Department of Health

No Voice Unheard, No Right Ignored

Key themes from consultation responses

Summary of an independent analysis

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No Voice Unheard, No Right Ignored

Key themes from consultation responses

Prepared by The Evidence Centre, an independent organisation

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Executive summary

Between March and May 2015, the Department of Health asked people and organisations to share their views about strengthening the rights and choices of people to live in the community, especially people with learning disabilities, autism or mental health conditions. This document summarises the main trends in responses to the consultation.

Background

'No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions' asked people and organisations for ideas about how people can:

- be supported to live independently, as part of a community

- be assured that their views will be listened to

- challenge decisions about them and about their care

- have more control over the support they receive using a personal health budget

- think about how health and care services could be arranged around people's needs

- be sure that professionals are helping with both physical and mental health needs

- think about possible changes to the Mental Health Act 1983

The consultation ran between 6 March and 29 May 2015.

Responses

There were 481 responses to the consultation (including all responses received up until 17 June 2015). Some people provided more than one response so these were grouped together, making a total of 468 pieces of feedback. Half of the responses came from individuals or families, and half came from organisations or groups. Most responses from individuals were from service users or family members and carers. Most responses from organisations were from voluntary sector groups, followed by local authorities and the NHS. There was a good spread of responses from different parts of England.

About half of responses addressed questions that the Department of Health asked in a 'full text' version of consultation documents. One third of responses responded to questions asked in an Easy Read version of consultation documents. The rest provided general comments.

Key messages

Table 1 shows what the consultation questions were and the main trends in responses. The questions asked in the full text consultation document were not the same as in the Easy Read version, but the topics were similar so the feedback has been combined.

It is important to remember that each response could represent many different people. For example, some responses were from meetings with many service users and carers. Other responses were from large national organisations. This means that the percentages of responses that agreed or disagreed with each question do not reflect the total numbers of people overall.

Right to be independent and be part of a community

Organisations and individuals thought that:

- NHS organisations that plan and buy services (commissioners) should have the same duty as local authorities under the Care Act to put people's wellbeing at the heart of what they do

- local authorities and the NHS should take into account factors that help people stay in their local communities

- local authorities and the NHS should make sure there are enough community-based support and treatment services

Right to be listened to and challenge decisions

Organisations and individuals thought that:

- people using services and their family, carers or other helpers should be given clear Easy Read or accessible information about their rights

- people should be able to challenge whether professionals have taken into account their wishes if they are going to be admitted to hospital under the Mental Health Act 1983

- people should be able to request a transfer or ask to be discharged, and these discussions should involve professionals based in the community

- a care plan with discharge plan should be required soon after people are admitted

- people who do not have capacity under the Mental Health Act 1983 should be automatically given an independent mental health advocate, on an opt-out basis

- the law could be changed so that people can choose their own 'nearest relative'

- a named social worker should be responsible for working with people and their family to keep them informed

There were mixed views about whether the NHS and local authorities should always have to seek people's consent before they are admitted and whether an approvals process should be used. Responses had mixed views about whether only organisations that include self-advocates and family advocates at a senior level should get contracts with local authorities or the NHS.

Rights under the Mental Health Act 1983

Organisations and individuals thought that:

- the Mental Health Act Code of Practice should apply to NHS commissioners

- it might be useful to have one set of criteria for keeping people in hospital for both assessment and treatment under the Mental Health Act 1983

- police cells should not be used for children or adults with learning disabilities, autism or mental health conditions

There were mixed views about whether the Mental Health Act 1983 should be changed for people with learning disabilities or autism. There were also mixed views about whether professionals other than the police should have the power to take a person from a public place to a place of safety.

Right to a personal budget and possible pooled budgets

Responses said that:

- personal health budgets might be useful for people with learning disabilities or autism

- it would be good to make local health and social care services put their money together to stop people being admitted or help them come out of hospital faster (pooled budgets)

- organisations providing special hospital or other accommodation should have to share information with the NHS and local authorities who are arranging their care

Responsibility for physical health as well as mental health

Responses agreed that it could be clearer which organisations and professionals are responsible for the physical health needs of people in mental health inpatient settings.

Overall impacts

Responses said that the changes in the consultation document that would have the greatest impact on people's lives were increased provision of services in the community, better engagement of service users and families in discussions and joint commissioning between health and social care.

The greatest risks to making change were thought to be a lack of ring-fenced additional funding, a lack of community services to help people stay out of hospital and difficulty aligning health and social care.

Individuals and organisations were positive about the vision of the consultation overall and wanted to continue to be involved as plans developed further.

Table 1: Summary of key trends in answers to consultation questions

Question	Number of responses	% Agree	% Disagree	% Other broad comments
Q1. The Care Act says that local authorities have to put individuals' wellbeing at the heart of what they do. We want to explore whether NHS commissioners should have the same duties, for example, for people with learning disability or autism who are at high risk of long stays in hospital in relation to their lifelong needs. What do you think of this idea?	211	94%	2%	4%
Q2. In determining living arrangements - (whether suitable accommodation or inpatient stays) - both local authorities and NHS commissioner could have to have regard for factors which support inclusion in the community, staying close to home, links with family and friends and opportunities for participation and the least restrictive setting. What do you think of this idea? AND Easy Read Q1. These ideas are trying to help people to be part of the community. Would they help to stop people being sent way from their home and family?	389	90%	6%	4%
Q3. What might the appropriate length of inpatient stay be where this should apply for the NHS?	182	-	-	5% consider for all lengths of stay 15% suggested a timeframe 15% short as possible 65% not appropriate to specify timeframe

Question	Number of responses	% Agree	% Disagree	% Other broad comments
Q4. What are your views on how this might impact on local authorities or the NHS?	163	-	-	Most commonly mentioned benefit was more joint working and co-ordination. Most commonly mentioned negative impact was cost pressure
Q5. We think that local authorities and clinical commissioning groups could have to think about how to ensure there is enough community based support and treatment services (for example for people with learning disability or autism most at risk of going into hospital). What do you think of this idea?	214	90%	4%	6%
Q6. What steps could we take to ensure such a duty is as effective as possible?	185	-	-	Most common suggestion was effective data collection for monitoring and oversight
Q7. What is your view on the likely cost and impact on the NHS or local authorities?	171	-	-	Most commonly mentioned impact was cost
Q8. What do you think about the idea to change the information required by Mental Health Act regulation in the application for detention and supporting medical recommendations?	167	69%	15%	16%
Q9. This would mean that Approved Mental Health Professionals and doctors have to consider and record whether assessment and treatment could be provided without detention in hospital. What is your view on the likely costs and impact of this idea?	161	-	-	Most commonly mentioned impact was cost to develop community alternatives

Question	Number of responses	% Agree	% Disagree	% Other broad comments
Q10. We want to explore whether a person and their family/carer or other nominated person should be given clear, easy read or accessible information by a named professional about their rights. What do you think of this idea? AND Easy Read Q2. These ideas are trying to help people play a full part in their care and make sure the NHS and local authorities listen them. Do you think they will help?	379	93%	2%	5%
Q11. What do you think about the idea that local authorities and NHS bodies should have to seek explicit and documented approval or consent from an individual to admit them to an inpatient setting? This could include a record of discussion around options and risks.	205	76%	19%	5%
Q12. What are your views on the idea of a gateway or approval mechanism for admissions to inpatient settings, in certain circumstances?	147	61%	23%	16%
Q13. What would be the essential elements of such an approval mechanism?	132	-	-	Processes, timing, accountability, participation and provision
Q14. If there were to be such a mechanism, should it be given statutory force?	131	47%	30%	23%
Q15. What do you think of the idea of strengthening (for example in statutory guidance) people's rights to request a transfer to a less restrictive setting or a setting closer to home or to ask for discharge?	191	87%	9%	4%

Question	Number of responses	% Agree	% Disagree	% Other broad comments
Q16. Do you agree that, as far as practicable, such discussions should involve professionals or staff based in the community or expert on community based options?	175	90%	3%	7%
Q17. How can we strengthen provider and commissioner accountability in their approach to such requests?	152	-	-	Pay attention to processes, personnel and accountability
Q18. We want to explore how everyone can receive care planning and discharge planning from the time when they are admitted to hospital. One way we could do this is through new statutory guidance (complementary to the Mental Health Act Code of Practice). What do you think of this idea?	187	65%	16%	19%
Q19. Should we require a care plan, including a plan for discharge, to be produced involving individuals and their family within a specified number of weeks of admission and to specify when it will be reviewed?	176	88%	6%	6%
Q20. Could more be achieved through any existing policies or guidance on delayed discharge?	110	28%	15%	57%
Q21. The Mental Health Act Code of Practice has just been updated. In line with this, we want to explore how people and their families can be more involved. One idea is that people and their families or advocates should be able to challenge whether an Approved Mental Health Professional has properly taken into account their wishes and feelings in the interview which takes place before they make an application for admission under the Mental Health Act. What do you think about this idea? (We would need to consult later on how the details of this process might work.)	178	76%	15%	9%

Question	Number of responses	% Agree	% Disagree	% Other broad comments
Q22. Which if these measures [3 potential options for safeguards around renewal] if any, do you think would have most impact?	102	-	-	15% option 1 27% option 2 45% option 3 13% combination
Q23. Do you have any views on risks or costs presented by any of these options?	73	-	-	Risk of difficulty sourcing professionals leading to additional work, delays and costs
Q24. Do you have any views on the decision making processes around Community Treatment Orders and how they could be improved?	82	-	-	Most common comments focused on involving people in decision-making
Q25. Guidance could say that only organisations that include self and family advocates in their governance should get contracts with the local authority or the NHS to provide services for people with learning disability or autism. What do you think about this idea? AND Easy Read Q3. Do you think that only services that involve people with a learning disability or autism and families running them should get contracts with the local authority or NHS?	320	68%	21%	11%

Question	Number of responses	% Agree	% Disagree	% Other broad comments
Q26. What are your views on making Independent Mental Health Advocates available to patients who lack capacity (or competence) on an opt out basis? AND Easy Read Q4. These ideas are trying to make sure more people get support from families, social workers and advocates called Independent Mental Health Advocates. They have a part to play in people's care and helping them to be listened to. Do you think they will help?	318	88%	7%	5%
Q27. Have we considered all the safeguards we would need to protect patient confidentiality?	103	45%	36%	19%
Q28. What do you think about the idea that we should explore changing the law so that people choose their own "nearest relative" (retaining a hierarchical list to be used if necessary)?	171	73%	20%	7%
Q29. Do you agree that this should reduce the cost of displacement and disputes?	119	55%	45%	-
Q30. A named social worker could be responsible for working with the person and their family to keep them informed and involved and to make sure less restrictive and community based plans are considered. What do you think about this idea?	197	78%	15%	7%
Q31. What else, if anything is needed to support people and families to raise issues if something has gone wrong? AND Easy Read Q5. Do you think anything else is needed to help people speak up is something has gone wrong?	278	-	-	Focus on appropriate processes, personnel, support services and system-level change

Question	Number of responses	% Agree	% Disagree	% Other broad comments
Q32. We are considering whether and how the treatment of learning disabilities and autism under the Mental Health Act could be changed. We have set out three potential options. Which of options 1), 2) and 3), if any seems most appropriate? AND Easy Read Q6. What do you think about the idea of people with learning disability and autism not being sent to hospital under the Mental Health Act or only in a smaller number of situations or only sent if a court sends them?	245	-	-	11% option 1 15% option 2 14% option 3 37% agree to treat people with learning disability or autism differently but no option selected 23% no change needed
Q33. What is your view on the potential risks or unintended consequences of the options?	123	-	-	Fewer safeguards, potential for people to 'fall through cracks', potential for criminalising behaviour
Q34. We want to explore changing the law so that there is one set of criteria for detention for both assessment and treatment under the Mental Health Act (amending sections 2 and 3). What do you think of this idea? AND Easy Read Q7. What do you think about the idea of making the Mental Health Act law easier to understand and follow with one path into hospital for assessment and treatment?	251	79%	17%	4%

Question	Number of responses	% Agree	% Disagree	% Other broad comments
Q35. We think we should clarify in law that the Mental Health Act Code of Practice should apply to clinical commission groups and to NHS England commissioning. What do you think of this idea? AND Easy Read Q8. Do you think we should change the law to make sure that people who plan and buy services for the NHS have to follow the Code of Practice guidance about the Mental Health Act like hospitals do?	260	97%	3%	-
Q36. We highlighted some parts of the Review carried out into the operation of Sections 135 and 136 of the Mental Health Act. What is your view on the proposal that young people aged under 18 detained under section 135 or 136 should never be taken to police cells?	166	88%	10%	2%
Q37. What is your view on the proposal that the use of police cells for those over 18 should be limited more in terms of frequency and length of detention as proposed by the review?	164	92%	1%	7%
Q38. Do you have a view on any other recommendations in the Review? AND Easy Read Q9. These ideas look at how to make things better for people who are being kept safe in police cells of are being help in hospital instead of prison. What do you think?	187	-	-	Comments focused on developing places of safety and providing information and support
Q39. What is your view on the review proposal to create powers for professionals other than the police to be able to take a person from a public place to a place of safety?	139	42%	44%	14%

Question	Number of responses	% Agree	% Disagree	% Other broad comments
Q40. Are there any practical considerations we should take into account during further developmental work and implementation of the Review (of the operation of Sections 135 and 136 of the Mental Health Act) proposals?	84	-	-	Comments focused on resources, teams, responding to individual needs and implementation issues
Q41. Do you think it would be desirable in principle to amend the Mental Health Act to enable restricted patients to be discharged by the Secretary of State for Justice or a Tribunal subject to conditions amounting to a deprivation of their liberty?	111	77%	13%	10%
Q42. Does the Mental Health Act need to provide for another form of detention for patients who do not need to be in hospital but who must be in effect deprived of their liberty in order to be discharged from hospital into a community based setting?	113	66%	30%	4%
Q43. We set out two possible options for introducing a legal right to have a personal health budget for some people with learning disabilities or autism. Which of the options (option 1 or option 2) do you think would be most effective? AND Easy Read Q10. What do you think about more people with learning disability or autism having personal health budgets?	266	-	-	16% option 1 11% option 2 5% combination 58% general support for personal budgets 10% did not support personal budgets
Q44. What else might need to happen in order for such Personal Health Budgets to enable people to choose new providers and/or new kinds of service or interventions?	122	-	-	Provision of information, support, services and clear safeguarding processes

Question	Number of responses	% Agree	% Disagree	% Other broad comments
Q45. How can we ensure that the new arrangements under the Children and Families Act can also be used to prevent unnecessary admissions in adulthood?	79	-	-	Most common suggestions focused on processes, prevention and personnel
Q46. We could seek to set up and mandate specific pooled funding, with joint planning, to help people with learning disability and/or autism get discharged from hospital or help prevent them being admitted. This could include specialised commissioning funding. What do you think of this idea? AND Easy Read Q11. What do you think about making local areas having to put in their money together to help people get out of hospital?	262	89%	6%	5%
Q47. Are there further ways we could strengthen local accountability, particularly to disabled people and their families?	89	-	-	Stronger engagement, clearer processes, increased resources
Q48. We want to explore whether providers of specialist hospital services and residential care services should be allowed to have a duty to share confidential patient information with case managers and other relevant commissioners directly involved in arranging a person's care in certain circumstances. What do you think of this idea? AND Easy Read Q12. Do you think is should be made clear when people who buy care have to share information to support people's care and keep them safe?	295	79%	15%	6%

Question	Number of responses	% Agree	% Disagree	% Other broad comments
Q49. What are your views on how we could be clearer around responsibilities of: clinical commissioning groups, providers, medical directors and responsible clinicians for the physical healthcare of people in mental health inpatient settings? AND Easy Read Q13. Do you think we should try and make it more clear who has to make sure people are physically well when they are in mental health hospitals?	240	64%	9%	Other comments focused on clearer responsibilities and enhancing service provision
Q50a. Which would have the greatest impact and benefit on people's lives? (so we know what should be highest priority) AND Easy Read Q14a. What do you think would make the most difference?	261	-	-	Increased community service provision, engagement and co-production and joint commissioning
Q50b. Which carry the greatest potential costs or risks? AND Easy Read Q14b. What do you think would not be so good, for example, because it might cost a lot of money?	83	-	-	Lack of ring-fenced additional funding, lack of community service provision and difficulty aligning health and social care

Note: Some of the proportions do not add to 100% due to rounding of figures.

Chapter 1: Responses received

Background

Between March and May 2016, the Department of Health sought views about how to help people with learning disabilities, autism and mental health conditions live well in the community.

No voice unheard, no right ignored: a consultation for people with learning disabilities, autism and mental health conditions outlined how everyone should have access to good life and career opportunities. The consultation asked about ways to:

- help people be in charge of their lives, supported by family and friends

- live independently and be part of their communities

- offer better support in the community so people are not sent to hospital by default

- make sure people receive the right care in the right place by putting their needs at the heart of decision-making

- make sure that organisations have clear responsibilities and work together, so people do not fall through gaps between services

- think about changes to the way the Mental Health Act 1983 applies to people with learning disabilities and autism

This document summarises key themes from responses to the consultation, based on analysis by an independent team.

The document presents the main ideas from responses, ordered according to sections of the consultation document and the consultation questions that people were invited to respond to.

Feedback from responses is reported without assessing the feasibility or factual accuracy of the suggestions made, or weighing the relative pros and cons of various suggestions. The purpose of the document is to provide an overview of what people and organisations said. The Department of Health is responsible for considering all of the trends and the more detailed comments in each of the full responses, considering factual accuracy and deciding how to use people's feedback.

This chapter describes how trends from the responses were drawn out and provides an overview of the number and type of responses. The following chapters describe feedback about each of the consultation questions.

Compiling consultation responses

Receiving responses

During the consultation period, the Department of Health disseminated information to organisations and stakeholder groups, asked groups to run events to promote the consultation and publicised the consultation using social media, tweets and blogs. There was a 'full text' version of the consultation document and answer booklet, as well as a shorter Easy Read version. Both versions outlined some proposals and asked people for their feedback.

The Department of Health accepted responses to the consultation by email, post, using an online feedback form and in notes from discussion events.

Identifying trends

The Department of Health asked an independent organisation, The Evidence Centre, to draw together the main themes from all of the responses. The analysis team was not involved in any other aspect of the consultation and had no vested interest in the outcome. The purpose of the analysis was to summarise the comments made by responses, so the Department of Health and other interested groups could have an overview of what people said. This is not a substitute for reading all of the individual responses to the consultation.

The Department of Health received and kept a log of all responses and sent the independent team copies. The independent analysis team read every response in detail and put all of the feedback for each question into an electronic spreadsheet, along with demographic details about the respondent, where available. All of the verbatim feedback for each question was then categorised to identify trends. Comments not relating to specific questions were also analysed.

The analysis team counted the number of responses that agreed and disagreed with each proposal. They also drew out comments about why people agreed or disagreed with proposals and counted other common things that responses said. All analysis and reporting was completed in June 2015, within one week of all responses being logged.

Reporting on trends

The independent team have reported on the proportion of responses that agreed or disagreed with each proposal. However the **percentages described throughout this report cannot be used to indicate strength of feeling or relative importance**. Some responses were from organisations or groups representing many hundreds or thousands of people or comprised notes from discussion events with many participants. One response does not equate to one person. This means it is important to treat the percentages with caution. They are designed to show general trends only. If very high proportions of responses agreed with a proposal, then this gives a good indication that people and organisations were generally positive. If less than three quarters of responses agreed with a proposal, this suggests there is a need to look in more depth because some of the responses that disagreed could have represented a large number of people.

Quotes have been used throughout the report to illustrate the types of things responses said. These were chosen to give good examples of something that many other responses said and to show the variety of different types of respondents, such as organisations and individuals.

Characteristics of responses

There were a total of 481 responses to the consultation, including all responses received up until 17 June 2015. This excludes duplicate responses, where people submitted exactly the same text in more than one format (for example emailing a response as well as posting the same response in hard copy). Some people and organisations provided more than one response containing different points. Responses from the same person or organisation were grouped together to avoid double counting, making the total number of unique responses analysed 468.

Types of responses

Six out of ten responses were received by email (64%), two out of ten were submitted using the Department of Health's online feedback form (21%) and the rest were sent through the post (15%).

35 responses (submitted by email or in hard copy) were labelled as notes from meetings/ events (7%) and other responses were also completed by groups following discussions.

Location

Responses were received from throughout England. There was a good geographic spread (see Figure 1).

