools and methods to increase awareness, participants' suggestions included the following:

- **In person events**: Visits and "Know your rights" events at local communities and groups, for example, mosques, hubs, Barnardos, befrienders. They can present the resources to communities in ways already being used by others, for example, Keep Well events. Campaigns at schools so children learn their rights early on.
- **Physical resources**: Printed copies and posters with key points available in a wide range of places and services including: gyms, leisure centres, libraries, local carers' centres, advocacy bodies, Community Healthcare services such as GPs, pharmacies, dentists, other waiting rooms, religious spaces, schools, youth clubs, public noticeboards, billboards, community hubs, university societies, disability services, third sector and charity organisations, supermarkets, and village halls.
- **Digital resources and social media**: Available online in all usual public websites, for example, NHS24, NHS homepage, Scottish Government websites, council websites, and all health and care websites. A QR code could help lead people to the documents online. Circulate them via WhatsApp groups and social media, for example, Instagram, Facebook and Threads.
- **Reaching communities**: Seek out local groups and allow time to build relationships with them to help spread the word. Proactively seek out marginalised groups that wouldn't be heard otherwise. Circulate to all relevant charities and third sector organisations and link in with existing organisations that have local networks such as Transgender Dundee, Scottish Trans and LGBT Scotland. It is beneficial for them to use these when supporting people as well. Give people who represent particular communities printed copies so they can present them to their communities in their own language to explain importance and answer questions.
- **Health and care staff**: Ensure health and care staff are aware of these, across all staff groups. Staff should ask service users about whether they know about these resources at appointments, have a short conversation about them with users, and signpost to them.

- **Advertising and other tools to increase awareness**: National campaign and advertising about knowing your rights, on TV and all media. Video about what National Care Service is, with voiceovers in different languages so people can understand. Promo video where people with lived experience say a few words on how these resources have helped them, “Real people, real stories”.
- **Signposting**: Signposted to from other relevant resources, for example any resources on the complaints process or around self-advocacy and patient rights. Include information on these in the Red Book[12], used especially by mothers.

Access to personal information

Throughout the interviews, the participants discussed the importance of being able to access their personal information and challenges they have experienced around this.

Some participants noted that they would expect the Charter to include more detailed information on how users can access personal information. A participant discussed the section on ‘Your rights over the information the National Care Service (NCS) holds about you’, which refers to service users’ right to accessing personal information. They said that, while the right is mentioned, there are no details on how to gain access to personal information, and in their experience this is not a straightforward process and takes time. They explained that they want to know their test results, and not to only find out if they’re normal or not, especially as the process of informing service users can go wrong. They said:

“I’d like to know what my results are exactly, not just information that it’s ‘normal’ or ‘negative’, but exact parameters, as they can matter. Sometimes we don’t find out our results at all, as we are contacted with bad news only. It should be common practice to be contacted in every case, because it causes a lot of anxiety not hearing anything”.

A participant said that they would like to see the process of how to access their medical information made more explicit, and the Charter to say that service users are entitled to this. Users could print this and take it to their GP when asking for their medical records, as the participant has had issues with this in the past. Another said they have had similar issues with accessing their records, as well as experiencing issues with health boards accessing their information. They said that a clear definitive way for people to do this is needed, and suggested for this to be outlined in the Charter. When wanting to access their information, one participant was told that there “wasn’t a good enough reason”, that it is a “waste of GP resources”, and the “receptionist said there wasn’t enough time”.

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[12] The Personal Child Health Record, also known as the PCHR or 'red book', is a national standard health and development record given to parents/carers at a child's birth.

Leading to improvement of health and care in practice

Throughout the interviews participants highlighted the importance of how the Charter translates into practice. Some participants discussed aspects around the implementation of what is in the Charter and the difference between things in writing and practice.

When discussing the section around user rights, participants highlighted the need to focus on ensuring that rights are implemented in practice, one saying:

"Rights are all well and good written on a piece of paper, as long as they are followed and everyone adheres to them".

A participant said that support should be provided to ensure rights are actioned in practice. Another said that more needs to be done to ensure rights and responsibilities are addressed and monitored, suggesting that this is not only about implementation but also evaluation. One participant said, referring to page 2 of the Charter and the section 'Involvement and Choice', that the way it is currently written implies that one's need to access Gender Identity health and care services is a choice and this could be misconstrued, particularly in the context of the current political climate.

Some implied that rights relevant to Community Healthcare should be considered further, beyond simply whether they apply, but thinking about how this might look in practice, with one saying "I feel like they all apply, but do feel they are not implemented well" and another highlighting that:

"if there is a right that can be violated, if anyone is a member of the characteristic groups, then the protections for their rights should be in place".

When discussing the Charter aims and objectives, one participant said that they feel that what is written in the Charter isn't implemented in a positive way, saying: "whatever is written, they don't really exercise it in a positive way". Another participant said " it's a good idea, but it needs to be followed by both professionals and public for it to work effectively."

One participant said that it is good to have the Charter developed, but it will be interesting to see if it works in practice. Another said that how rights are applied differs between services, saying:

"sometimes I may need the service (to be) changed slightly. The Keep Well team onsite knows my needs and background, while with the offsite weight loss service I need to reiterate my culture and ethnicity".

Another participant said that the section around communicating service user needs and coming up with mutual plans that work for both sides has not been applied in practice in their experience. It tends to be more about telling rather than a reciprocal conversation, with service users not being listened to. They noted that they have felt there has been scepticism about their family member's care needs before.

When discussing the Charter in the context of Community Healthcare and how it applies in practice, some participants mentioned concerns around the resourcing of services. A participant explained, for example, that it would be good if waiting times were "tightened up", and that more services and resources are needed to ensure people can be seen and have a better experience. Another participant said that "sometimes people are not treated with respect and this can often be a result of time or workload pressures".

Thinking of how the Charter should be implemented in practice, participants also discussed that it is important that:

- people receive the service they deserve
- people are treated the way they deserve to be treated, with dignity
- services come together in terms of practicalities and awareness, putting to practice what is in the Charter in writing
- staff listen to what people say
- the Charter protects people, and
- the basic right of having access to healthcare "for everybody in the country" is written and protected in an official document.

