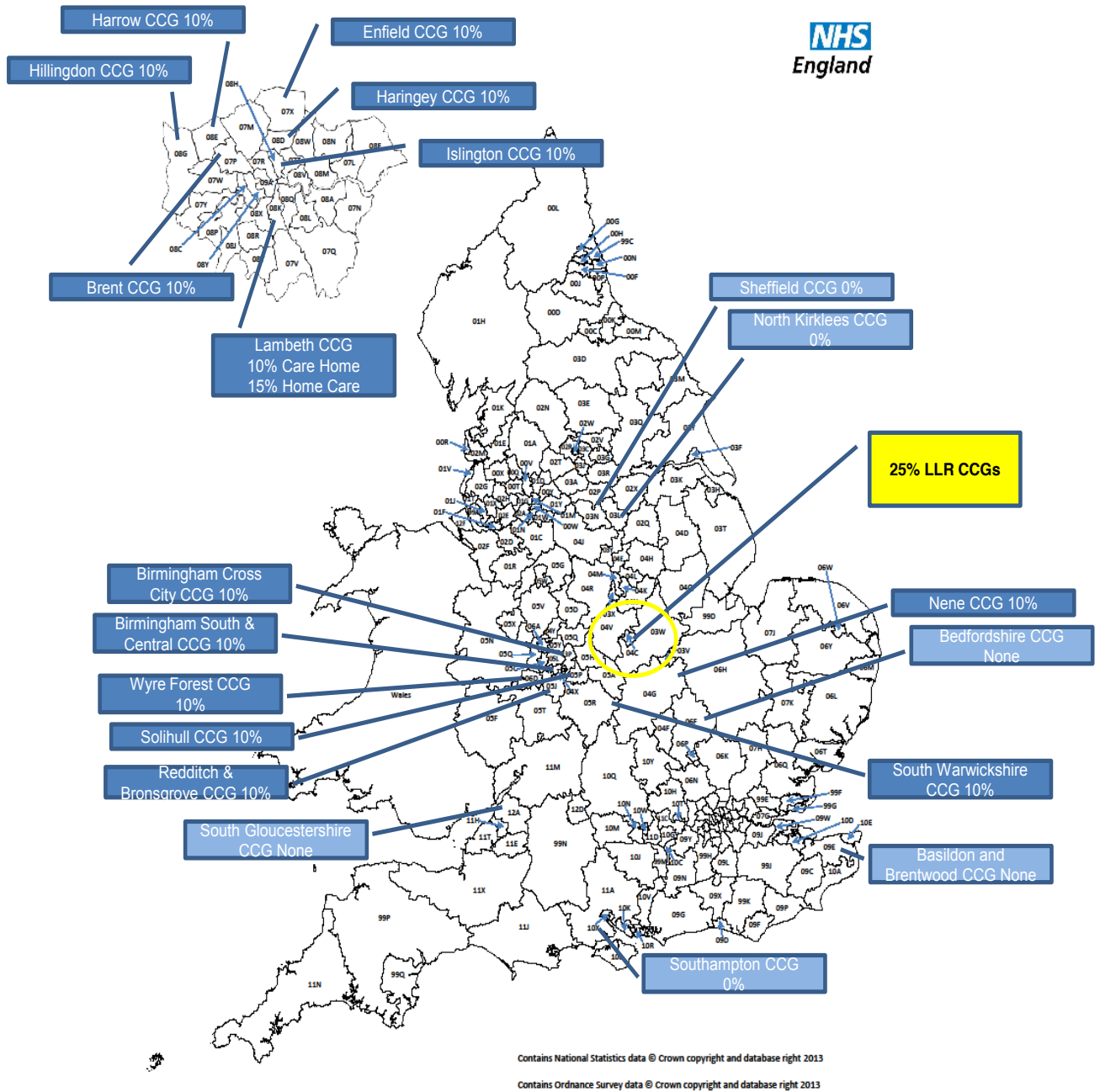


Appendix 1: Settings of Care Policy thresholds map



Birmingham CCGs – 10%

North Tyneside CCG – 0% threshold with a criteria in the policy that would enable decision to provide care at home

Sheffield CCG – 0% policy makes it clear that the cost of care provided within the home setting should not exceed equivalent cost of care within a registered care setting

Enfield CCG – 10% threshold

Waltham Forest - 0% criteria of exceptionality provided

Wirral CCG – 0% needs to be equivalent cost to residential care setting as appropriate – exceptional circumstances would be considered but does not state what these are

Southampton CCG – they base their criteria on the number of hours – home care packages in excess of 8 hours would indicate a high level of need therefore more appropriate to be

met within a residential/nursing home care setting for example and this is how they determine the appropriate setting of care.

South Gloucestershire CCG – same as Southampton based on hours

Wolverhampton CCG – 10% threshold in place

Camb & P'Boro CCG – same as Southampton and Gloucestershire CCG –any requirement of excess of 8 hours will trigger settings of care

South Warwickshire CCG – 0% clear criteria mentioned in the policy to consider home care



Leicester City Clinical Commissioning Group
 West Leicestershire Clinical Commissioning Group
 East Leicestershire and Rutland Clinical Commissioning Group

Settings of Care Policy

Reference number:	
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Version number:	Version 7 draft 4 (4 July 2017)
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Director:	[Full Name] [Full job title]

Version Control

Version number	Approval / Amendments made	Date (Month, Year)
Version 1	“Policy for Continuing Healthcare Settings of Care” (February 2011) inherited from predecessor organisations: Leicestershire County and Rutland Primary Care Trust and Leicester City Primary Care Trust.	February 2011
Version 2	Review of the Settings of Care Policy commenced, including the engagement event.	March 2016 – July 2016
Version 3	Proposed Settings of Care Policy drafted. Public consultation commenced on the proposed Policy.	January 2017 – February 2017
Version 4	Consideration given to the feedback and comments received through the public consultation process, Policy updated to reflect the feedback, however also ensuring the CCGs continue to meet their statutory obligations and duties.	May 2017 – June 2017
Version 5 and 6	Policy updated further to include discussions across the CCGs on the content.	June 2017
Version 7, draft 4	Updated version of the Settings of Care Policy to be presented to the Governing Bodies of East Leicestershire and Rutland CCG, West Leicestershire CCG and Leicester City CCG for approval.	July 2017

DOCUMENT STATUS:

This is a controlled document. Whilst this document may be printed, the electronic version posted on the intranet is the controlled copy. Any printed copies of the document are not controlled.

RELATED DOCUMENTS:

This document will reference additional policies and procedures which will provide additional information.

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1. Policy Statement

- 1.1. This Policy applies to East Leicestershire and Rutland Clinical Commissioning Group, Leicester City Clinical Commissioning Group, and West Leicestershire Clinical Commissioning Group. Hereafter collectively referred to as the Leicester, Leicestershire and Rutland Clinical Commissioning Groups (“LLR CCGs”) for the purpose of this Policy or “the CCGs”. The individual CCGs remain statutory bodies in their own right.
- 1.2. This policy describes the way in which the LLR CCGs will plan and commission services for people who have been assessed as eligible for an episode of fully funded NHS Continuing Healthcare (CHC), and patients who are eligible for CHC who wish to have a Personal Health Budget (PHB).
- 1.3. The LLR CCGs have developed this policy to help provide a common and shared understanding of the CCGs’ commitments in relation to individual choice and resource allocation.
- 1.4. Once an eligibility decision has been made NHS CHC packages of care are subject to a cost effectiveness test in the same way as all other NHS services. Whilst agreeing a package of care for eligible individuals that meet their reasonable needs, the CCGs have a statutory duty to consider the available resource. In coming to a decision on a package of care to be commissioned for a patient the LLR CCGs must balance the need to commission safe, effective and clinically appropriate care that makes the best use of available resources and in a manner that reflects the choice and preferences of individuals.

2. Scope of the Policy

- 2.1. The scope of this policy applies to guide decision making by all staff employed by or contracted to the LLR CCGs who are required to make decisions about the care packages for individuals that are eligible for an episode of fully funded NHS CHC (for the avoidance of doubt this includes PHBs).
- 2.2. This policy applies to all adults aged 18 years and over who are eligible for CHC.

3. Legal Compliance

- 3.1. Section 14v of the National Health Service Act 2006 places a procedural statutory duty on CCGs to take account of patient choices when making commissioning decisions. It provides:

“Each clinical commissioning group must, in the exercise of its functions, act with a view to enabling patients to make choices with respect to aspects of health services provided to them.”

- 3.2. Subject to the terms of this policy, the LLR CCGs will seek to commission services in accordance with choices made by individuals including as to their preferred setting of care.

However, there are some restrictions that the LLR CCGs are entitled to make to the choices that patients have expressed in order to ensure the CCGs commission safe, effective and clinically appropriate care which makes the best use of available resources. For these reasons there may be occasions where the LLR CCGs cannot offer to commission services which are the individual's preferred option. If this is the case reasons will be explained to the individual.

- 3.3. LLR CCGs aim to design and implement policy documents that meet the diverse needs of our services, population and workforce, ensuring that none are placed at a disadvantage over others. It takes into account current UK legislative requirements, including the Equality Act 2010 and the Human Rights Act 1998, and promotes equal opportunities for all. This Policy has been designed to ensure that no-one receives less favourable treatment due to their personal circumstances, their age, disability, sex (gender), gender reassignment, sexual orientation, marriage and civil partnership, race, religion or belief, pregnancy and maternity. Appropriate consideration has been given to gender identity, socio-economic status, immigration status and the principles of the Human Rights Act.
- 3.4. This Policy applies to adults 18 years and over. A separate process is in place for children and young people under the age of 18 years.
- 3.5. In carrying out their functions, the LLR CCGs are also committed to having due regard to the Public Sector Equality Duty of the Equality Act 2010 to: eliminate discrimination, harassment, victimisation; advance equality of opportunity; and foster good relations.
- 3.6. NHS CHC funded packages of care can minimise disadvantages suffered by people due to their disability and home/domiciliary care can support individuals with a disability and their carer(s) to participate in public life. The LLR CCGs recognise Article 8 of the Human Rights Act 1998 and that everyone has the right of respect for their private and family life, home and correspondence. Whilst the LLR CCGs will respect this right, there may be circumstances when the needs for the LLR CCGs to commission safe, effective and clinically appropriate care, which makes the best use of available resources, will not allow families to remain together.

4. Purpose, Aims and Principles

4.1. The purpose of this policy is to:

- a. define how and when the CCGs will support choice of care setting for individuals in relation to safe, effective and clinically appropriate care which makes the best use of available resources and to ensure that care is provided equitably across the LLR CCGs; and
- b. ensure that the reasonable requirements of eligible individuals are met in a manner which supports consistent and equitable decisions about the provision of that care regardless of the person's condition or disability.

4.2. The intentions of this policy are to:

- a. inform robust, fair and consistent commissioning decisions for the CCGs
- b. ensure that there is consistency in the local area regarding the services that individuals are offered
- c. ensure the CCGs achieve value for money in the purchasing of services for individuals
- d. facilitate effective partnership working between healthcare providers, NHS bodies and the Local Authorities in the area
- e. promote individual choice as far as is reasonably possible.

4.3. This policy aims to assist the CCGs to:

- a. understand the legal requirements, CCG responsibilities and agreed course of action in commissioning care that meets the assessed needs of the individual
- b. meet the responsibilities under the sources of guidance listed in Appendix A;
- c. make decisions about clinically appropriate care provision in a robust way, within the available financial envelope
- d. provide guidance for those staff who are designing the package of care with the eligible individual to develop a process whereby the cost of care provided is proportionate for the same level of need regardless of the setting the care that is provided, and to meet all of the individual's assessed health and associated social care needs
- e. take account of the wishes expressed by individuals and their representatives when making decisions as to the location or locations of care packages to be offered to individuals
- f. promote the individual's independence and to support individuals to take reasonable risks whilst ensuring that care provided is clinically safe, including through the use of a PHB subject to the factors set out below:
 - the individual's safety
 - the individual's choice and preference
 - ensuring services are of sufficient quality
 - the individual's right to family life
 - ensuring services are culturally sensitive
 - ensuring services are personalised to meet individual need
 - best use of resources for the population of the CCGs.

4.4. How should decisions be made by the CCG about settings in which care will be commissioned?

- a. The CCGs understand that many individuals with complex medical conditions wish to remain in their own homes and continue to live with their families with a package of support to aid them to do this. Similarly the CCGs accept that many patients might wish for other care options including other forms of supported living or care homes.
- b. Where an individual or their family expresses such a desire, the CCG will

investigate whether it is clinically feasible to provide a sustainable package of CHC funded care for the individual that is consistent with their preferences and the likely cost of commissioning care in accordance with choices made by patients.

