

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

Supporting decision-making for people who may lack mental capacity

Topic

The Department of Health in England has asked NICE to develop a guideline on supporting decision-making for people aged 16 and over¹ who may lack mental capacity.

The guideline will help health and social care practitioners who are supporting people who may lack capacity to make decisions about their health and social care needs. This may include decisions about where and how people live, their support, care and treatment and their security or safety.

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

- People using services who may (now or in the future) lack mental capacity, and their families and carers.
- Health practitioners working with people who may lack mental capacity.
- Social care practitioners (including personal assistants) working with people who may lack mental capacity.
- Advocates, including independent mental capacity advocates and independent mental health advocates.

¹ The definition of adults includes young people aged 16 and 17 years because they are covered by most aspects of the Mental Capacity Act (2005).

26 The guideline will also be relevant for:

- 27 • Practitioners working in services who may come into contact with people
- 28 who lack mental capacity, including housing, education, employment,
- 29 police and criminal justice services.
- 30 • Local authorities and clinical commissioning groups.
- 31 • Community and voluntary organisations representing or supporting people
- 32 who may lack mental capacity, and their families and carers.

33

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

37 ***Equality considerations***

38 NICE has carried out an equality impact assessment during scoping. The
39 assessment:

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

42 The guideline will look at inequalities relating to:

- 43 • people who may lack mental capacity and who also have a sensory,
- 44 cognitive or physical impairment
- 45 • people with mental health problems, including those subject to the Mental
- 46 Health Act
- 47 • people detained under the Mental Health Act, who are subject to
- 48 Deprivation of Liberty Safeguards (DoLS) or are under court order
- 49 • people with communication difficulties
- 50 • people with complex needs and long-term conditions
- 51 • people at risk of self-neglect
- 52 • people for whom English is a second or additional language
- 53 • people who do not have support from family members

- 54 • young people (aged 16 and 17 years) who may lack mental capacity, as
55 practitioners may not be aware that they are covered by the Mental
56 Capacity Act
- 57 • young people and young adults aged up to 25 years who may lack mental
58 capacity and are making a transition from children's to adults' services.

59 **1 What the guideline is about**

60 **1.1 *Who is the focus?***

61 **Groups that will be covered**

62 All people aged 16 years and over who may lack the capacity to make
63 decisions about their care, support or treatment now and in the future. Lack of
64 mental capacity can fluctuate, and may be associated with:

- 65 • a stroke or brain injury
- 66 • a mental health problem
- 67 • dementia or other neurodegenerative illness
- 68 • a learning disability
- 69 • autism
- 70 • confusion, drowsiness or unconsciousness because of an acquired injury,
71 illness or its treatment
- 72 • substance misuse.

73 **Groups that will not be covered**

- 74 • Children aged under 16 years who lack the capacity to make decisions
75 their care, support or treatment.

76 **1.2 *Settings***

77 **Settings that will be covered**

78 Any settings where health and social care practitioners support decision-
79 making by people who may lack mental capacity.

- 80 • Community settings.
- 81 – The person's own home.

- 82 – Extra care, supported housing, shared lives.
- 83 – Primary healthcare, outpatients and day hospitals.
- 84 • Care homes of any type (including specialist homes).
- 85 • Inpatient settings.
- 86 – Secondary and acute healthcare settings.
- 87 – Mental health inpatient settings.
- 88 • Hospices and palliative care settings.
- 89 • Educational settings.
- 90 • Criminal justice settings, including prisons.
- 91 • Family courts.

92 **1.3 Activities, services or aspects of care**

93 We will look at evidence on the areas listed below when developing the
94 guideline, but it may not be possible to make recommendations on all the
95 areas.

96 **Key areas that will be covered**

- 97 1 Supporting people who may lack capacity, or have been assessed as
98 lacking capacity, to make decisions about:
 - 99 – where they live
 - 100 – personal choices about how they live, including relationships
 - 101 – day to day decisions about daily living
 - 102 – care and support
 - 103 – treatment options
 - 104 – decisions on diagnostics and devices
 - 105 – safety and risk management.
- 106 2 Support for people to plan in advance for decision-making should they
107 lose capacity, especially if they have a condition likely to cause changes
108 in mental capacity.
- 109 3 Interventions, tools and approaches to support people, on the
110 presumption of capacity, to make decisions for themselves wherever
111 possible, including:
 - 112 – how to provide information

