



Department
of Health

Topics for new NICE quality standards and guidance to improve the quality of social care

Summary of consultation responses and outcomes

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Topics for new NICE quality standards and guidance to improve the quality of social care

Summary of consultation responses and outcomes

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Introduction

The National Institute for Health and Care Excellence (NICE) is the independent organisation responsible for providing guidance and quality standards for health and social care in England. Evidence-based guidance and other products from NICE help resolve uncertainty about best quality care and what represents value for money. The 2012 Health and Social Care Act, establishes it in primary legislation as an England only body and extends NICE's remit to adults' and children's social care

NICE guidance supports health and care professionals and others to make sure that the care they provide is of the best possible quality and offers the best value for money.

NICE guidance is for the NHS, local authorities, social care staff, charities, and anyone with a responsibility for commissioning or providing healthcare, public health or social care services. They also support these groups in putting this guidance into practice.

NICE does not decide on the topics for their guidance and standards. Instead, topics are referred to them by the NHS Commissioning Board for clinical topics and Department of Health in collaboration with the Department for education for social care based topics.

The Department of Health (DH) ran a consultation from 01st February 2013 to 03rd May 2013 as a way of identifying potential future topics for quality guidance/standards from the people who will benefit from their development and implementation. This includes commissioners, providers, front line staff, service users and carers.

The DH received over 270 responses to this consultation, from a variety of sources, including individual service users, Local Authorities, regional/local disability groups, charities, regional Clinical Commissioning Groups, and many more.

This report highlights the responses that were received and explains what the DH's next steps are for this work.

The Consultation

What we asked and why

1. NICE, work in collaboration with a 'social care external network' and a group of social care fellows. The external network is made up of leading National organisations in social care and the social care fellows who are professionals who advise and support NICE in the development of work in this area.
2. Part of the consultation was based on a list of potential topics for guidance and quality standards produced by NICE in collaboration with both groups. The list was for topics that they could work on from 2015 onwards to help improve quality in social care.
3. They considered areas where guidance/standards would be beneficial to the topic, the existing evidence-based guidance that could be used for the topics and social care priorities and pressures.
4. See Annex A for this list.

How the consultation was run

5. The first stage of the consultation was an on-line survey, seeking views on the initial list mentioned above of potential future quality standards and any ideas for new social care topics that weren't listed. The questions asked in the survey were as follows:

Q1. Do you agree with the initial list of future quality standards proposed in the consultation document (Annex A)?

Q2. Which ones do you disagree with?

Q3. Why do you disagree with the topic/s?

Q4. Are there any titles/topics that should be amended and in what way?

Q5. Are there any potential equality issues with these topics that may affect a particular protected characteristic group?

Q6. Are there any other topics you would like to see considered that aren't in the list?

Q7. What are the reasons for your suggestions?

6. The second stage of the consultation, which ran alongside the first, was active engagement with the sector, taking place from February to April. These sessions were held in conjunction with NICE and were focussed exploratory discussions based on the consultation questions.

Your Response

What you told us

7. This section is an overview of the questions asked during the consultation and the answers given.

Q1. Do you agree with the initial list of future quality standards proposed in the consultation document?

Yes	203
Some	62
No	7
Not answered	7

95% of respondents agreed with all or some of the proposed list

Q2. Which options do you disagree with? The number of respondents that commented on each option. They did not all disagree.