- c. The CCGs need to act fairly to balance the resources spent on an individual patient with those available to fund services to other patients and the wider health economy. In an attempt to balance the different interests (balance available resources vs meet the desire of bespoke services at home or an alternative setting), the CCGs will, save in exceptional circumstances or where otherwise provided for in this policy, be prepared to support a clinically sustainable package of care funded by the NHS which keeps a patient in their preferred setting of care provided the cost to the CCG is not more than 10% above the anticipated cost of the provision of a broadly similar service to be delivered in an appropriate alternative setting. This 10% threshold will be applied consistently to every case across the LLR CCGs unless the CCG decides that the patient demonstrates exceptional circumstances or the patient's circumstances come within paragraph 8.4 of this policy.
- d. The CCG will make a decision as to whether a patient is able to demonstrate exceptional circumstances or whether the circumstances outlined in paragraph 8.4 apply on a case by case basis.
- e. For any individual who lacks the capacity and where, in addition to making commissioning decisions, a best interest decision has to be undertaken, the decision will be made in accordance with the paragraph 6 of this policy.
- f. The Policy will apply to all new cases deemed eligible for CHC funding from the date the Policy is implemented. Existing patients will be subject to the Policy upon review of their case (either annual or 3 monthly) and only in cases where their assessed needs have changed and therefore a change to the care package is necessary. Where there is no change to the care package, existing patients will continue to be offered funding which ought to enable them to remain in their current setting of care.

5. The role of the CCGs

5.1 The CCGs will seek to take into account any reasonable request from the individual and their representative(s) in making the decision about the care provision subject to the factors set out in this policy; and endeavour to offer a reasonable choice of available, preferred providers to the individual. Where the individual wishes to receive their care from an alternative provider, the CCG will consider this, subject to the individual's preferred care setting being considered by the CCG to be safe, and effective and clinically appropriate in relation to the individual's needs as assessed by the CCG; and subject to the principles set out in section 4.4 of this Policy.

6. Mental Capacity and Representation

6.1. The Mental Capacity Act 2005 states that there should be an assumption of capacity.

However, where there is reason to believe that an individual may lack the capacity to make a decision regarding the provision or location of (or change to) their care and/or accommodation, a mental capacity assessment must be undertaken. If the assessment confirms that the individual lacks capacity to make the relevant decision, a 'best interest decision' should be undertaken in accordance with the Mental Capacity Act and its Code of Practice. Where necessary the CCG will appoint an Independent Mental Capacity Advocate (IMCA) to support the individual in decision making in accordance with the Act.

- 6.2. Where a personal welfare deputy has been appointed by the Court of Protection under the Mental Capacity Act (2005) or a Lasting Power of Attorney with powers extending to healthcare decisions has been appointed, the LLR CCGs will consult with that person and obtain a decision from that appointed person on the preferred care option.
- 6.3. Where there is no health and welfare deputy or attorney the LLR CCG will be the best interest decision maker.
- 6.4. In all cases there is an expectation that the decision maker will consult with relevant professionals, family members and / or carers. The CCG will make this decision in accordance with the Mental Capacity Act guidance referenced in Appendix A.
- 6.5. Commissioning option decisions will be taken first and then a best interest decision can be made from amongst the options that the CCG is prepared to fund.

7. Identification of Care Provision

- 7.1. Where an individual is eligible for an episode of CHC funding, the CCG will commission the care which meets the individual's assessed reasonable care needs giving effect to the patient's choices to the extent defined by this policy.

8. Exceptional circumstances

- 8.1. The CCG has resolved that, where the patient is able to demonstrate exceptional circumstances, it will be prepared to support a safe, cost-effective and clinically appropriate and sustainable package of care, which keeps a person in their chosen setting. Even where the patient shows that he or she has exceptional circumstances, the CCG retains a discretion to decide the extent to which, if at all, it is prepared to fund the care package for the patient to be delivered in an alternative appropriate location which costs more than 10% over the cost of delivering on the CCG's duties to the client in a cheaper location.
- 8.2. The CCG will make its decision as to whether the patient is able to demonstrate exceptional circumstances and if so what package should be funded based on the precise facts of each case. This may involve reviewing the complexity of the individual's condition and the level of clinical risk associated with any proposed placement, which would prevent adequate and timely care provision. The CCG may also be prepared to consider the extent to which a care package will result in breaking up a family unit of which the patient is part. However the purpose of allowing a 10% buffer is to ensure that families are not broken up where the difference in costs is marginal. Where the additional costs are more than 10% over the costs of an alternative package, the general approach of the CCG will be that the sad fact of breaking up a family is not to be treated as exceptional as this is an unfortunate

consequence of many CHC packages of care. However there may be exceptional cases where a family break up as a result of a CHC package does constitute exceptional circumstances.

8.3. Exceptionality will be determined on a case by case basis and will require agreement from the High Risk and Complex Care Panel. In exceptional circumstances a decision can be made outside of the panel by joint agreement of a CCG Director and a clinical lead. Authorisation outside of panel would be determined by the CCG's Standing Rules and Financial instructions.

8.4. In addition to the exceptionality provision outlined at 8.1-8.3, a care package costing more than 10% over the cost of an alternative care package may be funded for an individual who has an advanced, progressive, and incurable illness and is entering a terminal phase. The CCGs will deal with individuals that fall within this section on a case by case basis and packages of care will be assessed and offered accordingly.

9. Registered Care Settings

9.1. Where care is to be provided in a registered care setting (i.e. one that provides accommodation, such as a nursing home, residential home, independent hospital and some supporting living schemes), the CCGs will only place individuals with providers which are:

- a. registered with the Care Quality Commission (or any successor); and
- b. not subject to commissioning restrictions placed by the LLR CCGs or Local Authorities in LLR area as a result of quality and safety concerns, including the host CCG or Local Authority if the provider is not located in the area of the LLR CCGs.
- c. Unless there are exceptional circumstances, prepared to contract with an LLR CCG to provide care at the locally agreed tiered rate.

9.2. The CCGs will, subject to the other provisions of this policy, consider providing a placement in a registered care setting not already contracted to the CCGs as long as the requested care provision is clinically appropriate and meets the conditions in paragraphs 9.1.(a) to (c) above.

10. Preferred provider placements

10.1. Subject to the provisions of this policy, and in order to assist the CCGs in achieving consistent, equitable care, the CCGs will endeavour to offer and place individuals with providers that have undergone a procurement exercise with the CCG and have secured a place on the CCGs' approved lists.

10.2. Where a preferred provider is not available to meet the individual's reasonable requirements or the patient has expressed a wish to be provided with care by a provider who does come within paragraph 10.1, the CCG may make a specific purchase and place the individual with a care provider who is able to demonstrate that the provider

meets the individual's needs. Where such an arrangement has been agreed on a temporary basis, the CCG reserves the right to offer to move the individual to a suitable preferred provider when capacity becomes available if a move of placement will provide substantially better value for money to the CCG. For example, if an individual has a specific care need which cannot be met in the available preferred accommodation, the CCG will need to specifically commission accommodation for the individual, potentially through an individually negotiated agreement. The CCG should notify the individual and/or their representative that they may be moved should a preferred provider subsequently have capacity. In such circumstances, the CCG will give a minimum of seven days' notice to the individual and / or their representative; and will devise a transition plan with the individual and / or their representative to ensure safe transition within a period of 28 days from date of notice, unless the health and safety of the individual warrants transition to the alternative provider takes place sooner.

- 10.3. Where the CCG deems that a provider is not providing care of an acceptable standard, the CCG reserves the right to terminate a placement and will offer to move the individual to an alternative provider.
- 10.4. Where an individual's needs change, the CCG may offer a package of care with a different provider.
- 10.5. A PHB may be provided to an individual in a registered or a non-registered setting. It may cover all or part of the care needed by the individual. It may only be used to pay for care agreed as part of a care package, by the CCG.

11. The role of the Care Co-ordinator

- 11.1. The individual's Care Co-ordinator will be responsible for the following:
 - a. discussion of the proposed care provision with the individual and their representative(s) (where the individual gives consent for such a discussion or where the individual lacks capacity) including where the care and support may be provided;
 - b. identification of different options for providing the care and gain an indication which of these is preferred by the individual; and
 - c. preparation of a written care plan that must clearly identify and articulate the outcomes that the individual wishes to achieve and what actions need to take place for that to happen.

12. Domiciliary Care and domiciliary care providers

- 12.1. Many individuals with complex healthcare needs wish to remain in their own homes, with support provided in that environment. Where an individual or their representative(s) express such a desire, the CCG will investigate to determine whether safe, effective and clinically appropriate and sustainable care can be provided for an

individual in their own home.

- 12.2. The CCGs will also consider if domiciliary care for an individual is likely to be more costly than for an individual whose equivalent care is provided in a residential or nursing home placement as outlined at paragraph 4.4 above.
- 12.3. Where domiciliary care is to be provided, the CCGs will use domiciliary care agencies they have commissioned for other patients to provide such care. Where the CCGs are assured through a procurement process that domiciliary care will be provided by agencies suitably qualified to deliver the care that meets an individual's assessed needs they will ask family members if they are willing and able to supplement support. If they agree the CCGs will assume that family members will provide the agreed level of support when designing any domiciliary care package.
- 12.4. There will be occasions when a clear commitment by family members or others (whether paid or unpaid) to provide some elements of the patient's care needs could reduce the reasonable needs of the patient that the NHS is required to provide and thus reduce the services that the CCG is obliged to fund for the patient. In such cases, care by family members or others may have the effect of making a package of care at home a cost effective option having regard to the terms of paragraph 4.4 of this policy when, without those commitments, the home care package would be outside the terms of this policy.
- 12.5. CCG staff should ensure that no pressure is applied to family members or others to offer and provide such support. The CCG recognises that family members are under no legal obligation to offer care but equally recognises that family members can often be expert and reliable carers and that patients wish to continue to be supported by their family members. When deciding about the offer of a domiciliary care package, the CCG will take account of any voluntary offers from family members or other commitments to provide care to a patient when applying paragraph 4.4 of this policy in comparing the cost of any such package with the cost of a suitable package of care in a registered care setting.
- 12.6. Where the CCG decides to offer domiciliary care to an individual, the individual's home becomes the member of staff's place of work. Employee safety is an important consideration in domiciliary care packages. The individual's home must be a reasonably safe environment to work and deliver care to the individual. This includes cleanliness and safety of the environment, and interactions between the individual, family/carer and the employee. The CCG reserves the right to terminate any domiciliary care package if it appears that the patient's home is not an appropriate place of work for care staff for any reason.

13. Personal Health Budgets

- 13.1. Where the LLR CCGs receive a request for a PHB from or on behalf of an eligible person the CCGs must grant that request, unless it is not appropriate to do so. Where an LLR CCG decides to offer an individual a PHB, it will assess the cost of an appropriate package of care. The cost of a PHB is designed to permit a patient to make arrangements so as to enable the patient or those acting on the patient's behalf to purchase services to meet the individual's reasonable requirements. The setting of the indicative budget for calculating the value of a PHB must apply the principles set out in

this policy. The cost of a PHB will include any directly incurred additional expenditure, including but not limited to:

- a. administering managed accounts
- b. recruiting a Personal Assistant including any training and employment checks
- c. tax, national insurance and any other costs associated with directly employing staff
- d. costs associated with redundancy
- e. legal advice
- f. financial advice, including accountancy

13.2. Where the individual receives a direct payment as their PHB and they directly employ staff they assume responsibility for all of the obligations that apply to any employer. The CCGs will not accept any vicarious liability arising out of an individual's decisions to employ staff, funded by a direct payment.

13.3. The requirements for PHBs are laid down in the CCG's PHB Policy.

14. Availability of care provision

14.1. To enable individuals to receive the correct care promptly, they must be offered care as soon as possible. If an individual's agreed provider and placement does not have the capacity to provide the care at the point required, the individual will be offered another CCG preferred provider in the interim to ensure care is provided as soon as possible preventing any delays.

