

Breakout: patient & public involvement

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About National Voices

- A membership body for health and social care charities (non-profit organisations) in England
- 140 members, from very small to very large and representing different conditions and communities
- Working with national policy makers
- We stand for people being in control of their health and care

Levels of engagement

1-1

With experts by experience

With communities & the public

Less heard
people

Personalised care and support planning



3%

**Only 3% of
people with
a long-term
condition said
they had a
written care plan.**

I have honest discussions and the chance to plan



I have timely and honest conversations with those engaged in my care, support and treatment.

I am confident that staff and professionals are able to have difficult conversations with me, in order for us to decide the best treatment, care and support together.

The professionals I meet check that these conversations are happening and enter them on my record.

I can expect these conversations to be followed up, and revisited at key times during the course of my care and treatment.

I and my carer(s) are always given an explanation of terms that are new to us, like 'palliative'.

Ambition 1

Each person is seen as an individual

*I, and the people important to me,
have opportunities to have honest,
informed and timely conversations
and to know that I might die soon.
I am asked what matters most to me.
Those who care for me know that
and work with me to do
what's possible.*



High value involvement

| Level | Who? | Purpose | Outcomes |
|------------|---|--|---|
| Individual | Patients, caregivers, family & important others | To make appropriate decisions & manage the impact of Itcs | Better health outcomes & use of healthcare resources |
| Group | Relevant patients; experts by experience; patient organisations | To codesign new care models & decommission old | Get care design right first time |
| Governance | Patient representatives, leaders, experts by experience | To bring aggregated patient experience to system decisions | Better decisions, informed by user values & preferences |
| Community | Groups & organisations supporting people | To develop community based assets & approaches | Community resilience & support to wellbeing |