Arden&GEM

NHS
Arden and Greater East Midlands
Commissioning Support Unit

East Leicestershire and Rutland Clinical Commissioning Group

Settings of Care

Pre consultation engagement report (August 2016)

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The three local Clinical Commissioning Groups (CCGs) East Leicestershire and Rutland CCG, Leicester City CCG and West Leicestershire CCG – who plan and pay for local healthcare services, are reviewing the current ‘Settings of Care’ policy.

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The CCGs wrote to people in Leicester, Leicestershire and Rutland who receive NHS Continuing Healthcare (CHC) funding to ask them and their family/those important to them to share their views on the policy and potential changes to it. They assured them that no changes have yet been made and the CCGs are committed to taking people’s views into account. The survey ran from 24 June to 27 July and 205 completed questionnaires were received – 46 online and 159 hard copy.

An engagement event was held on 14 July and 15 people attended in addition to staff and clinicians from the CCGs and University Hospitals of Leicester NHS Trust.

Feedback

Most people felt it was important that there was consistency of care and care was delivered in a clinically safe and appropriate environment. When it came to the affordability of care to the NHS, most people felt it was important in some way. More than four fifths of people felt it was either important or very important that care was provided in the patient’s preferred setting.

Many people thought that it was important that patients and/or their families had a choice in their setting of care. Around one quarter of people felt the NHS should make the decision about the setting of care.

When asked about consistency with other settings of care policies across England, 68% agreed that there should be consistency but more than one fifth (21.5%) did not have a view, perhaps illustrating that people are less sure about this.

With regard to whether there should be an identified limit (threshold) to how much extra funding can be spent on care, responses were variable. Just over half (51.2%) agreed there should be a threshold, but 33.5% disagreed to some extent and 15% neither agreed nor disagreed.

Most people agreed or strongly agreed that the NHS should spend more to enable a patient to receive care in their preferred setting if there are exceptional circumstances.

When asked what they considered ‘exceptional’ a number of themes emerged:

- End of life care
- Specialist needs
- Family and friends – consideration of their needs
- Emotional needs
- Choice of setting
- Finance
- Individual circumstances.

The responses reflected the experience of those who responded, which gave them an in depth understanding of the issues in Continuing Health Care.

When asked if there was anything else they would like taken into consideration, certain themes emerged:

- Funding
- Carers’ concerns
- Assessments
- Personal stories

There was an awareness of the pressures the NHS is under, but also a plea for people’s individual concerns to be taken into consideration, and for carers’ needs to be considered.

The feedback from the engagement event also emphasised people’s concern that those receiving CHC should be treated as individuals, their carers’ needs should also be considered, and that exceptional circumstances should allow for additional funding, and should include end of life care and care in a preferred setting.

Conclusion

Those responding believe that the setting care is given in is important to the patient, in particular their mental health. It is also important to family and friends because they want their loved one to feel safe and at home, and because of access issues. Costs are talked about, but those responding are more interested in quality of care for individuals, and that individual needs are taken account of.

When it comes to exceptional circumstances, the answers reflect the view that the whole person should be cared for, and that sometimes this involves specialist care. End of life care is clearly seen as an exceptional circumstance. Particular settings are preferred by family and friends because of familiarity and better access. Where people were invited to add anything else the comments reflect the deep and personal knowledge of those responding to the questionnaires. Many respondents show awareness of the issues the NHS are grappling with. Many show gratitude, but are also asking for their personal and often difficult circumstances to be taken into consideration.

2. Introduction

The three local Clinical Commissioning Groups (CCGs) – East Leicestershire and Rutland CCG, Leicester City CCG and West Leicestershire CCG – who plan and pay for local healthcare services, are reviewing the current 'Settings of Care' policy. This is the policy that determines how and when CCGs will support individual choice of care setting (e.g. care at home, in a care home or elsewhere) for people receiving CHC funding. It also guides the level of funding (threshold) for providing care in that setting and includes criteria which ensure individual circumstances are taken into account.

The existing policy has been in place since 2011. It pre-dates recent developments such as Personal Health Budgets (PHBs) which provide an amount of money to individuals with identified health and wellbeing needs to support care which is planned and agreed between individuals, families and their local NHS team.

The local CCGs want to ensure the refreshed policy takes into account the introduction of PHBs and that it enables:

- robust, fair consistent and transparent commissioning decisions by the CCGs
- consistency in the services that individuals are offered
- value for money in the purchasing of services for individuals
- effective partnership working between healthcare providers, NHS bodies and the Local Authorities in the area
- individual choice as far as is reasonably possible

They have therefore carried out an initial process of engagement with those most likely to be affected by any review.

This report summarises the feedback from that engagement.

3. The engagement process

NHS East Leicestershire and Rutland Clinical Commissioning Group (ELR CCG) wrote to people in Leicester, Leicestershire and Rutland who receive NHS Continuing Healthcare (CHC) funding, to ask them and their family/those important to them to share their views on the policy. The letter explained that changes to the Settings of Care policy could mean changes to the care people receive in future. It assured them that no changes have yet been made and that the CCGs are committed to taking people's views into account. They asked them to complete and return a survey, or to complete the survey online. The survey opened on 24 June and the closing date was 27 July.

An event was also held at **2pm** on **Thursday 14th July** at The NSPCC National Training Centre, 3 Gilmour Close, Leicester LE4 1EZ to enable people to find out more and to ask questions.

4. The engagement event

Fifteen people attended the engagement event held at 2pm on Thursday 14th July at the NSPCC National Training Centre in Leicester, along with members of staff involved with reviewing the Settings of Care policy from West Leicestershire Clinical Commissioning Group (CCG), East Leicestershire, Rutland CCG and Leicester City CCG. A representative from University Hospitals of Leicester also attended.

The Deputy Chief Executive and Chief Nurse from ELR CCG opened the event by giving an overview of what the settings of care policy was and why the policy was being reviewed. Case studies were presented to explain how the settings of care policy was currently applied to people in receipt of Continuing Health Care. Members of the public attending were informed on the engagement process so far and how they could feedback their views to inform the policy review. It was also explained what the next steps following the engagement process would be and that if there were to be any significant changes proposed a public consultation would ensue. Throughout this part of the event people were invited to ask questions which were answered by CCG representatives present.

Table top discussions followed where attendees were asked to feedback on the following questions:

1) Which do you believe is most important in a decision about where continuing healthcare should be provided:

- **the patient's preferred setting of care**
- **the cost of the setting of care**
- **the preferred setting of care of the patient's family/those important to the patient**
- **the setting of care recommended by the NHS that is the best for meeting the patient's needs**

The respondents mainly felt that the patients and the family/carers were most important. Particularly, attendees felt that it was very important to involve and consider Carers as well as patients at every stage of the assessment process when the decision about the appropriate setting of care is being made.

2) Do you agree that there should be an identified limit (threshold) to how much extra funding can be spent to care for a patient in their preferred setting?

Most people did not have a particular view about the limit, but rather, the themes captured in response to this question were:

- The importance of identifying necessary need (need not want)
- The importance of individual assessment

3) Do you agree that the NHS should spend more to enable a patient to receive care in their preferred setting if there are exceptional circumstances?

The consensus to this question was yes, the NHS should spend more to enable a patient to receive care in their preferred setting if there are exceptional circumstances.

4) What circumstances do you think the CCGs need to consider as 'exceptional' when deciding whether or not a person should receive extra funding for care in their preferred setting?

End of life was seen as exceptional by many of the attendees.

5) In summary

Each table then fed back key discussion points to the room and any questions arising were answered. Following feedback to the room from each table, attendees were invited to talk further if they wished, individually to CCG staff on anything they needed to clarify, any questions they still needed answering or to give additional feedback on the Settings of Care policy review.

Attendees were thanked for their attendance and the very valuable feedback they had shared and encouraged to complete the Settings of Care questionnaire before the end date of 27 July 2016.

Attendees who completed the event evaluation form rated the event as good or excellent and rated the content and the value of personal learning to them as a result of the presentations at the event as excellent, good or satisfactory.

The full responses are listed at Appendix 4.

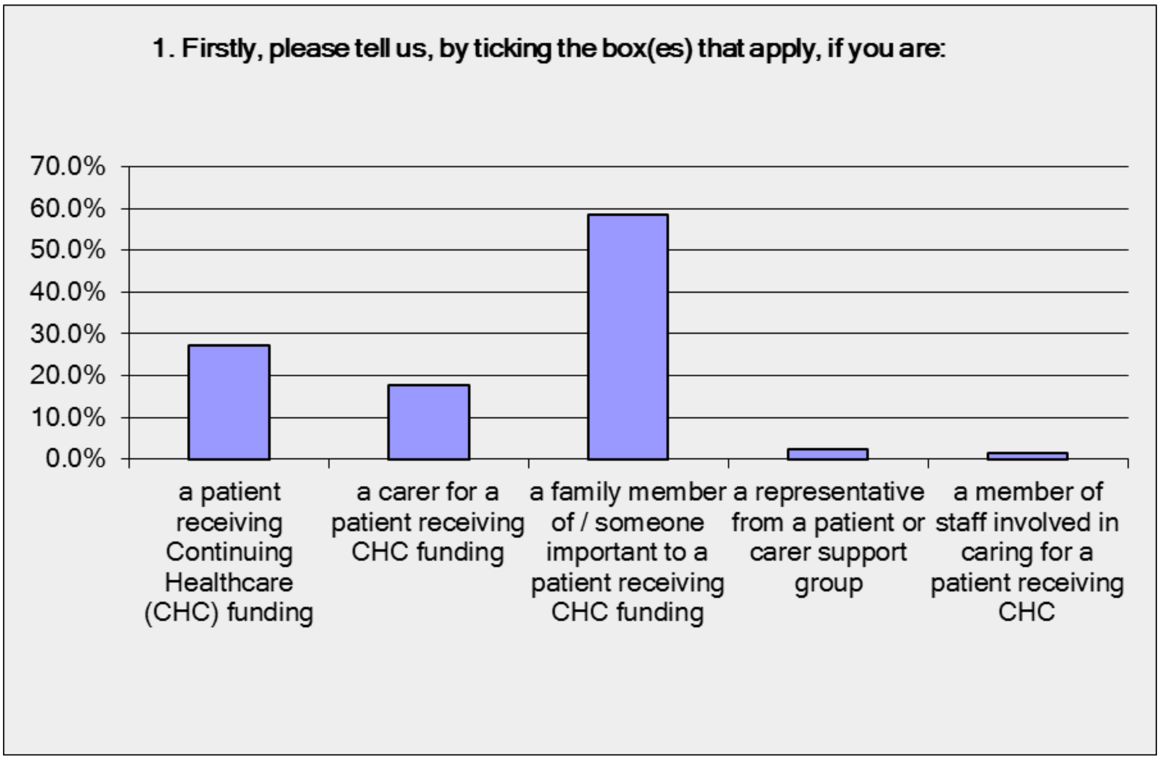
5. Response to the pre-consultation engagement questionnaire

This section of the report analyses the feedback received from completed questionnaires. 205 completed questionnaires were received, this included 46 online and 159 hardcopy received to the Freepost address. Not all respondents answered all the questions, and this accounts for some different totals in answers to some questions.

5.1 Question 1 asked the respondent to say the role in which they were completing the questionnaire.

1. Firstly, please tell us, by ticking the box(es) that apply, if you are:		
Answer Options	**Response Percent**	**Response Count**
a patient receiving Continuing Healthcare (CHC) funding	27.3%	54
a carer for a patient receiving CHC funding	17.7%	35
a family member of / someone important to a patient receiving CHC funding	58.6%	116
a representative from a patient or carer support group	2.5%	5
a member of staff involved in caring for a patient receiving CHC	1.5%	3
Other (please specify)		6
answered question		198
skipped question		6

Number	Response Date	Other (please specify)
1	Jul 25, 2016 1:38 PM	Caring husband
2	Jul 19, 2016 12:52 PM	Applying for CHC
3	Jul 19, 2016 10:45 AM	Manager of care home of CHC receiver
4	Jul 19, 2016 8:59 AM	A family member who cares for the patient
5	Jul 19, 2016 8:39 AM	I do not know
6	Jun 26, 2016 11:13 AM	family member AND carer



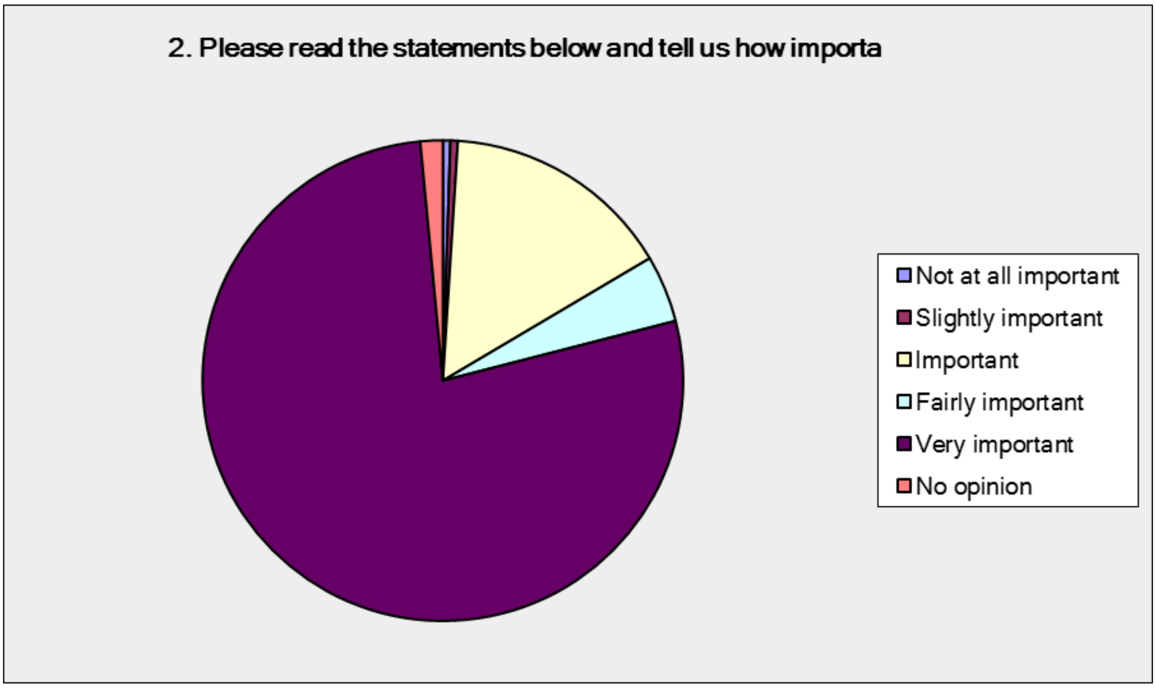
Commentary

The table and graph show that the largest group of people answering the questionnaire (58.6%) were a family member of or someone important to a patient receiving Continuing Health Care funding (CHC). Patients receiving CHC were the second largest group (27.3%) followed by Carers of patients receiving CHC at 17.7%.