14.2. If the individual requests care from one of the CCGs preferred providers which is currently unavailable, there are several options available to the CCGs:

- a. Temporary placement of the individual with alternative care provision until the care from the individual's preferred care is available. For example, alternative home care provider, alternative care home, respite care or a community bed;
- b. If the temporary placement is refused the individual may choose to go to their own or a relative's home without receiving the assessed care provision that has been offered by the CCG until the preferred care is available. The individual will retain the right subsequently to change their mind and elect to accept the care provision offered by the CCG. If the individual does not have mental capacity to make this decision, the CCG will exercise its duties under the Mental Capacity Act;
- c. If it has been agreed with the individual that the assessed needs can best be met through a care home placement, the CCG may choose to provide a package of care at home to cover the reasonable assessed care needs of the individual until the preferred care home is available. This must be considered in light of paragraph 4.4 (c) of this policy.

14.3. If there is a delay in the CCG being able to secure a placement in a care home due to non-availability of a preferred home, and the individual does not have the mental capacity to make this decision themselves, the CCG will follow due process in applying the LLR Safeguarding Children and Adults Policy and the Mental Capacity Act 2005 as

appropriate.

- 14.4. If the individual is in an acute healthcare setting, they must move to the most appropriate care setting as soon as they are medically fit for discharge, even if their first choice of care provision is not available. The individual's preference must be considered in line with this policy, when the CCG is deciding which package of care to offer to them. Where the individual's preferred choice is not available, but alternative provision which will meet their assessed needs is available, they must move and cannot remain in an acute healthcare setting once they are medically fit for discharge.

15. Acceptance of care provision

- 15.1. An individual is not obliged to accept a CHC package of care. Once an individual is eligible and offered a package of care, and they choose not to accept the CHC package, the CCG will take reasonable steps to work with the individual to help them understand their available options and facilitate access to appropriate advocacy support if necessary. Decisions regarding individuals without capacity will be taken in accordance with the Mental Capacity Act and the CCG will make an application to the Court Of Protection as necessary.

16. Continuing Healthcare review

- 16.1. A case review should be undertaken no later than three months after the initial eligibility decision, in order to reassess the individual's care needs and eligibility for CHC, and to ensure that the Individual's assessed needs are being met. Reviews should thereafter take place annually, as a minimum. The CHC review may identify an adjusted, decreased or increased care need, or no further health care needs.
- 16.2. Any review should take account of this policy.
- 16.3. The CCG will conduct an annual review of the provision of care to a CHC eligible patient or more frequently if an individual's care needs have changed. An assessment of the patient's clinical needs will be made to determine the most clinically appropriate package of care for that individual. At this point, and after full discussion with the individual or their carer where an individual does not have capacity, any decision about a future setting of care will need to take into account whether a package of care is being and/or will in the future be delivered in an individual's preferred choice safely. Keeping an individual safe must take priority, however this must be balanced with an individual accepting responsibility for their choices where they have capacity to make the decision about their care.
- 16.4. Where the individual is accommodated in a care home, the CCG will ensure that the care home is able to deliver to meet any changed care needs of the individual.
- 16.5. Where the care home is unable to meet this adjusted care need, the CCG will offer to fund an alternative package of care for the individual in accordance with this policy.
- 16.6. Where there is a decreased need, the CCG will consider the cost effectiveness of the package to be delivered in the current care home, and may move the individual to a suitable alternative provider in accordance with this policy.

- 16.7. If the review demonstrates that the individual's condition has improved to an extent that they no longer meet the eligibility criteria for CHC funded care provision, the CCG is obliged to cease funding accommodation and social care for the individual. This includes home care and care home provision. In these cases the CCG will carry out a joint review with the relevant Local Authority in the LLR area. At this point the Local Authority has 28 days to review the individual's requirements and the individual will be notified they may no longer be eligible for CHC. CCG funding for an individual's care may be continued for 28 days where a Local Authority is undertaking such a review or such longer period as seems reasonable in the circumstances.

17. Withdrawal or refusal of care provision

- 17.1. The NHS discharges its duty to individuals by taking account of its legal obligations including those outlined in paragraph 3 and makes an offer of a package of care to meet an individual's reasonable care needs. It is an individual's decision whether they choose to accept the offer of care made by the CCG.
- 17.2. An individual refusing to accept the CCG's offer of care. In these circumstances the NHS will not be responsible for arranging and paying for a care package for that patient.
- 17.3. Where an individual with capacity exercises their right to refuse, the CCG will ask the individual or their representative(s) to sign a written statement confirming that they are choosing not to accept the offer of care provision.
- 17.4. For individuals who do not have the capacity to make a decision about the location of their care provision the LLR CCGs will apply the principles of paragraph 6 and make applications to the Court of Protection where appropriate.
- 17.5. The CCG has a duty to ensure that all staff providing care are not subject to violence and abuse in any form. The CCG and care provider will work to ensure that positive behaviour support is reflected in an individual's care package where necessary. However, under extreme circumstances, it may be appropriate for the CCG to remove CHC services where the situation presents a risk of danger, violence to or harassment of care staff who are delivering the package and/or all attempts of positive behaviour support have failed.
- 17.6. The CCG may also withdraw the offer of CHC funded support in a home care environment where the clinical risks become too high. This can be identified through, or independently of, the review process. Where the clinical risk has become too high in a home care setting, the CCG may choose to offer CHC in a care home setting.

18. Disputes resolution and appeals

- 18.1 Where there is a disagreement with an individual or their representative about where someone may receive care, the CCG will aim to resolve the matter through the local dispute resolution process. A patient or their relatives are also entitled to lodge a complaint about the CCG's decision using the NHS complaints process; and where local resolution has been exhausted individuals or their representatives can request a review by NHS

England's Independent Review Panel.

19. Monitoring and review of the Policy

- 19.1. Performance against key performance indicators will be reviewed on an annual basis and used to inform the development of future procedural documents.
- 19.2. This policy will be reviewed on an annual basis, and in accordance with the following on an as and when required basis:
- a. legislative changes;
 - b. good practice guidance;
 - c. case law;
 - d. significant incidents reported;
 - e. new vulnerabilities; and
 - f. changes to organisational infrastructure
- 19.3 The policy will be reviewed once every three years or sooner where relevant changes occur in regard to the law, national policy or guidance.

20. References

- a. Care Act 2014
- b. Guidance on: National Assistance Act 1948 (Choice of Accommodation) Directions 1992. National Assistance (Residential Accommodation) (Additional Payments and Assessment of Resources) (Amendment) (England) Regulations 2001
- c. Guidance on NHS patients who wish to pay for additional private care (May 2009)
- d. Human Rights Act 1998
- e. Legal guidance Relevant case law
- f. Mental Capacity Act 2005 Code of Practice
- g. The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012
- h. National Assistance Act 1948 (Choice of Accommodation) Directions 1992 (as amended)
- i. National Health Service Income Generation - Best practice: Revised guidance on income generation in the NHS (1 February 2006)
- j. National Health Service Act 2006
- k. The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care - November 2012 (revised)
- l. Updated guidance on National Assistance Act 1948 (Choice of Accommodation) Directions 1992: Consultation outcome (14 October 2004)
- m. Who Pays? Establishing the Responsible Commissioner (December 2012)

Appendix 1: Definitions

- **Accommodation:** In the context of CHC, accommodation relates to an appropriately registered care setting or the individual's own home.
- **Care Co-ordinator:** Care Co-ordinator refers to the person who coordinates the assessment and care planning process. Care co-ordinators are usually the central point of contact with the individual.
- **Care provision:** Care provision takes two main forms:
 - Care provided in an individual's own home and referred to in this document as 'home care' or 'domiciliary care'.
 - Care provided in an appropriately registered care setting (such as a nursing home, a residential home or an independent hospital) and referred to in this document as 'registered care setting' or 'care home'.
- **Individual:** In the context of this policy the individual is the service user that has been assessed for and offered continuing healthcare, often referred to as the individual.
- **Representative(s):** Representative(s) refers to the people or person that liaises between individuals and the CCG. The individual receiving healthcare may elect to have representative(s) act with them or on their behalf, or there may be representative(s) where the individual does not have the mental capacity to make independent decisions. Representatives may be legal representatives, individual advocates, family, or other people who are interested in the individual's wellbeing. Where the individual has capacity, they must give consent for any representative to act on their behalf. A person who has formally been appointed as an Attorney or Deputy has defined responsibilities for the individual. The extent of these responsibilities will vary according to the nature of their appointment.
- **Local Authority:** Local Authority refers to Leicester City Council, Leicestershire County Council or Rutland County Council.
- **Clinical Commissioning Group (CCG):** CCG refers to NHS Leicester City Clinical Commissioning Group, NHS East Leicestershire and Rutland Clinical Commissioning Group or NHS West Leicestershire Clinical Commissioning Group.
- **Provider:** Provider refers to the organisation that provides NHS continuing healthcare on behalf of the CCG.
- **Preferred providers:** These providers have been assessed and accepted onto the Any Qualified Provider framework by the CCG as being able to fulfil the continuing healthcare requirements of defined categories of individuals at an agreed cost.



Findings of Leicestershire, Leicestershire and Rutland Clinical Commissioning Group 'Settings of Care' public consultation

1. Introduction

The 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.

A public consultation ran from 5 January 2017 to 20 February 2017 to seek people's views on making funding fairer and sustainable for all eligible patients across Leicester, Leicestershire and Rutland.

Settings of Care 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 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. The care is planned and agreed between individuals, families and their local NHS team.

The CCGs in Leicester, Leicestershire and Rutland 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

There are currently over 1,300 people in Leicester, Leicestershire and Rutland who receive NHS Continuing Healthcare funding. On an annual basis in LLR we spend more on CHC funding than the majority of other areas across England, spending over £73.5million in 2015/16.

At a time when pressures on the NHS have never been greater with an ageing population and a significant increase in the number of people who need CHC funding, the CCGs have a duty to ensure that services are clinically and financially sustainable and that everyone who is eligible has access to appropriate care. We will be taking these things into account as we review the policy.

2. Process

During the consultation, 1300 copies of a consultation document and questionnaire were distributed (**Appendix A**). They were sent to those in receipt of CHC funding. The survey was also available electronically. An electronic link to the survey was sent to stakeholders via all three CCGs, and the link was also available on East Leicestershire and Rutland CCG's website.

A list of media, public sector and voluntary sector stakeholders who received information about the consultation is at **Appendix B**. As well as recipients of care, the survey was targeted at voluntary sector groups with a particular interest in conditions requiring high levels of care and support.

A further 30 copies were distributed at a consultation event on 19 January at Leicester Race Course. Thirty people attended the event.

Altogether 212 people completed the questionnaire. Correspondence was also received by email from a number of organisations.

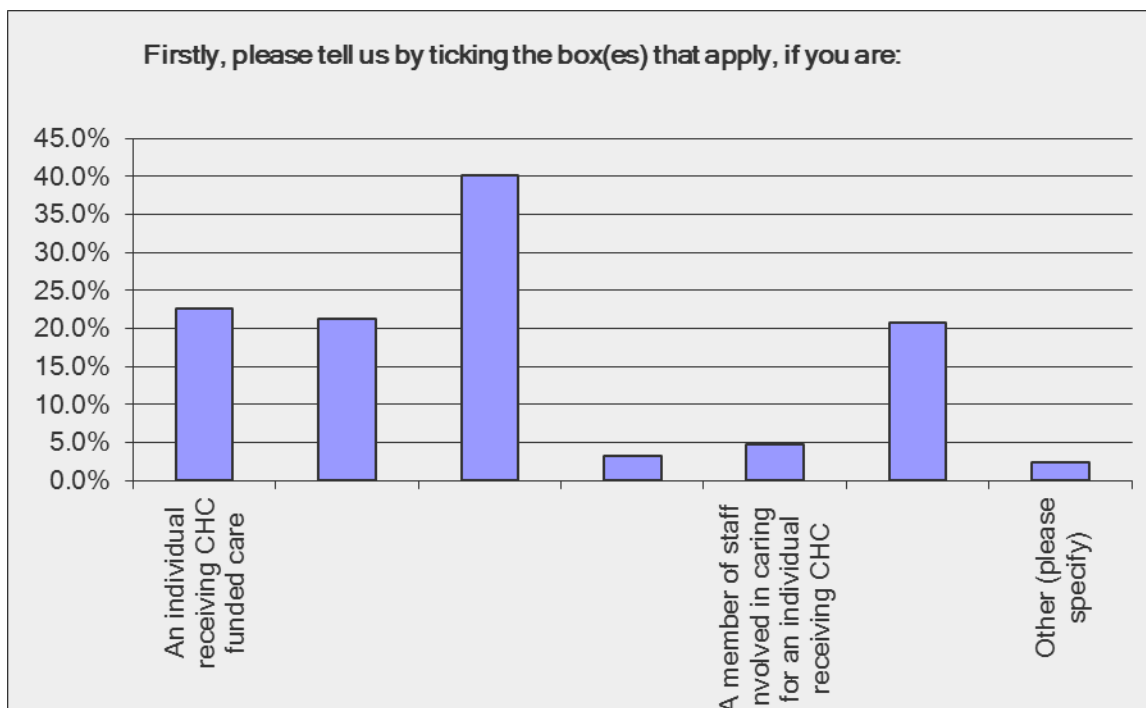
3. Survey results

Two hundred and twelve surveys were completed either electronically or on paper copies. Paper copies were returned by Freepost and logged with the electronic surveys. The data is analysed below.

