Patient Activation: Community Research - a summary report

December 2025 - February 2026

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Community Action Network

Patient Activation: Summary Report

Project Overview

Introduction

As an award-winning voluntary sector infrastructure charity, Community Action Network (CAN) plays a unique role in connecting, championing and strengthening our local voluntary and community sector. Our networks and relationships across Bournemouth, Christchurch and Poole mean we are trusted by a wide range of community groups, grassroots organisations and residents particularly those whose voices are often less heard in traditional engagement processes.

Through our day to day work supporting hundreds of community organisations, we have built strong links into diverse communities, including people who may not usually feel able, confident or invited to share their experiences with statutory services. This trust allows us to gather meaningful insight from individuals and groups who are not always represented in formal consultation, ensuring their lived experience informs how services are designed and delivered.

CAN partnered with NHS Dorset to ask our communities their views around the Patient Activation Measure and recognise the importance of involving communities developing tools, ensuring it reflects real experiences, real barriers and real motivations. By working together, we can ensure that voices from across our communities, especially those seldom heard shape the development, testing and refinement of this tool so it can be used effectively by health professionals across the system.

Our unique position, trusted relationships and deep community connections place us in an ideal role to support this work. We are proud to contribute to a more inclusive, insight led approach to service design, ensuring people and communities are genuinely listened to and truly influence the decisions that affect their health and wellbeing.

1. Methods

To gather the views of local people particularly individuals from minority ethnic backgrounds, people with learning or physical disabilities, and older adults we used a range of approaches to reach out through our established community and contacts. This included sharing the opportunity through:

- CAN relationships and partnerships
- CAN networks
- CAN newsletter's
- CAN social media channels.
- Direct contact with partners and providers, such as day opportunity services, older people's services, community groups and local community leaders.

Through these existing and trusted relationships, we asked partners to circulate the opportunity within their own communities and networks, encouraging people to share their experiences and take part.

People were invited to provide feedback in the way that suited them best, including:

- Online survey
- Face-to-face conversations
- Telephone or video call.

With a newsletter audience of over 800 Members, CAN has a significant and trusted reach into local communities.

"At CAN our networks are thematically and geographically focused and have evolved from conversations with our members about their needs. They are a great space to gather insight and also share updates with people interested in certain topics and themes and encourage collaboration."
Hannah Rees, Engagement Lead
Community Action Network

"I truly appreciate the important work you're doing. I will share this with our community members, and I'm confident they will respond positively to the call."
Umeononigwe, Azukaego U.
Nigerian Community Dorset

1. On a scale of 0 – 10 (0 being unhappy and 10 being very pleased) how do you feel about being asked the question:

"How good are you at taking care of your health?"

Answer: ☐

Social media post and flyer design and example, alongside questionnaire visual.

2. Engagement Event

CAN hosted an event at the Henry Brown Community Centre in West Howe in early January 2026, linking it to a feedback session for Community and voluntary groups who access support and training through CAN's Voluntary Sector Development service. This group represents a diverse mix of local people from our ethnic communities, and we were delighted to welcome 14 attendees with a fantastic turnout for the time of year and a clear reflection of their commitment to engaging with CAN's events and opportunities.

To help create a welcoming atmosphere, the project funding was used to provide a hot, nutritious and culturally diverse meal, catered by one of the local community groups. It was extremely well received and added real value to the session. We know sharing good food is a great way to bring people together and encourage meaningful conversations.

"I'm my own advocate but not by choice, but by force, by lack of support. I am my own carer. Will there be support provided to us to help support ourselves?"
*Event attendee, **member of community.***

"[It's] very helpful how [the PAM] sections are divided and to identify different levels, especially for neurodiverse person."

A member of the audience at the event raised - **How honest will people be in their answers? Will this be taken into consideration?**

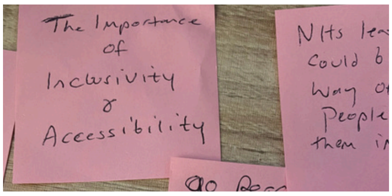
"GP's should trust their patients and take into consideration what they say – everyone knows themselves [best] and how they are feeling. Historically there is a lack of trust in patients from their GP's."

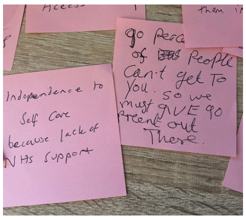
3. Findings from the Engagement Event

The in-person engagement session brought together participants from a diverse range of cultural backgrounds and lived experiences, including Traveller communities, people of Nigerian, Jamaican and Chinese heritage, and individuals with dyslexia and mental health needs. Across all groups, several strong and consistent themes emerged.