5.2 Question 2a was about the importance of consistency of care.

2. Please read the statements below and tell us how important you think they are when considering where care is provided for patients receiving Continuing Healthcare funding: 2a. Continuing Healthcare funding is provided fairly and consistently to all eligible patients across Leicester, Leicestershire and Rutland:

Answer Options	Response Percent	Response Count
Not at all important	0.5%	1
Slightly important	0.5%	1
Important	15.5%	31
Fairly important	4.5%	9
Very important	77.5%	155
No opinion	1.5%	3
	answered question	200
	skipped question	4



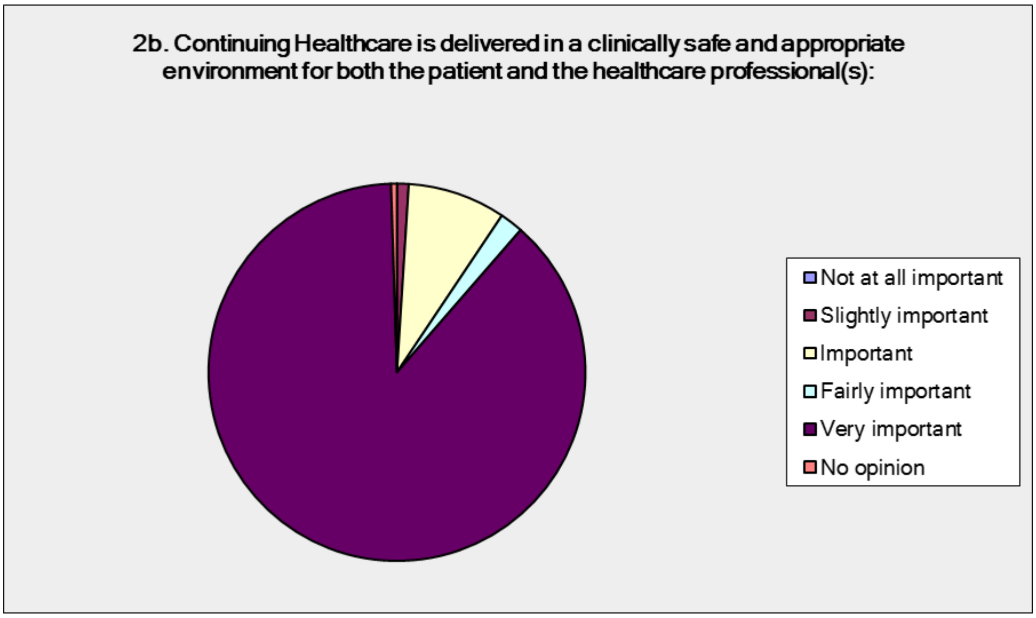
Commentary

When asked how important it is that Continuing Healthcare Funding is provided fairly and consistently to all eligible patients across Leicester, Leicestershire and Rutland, the majority of respondents (93%) said it was either very important or important to them:

- Very important 77.5%
- Important 15.5%

5.3 Question 2b was about care being delivered in a clinically safe and appropriate environment

2b. Continuing Healthcare is delivered in a clinically safe and appropriate environment for both the patient and the healthcare professional(s):		
Answer Options	**Response Percent**	**Response Count**
Not at all important	0.0%	0
Slightly important	1.0%	2
Important	8.4%	17
Fairly important	2.0%	4
Very important	88.1%	178
No opinion	0.5%	1
	answered question	202
	skipped question	2



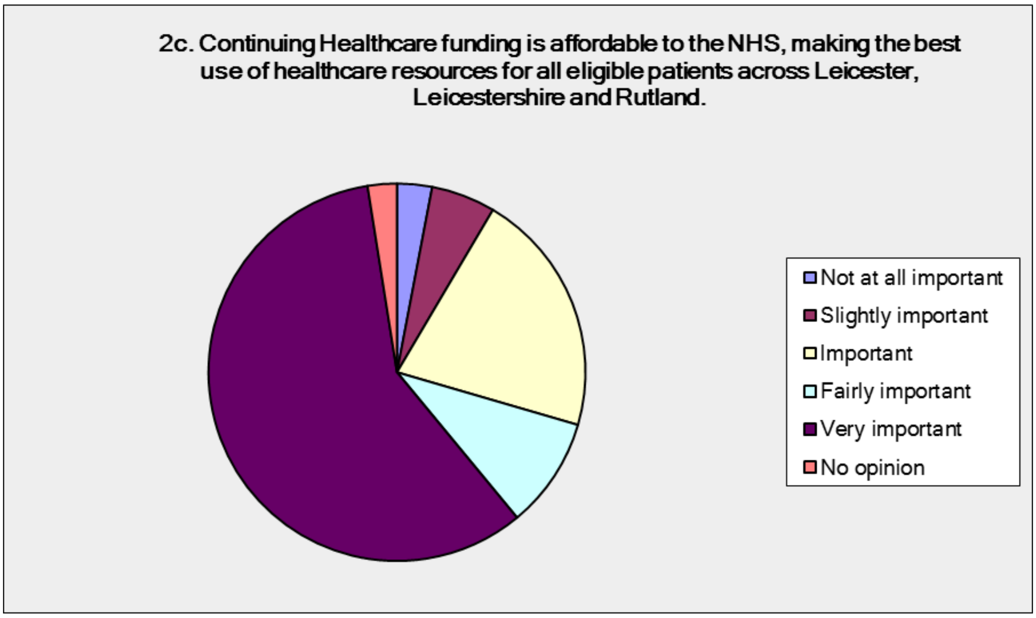
Commentary

When asked how important delivering CHC in a clinically safe and appropriate environment was to them the majority (96.5%) of respondents said that it was very important or important to them:

- Very important 88.1%
- Important 8.4%

5.4 Question 2c asked about how importance affordability is.

2c. Continuing Healthcare funding is affordable to the NHS, making the best use of healthcare resources for all eligible patients across Leicester, Leicestershire and Rutland.		
Answer Options	**Response Percent**	**Response Count**
Not at all important	3.0%	6
Slightly important	5.5%	11
Important	21.0%	42
Fairly important	9.5%	19
Very important	58.5%	117
No opinion	2.5%	5
	answered question	200
	skipped question	4



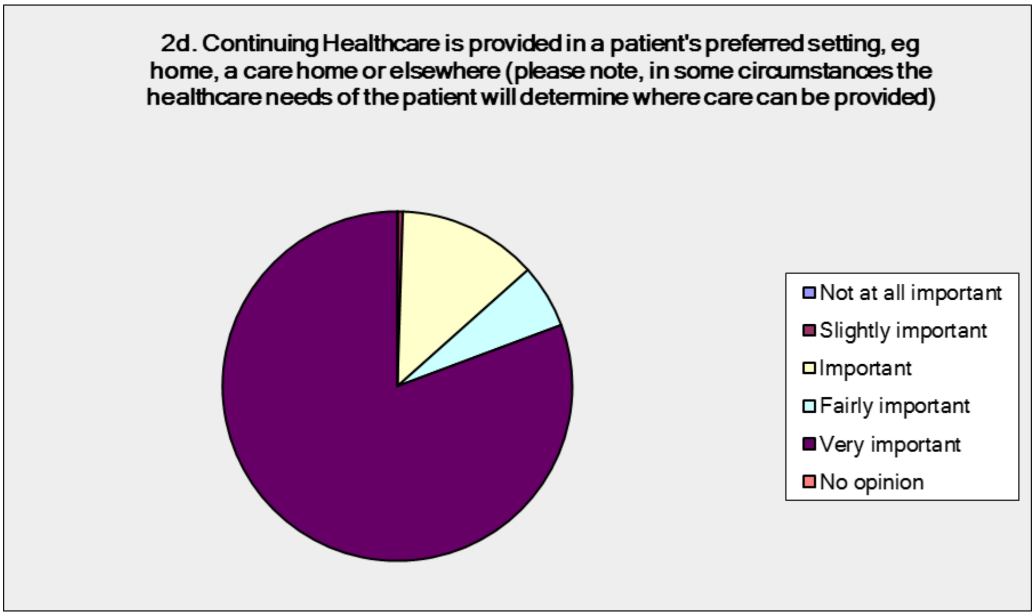
Commentary

When considering how important it was to them the CHC funding is affordable to the NHS, making the best use of healthcare resources for all eligible patients across LLR the majority of respondents (94%) felt it was important in some way:

- Very important 58.5%
- Important 21.0%
- Fairly important 9.5%.
- Slightly important 5.5%

5.5 Question 2d asked about the importance of healthcare being provided in a patient's preferred setting

2d. Continuing Healthcare is provided in a patient's preferred setting, eg home, a care home or elsewhere (please note, in some circumstances the healthcare needs of the patient will determine where care can be provided)		
Answer Options	**Response Percent**	**Response Count**
Not at all important	0.0%	0
Slightly important	0.5%	1
Important	12.9%	26
Fairly important	5.9%	12
Very important	80.7%	163
No opinion	0.0%	0
	answered question	202
	skipped question	2



Commentary

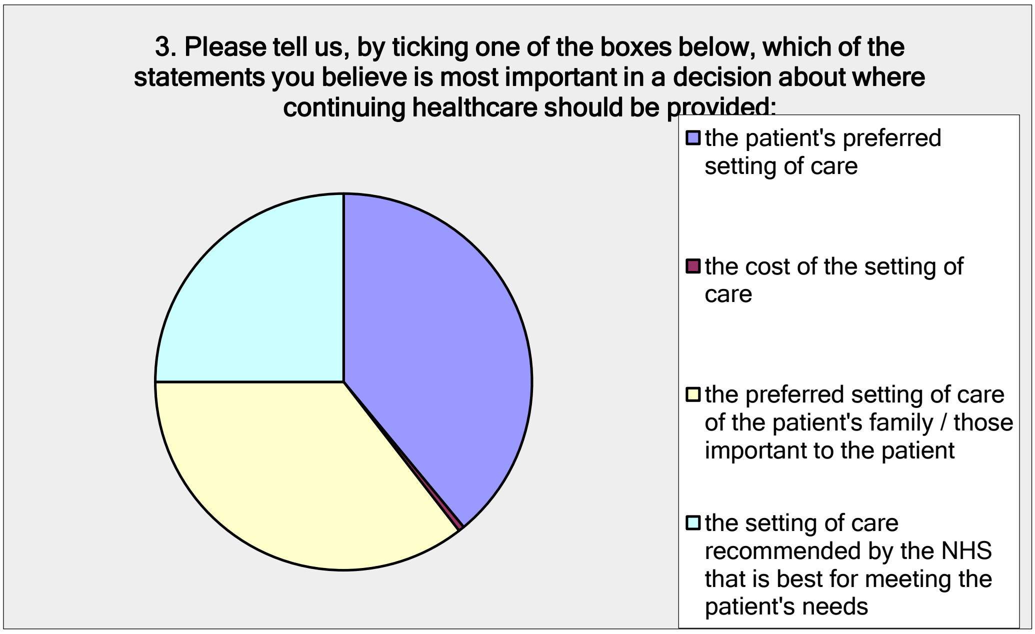
More than four fifths of the people who answered this question felt that the patient's preferred setting of care was very important. No-one felt it was not important.

- 163 people out of the 202 (80.7%) who answered this question felt that it was very important that CHC is provided in a patient's preferred setting of care
- It was important to 26 people (12.9%)
- 12 people said it was fairly important (5.9%)
- 1 person said it was slightly important (0.5%)

5.6 Question 3 asked what was most important in making a decision about where continuing healthcare should be provided.

3. Please tell us, by ticking one of the boxes below, which of the statements you believe is most important in a decision about where continuing healthcare should be provided:

Answer Options	Response Percent	Response Count
the patient's preferred setting of care	39.0%	78
the cost of the setting of care	0.5%	1
the preferred setting of care of the patient's family / those important to the patient	35.5%	71
the setting of care recommended by the NHS that is best for meeting the patient's needs	25.0%	50
	answered question	200
	skipped question	4



Commentary

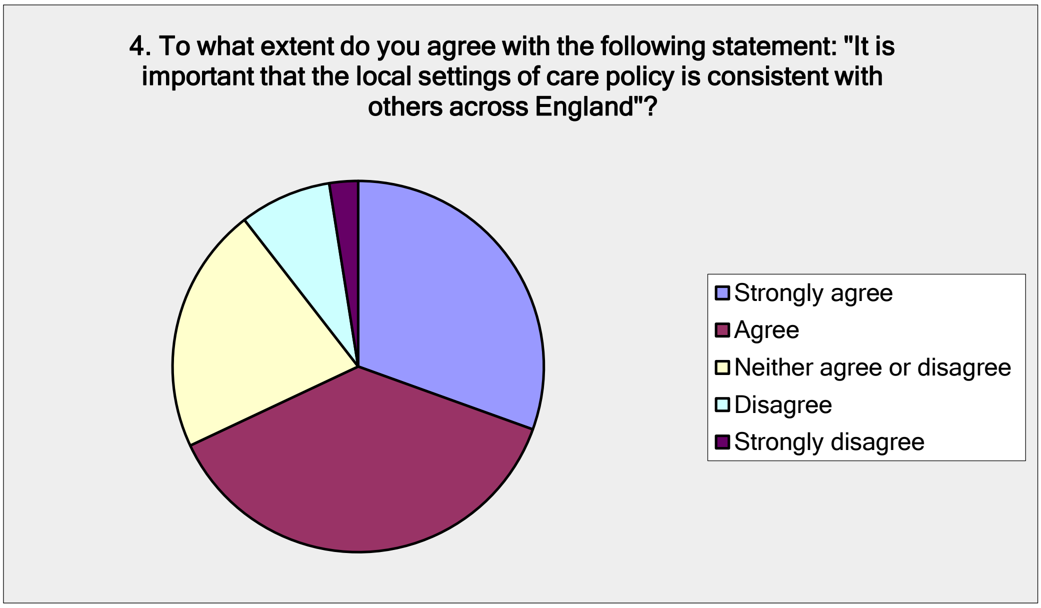
- 39% (78 people) respondents felt that it is most important for CHC to be provided in the patient’s preferred setting of care
- 35.5% (71people) respondents felt that it was most important for CHC to be provided in the preferred setting of care of the patient’s family/those important to the family
- 25.0% (50 people) felt that the setting of care recommended by the NHS was the most important statement in a decision about where CHC should be provided
- The cost of the setting of care was felt to be most important by the fewest respondents with only 1 person selecting this option

It is interesting that one quarter of people felt the NHS should make the recommendation of the setting of care, but virtually everyone else felt that the patient or the patient’s family should decide on the preferred setting of care.