- 113 – how to involve family members, carers and other people interested in
114 the person's welfare, with the person's consent.
- 115 4 Approaches to assessment of mental capacity, including:
116 – when assessment should be considered
117 – who should carry out assessment
118 – methods and tools for assessment.
- 119 5 Interventions, tools and approaches to support making best interests
120 decisions on behalf of people who have been assessed as lacking
121 capacity to make a particular decision, including:
122 – how to maximise the person's involvement in making the decision
123 – approaches to determining what is in the person's best interests
124 – ways of identifying family members, carers and other people
125 interested in the person's welfare, and supporting them to participate
126 in decision-making
127 – approaches to providing independent advocacy (independent mental
128 capacity advocates, independent mental health advocates or Care Act
129 advocates) for the person
130 – how to use DoLS as required
131 – safeguarding in the context of supporting decision-making, including
132 consideration of unwise decision-making and risk, and in relation to
133 best interests decision-making.

134 **1.4 Economic aspects**

135 We will take economic aspects into account when making recommendations.
136 We will develop an economic plan that states for each review question (or key
137 area in the scope) whether economic considerations are relevant, and if so
138 whether this is an area that should be prioritised for economic modelling and
139 analysis. We will review the economic evidence and carry out economic
140 analyses, using an individual and societal perspective, as appropriate.

141 **1.5 Key issues and questions**

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

- 144 1 Planning in advance.
- 145 1.1 What interventions, tools and approaches are effective and cost-
- 146 effective in supporting advanced planning for decision-making for people
- 147 who may lack mental capacity?
- 148 1.2 What are the views and experiences of people who may lack mental
- 149 capacity, their families and carers and others interested in their welfare,
- 150 on the acceptability of interventions, tools and approaches to support
- 151 planning in advance for decision-making?
- 152 2 Supporting decision-making on the presumption of mental capacity
- 153 2.1 What interventions, tools and approaches are effective and cost-
- 154 effective in supporting people, on the presumption of capacity, to make
- 155 decisions?
- 156 2.2 What are the views and experiences of people who may lack mental
- 157 capacity, their families and carers and others interested in their welfare
- 158 on the acceptability of interventions, tools and approaches to support
- 159 people, on the presumption of capacity, to make decisions?
- 160 3 Assessment of mental capacity
- 161 3.1 What interventions, tools and approaches are effective and cost-
- 162 effective in supporting the assessment of mental capacity?
- 163 3.2 What are the views and experiences of people who may lack mental
- 164 capacity, their families and carers and others interested in their welfare
- 165 on the acceptability of interventions, tools and approaches to support the
- 166 assessment of mental capacity?
- 167 4 Supporting decision-making for those who have been assessed as
- 168 lacking mental capacity to make a particular decision
- 169 4.1 What interventions, tools and approaches are effective and cost-
- 170 effective in supporting decision-making for people who have been
- 171 assessed as lacking capacity?
- 172 4.2 What are the views and experiences of people who may lack mental
- 173 capacity, their families and carers and others interested in their welfare
- 174 on the acceptability of interventions, tools and approaches to support
- 175 decision-making for people who have been assessed as lacking
- 176 capacity?

177 **1.6 Main outcomes**

178 The main outcomes that will be considered when searching for and assessing
179 the evidence are:

180 1 Person-focused outcomes.

181 – People being enabled to make decisions about their own lives and in
182 their best interests.

183 – People being safe.

184 – Dignity, human rights and rights under the [Mental Capacity Act 2005](#).

185 – Independence and social inclusion.

186 – Use of least restrictive options where some degree of deprivation of
187 liberty is required.

188 2 Service outcomes.

189 – Competence and confidence of practitioners to uphold the principles
190 of the [Mental Capacity Act 2005](#) and the [Care Act 2014](#).

191 – Transparency and quality of recording.

192 – Efficient use of resources.

193 **2 Links with other NICE guidance, NICE quality** 194 **standards and NICE Pathways**

195 **2.1 NICE guidance**

196 **NICE guidance about the experience of people using NHS services**

197 NICE has produced the following guidance on the experience of people using
198 the NHS. This guideline will not include additional recommendations on these
199 topics unless there are specific issues related to supporting people who may
200 lack mental capacity.

