

NORTHERN CANCER VOICES



Rooted in community. Driven by experience.





To amplify lived experience, reduce inequalities, and shape cancer services through trusted relationships, community-rooted engagement, insight, and partnership working.

Mission

Values



Cancer Connect: Emotional & Practical Support

Our promise to listen, guide, and support people through every part of their cancer journey.



Access to Care: Cancer Navigation and Reducing Inequalities

Our promise to make sure no one is left behind, especially people who face barriers because of their postcode, background, income, or personal situation.



Lived experience to impact: Lived Experience in System Change

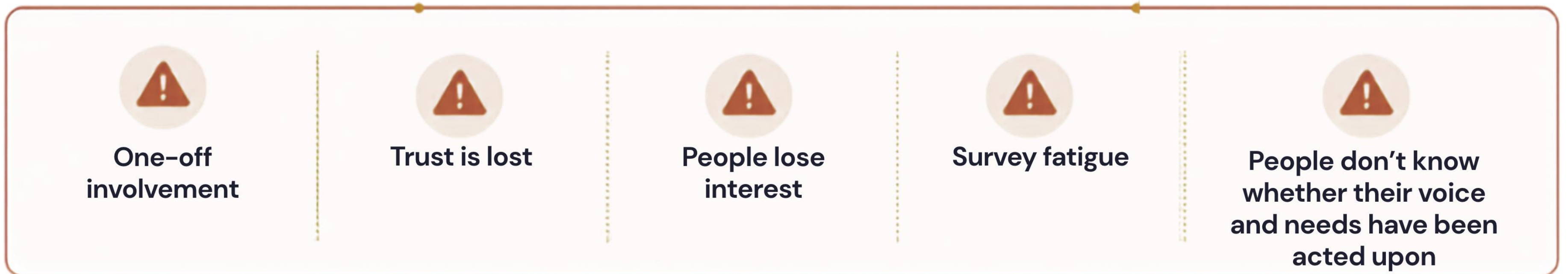
Our promise to make sure lived experience expert's voices shape how cancer services are planned, improved, and delivered

NORTHERN Traditional PPIE working

CANCER VOICES



Challenges of the traditional model



NCV Model of working

TURNING LIVED EXPERIENCE
INTO BETTER CANCER
SERVICES AND CARE



Community First



Trusted leaders and local partners
Building relationships through people communities already know

Community spaces and local settings
Including community centres, faith groups, support groups and local events

Listening sessions and informal conversations:
Creating space beyond surveys and formal meetings

Those who don't, won't or can't engage
People often missed by generic involvement methods



GOING WHERE PEOPLE ARE, BUILDING TRUST WITH THOSE THEY TRUST, AND LISTENING TO EXPERIENCES THAT FORMAL INVOLVEMENT OFTEN MISSES.



Lived Experience Led

- Our work is designed and led by people with lived experience. Every member of our staff, trustees and volunteers has been affected by cancer, giving us collective expertise grounded in real life.
- They encourage others to take action, get involved and make their voices heard.
- Volunteers and ambassadors share their experiences at events, helping people recognise how they can look after their health.
- They feed what they hear back into the system, so services reflect real experiences.
- They support people to become their own advocates and speak up for the changes needed across the cancer pathway.
- We facilitate involvement and build confidence, helping people turn experience into influence.

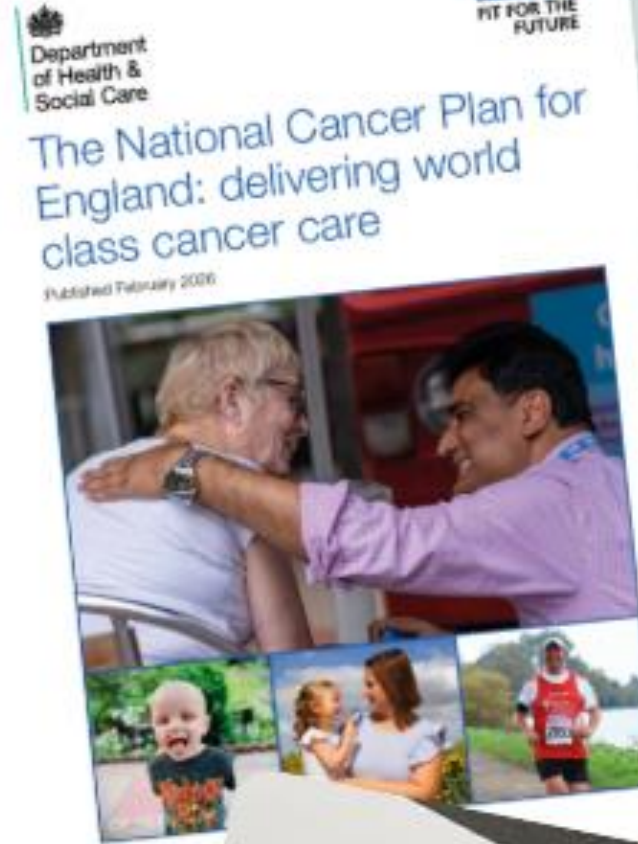
**WE DON'T JUST LISTEN TO
LIVED EXPERIENCE. WE
SUPPORT PEOPLE TO TURN IT
INTO ACTION, INFLUENCE AND
BETTER CANCER CARE.**



Representing public voices where they are seldom heard

- Steering groups
- Research
- Conferences
- Meetings & Events
- Cancer Plan
- Pathway Design
- Surveys
- PPIE

*DIFFERENT ROOMS... ONE SHARED PURPOSE...
ENSURING PUBLIC VOICES ARE HEARD, AND
ACTED UPON*



NORTHERN We are the bridge

CONNECTING PEOPLE TO THE RIGHT SUPPORT,
WHERE THEY ARE, WHEN THEY NEED IT.



