

Share for Better Care: What we learnt

About the Share for Better Care Campaign

The <u>Share for Better Care</u> campaign, launched by the Care Quality Commission (CQC) and Healthwatch England in collaboration with National Voices and a range of other excellent partners, aims to encourage everyone to give feedback on their experiences of care, particularly people who are more likely to experience poorer care and inequalities yet are less likely to give their feedback.

Other partners include:

- The Race Equality Foundation
- National Dignity Council
- Royal Association for Deaf people
- The Challenging Behaviour Foundation
- The Patients Association
- VoiceAbility
- Disability Rights UK

The Share for Better Care campaign aims to raise public awareness of why feedback on care matters and the difference it makes and encourage people to share their experiences. Reflecting our joint ambition to tackle inequalities in health and care, the campaign target audience is people more likely to experience poorer care inequalities, specifically:

- People with a learning disability and autistic people
- People from ethnic minority groups
- People on lower incomes
- Disabled people with physical or sensory impairments.

Charity number: 1057711
Registered office: The Foundry, 17 Oval Way,
Vauxhall, London SE11 5ER



National Voices' role in the Share for Better Care Campaign

National Voices joined the Care Quality Commission, Healthwatch England and other partners in support of the campaign in March 2024. While campaign activity was restricted after the announcement of the General Election on 4 July 2024, we were delighted to be able to continue this work from November 2024 until the end of March 2025.

This report will focus on the work undertaken in this later period, although we would like to say a special thank you to the Macular Society, Arthritis Action and Groundswell who were consulted in summer 2024. Thanks to their insights, the campaign toolkit shared by CQC was much improved in terms of accessibility and ease of use.

We supported CQC's campaign in three main ways: review of communications materials for Share for Better Care Week with accessibility and inclusion in mind; blog pieces published on the National Voices' website; and a comprehensive social media campaign to raise awareness of the scheme.

Media campaign

The National Voices communications team delivered consistent and effective external communications throughout the Share for Better Care Campaign. These were delivered across social media platforms, incorporating and encouraging further engagement with our 200 members and their beneficiaries through organic posts, the Share for Better Care communications pack, and through conversations with members regarding the campaign.

Platforms included: Twitter/X (14,900 followers) BlueSky (900 followers), LinkedIn (1,581 followers), our bi-weekly members and partners newsletter (almost 800 recipients), monthly external newsletter (almost 5,000 recipients), and our website. Please note that, during the campaign, we left X in early 2025 due the controversy surrounding the platform.

During Share for Better Care week, these efforts were stepped up even further, and saw our Chief Executive, Jacob Lant, contribute a blog to our website regarding the intentions and benefits of the campaign.

Recognising the collaborative drive needed to deliver the campaign, we proactively shared our partners social media outreach too. Over the course of the campaign, we published three blogs to help spread the word:

 <u>Encouraging everyone to give feedback on care</u> was authored by our member, <u>Patient Information Forum (PIF)</u> and explored why it is

Charity number: 1057711
Registered office: The Foundry, 17 Oval Way,
Vauxhall, London SE11 5ER



- important for everyone to share their experiences of care, and how to encourage people to do so.
- Share for Better Care: How people's experiences drive regulation of care services, was co-authored by our Chief Executive, Jacob Lant, alongside Chris Dzikiti, Interim Chief Inspector of Healthcare at CQC. In their blog, Jacob and Chris wrote about why it is important that people share their experiences of care, and how CQC are using people's experiences to improve care.
- Share for Better Care Week: the importance of patient experience was authored by our Chief Executive. In this blog, marking Share for Better Care Week, he explores further some of the work we have undertaken as part of the campaign and how it ties into our organisational strategy, especially around Shifting the measures of success.

Charity number: 1057711
Registered office: The Foundry, 17 Oval Way,
Vauxhall, London SE11 5ER

oundry, 17 Oval Way, Email: info@nationalvoices.org.uk

Bluesky: @nationalvoices.bsky.social



Learning from engagement with National Voices members and Lived Experience Partners

We gathered feedback on the campaign by facilitating detailed discussions with our National Voices members and Lived Experience Partners (LEPs). From this, we found that there was strong support for the premise and purpose of the campaign. The high value placed on patient reported metrics, particularly from underrepresented groups and communities, was welcomed.