Participants also discussed the importance of implementation, monitoring, and evaluation, highlighting that:

- "on paper everything is there" but implementation and evaluation are very important
- the Charter and its implementation must be reviewed frequently and monitored and evaluated appropriately to ensure it is fit for purpose and meets its aims, and any issues are picked up in a timely and appropriate manner
- charters and standards must be used in a positive way, and
- they also must evolve in time according to the changes in regulation, the changing population and its needs.

Leading to improved understanding and engagement in health and social care

Throughout the interviews participants discussed the importance of the Charter helping people to understand and navigate health and social care.

For example, participants discussed the information included in the Charter around the complaints process and what users should do when things go wrong. They highlighted the importance of people knowing how to make a complaint and what to expect in terms of rights. Participants highlighted that the Charter needs to include more information and a clear process for addressing concerns, and making sure that everyone understands and agrees. Some mentioned wanting more information on complaints, perhaps a dedicated section on this. Some participants explained they wanted more clarity and information around complaints and what happens, or needed to be done, when things go wrong. A participant said that the section on complaints is very general and doesn't provide much detail. They'd like the section to be populated with more practical guidance on how to make a complaint, for example, who to speak to and how. A participant thought it would be beneficial if it was a similar process to consumer rights, with a clear process for when someone is unhappy with a service. They also suggested including options for when a service has been a positive experience, saying:

"Similar process to consumer rights, so that if you are unhappy with the service you know the process for redress. Important to include where there has been positive service".

There was also lack of clarity around what happens if service users can be removed from services if they are seen as uncooperative or question whether the service is working for them, or what the participants described as "if they have a difficult accent", and whether this information would be contained in their medical record for all staff to see. A participant noted the need to be able to get a second opinion and alternative support, rather than not getting support from services.

One said they would like to see specific mention around complaints and unlawful discrimination, harassment, and victimisation, as it is important to include these when talking about protected characteristics. This should also include mention of the timeframe for complaining and how to make a complaint. Another said that it's unclear if complaints are recorded in service users' records, that they don't know what potential outcomes are, and whether complaints would be acted on or explained to the service user. The participant would like patients to be involved in the process and know the impact of their complaints, for example, lessons learned, and this should be clearly laid out in the Charter. They said:

"you don't know if a complaint will be recorded in your records, you don't know what the complaint process is, don't know what will be the outcome. Will a complaint be acted on, and that explained to the patient?"

Some participants also highlighted that people from ethnic minority backgrounds may be afraid to complain and that for the complaints process to work there needs to be a safe, trusted, person whom they can confide in and work to build up trust with the NCS, and healthcare service generally to enable this.

Participants discussed further aspects of health and care that they would like the Charter to help users understand and navigate, including helping people to:

- set clear expectations and understand where to find the information they need
- understand equality more in the contexts of health and care
- understand that people's opinions matter, that they are entitled to their voice and that it matters, that they are being involved, and feedback is welcomed
- understand that they have to be treated equally regardless of how they look, for example, if they have tattoos
- understand their rights more, for example the right to a second opinion, and see what services are available, so everyone can get the information they need
- know how to protect themselves and who can protect them, know that they will be taken care of, and that there are consequences if this doesn't happen
- know that their knowledge of their body is protected, as "we (users) are experts in our own bodies", and
- have a better understanding of how private and NHS care intersect, and how people can manage between these two, how to work out the best care for themselves and any implications, for example, regarding gender identity healthcare and post-surgery support.

Section 5: Conclusions and recommendations

5.1. Conclusions

This section of the report brings together the main conclusions drawn from the findings of this Gathering Views exercise and outlines recommendations.

The Charter in the context of Community Healthcare

It was clear for half of the participants that the Charter applies to Community Healthcare (10 out of 20). Most participants said there was nothing that should be added to make the Charter more applicable to Community Healthcare, or they were unsure.

In contrast, this was unclear for the rest of the participants, and many suggested improvements. These included improving how Community Healthcare is defined in the Charter, and what services and clinical and non-clinical roles are included. Another area for improvement was around users' understanding of the health and social care context, for example, what the differences are between Community Healthcare, social work, and social care and how they are linked. Participants also explained they wanted to see more specific information in the Charter, for example recognising and referring to condition-specific challenges more explicitly in the Charter. Participants wanted more information about charitable organisations to be included as well, and more information around the roles and rights of carers as opposed to legal guardians. Another area for improvement discussed was defining who the Charter is for in a clearer way. Participants noted that information on this can be found throughout the Charter, and thought that moving this to the beginning of the Charter would help users obtain a quick sense of whether the Charter is relevant to them and their particular needs and contexts.

Participants recognised the need for the Charter to be broad yet specific, but responses highlighted individuals' needs to find in the Charter the information that they are looking for, and which relates to their needs. Recognising that the Charter is a resource with a wide remit, it could be helpful for further resources to be developed for use by particular service user groups and for the Charter to signpost to where service users can find the more specialised information they may need. This could also support increased understanding of existing provisions, as there was lack of clarity in this area at times. This could be through signposting to relevant websites where the specialised information is already available.

Thoughts about service users' rights when accessing services and support

Half the participants were happy with the section around users' rights as it is, saying it is clear and easy to read. They felt the section was inclusive and that it covers the rights and protected characteristics they would expect to be relevant in the context of Community Healthcare. They also discussed how the Charter will be helpful in practice.

While many were positive, many participants discussed areas for improvement. For some participants their rights were not clear, they wanted more information on this and an exhaustive list of rights in healthcare in one place. Some discussed that they would like the language in this section to be clearer and easier to understand. Participants noted they would expect to see information in this section on what happens when user rights are not respected, for example information or a link to a resource on making complaints. Beyond this, participants also noted the need for staff to understand user rights, potentially through specific training in this area. Participants mentioned further rights they would like to see mentioned in the Charter, including rights around person-centredness, accessible formats and resources, for example translation and advocacy support, and rights around accessing further and better support and care, for example the right to get a second opinion or referral, and to be supported by specialised staff.