Question 1: Firstly, please tell us by ticking the box(es) that apply if you are:

Firstly, please tell us by ticking the box(es) that apply, if you are:		
Answer Options	Response Percent	Response Count
An individual receiving CHC funded care	22.6%	48
A carer for an individual receiving CHC funded care	21.2%	45
A family member of/someone important to an individual receiving CHC funded care	40.1%	85
A representative from a patient or carer support group	3.3%	7
A member of staff involved in caring for an individual receiving CHC	4.7%	10
A member of the public	20.8%	44

Other (please specify)	2.4%	5
answered question		212
skipped question		0



Eighty five people (40.1%) who responded to the survey were a family member of / someone important to an individual receiving CHC funded care. 48 people (22.6%) were individuals receiving CHC funded care and 45 people (21.2%) were carers for individuals receiving CHC funded care. 44 people (20.8%) were members of the public, 10 (4.7%) were members of staff involved in caring for individuals receiving CHC and 7 (3.3%) were representatives from patient or carer support groups.

Five people (2.4%) described themselves as “other” and specified:

“Husband 24/7”

“I look after my disabled son all the time”

“Local authority staff member”

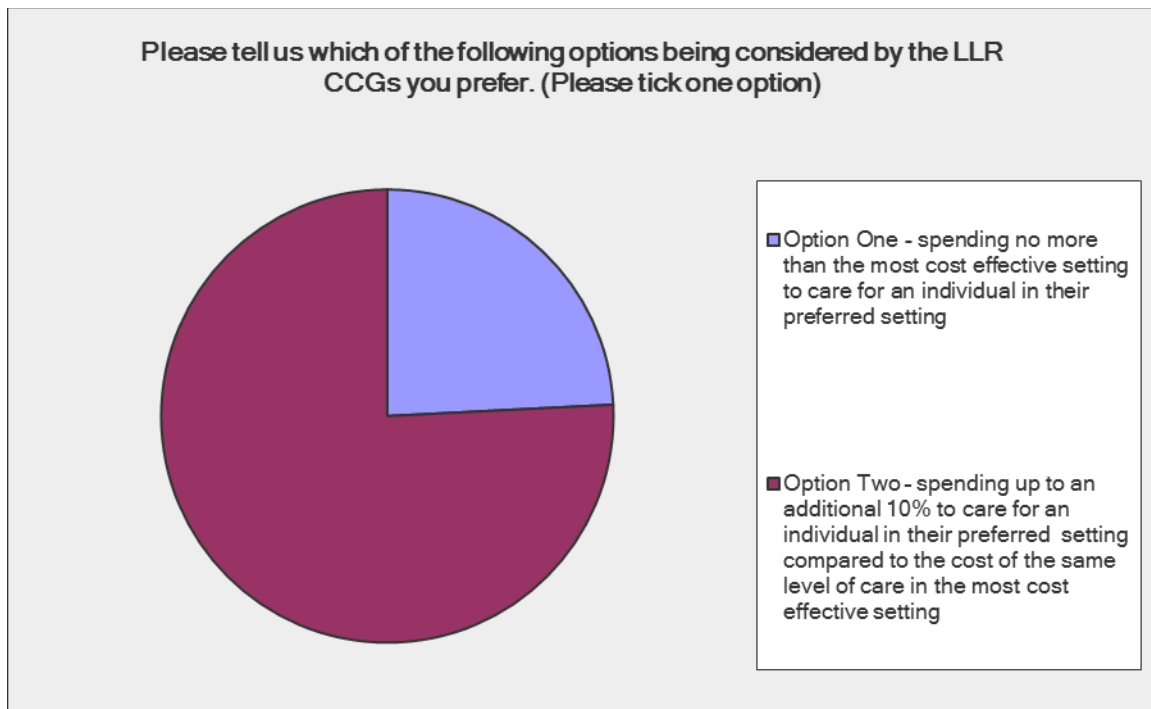
“A very concerned person with a spinal injury, who does not want to agree with any of your options as you give no opportunity to state other, but it appears the only way I can respond is by choosing options I do not agree with. This is not right for a public consultation.”

Question 2: Please tell us which of the following options being considered by the LLR CCGs you prefer:

Please tell us which of the following options being considered by the LLR CCGs you prefer. (Please tick one option)

Answer Options	Response Percent	Response Count
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Option One - spending no more than the most cost effective setting to care for an individual in their preferred setting	24.2%	50
Option Two – spending up to an additional 10% to care for an individual in their preferred setting compared to the cost of the same level of care in the most cost effective setting	75.8%	157
answered question		207
skipped question		5



Of the respondents, 157 (75.8%) said that they preferred Option 2. Fifty people (24.2%) preferred Option 1. Five people did not answer this question.

Question 3: The exceptionality criteria we are proposing is care for a patient at the end of their life. Is there anything else you think should be considered as an exceptional circumstance?

The exceptionality criteria we are proposing is care for a patient at the end of their life. Is there anything else you think should be considered as an exceptional circumstance? Please explain in the box below.

Answer Options	Response Count
	158
answered question	158
skipped question	54

This was an open question and was answered by 158 people. As well as the required information, the responses also consisted of many general comments and several people commented that they had used this open question as the only opportunity in the survey to make their more general views known.

A verbatim list of all the comments is attached at **Appendix C** and the responses are summarised below.

3i Wide range of circumstances

A wide range of conditions and circumstances were suggested that should be assessed as part of the exceptionality criteria:

- Alzheimer's / Dementia - It was suggested that a case might be made for patients with extreme Alzheimer's Disease or Dementia since their level of consciousness of the world around them can be very low or virtually non-existent. In cases where individuals' behavioural and emotional needs are being well managed, changes to care settings should not be made and the level of care provided should not be reduced.

"With dementia patients 'end of life' is often difficult to predict. My husband passed away in December but 20 months prior I was told to be prepared, so pleased I had him at home thanks to the funding I received."

Other conditions and circumstances suggested were:

- Persons that have received brain damage from accident or heart failure, so may have some time to live but require intensive specialist care 24hrs a day to survive.
- Patients with severe disability who potentially need care and assistance round the clock, but are not at the end of their life
- Those with communication difficulties
- Under 65s with a life changing injury such as spinal cord injury to allow them to live independently and have a fulfilling life
- Where the alternative care setting (own home) is of relatively poor quality and/or clearly inconvenient for carers/family etc.
- A younger person (eg. early 70s) who has no capacity whatsoever and needs more nursing expertise, intervention and care as the years go on and who could be in the care home for several more years
- A child should be allowed to stay at home with family at any cost
- Patients with locked in syndrome - *"My father has this following a stroke, and is currently cared for at home, with 24 hour supervision, as he is prone to having choking fits, which unattended would kill him. If he had to move back to a care home I doubt he would manage to survive much longer"*.
- Complex behavioural needs, that require increased and intensive staff support to keep service user and others safe within the setting
- People with learning disabilities who the family would like to be at home with them

- *“As a breast cancer patient my preference would be to have care in my own home with my family and friends around me.”*
- *“My mother is a sufferer of MSA, Multiple System Atrophy, where the use of the body for things we take for granted gradually shut down. This is not to be confused with MS. Initially she lost the ability to walk, then breathing, whereby a tracheostomy operation was undertaken, then going to the loo, with a bag being attached, then getting up and down, so a hoist had to be used, and now the ability to swallow, which involved having a feeding tube inserted into the stomach. No doubt further complications will ensue as the disease progresses. The carers during this time have been exceptional, but are continually under pressure to complete their ever increasing list of tasks in the same time as initially allocated despite their list of jobs to complete taking longer and longer. Despite numerous requests to increase the package of care to 24 hours, this has been ignored with half an hour extra being allocated only. Quite pathetic. My emails to CHC go ignored, and there is no cross communication between the various NHS departments, the GP, LOROS, numerous specialists, district nurses, etc. This means we are continually having to justify our requests, when simply looking up the total medical history, and making a personal visit to the patient involved would illustrate the problems being encountered first hand. Therefore in conclusion this is an exceptional circumstance, but it should be recognised that by simply deciding to allocate an extra 10% of resources will by no means address the problem. You have to look at each case individually and address those needs”*
- Patients that are over the age of 90 and suffering from several illnesses eg Alzheimer’s, strokes etc and require nursing care
- Anyone in a chronic comatose condition.
- People who have a long term condition should be considered individually.
- When a person is housebound and needs multiple care visits
- Persons with certain non-curable mental/neurological conditions whose end of life period cannot be predicted should be included in exceptional criteria - *“I work with people with Motor Neurone Disease. They have highly complex needs and are often young. Currently approximately 75 in total across LL and R. In my view they should be considered exceptional cases. The end of their life is often unpredictable, a lot of people with MND miss out on funding all together for this reason”*.
- Emergency medical care which may not immediately indicate or result in imminent end of life
- Exceptional family and / or other circumstances, such as care for a patient with no family or when a carer becomes ill or has conflicting priorities. *“In my case as carer for my wife. I am also carer for my 94 year old mother. Although in a home she relies on me for twice weekly visits and to manage all things for her. DETAIL OF DIFFICULT PERSONAL CIRCUMSTANCES I have needed all the help I can get to survive”*.

3ii Keeping patients happy and safe

Keeping patients happy and safe in a familiar environment was also considered a big priority by many people, as was keeping them close to family and friends. Comments included:

“It is important that if someone is happy and safe in their home, and the family are comfortable having them at home this is more important than any cost cutting exercise. My wife has PHB funding however, I believe the care provider should receive enough notice to keep the cared for happy as well as safe.”

“My wife is in a nursing home at the moment, and although the nursing home is very good, NAME has not settled at all she will not eat or drink and gets upset whenever I come to see her. She really needs to come home, so I can look after her as before she was eating and drinking with no problems at all.”

“Exceptional circumstances must address and assess the significant impact that a change of funding will enforce to the individual. It must consider impact upon health, emotional wellbeing, safety and belonging to a community/home of their choice in later life. Personal choice must be an option. The care my husband receives is excellent. If a patient has been at the same home for a considerable number of years and is very elderly, the patient should stay in the familiar surroundings and carers, especially if the care given is very good, safe and appropriate.”

“I am extremely concerned that the needs, in relation to setting of care, of my son will be affected detrimentally by this settings of care policy. My son lives as a tenant in supported living very successfully and safely. Please assure me this will not change.”

“The quality of care that can be given to the individual in their own setting is more important to them and retains their dignity, happiness, provides more security, quiet and feel in control as an individual than a number in another setting, quality of life is invaluable and should be preserved till the end.”

3iii Changes only applied to new applications

Several people suggested that those who were already in a particular setting should be protected and allowed to continue even if it is above the 10%. Changes in funding should only be applied to new applications. *“People already receiving care should not be impacted by this at future reviews - their care package was agreed on a set of terms and should not be changed”*. *“As I am receiving care in my preferred setting which has already been agreed I should not be forced to change so any new rules should only apply to new people coming on board.”*

One respondent also said: *“I feel that patients in their 70's 80's etc should, where possible and where families are prepared to care for them, also be included in an exceptional circumstance these are the generation that fully contributed to national insurance. Their final years should be spent in their own homes surrounded by loved ones...”*

3iv Broader definition of end of life

It was also suggested that the definition of end of life should be made broader by including those whose conditions are considered life limiting and whose condition is

deteriorating, but difficult to judge with any real accuracy. Appeals against any decisions made should be made as straightforward as possible with help from an advocate automatically available.

3v Funding

Comments about funding included:

“This should not be cut from 25% this is a much too drastic cut to 10% or nil. It should be reduced to no lower than 20%.”

“A better option would be spending up to an additional 25% to care for an individual in their preferred setting compared to the cost of the same level of care in the most cost effective setting.”