Figure 1: Geographic spread of responses to the consultation
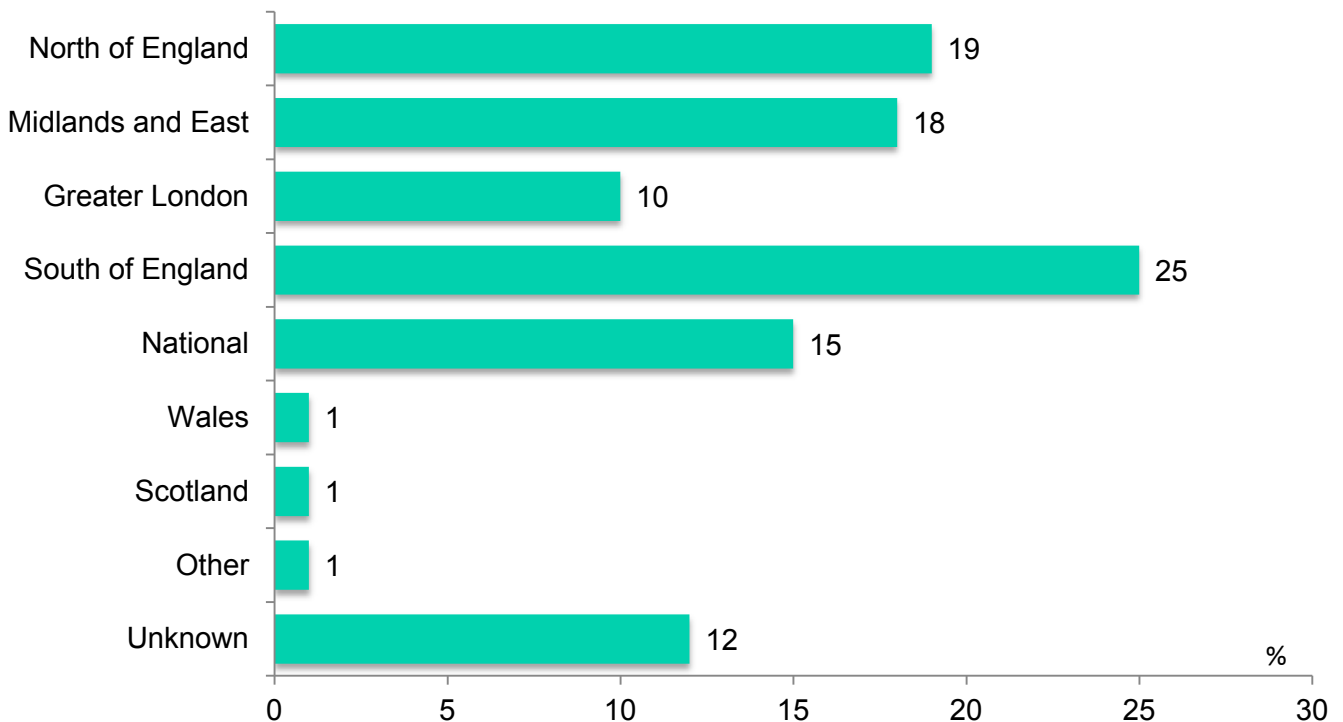
Note: Percentages are based on all 468 responses

Types of respondents

Half of responses came from an organisation or group (53%) and half were from an individual or family (47%).

Type of organisations

In total, 221 responses came from organisations and 28 came from other groups, such as specific forums or group meetings.

Of the 221 organisations, half were from the voluntary and community sector (54%). This included large national voluntary sector organisations and smaller organisations that may work in particular regions. About two out of every ten responses from organisations came from local authorities (18%) and one in ten were from NHS organisations (12%). Responses were also received from professional bodies such as Royal Colleges, independent sector service providers, legal and police organisations, academic institutions and regulators (see Figure 2).

Figure 2: Types of organisations that responded to the consultation
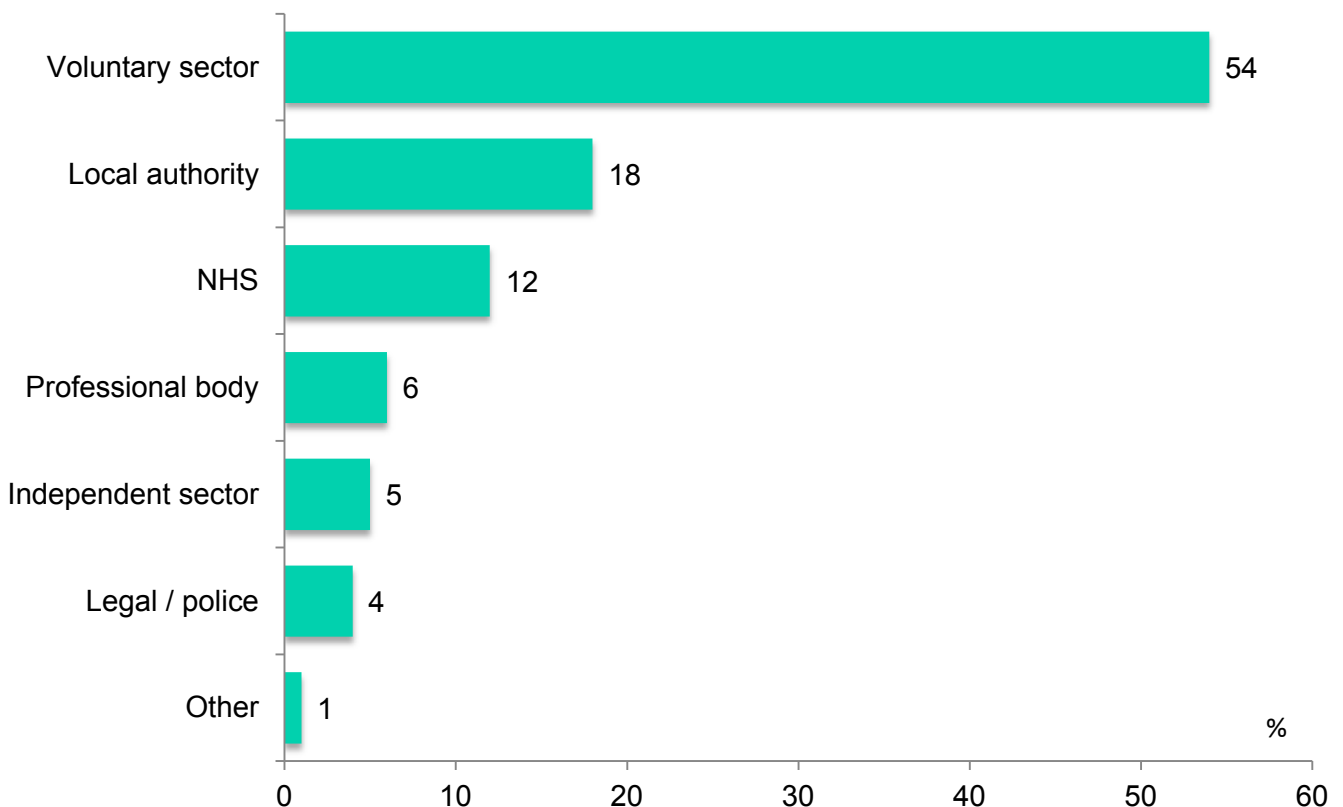
Note: Percentages are based on 221 responses from organisations

Type of individuals

Of the 219 responses that were from individuals, 198 provided details about what type of person they were. Half of these individuals were service users (48%) and one quarter were carers, family members or friends of service users (25%). Responses were also received from health and social care professionals, support workers and advocates and others (see Figure 3).

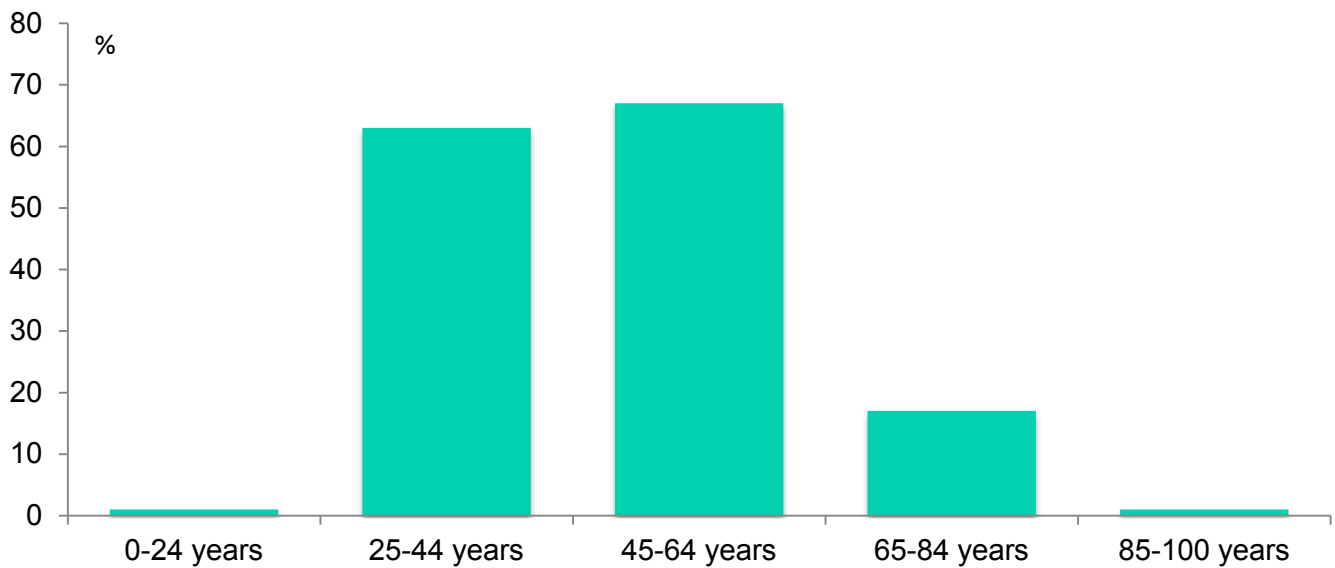Figure 3: Types of individuals that responded to the consultation
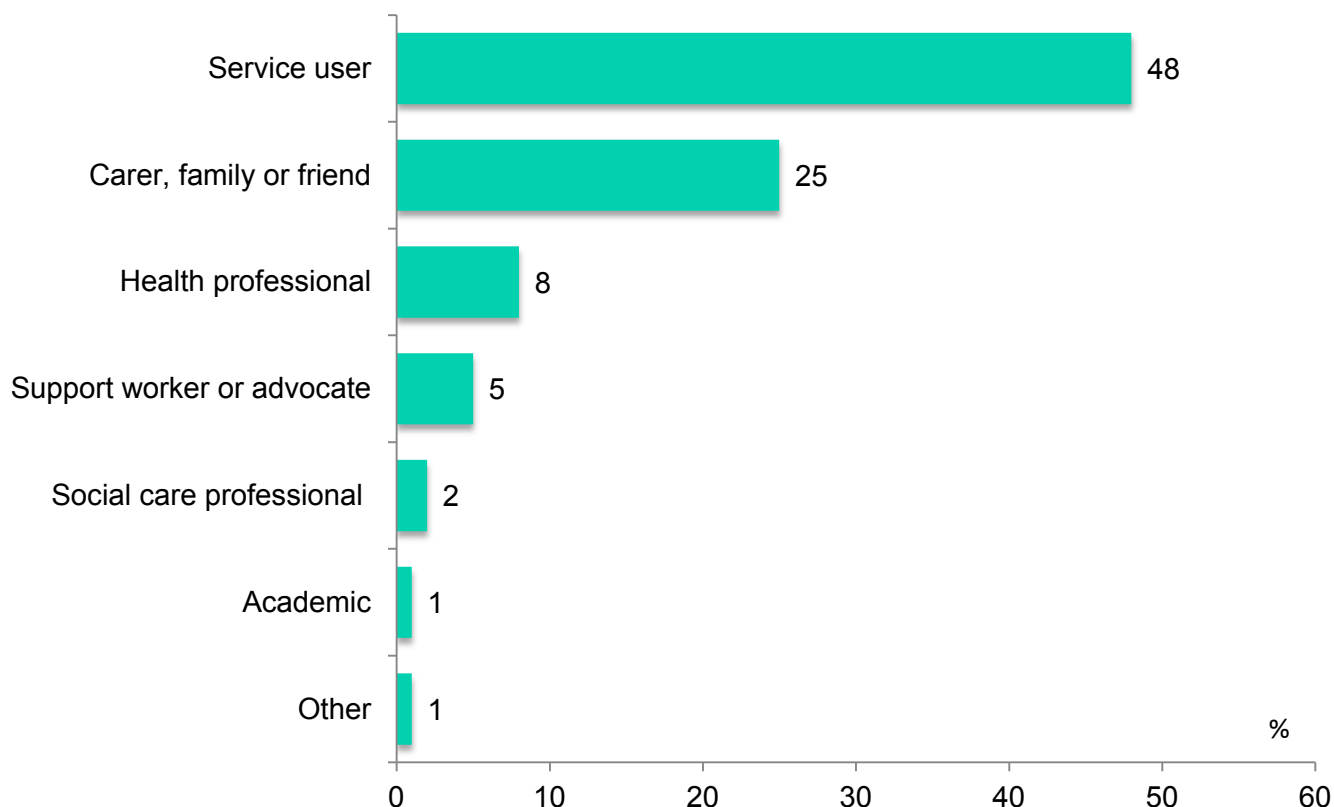
Note: Percentages are based on 198 responses from individuals that mentioned their role

Half of the responses from individuals (54%) said that the person providing feedback had a mental or physical health issue or a disability. These are not the same things, but different questions were asked in the Easy Read and other questions.

Six out of every ten responses from individuals were from women and four out of ten were from men. This is based on 193 responses that provided this information or where it could be extrapolated.

Overall, 148 responses from individuals listed the age of the person responding. These were all people who answered the online survey or those that completed the Easy Read or answer booklets, where a question was explicitly asked about this. People from a broad range of age groups shared their views (see Figure 4).
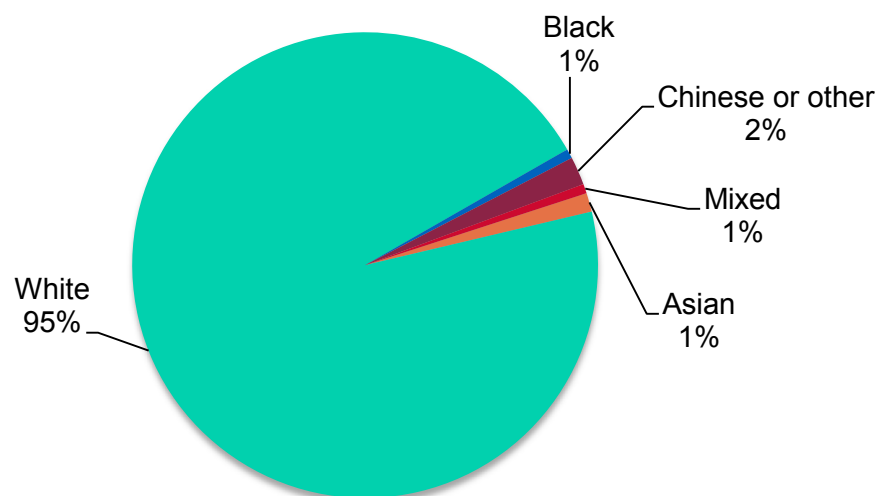
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Figure 4: Age groups of individuals that responded to the consultation

Note: Percentages are based on 148 responses from individuals that provided their age

In total, 153 responses from individuals stated the ethnic group of the person responding. Again, these were people who answered the online survey or those that completed the Easy Read or answer booklets, where a question was asked about this. Most people who answered this question said that they were White, though some Asian, Black, Chinese, Mixed and other people shared their views too (see Figure 5). This is largely representative of the ethnic make-up of people in England, but information was provided only by 153 out of 219 individuals (70%).

Figure 5: Ethnic groups of individuals that responded to the consultation

Note: Percentages are based on 153 responses from individuals that provided their ethnic group
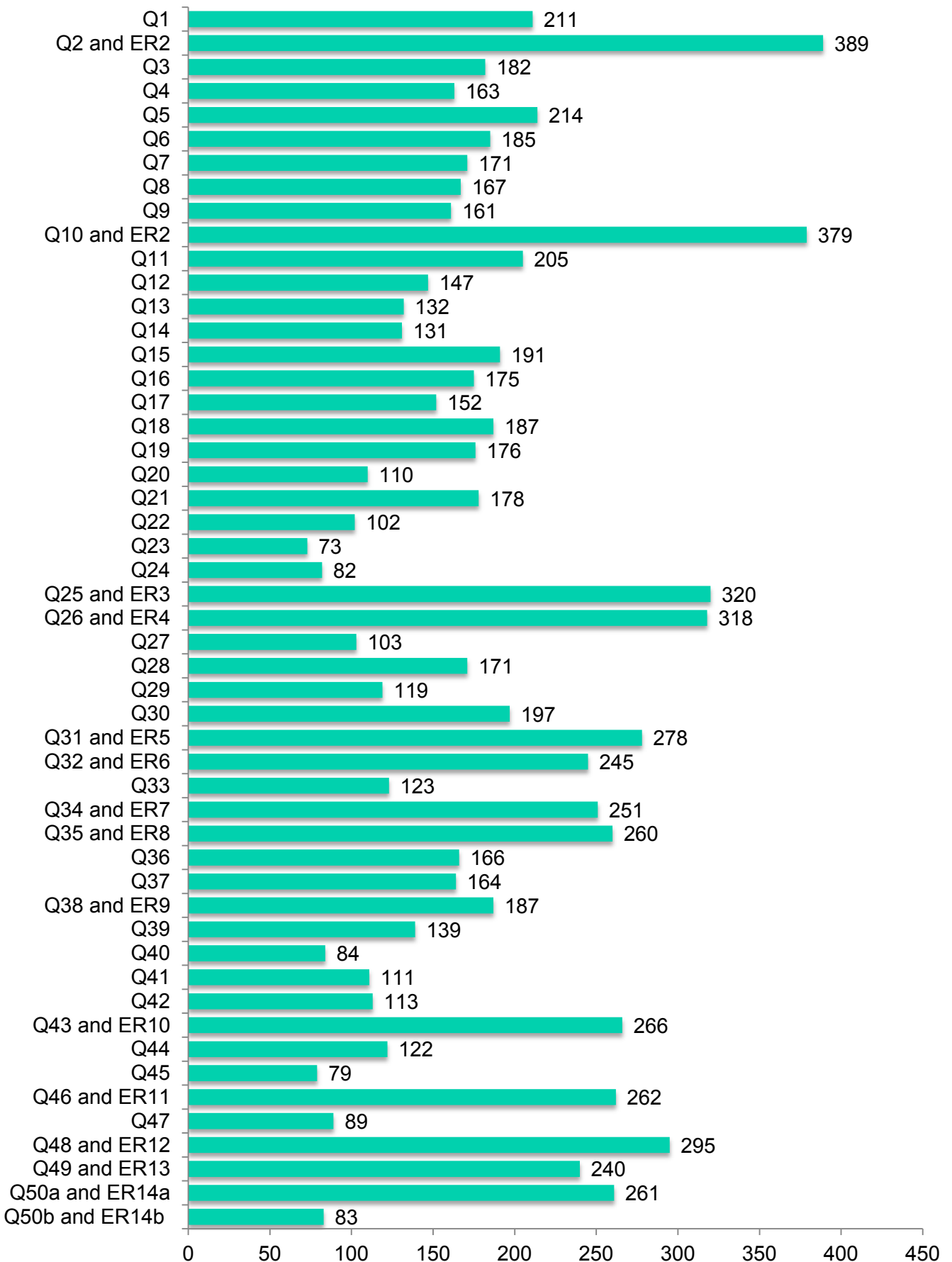
Questions addressed

Half of the responses (48%) answered questions from the full text version of the consultation answer booklet (either within the answer booklet itself or via email, online or in another format). One third of responses (35%) focused on questions from the Easy Read answer booklet (either within the answer booklet itself or in another format, including questions discussed at meetings). Sometimes organisations, including voluntary sector groups and local authorities, used the Easy Read version. About one fifth of responses provided broad comments that did not address the consultation questions explicitly, but were relevant to some sections (17%).

There were 50 questions in the full text consultation answer booklet (one of which had two parts) and 14 in the Easy Read version. The Easy Read questions did not map exactly to the longer version, but the topics covered were similar so the answers have been combined and analysed together.

Although there were 468 compiled responses overall, not every response answered every question. Figure 6 illustrates how many responses addressed each of the consultation questions. The exact wording of the consultation questions is provided in Table 1 and referred to throughout the document. The purpose of this figure is to show 'at a glance' which questions were most commonly responded to. The figure shows that there were a higher number of responses in questions covered by both the full text and Easy Read booklets.

This chapter has outlined how themes from consultation responses were analysed and the characteristics of the responses. The rest of this document explores what responses said about each of the consultation questions in turn.