5.7 Question 4 asked about consistency with other settings of care policies across England.

4. To what extent do you agree with the following statement: "It is important that the local settings of care policy is consistent with others across England"?

Answer Options	Response Percent	Response Count
Strongly agree	30.5%	61
Agree	37.5%	75
Neither agree or disagree	21.5%	43
Disagree	8.0%	16
Strongly disagree	2.5%	5
	answered question	200
	skipped question	4



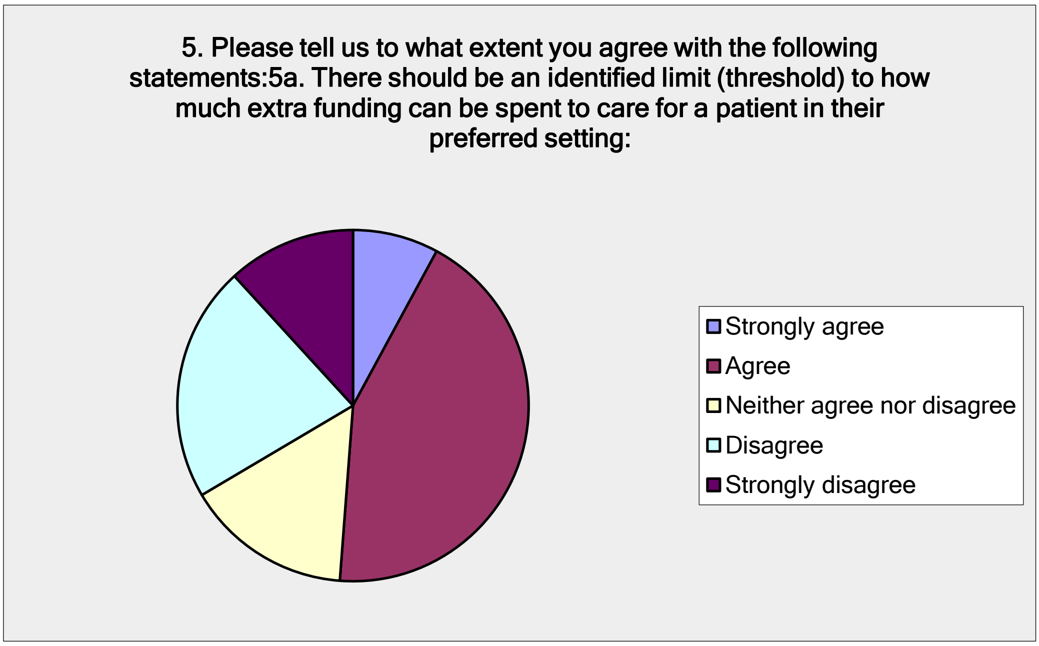
Commentary

Most people who answered this question agree or strongly agree that it is important that the local settings of care policy is consistent with others across England. However, nearly a quarter neither agreed nor disagreed, showing that a number of respondents were unsure of their views.

5.8 Question 5a was about whether there should be an identified limit (threshold) to how much extra funding can be spent to care for a patient in their preferred setting.

Please tell us to what extent you agree with the following statements: 5a. There should be an identified limit (threshold) to how much extra funding can be spent to care for a patient in their preferred setting:

Answer Options	Response Percent	Response Count
Strongly agree	7.9%	16
Agree	43.3%	88
Neither agree nor disagree	15.3%	31
Disagree	21.7%	44
Strongly disagree	11.8%	24
	answered question	203
	skipped question	1

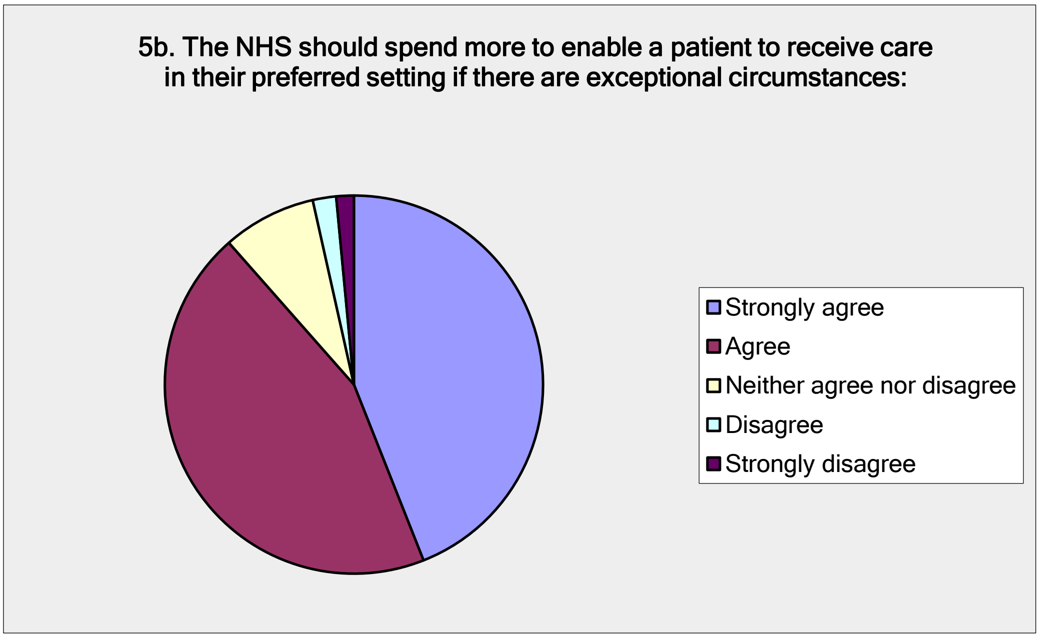


Commentary

Responses to this question were variable. Whilst just over half (51.2%) either agreed or strongly agreed that there should be a threshold, 33.5% disagree to some extent and 15% neither agreed nor disagreed, once again illustrating some level of uncertainty on this issue.

5.9 This question (5b) was about whether the NHS should spend more to enable a patient to receive care in their preferred setting if there are exception circumstances.

5b. The NHS should spend more to enable a patient to receive care in their preferred setting if there are exceptional circumstances:		
Answer Options	**Response Percent**	**Response Count**
Strongly agree	44.0%	88
Agree	44.5%	89
Neither agree nor disagree	8.0%	16
Disagree	2.0%	4
Strongly disagree	1.5%	3
	answered question	200
	skipped question	4



Commentary

The majority of respondents state that they agree or strongly agree that the NHS should spend more to enable a patient to receive care in their preferred setting (88.5%). Only seven people disagreed or strongly disagreed, and 16 people neither agreed nor disagreed.

5.10 Question 6 asked: What circumstances do you think the Clinical Commissioning Groups (CCGs) need to consider as 'exceptional' when deciding whether or not a person should receive extra funding for care in their preferred setting?

Respondents had the opportunity to answer this question with free text.

A number of themes emerged:

End of life care

It was felt that end of life care counted as ‘exceptional’. Comments included:

- The patients right to choose their appropriate end of life care
- If illness is terminal
- For terminally ill make them as safe and comfortable as possible
- Where a patient has a life threatening condition eg cancer
- When someone has lived in their house for 65 years and wants to die in their own home. Their family is caring for them all hours and only ask for night care help. But the lady in question (who has turned 90) is deemed not worthy.
- Their preferred place of dying

Specialist needs

Some people felt that where people had specialist or specific needs this counted as exceptional. For example:

- In the case of a patient requiring ‘one to one’ watch
- Patient safety, especially when they suffer from severe Alzheimers Disease
- Where patient falls frequently causing injuries and hospital treatment
- Condition or illness of patient eg Dementia etc
- For people who need extra supervision/care
- Special needs that require extensive resources over and above the normal care/nursing care

Family and friends

Many comments were about the importance of family and friends – some from the point of view of family, especially spouses. For example:

- Family/friends support network
- Age and mobility of spouse/partners as you can’t underestimate the importance of visiting on the person in case is to wellbeing or how heartbreaking for the person ‘left behind’
- Spouse ease of visiting
- People recover better at home with familiar surroundings and family

- The effect on the patient and family if care is not provided in their preferred setting - phsyically, mentally and how difficult the wrong setting would be for visiting, caring and loving the person
- Not to separate a longstanding married couple
- Safety, dignity and accessibility for partners (as they are generally older too)
- Proximity to family members and other natural social support eg child with challenging behaviour not manageable at home should be cared for in a setting that is at at reasonable distance from the parents' home

Emotional needs

Often linked to comments about family and friends, there were concerns for people’s emotional wellbeing as exceptional circumstances. For example:

- When a person with dementia has settled in a place where they feel safe and secure, which is extremely important in their care, they should not have to move
- If the patient is unable to settle and is unhappy
- When there is not a suitable provision out there. People need to be stimulated. Many care homes think that staring at a TV all day is good practice
- Quality of life, happiness, well-being, familiarity or surroundings, staff. Staff knowledge of the person

Choice of setting

People’s choices were mentioned, for example:

- Preference and choice is a main factor
- Mental wellbeing. It being an un-preferred setting will be detrimental to a patient’s mental and even physical wellbeing
- A person’s needs should be fully met wherever they choose to live

Finance

Some people talked about financial matters, for example:

- A person should not have their choice limited due to regional variations in living costs
- Access to family – not all able to pay to facilitate extra funding to pay towards their relatives care
- I travel almost 20 miles every day to see my partner, so any further would be a financial strain
- If the patient is being cared for at home and is very ill, Carers should be coming to see him/her 3 to 4 times a day. This has got to be costing less that being in hospital or a care home
- Extra support if care at home ends up being more expensive (I don't suppose that is the usual case) or if care at home needs to be temporarily increased due to

family carer illness / hospitalisation etc
- Consistency - not move the patient when they are settled- just to save money

Individual circumstances

Some respondents felt strongly that each case should be decided individually, according to their needs. For example:

- Needs case by case decisions
- Every case is exceptional: every patient has a unique set of needs and the care setting for managing these needs has a MAJOR impact on the wellbeing of the patient
- Rather than 'exceptional' each case should be viewed on its own merits. Ensuring that each person being cared for is given the care they need rather than what might be cost effective.
- I feel that a patient should receive care in their preferred setting provided this setting meets their physical, safety and psychological needs, I do not think that they need to provide “exceptional circumstances” to justify this individual need

Overall, the replies to this question reflected the experience of those who responded, which gave them an in depth understanding of the issues involved in Continuing Health Care, for both those receiving the care, and their loved ones and carers. They saw ‘exceptional circumstances’ in a way which reflected this. Full comments are at Appendix 3.

5.11 Question 7 asked: Is there anything else that you would like us to take into consideration as we update the Settings of Care Policy?

Many people also responded to this question. A number of themes again emerged. Some people again wrote about the importance of treating people as individuals and caring for all their needs. They also spoke about the importance of family once again.

Typical examples are:

- Look at people's feelings instead of looking at them as a number on a form.
- Every patient is unique, so care should be created for that person's needs, and not come down to pound signs.
- Please consider the distress you will cause to a dementia patient settled into their preffered setting if you decide you will no longer pay the required amount. This I believe would be of serious detrement to their condition.

Other themes which emerged were:

Funding

People talked in more detail about funding in answer to this question. For example:

- The extra money must directly benefit the person receiving the funds
- Being mindful of budgetary constraints many existing providers of care now fall below a satisfactory level of care for very vulnerable patients. The need to target resources is essential to prevent poor quality care and possible risks to become widespread.
- Understand that if the patient is returned to the community, there is no money in Social Services. Extra stress on local surgeries. Lack of community health workers for medication.
- In my experience the level of care and possible problems are very often under estimated. If something can happen - it will. This level of care does not come cheap but should problems arise then so do costs (exponentially). Don't try to cut costs but do try to get value for money spent.
- Market rate for dementia care not keeping pace with rising staffing costs
- There should be no favourable distinctions to patients who are new to this country at the expense of the local patients who have contributed to upkeep of NHS.
- We must be aware of not allowing City areas (ie Leicester City) to eat up disproportionate percentage of funding. This discriminates against suburban areas and in particular communities of White, Working Class backgrounds who already suffer under-resourcing across other areas such as education, transport and infrastructure funding.
- If it is a case of the preferred setting increases costs (but is still safe etc), then perhaps the person/family can have the option of paying the excess. Having both parents at times receiving 100%, I think it unfair and unlikely circumstance to go to 0%. Equally, I think that 100%, could still include a slight charge as say 10-15% to the patient as in any walk of life, living costs something. Also this would free up some money for others.
- I appreciate that funds are finite, but you cannot over rule established case law and The National Framework with policy. It is unlawful to do so. Are you attempting to impose/legitimise Top Up payments on people with fully funded care? That is unlawful.

