

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

People's experience in adult social care services: improving the experience of care for people using adult social care services

Topic

The Department of Health in England has asked NICE to develop a guideline on the experience of people who use adult social care services.

This guideline will provide recommendations on the aspects of social care services that are important to the people who use them. It will also provide recommendations on how to improve adults' experiences of social care services. It will apply to all settings where care is delivered, including people's own homes, residential care and community settings.

This guideline will be used to develop the NICE quality standard for this topic.

The guideline will be developed using the methods and processes outlined in [Developing NICE guidelines: the manual](#).

For more information about why this guideline is being developed, and how the guideline will fit into current practice, see the [context](#) section.

Who the guideline is for

- Practitioners working in adult social care services in all settings.
- Care managers and providers (statutory and non-statutory) of health and social care services.
- People using services, their families, carers, advocates and the public.

It is also relevant for:

- Commissioners of health and social care services, including people who purchase their own care.
- Professionals working in and providing housing support.
- Community and voluntary organisations representing people who use services and their families.
- Local authorities.
- Health and wellbeing boards
- Local healthwatch groups.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the [Welsh Government](#), [Scottish Government](#), and [Northern Ireland Executive](#).

Equality considerations

NICE has carried out [an equality impact assessment](#) during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope.

The guideline will look at a range of potential inequalities, for example relating to age, gender, disability, socioeconomic group, race, sexual and gender identity, and religious belief, taking into account the available evidence.

1 What the guideline is about

1.1 Who is the focus?

- All people aged 18 and older who use adult social care services.

1.2 Settings

- All settings where adult social care is provided. This includes services funded by local authorities and by people themselves, provided in any setting.

1.3 *Activities, services or aspects of care*

Key areas that may be covered

- 1 The key aspects of experience that are valued by people who use services, this is likely to include the following:
 - Access to services (including information, advice and support).
 - Assessment (including financial assessment) and care planning.
 - Choosing and managing care.
 - Delivering and coordinating care and support.
 - Monitoring, reviewing and evaluating care.
 - Involving people using services in policy and strategies for local service improvement
 - Transition between services, care settings and leaving care
- 2 The views of people who use services, including carers' or family members' perceptions, of how well services:
 - support them to be actively involved in their care planning and delivery
 - support them to participate in family, social and community life (including training, further education and paid and unpaid employment)
 - work with the people who use them to ensure the right care is delivered at the right time
 - meet their social and emotional needs and support their wellbeing.

Areas that will not be covered

- 1 Services and support specifically aimed at carers (this will be addressed in a separate NICE guideline). However, this guideline will include how carers' perceive the care provided to the people they care for.
- 2 Health services, including clinical mental health services.

1.4 *Economic aspects*

The guideline developers will take into account cost effectiveness when making recommendations. Economic review questions will be identified where appropriate. A review of the economic evidence will be undertaken in line with

the methods outlined in [Developing NICE guidelines: the manual](#). Economic analysis, where undertaken, will consider all relevant audiences, including commissioners, decision-makers, providers, people using services and carers.

1.5 Key issues and questions

While writing this scope, we have identified the following key issues, and key questions related to them:

- 1 Which aspects of the experience of using adult social care services are valued by people who use the services?
- 2 How should the experience of people who use services be monitored and evaluated locally?
 - 2.1 What methods and approaches are used to monitor and evaluate the experiences of people who use services?
 - 2.2 How effective are these methods and approaches for recording the experiences of people who use services?
 - 2.3 What methods and approaches are used to help services and organisations learn from the experiences of people who use services?
 - 2.4 How effective are the methods and approaches used to help services and organisations learn from the experiences of people who use services?
- 3 How effective are tools and approaches (such as digital technologies or advocacy services) that are specifically designed to improve the experience of adults using social care services?
- 4 What are the barriers and facilitators related to improving the experience of adults using social care services?

The key questions may be used to develop more detailed review questions, which guide the systematic review of the literature. A complete list of review questions will be agreed by the committee at the start of guideline development, covering all areas of the scope.