Thoughts about service users' responsibilities when accessing services and support

All participants were able to think of some responsibilities they have as service users. Responsibilities discussed included needing to inform staff about their needs and backgrounds, and needing to provide correct and honest information, ensuring good communication. Most also emphasised the responsibility to understand pressures on staff and services, and to treat staff with kindness, dignity and respect, mirroring the user rights discussed in the Charter. Some discussed users needing to reach out and seek the help they need, while others noted that this would be an unfair expectation on users. These findings suggest that, while some individuals are willing to take responsibility and seek additional information, it is crucial to prioritise equal access, particularly in light of existing health inequalities and challenges related to health literacy. More practical aspects were also mentioned, like the responsibility to attend appointments and change or cancel them if needed rather than not attending. Some participants wanted the section on user responsibilities to be expanded on, as these are "not always obvious to people", potentially adding information on standards of behaviour.

Further information needs when accessing Community Healthcare services and support

Some participants said they did not need any further information included in the Charter, but many noted further information they would like to see in the Charter. Suggestions included adding more information to the Charter around the NCS, how to access support, what it is, and limitations to it, and information about advocacy and inclusive communication. Participants also highlighted that it is important that the implementation of the Charter is accompanied by improved communication, including improving communication routes between staff and services to support the discussed rights and responsibilities, as well as a more person-centred and joined-up approach to care, with improved relationships.

Thoughts on whether the Charter meets its aims

The majority of the participants agreed that the Charter meets its aims, outlined in Appendix 1. Some participants mentioned specific aspects they liked, such as the clear mention of what a community is, the section on giving feedback and making complaints, and the importance of support in assessment planning. Some participants said it was good to know that the Charter defends users' rights and the value of feedback and complaints. One participant said they don't agree with the aims of the Charter, and they questioned how users would access the Charter. Some participants said that they would like the Charter aims to be referenced earlier in the document, with more detail and easier to access language, as well as more clear information around assessment processes.

The Charter in the context of service users' experience of Community Healthcare

Most participants agreed that the Charter applies to their experience of Community Healthcare and were positive about this. Some participants, however, thought the Charter was not relevant to them personally or their experiences, but recognised that they would be for others.

How service users may use the Charter and when

Most participants said they would use the Charter if they had issues with the care they, or people they support, were receiving, or if they wished to make a complaint. Participants discussed the Charter as a good resource to rely on and a useful reference, but some thought that the Charter wouldn't impact on their daily life. While it was positive that many would use the Charter if they had issues with health and care, it was clear that most participants didn't think they would use the Charter otherwise. Some participants didn't think the Charter was relevant to them, as they hadn't had issues with their care, and others highlighted the importance of increasing awareness of the Charter within communities through established, trusting relationships.

The 'Charter landscape': the Health and Social Care Standards and the NHS Charter of Patient Rights and Responsibilities

Most participants were not aware of the Health and Social Care Standards neither the NHS Charter of Patient Rights and Responsibilities. Three participants were only aware of one of these, and only five were aware of both. For the small number of participants that were aware, they found them online or when working on relevant activities, such as translating local NHS documents, working for organisations, or advocating for others and supporting them through the complaints process. Only four participants said they have used one or both resources, and this was through related activities, for example supporting another individual to receive the appropriate care.

Mirroring previous responses about the use of the NCS Charter, most participants said that these are good resources to have and that they would use these if they had issues with their care, needed to make a complaint, or to advocate for themselves or others. However, participants highlighted that, while these are good to have, low public awareness limits their benefit, and suggested ways to increase awareness and use. Some participants were unsure how these resources will work alongside the NCS Charter. Participants also discussed the need for further clarity around the remit of these resources, to make it easier for people to know which one to use. Some suggested merging these resources with the Charter, and others said they preferred these to be separate. Some participants also discussed how these are implemented and reminded of the importance of leading to positive behaviours and experiences in practice.

On the whole, it is important to recognise that the Charter and its awareness and use sit within the landscape of wider understanding of other relevant resources and the wider understanding of health and care. These findings suggest that general awareness of the resources outwith health and care settings may be relatively low, as none of the participants found out about these through word of mouth or informal contacts, such as friends and family.

Priorities and key areas for improvement around the NCS Charter of Rights and Responsibilities

When asked what matters most, and throughout the interviews, participants discussed key priorities which focused on access, inclusion, and equalities, leading to improvement of health and care in practice, and leading to improved understanding and engagement in health and care. Particular aspects discussed included:

- **Equalities legislation context**: participants asked for increased clarity around the equalities legislation context and the Charter's legal status and how it functions and fits within this, considering for example the Human Rights Act and the Equality Act 2010.
- **Inclusion, exclusion, and discrimination**: participants highlighted the importance of the Charter and relevant documentation to be as inclusive as possible. This is in terms of both the language it uses as well as the references it makes to communities and characteristics. Participants noted the importance of the Charter covering all equalities aspects and for everyone. They wanted the Charter to delve deeper into topics such as discrimination, racism, and misogyny, considering which communities may be more likely to experience these.
- **Gender identity**: some participants discussed improving language around gender identity and expression in the Charter by revising phrasing to include gender expression and identity as well as, or instead, of gender reassignment. However, they recognised that language used in the Charter at the time of interview mirrored the language used in the Equality Act 2010.
- **Language and barriers to understanding**: participants highlighted the need for the Charter and relevant documentation to be accessible and understandable to all. The participants highlighted the need for the Charter to use simple, plain and concise language, with a clear layout. Participants discussed that the Charter

draft at the time of interview required significant effort to fully understand. Participants also noted that the language used should enable users to relate to the document, in order to recognise whether it is relevant to them.