Carers' concerns

Many of the respondents were carers, and they talked about some of their concerns. For example:

- Welfare and health of chief carer (husband, wife, children) are vital. Patient care will deteriorate if the chief carer is unable to cope with the strain. High extra costs may result.
- Should give more autonomy to patient or carer about where they receive care from eg private/friends. Like a personal budget.

- The health of carers, (husbands, family members, etc) who have to do the job when proffesionals go home. It is a strain on people who are usually not young themselves.

Assessments

Some people expressed frustration with the assessment process. For example:

- Too many assessments on the elderly who do not improve. Waste of time and money. Assessors very good and could be used elsewhere in the Health Service. Meetings take hours and it is a total waste and others time. Assessment far too wordy and difficult to interpret so meetings take too long. Is the continuous health care checking on the Homes they have patients in? Can they alone improve care. Money should not go to care homes that are not caring for the elderly adequately. Are they coping? Should Continuous Health Care assessors send patients to homes that are not performing well? Who decides? Relatives need more information. When I have rang you, people have been very pleasant and helpful.

Personal stories

Several people told their stories. There is not space to reproduce many here – all the responses are in Appendix 3. Examples are:

- I have completed this form for my husband. He has vascular dementia and has not been able to write or communicate properly for a few years. He is totally bedridden and unable to do anything for himself including eating and drinking, washing - he is totally incontinent.
- I myself as a Carer for my husband who has dementia and cancer of the bladder among many other problems would like some time to myself!! But having him at home was what we both wanted
- There is a spectrum of care settings available: Our father has gone through self-funding support at home, and in a care home, and as his alzheimers has progressed to include psychotic and delusionary episodes / challenging behaviour he has been in receipt of CHC funding. The care home he is in now is the only place in Leicestershire able and willing to care for Dad. The fallback position is the NAME OF CENTRE which is unable to cope with the number of seriously ill patients - all with challenging behaviour. Our father was subject to assaults from other patients there, and the ward was subject to a safeguarding review. Please bear in mind patients who are at the severe end of the care setting spectrum, where there is a real need for rapid, efficient systems of payment and placement. Alternatives in the hospital sector are unsustainable and unsafe.

6. Conclusion

In conclusion, the data gives useful insight into the views and circumstances of those receiving continuing healthcare, and those caring for them, including their families and friends.

The discussions at the engagement event reinforced the themes that emerged from the questionnaire.

Overall, those responding believe that the setting in which care is given is important to the patient, in particular to their mental health. It is also important to family and friends both because they want their loved one to feel safe and at home, and because of access issues. Costs are talked about by those responding, but they are more interested in the quality of care for individuals, and some of the comments emphasise that individual needs must be taken account of.

When it comes to exceptional circumstances, the answers reflect again the view that the whole person should be cared for, and that sometimes this involves specialist care. Particular settings are preferred by family and friends because of familiarity and better access. End of life care is strongly seen as an exceptional circumstance.

In the final section, where people were invited to add anything else they wanted taken into consideration, once again the comments reflect the deep and personal knowledge of those responding to the questionnaires. Many respondents show awareness of the issues the NHS are grappling with. Many show gratitude, but are also asking for their personal and often difficult circumstances to be taken into consideration. One comment perhaps sums this up:

> “In all other areas of healthcare whether primary, secondary, tertiary, acute or mental health, patients and their relatives are not involved in funding discussions. Why, when patients are at their most vulnerable and relatives at their most distraught, is funding decided at individual patient level in the most bureaucratic way possible? I know this is national not local policy but please, whatever you come up, can you take into account that you are dealing with the most vulnerable in society. Your policy should remember the words of the NHS Constitution that 'the NHS touches our lives at times of basic human need, when care and compassion are what matter most’.”

Appendix 1: Demographic and monitoring data

The final section of the questionnaire gathered monitoring data. This enabled us to gain an awareness of demographic data to ensure the relevant people were heard.

8. What are the first 4 letters of your postcode?	
Answer Options	**Response Count**
	180
answered question	**180**
skipped question	**25**

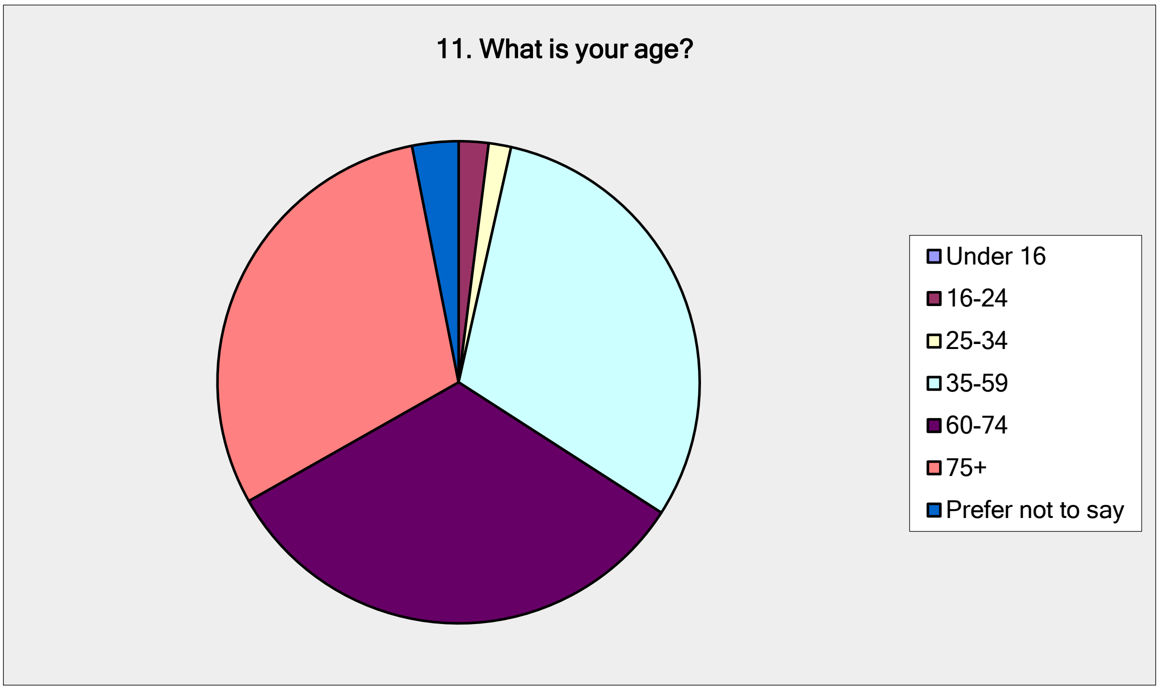
Response Text				
LE45	LE9 7	LE15	LE14	LE4 4
LE3 1	LE67	LE12	LE4 3	LE4
LE3	LE67	LE3 8	LE43	LE65
LE2 6	LE8	LE GQ	LE17	LE2 6
LE3 2	LE67	LE4 7	LE12	LE16
LE7 2BE	LE18	LE9 2	LE9 2	LE24
LE2 3	LE5 6	LE13	LE HL	LE80
LE67	LE11	LE2 P	DE12	LE72
LELF	LE HH	CV13	PEDX	BN11
LE4	LE7 4	LE13	LE2	LE10
LE67	LE4	LE3 9	LE18	LE4 4
LEPT	LE12	LE9 2	LE4O	LE16
LE5 1HE	LE7 2JX	LE13	LE5 1	LE11
LE7 3FA	LE15	DE12	LEJP	LE JS
LE18	LE10	LE11	LE13	LE16
DE75	LE9	LE3 P	LE48	LE44
LE JP	LE21	LE11	LE51	LE2 9
LE12	LE ER	LE12	Le15	LE4 4
DE12	LE2 8	LE4 4	DE 74	LE9 8
DE12	LE3 8	LE ET	LE BT	LE!5
LE65	LE11	LE13	B169	LE14
LE2	LE15	NG13	LE17	SW9 8AR
LE23	DE12	LE15	LE16	LE14
LE12	LE3 / LE8 9	LE4	LE4 5BU	LE14
LE12	LE7 9	LE4 6	LE7 8	DE12
LE56	LE15	LE2 9	NQ21	LE11
LE18	LE2 H	LE3 1	NGPJ	LE15
LE5	LE3 0	LE67	GL19	LE45 DN
LE5 1	LE10	le8 4	LE14	LE15
LE4 3	LE19	LE4 B	LE12	LE11
LE2 1	DE12	LE PG	LE10	LE50
LE9 1	LE3 6	LE7 2	NG31	LE10 0PL

LE JE	LE10	LE4	LE12	LE11
LE67	LE3 9	LE18	LE19	LE67
LE15	LE12	LE15	LE7 2	LE9 7
LE12	LE9	LE 67	LE18	LE98

Commentary

This lists shows that the people who responded to the questionnaire came from a wide area within Leicester, Leicestershire and Rutland.

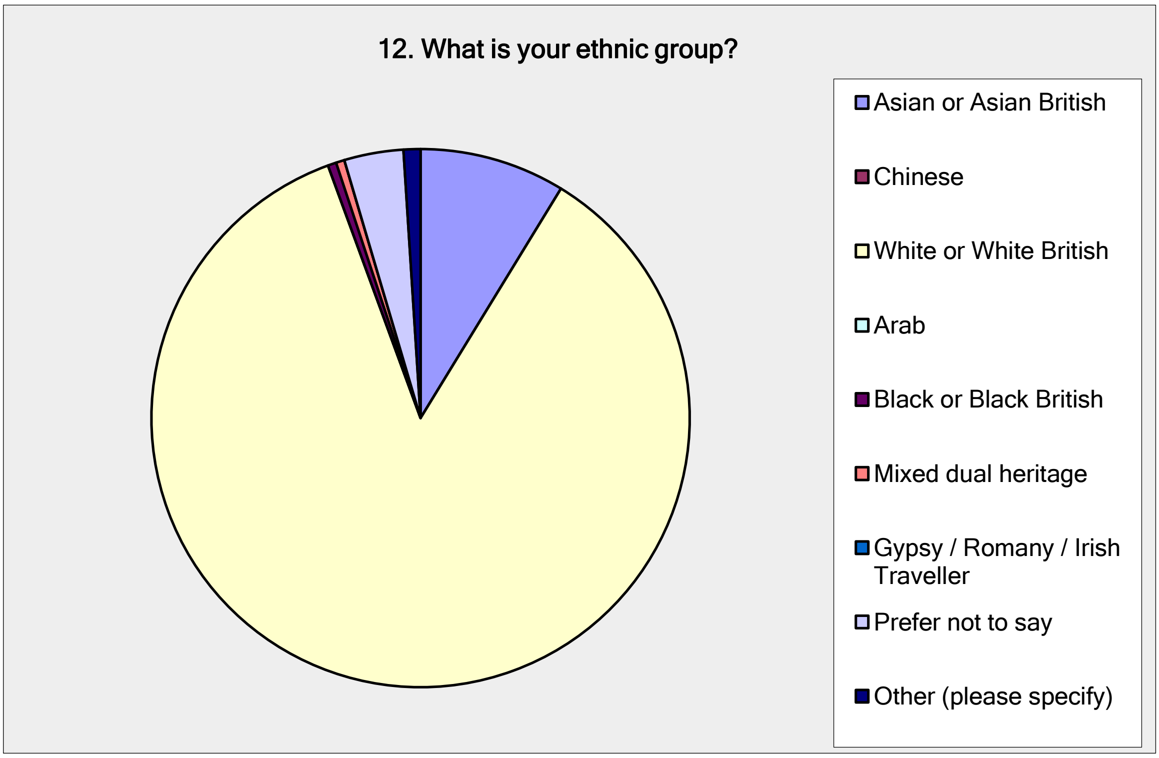
11. What is your age?		
Answer Options	Response Percent	Response Count
Under 16	0.0%	0
16-24	2.0%	4
25-34	1.5%	3
35-59	30.6%	60
60-74	32.7%	64
75+	30.1%	59
Prefer not to say	3.1%	6
	answered question	196
	skipped question	9



Commentary

The age groups represented were largely 35-59, 60-74 and 75+. This probably reflects the wider population who are most likely to be using CHC or caring for people using CHC. However, it may be that it would be useful to do some more targeted work with young people and their carers who use CHC.