Participants highlighted five core areas:

1. **Accessibility of Information** - A need for clear, accessible, visually supportive and culturally appropriate materials.
2. **Trust, Honesty and the GP Relationship** – Concerns about how responses will be used, whether honesty will be respected, and longstanding issues around trust in primary care.
3. **Self-Advocacy and managing complex health** – Many people act as their own advocate due to limited support, and questioned how well PAM reflects the reality of managing complex conditions.
4. **Importance of outreach and community based support** – Strong calls for the NHS to reach people where they are, especially those who face transport, cultural or digital barriers.
5. **Mental Health and communication needs** – The need for flexible, empathetic communication options, including phone and online support.





Across all communities, there was a clear message. **Accessible, trustworthy, culturally competent and community-led approaches are essential.**

Strengthening outreach, improving accessibility of materials, and building genuine partnerships with communities were seen as key ways to increase confidence, engagement and trust in healthcare.

> Local people from ethnically diverse backgrounds want the NHS and wider health system to understand the barriers they face, not only in accessing services, but in feeling heard, respected and included.

4. Group and individual sessions with people who live with care and support needs

We worked alongside a care and support provider where staff who have a relationship with the people who use their service, spent bespoke time with 11 people including those living with a learning disability, mental health challenges and physical disabilities to share their views around Patient Activation using bespoke printed versions of the survey and with staff briefed in patient activation.

Summary of Themes

1. Strong preference for **in person conversations**. People feel more comfortable, able to be more honest and more supported when spoken to face-to-face.

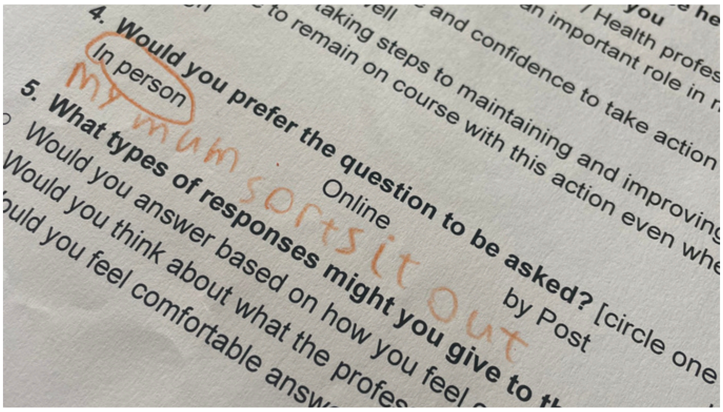
2. Many feel responsible for their health but still see the GP as central Health management is viewed as a shared responsibility, but for some it is heavily **weighted towards professionals' responsibility**.

3. Groups, workshops and peer support are highly valued. These were consistently mentioned as ways to build confidence in managing health.

> ***"[I'd] be happy to be asked the [activation] question".***

4. Understanding of 'patient activation' is low for this group. Most people do not feel they understand it well enough to describe it to others.

5. Accessibility barriers continue to shape experiences with people sharing long waits, difficulty contacting the GP, digital barriers and lack of support influence how people feel about activation and self management of their health.



Health profes
an important role in r
and confidence to take action
taking steps to maintaining and improving
to remain on course with this action even whe

4. Would you prefer the question to be asked? [circle one
[✓ In person] Online by Post
My mum sorts it out

5. What types of responses might you give to th
Would you answer based on how you feel
Would you think about what the profes
ould you feel comfortable answ

> "I don't have the ability to help myself healthwise."

> *"It would be nice if it could be face to face activation instead of online. I prefer talking to my GP instead of typing things up."*

5. Experiences of a Sight-Impaired Participant

CAN spoke to a severely sight-impaired lady living in Dorchester who also works in services supporting people with learning disabilities, autism, long-term mental health needs and complex disabilities. While sharing her personal experiences, they also reflected on barriers likely to be faced by the people they support. This person's views are captured in the online survey.

Key Insights

Expectation to join in-person groups

There are frequent assumptions that they can easily attend in person sessions or community groups. Travel is a barrier, particularly as people with severe sight loss do not drive. Attending such events requires additional planning and support.

Ability to seek help for tasks

Independence matters and accessible design should enable participation without relying on others. Ensuring accessible formats is essential for enabling equal participation in conversations about health and care.

Information provided in inaccessible formats

The participant often receives information in ways that assume they can see, such as letters, printed materials, or digital images without alternative text.

Services should adapt processes, ask people what they need, and design accessibly from the outset

Digital tools

The participant relies on a range of accessibility tech, including screen readers on their phone and laptop to access information. Online information is often the quickest and most accessible route when the content is designed accessibly.

Barriers in digital content

- PDFs are inaccessible when not formatted properly.
- Images lacking alternative text prevent access to event information and service details.
- Strings of emojis disrupt the screen reader experience, which reads each emoji aloud individually and takes a long time to sit through!
- Image based information sometimes requires separate apps or AI tools to interpret, which they described as impractical and burdensome.