Figure 6: Number of responses providing feedback about consultation and Easy Read (ER) questions

Question	Number of responses
Q1	211
Q2 and ER2	389
Q3	182
Q4	163
Q5	214
Q6	185
Q7	171
Q8	167
Q9	161
Q10 and ER2	379
Q11	205
Q12	147
Q13	132
Q14	131
Q15	191
Q16	175
Q17	152
Q18	187
Q19	176
Q20	110
Q21	178
Q22	102
Q23	73
Q24	82
Q25 and ER3	320
Q26 and ER4	318
Q27	103
Q28	171
Q29	119
Q30	197
Q31 and ER5	278
Q32 and ER6	245
Q33	123
Q34 and ER7	251
Q35 and ER8	260
Q36	166
Q37	164
Q38 and ER9	187
Q39	139
Q40	84
Q41	111
Q42	113
Q43 and ER10	266
Q44	122
Q45	79
Q46 and ER11	262
Q47	89
Q48 and ER12	295
Q49 and ER13	240
Q50a and ER14a	261
Q50b and ER14b	83

Chapter 2: Being part of the community

This chapter summarises feedback about the section of the consultation labelled 'My right to be independent, to be part of a community and to live in a home I have chosen.' Each consultation question is listed, followed by the number of responses that provided a view about this topic and the main themes.

Q1. The Care Act says that local authorities have to put individuals' wellbeing at the heart of what they do. We want to explore whether NHS commissioners should have the same duties, for example, for people with learning disability or autism who are at high risk of long stays in hospital in relation to their lifelong needs. What do you think of this idea?

In total, 211 responses provided feedback about this question. Most responses agreed that NHS commissioners should have the same duty as local authorities under the Care Act to put people's wellbeing at the heart of what they do (94%).

Figure 7: Feedback from responses that answered Q1
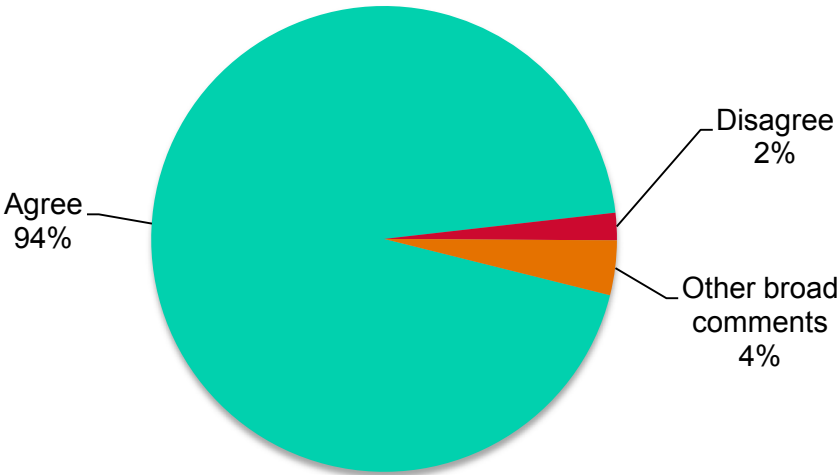
Note: Percentages are based on 211 responses

There was no difference between the overall views of organisations versus individuals or between various types of organisations or individuals.

27

Responses that agreed said that all organisations supporting people should have wellbeing at the centre of their principles and priorities and that this would help to develop common approaches.

> *"Everyone who supports us, or is involved in our care in any way at all should be thinking about what is best for us all the time, this should include doctors and nurses and bosses. They need to think about what we need first, then make sure their rules do not stop them getting what is best for us. Money might be a problem but they should fight for more." (Voluntary sector organisation)*
>
> *"Extending the wellbeing legal duty to the NHS would support the development of a common approach to working with individuals and families across local authorities and health."* (Local authority)

Some responses that disagreed said that it was important for health commissioners to have a balance between individual wellbeing and wider issues affecting larger groups or populations. In this view, individual wellbeing should be one of a number of important priorities for health commissioners, but not necessarily the sole or central priority.

> *"Commissioners have to take into account a wide variety of factors and it would be unwise to make an individual's well-being paramount. While the move to shared values would support the introduction of pooled budgets, it would not mean that they were given the same level of priority by local authorities and commissioners. For example, health commissioners will need to balance their responsibility to the individual with their public health obligations to the wider community and, on occasion, these will conflict."* (Professional body)

Others said that they did not perceive services to be prioritising people's wellbeing at present and that changing the law may not improve this.

Other common feedback to this question, regardless of whether responses agreed or disagreed, included:

More joint working

- if budgets and commissioning are joint between the NHS and local authorities, legal responsibilities and accountability should also be the same. Joint commissioning and budgets may have many benefits

- in order to address the needs of an individual, organisations should work collectively. People with complex needs generally have both health and social care problems so it makes sense for the same duty to apply equally to the NHS and the local authorities

- the duty should not be limited only to local authorities and the NHS, but apply to all stakeholder organisations

Recognising challenges

- guidance needs to give further detail about what 'wellbeing' covers, what 'good' looks like and how to implement changes in practice

- it is not clear how this would occur in practice, such as exactly how legislation would be altered

- more training on person-centred approaches is needed to make this a reality

- need to be clear who is ultimately responsible and accountable

- need to make sure that commissioners are not focused on finances at the expense of wellbeing

- need more resources to provide person-centred care

Potential additional features

- should include the wellbeing of all individuals, not solely people with certain conditions

- should include explicit reference to working in line with the Human Rights Act

- whilst useful, such a duty would not create rights to support for a person to live in their community as they choose

Q2. In determining living arrangements - (whether suitable accommodation or inpatient stays) - both local authorities and NHS commissioners could have to have regard for factors which support inclusion in the community, staying close to home, links with family and friends and opportunities for participation and the least restrictive setting. What do you think of this idea?

Easy Read Q1. These ideas are trying to help people to be part of the community. Would they help to stop people being sent way from their home and family?

A total of 389 responses addressed these questions. Most responses were favourable about local authorities and NHS commissioners having to think about factors that would help people stay close to home and maintain links with family and friends (90%).

Figure 8: Feedback from responses that answered Q2 or Easy Read Q1
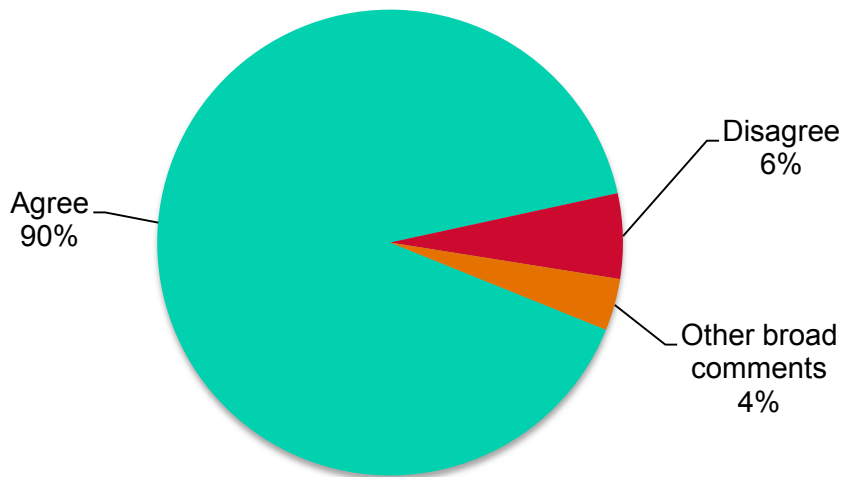
Note: Percentages are based on 389 responses

There was no difference in the views expressed by organisations compared to individuals or between various types of organisations or individuals.

Those that agreed said people's wellbeing is likely to be positively affected by having the support of family and friends and staying in a familiar environment. Responses also said that being able to be part of a local community could foster independence and improve morale.

> *"It is good to stay close to the community, this is important to us. We would like to see more support and choice in the community. We still think the hospital can help when people are really ill but staying at home can be really important to people… Should be able to rest at home in an environment that you are comfortable in. Having support close by will help people feel well."* **(Group of service users)**

> *"Contact with family, friends and other connections such as work, school, college, faith communities and social support groups and services can play a very important part in people's recovery. A crisis admission far from home can have a very negative impact, delay recovery and disrupt provision of community-based care and support."* **(Voluntary sector organisation)**

Some responses that disagreed said that commissioners should not be making decisions about living arrangements. Instead, they should be providing information and advice to help people make their own choices. Other responses said that in some cases relationships with families could be problematic and in a small number of cases people may benefit from being in a different community. Other responses that disagreed said that in some instances decisions about accommodation were made by the courts. The overall message from those that disagreed was that a 'one size fits all' approach may not be useful.

> *"Care must be planned to suit the needs of the individual who needs them. There is a risk that a headlong drive towards community care will undermine an approach that is focused on the needs of a particular person. One type of care, wherever it is located, is not suitable for all people."* **(Local authority)**

> *"Closer to home needs a caveat: each case needs to be dealt with on merit. Distance is not a sole criterion. Quiet rural locations may well be preferable for some people. The decision to place out-with local area can be to avoid risk from family and associates. Moving to a new locality can give people a fresh start, remove some of the contextual antecedents to emotional distress and allow some space to develop a life independent of family problems."* **(Professional body)**

Other common comments, regardless of whether responses agreed or disagreed, included:

Access to services

- it is important to have a range of good quality local services to support people and provide choice

- good primary care is important

- appropriate housing is important, but may not always be available

- employment opportunities should be considered

- should support people's use of technology to keep in contact with others

- assessments should be done at home or in the local community, rather than in hospital

- adequate resources are needed to provide local services

- needs to be some provision for highly specialised services for people who can only be accommodated in a small number of (non-local) settings

Support

- people may need sustained support to live successfully and independently within the community

- some people do not feel confident living in the community and need more support

- family members are often coping with many challenges so it is essential to have support for families too

Raising awareness

- NHS and local authority staff should have more training and knowledge to support service users and families

- people in the community may not be disability-aware or accepting of differences

Wording

- a small number of responses commented that the wording of the proposals should be altered to make taking local circumstances into account compulsory. A small number of other responses said it was important to use wording such as 'have regard for' rather than making this legally binding

- some responses stated that this principle was already part of the Mental Capacity Act and the Care Act. (This summary does not comment on the factual accuracy of feedback, only reports what responses said).

Q3. What might the appropriate length of inpatient stay be where this should apply for the NHS?

In total, 182 responses addressed this question, but the feedback was difficult to interpret. The question intended to ask about the time someone should stay as an inpatient before the NHS should have to consider factors which support inclusion in the community, as set out in question 2. However, a number of responses appear to have interpreted the question as asking about an appropriate length of inpatient stay generally.

Six out of ten responses said that it was not appropriate to specify a timeframe for inpatient stays as this would depend on individual circumstances (65%).

> *"Some individuals found this bemusing because it indicates a one size fits all perspective rather looking at individuals and making the system better at responding to each in a timely and efficient way. Length of stay should not be based on an arbitrary timeframe. It should be based on individual patient's needs. Commissioners and in-patient providers should be required to demonstrate that length of stay is for the shortest period required in every individual case."* **(Meeting of service users, carers and others)**

Fifteen percent of responses said inpatient stays should be as short as possible.

Fifteen percent of responses specified a timeframe, but this did not necessarily relate to the timeframe for considering factors which support inclusion in the community. Most appeared to be answering in terms of a potential ideal length of stay in inpatient care. Of responses that suggested a timeframe, about one third mentioned stays of less than one month, one third said between one and three months and the final third said between four and six months.

Five percent of responses said the NHS should consider factors which support inclusion in the community for <u>any and all lengths</u> of inpatient stay.

> *"As a simple matter of practice, ensuring that an individual is placed in the least restrictive appropriate setting should always be central to decisions on living arrangements, both short- and long-term. We do not, therefore put forward a suggested length of stay before this duty emerges. It should form part of the decision about where someone will live from the start, if not before admission."* **(Voluntary sector organisation)**

There was no difference in trends depending on whether responses were from organisations or individuals, or depending on the type of organisation or individual.

Q4. What are your views on how this might impact on local authorities or the NHS?

Overall, 163 responses answered this question. Responses suggested a range of potentially positive and negative impacts from the NHS and local authorities having to consider factors that support inclusion in the community. The most commonly mentioned positive impact was increased joint working, co-ordination and integrated commissioning. The most commonly mentioned negative impact was financial pressure.

The potential impacts mentioned by responses focused on processes, culture, service provision and finances. Table 2 lists the perceived impacts.

"Cost is obviously an impact. However, if we can provide the right accommodation whilst someone needs help to get better, it could significantly reduce the time they need to stay in that accommodation or how frequently. It would help to make them feel more valued, boost confidence and have an overall positive impact on them and their family." **(Service user)**

"This can only have a positive impact on both health and social care. There is a potential downfall in that we lose very specialist provision and need to consider a joined, regional approach to address special needs (forensic, medium and high secure provision). If people are placed in inpatient, out of county placements then support needs to be considered for the person to maintain links, family will need to be supported to visit and advocacy may need to be provided to support family contact. It will also develop additional skills within the community settings/services, thereby avoiding more crises." **(Local authority)**

There was no difference in the views expressed by organisations compared to individuals or between various types of organisations or individuals.

Table 2: Possible positive and negative impacts of considering community inclusion factors

	Potential positive impacts	Potential negative impacts
Processes	- more joint working and co-ordination, including integrated commissioning (26) - more streamlined working (5) - better training for health and social care staff (2)	- initially a lot of work to set up (5) - need for guidelines for all organisations to follow as not in place currently (1) - need for more robust regulatory framework to ensure accountability (4) - District Councils manage accommodation in some counties and may have different priorities (1) - definitions and criteria not agreed between local authorities and NHS (5) - cannot shift responsibility from one group to another (1) - may be rushed discharges (1)
Culture	- potential to change culture and mindset of professionals and organisations (2) - fewer complaints and adverse events (1) - more focus on person-centred care (3)	potential to demoralise staff when they cannot find places out of hospital (1)
Service provision	- more creative and appropriate commissioning and service provision with local care pathways (7) - less fragmented services (2)	- need to design and provide housing and support services in the community, as not available currently (13) - increased pressure on assessment process (2) - not enough support staff in the community and issues with skill mix (6) - may need to reduce other services in order to prioritise others (2)
Finances	- potential for cost reduction in the long term by minimising use of inpatient facilities and dependence on services (16) - reduced length of stay in NHS facilities (4)	- perceived lack of finances and staff to implement in practice and need for considerable investment (45) - local authorities relied on too much for funding (6)

Note: Responses could provide more than one comment each
The number of responses that mentioned each topic is listed in parentheses

Q5. We think that local authorities and clinical commissioning groups could have to think about how to ensure there is enough community based support and treatment services (for example for people with learning disability or autism most at risk of going into hospital). What do you think of this idea?

There were 214 responses that answered this question. Most responses agreed that local authorities and the NHS should have to consider how to provide enough community-based support and treatment services (90%).

Figure 9: Feedback from responses that answered Q5
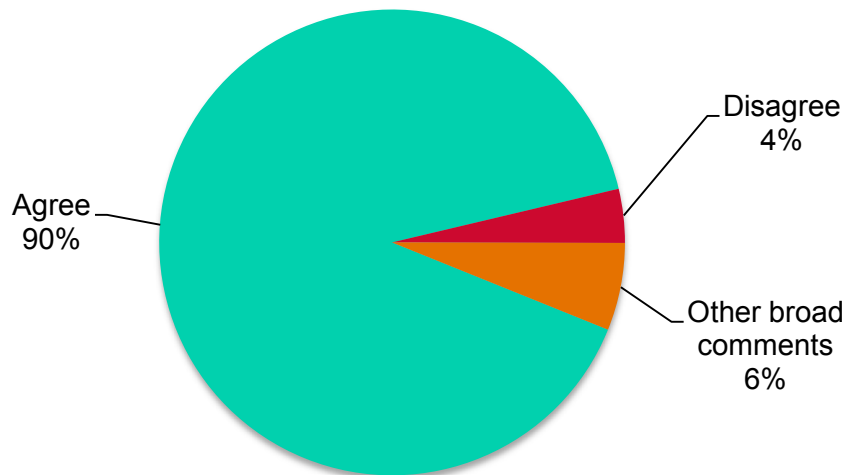
Note: Percentages are based on 214 responses

There was no difference in the views expressed by organisations compared to individuals or between various types of organisations or individuals.

Responses that agreed said good community provision was essential for person-centred care.

> *"Everything is underpinned by the need for sufficient community provision. Too often there is inadequate local provision. Community provision is essential. It must be mandatory to develop the right local expertise, support and services for this group. Community provision must include: professionals with appropriate knowledge, skills and experience."* **(Voluntary sector organisation)**
>
> *"If local authorities and NHS commissioners are to work together for the betterment of individuals and achieve a fit for purpose system then due regard must be given to the need for sufficiency of community support and treatment. Without the availability of such support and treatment, care of individuals will remain disjointed and fragmented. We believe that such a duty should be a part and parcel of care provisions."* **(Voluntary sector organisation)**

Some responses that disagreed said that this may mean that there is a reliance on primary or community care, rather than developing more specialist support services. Other responses that disagreed said there were financial and practical issues with providing community-based support.

> *"It is all very well to hand these responsibilities over to local authorities or clinical commissioning groups, but only do it if they receive sufficient funding from government to enable them to provide enough community based support and treatment services for these vulnerable people. Local authority budgets have been cut."* **(Family member of service user)**

Other common comments, regardless of whether responses agreed or disagreed, included:

Mandatory duties

- alter wording to be stronger than 'could have to think' so that it is a mandatory requirement
- there is already a market shaping duty for local authorities under the Care Act
- should apply to all groups

Practicalities

- need to draw on support from the voluntary sector
- need to map what is already available and identify gaps to fill
- need to be adequately resourced
- requires joint working between the NHS and local authorities
- requires monitoring and accountability

Q6. What steps could we take to ensure such a duty is as effective as possible?

In total, 185 responses provided feedback about this question. Responses suggested that key steps could focus on joint working, providing guidance, enhancing service provision and infrastructure. The most common suggestion was to set up robust data collection and monitoring processes to hold organisations to account publicly.

Common comments focused on:

Infrastructure

- the importance of clear responsibility and accountability (6 responses)
- require effective data collection and monitoring systems to be set up, including needs analysis, mapping of current provision and accountability for implementation. This may involve oversight by regulators (45 responses)
- ensure appropriate workforce numbers, skill mix and training (21 responses)
- provide extra funds to pump prime changes (24 responses)

Joint working

- combine health and social care budgets (12 responses)
- ensure joint commissioning and joint planning and working (12 responses)
- require a joint charter between the NHS and local authorities about principles and implementation (8 responses)

Guidance

- change the law so the Care Act applies to the NHS and so that support services must be provided in the least restrictive manner (18 responses)
- set out what appropriate provision is (17 responses)
- provide clear guidance about duties and funding priorities, including requirements to be included in the Joint Strategic Needs Assessment and Health and Wellbeing Strategy of each area (8 responses)

Service provision

- consult locally and set up the services needed by local people (17 responses)

- focus on person-centred service provision (9 responses)

- develop alternative community support, including 24/7 community teams (10 responses)

- provide personal health budgets (3 responses)

- make it a statutory requirement to provide preventive support (3 responses)

There was no difference in trends depending on whether responses were from organisations or individuals, or depending on the type of organisation or individual.

> *"A clarity at a national level as to specifications of models and services that would need to be in place would, alongside rigorous data on local population needs, make it possible to ensure local commissioners were held to account through audit of services provided and reviews of health and social care outcomes."* **(NHS organisation)**

> *"A greater emphasis on joint working, jointly held budgets and of co-production with service users needs to be encouraged from the top down and the bottom up. There needs to be greater local accountability with service users, carers and families having a strong voice on the provision of services."* **(Local authority)**

Q7. What is your view on the likely cost and impact on the NHS or local authorities?

A total of 171 responses answered this question. The main perceived impacts were financial impacts, joint working and infrastructure requirements, as listed below. The most common suggestion was that proposals would require significant investment or that there was potential for overall savings in the longer term.

Financial impacts

- requires significant cost investment (66 responses)

- potential cost savings in the longer term (66 responses)

- better value service provision in the longer term, not necessarily cheaper (14 responses)

Infrastructure

- requires more trained staff for both planning and service provision and support for commissioners to change (11 responses)

- requires more provision of step down facilities (4 responses)

- full impact assessment needed, accounting for all factors, not solely cost (7 responses)

Joint working

- there may be more partnership working and strategic planning (11 responses)

- an impact may be less duplication (3 responses)

There was no difference in trends depending on whether responses were from organisations or individuals, or depending on the type of organisation or individual.