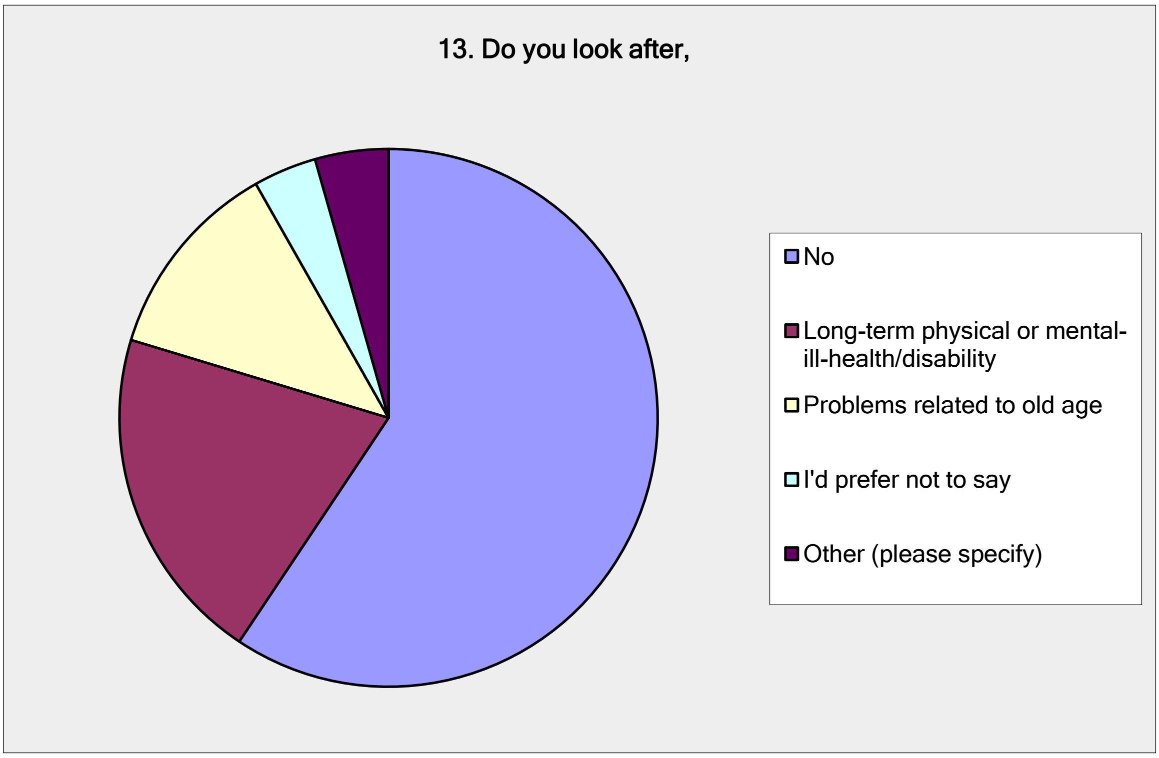
12. What is your ethnic group?		
Answer Options	**Response Percent**	**Response Count**
Asian or Asian British	8.6%	17
Chinese	0.0%	0
White or White British	84.3%	167
Arab	0.0%	0
Black or Black British	0.5%	1
Mixed dual heritage	0.5%	1
Gypsy / Romany / Irish Traveller	0.0%	0
Prefer not to say	3.5%	7
Other (please specify)	1.0%	2
	answered question	198
	skipped question	7



Commentary

Most of the people who answered the questionnaire were White or White British. There were much smaller percentages from other ethnic groups. This largely reflects the population of the counties of Leicestershire and Rutland but not so much the city of Leicester, so further targeted work may need to be carried out with some of the ethnic groups within Leicester.

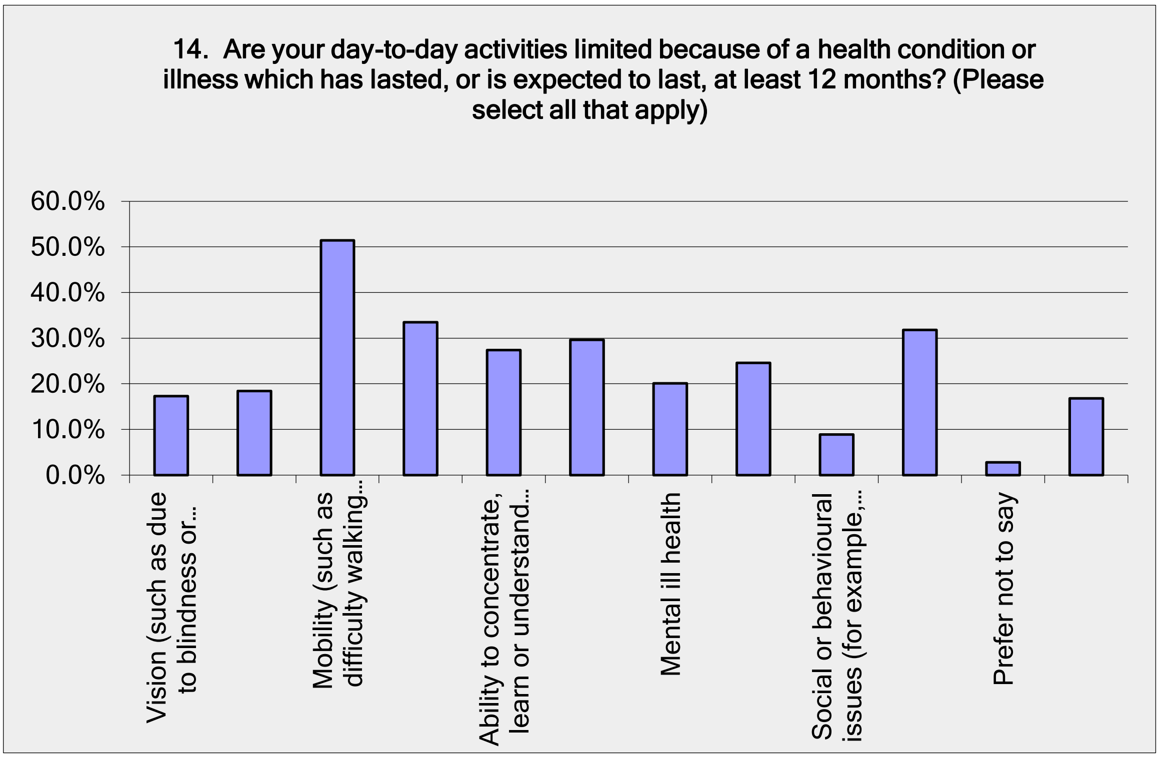
13. Do you look after, or give any help or support to family members, friends, neighbours or others who have any of the following. Please note this is not referring to the person you care if you have specified carer or if you are completing this survey on behalf of someone else.		
Answer Options	**Response Percent**	**Response Count**
No	59.3%	108
Long-term physical or mental-ill-health/disability	20.3%	37
Problems related to old age	12.1%	22
I'd prefer not to say	3.8%	7
Other (please specify)	4.4%	8
	answered question	182
	skipped question	23



Commentary

The answers to this question show that nearly 60% of those responding did not care for anyone other than the person receiving CHC, but that around 30% did care for someone with a disability or problems related to old age. Given that this is in addition to any care responsibilities for CHC, this indicates that some carers have considerable responsibilities.

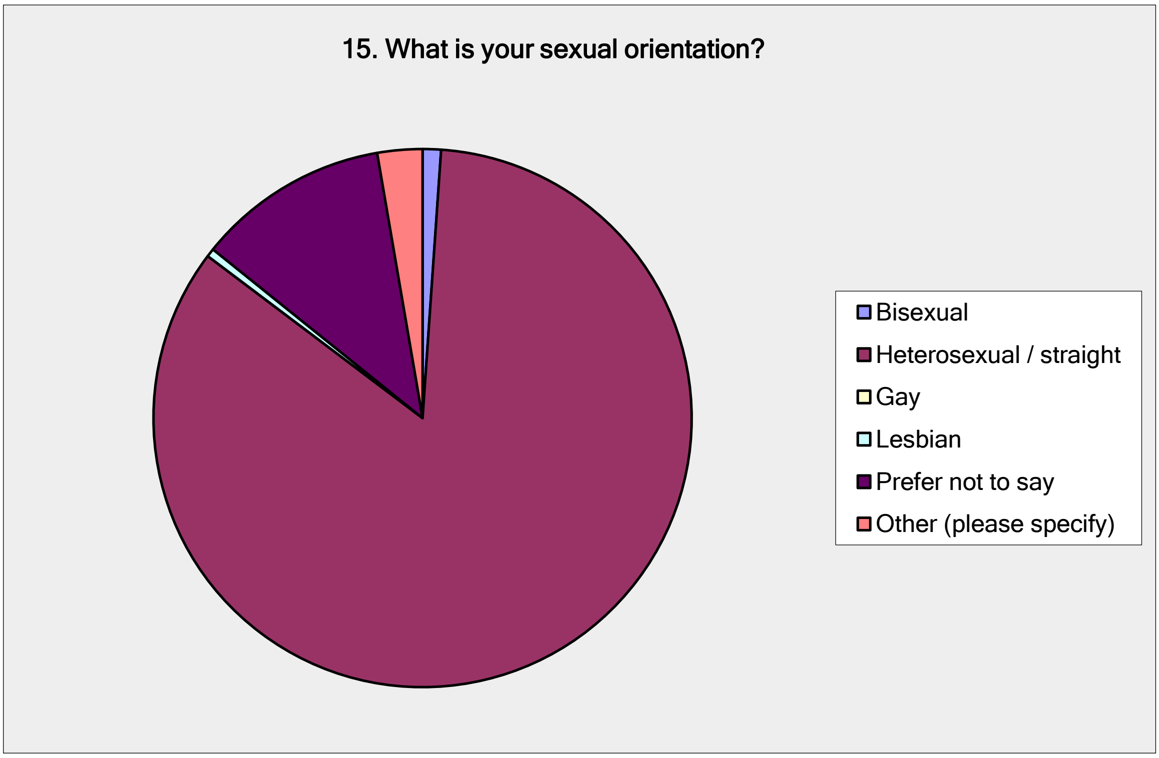
14. Are your day-to-day activities limited because of a health condition or illness which has lasted, or is expected to last, at least 12 months? (Please select all that apply)		
Answer Options	**Response Percent**	**Response Count**
Vision (such as due to blindness or partial sight)	17.3%	31
Hearing (such as due to deafness or partial hearing)	18.4%	33
Mobility (such as difficulty walking short distances, climbing stairs)	51.4%	92
Dexterity (such as lifting and carrying objects, using a keyboard)	33.5%	60
Ability to concentrate, learn or understand (Learning Disability/Difficulty)	27.4%	49
Memory	29.6%	53
Mental ill health	20.1%	36
Stamina or breathing difficulty or fatigue	24.6%	44
Social or behavioural issues (for example, due to neuro diverse conditions such as Autism, Attention Deficit Disorder or Aspergers' Syndrome)	8.9%	16
No	31.8%	57
Prefer not to say	2.8%	5
Other (please specify)	16.8%	30
	answered question	179
	skipped question	26



Commentary

The answers to this question showed considerable levels of health conditions or illnesses which limited people's daily activities. This could relate to the carers but also to the people receiving CHC, as some people stated that they completed the form on behalf of the person they were caring for. This means that these results are less easy to interpret than other questions. Overall, however, they show a level of ill health and disability among those who are affected by CHC policy.

15. What is your sexual orientation?	15. What is your sexual orientation?	15. What is your sexual orientation?	15. What is your sexual orientation?
Answer Options	Answer Options	Response Percent	Response Count
Bisexual	Bisexual	1.1%	2
Heterosexual / straight	Heterosexual / straight	84.1%	153
Gay	Gay	0.0%	0
Lesbian	Lesbian	0.5%	1
Prefer not to say	Prefer not to say	11.5%	21
Other (please specify)	Other (please specify)	2.7%	5
answered question	*answered question*	*182*	182
skipped question	*skipped question*	*23*	23



Commentary

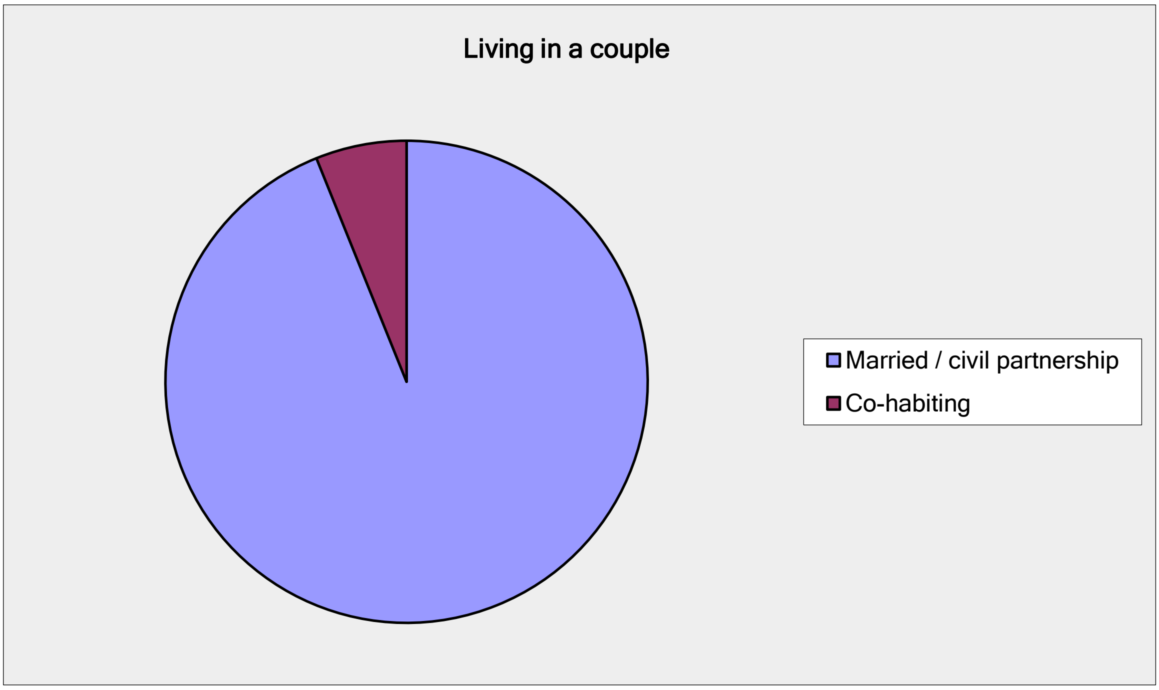
Most of the people who answered this question identified as heterosexual/straight. More than 10% preferred not to say and there were small numbers of lesbian and bisexual. Further engagement may wish to do some targeted work with the LGBT community.

16. Are you:Single		
Answer Options	**Response Percent**	**Response Count**
Never married or partnered	100.0%	29
	answered question	29
	skipped question	176

Commentary

Twenty nine people who answered the survey identified as single. This shows as 100 per cent because of the way the survey is structured but it is actually just under one sixth of those who answered the survey.