None	3
Continuing care	16
Deprivation of liberty safeguards	16
Falls	11
Homelessness	9
Substance misuse	12
Learning disabilities	11
Medicines management in home-based settings	15
Pain management	10
Pressure sore care	8
Promoting continence	7
Reablement	13
Service user experience	17
Sexuality, sexual identity and intimacy within the context of social care	12
Social isolation	14
Young carers	11

Attachment and permanence	14
Not answered	211

Q3. Why do you disagree with the topics? Below is a sample of the responses:

- Deprivation of liberty safeguards - there is a piece of work already being done by DH and Social Care Institute for Excellence now looking at developing some quality indicators.
- Substance misuse - This subject needs focus, not just on younger people, but also the impact of substance misuse, particularly alcohol, on older adults as well.
- Learning disabilities is such a large area that you may want to break it down.
- Medicines management in home based settings should not only be about pain management.
- General - Some need to be broader topics
- Carers - During consultation meetings Carers UK argued that the best approach to ensuring quality standards take into account carers' needs was to ensure that carers were mainstreamed into all the topic areas.

Q4. Are there any titles/topics that should be amended and in what way? Below is a sample of the responses:

- Child maltreatment is a very broad topic and the language is American. Would benefit from being broken down.
- Homelessness - A definition is required in order to develop a scope for interventions and quality standards; young people at risk of homelessness may be a particular important group to look at.
- Reablement to include the promotion of independence following a hospital stay
- Social isolation - there is evidence that those people who live most isolated in their communities are least likely to be in contact with services including social care; this is why this should be amended to include people who are not currently using social care
- General comment - as this is a new aspect to NICE I think the topics to start with are appropriate.
- Where care homes are mentioned this should be extended to 'all types of accommodation-based care and support' and where care is mentioned this should be extended to 'care & support'.

Q5. Are there any potential equality issues with these topics that may affect a particular protected characteristic group? Below is a sample of the responses:

- Cultural issues and language barriers are a must to be considered when undertaking each and all topics.

- Older age and alcohol misuse does not seem to currently be a priority in social care yet social care workers see its impact every day.
- Young carers need to be identified - usually schools are the first organisations to realise there are problems at home.
- Each topic needs to be considered against the various equality issues that any one user might face.

Q6. Are there any other topics you would like to see considered that aren't in the list?

Topic	Further Explanation given by those responding
Prevention of child sexual exploitation	<ul style="list-style-type: none"> • Preventing children from being exploited in their communities
Equality	<ul style="list-style-type: none"> • Equality in practice • Equality in mental health
Promoting independence	<ul style="list-style-type: none"> • Promoting independent living for adults through improved housing and related housing services • Warm and safe homes - Preventing functional decline and promoting wellbeing for adults in the community • Prevention of the development of or escalation of needs • Healthy Living and Diet in the Prevention of Illnesses
Staff	<ul style="list-style-type: none"> • In order to promote better outcomes for people requiring care Professional competency must be considered. • Care skills should be taken as a vital component in the delivery of care. NICE quality standards could be used as the medium by which improvements in professional competency can be achieved.
End of Life Care	<ul style="list-style-type: none"> • Care at end of life - Residential and nursing homes and domiciliary care agencies are both big providers of this care, and their interface with health services is a very grey area and anything to build on the initiatives already starting would be great.
Mental Capacity Act	<ul style="list-style-type: none"> • MCA application; best interest decisions • Compliance with MCA generally
Complaints	<ul style="list-style-type: none"> • Complaints handling: The key theme which emerged out of the Francis Report was the importance of complaints handling and the dangers if complaints are unresolved. • We recommend that NICE create guidance on the proper response to complaints, including learning and service improvement and how this can be integrated into providers daily work
Activities	<ul style="list-style-type: none"> • Social activities programme. • Purposeful engagement and meaningful occupation.

