

# **CONSULTATION ON CONTINUING HEALTHCARE IN NORTHERN IRELAND:**

## **INTRODUCING A TRANSPARENT AND FAIR SYSTEM**

### **ANALYSIS OF RESPONSES**

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# 1. BACKGROUND TO THE CONSULTATION

**1.1** Continuing healthcare, which is for adults, is the term used for the practice of the health service meeting the cost of any social care need which is driven primarily by a health need.

**1.2** In 2014, Age NI published a report entitled ‘The Denial of NHS Continuing Healthcare in Northern Ireland’, claiming that older people were being denied access to assessments for continuing healthcare, largely due to the lack of clear guidance. The report contained nine recommendations; this included a recommendation specifically for the Department to consider, which stated:

*‘Age NI recommends that the DHSSPS <sup>1</sup>draft and publish guidance on NHS Continuing Healthcare in NI to provide clarity and to require collation and monitoring of data in a standardised way.’*

**1.3** In addition to the Age NI report, the Department has continued to receive queries on the subject of eligibility for continuing healthcare from individuals and their families, MLAs on behalf of their constituents and other stakeholders.

**1.4** In view of this, the Department carried out a comprehensive review to examine the application of continuing healthcare across the Health and Social Care (HSC) Trusts. This was a complex piece of work involving analysing existing practice across each HSC Trust, reviewing continuing healthcare queries received directly by the Department, engaging with a range of key stakeholders including representatives from the Commissioner for Older People (COPNI) and Age NI, and examining continuing healthcare policy and practice across England, Scotland and Wales.

**1.5** The outcome of the review provided the Department with sufficient evidence that further clarity and revision to the local continuing healthcare policy was required.

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<sup>1</sup> The commencement of the [Departments Act \(NI\) 2016](#) resulted in changes to the structure of government. The Department of Health, Social Services and Public Safety has been renamed the Department of Health. This change came into effect on 9 May 2016.

**1.6** In February 2017, approval was granted by the former Minister, Michelle O'Neill, to launch a public consultation on continuing healthcare in Northern Ireland. The public consultation exercise commenced on 19 June 2017 providing details of four potential options for consideration:

- Option 1:** Do Nothing
- Option 2:** Introduce a Continuing Healthcare Decision Support Tool Model similar to England and Wales, where such tools determine an individual's eligibility for continuing healthcare.
- Option 3:** Implement a model along the lines of the Scottish framework. Under this option, the Department would introduce a single eligibility criteria question 'can your care needs be properly met in any other setting other than a hospital?' If the answer is yes, then the individual would be discharged to the appropriate care setting and depending on the type of care package, be subject to the relevant charging policy.
- Option 4:** Develop Standalone Guidance and Assessment Checklist specific to the HSC System in Northern Ireland.

**1.7** The consultation document was accompanied by a consultation questionnaire which could be completed and forwarded to the Department via email or post, or completed online via Citizen Space. Consultees were asked to respond to specific questions relating to the above options. The questionnaire also offered an opportunity for respondents to provide any additional comments and also to consider issues in relation to equality and human rights matters.

**1.8** The consultation ran for a period of 13 weeks and officially closed on 15 September 2017. Two respondents wrote to the Department to acknowledge the consultation but explained that they did not intend to formally respond. Three organisations requested further time to respond and were granted an extension by the Department to 22 September 2017 to submit their response.

**1.9** A total of 43 completed responses were received from a range of stakeholders including statutory agencies, voluntary and community groups, private sector organisations, political parties and individual members of the public.

**1.10** Of the 43 responses received, 12 respondents used Citizen Space to submit their response. A further 10 respondents chose not to complete the Department's questionnaire, instead submitting their responses in an alternative format including by email and letter. A full list of consultation responses can be found at **Annex A**.

**1.11** In line with best practice, the Department plans to publish copies of the written consultation responses on the Departmental website, the content of some responses will be anonymised where appropriate.