15

Community Cancer
Champions Trained

Long lasting impact in the
community, supporting earlier
diagnosis and self-advocacy

246

Surveys
Submitted

People sharing their
experiences to help make a
difference for others impacted
by cancer in the future

936

People supported
with sign-posting &
Link Working

Holistic person-centred sign-
posting. Ensuring no-one falls
through the gaps

1761

People attended
our support groups

Community based peer-to-peer
support, reducing isolation during
and after treatment to help ensure
people live well with cancer

3451

Conversations
about cancer

Reducing the stigma and fear
of cancer, encouraging
openness and support to
explore and understand safely

From lived experience to impact and beyond

ALAN'S STORY SHOWS WHAT TRUSTED, COMMUNITY-LED ENGAGEMENT CAN UNLOCK

01 THE CONNECTION

Alan found Northern Cancer Voices through his work as a Prostate Cancer UK volunteer. He uses his own experience to connect with other men — especially working-class men and “guys on the tools” — and encourage people to understand prostate cancer, stay well, and know the power of testing.

“KNOW YOUR NUMBER!”

03 A MOMENT OF IMPACT

At an engagement event, Alan’s story encouraged a working man who said he would not otherwise have attended lung screening. His manager helped make time for the appointment, and screening identified a diagnosis. He believes this model may have saved his life.

02 TURNING EXPERIENCE INTO ACTION

Alan keeps learning about the disease and works with other lived-experience experts to champion change in the pathway — especially earlier diagnosis and reaching people less likely to engage with services.

04 WHAT COMES NEXT

Alan continues to work with Northern Cancer Voices to influence policy and governance around earlier prostate cancer diagnosis, while helping develop community testing pilots.



“I WOULD NOT HAVE ATTENDED IF I HADN'T HEARD ALAN'S STORY THAT DAY.”

One trusted conversation can change what happens next.

NORTHERN CANCER VOICES Key Themes



Communication and information gaps are a major issue

Poor communication is consistently reported across diagnoses, treatment, and follow-up.



Care is often not joined up

Patients and carers are left to navigate tricky systems alone, contributing to inequity in healthcare.



Aftercare and 'what happens next' support is lacking

Patients living with long-term side effects and those on 'watch and wait' pathways feel disengaged and forgotten.



Barriers to screening and early diagnosis persist

There is strong support for proactive education and myth-busting, especially for underserved groups.



Mental health and emotional support is insufficient

People experience distress, loneliness, anxiety and despair, while specialist and community support can be difficult to access.



From lived experience to system change

HOW THE NORTHERN CANCER VOICES MODEL HAS GROWN, AND WHY TRUST POWERS EVERY STEP

Experts shape the model

Lived experience patients and carers, professional experience managers, corporate/ commercial experience, and NHS experience experts come together to create the working model.

Go where people are

community engagement builds relationships with community leaders and VCSE organisations to reach people who are seldom heard or hard to reach.

Join up existing voices

patient and carer collaboratives across the North East are connected into one joint-up voice aligned with the ICB structure.

Listen and gather insight

collect what people say matters most, alongside the evidence and data.



**TRUST +
RELATIONSHIPS**

**POWER
EVERYTHING WE
DO**

**INSIGHT FLOWS BOTH
WAYS: COMMUNITIES +
DECISION-MAKERS**

Analyse and share learning

turn insight into learning and share it with NHS and other statutory partners.

Act and challenge

empower people to make a difference in their own lives and challenge systems to ensure patient voices are acted upon.

Return to communities

show people what changed because of their contribution, completing the feedback loop.

OUR MODEL IS EVOLVING...

Developing and growing the model through Treat, Heat or Eat project

Supported by Northern Gas Networks, now in its fourth round of funding

Diversified engagement and funding to strengthen organisational stability

Supported by National Lottery Funding, to enhance lived experience impact and develop data analysis

**Unlike organisations focused on one or two elements, NCV connects the whole journey:
reach → listen → analyse → influence → report back.**

Why this matters

1 Voices must be heard and acted on

Patient and public voices reveal real needs, barriers, priorities, and what change would make the greatest difference. Listening only matters when it leads to action.



2 Designed with people, not for them

Co-design makes services more relevant, accessible, trusted, and responsive to real lives.



People at the heart of better cancer services

3 Why Northern Cancer Voices?

NCV connects lived experience with health system decision-making, bringing trusted relationships, community insight, and a focus on turning what people say into meaningful improvement.



4 Better engagement, better services

When people shape decisions, services are more equitable, practical, and likely to improve outcomes.