"Costs will depend on how the support is provided and costs will need to be revised with ongoing new developments in treatment and management. Community services with the right support may not be less expensive than hospital care initially, but in the long run may reduce direct and indirect costs. It is also good for the person's quality of life. The costs are likely to be seen as less if it is looked at as a common pot of money. The costs will appear high (especially on the local authority side) if the costs are looked at in isolation (i.e. from an oppositional NHS vs social care perspective)." **(Regulatory body)**

Q8. What do you think about the idea to change the information required by Mental Health Act regulations in the application for detention and supporting medical recommendations?

There were 167 responses that answered this question. There was mixed feedback, with some responses thinking the proposal was a good idea and others supporting the principle but saying that it was already a requirement so no changes were needed.

Although seven out of ten responses agreed that it was a good idea to change the information required, it is important to remember that each response does not represent one person. Some responses representing many hundreds or thousands of people did not agree with this proposal.

Service users, carers and voluntary organisations tended to be in favour of the proposal. NHS organisations, local authorities and professional groups often said that no changes were needed because the principles were already in place. Health and social care professionals were split, with some agreeing this was a good idea and others disagreeing.

Figure 10: Feedback from responses that answered Q8
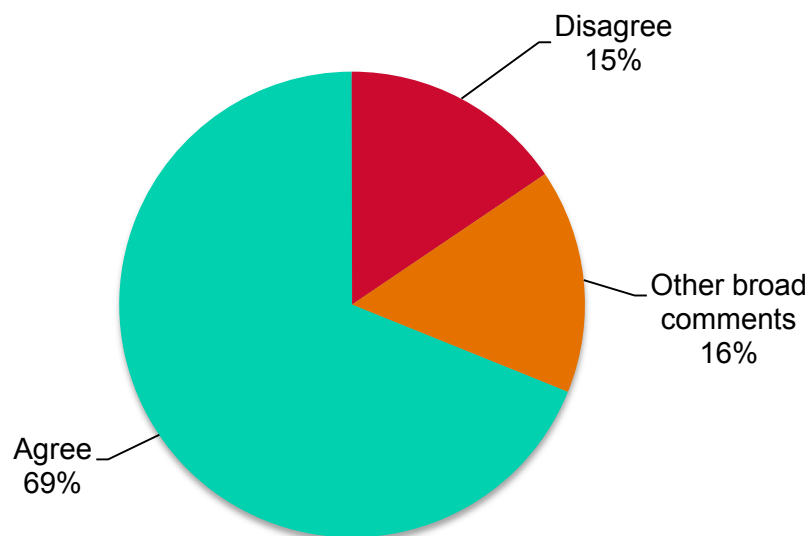
Note: Percentages are based on 167 responses

Responses that agreed with this proposal suggested it would promote greater accountability.

> *"I strongly support this idea. Clarity needs to be given on appropriate responses and not just 'there are no community services that are suitable' but rather specifics are needed. This should also be discussed with the service user/family. Within each organisation, there must be someone who has responsibility to review the forms and the comments should be published anonymously. There should be a review of the responses for all organisations by government."* (Health professional)

> *"As well as supporting protection of human rights, this could highlight the unavailability of suitable services in the community, and act as a driver to the development of appropriate local services to support people whose needs challenge existing community provision."* (National body)

Those that disagreed tended to say that this approach was already occurring amongst approved mental health professionals (AMHPs).

> *"I do not think this is the major issue. The system can be applied fairly well in its current form. I think that approved mental health professionals and doctors already consider whether admission is necessary before arranging it in nearly all cases."* (Health professional)

> *"We strongly support this aim but not the proposed solution. We do not feel this can be achieved by changing the Mental Health Act regulations as proposed in the consultation document. The key factor tipping the balance towards hospital admission is often the lack of early strengthening of community support packages due to scarce resources in the local authority."* (NHS organisation)

Other points made, in order of frequency, included:

- the capacity of professionals to choose community-based provision will be determined by the services available

- needs to be robustly monitored, potentially with a standardised report form

- important to take the views of service users and families into account

- needs to indicate where admission was due to insufficient community placement

- requires good training of staff

- may mean that it takes longer to undertake an assessment

"We welcome the idea to change the information required by MHA regulations in the application for detention and supporting medical recommendations so that it has to be considered and recorded whether assessment and treatment could be provided without detention in hospital. It is important that where it is recorded that the person could not be treated in the community because of a lack of the right community provision that this information is collected and used to inform commissioning. There should be a duty to collect and use this information in commissioning." **(Voluntary sector organisation)**

Q9. This would mean that approved mental health professionals and doctors have to consider and record whether assessment and treatment could be provided without detention in hospital. What is your view on the likely costs and impact of this idea?

In total, 161 responses answered this question. Fifteen percent of these said the proposals would have no additional impact or cost because the practice was already being implemented locally (24 responses). These responses were most likely to be from local authorities, NHS organisations, professional bodies and health professionals.

Other responses described potential costs and impacts. These focused mainly on financial implications and service provision. Responses could provide more than one comment related to this question.

Financial implications

- developing alternatives and ensuring adherence will have cost implications (32 responses)
- may result in long term savings (34 responses)
- will result in redistribution of funds rather than additional funds or cost savings (8 responses)
- should not base decisions on cost (10 responses)

> *"The cost of more consideration of the least restrictive community options and consultation with those that know the person well should be minimal, once clear information gathering and communication systems are established. Savings arising from the prevention of unnecessary admissions would offset this initial cost."* **(Voluntary sector organisation)**
>
> *"There are some set up costs in terms of guidance, training and paperwork. There is likely to be some cost implication to the CQC in terms of collecting and analysing this data unless their existing systems can adapt to this requirement. The main 'cost' will be … about having the available provision and services in place locally."* **(NHS organisation)**

Provision

- would need to make provision for providing assessments in the community and alternative service provision (10 responses)

- assessments would need to be provided locally and promptly, which has staffing and timing implications (9 responses)

- assessments may take slightly longer to do (7 responses)

- an up to date directory of local services would be needed and more knowledge amongst the workforce about local services (7 responses)

- health and social care need to work together to ensure suitable alternatives (9 responses)

"Such changes might mean that the admission process becomes more bureaucratic, takes longer, and is more time consuming for professionals involved. Therefore there would be likely to be a need to increase the numbers of professionals available to work on rotas to do the assessments. Workers would need to have training to update their knowledge following any change." **(Health professional)**

Chapter 3: Being listened to

This chapter describes responses to the section of the consultation document entitled 'My right to be listened to and have my wishes acted upon. My right to challenge decisions about me.'

Q10. We want to explore whether a person and their family/carer or other nominated person should be given clear, easy read or accessible information by a named professional about their rights. What do you think of this idea?

Easy Read Q2. These ideas are trying to help people play a full part in their care and make sure the NHS and local authorities listen them. Do you think they will help?

Overall, 379 responses answered these questions. Nine out of ten of these responses agreed that people should be given clear, accessible information to help people play a full part in their care.

Figure 11: Feedback from responses that answered Q10 and Easy Read Q2
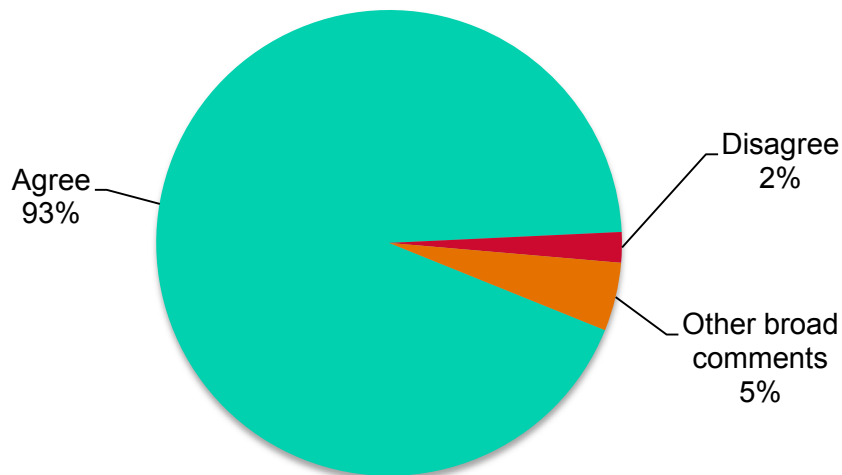
Note: Percentages are based on 379 responses

There was no difference in trends depending on whether responses were from organisations or individuals, or depending on the type of organisation or individual.

Common comments, in order of frequency mentioned, included:

- questions about how this would be implemented in practice, and the importance of making a range of communication approaches available

- this will require good advocacy support

- staff will need more training to ensure good communication

- it may be useful to specify the minimum information to be provided

"It is really important that people are listened too. You can only have a voice if you understand what is happening and the information you are being told. People need to learn about how to speak up and how the system works in school. Everyone should be given information in a way that they can understand, this might mean the information is given to them several times, at each stage of the plan. Self-advocacy groups have a crucial role to play in this. It is also really important for families and friends to have a role in this too. People will need support to challenge decisions or to complain." **(Voluntary sector organisation)**

"The general feeling of this is that it should be standard procedure to offer information to people in a format or way that suits the individual's needs. There are considerations as to resources and availability of the information, but this could potentially be done through the advocacy services. However, we must also pay attention to the appropriateness of providing this information to the individuals." **(Local authority)**

Responses that disagreed with this proposal thought that this approach was already required by law. They suggested that mechanisms should be put in place to ensure accountability and compliance with current requirements.

Q11. What do you think about the idea that local authorities and NHS bodies should have to seek explicit and documented approval or consent from an individual to admit them to an inpatient setting? This could include a record of discussion around options and risks.

There were 205 responses that answered this question. The feedback was mixed. Three quarters of responses agreed that health and social care should have to seek documented consent before making an admission (76%). However a number of responses from organisations, including some NHS and local authority responses, did not agree with this approach.

Figure 12: Feedback from responses that answered Q11
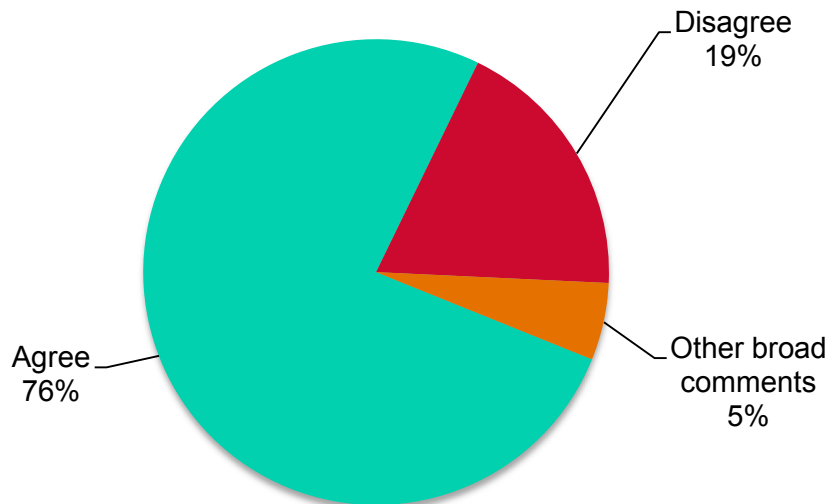
Note: Percentages are based on 205 responses

Common comments, regardless of whether responses agreed or disagreed, included:

- concerns about the practicality of gaining consent in some circumstances
- it is important to have better record keeping about the decision-making process
- perception that this was already a requirement
- more clarity needed over who holds responsibility for making the decision and the arbitration process should there be any disagreement
- need to define 'inpatient setting'
- the proposals talk about residential settings, but this is not covered in the question

Some responses that agreed with this proposal stated that implementation would depend on individual circumstances.

"Whilst this is a good idea in principle, some people with a mental disorder have little or no insight into their condition, or the potential risks to themselves or others that can exist. Where someone is violent, aggressive, or lacking insight into their mental health needs and the risks posed to themselves and/or others, it is unlikely they will consent to in-patient treatment, even when it is very necessary." **(Local authority)**

Some responses that disagreed suggested that documenting consent and decisions was already a legal requirement and that adding another requirement would not be an improvement. Health and social care professionals, professional bodies and NHS organisations were most likely to express these views.

"Existing legislation and Codes of Practice should be properly administered (MHA, MCA, Equality Act) and appropriate actions taken when it is not. Further legislation in this area will risk creating further levels of confusion and misapplication. It needs to be remembered that inpatient settings apply to areas of health, mental health and behaviour; adding such consents would potentially prevent people having access to appropriate investigation and treatment for their physical health. It would be better to ensure that individuals are well supported and that the role of a parent/paid carer/family member to advocate on the individual's behalf is recognised and supported." **(NHS organisation)**

Q12. What are your views on the idea of a gateway or approval mechanism for admissions to inpatient settings, in certain circumstances?

There were 147 responses that answered this question. The feedback was very mixed. Six out of ten responses agreed that a gateway or approval approach may be useful, two out of ten did not and the rest provided other broad comments, particularly in terms of practicalities and a lack of information about how the process would work.

Figure 13: Feedback from responses that answered Q12
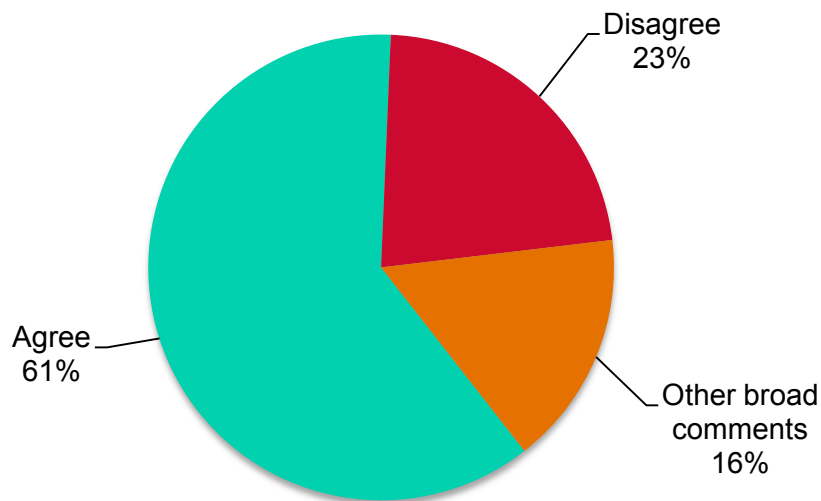
Note: Percentages are based on 147 responses

NHS organisations, professional bodies and health professionals were more likely than other responses to disagree with this proposal, though some service users and voluntary sector groups also disagreed.

Responses that disagreed said that this would be an added process, resulting in more paperwork and delay. They stated that there is already an approval mechanism under the Mental Health Act 1983 and Care Act.

> *"I don't think you should make too many barriers to admit people to inpatient settings. If you try to admit less people to inpatient to save money, you could cost lives."* (Service user)
>
> *"We do not support this idea. We believe that it may prevent people with LDs receiving the assessment and treatment they need particularly in urgent and crisis situation. We cannot see that any additional mechanism could work 24 hours a day seven days a week. Moreover, we cannot understand how someone who has never met the person before could make a judgment about their needs. What is essential is that the decision to admit to in-patient services and the objectives of any such admission are clearly documented so that they are transparent and challengeable."* (Academic / research organisation)

Other common comments, regardless of whether responses agreed or disagreed, included:

- this approach may increase the process time and have resource costs
- potential to be a lip service approach rather than considering applications in detail
- there would need to be a consistent and transparent approach
- could include voluntary sector and other service users on the panel
- potential negative connotations of the term 'gateway'
- requires the provision of alternatives in the community

> *"If such a system enables appropriate decision making and adds clarity then it should be helpful, however one would not wish it to be such a bureaucratic process that necessary admissions are delayed as this adds more stress to families and those in need of support. It will also hinge on the availability of other provision. It will be an empty process if there is not alternative."* (Family member of service user)

Q13. What would be the essential elements of such an approval mechanism?

In total, 132 responses commented about components of an approval approach that may be most important. Comments focused on processes, timing, accountability, participation and service provision, as listed below.

Processes

- should provide specific guidance about when a gateway review is needed
- provide a standardised set of safeguards and criteria
- make this a statutory requirement
- ensure a transparent process with records provided
- make sure people have a right to challenge
- have due regard to the relevant components of the Human Rights Act, Equality Act, Mental Capacity Act and Mental Health Act 1983

Timing

- make sure there are agreed timeframes for completion
- ensure that the processes can begin early enough in the care pathway
- ensure availability 24 hours a day

Accountability

- make sure there is independence in the process
- provide independent scrutiny

Participation

- include a multidisciplinary decision-making body, including clinical judgement
- make sure there is a strong emphasis on advocacy
- focus on good communication with service users and carers
- ensure the individual has been given full information to decide whether or not to consent to admission (including options and risks)
- make sure the process considers the individual's and carers' choices and preferences
- examine capacity to consent

Provision

- include evidence that other options have been considered and exhausted

- requires knowledge of alternatives and least restrictive options

- should assess the needs of the person and risks for themselves and others

There was no difference in the views expressed by organisations compared to individuals or between various types of organisations or individuals.

> *"The essential elements would have to be prompt system, involving people with the right level of expertise and able to make decisions including those involving funding, otherwise this could leave the person, their peers and supporters at greater risk. A clear flagging system to identify people at risk would be required, alongside individual crisis and contingency plans that identify the criteria and circumstances that might require increased support or admission."* **(NHS organisation)**
>
> *"The approval mechanism should involve a range of people in the decision making process (and this should be documented) and this range of people should ideally include family and professionals from at least two different organisations; one of which should be from a community based setting (or local authority; ideally the home authority). Most importantly, this must not just be, say, two medical professionals from the same acute treatment unit or community team, the range should be a true range and there should be independent scrutiny and periodic checks on the process."* **(Voluntary sector organisation)**

Q14. If there were to be such a mechanism, should it be given statutory force?

In total, 131 responses answered this question. There were mixed views. About half of the responses agreed that an approval mechanism should be given statutory force (47%). About one third thought it should not (31%) and the rest of responses were unsure, saying it depended on how the statutory duty was worded and implemented (23%).

Figure 14: Feedback from responses that answered Q14
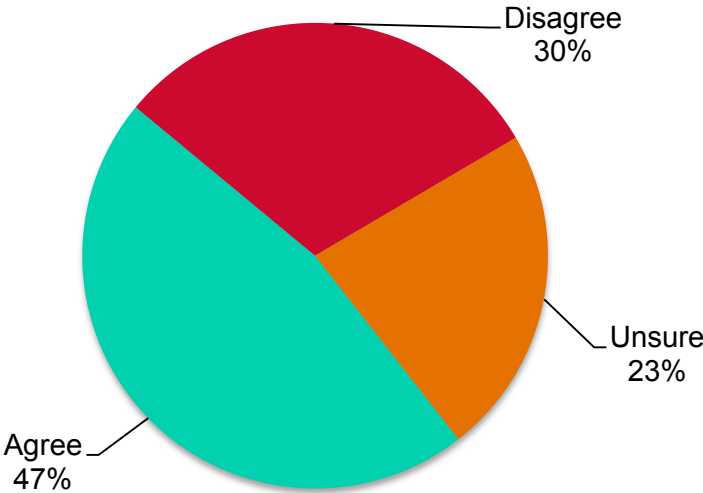
Note: Percentages are based on 131 responses

There was no difference in the views expressed by organisations compared to individuals or between various types of organisations or individuals.

Those that disagreed said that other similar mechanisms were already in place or that statutory force could lead to delays.

> *"We caution against introducing a statutory obligation as this could increase the likelihood of legal arguments and delays in care progression, additional costs and confusion with no clear benefit to the service user. We instead suggest that the mechanism be implemented through contracts and sharing best practice."* **(NHS organisation)**

A significant number of responses, including those from the NHS, local authorities and professional bodies, said that more information was needed about how the process would work before drawing conclusions.

> *"Because of the legal complexity of this aspect and the need to ensure that it doesn't introduce onerous new burdens and so that that the mechanism works sensibly in favour of the individual we would like to see further consultative work carried-out before any final decisions are made. These discussions should include the NHS, local authorities, providers, family representative groups, advocacy organisations, mental health specialists and critically the Law Commission. It will be important to understand how any new statutory duties interact with existing requirements and recent changes in the Mental Health Act Code of Practice."* **(Professional body)**
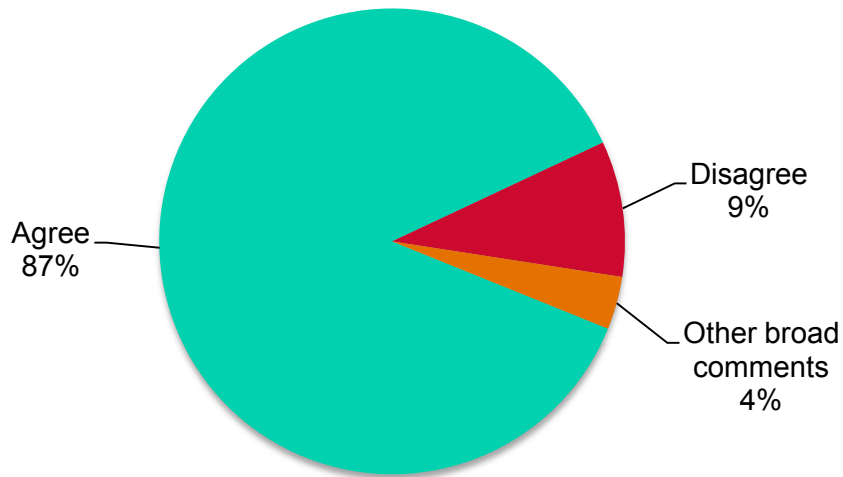
Q15. What do you think of the idea of strengthening (for example in statutory guidance) people's rights to request a transfer to a less restrictive setting or a setting closer to home or to ask for discharge?