## 2. SUMMARY OF CONSULTATION RESPONSES

2.1 Due to the considerable number of responses received, this summary does not reflect each and every view on all of the issues, but seeks to highlight the main issues raised from the specific questions asked at each section within the consultation document.

### RESPONSES TO INDIVIDUAL CONSULTATION QUESTIONS:

#### SECTION 1 – About You

2.2 Section 1 of the questionnaire captured information on the respondents.

#### SECTION 2 - Questions relating to the proposed amendment to the continuing healthcare policy in Northern Ireland

2.3 In Section 2 of the consultation questionnaire, respondents were asked questions about the proposed amendment to the continuing healthcare policy in Northern Ireland and the alternative options.

#### QUESTION 1

**The Department's preferred option is Option 3. This would involve introducing the following single eligibility criteria Question:-**

***'Can your care needs be met properly in any other setting other than a hospital?'***

**If the answer is yes, then the individual would be discharged to the appropriate care setting and the relevant charging policy would apply. This is similar to the model which currently operates in Scotland.**

**Having read the consultation document, do you agree with the Department's view that Option 3 is the most suitable approach to ensure that there is a transparent and fair system for all individuals who require nursing or residential home care in Northern Ireland?**

2.4 All respondents answered this question. A total of 15 respondents agreed that Option 3 is the most suitable approach, with the remaining 28 respondents

indicating they were not in support of the Department’s preferred option (a breakdown of responses is detailed in Table 1 below).

Table 1

<b>Q 1 - 3 (Options)</b>	
<b>Option 1 – Do Nothing</b>	None
<b>Option 2 – Continuing Healthcare Decision Tool Checklist Model</b>	8
<b>Option 3 – Single Eligibility Criteria Question (Department’s preferred option).</b>	15
<b>Option 4 – Develop standalone guidance specific to NI</b>	13
Alternative Option	3
No Clear Option	4

**2.5** There was some criticism that the consultation document did not provide sufficient detail on the review carried out by the Department. Comments were also received citing a general lack of detail in the consultation document which it was suggested hindered meaningful consideration of the potential options.

### **Option 3: Single Eligibility Criteria Question**

**2.6** Primarily, respondents in support of Option 3 noted that it appeared to be the fairest option. It was suggested that the proposed eligibility question was straightforward, with no requirement for additional administrative processes. Several respondents noted that the implementation of Option 3 would ensure equality, consistency and a standardised approach across Northern Ireland. There was also support for Option 3 mirroring the Scottish framework which has been operational for more than 2 years and is therefore ‘tried and tested’.

**2.7** A range of reasons were put forward by those respondents not in favour of Option 3. This included concern that the proposed eligibility criteria question would essentially mean that no one would be eligible for continuing healthcare and consequently Northern Ireland would remain devoid of continuing healthcare. It was

also suggested that Option 3 would amount to the abolishment of continuing healthcare funding in Northern Ireland.

**2.8** Some of those respondents who indicated their support for Option 3 did so whilst also outlining their concerns about the difference between the health and social care systems in Northern Ireland and Scotland. Specifically, this focused on the existence of Free Personal Care in Scotland which has been available to individuals over the age of 65 from 2002. Free Personal Care was extended to include all adults over the age of 18 who are assessed by their Local Authority as needing this service from 1 April 2019.

**2.9** Concern was expressed that Option 3 would provide a perverse incentive for patients to remain in hospital where there are not enough hospital beds. Some respondents also commented that Option 3 would merely serve to simplify the financial system for payment.

**2.10** Comments were also received suggesting that the Department's consultation paper lacked sufficient information about the preferred option. Further, it was suggested that it was not clear that Option 3 would result in a more transparent and fair system, nor was it consistent with the aim of the Transforming Your Care agenda and the move from hospital care to community based social care provision.