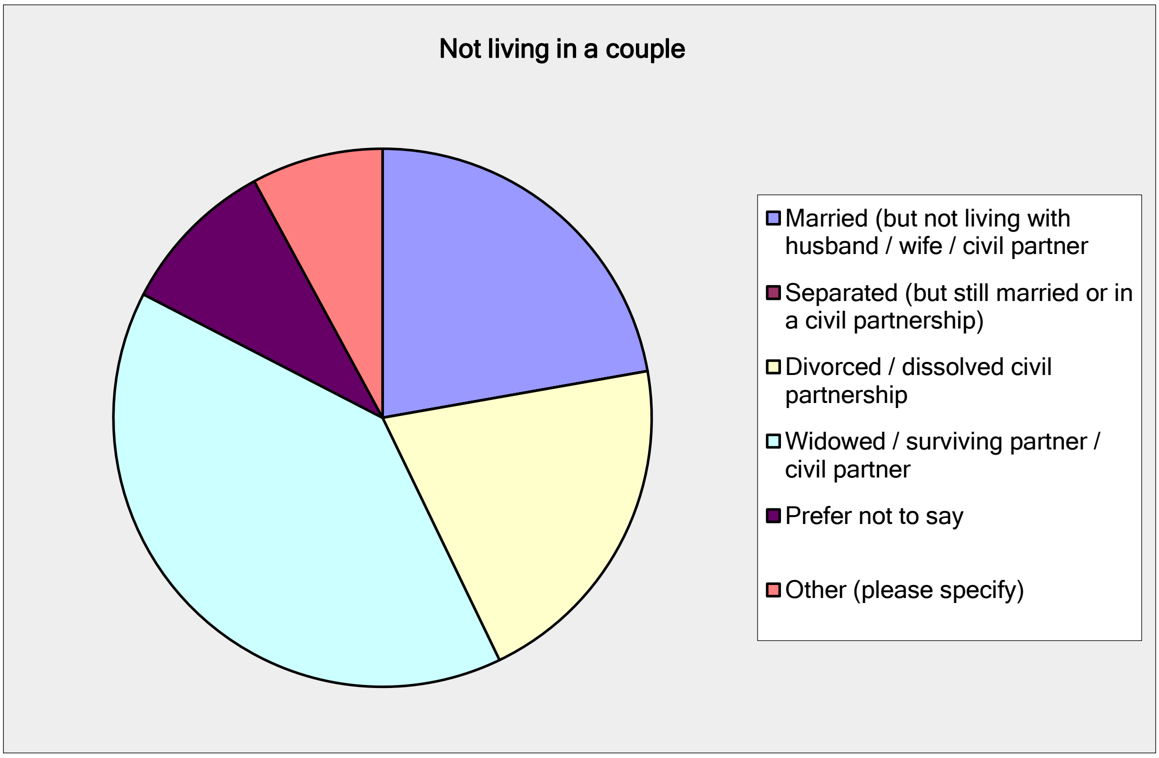
Living in a couple		
Answer Options	**Response Percent**	**Response Count**
Married / civil partnership	93.9%	93
Co-habiting	6.1%	6
	answered question	99
	skipped question	106



Commentary

Ninety three people said they were married or in a civil partnership, and six said they were co-habiting.

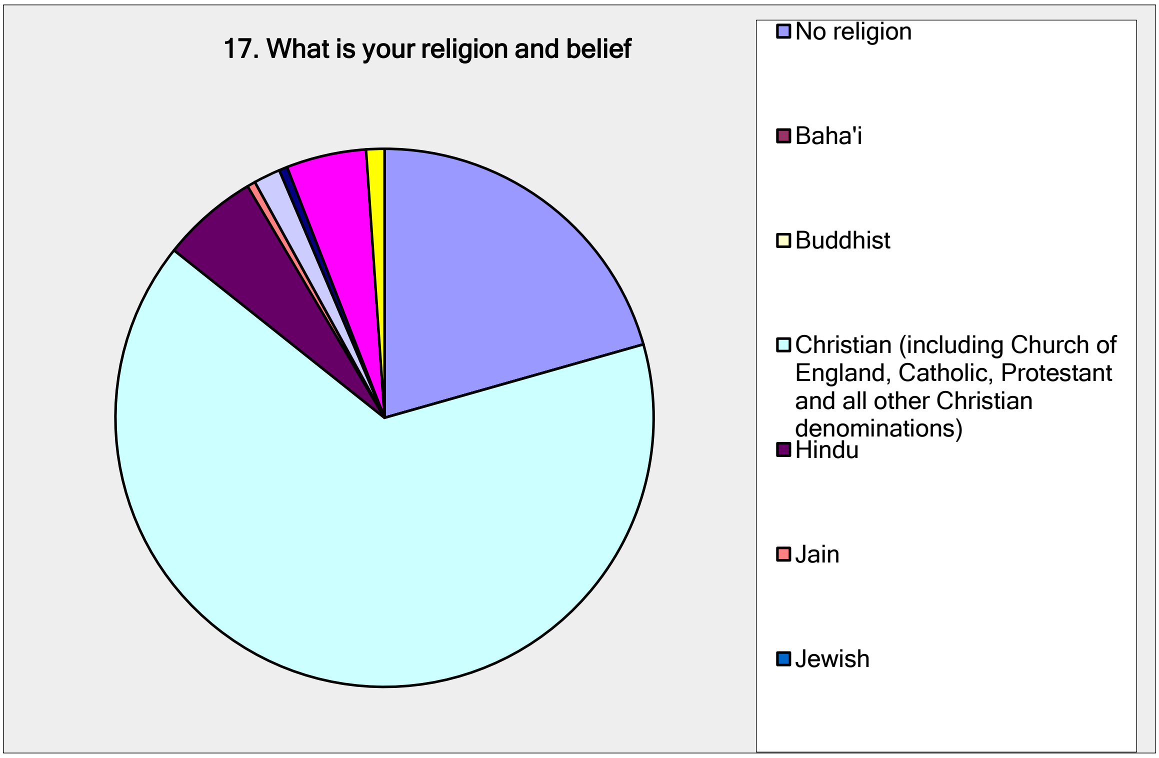
Not living in a couple		
Answer Options	**Response Percent**	**Response Count**
Married (but not living with husband / wife / civil partner	22.2%	14
Separated (but still married or in a civil partnership)	0.0%	0
Divorced / dissolved civil partnership	20.6%	13
Widowed / surviving partner / civil partner	39.7%	25
Prefer not to say	9.5%	6
Other (please specify)	7.9%	5
	answered question	63
	skipped question	142



Commentary

Among those not living in a couple, 14 people were married but not living with their partner – this may have been because the partner was in some kind of care home. Twenty five people were widowed, which may reflect the relatively older age group who completed this survey. Thirteen were divorced.

17. What is your religion and belief		
Answer Options	**Response Percent**	**Response Count**
No religion	20.6%	39
Baha'i	0.0%	0
Buddhist	0.0%	0
Christian (including Church of England, Catholic, Protestant and all other Christian denominations)	65.1%	123
Hindu	5.8%	11
Jain	0.5%	1
Jewish	0.0%	0
Muslim	1.6%	3
Sikh	0.5%	1
Prefer not to say	4.8%	9
Other (please specify)	1.1%	2
	answered question	189
	skipped question	16



Commentary

Most of the people who completed the survey identified as Christian, and one fifth said they had no religion. There were small numbers of people from other religions, and once again this does not reflect the population of Leicester City, so further engagement may wish to target some people from some of the ‘minority’ religions.

Appendix 2: Questionnaire (separate document)

Appendix 3: Full written responses

6. What circumstances do you think the Clinical Commissioning Groups (CCGs) need to consider as 'exceptional' when deciding whether or not a person should receive extra funding for care in their preferred setting

- Sensitivity to patients background and culture ... Ability of the patient to embrace the environment and the provisions for a humanely life
- I consider that the end of care is very important to the patient and also the person looking after them
- A meeting should be held with all involved in the care/wellbeing of the persons exceptional circumstances
- If there were mobility problems for the visiting spouse/family members. If the patient's conditions was to be exacerbated by change of setting
- This must be decided on individual requirements
- When a patient is approaching or at the end of their life
- Where the patient is situated, say 20 miles away with not direct public transfer links and the parent becomes unable to driver
- End of life
- in the case of a patient requiring a 'one to one' watch
- to look at income Support (external)Patient needs
- Would their quality of life be better overall
- A person should not have their choice limited due to regional variations in living costs.
- A persons needs should be fully meet where ever they wish to live
- A persons safety and that of their family and friends should be maintained regardless of cost.
- The standard of care in the preferred setting should meet the needs of the patient and their family
- When someone has lived in their house for 65yrs and wants to die in their own home
- Their family is caring for them all hours and only ask for night care help.
- But the lady in questions (who has turned 90) is deemed not worthy
- If things get worse extra funds to keep him in his own home
- to enable the patient to feel clean and safe in a pleasant environment, (many care homes do not meet the required standards)
- Where the person wants to live
- To provide funding to allow patients to live in their, or families preferred setting
- The amount of nursing care a person requires
- One to one specialist care.
- Where patient falls frequently causing injuries and hospital treatment.

- Management of uncontrolled actions which otherwise may lead to self-harm and harm of others
- Need for careful administration of food where patients cannot feed themselves
- End of life care
- Exceptional/complex needs where choice is limited Distance from carers/close relatives to take account as far as possible of each person's individual circumstances. For example, a recent bereavement may make it difficult for the person to make a long term choice immediately and a move away from home could be like a double bereavement
- If a person has exceptional circumstances the most important thing is that wherever that person is they receive the dedicated care that they require, given by dedicated and caring staff who totally understand their everyday needs
- Age and mobility of spouse/partners as you can't underestimate the importance of visiting on the person in care is to their well being or how heartbreaking it is for the person 'left behind' - which also has an impact on their health and in turn a cost to the NHS.
- Patient's peace of mind is vital. Being in familiar surroundings (house, garden, neighbours, pets) is most important
- Easy access to cater for visiting.
- It would be to meet the patients individual needs which are paramount
- Family/friends support network. Type and level of care Health and Wellbeing of family/friends living with the patient
- Preference and choice is main factor. Options could be explored to offer a informed choice. Wellbeing and control indecisions will affect health.
- Condition or illness of patient eg Dementia etc.
- I am not aware of exceptional circumstances and what they are. Though it should have been stated to help people what these are. These need to be very exceptional. I want a fairer system throughout the country. At present very unfair eg Derbyshire pays to UDS (?) care.
- When they state they would rather die at home or not.
- When a patient has Dementia or Alzheimers disease.
- Age and ability to look after themselves also mental health issues
- The quality of other settings available to meet the patients needs in the area.
- Careful thought to the individual's needs rather than just blindly following "check tick lists". For example over emphasis on aggressive behaviour when those of a placid nature may have a far more debilitating illness (eg Parkinsons)
- To enable a patient to stay safely in their chosen place, ensuring the best outcome for a patient emotional , psychological and physical wellbeing is the foremost in the decision (- NOT the overall cheapest option)
- How independent they are, how poorly, how it would affect the person to have change a lot of people with special needs, have to be in the same environment, with the same people around them especially if they can't speak, the carer will get to know if they are in pain etc.

- Their medical/health needs suitability and qualification of staff in order to meet patients' needs.
- For people who need extra supervision/care where their environment is a contributing factor to their welfare
- I'm not aware of list of "Exceptional circumstances". It should not apply just because of family needs. Patient only to be looked at.
- Extreme agitation, anxious, behavioural issues, putting self and others at risk
- when the person can not do anything for himself and needs carers to do everything for him, being moved every two hours
- The patients personal finances
- The patients Degree of Illness
- The safety of the patient. It depends what the exceptional circumstances are.
- A person who suffers from anxieties needs to feel at ease in their surroundings If there are changes and they are moved to an area in which they are not comfortable, their anxieties could increase and this can make them unwell.
- If the chances of recovery (long-term) are better in their preferred setting.
- The patient is more at ease at home if there is someone to look after ie Husband wife going each day to hospital etc is a strain on those who care
- Vulnerable and totally dependent patients condition
- Needs case by case decisions
- Age/state of health/proximity of family
- When a person with dementia has settled in a place where they feel safe and secure, which is extremely important in their care, they should not have to move.
- Mental state of the patient.
- Location if patients family live far away.
- Everyones circumstances are so different, I am not sure how to make hard and fast rules.
- Being close to relatives who visit.
- All circumstances are different.
- When the patient's needs are such that they can only be provided by professionals as recommended by the NHS
- Quality of life
- Safety, dignity, accessability for partners (as they are generally older too
- Would it really be better for that person, physically or mentallyIt is not about preferred setting it is about the setting that can care appropriately. Our father had multiple admissions to UHL & LPT because he was placed in care settings who were unable to cope with challenging behaviour. This was exceptional behaviour requiring exceptional funding. It is not really about preferred setting for our father – he has to be in a secure setting because of his challenging behaviour. There was only one place willing to take him and who can cope with his behaviour with appropriately trained staff.
- A young person with young family may need to remain in their own home. Family commitments and responsibilities should be considered. Relationships and friendships are important to where people live.
- All judgements must be complied with by the law - especially case law

- Life expectancy. Transport routes / availability of transport for elderly/disabled next of kin
- End of life
- Quality of life
- The patients right to choose their appropriate end of life care. (1) Safety - under all circumstances inc. rare ones. (2) The higher the vulnerability the greater the funding. (3) If a person has very high needs - family carers must feel confident in entrusting their loved one to other setting – or family break down can occur.
- Special needs that require extensive resources over and above the normal care/nursing care.
- The exceptional severity of patient's condition and unpredictability caused by the patient's deterioration and vulnerability over time. Location of setting should allow accessibility for family members.
- Access to Family - Not all able to facilitate extra funding to pay towards their relatives care
- Severe Mental Health Issues
- The emotional ties are often overlooked to meet the local standard.
- The wellbeing of the patient. Inability for spouse to cope with patients symptoms. Health and wellbeing of spouse/carer. No money in Social Services for support. Regular medication / injections. Exceptional circumstances might include living as my mother does in council property in relative poverty or not having enough money to support ones needs.
- Persons physical as well as mental capability to perform daily required tasks to carry on living. Extent of dependency on carers and other family members. Dependence on equipments for mobility and to carry out daily living activities.
- Patient way of life in past ie to try to keep same standards, or better standards.
- Due to total immobility and being bed-ridden it is important that CCG's are allowed to assist in preferred settings. It good for the familys which have a person who needs extra funding, so it can help the familys finance. The needs and wishes of the PATIENT and their immediate family must always be paramount and not be compromised by budgetary constraints, being mindful of a patients health needs and risks.
- If the patient wishes to stay at home funding should be available
- If there is no family or friend's support and the patient wishes to stay in a preferred setting then extra care may be required to support patient, in which case more funding would be needed to maintain.
- Special needs - mental health
- Patient safety, especially when they suffer from severe Alzheimers Disease. In these cases the family, especially the spouse, need to know they are safe from unpredictable behaviour of such patients, plus other patients in the same facility and the staff caring for them.
- End of life
- If the patient cannot look after themselves
- Completely dependant on a nursing home. NAME has P.S.P; he understands everything one says, so he is exceptional because being in his preferred setting,

he feels a lot at ease, he walks with eyes closed (can't keep his eyes open in P.S.P.).