Our insights indicate that the campaign is valued by people and communities, however, to maximise its impact and reach there are adaptations that could be made to improve its accessibility, inclusivity and relatability.

Participants highlighted five key ways in which the campaign could have been designed more effectively to maximise its reach and engagement. These were:

- 1. Ease of use
- 2. Data and statistics
- 3. Tone and language
- 4. Accessibility
- 5. Impact

Ease of use

The campaign and the <u>'Give Feedback on Care'</u> webpages were generally seen as very clear and easy to navigate with one member who has ADHD and Dyslexia, sharing that she found it "easy to read and not too overwhelming."

The short three-minute completion time to provide feedback supports this but the expected completion time should have been made explicit from the start as uncertainty on what was required was recognised as a possible barrier to engagement. Additionally, one Lived Experience Partner did feedback that the search function to find the GP some wanted to provide feedback on was "clunky and took a long time to use."

Moreover, the campaign's online approach excludes people who face digital exclusion and will pose a barrier in engaging those that experience this inequality. Members recommended a hybrid approach to circumvent this. For example, this could involve having tablets and posters with QR codes in waiting rooms in GPs, pharmacies and other healthcare settings where members of the public can easily access the information and support for completion. This could also include public areas (such as a bus stop) and

Charity number: 1057711
Registered office: The Foundry, 17 Oval Way,
Vauxhall, London SE11 5ER





safe spaces that communities trust, including places of worship and local community cafes.

Data and statistics

Multiple colleagues reflected that the use of statistics, particularly in the Audience Insights feedback, were "really informative" and "valuable" as it corroborates the reasoning behind the campaign and "makes people sit up and listen." Having a dedicated slide deck for different audiences and the transparency of the data were well-received and appreciated. However, there were a few significant improvements that were suggested.

Firstly, specific statistics tailored to particular communities would have been welcomed as opposed to the generalised numbers approach. For example, there could be information around race health inequalities as it provides the necessary context and prompt for individuals to share experiences and opinions which they may not otherwise realise would be valuable.

Furthermore, the accuracy, framing and limitations of the data and figures must be reviewed. There was a general feeling that the percentage of people with autism seemed low and misleading as many of the figures were drawn from the GP health survey which can reflect incorrectly recorded diagnoses at practice level. There was also a concern around the statistic 'white people are proportionately more likely to have autism than average, whilst those from Asian or Asian British ethnic groups were nearly half as likely' which may be problematic as it is known that there is an issue of underreporting in some communities.

Tone and language

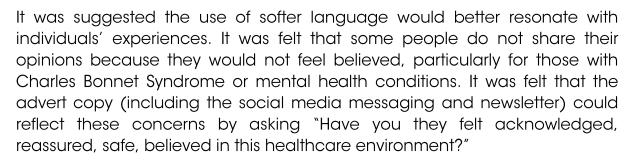
Our members and LEPs provided constructive feedback on the tone and language of the campaign's webpages and social content felt that the language used was very formal and professional and may deter people from engaging and was "unlikely to grab anyone's attention and inspire them." This was particularly felt for younger audiences – one member shared that his younger son with autism fed back that he would think "that's not for me, that's for my mum and dad".

Public Health England was highlighted as a strong example of using a good tone of voice that can engage people on serious issues. From an inclusion standpoint, this involves presenting ideas in a more accessible way by using plain language and avoiding words such as 'regulatory' and swapping 'accessed' with 'used,' as one example.

Bluesky: @nationalvoices.bsky.social

Email: info@nationalvoices.org.uk





There should also be encouragements to share positive experiences as by doing so people may then be more willing to report negative experiences at a later stage. The importance of sharing either/both positive and negative opinions should be highlighted in the landing pages for the form and Share for Better Care webpages. In terms of social media posts, this could be done by mocking up a quote or an anonymised submitted example to demonstrate that feedback does not have to constitute extremes of experiences.