Overall, 191 responses considered this question. There was widespread support for this proposal.

Figure 15: Feedback from responses that answered Q15

Note: Percentages are based on 191 responses

There was no difference in trends depending on whether responses were from organisations or individuals, or depending on the type of organisation or individual.

"Guidance to strengthen individuals' rights around the care and treatment they receive are always welcomed. However, the risks to that individual making certain choices must also be taken into account and the capacity of an individual to make those decisions robustly assessed. In addition mechanisms to ensure individuals safety must also be built into any statutory guidance, as in the MHA." **(Local authority)**

"These rights do, in reality, already exist and people do exercise these rights. However, it is not always possible for NHS commissioners to move them nearer home. Similarly clinicians as well as service users may request a move for the service users to a less restrictive setting but NHS commissioners at times struggle to accommodate this even if recommended as beneficial clinically. If this was strengthened in statutory guidance, the mechanisms for NHS commissioners to be able to achieve this would need to be improved." **(Independent sector service provider)**

Responses stated that this would require appropriate alternative provision to be available.

Those that disagreed said that there were already mechanisms in place to support this or raised questions about practicalities.

Q16. Do you agree that, as far as practicable, such discussions should involve professionals or staff based in the community or expert on community based options?

There were 175 responses that considered this question. There was widespread support for this proposal.

Figure 16: Feedback from responses that answered Q16
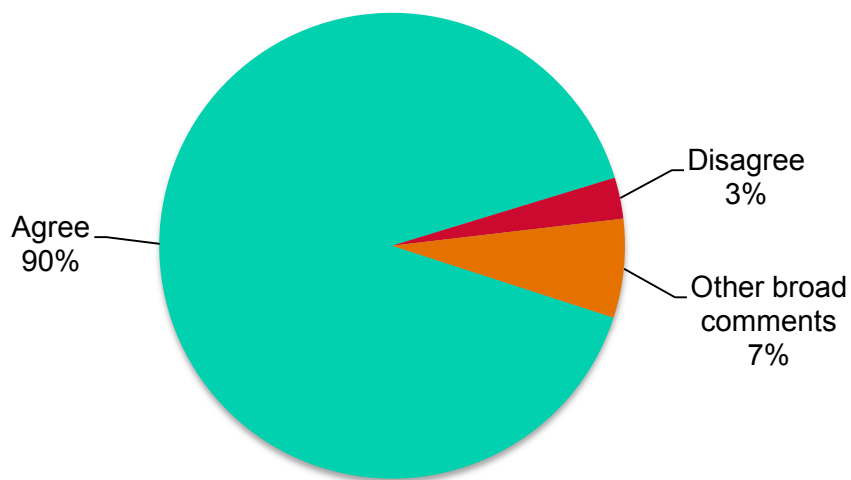
Note: Percentages are based on 175 responses

There was no difference in trends depending on whether responses were from organisations or individuals, or depending on the type of organisation or individual.

Responses that did not agree with this proposal were largely concerned that this may dilute the involvement of specialists or that this may not be practical.

Other common comments, regardless of whether responses agreed or disagreed, included:

- discussions should include experts by experience: service users and carers
- discussions should include a wider team such as social workers, advocates and voluntary sector organisations
- it will be important to have clarity about decision-making authority and how disagreements will be resolved
- it is essential to improve staff training and skill mix
- the wording 'as far as practicable' may be used as a reason not to implement this

"Discussions should involve family and other people who know the individual well, including professionals, community based support and experts. In many cases individuals have long-standing conditions, so any professional involved must have experience of the condition, and the impact it has on the individual. This should be part of a multi-disciplinary approach." **(Voluntary sector organisation)**

Q17. How can we strengthen provider and commissioner accountability in their approach to such requests?

In total, 152 responses provided feedback about this question. Suggestions for strengthening accountability focused on processes, personnel, monitoring and responsibilities. The most common suggestions were to make this a statutory requirement, use standardised public reporting mechanisms and have a clear process with agreed timescales for action.

Processes

- need a clear process with paperwork, record keeping and timescales (23 responses)
- build this into contracts and commissioning frameworks (14 responses)
- have a clear process for challenge and complaints, with an independent arbitrator (12 responses)
- provide clear central guidance (3 responses)
- promote best practice models (1 response)
- transparent process, such as meeting in public or recording meetings (3 responses)

Personnel

- involve carers, voluntary sector, advocates and community staff (12 responses)
- each organisation could have a named link worker or someone who is responsible for compliance (8 responses)
- enhance staff training will strengthen knowledge and skills (3 responses)

### Monitoring and responsibilities

- make this a statutory duty (27 responses)
- set up clear accountability arrangements (11 responses)
- use standardised reporting mechanisms such as publishing anonymised data about the number of requests and outcomes (25 responses)
- build this into CQC and Mental Health Act 1983 Tribunal processes (12 responses)
- ensure regular review of the process (5 responses)
- have sanctions for lack of compliance or incentives for compliance (4 responses)

There was no difference in the views expressed by organisations compared to individuals or between various types of organisations or individuals.

Q18. We want to explore how everyone can receive care planning and discharge planning from the time when they are admitted to hospital. One way we could do this is through new statutory guidance (complementary to the Mental Health Act Code of Practice). What do you think of this idea?

Overall, 187 responses answered this question. Responses generally agreed that people should receive care planning and discharge planning from the time when they are admitted, but there were mixed views about whether this should be a statutory responsibility. Although two thirds of responses broadly agreed (64%), many of these appear to have been agreeing with the principle of early discharge planning, rather than statutory guidance. One in five responses made other broad comments, particularly in terms of supporting early discharge planning as a principle.

Figure 17: Feedback from responses that answered Q18
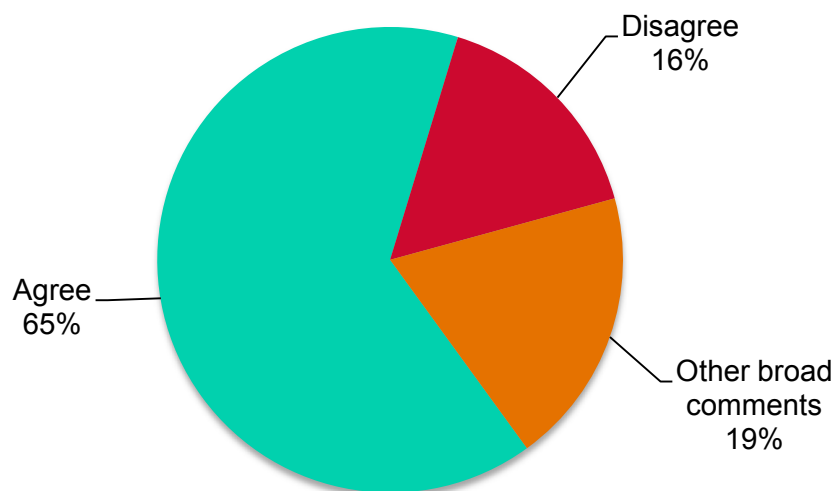
Note: Percentages are based on 187 responses

There was no difference in trends depending on whether responses were from organisations or individuals, or depending on the type of organisation or individual.

Responses that agreed with this proposal said it would ensure good practice and earlier discharge.

> *"Early discharge planning involving individuals and their families is crucial to ensure that people do not get stuck in hospitals. Therefore we agree that this should be supported by statutory guidance that specifies timescales and the requirement to involve the individual, family members or carers. We think that discharge planning should begin within the first three weeks and that the review period should be specified in the plan (and that should be at least every 14 calendar days)."* **(Voluntary sector organisation)**

> *"Effective and timely discharge planning is crucial in order to prevent people from becoming stuck in the hospital system. It is essential that people receive discharge and after-care planning from the time they are first admitted to hospital and that they, or their representatives, are supported to be centrally involved in this process. It seems unlikely that this aspect of care planning is currently being monitored in a reliable, nationally co-ordinated way and we think that the system used in Wales which ensures that those receiving secondary mental health services have an eligible care co-ordinator and a statutory care and treatment plan has much to recommend it."* **(Professional body)**

Some responses that disagreed said that this was already happening in practice or that there were other frameworks that applied, such as the Mental Health Code of Practice or Court of Protection. Other responses that disagreed felt that more fundamental culture change was needed, not new legislation.

> *"Care planning and discharge planning in particular is already built into Mental Health Act application / code of practice and is embedded in CPA. The issue isn't that it's not there, it's that it isn't routinely applied or discussed. Making it statutory may not improve this. It's about changing culture and practice that will make the difference."* **(NHS organisation)**

> *"This is something locally we already seek to do. Discharge into the community is not always as early as one would prefer due to the absence of robust and effective community placements. Statutory guidance would not speed up the process of discharge in this area."* **(Health professional)**

Q19. Should we require a care plan, including a plan for discharge, to be produced involving individuals and their family within a specified number of weeks of admission and to specify when it will be reviewed?

Overall, 176 responses considered this question. There was widespread agreement with this proposal.

Figure 18: Feedback from responses that answered Q19
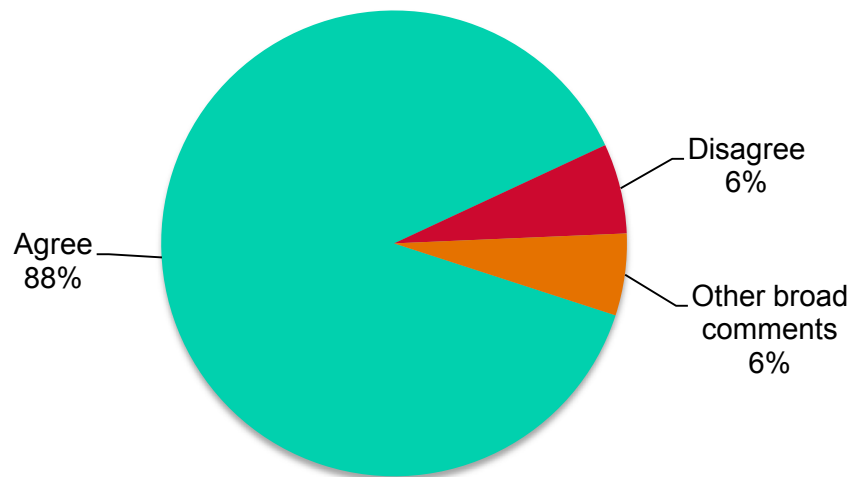
Note: Percentages are based on 176 responses

There was no difference in the views expressed by organisations compared to individuals or between various types of organisations or individuals.

Those that agreed said that this could be useful for ensuring processes were followed and that there was wider involvement.

> *"We welcome a duty for care plans and discharge plans to be produced at the earliest opportunity with the individual and their family carer. Meetings must be timely and reviewed appropriately – we know that 'reviews' have taken place with little input or real thought about the individual's situation. Reviews must not simply be a 'box ticking' exercise. Consideration must be taken about who attends meetings and advocacy support must be available for family carers."* **(Voluntary sector organisation)**

Those that disagreed said they did not believe that rigid timelines or prescribed templates were helpful.

> *"Not everyone is ready for this type of plan within a number of weeks. For some people, it can take a long time to work out what level of support they will need at the time of discharge to maintain recovery. Assessment, leave, planned visits are all part of this and it depends very much on the needs and circumstances of the individual."* **(Social care professional)**

Other common comments, regardless of whether responses agreed or disagreed, included:

- a care plan should be produced more promptly, not within a specified number of weeks
- a care plan should be prepared within two weeks
- a review date should be specified
- service users and carers should be involved in the development of a care plan
- information should be collected centrally to monitor adherence
- the proposal should apply to all, not just certain groups of service users

Q20. Could more be achieved through any existing policies or guidance on delayed discharge?

In total, 110 responses answered this question. However most did not agree or disagree with whether more could be achieved through existing policies. Instead, responses concentrated on providing other broad comments about areas that could be developed further.

Figure 19: Feedback from responses that answered Q20
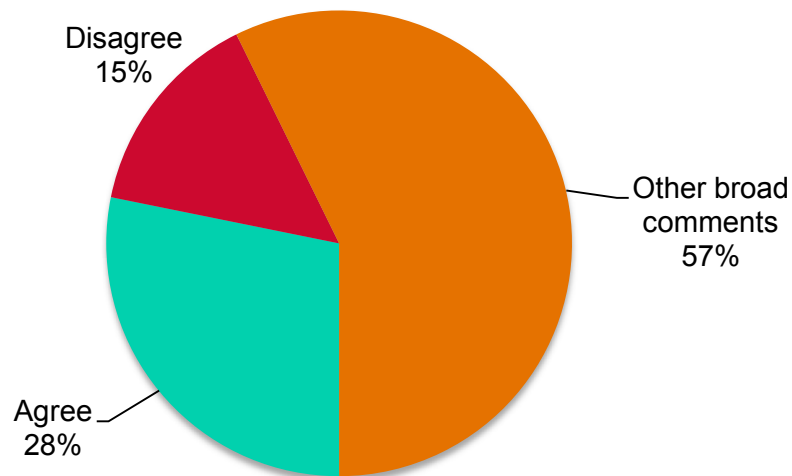
Note: Percentages are based on 110 responses

There was no difference in trends depending on whether responses were from organisations or individuals, or depending on the type of organisation or individual.

Responses that agreed stated that more could be done to implement relevant components of the following policies and guidance:

- Delayed Discharge Act
- Mental Capacity Act
- Mental Health Act Code of Practice
- Community Care Act
- Human Rights Act
- care programme approach (CPA)
- care and treatment reviews
- NHS standard contract

Some responses that disagreed said that current policies and guidance were not fit for purpose.

Most responses made broad comments about areas that could be developed further. Common comments included:

- need enough resources to put existing policies into practice
- need to share local policies and good practice
- should set standards for how to define delayed discharge
- should hold organisations to account for delayed discharges, including financial penalties
- need public reporting of outcomes
- need to better incorporate the views of service users and carers
- existing policies focus on older people rather than younger people

> *"We feel that the main issue in respect of existing policies and guidance relates to a lack of resources and a joined up approach by which to facilitate an individual's discharge and care in the community. It would for example be useful for a member of the community team to visit the individual as soon as practicable to plan a mutually beneficial discharge but this does not always take place. It is for reasons such as this that we feel statutory guidance will assist in ensuring that appropriate plans are in place to ensure the needs of the individual are met."* **(Voluntary sector organisation)**

Q21. The Mental Health Act Code of Practice has just been updated. In line with this, we want to explore how people and their families can be more involved. One idea is that people and their families or advocates should be able to challenge whether an Approved Mental Health Professional has properly taken into account their wishes and feelings in the interview which takes place before they make an application for admission under the Mental Health Act. What do you think about this idea? (We would need to consult later on how the details of this process might work.)

Overall, 178 responses considered this question. There were mixed views. About three quarters of responses thought that people and their families should be able to challenge decisions (76%). However, NHS organisations, professional bodies and health professionals were more likely than others to disagree or query practical issues.

Figure 20: Feedback from responses that answered Q21
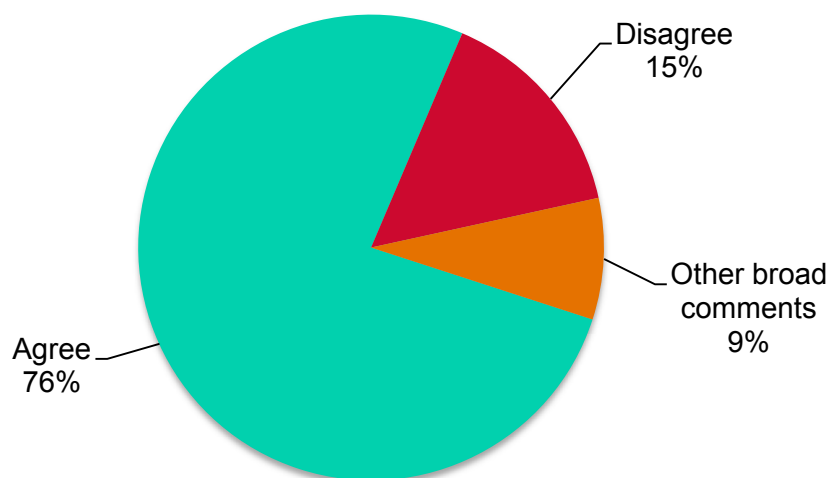
Note: Percentages are based on 178 responses

Responses that agreed with this proposal emphasised the importance of family involvement and the need for good advocacy.

> *"Fundamental to protecting people's rights is a robust process to enable people to challenge an admission or renewal under the Mental Health Act (MHA). Independent advocacy has an important role to play for people at risk of admittance to inpatient services."* **(Voluntary sector organisation)**

> *"Several families have spoken to us about how they felt particularly shut out of decision-making when the individual in question was under section. They also raised concerns that they were often only informed / consulted after a decision was made. A right to challenge this … would provide an important check against wrongful deprivation of liberty. It would also acknowledge that families have a huge amount of expertise and knowledge about the person receiving treatment that could be of use to professionals."* **(Voluntary sector organisation)**

Both responses that made broad comments and responses that disagreed with this proposal focused on how the process would be implemented in practice and whether it may lead to delays.

> *"The current Mental Health Act assessment process already involves three professionals and consultation with the nearest relative and a robust opportunity to hear the views of the patient which already must be taken into consideration as part of the assessment. The proposals will not change the outcome of Mental Health Act assessments but will be costly and difficult to administer. The risk of delays in hospital admission are real."* **(NHS organisation)**

> *"This is a very sensitive area and whilst I agree that absolutely the patient and/ or families views, wishes and feelings need to be taken into account I have seen occasions during care and treatment reviews where this has had a negative impact on the patients outcome. An example of this is where the family may be in denial as to the serious risk their child puts others in. Watching a loved one being admitted to hospital for the first or even second time and particularly when it may be without their consent is emotionally draining for the family."* **(Health professional)**

Q22. Which of three potential options for safeguards around renewal do you think would have most impact?

In total, 102 responses commented about the three options outlined in the consultation documents. There was no clear majority view.

- 15% of responses supported Option 1, which involved requiring section 12 doctors to agree renewals of detention, as well as admission and that this section 12 doctor should be from a different organisation

- 27% of responses supported Option 2, requiring that one of the responsible clinicians involved in agreeing renewals of detentions should be from the home locality which is responsible for that person if they are placed out of area

- 45% of responses supported Option 3, requiring that one of the responsible clinicians involved is from a different organisation and has strong community knowledge and experience

- 10% of responses suggested that a combination of all three options would be useful

- 3% of responses suggested a combination of Options 2 and 3

It is important not to view these proportions as a vote, because they mix responses representing one person with responses representing larger groups or whole organisations.

There was no difference in trends depending on whether responses were from organisations or individuals, or depending on the type of organisation or individual.

Q23. Do you have any views on risks or costs presented by any of these options?

In total, 73 responses commented on the potential risks and costs of options, as listed below.

Option 1

- risk of collaboration / lack of impartiality
- additional work, delays and costs
- difficulty accessing section 12 doctors
- contracting complexities: clear agreements, funding and commissioning routes would be needed, due to cross-organisation working
- not taking into account service user and family views

Option 2

- impractical as consultant psychiatrists and GPs are reluctant and seldom have the time to travel out of area
- additional work, delays and costs
- difficulty accessing doctors
- without someone of equivalent professional status, professionals may cede power to the original clinician
- risk of bias if the assessing clinician does not feel there are sufficient resources locally to meet the service user's needs

Option 3

- difficult to achieve in practice given demands / resources / capacity
- difficult to co-ordinate
- may open up decisions to a large number of people
- additional work, delays and costs
- risk of setting unrealistic expectations on other agencies if person does not know the area
- clear agreements, funding and commissioning routes would be needed due to cross-organisation working

There was no difference in trends depending on whether responses were from organisations or individuals, or depending on the type of organisation or individual.