- Elderly people living alone with no family support
- Age of the patiant and state of mind
- I travel almost 20 miles, everyday to see my partner, so any further would be a financial strain
- Not to separate a long standing married couple
- Where there has been a death in the family to try and keep things as normal as possible to the person who is getting the Funding
- life and death situations-end of life terminally ill
- For very old people with mental problems a change of environment can be extremely distressing. People recover better at home with familiar surroundings and family. They eat better, as hospital food is very poor.
- for a bloke who has got serious illness who needs feeding, if they want mobile assistance
- Patients with no family input. If patient is not safe in their own home. Needs of the spouse/partner of elderly patients
- If illness is terminal
- For terminally ill to make them as safe and comfortable as possible
- The level of disability, care givers (Age, health and own abilities) money could be better spent on properly facilitated day care services.
- if the illness becomes worse
- family support system (support)
- circumstances where the patient cannot receive treatment locally. Where it would be detrimental to the person to be seen elsewhere
- If the patient has a severe, or life threatening or terminal disability
- Each case is individual to the patient, all patients cannot be cared as each other the needs of the patient is surely the major factor a) to be provided if needed b) to be provided if affordable
- If the person receiving the care needs to stay in their own home for mental stability
- Individuals health care needs are all exceptional.there cannot be a generic formula for 'exceptional'
- All patients needs should be assessed by someone who is expert, medically qualified! Not financially blinkered the happiness and wellbeing of the person FAMILY - CHILDREN, PARENTS. WORK OPPORTUNITIES SOCIAL AND MENTAL HEALTH
- If the patient is being cared for at home and is very ill, Carers should be coming to see him/her 3 to 4 times a day. This has got to be costing less that being in hospital or a care home
- End of life care
- behavioural problesm
- Where a patient has a life threatening condition e.g cancer
- Levels of disability, care needs, nursing care needed, suitability of staff concerned, and facilities

- Terminal illnesses
- The effect on the patient and family if care is not provided in their preferred setting - phsyically, mentally and how difficult the wrong setting would be for visiting, caring and loving the person.
- If it improves their quality of life or if they have limited family who need them to have care close to their location. Each case should go to a panel for the final decision.
- their preferred place of dying
- I am bedridden, I cannot get out of bed for any reasob
- complex needs - location in easy reach for relations and friends (not isolated)
- As my husbands carer, I need more support over night to allow me to keep him at home for the rest of his life close to family. If a person feels extremely upset in their surroundings but is content in the preferred setting - that will affect their health and wellbeing
- End of life care. If a patient is totally reliant on family members for every aspect of care and is unable to understand or communicate and moving them would shorten life expectance a patient who has complete mobility limitations would need more care that a patient who could move around where the person would need to be moved from current setting due to cost particularly in cases where patient has dementia
- To enable the person to be near family of friends to enable their social interaction depend on Consultant and Doctor
- a patient's opinions should always be the most important consideration, even if it costs more
- A skin removal operation at City Hospital Nottingham
- If the patient is unable to settle and is unhappy
- Any circumstances that are for the good of the patient and that are person centred
- Age and health of spouse.
- When there is not a suitable provision out there. People need to be stimulated. Many care homes think that staring at a TV all day is good practice
- Reasonable proximity to familySo they can live a reasonable life in their own home/setting with care provided as this patient requires to live
- Safety
- Lack of accessability to health facilities eg Hospitals
- Decision should rest jointly between the CCGs and the patient's need
- Immediate medication in situ which can be given by qualified nurses, to a patient who is unable to care for any of their own needs - bathing, eating, toileting and speech.
- End of Life Care Living alone
- Accessibility for other family member who are/maybe limited by age or mobility You have no interest in caring for the elderly ill. You want to save money. This questionnaire is biased towards the outcome you want. Shame on you!
- Quality of life/further risk of harm
- Security

- Familiar surroundings, interaction
- Risk of others and themselves
- With their best interests always
- End of Life Care - wishes of patient
- Specific communication needs.
- The need for a particular level of care.
- Serious concerns for mental health well-being.
- Previous health issues.
- Personal dignity; accessibility for carers/close family members
- Rather than 'exceptional' each case should be viewed on its own merits. Ensuring that each person being cared for is given the care they need rather than what might be cost effective.
- Consistency - not move the patient when they are settled- just to save money. If the patient's needs become greater and greater care is required but that care can be offered in the same setting but requires more funding.
- Patients nearing the end of life
- Vulnerable patients eg those who lack capacity
- Severely disabled patients life expectancy less than 3 months
- Ability of close relatives to visit the person receiving care If they are on their own.
- If the patient has a life threatening illness.
- extra funding should be received to enable a patient to have end of life care in their own home
- mental wellbeing, it being in an un- preferred setting will be detrimental to a patient 's mental and even physical well being
- Quality of life. If CCG need place somebody hundreds of miles away from loved ones/or if family don't drive and visiting entails an arduous journey on public transport.
- The psychological and physical well being of the patient
- The patient's own clinical needs, and, if possible, distance from the patient's carers/next of kin together with ease of access for these people.
- The Coughlan and Pointon judgements give adequate legal guidance on this.
- I feel that a patient should recieve care in their preferred setting provided this setting meets their physical, safety and psychological needs, I do not think that they need to prove "exeptional circumstances" to justify this.
- individual need
- On person circumstances
- Level of care need Spouse ease of visiting
- Quality of life, happiness, well-being, familiarity or surroundings, staff. Staff knowledge of the person
- End of life care should be as close to family as possible.
- Every case is exceptional: every patient has a unique set of needs and the care setting for managing these needs has a MAJOR impact on the wellbeing of the patient.
- Proximity to family members and other natural social support eg child with challenging behaviour not manageable at home should be cared for in a setting

that is at at reasonable distance from the parents'home.

- Extra support if care at home ends up being more expensive (I don't suppose that is the usual case) or if care at home needs to be temporarily increased due to family carer illness / hospitalisation etc
- Needs of the patient or their carers/accessibility for family
- When the patient has needs that the "system" does not currently provide. People need stimulation and interaction, not staff who sit them in front of tvs all day!
- Limited lifespan. Availability of suitable local care

7. Is there anything else that you would like us to take into consideration as we update the Settings of Care Policy?

- There should be no favourable distinctions to patients who are new to this country at the expense of the local patients who have contributed to upkeep of NHS.
- How things will affect the person and family short an long term
- NA
- Look at people's feelings instead of looking at them as a number on a form.
- Every patient is unique, so care should be created for that person's needs, and not come down to pound signs.
- Staffing levels are always a cause for concern and this is something that care home companies should correct by whatever means
- Nothing at all
- When the patient has multi health problems
- When the person can't manage medication or get to the bathroom on own
- When the patient cannot manage medication, or get to the bathroom on own
- Close proximity to allow relatives to visit - especially those who are old and not mobile. There is a need to be able to attend promptly in times of need. The whole family needs to be as happy as possible with the circumstances otherwise more lives can be very upset and ruined even more.
- See below comment relating to Q2c
- Government ought to make the necessary funding available
- Market rate for dementia care not keeping pace with rising staffing costs
- Very satisfied with the care policy as it is
- Welfare and health of chief carer (husband, wife, children) are vital. Patient care will deteriorate if the chief carer is unable to cope with the strain. High extra costs may result.
- I think the present situation is adequate. (In answer to question 3) The setting of care recommended by the NHS with agreement from the patient
- When a patient is handed to the care setting are there on going checks on the organization if they are following whats on the careplan... ie Ratio of carers per patient etc.
- Should give more autonomy to patient or carer about where they receive care from eg private/friends. Like a personal budget. How do families get informed of

CHC pathway initially? Realistic timeframes for reviews/recordings and to be 'person centred' in style

- Importance to patient.
- Too many assessments on the elderly who do not improve. Waste of time and money. Assessors very good and could be used elsewhere in the Health Service. Meetings take hours and it is a total waste and others time. Assessment far too wordy and difficult to interpret so meetings take too long. Is the continuous health care checking on the Homes they have patients in? Can they alone improve care Money should not go to care homes that are not caring for the elderly adequately. Are they coping? Should Continuous Health Care assessors send patients to homes that are not performing well? Who decides? Relatives need more information. When I have rang you, people have been very pleasant and helpful.
- More communication would be good.
- Without funding who would be responsible for the care and well being of the patient and where would funding come from?
- Consideration to other disabilities that do not fall within a 'check list', eg Blindness. Plus make the awarding of a care policy less of an academic battler and be more supportive towards families at distressing times. In answer to question 3 - Power of attorney (eg the patient's family choosing on behalf of the patient)
- (In answer to the question) How to recognise the effects on carers and the importance to provide appropriate services, to give carers the breaks they require to ensure their physical and mental wellbeing is also being met.
- Overall - questionnaire was a little unclear if filling in on behalf of someone. Did you require the patient's details or the carer's, hence some double answers
- The need for continuity.
- To have knowledge of epilepsy, and be able to suction, have knowledge of special needs.
- I have filled in the form for my daughter, she has no capability of filling in forms and is unable to give her opinion so I have done this for her. (Mum). The questions below are filled in as if for our dependant. Found this a bit confusing as not clear if it referred to us as carers of our dependant.
- The level of expertese is not always sufficient for delivering the level of care needed, or there are too few staff.
- No
- Evidence to proof behaviour is problematic
- I do not consider these questions (below) applicable as health and financial support should be available in all cases
- I have completed this form for my husband.
- He has vascular dementia and has not been able to write or communicate properly for a few years. He is totally bedridden and unable to do anything for himself including eating and drinking, washing - he is totally incontinent.
- The continuity of support by well trained staff in a caring community will sustain a person's quality of life. Access to friends and recreational facilities will also be therapeutic.

- On a personal level - our daughter is happy in NAME OF PLACE as she knows it well and people know her. She lives in a house that we own, but she needs the support of carers to live there safely.
- Keep up the work.I have filled in this questionnaire on behalf of my wife who is very ill so have not filled or answered all the Questions as above patients should not be disadvantaged and get less support/care/finance/or guidance from health care professionals.
- This survey is too simplistic and reductionist to provide useful policy comments
- Please consider the distress you will cause to a dementia patient settled into their preffered setting if you decide you will no longer pay the required amount. This I believe would be of serious detrement to their condition. I also believe if a person has been awarded CHC because of dementia they and their familys should not have to suffer the torture of yearly assessment as their condition is not going to get better and continuity for these poor people should be paramount
- Where it is a nursing home, residential home etc. we who have to find a home should be told exactly what sort of home is required, needed and the price of such a place should be made known. This will prevent wasted time, visits, hassle finding a place that is suitable. (In answer to question 3): Personally all the items below should be taken into consideration but who should have the final say?
- For assessment dates to be reached. My mother-in-law was set a date, and a appeal neither of which happened.
- Best practice.
- (In answer to question 3) The patient's preferred setting of care and the setting of care recommended by the NHS that is best for meeting the patient's needs - in the hope, not mutually exclusive
- (In answer to question 4) Should be best possible
- Continuity – familiarity
- The health of carers, (husbands, family members, etc) who have to do the job when proffesionals go home. It is a strain on people who are usually not young themselves. (In answer to question 2b) However there are few places which hare capable and willing to take severely challenging patients. There is a local places. (In answer to Q2c) With the ageing population you will never have sufficient resources for eligible patients, the question is irrelevant really - this is a policy problem not one that should be transferred onto the vulnerable. (In answer to question 3) It's not as simple as this - our father has to be in a secure environment for his own and others' safety. (In answer to question 7) There is a spectrum of care settings available: Our father has gone through self-funding support at home, and in a care home, and as his alzheimers has progressed to include psychotic and delusionary episodes / challenging behaviour he has been in receipt of CHC funding. The care home he is in now is the only place in Leicestershire able and willing to care for Dad. The fallback position is the NAME OF CENTRE which is unable to cope with the number of seriously ill patients - all with challenging behaviour Our father was subject to assaults from other patients there, and the ward was subject to a safeguarding review Please bear in mind patients who are at the severe end of the care setting spectrum, where there is a real need for rapid, efficient systems of payment and placement.