- **Translation needs**: participants highlighted the importance of translated versions of the Charter and all relevant resources to be readily and easily available, and for these to be easily available for staff to provide to users when needed.
- **Charter format**: participants said the Charter should be available in various formats, for example printed and digital versions, and shorter versions highlighting key points. Digital exclusion was also discussed as important to consider.
- **Charter awareness and dissemination**: participants noted that the Charter must be communicated appropriately and effectively to increase awareness, which requires the Charter to be shared through a range of methods and channels. Participants highlighted that awareness of the Charter must be increased for it to have impact, and this requires the Charter to be easy to find and accessible. Suggestions to increase awareness of the Charter included in person events, printed resources, digital resources and social media, ensuring reach within communities through organisations, local networks and existing relationships, ensuring staff awareness, national advertising campaigns and relevant tools such as promo videos, and signposting to the Charter from other relevant resources. Participants also noted the importance of tapping into local community knowledge and existing relationships and networks to ensure communities understand the importance of the Charter and how to use it. Participants also noted that communities may be comprised by sub-groups with different needs, and this should be taken into consideration.
- **Access to personal information**: participants discussed the importance of being able to access their personal information and challenges around this. They felt the process should be made more explicit and clear in the Charter, as well as what options users have if access is denied or obstructed.
- **Leading to improvement in practice**: participants highlighted the importance of how the Charter will be implemented in practice, and the need to ensure that what is written is put to practice in a positive and consistent approach, with clear processes for when things go wrong. What this may look like in practice and next steps in relation to this should be communicated to communities alongside the final Charter. Participants' responses suggest a potential lack of trust in how the Charter will be implemented in practice, mentioning experiences where things didn't happen as outlined in the Charter for example. They also noted the importance of monitoring and evaluating the implementation of the Charter, to ensure it brings about improvement and is used positively. This suggests that the participants had concerns around how the Charter will be implemented and used in practice, and its potential for impact. It may be helpful to consider how positive impact can be supported and how to communicate this to the public.

- **Leading to improved understanding and engagement**: participants discussed the importance of the Charter helping people to understand and navigate health and care, for example adjacent processes, such as that for accessing personal information and for complaints. It would be helpful to consider adjacent and relevant processes to ensure they are fit for purpose when including relevant rights in the Charter. Participants explained that they would like to see more, and clearer information, around the complaints process and any implications, for example if complaints become part of one’s medical record. Other aspects participants would like the Charter to help people understand included expectation-setting, equality aspects in health and care, the value of their voice, how to protect themselves, and how private and NHS care intersect and how to navigate this.

5.2. Recommendations

These recommendations are for Scottish Government to consider in the development of the NCS, and the NCS Charter specifically, working where appropriate with partner organisations, such as NHS Scotland, COSLA and others.

Recommendation 1: Consider implementing changes in the content, language, and structure of the NCS Charter based on these findings to increase clarity and understanding, and address information needs.

Improvements discussed in this report include:

Language and structure

- Ensure language throughout the NCS Charter is clear and accessible, using plain English.
- Discuss the Charter aims as early in the document as possible.
- Revise phrasing around sex and gender to include gender expression and identity as well as, or instead, of gender reassignment.

Further information and clarity

- Charter audience, remit and use: include information around the remit and intended use of the Charter. This should include who the Charter is for and who it is not for. This should also address why the NCS Charter is relevant to all, no matter the level of their care needs or service use. This could also consider how to make it clear to users that the Charter applies to them personally.
- Accessing personal information: include information on the process of getting access to personal information and what to do if this proves challenging.
- Health and care context: increased clarity around the different aspects of care, for example social care, social services, and Community Healthcare, and how they are linked. This could include signposting to resources on this to increase understanding, for example a visual or animation.
- Feedback processes: include information on how users can feedback to services.
- User rights and responsibilities: consider the further rights and responsibilities discussed in these findings and whether they should be added to the Charter. For example, participants discussed more “practical” responsibilities, such as making sure they change appointments rather than not attending. This should also include clearer information on why user responsibilities are important and what impact they have. Responsibilities should be outlined clearly, without assumptions regarding prior knowledge or understanding of health and care, and including or signposting to information about standards of behaviour. Consider including an exhaustive list of rights in the relevant section, or signposting to a longer, more exhaustive list outwith the core Charter text. Consider adding some information around the context of user rights highlighting that current pressures, e.g linked to COVID-19, don’t impact on user rights.

- Community Healthcare: increase clarity around the definition and scope of Community Healthcare, for example by signposting to a list of services and roles that also explains what these roles are and how they are involved in Community Healthcare. This should also explain whether non-clinical staff are also included in this remit.
- Complaints processes: include further information about complaints processes, and signpost to relevant resources, in the user rights section to highlight avenues for users when they feel their rights are not upheld in practice and potential implications.
- Equalities aspects: include further information around equalities aspects, such as on racism, misogyny, discrimination, harassment, and victimisation, as discussed in these findings. This should include what these are and explain terminology, how to address these, and link to relevant resources. Consider whether it is possible to include reference to more communities that are likely to experience discrimination.
- Legislative context: include more and clearer information on the legislation context around the NCS Charter, for example the Equality Act 2010 and the Human Rights Act. This should clarify how the Charter fits and functions in this context, clarifying the legal status of the Charter, and explaining that any changes to legislation would lead to changes to the Charter accordingly.

Recommendation 2: Ensure the NCS Charter helps users find the specialised information they need through appropriate signposting.

Recognising that the Charter is a resource with a wide remit and diverse users, it would be helpful for the Charter to signpost to further, more specialised resources. This could be, for example, signposting to websites with detailed information that will address the information needs of different users, such as those looking for information specifically around advocacy or for information related to particular conditions. Other aspects where participants wanted more information were around the needs of frequent users, details of charitable organisations and support they can provide, information around carer and guardian roles, processes of accessing personal information, and assessment processes.

It would also be worthwhile to consider what knowledge and understanding is assumed and ensure that relevant resources are signposted to support users in developing this, for example information on how health and care works in Scotland and what private healthcare is.

This would address the participants’ requests for more specific and specialised information, also supporting increased overall understanding of existing services.

Recommendation 3: Work towards increased clarity within the ‘Charter landscape’.