Q24. Do you have any views on the decision making processes around community treatment orders and how they could be improved?

Overall, 82 responses answered this question. Responses suggested that decision-making processes about community treatment orders should involve service users, carers, advocates and a multidisciplinary team and that more consistent approaches could be used. Common comments are listed below:

Participation

- service user, carers, advocates and a multidisciplinary team should be involved in decision-making (28 responses)

- need more clarity around whether the individual needs to understand the criteria which may result in them being recalled. Issues of capacity mean that community treatment orders are not usually used with people with learning disability (15 responses)

- should require two medical recommendations as well as approved mental health professional input throughout, rather than only at a late stage (6 responses)

- consider extending the role to other health and social care professionals (6 responses)

- people should be informed of their right to an independent advocate (1 response)

Processes

- needs more consistency with other approaches for detention and renewals (13 responses)

- needs to have a clear timeframe (1 response)

- have a formal meeting and structure at the time of renewal (3 responses)

- difficult to enforce (5 responses)

- should be backed up by clear crisis contingency plans (1 response)

- much of the effectiveness is dependent on the availability of funding and resources to ensure supervision and care (3 responses)

- there may be a lack of evidence of effectiveness of community treatment orders (2 responses)

There was no difference in trends depending on whether responses were from organisations or individuals or depending on the type of organisation or individual. Organisations were more likely to respond to this question than individuals.

Q25. Guidance could say that only organisations that include self and family advocates in their governance should get contracts with the local authority or the NHS to provide services for people with learning disability or autism. What do you think about this idea?

Easy Read Q3. Do you think that only services that involve people with a learning disability or autism and families running them should get contracts with the local authority or NHS?

In total, 320 responses answered these questions. There were mixed views. Two thirds of responses supported this proposal (67%). However individuals were more likely than organisations to agree. Organisations may represent many people, so it is important to weight their feedback appropriately. There was no difference in trends between different types of organisations.

Figure 21: Feedback from responses that answered Q25 and Easy Read Q3
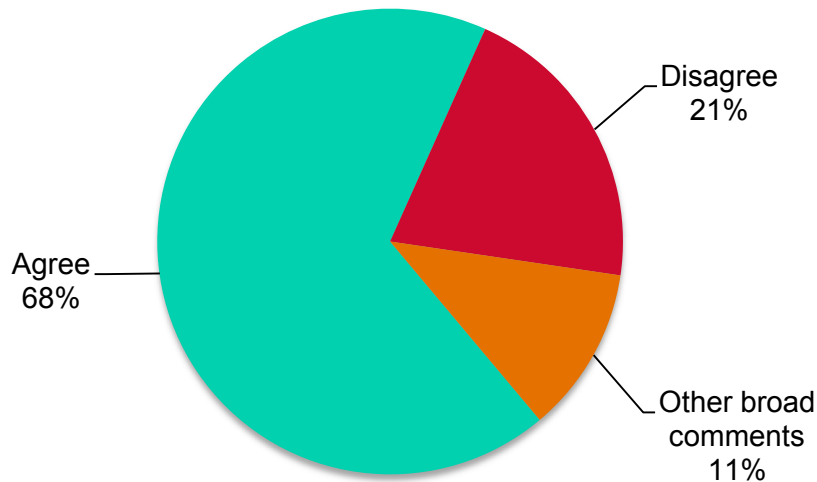
Note: Percentages are based on 320 responses

Responses that agreed with this idea thought it would help make sure that the views of service users were listened to when planning services.

"We are in agreement with this idea; the lived experiences of individuals should form the basis of all decision making processes and in turn organisations who adhere to this view should receive contracts to provide services." (Voluntary sector organisation)

Some responses that disagreed with this suggestion thought that it could lead to tokenism. Others said that it was important that some organisations maintained independence and not rely on funding from the NHS or local authorities. Others were concerned that this may mean that only larger organisations would fulfil requirements. Responses that disagreed generally thought the principle of involvement was worthwhile, but did not necessarily agree with making it a requirement for contracts.

"We do not believe the proposal … to make it a contractual requirement for providers to engage people with learning disabilities and autism as board members is enough on its own to effectively sustain the rights of individuals with highly complex needs and enable their voices to be heard. Specifically we have a concern that making this a contractual requirement risks tokenism, could lead to poor governance and risks excluding providers who are otherwise well-equipped to deliver good outcomes for people with learning disabilities or autism from the care market." (Voluntary sector organisation)

"It is not clear what the benefit could be in limiting who commissioners should contract with through tendering process. Families and individuals must be listened to, but it must be noted that their assessment of a set of needs could be radically different to those of commissioners and professionals who assess needs. There do need to be transparent methods to resolve differences of opinion. Tendering for this service needs to be clear about the make-up of people employed to deliver advocacy service and the expected values required." (Local authority)

Other common comments, regardless of whether responses agreed or disagreed, included:

- must be accompanied by effective guidance on how to meaningfully involve people

- could use a 'kite mark' system to assure people that a service meets certain standards

- concern that the involvement of people with learning disabilities and family carers would be tokenistic and done in the cheapest way possible to be eligible for funding

- might restrict contracts to big centralised organisations. Small local provision may not be able to meet or evidence the requirements of commissioners

- it is important that people with more severe and profound issues are able to shape services as well as those with mild or moderate issues

- should apply to all conditions

Q26. What are your views on making Independent Mental Health Advocates available to patients who lack capacity (or competence) on an opt-out basis?

Easy Read Q4. These ideas are trying to make sure more people get support from families, social workers and advocates called Independent Mental Health Advocates. They have a part to play in people's care and helping them to be listened to. Do you think they will help?

There were 318 responses that answered these questions. There was widespread support for this proposal, with nine out of ten responses thinking that this was a good idea (88%).

Figure 22: Feedback from responses that answered Q26 and Easy Read Q4

Agree
88%

Disagree
7%

Other broad
comments
5%
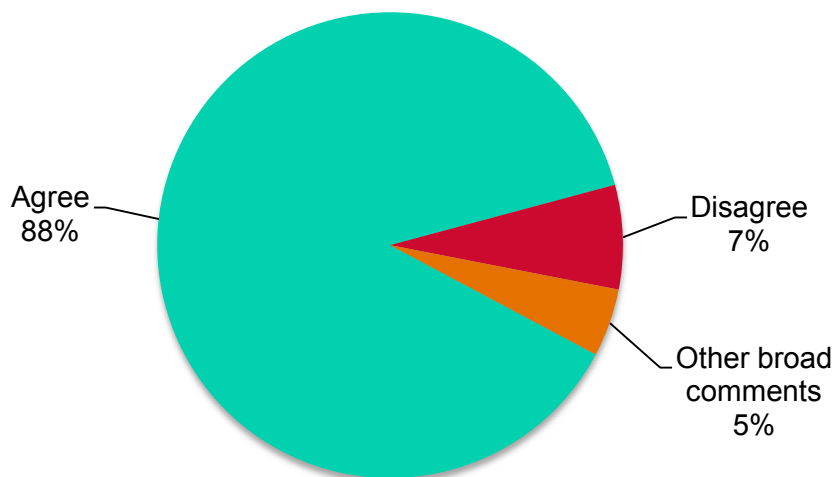
Note: Percentages are based on 318 responses

There was no difference in the views expressed by organisations compared to individuals or between various types of organisations or individuals.

Responses that disagreed sometimes expressed concern about how people with limited capacity would be able to opt out. Other responses that disagreed felt that families could be more useful, where available and appropriate.

Both responses that agreed and disagreed noted that there were currently issues with access to advocacy services.

> *"[We] would support this view. However, we are very aware that the funding and accessibility arrangements would need to be substantially strengthened in order to facilitate this as IMHA availability is currently inconsistent in some geographical locations."* **(Independent sector service provider)**

Responses that agreed and disagreed also noted that it was important for advocates to be truly independent.

Q27. Have we considered all the safeguards we would need to protect patient confidentiality?

Overall, 103 responses answered this question. There were mixed views. Two fifths of responses agreed that the Department of Health had considered all safeguards needed to protect confidentiality (45%) and two fifths thought this was not the case.

Figure 23: Feedback from responses that answered Q27
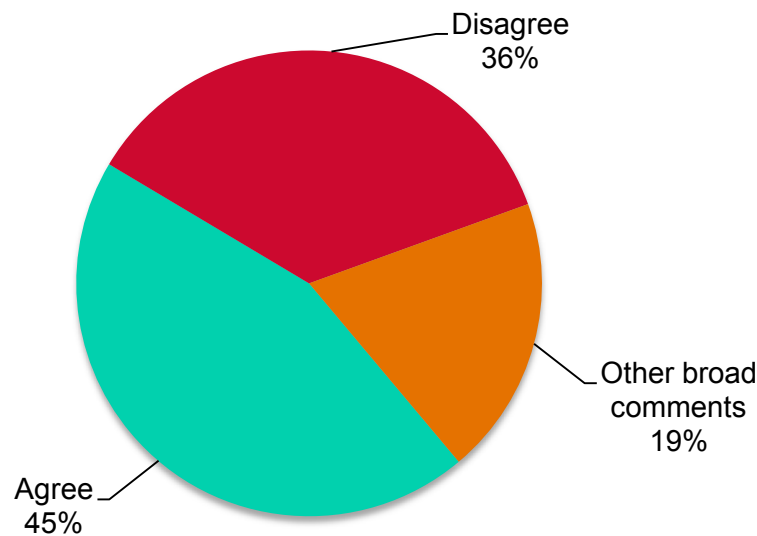
Note: Percentages are based on 103 responses

There was no difference in trends depending on whether responses were from organisations or individuals, or depending on the type of organisation or individual.

Issues that some responses did not think had been adequately addressed included:

- practical issues with maintaining confidentiality and what happens if it is breached

- ensuring advocacy organisations and advocates have clear information governance protocols

- the process for capacity assessments

- may assume that families will always act in people's best interests

- strategies for continuously reviewing mechanisms

- additional safeguards for people with special needs, such as those who are deaf

- aspects of the Data Protection Act

Q28. What do you think about the idea that we should explore changing the law so that people choose their own "nearest relative" (retaining a hierarchical list to be used if necessary)?

In total, 171 responses answered this question. There were mixed views. About three quarters of responses thought it was a good idea to explore changing the law, but others felt strongly that this was not needed. There were a number of broad queries about how this would be implemented in practice. Whilst there was a general trend towards supporting this proposal, responses thought that more work was needed to address implementation issues.

Figure 24: Feedback from responses that answered Q28
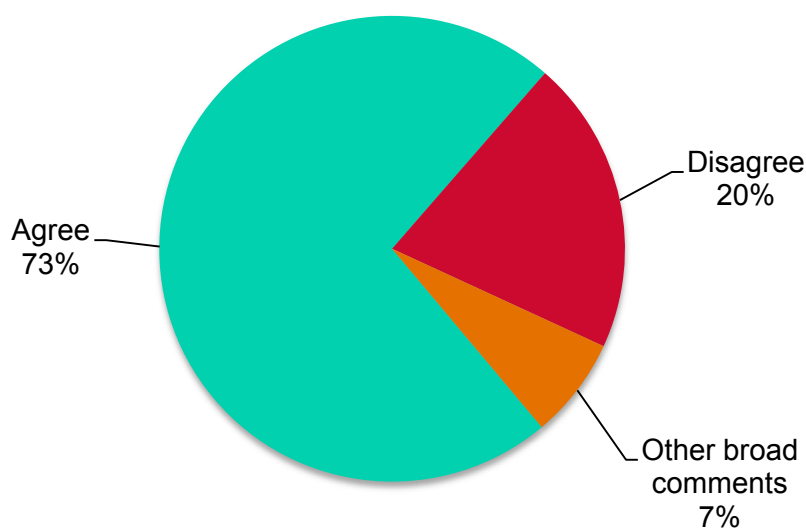
Note: Percentages are based on 171 responses

Organisations were more likely than individuals to respond to this question. However there was no difference in the general trends from organisations or individuals, or depending on the type of organisation or individual.

Responses that agreed said that this proposal would support more person-centred care and make the nearest relative more appropriate and meaningful for service users.

"This change in the law … would better reflect an individuals' reality of what they consider a 'near relative' to mean to them. The concept needs to be updated and consistent to reflect other guidance. This change in the law fits with our view that an individual should be central to the decision making process and have choice and control." **(Voluntary sector organisation)**

Responses that disagreed sometimes felt that the current system was appropriate or that changes may add an extra layer of complexity.

"Choice implies capacity and patients without capacity to decide who their nearest relative is will not be able to choose. Will the current hierarchical list remain as default for those cases? If so, it is likely that challenges will arise as patients will argue that they did/didn't have capacity to decide and change their mind about who their nearest relative should be. Relatives who are not chosen will challenge decisions made by patients and allege that they lacked capacity to decide. We believe the system works as it is as the nearest relative can be changed, displaced or not consulted (and application made to court by local authority)." **(NHS organisation)**

"There would undoubtedly be some benefit to the identification of individuals who know the person well, but are not a family member, acting as nearest relative and giving people a choice would help. This does, however, potentially set carers and families at odds in making some choices. It is unclear that the complexities involved in changing the legislation to this end would bring about significant improvement to the situations where it is currently problematic without, at best, further complicating the process and at worst increasing some peoples vulnerability." **(Professional body)**

Common comments, regardless of whether responses agreed or disagreed, included:

- the appropriateness of this approach depends on the capability of the person to understand the concept and be able to choose without coercion

- a process would need to be in place to stop people from trying to please persuasive relatives

- guidance should address instances when parents are divorced and not on good terms and other specific circumstances

- it would be useful to strengthen the rights of nearest relatives in relation to involvement in decision-making

Q29. Do you agree that this should reduce the cost of displacement and disputes?

There were 119 responses that considered this question. Around half of these responses thought that changing the law about nearest relatives would reduce the cost of displacement and disputes (55%). About half did not think this was the case (45%).

Figure 25: Feedback from responses that answered Q29
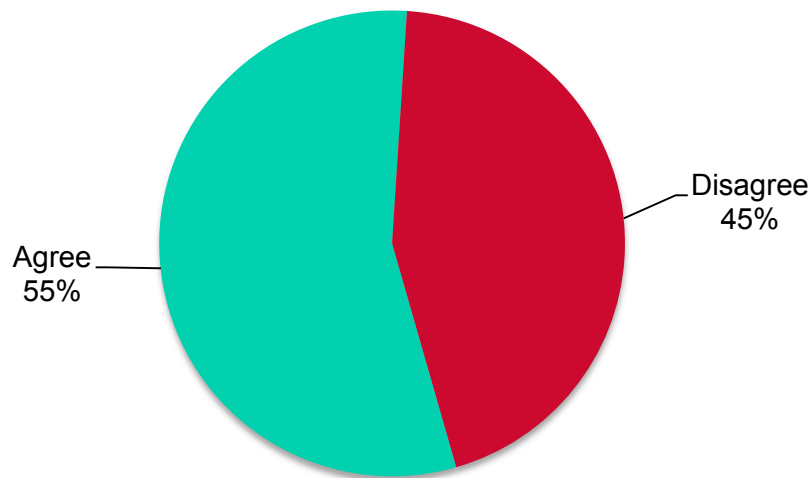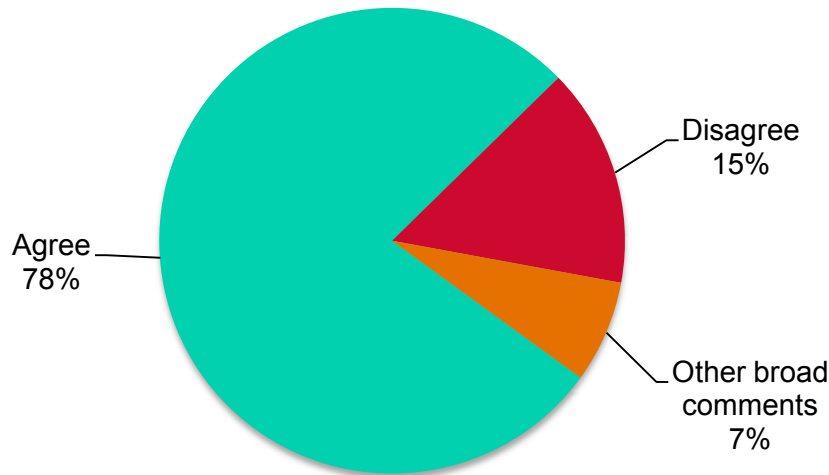

Note: Percentages are based on 119 responses

Responses that disagreed felt that either the change would have a negligible impact or that disputes may increase because biological 'nearest relatives' may make complaints if another person was chosen by a service user without proven capacity to make this choice.

There was no difference in trends depending on whether responses were from organisations or individuals, or depending on the type of organisation or individual. Organisations were more likely than individuals to comment on this question.

Q30. A named social worker could be responsible for working with the person and their family to keep them informed and involved and to make sure less restrictive and community based plans are considered. What do you think about this idea?

In total, 197 responses answered this question. There was broad agreement that having a named social worker would be a good idea, though responses were concerned about the feasibility of this.

Figure 26: Feedback from responses that answered Q30

Note: Percentages are based on 197 responses

Responses that disagreed tended to come from service users, carers or voluntary organisations representing service users and carers. Those that disagreed often said social workers may prioritise their responsibilities to their employer rather than to service users and families. Other responses that disagreed stated that social workers may not be best placed to fulfil this role.

> *"Disagree with this idea because social workers are working for local authorities and therefore acting on the council's behalf and not on behalf of the vulnerable person. They do not have the power to give information to people and their families/carers and do not have authority to make decisions."* **(Family member of service user)**

Common comments, regardless of whether responses agreed or disagreed, included:

- there may be too few social workers available

- a named worker may be appropriate but this need not always be a social worker

- this may place a significant financial burden on local authorities

"We agree with this proposal provided that proper resources and funding are made available to support the implementation and effectiveness of such added responsibilities. We do not see any merit in adding to the burdens of social workers if at the same time measures are not taken to ensure that they are in fact able to fulfil the expectations." **(Voluntary sector organisation)**

"A named person to act as a contact is a very good idea. It does not necessarily need to be a social worker. Unless there is some legal requirement, this should be about skills and knowledge rather than profession. All staff involved in care should be expected to have the skills required." **(Local authority)**

Q31. What else, if anything, is needed to support people and families to raise issues if something has gone wrong?

Easy Read Q5. Do you think anything else is needed to help people speak up is something has gone wrong?

There were 278 responses that answered these questions. The key things that responses thought would help people and families raise issues were good processes, support services, appropriate personnel and wider culture change, as outlined below. The most common suggestions included providing clear information about rights and processes, having a simple complaints process and providing fully funded advocacy support.

Processes

- information about rights and how to speak up and raise issues, including in easy read, pictures and different languages (58 responses)

- clear simple route for complaints with signposting and contact list of helpers (45 responses)

- requirement to respond to issues within short set time period (18 responses)

- one point of contact for all complaints, not separate for health, social care and independent providers (8 responses)

- routine use of short standardised questionnaire to gain feedback from service users and carers, including anonymous online survey (3 responses)

- publishing findings about reviews of complaints and safeguarding (4 responses)

- follow-up review within a certain period to ensure issues have been dealt with (5 responses)

- use a range of methods to allow people to raise issues such as online, contacting a named individual, completing a form and complaints boxes (6 responses)

- have an easy appeals process (4 responses)

- use cameras to monitor staff behaviour (3 responses)

Support services

- fully funded independent advocacy for service users, carers and nearest relatives, perhaps with a weekly drop-in at units and ability to supply an advocate promptly (51 responses)

- finances for local self-help groups to provide resources and advice (10 responses)

- impartial arbitration service (12 responses)

- access to free independent legal advice (12 responses)

- national helpline (2 responses)

Personnel

- single point of contact such as a key worker or someone identified to go to for help (25 responses)

- independent liaison officers or similar (15 responses)

- senior named officer who has responsibility for monitoring issues (5 responses)

- circles of support and peer support (7 responses)

- training for staff to help people complain (4 responses)

- inspections by people with lived experience of learning disabilities and mental health issues and service users working in complaints teams (3 responses)

Wider systems issues

- work to change organisation culture so there is more of a focus on areas of improvement, not defensiveness (13 responses)

- system for regulators, professional bodies or other central body to address concerns about practice (6 responses)

- better support for whistle-blowing, such as a centralised service (6 responses)

There was no difference in the suggestions made depending on whether responses were from organisations or individuals, or depending on the type of organisation or individual.

Chapter 4: The Mental Health Act 1983

This chapter describes feedback about the section of the consultation documents labelled 'My rights under the Mental Health Act.'

Q32. We are considering whether and how the treatment of learning disabilities and autism under the Mental Health Act could be changed. We have set out three potential options. Which of options 1), 2) and 3), if any seems most appropriate?