1.6 Main outcomes

Outcomes that relate to the experience of people who use services will be considered. They are likely to include:

- 1 Wellbeing and quality of life (related to health, mental health and social wellbeing).
- 2 Engagement with services and care, including understanding relevant care and management issues where appropriate.
- 3 Choice and control.
- 4 Satisfaction of people who use services (including carer, family and advocate perceptions of how satisfied the people who use services are).
- 5 Perceived and objectively measured independence.
- 6 Ability to carry out activities of daily living with or without support.
- 7 Continuity of care.
- 8 Participation in social and community activities, including training and education, paid and unpaid employment.
- 9 Resource use.
- 10 Security and personal safety.

2 Links with other NICE guidance, NICE quality standards, and NICE Pathways

2.1 NICE guidance

NICE guidance about the experience of people using NHS services

NICE has produced the following guidance on the experience of people using the NHS. The recommendations in the following guidelines will be considered for use in this guideline:

- [Patient experience in adult NHS services](#) (2012) NICE guideline CG138.
- [Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services](#) (2011) NICE guideline CG136.

NICE guidance that is closely related to this guideline

Published

- [Transition between inpatient hospital settings and community or care home settings for adults with social care needs](#) (2015) NICE guideline NG27
- [Social care for older people with multiple long term conditions](#) (2015) NICE guideline NG22

In development

- [Transition from children's to adults' services](#). NICE guideline. Publication expected February 2016.

2.2 NICE quality standards

NICE quality standards that are closely related to this guideline

- [Quality standard for service user experience in adult mental health](#) (2011) NICE quality standard QS14.

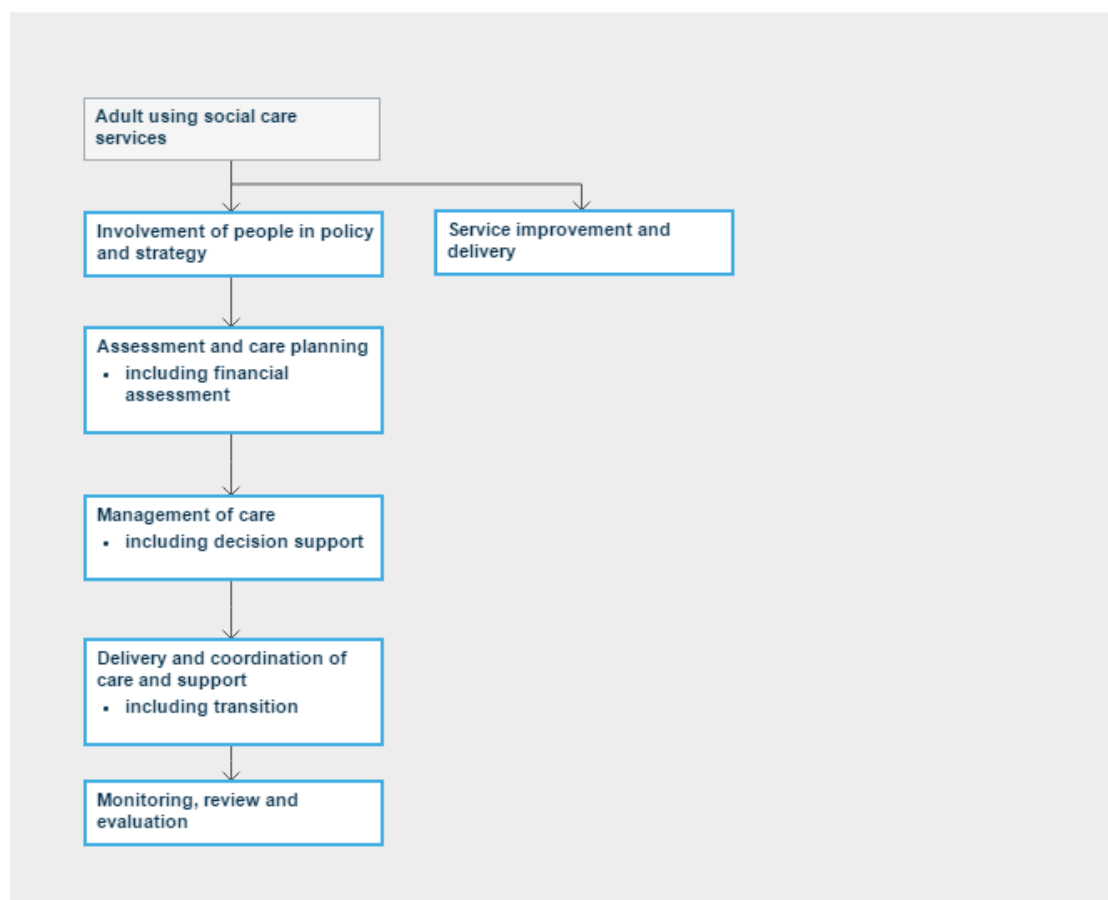
2.3 NICE Pathways

When this guideline is published, the recommendations will be added to NICE Pathways. NICE Pathways bring together all related NICE guidance and associated products on a topic in an interactive, topic-based flow chart.