Consider what can be added to the Charter and relevant resources to clarify the ‘Charter landscape’. This should clarify the remit, and differences and similarities between the NCS Charter, the Health and Social Care Standards, and the NHS Charter of Patient Rights and Responsibilities, and how they work together, potentially including references to further relevant documentation. Further resources could be developed to explain this via visual or animation/video to ensure users know which one to refer to according to their needs and context.

Recommendation 4: Ensure the appropriate implementation of the NCS Charter and that it is supported by relevant processes as needed.

It is important that the content of the NCS Charter is implemented in practice. What this will look like in practice should be communicated to the public and users of the Charter, to set expectations appropriately. Next steps and implementation aims should be communicated to communities alongside the final Charter.

It could also be helpful to consider adjacent and relevant processes, possibly starting with those discussed in this report, for example complaints processes, to ensure they are fit for purpose and support the implementation of the rights discussed in the Charter. If secondary processes are not aligned, this will impact what the NCS Charter translates into in practice. This could include, for example, considering what processes must be in place for all user rights mentioned in the Charter to be upheld, such as users being able to communicate their needs to staff in advance of appointments.

Recommendation 5: Ensure the impact and use of the NCS Charter is monitored, evaluated, and communicated to the public.

Monitoring and evaluation should take place throughout the implementation of the NCS Charter. This could involve consulting with users on the best ways to evaluate impact and communicate it to the public. Evaluation plans should also consider the different stages in the development and establishment of the NCS itself, and the impact and use of the NCS Charter should be evaluated at different stages of this to ensure that it is assessed at different points in time within the timeline of the NCS being established. Evaluation should also include assessment of awareness around the NCS Charter.

Recommendation 6: Work towards increasing awareness and understanding of the NCS Charter, among public and staff.

The NCS Charter and all relevant resources should be translated into a range of languages and readily available, as opposed to being translated on request. Consider adding these to an online repository so staff can download and print as needed. It may also be worthwhile creating a shorter version or summary of the Charter with key points, as well as more visual or easy read versions.

The Charter should be available in a wide range of places, via different mediums and in different formats, to match the diverse needs and preferences of users. It should be available both online and offline, and “in plain sight”. Ideas discussed in these findings include the Charter being signposted to in the Red Book[13] and by health visitors. Any activities to increase awareness should also consider this, ensuring the Charter is accessible for all, for example including in person events, printed resources, digital resources and social media, ensuring reach within communities through organisations, local networks and existing relationships, ensuring staff awareness, and signposting to the Charter from other relevant resources.

Consider developing engaging resources to increase awareness and understanding by both public and staff. For example an animation summarising key points of the NCS Charter, or short online training that highlights the remit and intended use of the Charter, or a visual on what the Charter can do for users. Specific aspects that could benefit from resources to increase understanding include the section on user rights and responsibilities, for example developing short training on what user rights are and what users can do if they feel their rights are not being upheld. Guidance for staff on user rights could highlight user expectations around their rights and both staff and user responsibilities.

Activities to increase awareness could utilise key community members and existing trusting relationships, for example by developing materials to support community members to "train" their peers on this, while also recognising diversity within communities. Another key element would be to consider how to utilise word of mouth to increase awareness, with resources being developed accordingly.

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[13] The Personal Child Health Record, also known as the PCHR or 'red book', is a national standard health and development record given to parents/carers at a child's birth.

Section 6: Next steps and acknowledgements

Early findings from this work were shared with Scottish Government in December 2023. Based on these, Scottish Government officials have made some early updates to the draft Charter, with the next version expected to be made available online in due course. A number of insights have also generated wider work beyond updates to the document itself and some will be further explored in the next phase of co-design. An overview of some of the updates made to the draft Charter in response to the views expressed in this research so far include:

- Work to increase clarity and understanding including moving, adding and changing content based on views expressed by people with lived experience. This has included work with content designers to improve plain English.
- Reviewing language, including using ‘gender identity’ and ‘gender reassignment’.
- Adding further information making it clearer who the Charter is for.
- Adding reference to a community of people experiencing similar conditions or support to users as an example of a support network.
- Adding clearer information about what to do if users feel like their rights are not being met. This is part of wider work happening to improve complaints services as well as a number of other processes.
- Signposting more to further details and specialist information.
- Adding assurances that everyone that works under the NCS must uphold rights, not just people directly providing care.
- Adding more information about what users can expect to happen at social care assessments.
- Making clearer the Charter’s place in a landscape where similar Charters and Standards already exist, while striking a balance with the desire for the document to be short and concise. This is part of wider work happening which seeks to establish how to present the Charter alongside existing documents to help readers get to the right information at the right time.
- Initial exploration of how Charter impact will be monitored and evaluated. This includes work to build the Charter into wider NCS monitoring and improvement functions which are also under development.
- Early work to consider ways to ensure awareness and understanding of the Charter when it us published.

This full report has also been shared with the Scottish Government. The findings from this work have and will continue to inform updates to the next draft of the Charter to ensure that it meets the needs and expectations of those that are likely to use it, setting out people’s rights and responsibilities clearly when accessing support through the NCS.

Healthcare Improvement Scotland will liaise with relevant stakeholders to collect information around the impact of these findings and recommendations 6, 12 and 18 months after this report's publication. A summary of this information on impact will be posted on our website and circulated to participants to evidence how their feedback outlined in this report has been used.

We will use the learning and experience of this exercise including the equality monitoring information within our work to inform future methods of Gathering Views.

We thank everyone who took part and shared their experiences, thoughts, insights, comments and suggestions. We are incredibly grateful to the organisations who supported us to link with groups and individuals and for the time they gave us to discuss the issues covered in this report.

Appendix 1 – The questions used in this Gathering Views exercise

1. **Where did you hear about this work? This is to help us understand the best ways to get information out and reach people.**

2. **What Community Healthcare services or support have you used in the last 12 months? What services have you used in the last 12 months and when? Tell us a bit about this.**

Community Healthcare services are services that are provided in the community, and not in a hospital. Community Healthcare services can be accessed in a range of settings, for example at health and care sites or agencies, in residential homes or peoples' own homes supported remotely by technology where appropriate.