Another general comment was *“Nursing for someone for whom a religion focused environment is important. The preferred setting choice should include the option of a nursing home that operates within a faith based framework. The mental and spiritual support that this environment can give to individuals and family members who are religious, should not be underestimated. For some families this would not make a difference, for others it can have a profoundly comforting effect, please, please continue to offer this option wherever it is possible.”*

3vi Consider people as individuals

Overall, the general feeling was that all patients and circumstances should be considered individually and exceptions should be made wherever it was in the best interest of an individual patient.

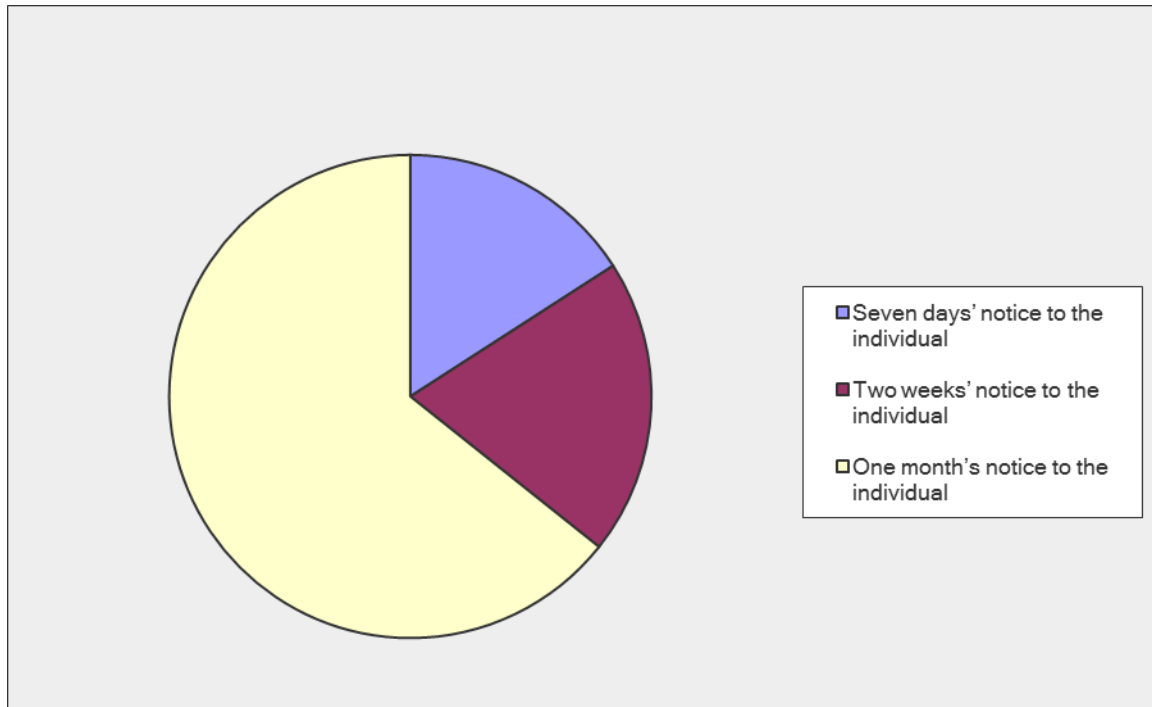
“The process has to be centred around the individual patient and therefore judged on the individual patient’s needs and wishes.”

Question 4: Sometimes the care provider and/or setting might need to change for an individual for a number of reasons. If the CCG deems that a provider is not providing care of an acceptable standard, patients will be moved as soon as possible to ensure their safety. Please select one of the following options to indicate the minimum notice period you think the CCG should give to an individual in relation to changes to their settings of care, where a move does not compromise the quality of service provided:

Sometimes the care provider and/or the setting might need to change for an individual for a number of reasons. If the CCG deems that a provider is not providing care of an acceptable standard, patients will be moved as soon as possible to ensure their safety. Please select one of the following options to indicate the minimum notice period you think the CCG should give to in relation to changes to their setting of care, where a move does not compromise the quality of service provided: (Please tick one option)

Answer Options	Response Percent	Response Count
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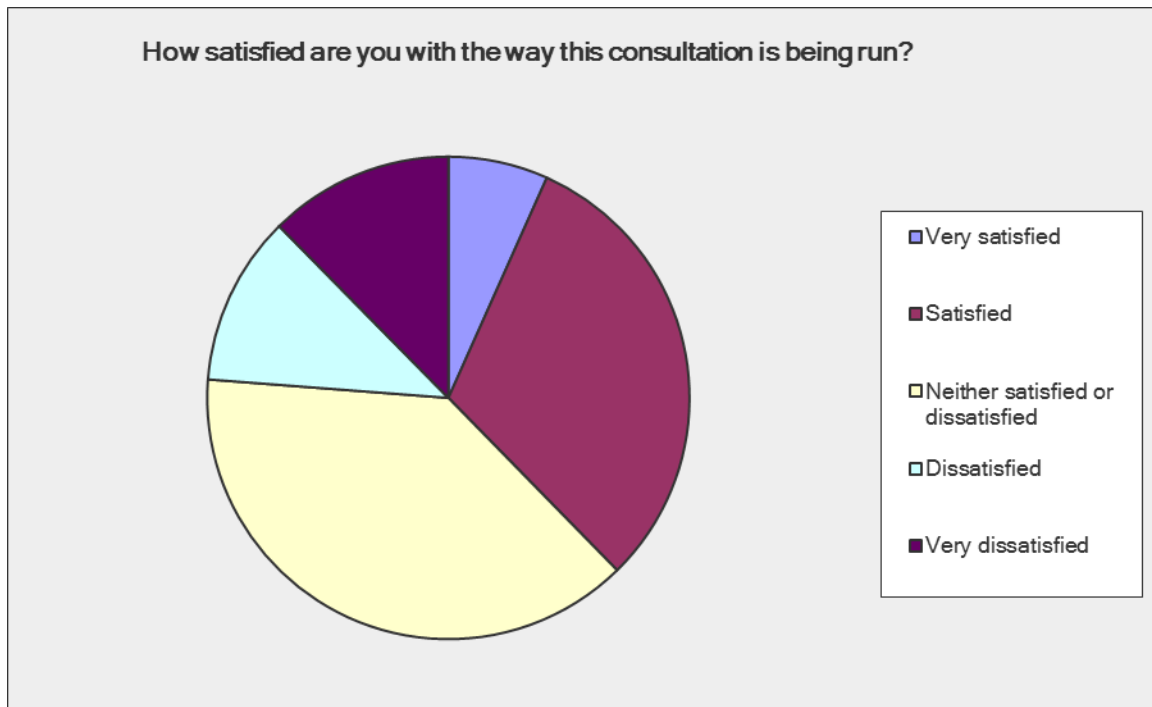
Seven days' notice to the individual	15.9%	33
Two weeks' notice to the individual	19.8%	41
One month's notice to the individual	64.3%	133
<i>answered question</i>		207
<i>skipped question</i>		5



133 people responding to the survey (64.3%) thought that one month's notice should be given to the individual. 41 people (19.8%) thought that two weeks' notice should be given and 33 people (15.9%) thought that seven days' notice should be given. Five people did not answer the question.

Question 5: How satisfied are you with the way this consultation is being run?

How satisfied are you with the way this consultation is being run?		
Answer Options	Response Percent	Response Count
Very satisfied	6.7%	14
Satisfied	31.0%	65
Neither satisfied or dissatisfied	38.6%	81
Dissatisfied	11.4%	24
Very dissatisfied	12.4%	26
	<i>answered question</i>	210
	<i>skipped question</i>	2



The majority of people (38.6%) said they were neither satisfied nor dissatisfied with the way the consultation was being run, whilst 79 people (37.7%) said they were satisfied or very satisfied. 50 people (23.8%) were dissatisfied or very dissatisfied and 2 people did not answer the question.

Monitoring data

Monitoring data received is at **Appendix D**. The data reflects the targeted distribution of the consultation.

4. Conclusion

Over 75% of people who took part in the consultation are in favour of **Option Two – Spending up to an additional 10% to care for an individual in their preferred setting compared to the cost of the same level of care in the most cost effective setting**. Although there was no opportunity for people to comment on their preferred option, comments that were made elsewhere in the survey indicated that many people are worried that limiting funding to an additional 10% will lead to patients having to move from familiar environments in which they feel happy and safe and this could be detrimental to their health and be a barrier to many patients being cared for in their preferred setting.

With regard to the exceptionality criteria, there is general agreement that end of life should be considered as an exceptional circumstance, but the open style of this question invited many comments and deliberations about the broader definition of end of life and other personal situations that could be defined as exceptional circumstances. In conclusion, the general view of those responding to the consultation is that no two patient/carer scenarios are the same and exceptionality should be based upon individual patient and carer circumstances. There is

suggestion that the definition of end of life could be made broader for the purpose of settings of care by including those whose conditions are considered life limiting and whose condition is deteriorating, but difficult to judge with any real accuracy.

There is concern that annual reviews of existing continuing care patients may lead to an unfavourable decision on their setting of care forcing them to move from their preferred setting. CCGs could consider only applying the new criteria to new patients entering the system to avoid unnecessary upheaval in the lives of very vulnerable people.

The majority of people who took part in the consultation believe that at least one month's notice should be given to an individual in relation to changes to their setting of care, where a move does not compromise the quality of care provided.

Appendix B – distribution list for the consultation document and information about the consultation

The document went to the following media:

- BBC Radio Leics
- BBC EMT
- Cathy Buss – Leic Mercury
- Central News
- GEM 106
- Harborough FM
- Harborough Mail
- Lutterworth and Rugby Observer
- Melton Times
- Rutland and Stamford Mercury
- Rutland Radio
- Rutland Times

A stakeholder email went to:

- Leicestershire and Rutland HOSCs
- Leicestershire and Rutland Healthwatches
- City, County and District/Borough Councils in Leicester, Leicestershire and Rutland
- CHC Stakeholder list
- Local MPs
- Patient and Public Engagement Groups including PPG databases and PPG/PRG network
- UHL/LPT comms leads
- GP/clinical leads databases
- Practice nurse databases
- Staff databases

It was also sent to a large number of groups representing the ‘nine protected characteristics’, and to general voluntary sector groups throughout Leicester, Leicestershire and Rutland. It was particularly targeted at groups whose members are likely to have a specific interest in Continuing Health Care, including:

- Age UK
- Alzheimer’s Society
- British Lung Foundation
- Diabetes UK
- Leicestershire Downs Syndrome Group
- Downs Syndrome Society
- Headway
- Jigsaw
- Leicestershire Action for Mental Health
- Leicestershire Aids Support Services
- Leicester Centre for Independent Living
- ME Positive
- Menphys
- Mosaic Disability Services
- Motor Neurone Society

- MS Society
- Parkinsons Support Group
- Parkinsons UK
- Rethink
- Rutland Carers
- Stroke Association
- Motor Neurone Disease Association
- Meningitis Trust
- Marie Curie Cancer Care
- CLIC Cancer & Leukaemia in Children
- Support for Carers Leicestershire
- Aspergers Syndrome Support Group
- Hospice at Home
- LOROS
- Crohn's & Colitis UK

Complete lists are available from the three CCGs if required but cannot be shared in detail because of data protection.

Appendix C – full responses

- A case might be made for patients with the most extreme Alzheimer's disease or dementia since their level of consciousness of the world around them can be very low or essentially non-existent. These questions are not really suitable for someone who is unable to understand. Though their questions have been answered the patient is not fully cognisant of the implications.
- Emergency medical care which may not immediately indicate or result in imminent end of life
- A circumstance where the patient has specific difficulties such that care provision is essential (i.e. Onset of changing circumstances which renders the patient into a condition that they are not familiar with or able to properly cope with - for example onset of reduced/loss of vision)
- Individuals with Dementia whose behavioural and emotional needs (e.g. challenging behaviours, high anxiety) are being well managed. Good management is part of appropriate care and should not be grounds for changing the care setting or reducing the level of care provided. ** Re. Question 4 below: Confusing Issues: Paragraph 1 - Talks about care provision that isn't "of an acceptable standard". In this instance, the move should be as soon as possible. Paragraph 2 - Seems to address changes that won't "compromise the quality of service provided". In this, case the maximum possible notice might well be the most appropriate.
- Persons that have received brain damage from accident or heart failure, so may have some time to live (not at end of life) but require intensive specialist care 24hrs a day to survive.
- Any individual where change of setting would cause distress. For example, people with dementia and people with autism. It is disappointing that the CCGs have failed to consult adequately while maintaining the opposite view, and have left no suitable spaces for feedback on the process, the manner, and how the options have been presented. There has also been no investigation into why so few people appear to have received their notification of the meeting and/or the consultation.
- Mental Capacity. Clinical Needs including physical How will you determine that a patient is at the end of their life ie age/illness? people with Motor Neurone Disease have highly complex needs and are often young. Currently approximately 75 in total across LL and R. In my view they should be considered exceptional cases. The end of their life is often unpredictable, a lot of people with MND miss out on funding all together for this reason.
- Having provisions in place so that I don't have to go to hospital and to keep me as healthy as possible on a ventilator.
- Where a person suffers from a life limiting neurological disease which is in an advance stage e.g. DSA, and DAD and similar conditions, but not necessarily end of life.
- It is important that if someone is happy and safe in their home, and the family are comfortable having them at home this is more important than any cost cutting exercise. NAME has PHB funding however, I believe the care provider should receive enough notice to keep the cared for happy as well as safe
- Exceptional circumstance are where an individual is completely vulnerable, dependent on trusted and capable well trained and caring staff, needing 24/7

attention and assistance in all aspects of living with familiar staff and surroundings.