NICE has pathways on patient experience in adult NHS services and service user experience in adult mental health services. We are also developing a pathway on transition between inpatient hospital settings and community or care home settings for adults with social care needs.

The pathway on the experience of adults who use social care services will show clearly how they fit together. A draft outline of the pathway, based on the draft scope, is included below. It will be adapted and more detail added as the recommendations are written during guideline development.

People's experience in adult social care services overview



3 Context

3.1 Key facts and figures

Adult social care services include personal care and practical support for people with learning disabilities, physical disabilities, sensory impairment and mental health or physical conditions. This care and support is delivered in a variety of settings, for example, in people's own homes and in community or healthcare environments, and by various services and carers.

In conjunction with the [Children and Families Act 2014](#), the [Care Act 2014](#) places a duty on local authorities to give young people and their families more choice and control over their care and support (rather than simply providing services).

The Children and Families Act introduced a system of support that extends from birth to 25. The Care Act covers adult social care for anyone over 18. Both pieces of legislation ensure that people aged 18–25 are entitled to support, and both emphasise the importance of considering the wide range of outcomes people want to achieve in their lives, personalising care and the integration of services.

Adult social care represents a significant cost to the public sector. Nevertheless, most social care – with an estimated value of £55 billion in 2012/13 – is provided informally by family, friends and neighbours ([Adult social care in England: overview](#) National Audit Office). The ‘Adult social care in England: overview’ also states that around £19 billion of funds managed by local authorities were spent on adult social care in 2012/13. This included around £2.5 billion paid by users themselves. (Even where local authorities manage services, some users may have to pay a contribution.)

3.2 Current practice

The Health and Social Care Information Centre publishes an [annual personal social services adult social care survey](#) to monitor the views and experiences of people who use services. In 2014, 65% of people who responded said they were either extremely or very satisfied with the care and support they received. However, only 32% reported that they had as much control as they wanted over their daily life, 19% said they had some, but not enough, control and 5% had no control at all.

Local authorities, voluntary and community organisations and other care providers use a range of approaches to find out what people who use their services think of them. This data, in turn, supports decision making. The methods used can include providing information and decision support materials, advocacy, outreach and service evaluation activities.

3.3 Policy, legislation and regulation

Policy

Increasing people's control and choice over the services they use, and ensuring their views and experiences inform service design and planning, have become the central principles of social care policy. In [Putting people first](#) the government outlined how people who use services and their carers should be involved in planning and managing their own support.

National and local policy has shifted towards 'personalised' or 'person-centred' approaches.

This involves tailoring support to the person's needs and preferences. For example, by providing them with information and advice to enable them to make choices about their care. It also involves working with them, their families, carers and communities to 'co-produce' the services they use, rather than treating them as passive recipients of care.

Legislation and regulation

The principles of user-focused service provision are enshrined in the [Care Act 2014](#). Under the Act, it is the duty of local authorities to support the wellbeing of people who use services and their carers. Wellbeing is defined as including:

- personal dignity
- physical and mental health
- control by the person over day-to-day life
- participation in work, education, training or recreation
- emotional, social and economic wellbeing
- domestic, family and personal relationships
- the person's contribution to society.

The Act also requires local authorities to have regard to the person's views, wishes, feelings and beliefs.

People's views and experiences provide vital information about how well the services they use are meeting their needs and supporting their goals.

Commissioners and providers can use this data as evidence about how well a service is performing, and where it may need to change.

4 Further information

This is the final scope, incorporating comments from registered stakeholders during consultation.

The guideline is expected to be published in January 2018.

You can follow progress of the [guideline](#).

Our website has information about how [NICE guidelines](#) are developed.