	<ul style="list-style-type: none"> • Activities in care and nursing homes/domiciliary care
Mental health	<ul style="list-style-type: none"> • People with mental health issues who need social care support. • 'Mental health of adults and young people in residential care' • The majority of mental health services are delivered in a community setting and the interplay between health and social care needs is complex and often impossible to separate one from the other.
Carers	<ul style="list-style-type: none"> • Carers and employment. • Carers in general or perhaps one on respite care • Support for carers • Promoting the well-being of adult carers
Assistive Technology	<ul style="list-style-type: none"> • The use of assistive technology especially for people with long term conditions.
Advice, Information and Advocacy	<ul style="list-style-type: none"> • We propose a quality standard on 'advice, information and advocacy' - very relevant to both the Draft Care and Support Bill and in promoting good access to help and advice for people seeking care and support whether they pay for their care or not.
Older People	<ul style="list-style-type: none"> • Various themes related to older people e.g. sleep, living well with cognitive impairment
Care of patients with Specific Clinical Conditions	<ul style="list-style-type: none"> • No Additional comments given
Integration/Joint Working	<ul style="list-style-type: none"> • Integration of budgets, joint working and continuous care plans. • Liaison between social care and health including children. • Coordinated care
Housing	<ul style="list-style-type: none"> • Housing for people with disabilities. • Housing as an impact on health - Managing the health and well-being of People in poor accommodation
Restraint	<ul style="list-style-type: none"> • Use of restrictive physical intervention. While this will need to be considered in relation to the standard on deprivation of liberty, we believe that it warrants separate consideration.
Risk Taking	<ul style="list-style-type: none"> • Guidance from NICE that specifically looks at balancing the rights of the service user to take risks that understands and provides proportionate protection of the paid carer/organisation who supports the right of the individual to make a 'wrong decision'.
Nutrition	<ul style="list-style-type: none"> • Improving nutrition for people in care homes and in the community; dignity and nutrition;
People with sensory disabilities	<ul style="list-style-type: none"> • People with sensory impairments need additional support • Including how to care for people who have both sensory and cognitive impairment.
Physical disabilities	<ul style="list-style-type: none"> • Physical disabilities, housing and support, employment • Social care support in the community for people with serious

	physical disabilities
Personalisation	<ul style="list-style-type: none"> • Personalisation, self-directed support and eligibility for social care. • Assessment and support planning in relation to personalisation

Q7. What are the reasons for your suggestions? Below is a sample of the responses:

- The use of assistive technology especially for people with long term conditions- this is a massive area and one where health and social care can work together to use this as tool to prevent use of services.
- Promoting Independence - need for wider approach to support and care incl. all forms of accommodation based care and move away from defining people by conditions towards recovery and promoting independence
- Mental health is a hugely important and very 'live' issue, especially the interface with adult social care

8. This is a breakdown of the groups that responded to the consultation. A full list of who organisations/charities that responded can be found at Annex B

Local authority	41	15%
Joint Local Authority/NHS	2	0.7%
NHS commissioner	12	4%
NHS provider	53	19%
Professional organisation	9	3%
Service user	6	2%
Carer	9	3%
Private sector	39	13.5%
Academia	10	4%

Voluntary sector	56	20%
Other	40	14%
Total	277	

The Decision

What we chose and why

9. Below is the list of topics that came out of the consultation. Over the last 8 months we have been working closely with NICE, the Department for Education, the Home Office and our DH colleagues to consider these topics and if they should be referred to NICE to work on.
10. As part of these discussions we have considered what work was already in place or being produced by NICE in the Public Health and Health fields and whether the social care topic could be incorporated for a more integrated approach. We also had to look at what guidance/standards already exist in the sector and therefore the value of producing NICE quality guidance/standards as well. Our conclusions can be seen in the grid below.
11. The topics in highlighted in bold in the grid are the first group that will be referred to NICE to work on from 2015 onwards. The titles have been altered to reflect comments received via the consultation.