201 • [Patient experience in adult NHS services](#) (2012) NICE guideline CG138

202 • [Service user experience in adult mental health](#) (2011) NICE guideline
203 CG136

204 • [Medicines adherence](#) (2009) NICE guideline CG76

205 **NICE guidance that is closely related to this guideline**

206 ***Published***

207 NICE has published the following guidance that is closely related to this
208 guideline:

- 209 • [Medicines optimisation: the safe and effective use of medicines to enable](#)
210 [the best possible outcomes](#) (2015) NICE guideline NG5
- 211 • [Care of dying adults in the last days of life](#) (2015) NICE guideline NG31
- 212 • [Developing and updating local formularies](#) (2014) NICE guideline MPG1
- 213 • [Managing medicines in care homes](#) (2014) NICE guideline SC1
- 214 • [Service user experience in adult mental health; improving the experience of](#)
215 [care for people using adult NHS mental health services](#) (2011) NICE
216 guideline CG136
- 217 • [Dementia: supporting people with dementia and their carers in health and](#)
218 [social care](#) (2006) NICE guideline CG42

219 ***In development***

220 NICE is currently developing the following guidance that is closely related to
221 this guideline:

- 222 • [Transition between inpatient mental health settings and community and](#)
223 [care home settings](#) NICE guideline. Publication expected August 2016
- 224 • [Mental health problems in people with learning disabilities](#) NICE guideline.
225 Publication expected September 2016
- 226 • [Dementia: assessment, management and support for people living with](#)
227 [dementia and their carers](#) (update) NICE guideline. Publication expected
228 September 2017
- 229 • [Care and support of older people with learning disabilities](#) NICE guideline.
230 Publication expected May 2018
- 231 • [Supportive and palliative care in adults](#) (update) NICE guideline.
232 Publication expected January 2018

- 233 • [People's experience in adult social care services: improving the experience](#)
234 [of care for people using adult social care services](#) NICE guideline.

235 Publication expected January 2018

236 **2.2 Related NICE quality standards**

- 237 • [Medicines optimisation](#) (2016) NICE quality standard 120
238 • [Medicines management in care homes](#) (2015) NICE quality standard 85
239 • [Dementia: independence and wellbeing](#) (2013) NICE quality standard 30
240 • [Service user experience in adult mental health services](#) (2011) NICE
241 quality standard 14
242 • [Dementia: support in health and social care](#) (2010) NICE quality standard 1

243 **2.3 NICE Pathways**

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

247 A draft pathway outline on decision making for people who may lack capacity,
248 based on the draft scope, is included below. It will be adapted and more detail
249 added as the recommendations are written during guideline development.

250 Links to other relevant NICE guidelines and pathways will be included.

Decision-making for people who may lack mental capacity overview



251

252 3 Context

253 3.1 Key facts and figures

254 This guideline is about supporting decision-making for people who may lack
 255 the capacity to make specific decisions about their care and support. People
 256 may lack capacity to make decisions or participate in decision-making for a
 257 number of reasons. Lack of mental capacity may be a temporary result of
 258 illness, treatment or substance abuse, or an ongoing organic impairment,
 259 such as dementia, severe learning disability or brain injury.

260 The [Care Quality Commission](#) estimates that around 2 million people in
 261 England and Wales may lack the capacity to make certain decisions for
 262 themselves at some point due to illness, injury or disability. Many of these
 263 people will be supported to make those decisions, or have best interests
 264 decisions taken on their behalf, as part of their routine care and support. A

265 smaller number require specific supports and safeguards in relation to mental
266 capacity.

267 The [Independent Mental Capacity Advocacy Service: 7th annual report](#) states
268 that 13,301 referrals were received in 2013/14: more than double the number
269 in 2007/2008. The majority of referrals (64%) were for adults aged 66 and
270 over. The most common mental impairments associated with a referral to the
271 Independent Mental Capacity Advocacy service were dementia (42%),
272 learning disability (20%) and mental health problems (13%).

273 Similarly, [Health and Social Care Information Centre statistics](#) report that
274 there has been a year-on-year increase in applications to local authorities for
275 deprivation of liberty under the DoLS since their introduction in 2009–10, with
276 11,877 applications made in 2012–13. The majority of applications (71%) in
277 2012/13 were completed on behalf of people with mental health conditions,
278 with dementia accounting for more than half (54%).

279 It is difficult to estimate the costs of supporting decision-making people who
280 may lack mental capacity, particularly as many of the costs will be embedded
281 in the overall provision of support and services. Some research (Shah et al.
282 Deprivation of Liberty Safeguards in England: implementation costs, 2011)
283 suggests that the cost of undertaking a DoLS assessment is higher than the
284 initial government estimate of £600, with an average cost in 5 DoLS offices of
285 £1,266 (95% confidence interval £506 to £2,048). But clearly this relates to
286 only one aspect of practice in this area.