People may need Community Healthcare services for many reasons and they are at least 90% of all health contacts between people and the NHS. Many needs are identified, managed, or resolved within the community, making it one of the largest sectors of healthcare and one of the most crucial. Most services that are accessed locally or are based in the community address the majority of health and wellbeing concerns without escalation and reduce harm by early identification of needs.

About the Charter sections

Looking at the introduction

3. **Is it clear that this Charter applies to Community Healthcare? What would make it clearer?**

4. **Thinking of Community Healthcare services, what else would you like to see mentioned?**

Looking at the rights section

5. **Thinking about Community Healthcare, are there rights that are not included in these pages that you think should be added? What other information about rights do you think should be included here?**

6. **Are there any rights on these pages that you think don't apply in Community Healthcare?**

7. **Do you have any other thoughts about this section on rights?**

Looking at the 'Getting the best out of your relationship with the NCS' section

8. **Thinking about Community Healthcare, what responsibilities do you think you have when accessing services and support? Tell me what you think about this.**

9. **Is there any other information that would be helpful for you to know when accessing Community Healthcare services and support? What else would you like to see in this section?**

About the Charter overall

Charter aims: The Charter will help people better understand their rights and what they can expect from the NCS. It will also provide clear instructions on how to get more advice or make a complaint if their rights are not being met. By doing this, the Charter will support people accessing NCS services to better hold the system to account and receive the services they need to thrive. As a minimum, the Charter will set out:

- *The rights and responsibilities of people accessing NCS support and those with an interest in the wellbeing of others accessing NCS services, such as a family member or carer.*
- *Details about how to make a complaint and seek resolution through the NCS if your Charter rights are not met.*

10. **Do you feel the Charter meets these aims? What else would you like to see in the Charter for it to meet these aims? What is missing?**

11. **Thinking about your experience, is there anything in the Charter that you feel wouldn't apply? What changes would help make the Charter apply to your experience?**

12. **Is there anything that should be added or changed to make the Charter more applicable for Community Healthcare? What could that be?**

13. **How do you think you would use this Charter and when?**

14. **If you don't feel the Charter meets these aims, could you explain why? What could be changed to help it meet these aims?**

The Charter "landscape" – The NCS Charter and other Charters and Standards

1. *The NHS Charter of Patient Rights and Responsibilities*

The NHS Charter of Patient Rights and Responsibilities ('the NHS Charter') summarises what you are entitled to when you use NHS services and receive NHS care in Scotland, and what you can do if you feel that your rights have not been respected. The NHS Charter also explains what is expected of you when using the NHS in Scotland. Some of your *responsibilities are set out in law. Others are what everyone is expected to do to help the NHS work effectively in Scotland and to help make sure it uses its resources responsibly.*

2. *Health and Social Care Standards*

The Health and Social Care Standards set out what we should expect when using health, social care or social work services in Scotland. The Standards are built upon five principles: dignity and respect, compassion, being included, responsive care, and support and wellbeing.

15. **Were you aware of these before we told you about them?**

    If yes for any or both
    15a. How did you know about these?

    15b. Have you used them? How?

    If no for any or both
    15c. Now that you know that there are other Charters and Standards discussing rights and responsibilities, what do you think?

    15d. How do you think you might use them?

16. **How do you think these Charters and Standards should be presented, shared or explained so that people can get to the information they need effectively?**

17. **How would you like these Charters and Standards to work together? How would you use these Charters and Standards?**

What matters to you

18. **What matters to you most about the Charter of Rights and Responsibilities for Scotland's National Care Service?**

Appendix 2 – Materials circulated to participants before the Gathering Views discussions

Before the interviews we circulated the following to participants:

- The draft Charter of Rights and Responsibilities (the draft Charter used in co-design between June and December 2023)
- An information sheet and consent form
- The question set

Participant Information Sheet
Gathering Views - National Care Service Charter of Rights and Responsibilities

About this work

Healthcare Improvement Scotland Community Engagement and Service Redesign has been asked by the Scottish Government to carry out a Gathering Views exercise about the National Care Service (NCS) Charter of Rights and Responsibilities.

We are looking to speak to people from the following 4 particular protected characteristic groups and who have accessed community health services 2 or more times in the last 12 months.

- **the trans community, including non-binary people**
- **pregnant people and mothers of children up to 18 years old**
- **people from minority ethnic communities, and**
- **people from minority religious communities.**

Engagement for this piece of work will be taking place from Monday 2nd October 2023 to Friday 13th October 2023.

This work will ensure that the development of the Charter is informed by the views and needs of people with the above protected characteristics, in order to be effective at supporting the rights of diverse communities. This is important as the Charter aims to advance equality of opportunity for everyone and eliminate unlawful discrimination, harassment and victimisation for all people with protected characteristics, as defined by the Equality Act 2010, that use the NCS. The findings from this work will ensure the suitability of the Charter in the context of community health services, in order to support people to understand and claim their rights. These findings will be used alongside the outcomes from further engagement and co-design activities, to further develop the Charter.

Background to the Charter

The Scottish Government is improving social work, social care support and community health in Scotland. They want everyone to have access to consistently high-quality support across Scotland, whenever they might need it. That is why they are introducing the National Care Service (NCS). It is being shaped by people who have experience of accessing and delivering support.

Scottish Government are in the process of co-designing and developing a NCS Charter of Rights and Responsibilities, which will set out people's rights when accessing social work, social care or community health support, so that they know what to expect from services. The Charter will also provide a clear pathway to get further advice and support or make a complaint if people feel their rights are not being met. Co-designing the Charter means asking people with lived experience of accessing and providing social care, social work and community health services about their rights and what they expect to see in a charter, then developing content in partnership with them. All of their co-design work so far has meant we are now in a position to share the early draft Charter and seek feedback and suggestions on how it can be improved. None of this content is set and we expect it to change over the coming months based on the views of more people with lived experience.