Topic	Decision on Topic
Continuing care	It was decided between NICE and the DH, that work on this topic would not add value to the already existing extensive guidance.
Deprivation of liberty safeguards	Further investigation/engagement required on the potential of this topic
Falls	“Falls: regaining independence in older people who experience a fall” will be referred to NICE as a topic for them to work on in the future
Homelessness	An existing public health referral on marginalised groups may include homelessness through scoping. Depending on the outcome of the scoping process, this topic could be revisited.
Substance	Further investigation/engagement required on the potential of this topic

misuse	
Learning disabilities	“Care and support of older people with learning disabilities” will be referred to NICE as a topic for them to work on in the future
Medicines management in home-based settings	“Medicines management: managing the use of medicines in community settings for people receiving social care” will be referred to NICE as a topic for them to work on in the future
Pain management	NICE will consider building pain management in social care into a topic on “persistent pain in young people and adults” that they are already working on
Pressure sore care	Further investigation/engagement required on the potential of this topic
Promoting continence	Further investigation/engagement required on the potential of this topic
Reablement	“Regaining independence: short term interventions to help people to regain independence” will be referred to NICE as a topic for them to work on in the future
Service user experience	“Service user and carer experience: service users and carer experience of social care” will be referred to NICE as a topic for them to work on in the future
Sexuality, sexual identity and intimacy within the context of social care	Further investigation/engagement required on the potential of this topic
Social isolation	This topic will be considered in the review of the existing NICE public health quality guidance on social and emotional wellbeing in older people. There is potential to expand the topic to cover social isolation more fully
Young carers	This topic will be considered alongside adult carers (see carers)
Attachment and permanence	This topic has already been referred to NICE by the Department for Education as “Children's attachment: attachment in children and young people who are adopted from care, in care or at high risk of going into care”. The final draft of this scope is available at: http://www.nice.org.uk/guidance/index.jsp?action=download&o=66022
Prevention of child exploitation	This will be considered by NICE in Scoping discussion for a topic on “The identification and management of young people at risk of sexually harmful behaviour” alongside the existing social care referral on child abuse and neglect
Equality	Equality is considered in the production of all quality standards/guidance so an individual topic in this area is not required
Promoting independence	Further investigation/engagement required on the potential of this topic
Staff	Further investigation/engagement required on the potential of this topic
End of Life Care	End of Life Care in social care will be incorporated in the clinical standard when it is revisited

Mental Capacity Act	Further investigation/engagement required on the potential of this topic
Complaints	This was not considered as an appropriate topic for quality guidance due to existing legislation and guidance
Activities	There is already a lot of useful guidance in existence and NICE quality guidance/standards would not add value
Mental health	Further investigation/engagement required on what this topic might include as mental health is such a big area topic on its own
Carers	“Service user and carer experience of social care” will be referred to NICE as a topic for them to work on in the future Carers will also be considered in all relevant social care topics
Assistive Technology	NICE will build this topic into other relevant guidance/standards and also into their technology appraisal topics
Advice, Information and Advocacy	NICE will build this topic into other relevant guidance/standards rather than it being a separate topic
Older People	This is too large as a single topic so is being considered within various other topics such as the “Mental wellbeing of older people” and ‘older people with learning disabilities’ as mentioned above
Care of patients with Specific Clinical Conditions	Clinical quality standards already consider all aspects of the specific conditions
Integration/Joint Working	Further investigation/engagement required on the potential of this topic
Housing	Further investigation/engagement required on the potential of this topic with links to learning disabilities
Restraint	Further investigation/engagement required on the potential of this topic
Risk Taking	Further investigation/engagement required on the potential of this topic
Nutrition	Further investigation/engagement required on the potential of this topic
People with sensory disabilities	Further investigation/engagement required on the potential of this topic
Physical disabilities	Further investigation/engagement required on the potential of this topic
Personalisation	This is being considered as a care planning topic but further investigation/engagement required on the potential of this topic

What Next

What Next

12. The first set of five topics that have come out of the consultation will be formally referred to NICE in January 14. They will then add them to their social care work plan.
13. We will continue to work with NICE etc. on the other topics from the list to determine whether they are suitable for referral or not. We will have another group of topics ready for referral by March 2015.

