



We the patients...

We know that you want to 'put us at the heart' of everything you do, but we think you are not always clear what that means. You use lots of different terms to express this: putting patients first, patients at the heart, person-centered care, shared decision making, no decision about me without me, patient involvement, patient participation, patient engagement, patient experience, personalisation... and more.

We think all these different terms, though well-meaning, cause confusion and blur some important distinctions. Research shows that all this language betrays your anxieties about how best to relate to us.

We would like to set out some different ways of thinking about us, the patients. All are important, each can reinforce the other, but they are distinct. We think that being mindful of these different categories will help you be clearer about your purpose, the relationships and conversations you want to have, and the power you want to share.

We are the same as you, we are all patients sometimes.

We the patients...

...are people

Each one of us is a whole person. We are not defined by our condition or disability.

Some of us don't like the term "patient". We need you to think about the impact of decisions on our whole lives and over time. We expect you to take our safety seriously. We expect to be treated with respect and compassion. We need services that are joined up around our needs and preferences, not fragmented.

...are citizens

Health is a human rights issue. We have fundamental rights of access to safe, high quality

healthcare set out in law and reflected in the NHS Constitution. These rights are there to protect us regardless of our age, sex, race or other characteristics. We accept that with rights come responsibilities to look after our health and to use services thoughtfully. Many of us want to be equipped to make fewer demands on the NHS.

...are owners

The NHS belongs to us all. We are all owners of the health service. We want to know how to access

services in the best way. We want to know what is going on and how well you are doing. We expect you to be accountable for how well you run services on our behalf. Many of us are volunteers. We want to participate, contribute and help.

...are leaders

Many of us play a leadership role or would like to.

We want you to help us to get involved, to understand and embrace the role we can play and have access to the training and support to do this well.

...are partners

You are experts about care, and we are experts about our lives. We want to be more involved in

decisions about our health and care, so that they are built around our goals and preferences. That requires good information, advice and guidance, good conversations and a sharing attitude. If we have continuing care needs we need to be part of the care planning and we want support to live as independently as we can. Some of us want to take more control, for example using personal budgets, and we need you to let go.

...are customers

We expect good customer service as well as expert care. We need you to care about our

experience. We want you to treat us as though we could take our custom elsewhere, even if we can't. We want to make informed choices that are meaningful to us. We want you to know us and understand us. You need to make it easy for us to communicate with you and tell you what we think. We expect you to act on this information.

...have families

We need you to involve our family members and those who care for us and to recognise and respond to

their needs. If you exclude or thwart them, we suffer.

...live in communities

We need to be involved as communities not just as individuals.

We are brought together by what we have in common: a locality, our life stages, the roles we play in our work, families and society, and our health conditions. You need to understand these different communities of interest.