Alternatives in the hospital sector are unsustainable and unsafe

- Patient voice - do as much as possible to make the patients life as happy as you can, irrespective of the cost although financial decisions will need to be adhered to.
- We must care for the frail and elderly within our society - also we must support their carers and families who suffer great stress in an effort to meet the needs of their loved ones.
- No
- CHC should not be taken as an issue in isolation. Your letter talks of robustness, fairness, consistency, transparency but not of efficiency, simplicity, common sense.
- In my experience the level of care and possible problems are very often under estimated. If something can happen - it will. This level of care does not come cheap but should problems arise then so do costs (exponentially). Don't try to cut costs but do try to get value for money spent.
- How able/trained the staff are in the home that they recommend to families to use. The resources that are available in the care setting.
- The care policy should be adjustable with ref. to circumstances.This survey was filled in by me, husband. NAME (wife) is not capable.
- Understand that if the patient is returned to the community, there is no money in Social Services. Extra stress on local surgeries. Lack of community health workers for medication.
- How rare the illness or disability. What are the chances of recovering. Possibility of prediction of life expectancy. Willingness of family members to help and spend time.
- Patient wishes
- As above constant care required due to total immobility.
- I don't know much about it, my partner as only been with CCG since May 2016.
- Being mindful of budgetary constraints many existing providers of care now fall below a satisfactory level of care for very vulnerable patients. The need to target resources is essential to prevent poor quality care and possible risks to become widespread.
- No
- No
- Alzheimers needs to be kept under the umbrella of mental health and patient safety and safety of others should remain paramount.
- Because of an overstretched NHS with limited bed resources, it is more effective of resources to try and suit the wishes of the patient if that means keeping them out of hospital, and keeping them in a more familiar environment
- I have been extremely lucky and I have no words to appreciate the help I get from care policy, but if I can get an extra rise and recline chair for the dining table, would be a lot easier to move him
- Mobility, and being near to family
- it is important to patients family to be in fairly close proximity so they can visit their loves ones quickly in emergency

- Can relax more and benefit from care
- A care policy should be kept to the plan put in place when returning home, and timings of care not changed by the carers. Regular updates with the patient and not amongst themselves.
- No
- No
- need to consider mental health needs of the person recieving care and the mental health needs of the family of this person
- not at this time
- Certain conditions need exceptional treatment and, therefore, should be treated exceptionally. Where conditions are of like situations then these could be treated similarly. This is necessary to ensure fair meeting of needs
- if the patients has serious medical and /or nursing needs requiring frequent or constant attendance, and wishes to be at home they should be supported to do so
- Disabled patients would rather be able bodied and able to maintain a normal life. they are not able to and should not be treated as a 2nd class person
- Full details to be given of considerations you are considering and any details of any equality impact assessments that have been conducted.
- Impact of considerations on Carers!
- The extra money must directly benefit the person receiving the funds
- DON'T USE CARE HOMES FOR ADULTS, CARE SHOULD BE IN INDIVIDUALS HOME, NOT RESIDENTIAL CARE SETTING.
- I myself as a Carer for my husband who has dementia and cancer of the bladder among many other problems would like some time to myself!! But having him at home was what we both wanted
- Most vulnerable and more aggressive patients to be segregated
- Money shoud not be the principle guiding force. We are a caring society and a person and their family needs should be paramount.
- The most important matter is the individual and it is excepted that there is a limitd fund and maybe a threshold could assist the NHS.
- More funding for a sitting service to combat the isolation suffered by cares
- The age and health of the carer.
- Dementia patients wherever possible are best cared for at home in familiar settings
- It is no good idealising about the settings of care when delays waiting for social workers to have meetings to go through the frame work for CHC mean opportunities in preferred settings are lost as places are taken by others due to severe delays
- Patient progress
- Yes the way in which funding is granted because the funding is needed for the above as soon as possible
- Care local to a patients home allows for more family and friend contact which is very important
- All things for the benefit of the person

- Abuse is a real concern. It is one reason why people struggle on at home rather than opt for a care setting. Caring staff should be paid more.
- 2a) It should be tailored to the individual. (2c) It's about need not cost. If you take away NHS funding for IVF, cosmetic surgery and self induced conditions like drugs the NHS would have more money! (4) It should not be a 'one size fits all' system its about the needs of the individual. (5a) People dismiss the emotional effect of putting people into an environment where they are unhappy. Why did you not send a prepaid envelope! Free Post is not free if you have to buy stationary.
- Lack of employment
- My wife was moved from Leicester Royal Infirmary to her present Nursing Home. I can't speak highly enough of all the staff at this time, and admire then all greatly.
- Better co-ordination of services. Greater flexibility for care packages for End of Life due to nature of rapid changes
- In addition, anyone who receives CHC funding is to ill to attend any meeting.
- Everyone should be an individual and if it is going to be a decision which is going to be detrimental long term to their health then we need to assess the risk and treat people sympatheticly and with respect not a number or a £ note sign
- Decisions must be person centred. Each one is an individual with differing needs. Each one could be one of YOUR relatives and should be considered as such.
- To minimise disruption/unnecessary upset and stress to existing patients on continuing care and their families, any proposed changes should be phased in as new awards are made. Whilst I appreciate that this would mean there wouldn't be as large and immediate savings to budgets, people's dignity and quality of life will be protected at a time when most needed.
- The question of care for patients with dementia. There seems to be a discrepancy between the way in which patients with this condition are considered compared to those with other serious conditions such as cancer or heart disease. The fact that patients with dementia are subject to constant monitoring for continuation of funding and therefore at the risk of having vital care withdrawn or worse, moved from their current care facility is a matter which needs immediate attention. I feel that it is not acceptable practice and instead, patients with vascular dementia and Alzheimer's, once diagnosed, should continue to receive the same level of care throughout the duration of their life in the name of dignity and respect, just as they would were they suffering from another incurable illness.
- A person suffering with dementia is at their most vulnerable in their final years. If they had cancer or heart disease, for instance,they would be funded by the NHS, and receive the appropriate care. Why should dementia be different? We shouldn't have to fight to keep funding in place and therefore consistency of care. My Mum was deemed suitable for CHC funding as she suffers from a now debilitating, vascular dementia, but as we have to watch her deteriation day by day, we are also asked to go through a change in this funding, and then possibly the level of care she is entitled, in her most vulnerable stage of her life. Who

knows how long she has left, but I don't think questions about her funding should be posed at this stage of her life.

- If it would be inappropriate to move the patient due to the disruption this would cause.
- In all other areas of healthcare whether primary, secondary, tertiary, acute or mental health, patients and their relatives are not involved in funding discussions. Why, when patients are at their most vulnerable and relatives at their most distraught, is funding decided at individual patient level in the most bureaucratic way possible? I know this is national not local policy but please, whatever you come up, can you take into account that you are dealing with the most vulnerable in society. Your policy should remember the words of the NHS Constitution that 'the NHS touches our lives at times of basic human need, when care and compassion are what matter most'.
- No
- Standards of nursing homes. Having recently needed to find a nursing home for my mother who receives CHC, I was shocked at the facilities available on the NHS list. Most of them smelt strongly of urine and were sad, dreary, grubby homes. Amazingly most of these had passed QCC inspections. I was able to secure a place in a fresh clean home which was also in my mother's community. However it fills me with horror that my mother was expected to end her days in some of the dreadful places that I visited. The nursing home she is now in is superb. It is therefore not necessary for these other places to be of such a poor standard. This needs addressing.
- We must be aware of not allowing City areas (ie Leicester City) to eat up disproportionate percentage of funding. This discriminates against suburban areas and in particular communities of White, Working Class backgrounds who already suffer under-resourcing across other areas such as education, transport and infrastructure funding.
- If it is a case of the preferred setting increases costs (but is still safe etc), then perhaps the person/family can have the option of paying the excess. Having both parents at times receiving 100%, I think it unfair and unlikely circumstance to go to 0%. Equally, I think that 100%, could still include a slight charge as say 10-15% to the patient as in any walk of life living costs something. Also this would free up some money for others.
- This questionnaire is too simplistic for what is a complicated subject area.
- No.
- I appreciate that funds are finite, but you cannot over rule established case law and The National Framework with policy.It is unlawful to do so. Are you attempting to impose/legitimise Top Up payments on people with fully funded care? That is unlawful.
- This questionnaire has been written in a way to give biased results.
- 5a Has two strongly agree categories
- There is an assumption that thresholds/bandings will be set, that patients will not have full choice of settings and choices will be made on basis of costing to NHS.
- I feel this questionnaire is a waste of time as the policy changes have already been decided. it needs to be affordable

- Improvement in communications,my GP,District Nurse and I have all found it almost impossible to contact CHC.
- We must be given a name and tel. No.
- No
- I work as an advocate and everyday see people who need more information. Copies of checklist and DST should be given to family members before they are expected to attend an MDT.
- Better and more accessible information about CHC. Better communication about decisions with patients, families and care homes.
- Ensure all patients have good quality nursing, in a safe comfortable environment.
- I'm afraid this survey sounds like a pretty obvious attempt to get people's 'buy-in' for the NHS to decide the 'best' setting for an individual, based on cost.
- The family's opinion of the preferred setting
- If car is taking place at home, the budget should be the same as if they were in a care home, currently it is not and families can struggle.
- More involvement consultation

Appendix 4: Feedback from the engagement event

Notes from Settings of Care event on July 14 2016 including emerging themes and questions asked and answered throughout the event:
What do you believe is most important in a decision about where continuing healthcare should be provided?

- Patients preferred setting of care should be considered it patient is capable of making decisions
- Family's preferred setting of care
- Look at what is best for the patient not everyone else
- Consultation with everyone that is involved so that everyone can hear everyone else's point of view and the NHS and then make a decision
- Opportunity to be heard at DST stage not a tick box exercise
- Family involvement from the start
- not always a choice once setting is agreed
- priority family/patient if possible –vulnerable people on own
- if CHC only funded social worker is taken away vulnerable people
- Social worker came to review but hadn't met my Mum
- make decision on advice given
- Patients decisions important a as situations and needs
- Can't say what is most important as different situations and needs x 2
- Patient's preferred options
- Family also very important
- Costs of caring
- Patient preferred setting, if patient is capable, if not then someone else who knows the patient well will have to have their input acknowledged – this is not always the case for relatives and Carers
- If someone is not capable of suggesting or having input due to inability to communicate then rels/Carers need to speak on their behalf. It is important also to take into consideration the needs of the potential Carer – are they capable to care
- By the time people get to CHC 100% health care funding they often need very specialist care
- Reviews are not acted on as quickly as they should be
- Need risk assessments to see if it is safe for the patient to be at home
- Need for someone to be in overall control of each case as currently the service is

fragmented. Things don't happen in a timely manner. This adds stress, difficult to talk to anyone for advice as no one answers the phone

- Need for no pre-conceived assessments. What is an issue for Carer/Carers who are relatives/spouse is not always seen as an issues by professional Carers eg incontinence. What is reasonable to expect a spouse/relative to do needs to be explored further
- Cares and relatives need to be communicated with once a panel has reviewed their loved one. They need to understand what was discussed by the panel. Carers need feedback

Main theme from this part of the workshop discussion:
The importance to involve and consider Carers as well as patients at every stage of the assessment process when the decision about the appropriate setting of care is being made

Do you agree that there should be an identified limit (threshold) to how much extra funding can be spent to care for a package?

- Yes there has to be
- Ability to top up
- Everyone should be treated as an individual – not a blanket
- No ones the same, individuality is so important to assess
- Limit to what is perceived as necessary – necessary need
- People need to be reasonable with what is extra
- There has got to be limits but within that people will be in need of more or less, need to be individually assessed
- No set threshold but each individual to be assessed regardless of cost, should not be a defined threshold but based on care needs

Themes from this part of the workshop discussion:

- ***The importance of identifying necessary need (need not want)***
- ***The importance of individual assessment***

Do you agree that the NHS should spend more to enable a patient to receive care in their preferred setting if there are exceptional circumstances:

- Yes
- As long as it is not infinite (expense should be reasonable)
- Yes
- If not open ended then Yes

The consensus on this was that Yes, the NHS should spend more to enable a patient to receive care in their preferred setting if there are exceptional circumstances

What circumstances do you think the CCG's need to consider as exceptional when deciding whether or not a person should receive extra funding for care in their preferred setting:

- End of life
- No limit
- Patient or family should decide
- End of life
- If **people are completely alone with no support whatsoever**

End of life was seen as exceptional by many of the attendees

Question and answers at the event:

Does the policy include timescales? (Sarah, HW Rutland)
There is a separate operations policy that includes timeframes for approving CHC applications.

I believe the timescale is 28 days?
Yes

Is there a more detailed description of PHBs available?
PHBs are included in the presentation as they are one of the reasons why we need to update the policy. We can provide more information on PHBs – either leave your details or you can look on our website which has just been updated with the latest information on PHBs.

Can you provide an explanation of thresholds?
Carmel O'Brien provided an example of how the 25% threshold currently works and emphasised that each case is assessed individually.

Can patients/relatives top up a CHC payment?
That's not how it works. We would usually look at which providers could give the care required within the money available. More money doesn't mean more care. Care is based on need.

If care at home is more expensive will patients have to go into a home?
CHC is about making sure the patient's needs are met. No-one is forced into a care home. There are always discussions with patients/families and in some cases exceptionality will apply.

Who decides the cost of the care home – the CCG or the care home?
There is a common pricing structure in bands according to the level of healthcare required – different rates according to the level of care.

(With reference to the Carl's case study) If mum had insisted that Carl could not go into a residential care home, would she be able to pay the difference?
In this instance it would have gone back to the panel for further discussion. This is not about financial 'top-ups' but the value of the healthcare provided. The CCGs are working with providers to make pricing etc more transparent.

Have you done market research around the price of packages of care in line with what people can afford?
Yes, as much as possible. We are currently working on applying the same systems [quality and safety] to domiciliary care that we currently apply to providers such as UHL and LPT.

When do you decide to put people into care homes?
[Joyce Bowler] In my time on the panel we have never forced anyone into a care home against their wishes.

Have you looked at costs of care homes?
This has already been looked at and included. We have more confidence across LLR in the partnerships and contracts we now have. We now have a joint quality monitoring system with LAs and share information with the CQC. We also get user feedback and work with Healthwatch on this.

How many people currently receive care above the 25% threshold/exceptionality applies to?
We don’t have that information to hand. Exceptionality usually applies to patients approaching end of life and so time is a factor.

Can we see the existing policy?
Yes we can send this out. Please leave your details.

When is consultation required?
If there is a significant change that will affect patients/delivery of care.

Does the budget/allocation [for CHC] take into account the significant increase in numbers of people in the two counties?
The CCGs received their allocations by the NHS annually. We are not changing eligibility but trying to improve the way we administer the budget.

Is the NHS taking back in-house the care of people?
There is a mix of NHS and private providers.

Is there a difference between who is entitled to health and social care?
A DST (national tool) is used to determine healthcare needs – for CHC these are complex needs and above what social care can legally provide.

CHC assessment seems to be a tick box exercise and doesn’t take into account the family’s need.
Usually after the assessment is completed there is a discussion with the patient/family about needs and provision. Using ‘Carl’ as an example, we were able to have a discussion about what the family was willing and able to provide before a decision was made that was agreeable to all. [This was taken away to be discussed on an individual basis]