Easy Read Q6. What do you think about the idea of people with learning disability and autism not being sent to hospital under the Mental Health Act or only in a smaller number of situations or only sent if a court sends them?

In total, 245 responses answered these questions. There were mixed views, with no clear consensus on the best way forward.

- 11% of responses supported Option 1, which was excluding learning disability and autism from the Mental Health Act 1983 definition of 'mental disorder'

- 15% of responses supported Option 2, which was about changing the definition of 'mental disorder' to make it more specific or narrower, including altering the current learning disability qualification and adding a new 'autism qualification'

- 14% of responses supported Option 3, which was excluding learning disability and autism from the Mental Health Act 1983 definition of 'mental disorder' under part 2 (civil sections) but not part 3 (criminal justice sections)

- 37% of responses said they approved of treating people with learning disabilities and autism differently under the Mental Health Act 1983, but did not support a particular option

- 23% said that no change was needed, the current legislation could be applied more robustly

There were no clear trends in whether organisations were more likely to prefer a certain option than individuals or whether different types of organisations and individuals had varying preferences. There appeared to be a slight preference amongst statutory services for Option 2 or 3.

Q33. What is your view on the potential risks or unintended consequences of the options?

In total, 123 responses answered this question. Suggestions that responses made about potential risks with each of the options are summarised below.

Option 1

- fewer safeguards for people, such as right to an advocate

- will not be compliant with Human Rights Act as is not inclusive

- increase in Deprivation of Liberty Safeguards applications

- generic mental health teams may not fully understand the needs and requirements of those with learning disabilities and autism

- a clear and separate process for dealing with aggressive and challenging behaviour will be required

- people may be denied appropriate treatment and end up in the criminal justice system

- risks to self and others may not be appropriately managed

- potential for increased restrictive practices and inappropriate care

- may complicate and dilute the current law

- removing these definitions from the criminal justice sections would mean that a person could not use a learning disability or autism diagnosis as part of a defence in a criminal case

Option 2

- potential for people to 'fall through the net' if the definition is very narrow

- less appropriate management of vulnerable people with learning disabilities or autism who display behaviour that challenges

- subjective decision making of when intervention is required in the best interest of the service user

- may create two 'classes' of people

- does not tackle the fundamental issue so people could still be detained indefinitely on the grounds of a disability

- difficult to implement

Option 3

- more people may be pushed through to the criminal justice system

- there could be stigma attached from using the criminal justice system when people could have been diverted using civil sections

- less appropriate management of vulnerable people with learning disabilities and/or autism who display behaviour that challenges

- generate debate about which condition is the primary disabling condition

- appears to confuse the legitimate aim of mental health law, as though mental health detention is just an alternative criminal justice sanction

- may complicate and dilute the current law

- difficult to implement

Q34. We want to explore changing the law so that there is one set of criteria for detention for both assessment and treatment under the Mental Health Act (amending sections 2 and 3). What do you think of this idea?

Easy Read Q7. What do you think about the idea of making the Mental Health Act law easier to understand and follow with one path into hospital for assessment and treatment?

There were 251 responses that answered these questions. Around eight out of ten responses agreed with the proposal (79%) though many of these were agreeing that the Mental Health Act 1983 should be easier to understand, rather than agreeing about a single path for assessment and treatment.

Figure 27: Feedback from responses that answered Q34 and Easy Read Q7
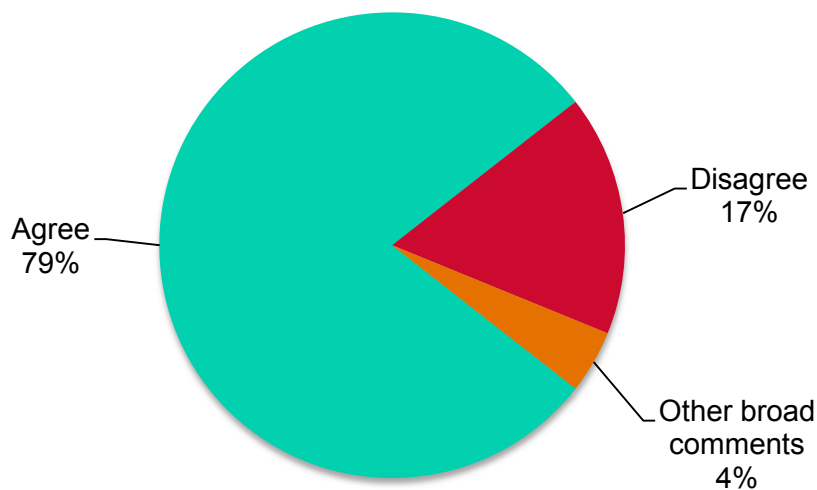
Note: Percentages are based on 251 responses

Responses that disagreed suggested that it was important to maintain some differentiations in terms of timelines and purpose. These responses were most likely to come from NHS organisations and professional bodies.

> *"It is our experience that section 2 and 3 of the MHA offer very different and specific roles which are designed to meet different needs, particularly in the interest of patient outcome. We would be particularly concerned that this change would impose the ramifications of those requiring treatment under section 3 on patients who otherwise benefit from short often isolated assessment under section 2, without any ongoing implications for that individual."* **(NHS organisation)**

> *"There is a risk that by conflating these sections one loses the distinction between their purposes and increases the likelihood that patient moves into a treatment phase that is not necessarily required, without the option of a rapid assessment and discharge with a much shorter statutory period."* **(Professional body)**

Common comments, regardless of whether responses agreed or disagreed, included:

- the need to make criteria available in an easy to understand format

- the need to make people's rights clearer to service users and families

- the importance of making sure safeguards stay in place, especially the right to apply for a tribunal as early as possible

- detention should never be for a period of more than 28 days without the right to appeal

- detention should be differentiated for 'first episode' and 'relapse' or 'recurrent' issues

- have one process which covers both the Mental Health Act 1983 and Mental Capacity Act

- if entitlement to section 117 aftercare were to apply to all those on the new single detention criteria it would impact on local authority costs and to a lesser extent NHS costs

Q35. We think we should clarify in law that the Mental Health Act Code of Practice should apply to clinical commission groups and to NHS England commissioning. What do you think of this idea?

Easy Read Q8. Do you think we should change the law to make sure that people who plan and buy services for the NHS have to follow the Code of Practice guidance about the Mental Health Act like hospitals do?

In total, 260 responses answered these questions. There was widespread support for this proposal.

Figure 28: Feedback from responses that answered Q35 and Easy Read Q8
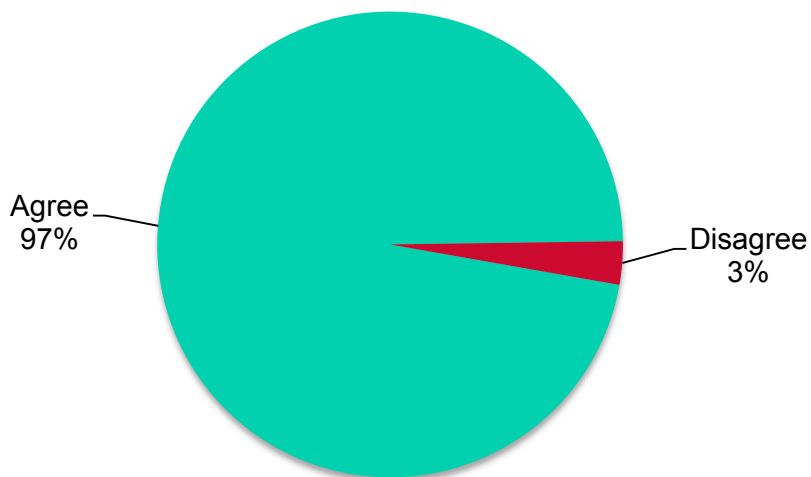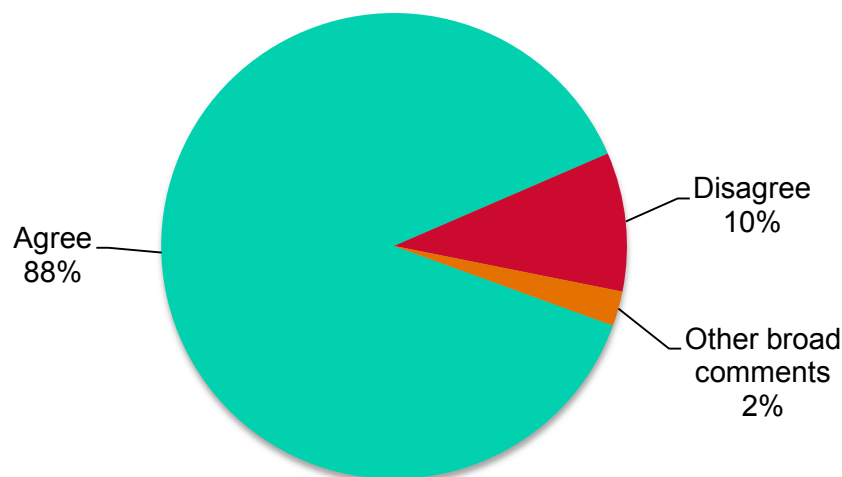

Agree
97%

Disagree
3%

Note: Percentages are based on 260 responses

Responses that disagreed said that they were unclear what benefits this proposal would bring. These responses were from individuals.

Q36. We highlighted some parts of the Review carried out into the operation of Sections 135 and 136 of the Mental Health Act. What is your view on the proposal that young people aged under 18 detained under section 135 or 136 should never be taken to police cells?

Overall, 166 responses provided feedback about this question. There was widespread agreement that people aged under 18 years detained under section 135 or 136 should never be taken to police cells.

Figure 29: Feedback from responses that answered Q36

Note: Percentages are based on 166 responses

Responses from police and legal organisations were just as likely as others to support this proposal.

Responses that disagreed said that 'never' was a strong word and that there may be circumstances where risks warranted taking young people to police cells temporarily.

Common comments, regardless of whether responses agreed or disagreed, were:

- other suitable places of safety would need to be available

- making other places of safety available requires further staffing and investment

- decisions should be made based on risk, not age

Q37. What is your view on the proposal that the use of police cells for those over 18 should be limited more in terms of frequency and length of detention as proposed by the review?

Overall, 164 responses answered this question. There was widespread support for this proposal.

Figure 30: Feedback from responses that answered Q37
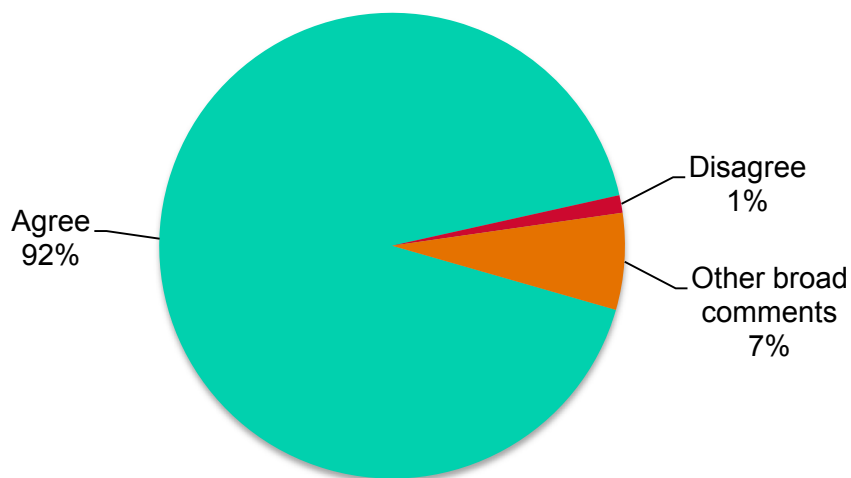
Note: Percentages are based on 164 responses

Responses from police and legal organisations were just as likely as others to support this proposal.

> *"The length of time for which an adult can be detained in a police cell must be reduced. In law, no one suspected of an offence can be detained in a police cell without charge for more than 24 hours. It therefore raises serious questions of fairness and equality that an individual thought, but not confirmed to be, in mental health crisis can be detained in a police cell for up to 72 hours. The overall permitted period of detention for adults in a police cell under Section 136 must be reduced."* **(Police / legal organisation)**

Common comments made by a wide range of organisations and individuals included:

- need for more alternative places of safety
- reduce the time for those with a mental health condition to be moved out of police custody
- police stations could have specific accommodation that could facilitate the needs of individuals with disabilities and other special conditions
- more investment is needed
- more training of the police is needed

Q38. Do you have a view on any other recommendations in the Review?

Easy Read Q9. These ideas look at how to make things better for people who are being kept safe in police cells or are being held in hospital instead of prison. What do you think?

There were 187 responses that answered these questions. Suggestions focused on reducing the use of police cells and developing more alternative places of safety. Other suggestions are listed below.

Places of safety

- support reducing the use of police cells (90 responses)

- need to provide alternative places of safety, including review and mapping of current provision to identify gaps (53 responses)

- duration of Section 136 should be limited to 24 hours rather than 72 hours (7 responses)

- police stations should have more comfortable places for people to wait (2 responses)

- more investment is needed to develop places of safety (6 responses)

- in some instances people may need to be placed in a cell if they pose a danger to themselves or others (6 responses)

Information and support

- more training is needed so police and others can support people with learning disabilities, autism or mental health issues (14 responses)

- need to provide more follow-up information and support (5 responses)

- a rapid response team could be set up in each county to respond to anyone who has been detained in a police cell (9 responses)

- need preventive support so people do not get into this situation (3 responses)

Other review recommendations

- support review recommendation not to alter powers under s135 to allow intervention in private premises (6 responses)

- requiring the police to consult a suitable health professional prior to detaining a person under section 136 may be better expressed as guidance rather than legislation (2 responses)

- co-ordinate review of sections 135 and 136, the Crisis Concordat, the increase in Liaison and Diversion services and the planned transfer of Police custody healthcare commissioning (1 response)

Q39. What is your view on the review proposal to create powers for professionals other than the police to be able to take a person from a public place to a place of safety?

There were 139 responses that answered this question. There were mixed views. About two fifths of responses thought that professionals other than police should be able to take people to a place of safety (42%). The same proportion did not agree with this (45%).

Figure 31: Feedback from responses that answered Q39
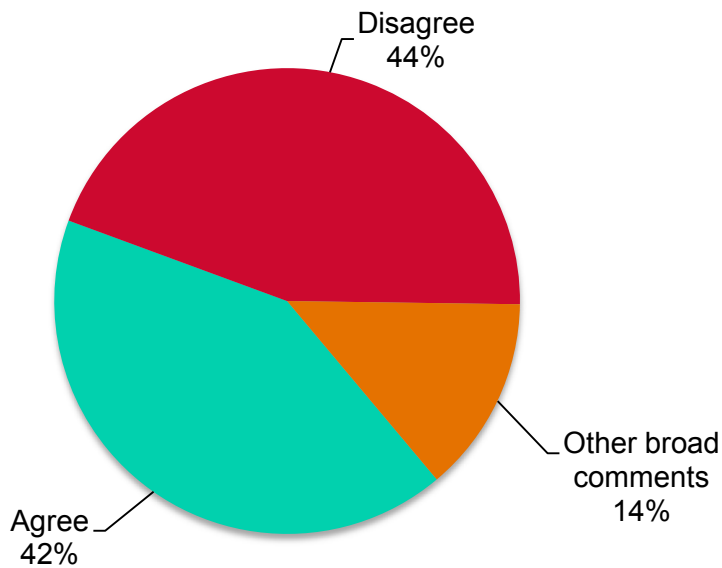
Note: Percentages are based on 139 responses

Responses that agreed said that this may save time, reduce stigma and allow people who are more familiar or 'friendly' to interact with those in crisis. Some responses said this might be particularly useful for young people.

> *"Using professionals other than police may reduce the fear and concern of the person needing a place of safety. This would need to ensure that appropriate training and support is in place for these professionals."* **(Voluntary sector organisation)**

Responses that disagreed said that it was unclear how this would work in practice, that it would require extensive training of other staff, that some of these powers already exist and that it may be dangerous for other staff. Responses that disagreed were more likely to come from statutory organisations and professional bodies.

> *"Doing this is often very difficult with resistant people – the police role in this is invaluable in terms of the 'authority' and approach to manage these types of situations. This is not a role that would sit easily with other professionals – and feel that they would be calling on the police to assist."* **(Local authority)**

Police and legal organisations had mixed views, with some saying there was a need for more detail about the proposals.

Regardless of whether responses agreed or disagreed, organisations and individuals were concerned about which type of professionals would carry out such functions and how this would be subject to governance and safeguarding.

Q40. Are there any practical considerations we should take into account during further developmental work and implementation of the review (of the operation of Sections 135 and 136 of the Mental Health Act) proposals?

In total, 84 responses provided feedback about other things that could be taken into account in the review. These focused on developing resources, ensuring appropriate teams and having robust implementation plans, as listed below.

Resources

- need to ensure that community-based provision is available, including mapping existing places and developing new ones (22 responses)
- cost and capacity needs further consideration as part of the review (11 responses)
- recognise differences in rural and urban service availability (2 responses)
- conveyance to places of safety needs more consideration, including who will provide and fund this (4 responses)

Teams

- appropriate staff training is needed for police and other teams (14 responses)
- need closer links between police, mental health and other services (9 responses)

Responding to individual needs

- important to take into account the diversity of individuals (3 responses)
- consider those with least capacity (2 responses)

Implementation

- clarify and consult more widely on proposals before they are agreed (8 responses)
- need to consider whether current legal powers and legislation already allow for the proposals (5 responses)
- have a robust communication plan and achievable timescales to make sure that all parties are aware of their powers and expectations (1 response)
- Deprivation of Liberty in the community requires review (6 responses)
- better discharge arrangements are needed (3 responses)
- ensure an appropriate monitoring strategy is in place (2 responses)

Q41. Do you think it would be desirable in principle to amend the Mental Health Act to enable restricted patients to be discharged by the Secretary of State for Justice or a Tribunal subject to conditions amounting to a deprivation of their liberty?

In total, 111 responses answered this question. There was some agreement with this proposal.

Figure 32: Feedback from responses that answered Q41
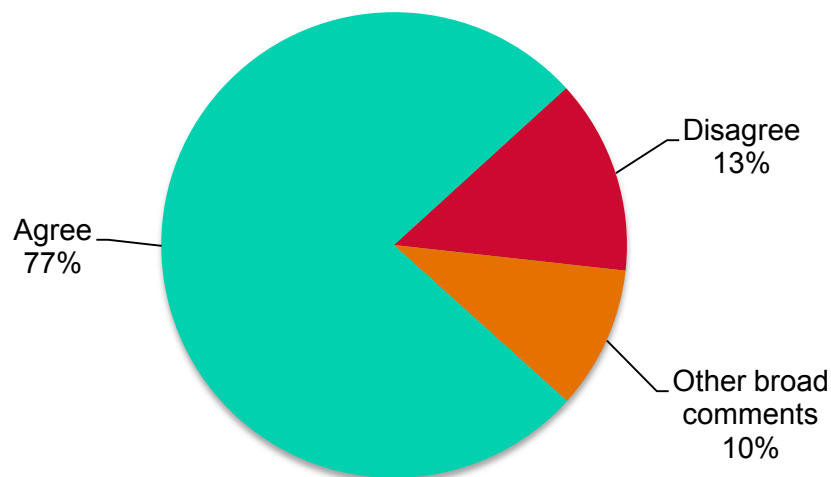
Note: Percentages are based on 111 responses

There were no clear trends in whether organisations were more likely to prefer a certain option than individuals, or whether different types of organisations and individuals had varying preferences.

Responses that agreed with this approach suggested that it was important to use the least restrictive options so that people were not in institutions unless they needed to be.

Responses that disagreed were concerned about the safety of individuals, the proportionality of restriction versus risks to self and others and practical difficulties implementing the law.

> *"We are in sympathy with the aims of this proposal but do not agree with it. We understand it aims to allow a less restrictive option and provide for a better quality of life for some restricted patients who might otherwise stay indefinitely, potentially the rest of their lives, in a secure hospital setting. There is a flaw in the reasoning behind the proposal. By saying that a number of patients are continuing to be detained in secure hospitals even after they may be in a position appropriate for conditional discharge, you are saying that persons who no longer meet the criteria for detention are being unlawfully deprived of their liberty. They are being detained because they present a risk to the public despite no longer having a mental disorder in need of treatment in hospital. We cannot agree with using the Mental Health Act solely for purposes of public protection and not the assessment and treatment of the individual's mental health problems."* **(Voluntary sector organisation)**

Common comments, regardless of whether responses agreed or disagreed, included:

- need to have safeguards in place
- need a transparent and robust procedure
- depends on individual circumstances
- could complicate the law

Q42. Does the Mental Health Act need to provide for another form of detention for patients who do not need to be in hospital but who must be in effect deprived of their liberty in order to be discharged from hospital into a community based setting?