What we mean when we say Community Health Services

When we say community health services we mean health services that are provided **in the community** instead of in a hospital setting.
Below is a list of Community Healthcare examples. This list is not exhaustive so please speak to us if you would like to take part and think you have accessed services in the community that are not listed.

- Adult Community Nursing services including District Nursing services
- Community Allied Health Professions for adults and children
- Primary care dentistry and Oral Health Improvement Services
- Primary Care Multidisciplinary Team Members
- Optometry
- Community Pharmacists
- Adult Community Based Palliative Care
- Child and Adolescent Mental Health Services (CAMHS)
- Children's nursing services in the community
- Social Care Teams
- Maternity Services
- Drug and Alcohol Services
- Community Treatment and Care
- Specialist Sensory Loss Support Services
- Sight Loss Rehabilitation and mobility training Advice and Guidance for People with Sensory Loss
- Communication support
- Specialist social work, e.g., BSL social work
- Care Home Liaison Roles
- Adult Mental health services including Forensic Mental Health
- Forensic Medical Services
- Prisoner Healthcare services

How you can take part

You can take part in this work by providing your feedback through an individual or group interview. These can be done in person, by telephone or online, and our Engagement Officers can discuss with you what you might prefer or need and how we can support you to participate in this work. We are committed to inclusive communication. Please let our Engagement Officers know if you need further support to participate. This could be, for example, having a BSL interpreter during the interview.

The discussion during the interview will focus on the Charter, so before the interview takes place we will give you some information, including the draft Charter. We will also give you the questions that we'll be asking you to provide your feedback on, so you know what to expect and can start thinking about them. Reading the Charter before the interview to become familiar with it and think about your answers to the questions we'll be asking you should take you around one hour.

The interview should take between 30 minutes to one hour. During the interview we will take notes to ensure we capture what you've said accurately. We may also ask you if we can record the discussion to help us take notes.

In the interview we will be asking you what you think about the Charter, how it will be used, and what might be missing or need improved, thinking specifically about your experience of accessing community health services.

Your participation is voluntary. You are free to withdraw your comments or views at any time without giving a reason and this will not affect you. If your comments or views have already been shared online or on social media, or included in wider pieces of work, for example in a published report, it may not be possible to remove them and stop their use completely. However, we will delete any images or recordings from our database and will go to all reasonable efforts to stop using them in future.

Your information and how we will use your comments

We may use direct quotes from you but they will be made anonymous and will not include your name or any other identifying information. Anonymised quotes, summaries or analysis of your comments or views may be used in the following ways:

- published reports
- presentation materials for education or improvement workshops, conferences or events
- information or promotion leaflets
- Healthcare Improvement Scotland's websites or social media, or the websites or social media of partners mentioned in this document, and
- we may also use your contact details to get in touch with you after the work is completed, to find out about your experience with the interview process and how we can improve.

To support our work we will hold information relating to you, such as:

- personal details. This may include contact details, health condition or diagnosis, and so on
- written notes of the comments and views you have given us, and
- audio or video recording of the interview.

Equality monitoring information: As part of this work, we will also be collecting equality monitoring information, such as information regarding sex, sexual orientation, disability, age, religion and ethnic group. Providing this information is optional but important. It helps us ensure we gather feedback from people from a range of backgrounds and contexts, and consider health inequalities. This information is anonymous and will not be linked to your feedback. You can complete the equality monitoring form online at this link:
https://www.smartsurvey.co.uk/s/EMGVNCSCHARTER/
Or if you prefer you can ask our staff to help you with this.

We will hold records of our engagement with you only for as long as necessary after this work is completed. All information will be held in accordance with the General Data Protection Regulation and the Data Protection Act 2018.
You can find out more about how Healthcare Improvement Scotland use your personal information here:
http://www.healthcareimprovementscotland.org/footernav/respecting_your_privacy.aspx

For our full privacy policy, please go to www.hisengage.scot/privacy.
For more information about how we process your personal data, or if you have a concern, contact our Data Protection Officer at his.informationgovernance@nhs.scot. Alternatively, you have the right to complain to the ICO https://ico.org.uk/concerns/.

Next steps and getting in touch

Please read this information sheet carefully and discuss with others if you wish to. If you have any questions, please get in touch as outlined below.

If you want to participate in this work, please complete the consent form or tell the Engagement Officer you are speaking with that you consent to take part. You can also let the Engagement Officer know if you would like to receive a digital copy of the report from this work once it is published. They may also ask you whether you are happy for us to get in touch with you in the next months to ask you how you found your experience participating in this work.

If you have any questions, please get in touch with your local Healthcare Improvement Scotland – Community Engagement and Service Redesign staff.

Or you can contact: Helen Gourlay – Acting Area Manager West Region - Community Engagement and Service Redesign - email: helen.gourlay1@nhs.scot - telephone 07929025817

Your rights

The Data Controller for this information is: Healthcare Improvement Scotland (HIS)
Under data protection laws you have the right to be informed of what your information will be used for; access to the information held about you; to rectification if there are any errors in the information held; of erasure; and to withdraw consent.

HIS Data Protection Officer: If you have questions or concerns about how we process your personal data, or if you wish to exercise your rights, email his.ig@nhs.scot

If you would like to know more about how Health Care Improvement Scotland use and protect your personal information see our privacy notice here:
http://www.healthcareimprovementscotland.org/footernav/respecting_your_privacy.aspx

Healthcare Improvement Scotland

Participant Consent Form
Gathering Views – NCS Charter of Rights and Responsibilities

By ticking the options below you are giving your consent to take part in a Gathering Views discussion.

If you wish to proceed, please confirm the following, verbally or in writing:

1 I have read and understood the information sheet. ☐

2 I have been able to ask questions about this work and am happy with the answers I got. ☐

3 I understand that I can choose whether or not I will take part in this discussion and that I can choose not to answer any question or stop taking part at any time, without having to give a reason. ☐

4 I agree for what I say to be used in reports and publications about this work, but that my name will not be used. I give permission for Healthcare Improvement Scotland to hold relevant personal data about me and I understand that my comments are anonymous. ☐

5 I agree to take part in this work. ☐

Name

Signature

Date

Appendix 3 – Equality monitoring form

About this Equality Monitoring form

We are capturing equality monitoring information, including data relating to sex, sexual orientation, disability, age, religion and ethnic group to ensure we gather feedback from people from a range of backgrounds and contexts. We want to understand how representative the people we talk to are.
You are not required to answer any questions you do not wish to answer. The information you provide is not linked to your name or any other personal details and will be kept anonymous.