**2.11** Below are some examples of comments made:

*"Option 3 appears to be the fairest option and should ensure equality across the region."* **(Individual)**

*"It is the most likely of the options outlined to secure consistency and the administrative burden seems low."* **(Positive Futures: Achieving Dreams. Transforming Lives)**

*"The proposed single eligibility criteria question is a lot clearer for multi-professional teams, patients and their families to understand."* **(South Eastern Health and Social Care Trust)**

*"The simplicity of this option and the fact that it has been implemented in Scotland is the reason why we have supported this proposal. However, there are greater complexities in terms of defining healthcare and its consequences."* **(Home-Start UK)**



*“We believe that this option would, in effect, bring about an end to the provision of continuing Healthcare in Northern Ireland and may provide a perverse incentive for individuals to remain in hospital, contrary to the current policy of community based care.....To revise the Continuing Healthcare eligibility criteria in line with the model in Scotland would, we believe, require the Department to draft and implement legislation guaranteeing free personal care in Northern Ireland” (Age NI)*

*“With such a rapidly ageing population, and so many people living with complex and terminal illnesses, now would be the absolute worst time to get rid of Continuing Healthcare support in Northern Ireland.” (Marie Curie)*

*“From the information provided, introducing a model similar to Scotland will not adequately address the flaws in the current system and may exacerbate regional variance.” (Citizens Advice)*

## **QUESTION 2**

**If your answer to question 1 was ‘No’, do you have a preferred choice from the alternative options (1, 2 or 4) listed in the consultation document?**

**2.12** Of the 28 respondents not in favour of the Department’s preferred option, 22 respondents indicated a preference for an alternative option, 5 respondents indicated they had no alternative preferred option and 1 respondent did not give an answer.

### **Option 1: Do Nothing**

**2.13** All respondents agreed with the Department’s position that doing nothing is not a viable option.

### **Option 2: Introduce a Continuing Healthcare Decision Tool Checklist Model (as is currently implemented in England and Wales)**

**2.14** A total of 8 respondents favoured Option 2 as their preferred option.

**2.15** Of those respondents in support of Option 2, the majority were of the opinion that this option would provide clear, transparent and consistent guidance, directly relating to health needs and would introduce standardisation across Northern Ireland, thereby reducing regional variation between Health and Social Care Trusts.

**2.16** Below are some examples of comments made:

*“This option provides consistent guidance on decisions to all health trusts and should introduce standardisation across NI and with other parts of the UK.”*  
**(Individual)**

*“This would give practitioners from across the professions clear guidance on the assessment of continuing healthcare and provide a standardised approach.”* **(Royal College of Occupational Therapists)**

*“After examining the English decision tool online, the criteria is very clear and transparent and directly relates to health needs. The domains in the tool are well defined and straightforward to follow, and the criteria set for eligibility are also clear, to the point that confusion or mis-interpretation is minimised.”*  
**(Individual)**

#### **Option 4: Develop standalone continuing healthcare guidance and an assessment checklist specific to the Health and Social Care (HSC) system in Northern Ireland**

**2.17** The 13 respondents who indicated that Option 4 was their preferred option did so on the basis that it would provide a means of addressing issues around a lack of clarity and transparency on the arrangements for continuing healthcare in Northern Ireland, along with the opportunity to develop bespoke guidance specific to the HSC system in Northern Ireland. It was also mentioned that Option 4 would fit best with the Department’s agenda for Transforming Your Care.

**2.18** Below are some examples of comments made:

*“This option would provide clarification for the Department, HSCB, HSC Trusts, individuals and their families, the general public and other key stakeholders.”* **(Individual)**

*“The process does not need to be overly resource intensive or time consuming as there are a number of community/voluntary groups and other stakeholders – Marie Curie included – who would be willing to work in partnership with the Department and feed into the process.....There is a wealth of evidence to help shape the development of effective and fair guidance for Northern Ireland.”* **(Marie Curie)**

*“Option 4 offers an opportunity to address issues around clarity and transparency on arrangements for Continuing Healthcare in Northern Ireland.”*  
**(Age NI)**

*“Whilst this may well constitute a “potentially intensive exercise” requiring “significant input from clinicians and practitioners”, this is not an acceptable reason to refuse to act and indeed, the resources required may not be at the level of England.”* **(The Commissioner for Older People Northern Ireland)**

### **QUESTION 3**

**If you do not agree with any of the options listed in the consultation document, do you have an alternative option which you would like the Department to consider?**

**2.19** Three respondents indicated their preference for an alternative option. This included a suggestion to amend the question proposed by the Department to read “Do your continuing health needs require the constant application or supervision of medical expertise or devices?”

