

Cardiomyopathy UK response to the NICE consultation on working alongside people and communities: A strategy

Please see the [NICE consultation documents](#) referred to in this document.

Section 1 – about you

1. What is your role? Please choose one answer most closely matches your perspective.

- Employee/volunteer of a voluntary or community sector organisation

2. Are you responding on behalf of an organisation?

- Yes (go to question 3)

3. If you are responding on behalf of an organisation, please state the name of your organisation

Cardiomyopathy UK

4. What type of organisation do you represent?

- Voluntary and community sector organisation

5. To what extent do you agree or disagree that people and communities will know the strategy is working for them through the proposed progress measures

3 – neither agree nor disagree

Why did you give that answer? Please feel free to comment on the proposed progress measures, and/or highlight anything you would wish us to consider.

With regards to the measures, the main issue is that the measurements are currently not quantifiable. In a focus group with people with cardiomyopathy, the participants reported that they would not know that the strategy is working based on the proposed progress measures without more information on the baseline data and ambitious percentage increases.

In terms of the core focus on tailored approaches, the measures are around improving the reputational research survey and increasing participation from underrepresented groups. What is missing here, is a measure on the number of times that qualitative data has contributed to the decision-making processes at NICE. One of the criticisms of involvement in a NICE technical appraisal from people with cardiomyopathy is that they feel that listening to people with lived experience is a mere box-ticking exercise. In order to demonstrate that lived experience does contribute to the decision-making at NICE, there must be a measure on the number of times that lived experience has been considered in new guidelines or technical appraisals.

Furthermore, some of the proposed measures are not measurements. For example, one measure under impactful involvement and engagement, is “Involvement and engagement activity is underpinned by a fair and transparent payment policy.” This statement is a method for increasing diversity in involvement and engagement, it is not a measure for success.

Section 3 – further comments

6. If you have any further comments on the strategy, which you would like us to consider, please share them here. Where appropriate, please include the page reference of the strategy (Word document) you are referring to.

Cardiomyopathy UK is the specialist national charity for people affected by cardiomyopathy, a condition that affects the heart muscle. Our vision is that everyone affected by cardiomyopathy should live a long and fulfilling life. We do this by providing services, such as a national helpline and peer support, and campaigning for change in health services.

Cardiomyopathy UK has most recently enabled a person living with cardiomyopathy to take part in a NICE technical appraisal for the medication, Mavacamten.

Cardiomyopathy UK has a network of volunteers who advocate for people with cardiomyopathy with the aim of improving health services. This group is called Change Makers. Cardiomyopathy UK ran a focus group with five Change Makers to gather their views on the NICE draft strategy on engaging with people and communities.

Implementation

While there is much to be praised in this strategy, which is admirable in its aims to improve the engagement of people and communities in NICE's work, what is lacking is how NICE intends on achieving its aims. This has made it challenging to respond to the consultation, but Cardiomyopathy UK recognises that more detail is probably in the implementation plan. For example, it would be useful to have some indication of what actions will be taken to increase participation from underrepresented communities, does NICE already have the knowledge and expertise to undertake this, and how do you know if this is the case?

In the sections below, Cardiomyopathy UK has set out some ways that NICE can achieve the core areas of focus.

Improving accessibility and inclusion

Cardiomyopathy UK has supported an individual to participate in a technical appraisal, for the drug Mavacamten, and has noted the challenges involved in this. There are complex forms to complete beforehand, which need to be completed in a specific way. Cardiomyopathy UK supported the individual to complete paperwork, which enabled her participation. While Cardiomyopathy UK had the knowledge to do this, it would not always be the case that a patient organisation understands the technicalities of NICE paperwork. Cardiomyopathy UK was not supported and approached the NICE Patient Engagement team for support in the process, but did not receive a response until it was too late. NICE should work in partnership with the VCSE sector to build capacity and awareness in how to participate in NICE activity. The NICE Patient Engagement team should have the resources to be proactive in reaching out to patient organisations to offer support in circumstances such as this.

People with cardiomyopathy took part in a focus group to discuss the NICE strategy on people and community engagement. Those people with cardiomyopathy who have taken part in a technical appraisal meeting say that it is an intimidating experience. The meeting takes place in a large room, and the patient is often the only person with lived experience present. The relevant patient organisation is not able to participate in the meeting. Other participants are not necessarily experts in the health condition, nor in the drug. The discussion is all about health economics and focuses on whether the cost of the drug can be justified. This can be an unsettling experience for a person with lived experience. One person said:

“They were talking about me and whether I was worth giving the drug.”

The discussion went way beyond her comprehension. Another person, who had been involved in the development of the NICE heart failure guidelines, and is an Arrhythmia Nurse, said that she could not contribute to the discussion, and she was made to feel small.