- *NAME* is in a nursing home at the moment, and although the nursing home is very good, *NAME* has not settled at all she will not eat or drink and gets upset whenever I come to see her. She really needs to come home, so I can look after her as before she was eating and drinking with no problems at all.
NAME
- Please refer to engagement report (Aug 2016) for broad range of issues beyond reducing exception to only end of life
- It takes a long time for a patient to get used to a setting and the staff. Will the settings be within travelling distance to the family because daily visits are very important to both. Activities and communication are important to the patient and the nurses and carers don't have time. Only 2 carers per floor during day and only this one carer at night. CHC 'visit & review' care once a person has been placed in a care setting. No other health person visits the setting such as OT etc.. the home has no one visiting ... no recommendations for recovery progression
- What I receive now is very good and the carers look after me very well.
- Better "training" for carers who look after dementia patients. Explanation of what is available long before the patient has reached the latter stages
- I assume an individual could choose to make up the financial difference to enable them to stay in their preferred setting if this is above/about 10% of the cheapest cost or if at home family members could choose to take on more of the care themselves. If the cheaper option is in their own home and the individual is in an institution, provision MUST ensure that community care really is properly in place (I am aware of the disruption to the service in the recent LCC shake up of care agency services).
- Please note option 2 only ticked as no other suitable option. Exceptional circumstances must address and assess the significant impact that a change of funding will enforce to the individual. It must consider impact upon health, emotional wellbeing, safety and belonging to a community/home of their choice in later life. Personal choice must be an option. The care *NAME* receives is excellent. If a patient has been at the same home for a considerable number of years and is very elderly, the patient should stay in the familiar surroundings and carers, especially if the care given is very good, safe and appropriate.
- Exceptional family and / or other circumstances in my case as carer for my wife. I am also carer for my 94 year old mother. Although in a home she relies on me for twice weekly visits and to manage all things for her
ACCOUNT OF ADDITIONAL PERSONAL CIRCUMSTANCES. I have needed all the help I can get to survive.
- Regardless of religion, colour or background preference should be given to those people who have contributed most to the NHS contributions over the years i.e. a high scale of benefits for a couple who have paid over 40 years than those having only contributed for 3-4 years
- Patients should have a choice where they want their care given
- Those who are already in a particular setting should be protected and allowed to continue even if it's above the 10%
- Someone suffering from severe advanced dementia

- I feel that patients in their 70's 80's etc should, where possible and where families are prepared to care for them, also be included in an exceptional circumstance these are the generation that fully contributed to national insurance. Their final years should be spent in their own homes surrounded by loved ones. The quality of care is above and beyond even the best CQC care home available. I am unable to attend your consultation event as I am a full carer.
- I am extremely concerned that the needs, in relation to setting of care, of *NAME* will be affected detrimentally by this settings of care policy. *NAME* lives as a tenant in supported living very successfully and safely. Please assure me this will not change
- Circumstances of extreme disability
- Persons with certain non-curable mental/neurological conditions whose end of life period cannot be predicted should be included in exceptional criteria
- Family and patients should have all the support and stress free transition to CHC. Should not have to argue and shout to get the care package they have a right to. Agencies provide the service they want to deliver and absorb most of the money. Patients and family may be able to reduce the cost if given flexibility and people who listen
- Somebody who is life limited is equally important.
- Specific health issues -of a complex nature Those with communication difficulties
- With dementia patients 'end of life' is often difficult to predict. *NAME* passed away in December but 20 months prior I was told to be prepared, so pleased I had him at home thanks to the funding I received.
- Agree with end of life. Continuity of setting when changing setting is dangerous to the person
- Often when people are severely disabled communication is very difficult. I know from experience that if these people are moved to a care home or hospital they are ignored and left to vegetate. Their life expectancy is severely diminished as they lose their will to live. You would effectively be killing them by moving them into a hospital/care home. (I hope that you think this is a good idea)
- That everyone is treated with great care and dignity -that all involved do their best and can truthfully say -yes- I did my very best for the patient.
- The options offered are not realistic for many people with profound multiple learning disabilities. These options do not offer person centred care, any choice or any control. Clinical needs not financial ambitions should be the driver. Invest in people, all people
- Under 65s with a life changing injury such as Spinal cord injury to allow them to live independently and have a fulfilling life
- The individual's actual disability and specific care needs. NOT finance!
- Where the alternative care setting (to own home) is of relatively poor quality and/or clearly inconvenient for carers/family etc.
- This should not be cut from 25% this is a much too drastic cut to 10% or nil. It should be reduced to no lower than 20%
- Give people who can no longer speak for themselves the option to be cared for until their death at home near the people they have shared their life with,

with support for the carer to the extent to prevent the carer's health from deterioration too

- When a person is still quite young I think more help should be given to help them walk again. I am also unhappy thatI receive no physio help and I also have to payfor a chair to sit in
- Nursing for someone for whom a religion focused environment is important. The preferred setting choice should include the option of a nursing home that operates within a faith based framework. The mental and spiritual support that this environment can give to individuals and family members who are religious, should not be underestimated. For some families this would not make a difference, for others it can have a profoundly comforting effect, please, please continue to offer this option wherever it is possible.
- Someone with advanced dementia and being cared for in their own home by very good care providers. Also many patients of a great age have built up a good relationship with their carers and it seems unfair to put them through more trauma with changing the system. Remember a lot of these patients have served their country in war and have post-traumatic stress now, they deserve to be looked after
- A person who is younger than the majority (eg. early 70s) who has no capacity whatsoever and needs more nursing expertise, intervention and care as the years go on and who could be in the care home for several more years
- A child should be allowed to stay at home with family at any cost
- Individuality
- Residents that are over the age of 90 years, suffering from several illness i.e. Alzheimer's, strokes etc and require nursing care should be fully funded by the NHS, abolishing the need for yearly reviews which would save time on NHS resources
- I feel everyone with exceptional needs should be offered care at home if it is safe to do so
- Exceptionally criteria language note: criteria the plural of criteria is not acceptable as a singular noun. This criteria is not valid, these criteria are not valid
- Complex care patients like myself with locked in syndrome require care as needs differ on a daily basis and need more care
- Adverse behaviour Aggression Unpredictable care needs
- Complex behavioural needs, that requires increased and intensive staff support to keep service user and others safe within the setting e.g. falls risk, not of unpredictable and hostile behaviour towards others
- Ongoing terminally ill.
- Ongoing terminal conditions
- Mental issues where a familiar home environment is beneficial to the "health" of the patient
- The quality of care that can be given to the individual in their own setting is more important to them and retains their dignity, happiness, provides more security, quiet and feel in control as an individual than a number in another setting, quality of life is invaluable and should be preserved till the end.
- Patients with complex health needs
- I think all individuals must be considered as exceptional circumstances, not only at the end their life, but for while well to be happy in their preferred

settings. This will cost less in the long run, I believe exceptional circumstance should be given to patients with severe disability

- People with learning disabilities who the family would like to be at home with them. As family members look after them in between carers calls i.e. feeding and giving medication, and general companionship
- After caring for loved ones long term there are numerous circumstances that come to mind i.e. earlier diagnosing with a much quicker response and information to help with the knowledge that you are caring effectively, without the added frustration of trying to get medical supplies to make life more comfortable for the sufferer
- That a patient has care round the clock and not left for periods. It should be the patient's wish where they want to be, and not that of anyone else close to them. Or instead of this if the monies were available you could have like a home setting in hospital grounds, away from the wards, a purpose built house in the grounds where it would be more like home from home. Like you have made rooms in Maternity for persons to have like a home birth. People could then bring in a few things from home to comfort them.
- Caring for someone who has complex needs
- The right to be cared for at home
- It is that all people who need continuing healthcare are treated with respect and that you comply with the United Nations Convention on Human Rights for People with Disabilities which includes the right to Family Life. It is degrading, humiliating for a young person under 70 to be placed in a care home when they can be cared for and given the right support in a family home. They have the right to as normal a life as possible, many being able to contribute to public life, something that an NHS clinical commissioning group has a duty to promote under the Equality Act 2010 Equality Duty. Equality is never achieved by treating disabled people as non-disabled people or by treating people with different impairments the same way. The CCG has a duty to provide the right continuing healthcare to meet the individual person's needs. Imagine tomorrow that you got a spinal injury, given the correct care, training and support you should eventually be discharged from a spinal injury unit into a caring family home, with your brain still as active as before the injury, trying to get back some normality. Would you put Professor Stephen Hawking, or Baroness Jane Campbell in a nursing home, so that they could no longer play an active part in Public Life? Nobody knows what tomorrow will bring. Yes there are those who think disabled people are a burden on society, and we should be assisted to die, or treated as vegetables even though our brains still function, just so you can balance your books more easily. I have not answered your other questions because they do not give the opportunity for status quo or other response. This means your whole survey is extremely biased, and certainly would be thrown out if subjected to the same standards of peer reviewed papers. These are people's futures and lives you are playing with. What equality do disabled people have if you throw most of us in care home with no regard to basic human rights. The right continuing healthcare must be decided by the person who needs the care, not by someone who does not understand what they are about to subject these people to and turn the clocks back 50 years.
- Care for a patient with no family.

- This is not just about end of life. You need to look at the true cost of meeting the assessed needs (health, social and personal care) of the person in line with the National Framework 2012 for them to live in the community. This may be a young disabled person with a long term condition with a family. They may work – (yes a person can be eligible for CHC and work it may surprise you). You cannot lawfully put an arbitrary limit on the cost of their care based on notional cost of care in an institution, much as you may wish to. You need to heed the personalisation agenda of the NHS. Constraining care packages as proposed will lead to avoidable healthcare complications and hospital admissions.
- Certain disabilities
- The Right to a family life European Human Rights Act
- He wants to be at home
- A better option would be spending up to an additional 25% to care for an individual in their preferred setting compared to the cost of the same level of care in the most cost effective setting.
- Compassion for both the patient and family
- Life changing illnesses such as Locked In Syndrome. *NAME* has this following a stroke, and is currently cared for at home, with 24 hour supervision, as he is prone to having choking fits, which unattended would kill him. If he had to move back to a care home I doubt he would manage to survive much longer.
- As a breast cancer patient my preference would be to have care in my own home with my family and friends around me.
- Long term health conditions
- The wishes of the patient.
- Locked in syndrome as it leaves the person completely reliant on safe and continuous care
- People who have proven to be better cared for in their own home and people who have conditions such as locked in syndrome who need the care to make sure there are no risks of choking etc which is a very real and dangerous risk to take for someone who cannot control this themselves
- Locked in syndrome
- Patients with severe disability who potentially need care and assistance round the clock, but are not at the end of their life.
- It is detrimental to individuals health and quality of life that they receive care at home
- *NAME* has already been in nursing homes and besides him being extremely down whilst under their care, the care he was getting was at best insufficient for his needs. The care he is getting now is by far better for *NAME* in himself and his health as he has constant care.
- People already receiving care should not be impacted by this at future reviews - their care package was agreed on a set of terms and should not be changed
- Offer more packages to all social care settings.
- Patients must be placed near to their families
- The patient should be in a facility that is nearest to their family
- *NAME* is a sufferer of MSA, Multiple System Atrophy, where the use of the body for things we take for granted gradually shut down. This is not to be confused with MS. Initially she lost the ability to walk, then breathing,

whereby a tracheostomy operation was undertaken, then going to the loo, with a bag being attached, then getting up and down, so a hoist had to be used, and now the ability to swallow, which involved having a feeding tube inserted into the stomach. No doubt further complications will ensue as the disease progresses. The carers during this time have been exceptional, but are continually under pressure to complete their ever increasing list of tasks in the same time as initially allocated despite their list of jobs to complete taking longer and longer. Despite numerous requests to increase the package of care to 24 hours, this has been ignored with half an hour extra being allocated only. Quite pathetic. My emails to CHC go ignored, and there is no cross communication between the various NHS departments, the GP, LOROS, numerous specialists, district nurses, etc. This means we are continually having to justify our requests, when simply looking up the total medical history, and making a personal visit to the patient involved would illustrate the problems being encountered first hand. Therefore in conclusion this is an exceptional circumstance, but it should be recognised that by simply deciding to allocate an extra 10% of resources will by no means address the problem. You have to look at each case individually and address those needs.