287 **3.2 Current practice**

288 Practice under the [Mental Capacity Act 2005](#) should be underpinned by 5
289 principles:

- 290 • a person should be presumed to have mental capacity unless they are
291 assessed as lacking it in relation to a particular decision
- 292 • all practicable steps must be taken to help the person make the decision
- 293 • a person has the right to make an unwise decision

- 294 • an act done or decision made under the Act or on behalf of the person who
295 lacks mental capacity must be in the person's best interests
- 296 • consideration must be given to achieving the least restrictive means of
297 accomplishing the purpose of the act or decision.

298 A key additional element of practice is applying DoLS if restrictions and
299 restraint used in the best interests of a person who lacks mental capacity will
300 deprive the person of their liberty. Under DoLS, it is illegal to restrict a
301 person's liberty unless authorised by due legal process, which involves either
302 the Court of Protection or, in health and social care settings, the supervisory
303 body, which is the local authority.

304 In 2014 the House of Lords Select Committee on the Mental Capacity Act
305 published its [post-legislative scrutiny report](#). Its key findings were that the
306 Mental Capacity Act is not widely and adequately implemented. In particular:

- 307 • the 'empowering ethos' of the Act has not been widely implemented
308 • the prevailing culture is one of risk aversion and paternalism
309 • the wishes, thoughts and feelings of the person are not routinely prioritised.

310 The Select Committee report suggests that there is a general lack of
311 awareness of the provisions of the Act, as well as of the rights and
312 responsibilities of different stakeholders as conferred under the Act. It also
313 suggests that many practitioners misunderstand the presumption of mental
314 capacity. Particular concern was expressed regarding the assessment of
315 capacity in adults with specific conditions such as Down's syndrome, autism
316 and brain injury.

317 The report also identified that DoLS are frequently not applied when they
318 should be, and that the complexity of the legislation can cause confusion.

319 **3.3 Policy, legislation, regulation and commissioning**

320 **Policy, legislation, regulation and guidance**

321 The [Mental Capacity Act 2005](#), including DoLS (and its accompanying [Code](#)
322 [of Practice](#)), provides the legal framework for acting and making decisions on

323 behalf of people who lack the mental capacity to make decisions for
324 themselves.

325 But, as highlighted by the Select Committee report, practitioners can struggle
326 to implement the provisions of the Act. This guideline aims to provide
327 evidence-based recommendation on how best to apply the Act and Code of
328 Practice, focusing on interventions, practices and approaches that have been
329 shown to be effective.

330 In developing the guideline, we will need be aware that the Law Commission
331 has undertaken a consultation on DoLS, and is expected to publish a report
332 and draft Bill proposing changes to these arrangements in 2016.

333 In developing the guideline we will also need to be aware of the following
334 pieces of legislation:

- 335 • the [Care Act 2014](#), which introduced new legislation to ensure that people's
336 wellbeing and the outcomes that matter to them are at the heart of every
337 decision made. It also introduced new rights to advocacy. The principles of
338 the Care Act could be said to underpin the legislation on supporting
339 decision-making
- 340 • the [Mental Health Act 1983](#) (amended by the [Mental Health Act 2007](#)),
341 which governs the involuntary admission, treatment and detention of
342 people in mental health inpatient settings.

343 Practice in this area is also influenced by international law, including:

- 344 • the UN [Convention on the Rights of Persons with Disabilities](#), article 12 of
345 which sets out the right to legal capacity on an equal basis with others
- 346 • the [European Convention on Human Rights](#), article 5 of which guarantees
347 the right to personal liberty and provides that no-one should be deprived of
348 their liberty in an arbitrary fashion.

349 **Commissioning**

350 People who may lack mental capacity will be supported through a range of
351 commissioning relationships, including:

- 352 • services provided directly by local authorities or the NHS

- 353 • independent sector providers commissioned by local authorities or clinical
354 commissioning groups
- 355 • providers commissioned by people who use services, for example through
356 the use of personal budgets or self-funding.

357 The guideline will need to reflect this range of commissioning relationships.

358

359 **Further information**

This is the draft scope for consultation with registered stakeholders. The consultation dates are 18 May to 15 June 2016

The guideline is expected to be published in July 2018.

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

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

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