These are both people who are well informed about their conditions and can engage in NICE processes. In order to increase the diversity of the people and communities in NICE's work, NICE should consider ways to make engagement more accessible.

Methods could include:

- Using plain English to inform people and communities of opportunities to participate in technical appraisals and development of guidelines, and in the associated paperwork.
- Widen the selection criteria for individual participation in technical appraisal meetings by making adjustments in the application process to take into account people who may not have English as a first language, people with a learning disability/difficulty or people from a variety of socio-economic backgrounds (for example do not dismiss a person based on grammatical errors or the lack of use of technical vocabulary).
- Allow patient organisations to join in the technical appraisal meetings as support or an advocate to an individual.

Recommendation: NICE should consider ways to make engagement more accessible.

Methods could include:

- Using plain English to inform people and communities of opportunities to participate in technical appraisals and development of guidelines, and in the associated paperwork.
- Test NICE text against the plain English principles as set out in the NHS Constitution.
- Widen the selection criteria for individual participation in technical appraisal meetings by making adjustments in the application process to take into account people who may not have English as a first language, people with a learning disability/difficulty or people from a variety of socio-economic backgrounds (for example do not dismiss a person based on grammatical errors or the lack of use of technical vocabulary).
- Allow patient organisations to join in the technical appraisal meetings as support or an advocate to an individual.

Different research methodologies

Another key consideration for NICE to improve on its people and community engagement is to give equal weighting to qualitative evidence as it does to quantitative evidence.

Those people with lived experience of cardiomyopathy, who have taken part in NICE processes, have felt that their voice is not taken into account. It feels like it is a box-ticking exercise to have a patient participate in a meeting, while the statistics and economics are given a higher priority.

More needs to be done to ensure that qualitative evidence is valued to the same extent as the economic case in technology appraisals. In order to do this, NICE should consider the inclusion of qualitative researchers or ethnographers to gather evidence for the development of guidelines or in technical appraisals. This qualitative evidence should demonstrate, not just the impact on individuals, but a community at large, which can be used to inform NICE decision-making.

This could also increase the diversity in backgrounds of people and communities taking part in the work of NICE. Qualitative research could consider a wider range of methodologies to collect data from people and communities. This could include surveys and in-depth interviews, with researchers working across regions and in the communities around England and Wales.

NICE should also consider accepting data that is held by patient organisations to inform their decision making. This could include anonymised data from helplines and from services. As an example, Cardiomyopathy UK is currently receiving calls to the helpline, and hearing the same question in peer support groups, about access to Mavacamten, and, as such, is using this information to communicate to Inherited Cardiac Clinics that the drug is now approved and available for suitable patients.

By using data such as that from helplines, NICE can also increase the diversity of the people and communities in their engagement.

Recommendation: In order to make engagement meaningful and to remove barriers to involvement, NICE should:

- Include qualitative researchers in evidence gathering consistently across all NICE areas of work.
- Introduce different research methodologies, such as surveys or in-depth face to face interviews in the community, consistently across all NICE areas of work.
- Build partnerships with the VCSE sector and understand the data community organisations hold, and how these data can be used in decision making.

Empowering people and communities

One comment that has repeatedly come up with regards to NICE's engagement with people and communities is that the qualitative evidence provided by people with lived experience is not taken on board in the decision-making process or does not change the outcome of a NICE decision. While this links back to the point around the priority given to quantitative and economic evidence, it can be the case that people and communities have not been made aware of the impact of their lived experience. This can lead to feelings of disempowerment.

NICE needs to communicate back to people and communities to demonstrate that they have effected change, or their stories have been considered in the decision-making. This is applicable even if the people and communities have not achieved their desired outcome in the process.

Recommendation: NICE should open a dialogue with the VCSE sector to demonstrate how the voice of people has been taken on board and made a difference or provide a justification for certain qualitative evidence not being considered.

On a different angle, people and communities could also be empowered to make decisions about their health and care by using NICE guidelines. In a focus group with people with Cardiomyopathy UK Change Makers, a well-informed and knowledgeable group from the cardiomyopathy community, one person stated that she uses NICE guidelines when seeking advice on a health issue. She uses the plain English versions to understand her rights and what she can ask for from the GP.

This provides a good example of empowering people to understand their rights in health services, but this is probably not typical of the whole population, or even the whole cardiomyopathy community. NICE should take some responsibility for increasing public awareness in the work they do, and how people and communities can use the guidelines to make informed decisions about their health. Doing so would empower people and communities to make decisions about their health and care.

Recommendation: NICE should introduce a measure of success to this strategy around increasing public awareness in the work they do, and how many people and communities use the guidelines to make informed decisions about their health.