- Concerned that comparing with similar places won't be of the same quality and therefore not adequate enough
- As I am receiving care in my preferred setting which has already been agreed I should not be forced to change so any new rules should only apply to new people coming on board.
- People should not be placed so far away from their family members that visiting becomes difficult. Consideration should be given to maintaining relationships.
- The provision of convalescence homes should be available to assist with the patient's recovery to ease the pressure of bed blocking in hospitals.
- Special characteristics in line with DRE
- If local care settings are not available, then local alternatives irrespective of costs should be available. I refer to people with learning disabilities.
- Seriously complex needs - eg vascular dementia and other comorbidities such as CHD, immobility and challenging behaviour
- The real risk of destroying the client's mental health due to stress brought on by an imposed relocation or change of provider to 'save money on care'.
- Acute illness of carer. To keep patient at home if possible if carer suddenly becomes ill
- Conditions such as MND/ late stage MS/PD when end of life cannot be predicted
- Or where a move would present a clear danger to wellbeing/life. Or where an individual would suffer extreme distress at being moved
- Anyone in a chronic comatose condition.
- People who have a long term condition should be considered individually. For example, someone could need continuing care and be placed hundreds of miles from their home on a long term basis. This is not acceptable. Patients need family and friends close by as well as medical care
- Flare up of present condition.
- Definition of end of life made broader by including those whose conditions are considered life limiting and whose condition is deteriorating, but difficult to

judge with any real accuracy. Appeals against any decisions made should be made as straightforward as possible with help from an advocate automatically available

- When a person is housebound and needs multiple care visits
- When good quality care reduces risk of falling and patient funding is cut because of it. If a patient is at risk of attempting to stand and can't due to inability to accept their condition, it is still very high risk of falling not NO RISK. You are cheating thousands out of funding because of decisions like this. A patient shouldn't be no risk unless they can perform the task unaided safely
- Patients who have suffered severe disability as a result of an operation/stroke/heart attack etc. Not just end of life. Patient choice should be allowed. If a patient or family want the person to be in a care home or equally at home, this should be respected. Decisions such as these are not taken lightly by anyone and if one was in that position, undoubtedly one would seek to be in a care setting of their choice. Perhaps if care staff were better trained also, this may increase confidence in family members. How are the general public being made aware of this questionnaire? I do hope this is being advertised openly through news channels and newspapers so that those that this may affect more than anyone e.g. Elderly patients have access to this survey even if they don't have use of the internet! No comments box so had to type here.
- Where any change in the care setting would have a substantial impact on a person's wellbeing, due to the need to move resulting in the risk of a hospital admission or the involvement of contracted support. E.g. ASD/mental health. Crisis or outreach need
- Trying to keep people in their own home if that is their wish and the wish of their family; when care homes are under resourced inevitably leading to poor care - this must be checked by the CCG commissioning care to prevent poor care even if unintended due to poor staffing levels
- Care for patients with dementia/Alzheimer's
- Long term mental / physical disability +/- long term chronic illness
- Yes when an emergency situation arises, the illness of a carer for instance. Please note your survey does not allow sufficient response, question 2 does not allow for explanation, my reply is the best of two evils not the required solution
- Complex cases
- Where the carer is ill.
- The process has to be centred around the individual patient and therefore judged on the individual patient's needs and wishes.

Appendix D – Monitoring data

Question 6: Please state the first letters and numbers of your postcode:

Please state the first letters and numbers of your postcode, e.g., LE1.	
Answer Options	Response Count
	204
<i>answered question</i>	204
<i>skipped question</i>	8

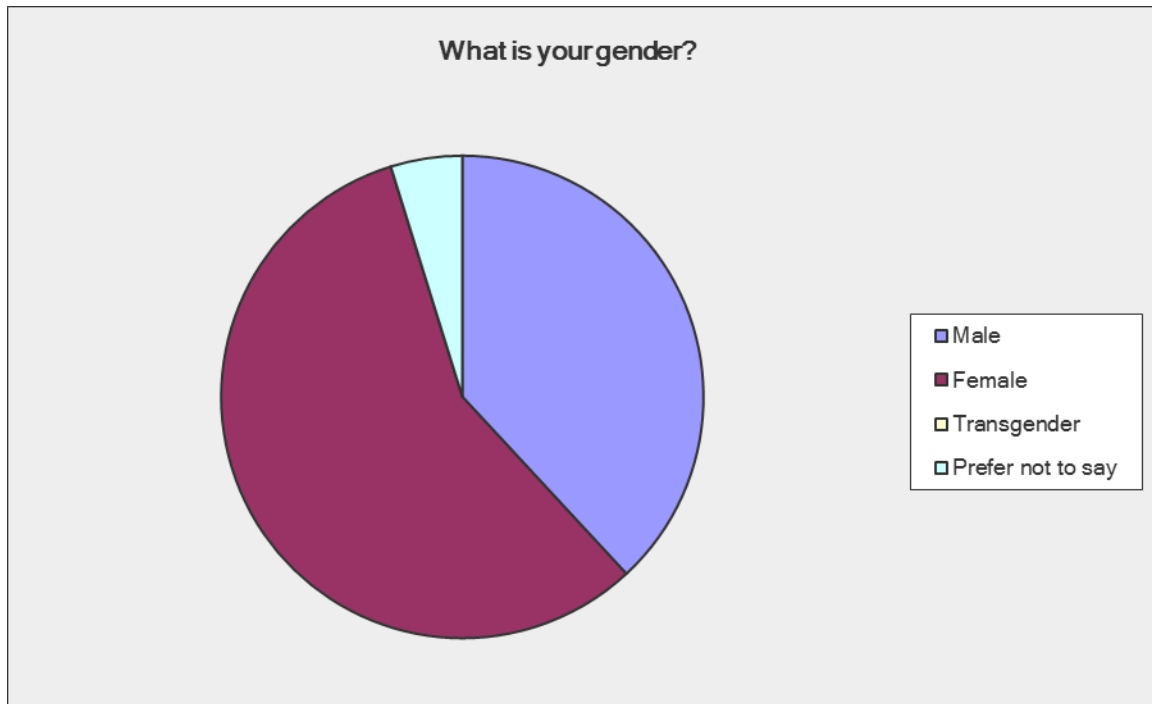
The following is a breakdown of the answers people gave to this question:

Postcode	Number of responses
LE1	9
LE2	19
LE3	24
LE4	13
LE5	9
LE6	9
LE7	9
LE8	7
LE9	17
LE10	6
LE11	5
LE12	10
LE13	5
LE14	2
LE15	9
LE16	9
LE17	3
LE18	5
LE19	4
LE65	2
LE67	8
PE26	1
PE28	1
DE12	2
DE74	2
B76	1
B79	1
CV13	2
CO6	1
ST1	1
ST4	1
ST7	1
TF3	1
SO3	1
NO1	1

LE	3
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Question 7: What is your gender

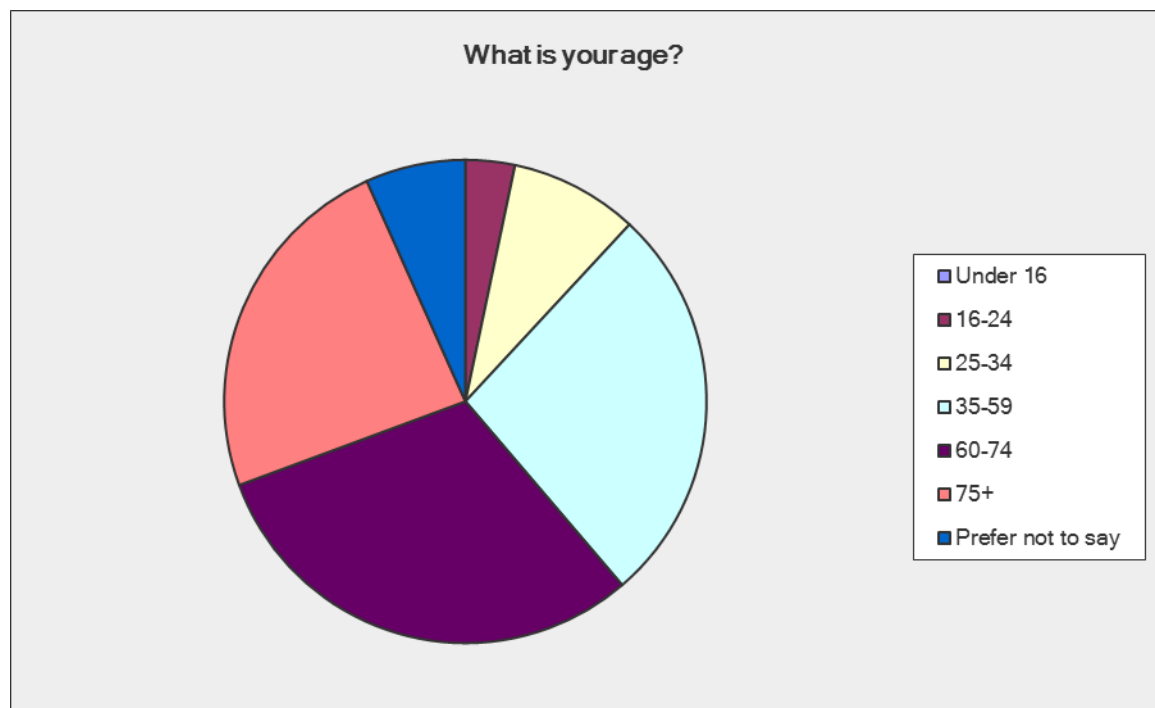
What is your gender?		
Answer Options	Response Percent	Response Count
Male	38.1%	80
Female	57.1%	120
Transgender	0.0%	0
Prefer not to say	4.8%	10
<i>answered question</i>		210
<i>skipped question</i>		2



120 of the people responding to survey (57.1%) were female and 80 (38.1%) were male. Twelve people preferred not to say or did not answer the question.

Question 8: What is your age?

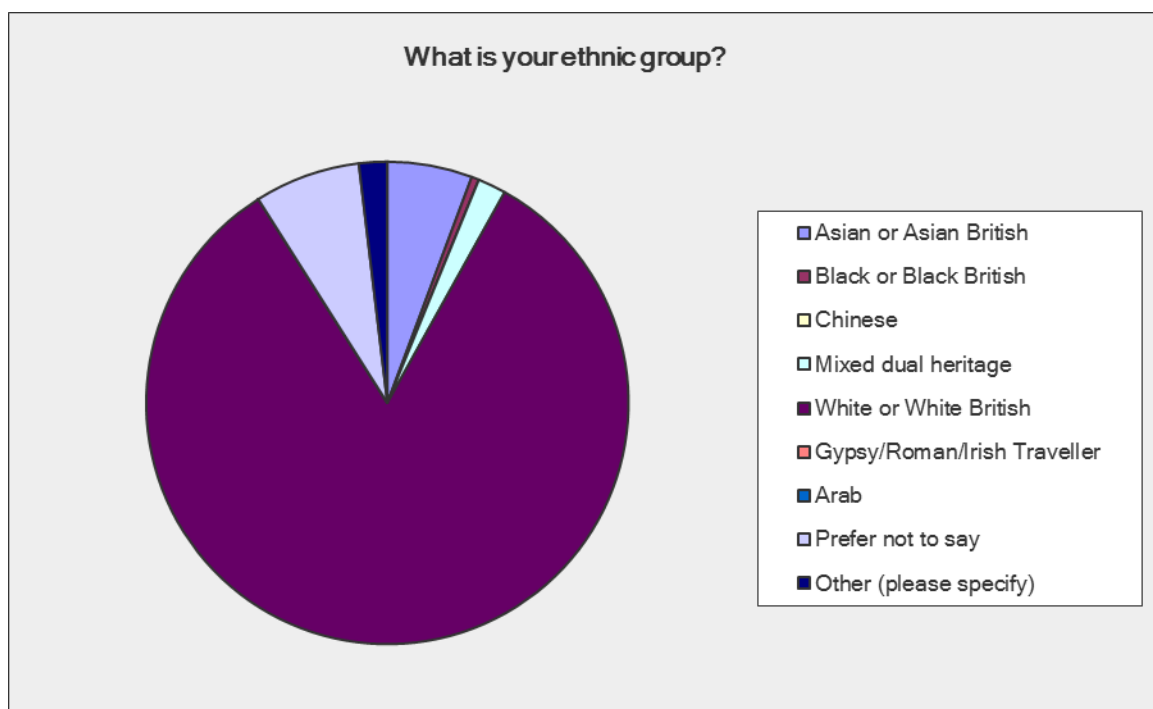
What is your age?		
Answer Options	Response Percent	Response Count
Under 16	0.0%	0
16-24	3.3%	7
25-34	8.6%	18
35-59	26.8%	56
60-74	30.6%	64
75+	23.9%	50
Prefer not to say	6.7%	14
answered question		209
skipped question		3



The majority of people responding to the survey (64 people – 30.6%) were aged 60-74. 56 people (26.8%) were aged 35-59 and 50 people (23.9%) were aged 75 or over. 25 people (11.9%) were aged under 35 and nobody was under 16. 17 people preferred not to say or did not answer the question.