Preferred communication

The participant prefers face-to-face communication, finding it more meaningful and engaging. They compared this with their annual asthma review, where structured questions become valuable when paired with real conversation. They emphasised that people should be able to participate in a way that suits their individual accessibility needs, rather than through a single fixed method.

> "I could of got someone to help me fill it out, but when I reached out to you I thought it would be nice to have a chat."

6. Overview of survey respondents demographics

We received a total of 32 responses to the online survey, with a broad mix of participants. Some people completed the survey for themselves, while others responded on behalf of someone else, including one submission made for a person experiencing homelessness.

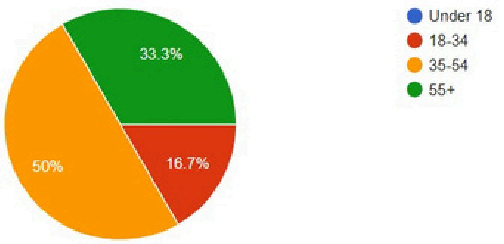
Just over 70% of respondents reported having caring responsibilities, and more than 75% said their day-to-day activities were limited by a health condition or disability. Around half of all respondents were aged 35–54, and the majority were women.

Respondents also reported a wide range of disabilities and health conditions, including neurodivergence (such as autism, ADHD and dyslexia), mental health conditions, vision impairment or blindness, hearing impairment, learning disabilities, mobility difficulties and long-term conditions such as peri-menopause symptoms and long COVID.

While most respondents identified as White British, the survey also achieved meaningful representation from Indian (over 20%) and African (over 7%) communities, alongside contributions from people with Irish, South American, Filipino, Caribbean and Japanese backgrounds.

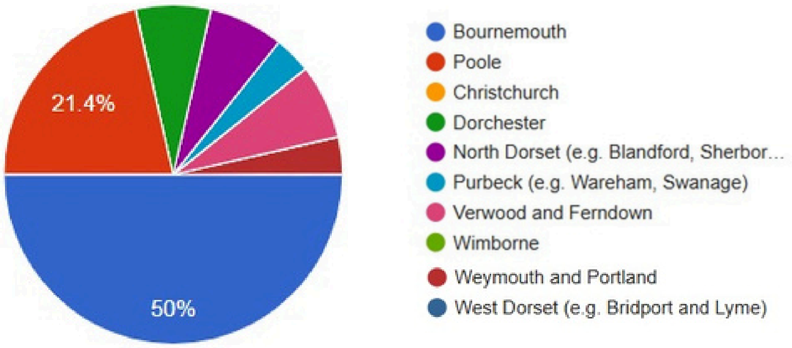
This diversity brings a rich and valuable range of perspectives to the findings alongside our face to face and telephone conversations.

What **age group are you** in?



Please note the age question was added after the survey had launched, as the research team recognised its value as an important demographic factor. As a result, not all participants were asked this question, and we have age information for 18 out of the 32 people who completed the survey, however we do believe this gives a strong indication of the overall age of online respondents.

Participants were based across Bournemouth, Poole, Dorchester, Weymouth & Portland, North Dorset and Purbeck, providing a strong geographical spread.



7. Summary of findings from survey responses

How people felt about the activation question’ **How good are you at taking care of your own health?**

Overall, most online participants felt positively about being asked the activation question.

Perceived impact on NHS care

Hopeful but sceptical, people want the answer to matter but doubt it will result in real support.

How people see health management

We heard from a good range of people from varying levels of activation. How people see their role in the management of their health shows a mixed picture. The majority of respondents feel capable, but some still rely heavily on professionals or feel unsure.

The most common belief highlighted people felt they have an important role in managing their health. This was the most frequently selected option.

> *“It would be nice if it could be face to face activation instead of online. I prefer talking to my GP instead of typing things up.”*

Preferred way to be asked the activation question

Clear patterns emerged:

- In-person was strongly preferred (by most respondents).
- Online was the second most common.
- Text and post were preferred by some, especially those:
  - with mental health challenges
  - with learning disabilities
  - who feel unstable answering face-to-face

Overall face to face conversations matter, but flexibility is important for accessibility.

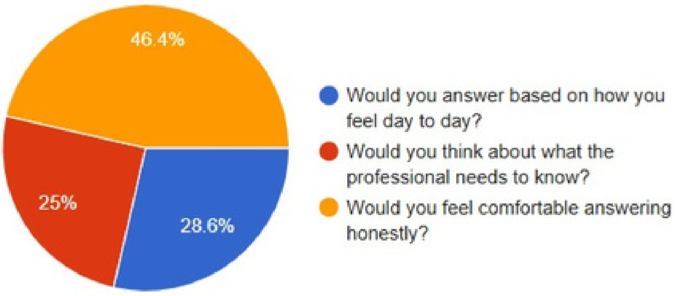
How people might respond to the question

Most common themes:

- Many said they would answer honestly.
- Others said they would answer based on how they feel on that day.
- A large group said they would answer based on what the professional ‘needs to know’.
- Some weren’t sure how to answer the question at all.