In total, 113 responses considered this question. There were mixed views about this proposal.

Figure 33: Feedback from responses that answered Q42
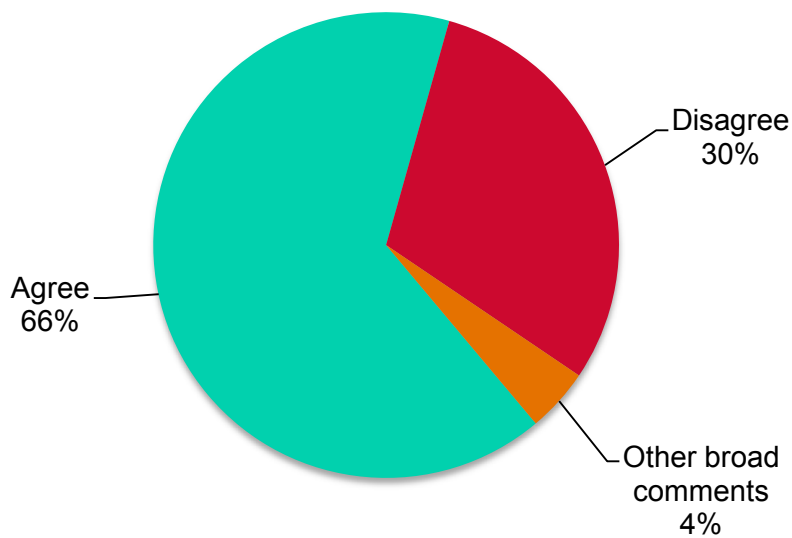
Note: Percentages are based on 113 responses

Responses that disagreed said that this was already covered by existing legislation and provisions and that proper legal safeguards need to be in place. Organisations were more likely to disagree than individuals.

Chapter 5: Budgets and finances

This chapter summarises feedback about the section of the consultation documents entitled 'My right to control my own support and services with a personal budget, My right for the NHS and local authority to work together for my benefit.'

Q43. We set out two possible options for introducing a legal right to have a personal health budget for some people with learning disabilities or autism. Which of the options (option 1 or option 2) do you think would be most effective?

Easy Read Q10. What do you think about more people with learning disability or autism having personal health budgets?

In total, 266 responses considered these questions. There was general support for the concept of personal health budgets for everyone, rather than selected groups. There was no clear preferred option.

- 16% of responses favoured Option 1: personal health budgets for people with learning disability and/or autism who are currently in specialist inpatient care, but have been assessed as able to be supported in the community with the right package. The budget would not be used to pay for their institutional care, except in exceptional circumstances

- 11% of responses favoured Option 2: personal health budgets for people with learning disabilities who have mental health needs or challenging behaviour and are subject to Care Programme Approach, whether that is in the community or institutional care

- 5% favoured a combination of both options

- 58% of responses said they supported personal health budgets for everyone

- 10% of responses did not support personal health budgets due to practical implementation issues

Responses said it was important that there were appropriate safeguards and support for people to use personal health budgets.

There was no difference in the overall trends expressed by organisations compared to individuals or between various types of organisations or individuals.

Q44. What else might need to happen in order for such Personal Health Budgets to enable people to choose new providers and/or new kinds of service or interventions?

There were 122 responses that considered this question. Suggestions focused on:

Support

- independent support for service users and families to set up packages of care (41 responses)
- workforce training to support people to use personal health budgets (9 responses)

Information provision

- clear information about processes and guidance about entitlements (14 responses)
- spend time researching and communicating about local services, perhaps using an online directory (12 responses)
- need a quality standards framework to 'score' local agencies for service users and families (3 responses)

Service provision

- development of market / appropriate services, including co-production (18 responses)
- more choice available locally (14 responses)
- development of services for people with more complex and challenging needs (4 responses)
- guidance about adequate resourcing (8 responses)
- jointly commissioned integrated services and pooled health and social care budgets (14 responses)
- more focus on housing (3 responses)

Processes

- safeguards against misuse (7 responses)

- adequate processes for assessing capacity (3 responses)

- additional mechanisms to administer personal budgets for those who do not have family or Court of Protection, such as nominated advocates or trusts (4 responses)

- using streamlined joint health and social care paperwork (3 responses)

- having a process for monitoring the way that funds are used (3 responses)

- matching the costs of care and consider capped costs (2 responses)

There were no clear differences between the views of organisations and individuals or between various types of organisations and individuals.

Processes

Q45. How can we ensure that the new arrangements under the Children and Families Act can also be used to prevent unnecessary admissions in adulthood?

There were 79 responses that answered this question. The most common suggestions were:

Processes

- robust transitional arrangements and clear transition period (23 responses)
- good liaison and joint working between health and social care (18 responses)
- holistic education and health and care plans with regular reviews (10 responses)
- effective transfer of data between systems and services (5 responses)
- join up the Acts (6 responses)
- guidance about pooled budgets (2 responses)
- less demarcation between support for children and adults (4 responses)

Prevention

- early detection and prevention assessments (8 responses)
- analyse data and forecast need (2 responses)

Personnel

- involving families in planning (5 responses)
- involvement of a named social worker (2 responses)

> *"Too many families report their child reaching 18 and "falling off a cliff" of support: this can lead to crisis situations and ultimately to admissions to inpatient units. This can be prevented by good transition planning, involving all health, care and education agencies, getting the right support to people at the right time."* **(Voluntary sector organisation)**

There were no clear differences between the views of organisations and individuals or between various types of organisations and individuals.

Q46. We could seek to set up and mandate specific pooled funding, with joint planning, to help people with learning disability and/or autism get discharged from hospital or help prevent them being admitted. This could include specialised commissioning funding. What do you think of this idea?

Easy Read Q11. What do you think about making local areas having to put in their money together to help people get out of hospital?

In total, 262 responses answered this question. There was wide support for pooled funding, though some questioned whether this needed to be mandated or should instead be promoted as good practice.

Figure 34: Feedback from responses that answered Q46 and Easy Read Q11
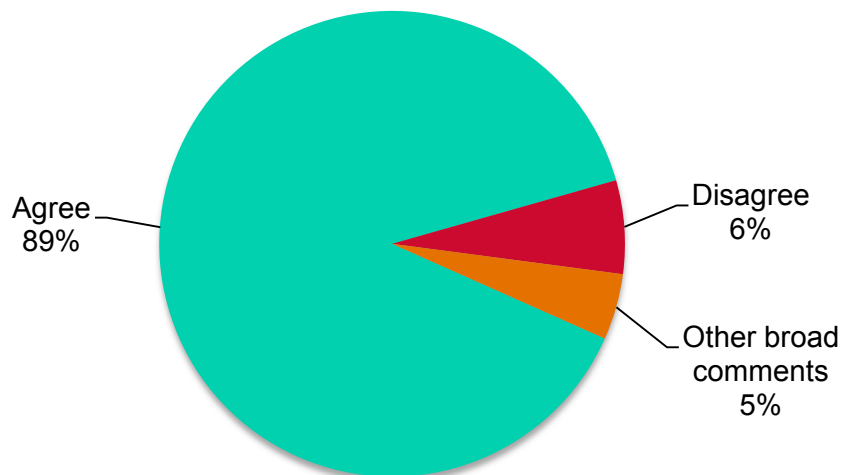
Note: Percentages are based on 262 responses

Responses that agreed said that pooled budgets would help to streamline services, reduce delays due to discussions over responsibilities and have the potential to provide more holistic person-centred care. Some responses said that budgets should be pooled for all service users, not solely those hospitalised.

> *"The current system leads to arguments about hospital funding when moving from 'low secure' provision. Local authorities and the NHS should be made to put their money into one pot to support people to leave hospitals. A pooling of funds should ensure a continuity of funding when changes of setting occur."* **(Meeting with group of service users)**

> *"Joint planning and pooled funding that follows the individual would allow for more creative ways of budget spending to prevent admissions and to speed up discharge processes. Experience shows that bureaucracy often delays and prevents personalised approaches to supporting individuals which is proven to be most effective."* **(Voluntary sector organisation)**

Responses that disagreed said that this may be difficult to manage and that this may result in an overall reduction in the funds available. Some individuals were concerned about whether this would impact on the cost of their care. Other responses said they supported pooled budgets but did not think this should be mandatory. Responses from individuals were most likely to disagree with this proposal, although some statutory organisations also disagreed.

> *"Given that it is unlikely that any new money would be forthcoming it is hard to see what this would do which is not covered by existing rules. What might be helpful is a requirement for greater openness and accountability in what happens to funds emerging from closed inpatient beds to ensure that the enhancement of community provision is a first call on any such funds."* **(Local authority)**

> *"I am very much in favour of creating the possibility of pooled funds that include specialised commissioning funding. However, I am very wary about making pooled budgets mandatory. All the evidence from joint commissioning shows that success is based on mutual agreement, not forced marriage. A pooled budget should be the financial expression of a shared plan for the commissioning of services and support. I would therefore prefer the emphasis to be on requiring authorities to develop joint plans and show how they will make the money work to support those plans, including use of pooled budgets where appropriate."* **(Individual, type unknown)**

Q47. Are there further ways we could strengthen local accountability, particularly to disabled people and their families?

There were 89 responses that considered this question. Common suggestions focused on engagement, improving processes and enhancing resources, as listed below.

Engagement

- ensure Councils and NHS have service users on their Boards (7 responses)

- make sure that there is input from service users and families into service planning, delivery and monitoring, such as the presence of families and carers at the pooled budget joint management group (13 responses)

- strengthen forums for engagement and local partnership boards (20 responses)

- when commissioning services, build into the specification that service users should be employed as a proportion of the workforce (2 responses)

Processes

- ensure a clear independent process for raising triggers and complaints (6 responses)

- expand quality checker programmes and scrutiny by experts by experience (4 responses)

- routine monitoring and public reporting of outcomes and action plans (22 responses)

- ensure HealthWatch is well publicised (2 responses)

- joint governance structures between health and social care (5 responses)

- improve training of commissioners and providers (2 responses)

- make this mandatory and use sanctions (10 responses)

Resources

- provide accessible information (3 responses)

- make sure advocacy networks are available (8 responses)
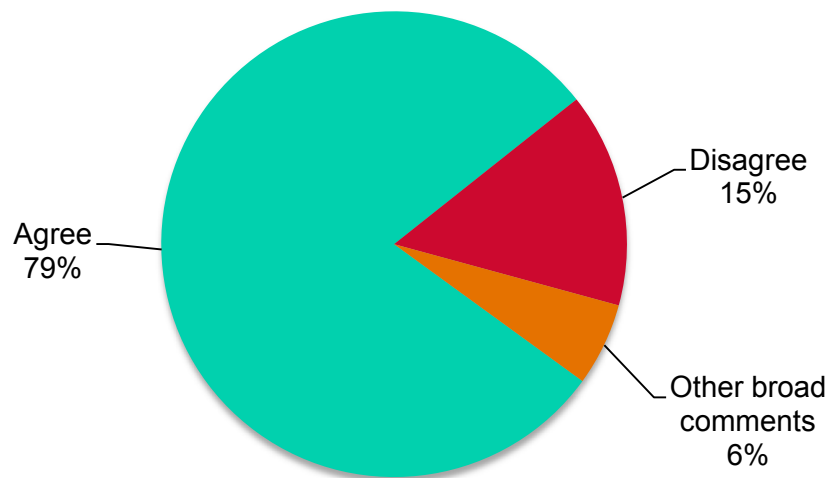
- provide ring-fenced budgets (2 responses)

There were no clear differences between the views of organisations and individuals or between various types of organisations and individuals.

Q48. We want to explore whether providers of specialist hospital services and residential care services should be allowed to have a duty to share confidential patient information with case managers and other relevant commissioners directly involved in arranging a person's care in certain circumstances. What do you think of this idea?

Easy Read Q12. Do you think it should be made clear when people who buy care have to share information to support people's care and keep them safe?

There were 295 responses that considered these questions. There was broad agreement about sharing information. About eight out of ten responses thought that this was acceptable, with appropriate safeguards.

Figure 35: Feedback from responses that answered Q48 and Easy Read Q12

Note: Percentages are based on 295 responses

There were no clear differences between the views of organisations and individuals or between various types of organisations and individuals.

Responses that agreed said that sharing information, with appropriate safeguards, could help to improve the quality of care.

> *"Effective and appropriate information sharing is essential to the provision of integrated health and care services, and to gaining assurance that an individual is receiving the correct care in the correct setting. Until the boundaries between health and social care are more permanently removed, we would welcome improved information sharing between providers and commissioners. This would have to operate within a robust data protection framework with appropriate safeguards, to ensure information is only shared with those directly involved in arranging or delivering a person's care, and only in specific circumstances (e.g. transfer between services, care plan review)."*
> **(Independent sector service provider)**

Responses that disagreed said information should only be shared with the consent of the individual. Some said that there was already a provision for sharing when there was consent or justification, so no changes were needed.

Common comments, regardless of whether responses agreed or disagreed, included:

- people should know what information is being shared and consent to it

- there must be adequate safeguarding of confidentiality

- it is important to ensure that the information shared is accurate and that service users have an opportunity to see it and make comments

- it is important to keep good records about the information shared

> *"Such an information sharing exercise should only take place where deemed necessary for the wellbeing of the individual and only to those directly involved in arranging treatment or care. Confidentiality is a serious matter, especially in regards to such personal and intrusive information; where possible the individual's consent should be obtained. Where information has been shared to others this should be recorded in order to maintain transparency and accountability."*
> **(Voluntary sector organisation)**

Chapter 6: Physical and mental health

This chapter describes feedback about the section of the consultation documents entitled 'I want to know is responsible for supporting my physical as well as my mental health.'

Q49. What are your views on how we could be clearer around responsibilities of: clinical commissioning groups, providers, medical directors and responsible clinicians for the physical healthcare of people in mental health inpatient settings?

Easy Read Q13. Do you think we should try and make it more clear who has to make sure people are physically well when they are in mental health hospitals?

There were 240 responses that answered these questions. Overall, two thirds of responses said that responsibilities should be clearer (64%). One in ten responses said that no changes were needed because it is already clear who is responsible (9%). Other common comments focused on different levels of responsibility and service provision, as listed below:

Responsibilities

- the placing authority should have responsibility (8 responses)
- local clinical commissioning groups where a unit is located should be responsible for the physical healthcare of anyone resident in their area (6 responses)
- the local provider organisation should be responsible (8 responses)
- principal accountability should rest with the responsible clinician (10 responses)
- joint governance arrangements would be useful (5 responses)
- make it a legal requirement to monitor physical and mental health and check compliance (11 responses)

Service provision

- involve a multidisciplinary health and social care team in inpatient settings (21 responses)
- use health passports and health action plans (10 responses)
- make annual health checks and other services available from local GPs in inpatient settings (17 responses)
- use a case management approach, with assessment of physical and mental health (5 responses)

Chapter 7: Overall impact

This chapter covers the final questions in the consultation documents, focusing on overall impacts and risks.

Q50A. Which would have the greatest impact and benefit on people's lives? (so we know what should be highest priority)

Easy Read Q14A. What do you think would make the most difference?

There were 261 responses that considered these questions. The greatest perceived impacts could be grouped into engagement, commissioning, service provision, detention and monitoring.

The most common comments were about the need to develop more community-based services, the importance of listening to service users and carers and the potential for joint commissioning and pooled budgets.

Engagement

- listening to the voices of service users and carers and co-production (38 responses)
- holistic person-centred care (21 responses)
- improved advocacy (13 responses)
- recognise the importance of families and carers (5 responses)
- redefine define nearest relatives (1 response)

Commissioning

- joined up working and commissioning, with pooled budgets (30 responses)
- adequate resourcing to develop services and implement changes (24 responses)
- planning for the needs of the whole population (4 responses)
- personal budgets (5 responses)
- make NHS responsible under the law for considering people's wellbeing (2 responses)

Service provision

- more development of services in the community to reduce admissions (40 responses)
- support to live in the community (34 responses)
- support employment and housing schemes (5 responses)
- support after discharge and continuity of care (6 responses)
- easier access to services, including preventive services (12 responses)
- improved choice (12 responses)
- quick and accurate assessments (2 responses)
- workforce development and training (19 responses)
- better social work services, including a named social worker (3 responses)
- more holistic mental and physical health provision, such as GPs in inpatient units (1 response)
- single point of contact (2 responses)
- consider the needs of children and young people (2 responses)

Detention

- strengthening the right to transfer to a less restrictive setting (1 response)
- right to challenge decisions (5 responses)
- reducing the use of police cells (4 responses)
- people with learning disabilities or autism should not be treated as though they have a mental health condition if they do not have one (9 responses)

Monitoring and information

- more scrutiny, monitoring and accountability processes, especially around people being admitted (7 responses)
- more accessible information and communication (17 responses)
- information sharing between organisations (2 responses)

There were no clear differences between the views of organisations and individuals or between various types of organisations and individuals.

Q50B. Which carry the greatest potential costs or risks?

Easy Read Q14B. What do you think would not be so good, for example, because it might cost a lot of money?

There were 83 responses that answered these questions. Areas that responses commonly thought may be difficult to achieve or may pose risks focused on engagement, changing legislation, lack of funding and lack of service provision. The two most commonly mentioned risks were a lack of ring-fenced funding to implement proposals and not developing enough appropriate services in the community to allow people to stay out of hospital.

Service provision

- not ensuring enough community-based support and treatment (21 responses)
- no time or capacity to provide the support needed (6 responses)
- not enough consideration of housing needs (5 responses)
- closure of specialist units (4 responses)
- lack of staff training or resistance from staff (6 responses)
- not implementing preventive services (1 response)
- not covering services and support for children and young people (3 responses)
- insufficient coverage of those at risk of offending (1 response)

Commissioning

- lack of ring-fenced additional funding (22 responses)
- difficulty aligning health and social care for joint working (10 responses)
- pooled budgets (1 response)

Engagement

- not recognising individuals and their families as equal partners (6 responses)
- insufficient advocacy (1 response)
- lack of accessible information (1 response)
- people may not be able to manage their rights and resources in a way that gives them the best outcomes (1 response)
- barring some organisations out of contracts if they do not have service users on their board (2 responses)

Legislation

- proposed changes to legislation may isolate people with learning disabilities (3 responses)

- proposed changes in legislation may lead to delays in assessment and treatment (4 responses)

- proposed changes to allow other professionals to detain (1 response)

- tensions caused by provisions in different legislation or changing legislation (5 responses)

There were no clear differences between the views of organisations and individuals or between various types of organisations and individuals.

Chapter 8: Other comments

This chapter summarises other comments that responses made, that were not linked to particular consultation questions.

General comments

In total, 69 responses provided comments about other issues. The most common themes included:

Vision

- positive about the overarching principles in the proposals and the direction of travel (20 responses)

- more clarity of vision is needed to move towards a White Paper with a firmer set of proposals (2 responses)

- should include a set of principles, similar to the Mental Capacity Act (1 response)

- could include the agreed model of care being written by NHS England (1 response)

- should make reference to NICE clinical guidelines and Quality Standards being published in 2015 about challenging behaviour and learning disabilities (1 response)

- consider in the context of the wider work going on within the Transforming Care programme (1 response)

- consider in line with the Winterbourne Concordat 2013 (1 response)

Scope

- potential to extend the scope to include young people, older people and other groups (6 responses)

- grouping together people with learning disabilities, autism and mental health conditions may be unhelpful (3 responses)

- there are particular hurdles and barriers faced by those affected within Black and Minority Ethnic communities that need to be considered and addressed, including issues related to faith (1 response)

- it is important to consider the needs of people who are deaf or are coping with other issues (2 responses)

Other content

- comments about the consultation process itself (23 responses)

- concerns about potential changes to a specific life-sharing community (Botton Village) (6 responses)

- new legislation is not needed. Instead, more time and effort should be put into embedding existing initiatives and laws (7 responses)

- importance of ensuring that the system is adequately resourced (5 responses)

- consider extra financial and practical support for carers (4 responses)

- need to revise the Mental Health Act (3 responses)

- need to include monitoring and accountability requirements (2 responses)

- consider reducing reliance on medication (2 responses)

- consider access to solicitors (1 response)

- consider the role of CQC (1 response)

- there have been many consultations about similar topics so it is time to change (2 responses)

- recognise Disabled People (Community Inclusion) Bill 2015 (1 response)

"We support the ambition to enshrine a consideration of individual wellbeing, choice and preferences in the provision of services to those with mental health conditions, learning disability and autism. This is an important first step in constructing a health and care system for these client groups which is personalised, effective and affordable. However we believe that such a change will only have a transformational impact on the lives of those accessing services if it is accompanied by significant reform to the funding, commissioning, and planning of services." (Independent sector service provider)