Question 9 : What is your ethnic group

What is your ethnic group?		
Answer Options	Response Percent	Response Count
Asian or Asian British	5.7%	12
Black or Black British	0.5%	1
Chinese	0.0%	0
Mixed dual heritage	1.9%	4
White or White British	83.0%	176
Gypsy/Roman/Irish Traveller	0.0%	0
Arab	0.0%	0
Prefer not to say	7.1%	15
Other (please specify)	1.9%	4
answered question		212
skipped question		0

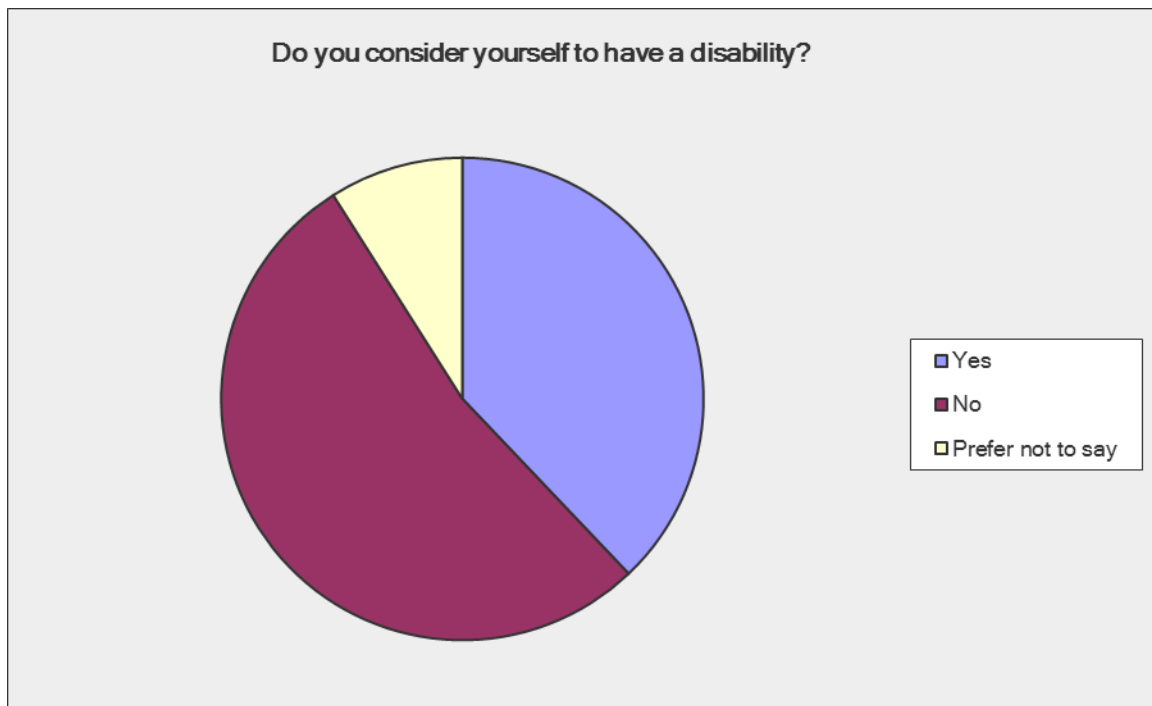


The majority of people responding to the survey (176 – 83%) were white or white British. 12 people (5.7%) were Asian or Asian British, 4 people (1.9%) were of mixed

dual heritage and 1 person was Black or Black British. Three of the 5 people who described themselves as “other” were Irish, English and White English. The other 2 did not specify. 15 people (7.1%) preferred not to say.

Question 10: Do you consider yourself to have a disability?

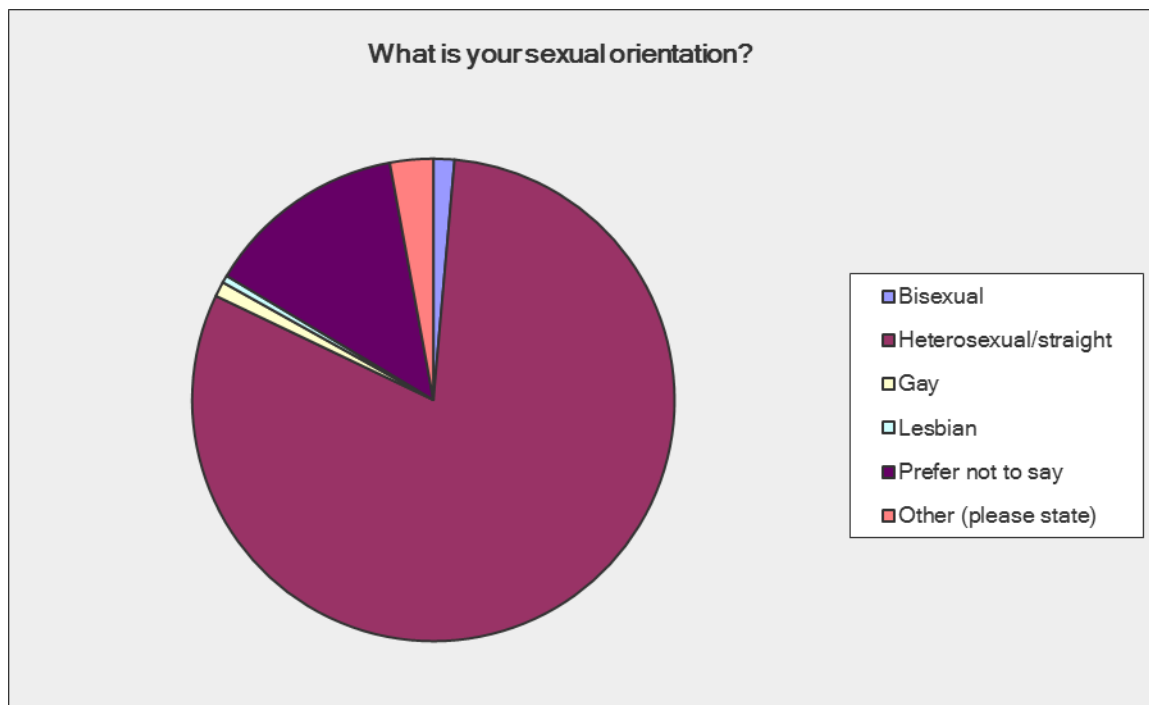
Do you consider yourself to have a disability?		
Answer Options	Response Percent	Response Count
Yes	37.9%	80
No	53.1%	112
Prefer not to say	9.0%	19
<i>answered question</i>		211
<i>skipped question</i>		1



80 people who responded to the survey (37.9%) said they did consider themselves to have a disability. 112 people (53.1%) said they did not consider themselves to have a disability and 20 people (9%) preferred not to say or did not answer the question.

Question 11: What is your sexual orientation?

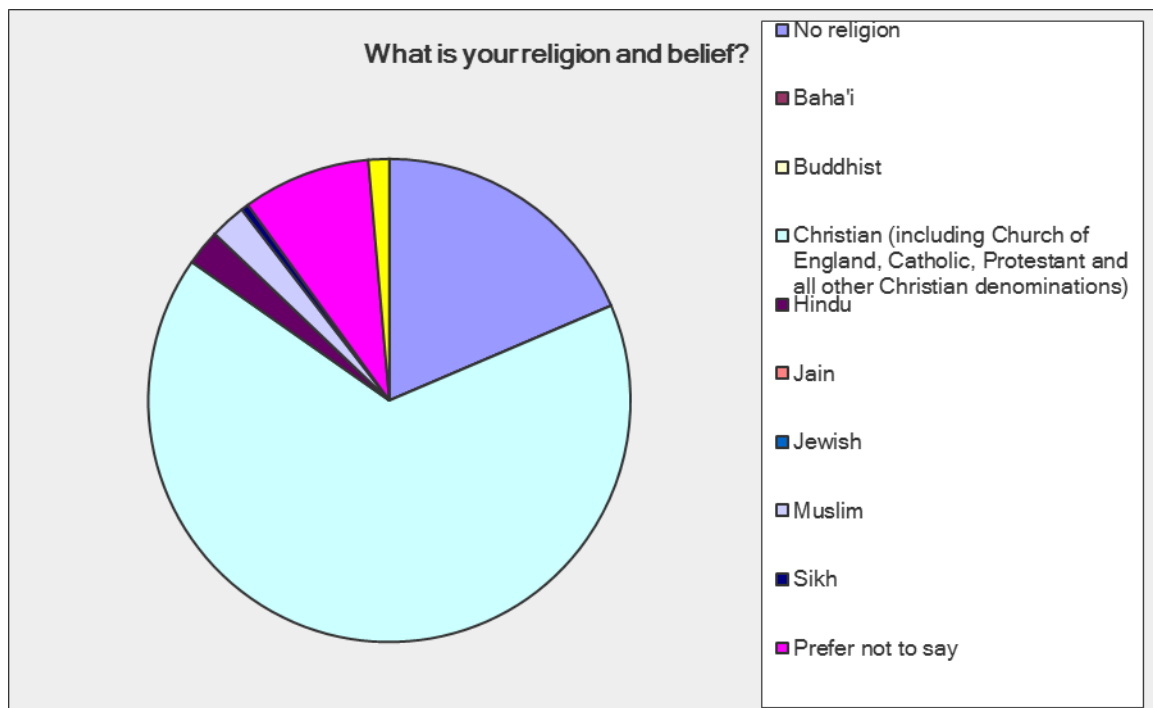
What is your sexual orientation?		
Answer Options	Response Percent	Response Count
Bisexual	1.4%	3
Heterosexual/straight	80.7%	167
Gay	1.0%	2
Lesbian	0.5%	1
Prefer not to say	13.5%	28
Other (please state)	2.9%	6
<i>answered question</i>		207
<i>skipped question</i>		5



167 (80.7%) of people responding to the survey described their sexual orientation as heterosexual / straight. 3 people were bisexual, 2 were gay and 1 lesbian. 6 people (2.9%) described their sexual orientation as “other” and 2 of them specified “don’t know” and “female”. The other 4 did not specify and 5 people did not answer the question at all. 28 people (13.5%) preferred not to say.

Question 12: What is your religion and belief?

What is your religion and belief?		
Answer Options	Response Percent	Response Count
No religion	18.6%	39
Baha'i	0.0%	0
Buddhist	0.0%	0
Christian (including Church of England, Catholic, Protestant and all other Christian denominations)	66.2%	139
Hindu	2.4%	5
Jain	0.0%	0
Jewish	0.0%	0
Muslim	2.4%	5
Sikh	0.5%	1
Prefer not to say	8.6%	18
Other (please specify)	1.4%	3
<i>answered question</i>		210
<i>skipped question</i>		2



139 (66.2%) of the people responding to the survey were Christian. 5 people (2.4%) were Hindu, 5 people (2.4%) were Muslim and 1 person was Sikh. 2 of the 3 people

who answered “other” specified “human being” and “spiritualist”. The third did not specify. 39 people (18.6%) had no religion, 18 people (8.6%) preferred not to say and 2 people did not answer the question.

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