Annex A

(Proposed) Short title	Long title
Continuing care	Managing the health and social care needs of people ¹ whose care is funded by the NHS in care homes and the community ²
Deprivation of liberty safeguards	Protecting adults who do not have the ability to make decisions about their care from being inappropriately deprived of their liberty in care homes and hospitals
Falls	Reducing and managing falls in adults in care homes and the community ²
Homelessness	Supporting the health and social care needs of people ¹ who are homeless
Substance misuse	Supporting children and young people, and their families, dealing with substance misuse in the community ²
Learning disabilities	Supporting the social care needs of people ¹ with learning disabilities in care homes and the community ²
Medicines management in home-based settings	Supporting adults to manage their pain in the community ²
Pain management	Managing pain for people ¹ in the community ²
Pressure sore care	Preventing and managing pressure sores in adults in care homes and the community ²
Promoting continence	Promoting continence and managing incontinence in adults in care homes and the community ²
Reablement	Promoting independence in adults following deterioration in health or increase in support needs in care homes and the community ²
Service user experience	Improving the experience of care for people ¹ using social care services in care homes and the community ²
Sexuality, sexual identity and intimacy within the context of social care	Respecting sexuality, sexual identity and intimacy needs in adults and young people in care homes and the community ²
Social isolation	Preventing social isolation for people ¹ who use care services in the community ²

Young carers	Promoting wellbeing in children and young people who provide care to a family member in the community ²
Attachment and permanence	Promoting permanence for adopted children and all children with attachment disorder issues across health and social care

1 People = adults, children and young people

2 Community = people's own homes and community based activities

Annex B

Detailed list of Organisation/charities that completed the consultation

2gether NHS Foundation Trust	Dudley MBC	London Borough of Richmond upon Thames	SCA Hygiene Products
ABMU Health Board	East Quay Medical Centre	MacIntyre	Scope
Acromas Healthcare (inc Allied HC Saga Homecare , Nestor HC, Primecare)	EDI	Marie Curie Cancer Care	Sheffield Clinical Commissioning group
Action on Hearing Loss	Extra Choices in Herefordshire Ltd	Mears	SignHealth
Alzheimer's Society	FASD Network www.fasdnetwork.org	Medacs Healthcare	Skills for Care
Anchor Trust	Friends, Families and Travellers	Mind	Social Care Institute for Excellence (SCIE)
Archer Business Solutions	Gateshead Carers Association	MITIE Healthcare Solutions	Society for Endocrinology
Association Living with voices (Dutch) and Intervoice (International)	GlaxoSmithKline	Motor Neurone Disease Association	South Devon and Torbay CCG
Association of Directors of Adult Social Services (ADASS)	Gloucestershire Care Services NHS Trust	Multiple Sclerosis Trust	South Essex Partnership University Trust Foundation
Astellas Pharma Ltd.	Gloucestershire County Council	Napier University	Southern Health NHS Foundation Trust
B&NES Council	GMB	National Association for Providers of Activities	Southern Healthcare (Wessex) Ltd
BCUHB	Greater Manchester Neurosciences Network	National Children's Bureau	Staffordshire & Stoke on Trent Partnership Trust
Berkshire Healthcare Foundation Trust	green trees care home	National Family Carer Network	Stoke on Trent College
Birmingham women's hospital	Guideposts Trust	National LGB&T Partnership	Stoke-on-Trent City Council - People, Adults & Neighbourhood Services
Blackpool Teaching Hospitals NHS Foundation Trust	Guy's and St Thomas' NHS Foundation Trust	National Sensory Impairment Partnership	Sussex Partnership NHS Foundation Trust