This suggests context and framing matter, and the question may land differently depending on mood, confidence, and trust.

What types of responses might you give to the [Patient Activation] question?



8. Summary of findings from survey responses cont...

What would help increase confidence, knowledge and skills

Top four most common answers include:

1. Self-help groups/workshops
2. Peer and community support
3. Signposting to reputable websites / information sources
4. Webinars

Other suggestions include:

- accessible information formats (e.g., large print)
- better communication from professionals
- more face-to-face contact
- AI tools for self-monitoring (one respondent).

People consistently want practical, accessible and **community-based support.**

> ***"I would be okay with my answer helping to draw up what support I need."***

> *"I'm not optimistic being asked this question would result in ongoing support beyond generic advice given during an appointment or endless waitlist for services that start to late."*

Understanding of 'patient activation'

This varied widely. Most common response was "Not sure / don't know."

Many respondents did not understand the term even after viewing the short video provided by CAN.
Those who did offered explanations which use everyday language such as:

- Taking responsibility for your health
- Knowing your body and when to seek help
- Being aware of health options
- Managing lifestyle to improve outcomes
- A measure of knowledge, skills and confidence

Other rich qualitative themes emerging:

- need for accessible information
- concerns about GP access ("can't get hold of my GP", "no phone", long waits)
- requests for face to face conversations
- frustration with digital barriers
- worries that the question alone won't lead to real support
- mental health impact on self-care
- feeling judged or patronised by professionals.

Overall findings show a strong call for good communication, trust, accessibility and genuine follow up and care given.

9. Overall Conclusion

Across all the engagement methods used online surveys, in person sessions with ethnically diverse communities, one to one and group conversations with people with people who use care and support and day opportunity services and an in depth discussion with a visually impaired participant a consistent picture emerged about what people need in order to feel confident, supported and included when discussing their health and the Patient Activation Measure (PAM).

Participants expressed a strong desire for accessible, trustworthy, culturally competent and person-centred approaches. Many people highlighted that it is not simply the question itself that matters, but the way it is asked, the context in which it is presented, and whether their answer will genuinely influence their care. Trust particularly trust in GP services was a recurring theme, shaped by personal experience, cultural background, and past barriers in accessing healthcare.

Across all groups, accessibility challenges were repeatedly emphasised. People with visual impairments called for accessible formats, meaningful alternative text and digital tools designed inclusively from the outset. People with learning disabilities valued one to one support, easy-read versions and familiar staff who could guide the conversation. Those with mental health issues, neurodivergence or dyslexia stressed the importance of clear visuals, simple language, and communication that feels safe and compassionate.

Ethnically diverse communities highlighted longstanding barriers to access, including difficulty obtaining GP appointments, language and cultural barriers, and experiences of not feeling listened to or taken seriously. They reinforced the need for outreach and community-based support, emphasising that many people cannot travel to services and therefore rely on the NHS and other agencies to meet them where they are. Participants also questioned whether PAM scores would lead to real action, expressing concerns about honesty, accuracy and the need for support, especially for those who already act as their own advocate due to system pressures.

Despite differences in background and lived experience, people consistently described the same core requirements:

- accessible information in formats they can understand and use
- meaningful, human conversations rather than tick-box exercises
- trust and transparency about how their responses will be used
- respect for cultural differences and individual circumstances
- support to increase skills, confidence and knowledge through groups, workshops, peer support and clear signposting
- services that reach people who cannot easily access traditional routes.

10. Next Steps

Together, these findings from up to 60 local people, show that Patient Activation can be a useful tool, but only if delivered within a system that is inclusive, relational and responsive.

Participants are willing to engage with the tool, but need reassurance that their voices matter, their barriers are understood and that the health system will work with them, not around them to support their wellbeing.

It would be fantastic to see this learning embedded into the design and roll out of patient activation in Dorset.

Sharing the learning and plans back with Community Action Network so we can share with those that took part in this research.

Thank you for partnering with us.

To view the CAN Patient Activation explainer video as part of this research search Community Action Network on YouTube and search for the video 'What is Patient Activation'.

We would like to say a big thank you CAN members, partners and friends in sharing this opportunity within your communities and to everyone who took part in sharing their views. A thank you and shout out to Help & Care for sharing their data collection tool for which CAN used to develop their online and printed surveys.

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