We heard the CQC should be more explicit in stating that it is proactively seeking the views of seldom heard communities and why. This can be done by directly addressing the group and making the social media copy available in other languages, particularly for hard copy assets and posting images which are not automatically translated based on the primary language selected in mobile settings.

1 member suggested including a statement on the feedback page itself to say: "We are particularly looking for stories from Black people and we would love to hear from you specifically." Another recommendation to widen appeal was to conduct video interviews with some of the targeted groups to ensure that it is very clear who the campaign is trying to welcome into this space.

Accessibility

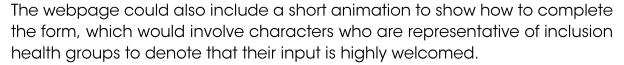
National Voices' members and LEPs made a number of recommendations to raise the level of accessibility for this campaign, this were:

- Using plain language
- Translating social media posts into other languages
- Closed captioning on videos
- Using images that includes the groups that are being targeted but not in a tokenistic way (such as avoiding a stereotypical portrayal of someone with disabilities as a wheelchair user)

1 member also suggested that there should be a consideration of wider neurodiversity as exclusively targeting people with autism and those with learning disabilities risks not hearing from people with conditions such as ADHD, dyspraxia or dyslexia.

Charity number: 1057711
Registered office: The Foundry, 17 Oval Way,
Vauxhall, London SE11 5ER





Further to this, it was made clear that British Sign Language (BSL) videos should have sound as someone using a screen reader will expect to play a video with sound and it would allow people who are not fluent in BSL to engage in a different way. Another omission was that there should be a clear instruction on alternative ways of submitting the form, for example in Easy Read format or other languages, to make it easier to interact with for certain groups.

Additionally, there should be a clarification that the form can be filled out by a carer or on the behalf of a loved one and that the information submitted will be anonymised. This will help build trust that their data will not be misused. For comparison, the Healthwatch feedback form was cited as stronger in this aspect.

Impact and closing the feedback loop

Whilst the discussions expressed enthusiasm for the ambitions of the campaign, it was not lost that insight fatigue is a very real barrier to reaching out to populations outside of white and middle-class backgrounds. Members highlighted that to navigate this, there must be greater explanation or signposting as to how contributions have, or will, make an active difference and demonstrate impact.

This could be achieved through social media posts on the CQC's page, joint blogs and showcasing examples from the State of Care report. One LEP shared that they only saw an update about the campaign through National Voices' social media so CQC's platform could be better utilised to communicate the impact of getting involved. A 'you said, we did' approach could be adopted with a video of a clinician or a CQC colleague breaking down the campaign and saying why it matters for people to share their experiences of care.

A part of this, having a clear, upfront explanation on who the CQC is and "why should they matter to me?" it vital. This will more effectively communicate why the public should get involved and gain more traction in groups it would otherwise not have reached. This messaging can be amplified through partnership and joint working with the Voluntary, Community and Social Enterprises (VCSE) as a few members had expressed that the campaign directly correlates to current projects, and they could help reach the audiences that it aims to target.

Charity number: 1057711
Registered office: The Foundry, 17 Oval Way,
Vauxhall, London SE11 5ER



Acknowledgments

National Voices would like to thank the Care Quality Commission (CQC) for funding our work supporting its Share for Better Care campaign.

We would also like to thank our members who shared their expertise and valuable insights during one-to-one conversations.

Member organisations included:

- Crohn's & Colitis UK
- Esme's Umbrella
- Neurobetter
- National Rheumatoid Arthritis Society (NRAS)
- Patient Safety Learning
- Thelma Matilda Alves Foundation

We also extend thanks to our Lived Experience Partners; Helen Hassell, Kevin Coffey and Richard Falvey, for sharing their valuable insights in two group conversations.

Charity number: 1057711
Registered office: The Foundry, 17 Oval Way,
Vauxhall, London SE11 5ER