Boars Tye Residential Home	Hackney Council Adult Social Care	Newbury College	Sutton Community Transport
Borough of Poole	Hampshire County Council Adult Services Department	Newcastle upon Tyne Hospitals NHS Foundation Trust	Teenagers and Young Adults with Cancer
Bournemouth People First	Heritage manor limited	NFOP	Tees Valley Alliance
Bradford Teaching Hospitals NHS Foundation Trust	Hertfordshire Partnership NHS Foundation Trust	NHS Clinical Commissioning Group	The Avenues Group
Brighton and Hove City Council	Hip Impact Protection	NHS greater Glasgow and Clyde	The Disabilities Trust
Bristol Community Health	HME Ltd	NHS Plymouth	The Hesley Group
Bristol Urological Institute	Homeless Link,	NHS Suffolk	The Lesbian & Gay Foundation
British Psychological Society	Hounslow & Richmond Community Health NHS Trust	NHS Walsall - Medicines management	The Loddon Training & Consultancy
BS Social Care	Humberside Fire and Rescue Service	Norfolk Coalition of Disabled People.	The Mental Health Foundation
BSN medical	Inclusion London	North Somerset Council	The National Deaf Children's Society (NDCS)
Bury Council	Independent Consultant Jan-Net Ltd	Northamptonshire County Council	The Newcastle upon Tyne Foundation Trust
Cardonald College Glasgow/ Glasgow City Council	Isle of Wight community worker	Northern Pensioners Association Crewe & District	The Stroke Association
Care & Repair England	Jan-Net Ltd	Nottinghamshire County Council	The Vegan Society
Care Plus Group (social enterprise NE Lincs)	Joint Commissioning Unit	NUH NHS Trust	Tilda Goldberg Centre, University of Bedfordshire
Care Quality Commission	Keele university	Optima care	Tomms Pharmacy
Carers Trust	Kent community health NHS trust	Oxfordshire County Council	Torbay Council/Torbay & Southern Devon Health & care trust
Carers UK	Kent County Council – Social Services Research Group	Paediatric Continence Forum	Transformation Assembly
Central London Community Healthcare	King's College Hospital	Peninsula Community Health	TrueCall Ltd
Central Manchester university hospitals	Kirklees PCT and Yorks and Humber	Pennine care currently	Turning Point

NHS FT	Deanery		
Chelsea and Westminster Hospital	Lancashire Care Foundation Trust	Personal Social Services Research Unit	Tytext UK
Cheshire West and Chester Borough Council	Lancashire Care NHS Trust	Peterborough and Stamford Hospitals NHS Foundation Trust	United Kingdom Homecare Association (UKHCA)
College of Occupational Therapists	Leeds City Council / NHS Leeds	Play Therapy UK	University College London
Countess of Chester NHS Foundation Trust	Leonard Cheshire Disability	Plymouth City Council	University of Southampton
County Durham & Darlington NHS FT	Lewisham Healthcare Trust	Public Health Dorset	University of Technology, Sydney
Coverage Care	Linkage Community Trust	Real Life Options	Verulam House Residential and Nursing Home
Derbyshire Community Health Services NHS Trust	Local Council and The R A F A Hon Welfare Officer North Devon.	Relationships Alliance	Virgin Care
Derbyshire Healthcare Foundation Trust	London borough of Camden social services	Rethink Mental Illness	Wandsworth Council
Devon Senior Voice(Teignmouth Branch)	London Borough of Enfield	Royal Borough of Kingston	West Sussex Adults' Services Customer & Carer Group
Dimensions UK Ltd	London Borough of Hackney - Adult Social Care	Royal College of Nursing	West Sussex County Council
Disabled Living	London Borough of Newham	RUILS	Wirral Community Trust
Disclosure and Barring Service	Mencap	Salisbury Healthcare NHS Trust	Wirral Older People's Parliament
Oxfordshire Clinical Commissioning Group	WSSCC Adults social worker	YoungMinds	People With Learning Disabilities (UK).
Your Voice Counts	Stockton Borough Council	The Law Society of Scotland	Talk 2 Us
English Community Care Association's	Local Government Ombudsman's	Parkinson's UK	Optical Confederation
Macmillan Cancer Support	NHS Confederation	Standing Commission on Carers	Royal National Institute of Blind People