1. What is your sex?

☐ Female
☐ Male
☐ Non-binary[14]
☐ Prefer not to say

2. Do you consider yourself to be a trans person or have a trans history? Trans is an umbrella term to describe people whose gender does not correspond with the sex they were registered at birth.

☐ Yes
☐ No
☐ Prefer not to say

If you answered yes, please tell us your preferred terms - e.g. non-binary, trans man, trans woman (optional).

☐

3. Which age group do you belong to?

☐ Under 16
☐ 16-25
☐ 26-35
☐ 36-45
☐ 46-55
☐ 56-65
☐ 66 and over
☐ Prefer not to say

4. If you are under the age of 26, please can you tell us whether you have ever had any experience of being in care? This can include foster care/supported care, kinship care, residential care, looked after at home (supervision order).

☐ Yes, I have had experience of being in care

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[14] As a standard, our equality monitoring forms follow the format and content of the Scottish Census questions. In this case, due to this work's particular focus on engaging with trans and non-binary individuals alongside a small number of other characteristics and groups, it was considered important to include a further answer option for 'non-binary' in the question around sex.

☐ No, I have not had experience of being in care
☐ Prefer not to say
☐ Not applicable

5. Do you consider yourself to be disabled?

(The Equality Act 2010 defines a disability as a physical or mental impairment that has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities. Substantial means the effect is more than minor or trivial and long-term means the condition has lasted or is likely to last 12 months or more).

☐ Yes
☐ No
☐ Prefer not to say

If yes, please include any more information you are happy to share:

6. Can you use British Sign Language (BSL)?

☐ Yes
☐ No
☐ Prefer not to say

7. Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- long-term physical/mental ill-health/disability; or
- problems related to old age?

☐ Yes
☐ No
☐ Prefer not to say

8. Which of the following best describes your sexual orientation?

☐ Bi/Bisexual
☐ Gay/Lesbian
☐ Heterosexual/straight
☐ Prefer not to say
☐ Something else. Please write in:

9. How would you describe your religion, religious denomination or belief?

☐ Buddhist
☐ Christian - Church of Scotland
☐ Christian - Roman Catholic

☐ Christian - another denomination
☐ Hindu
☐ Jewish
☐ Muslim
☐ Sikh
☐ Pagan
☐ None
☐ Prefer not to say
☐ Other, please write in:

10. What is your ethnicity?

☐ African, African Scottish or African British
☐ Arab, Arab Scottish or Arab British
☐ Bangladeshi, Bangladeshi Scottish or Bangladeshi British
☐ Black, Black Scottish, Black British
☐ Caribbean, Caribbean Scottish or Caribbean British
☐ Chinese, Chinese Scottish or Chinese British
☐ Indian, Indian Scottish or Indian British
☐ Mixed or multiple ethnic groups
☐ Pakistani, Pakistani Scottish or Pakistani British
☐ Roma
☐ Showman/Showwoman
☐ White Gypsy/Traveller
☐ White Irish
☐ White British
☐ White Polish
☐ White Scottish
☐ Prefer not to say
☐ Other, please write in:

11. Do you usually have enough money each month to pay bills, buy the food, clothing and essentials you need and participate in your community?

☐ Yes
☐ No
☐ Prefer not to say

12. Please use this space to tell us anything else you would like us to know about how you identify in relation to any of the above questions.

Appendix 4 – Equality monitoring data

Response rate

Providing equality monitoring information is optional, and 15 out of the 20 participants completed this (75%).

Equality monitoring questions, in the form of an online survey, were shared with the participants, either before or during the interview. We also offered alternative ways to provide this information, via email or through a paper copy.

Participant characteristics (N=15):

- Sex: 12 of the people we engaged with are female and 3 male.
- Gender reassignment and gender identity: none of the 15 who answered this question consider themselves to be trans or have a trans history. [15]
- Sexuality: all said they are heterosexual/straight.
- Age: 1 participant was between 16-25 years old, 4 between 26-35, 6 between 36-45, 3 between 46-55 and 1 66 years old and over.
- Care experience: None said that they have had any experience of being in care, such as foster care.
- Disability and long-term health conditions: 2 said they consider themselves to be disabled or have a long-term health condition as described in the Equality Act 2010.
- Use of BSL: None said that they use British Sign Language (BSL).
- Carers: 7 said that they look after or support family members.
- Religion and beliefs: 6 participants are Muslim, 3 are Christian Catholic, 1 is Buddhist, and 1 Christian of another denomination. 3 said they have no religion or religious beliefs. 1 preferred not to say.
- Ethnicity: 4 participants are Pakistani, Pakistani Scottish or Pakistani British, and 4 are White Scottish. 3 are White Polish, 1 is African, African Scottish or African British, 1 Chinese, Chinese Scottish or Chinese British. 1 is White Gypsy/Traveller, and 1 White Palestinian[16].
- Deprivation: 12 said they usually have enough money each month for essentials and to participate in their community, 2 said they don't and 1 preferred not to say.

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[15] Due to the voluntary nature of completing equality monitoring forms, our monitoring may not fully capture all protected characteristics, especially regarding gender identity. Our approach to engaging with trans and non-binary individuals involved outreach through relevant groups for participation.

[16] As a standard, our equality monitoring forms follow the format and content of the Scottish Census questions. "Palestinian" was entered under 'Other' in the White response category, hence is reported as 'White Palestinian'.

You can read and download this document from our website.
We are happy to consider requests for other languages or formats.
Please contact our Equality and Diversity Advisor on 0141 225 6999
or email his.contactpublicinvolvement@nhs.scot

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