**2.20** Another alternative option recommended that all outstanding applications for continuing healthcare in Northern Ireland be brought in line retrospectively with the way such applications have been dealt with in England and moving forward adopt one system for assessing continuing healthcare applications, introducing parity between England, Scotland, Wales and Northern Ireland.

**2.21** The third alternative option recommended the Department adopting the Scottish model in its entirety.

**2.22** Of the remaining 4 responses, one respondent asked that the Department reconsider the other alternatives presented in the consultation document (i.e. the potential to develop guidance). Another respondent provided some comments against option 4 which included a request that the Department draft and publish guidance. Despite this, the respondent chose not to indicate a preferred choice from the alternative options presented. The final respondent advised that they were

unable to give a recommendation on any of the proposals due to a lack of detailed information in the consultation document.

#### **QUESTION 4**

**The Department is proposing that individuals already in receipt of continuing healthcare will continue to receive it for as long as they remain eligible to do so.**

**This means that irrespective of the Option implemented, those individuals will not be disadvantaged by the new arrangements.**

**Do you agree with the Department's proposal regarding the plan for existing continuing healthcare recipients?**

Table 2

<b>Q4 (Proposal for existing continuing healthcare recipients)</b>	
Yes	32
No	5
Did not answer	6

**2.23** Table 2 above shows that 32 respondents agreed with the Department's proposal that individuals already in receipt of continuing healthcare should continue to receive it for as long as they remain eligible to do so, irrespective of the outcome of the consultation.

**2.24** Five respondents disagreed with the Department's proposal and the remaining 6 respondents did not answer the question.

## **QUESTION 5**

The Department outlined two possible approaches for dealing with applications for continuing healthcare which have already been submitted to the Health and Social Care (HSC Trusts).

The first approach would require HSC Trusts to assess these applications for continuing healthcare in line with the existing guidance.

The second approach would require HSC Trusts to retain applications for continuing healthcare until the outcome of the public consultation exercise is known. Following this, HSC Trusts would then arrange to assess these applications in line with the new arrangements introduced.

Respondents were asked to indicate their preferred approach.

Table 3

<b>Q5 (Existing applications)</b>	
Assess in line with existing guidance	21
Assess in line with new arrangements	15
Did not answer	7

**2.25** Table 3 reveals that 21 respondents indicated that their preferred approach was to assess applications under the current guidance, in order to avoid any unnecessary delay for individuals, which may have an adverse impact on their care.

**2.26** A further 15 respondents indicated their preferred approach was to assess under new arrangements. Whilst some respondents did not give a reason for their answer, others commented that in their opinion the current method was neither fair nor transparent. It was also suggested that if the outcome of the consultation was rapid, applications already submitted to the HSC Trusts should be assessed under new arrangements to ensure standardisation.

**2.27** The remaining 7 respondents declined to provide an answer.

## **QUESTION 6**

**Do you have any other comments you want to offer or are there any particular points which you think the Department should consider when making any policy decision about continuing healthcare in Northern Ireland?**

**2.28** A total of 39 responses were received to this question. In some instances, the comments did not refer to the continuing healthcare consultation specifically, but focused on a wider range of issues associated with health and social care service provision in Northern Ireland.

**2.29** There was consensus among some respondents about an increase in demand on the health and social care system in Northern Ireland and a suggestion that public expectation about what the health and social care system can provide was, on occasion, unrealistic.

**2.30** It was suggested that the current continuing healthcare policy forces families to provide most of the care at home; this impacts not only on family members who adopt the role of carers but also on children living in the family home.

**2.31** Some respondents criticised the lack of accessible information for individuals and families who find themselves in the position of needing to consider different care options. Respondents requested the provision of clear guidance and asked that social workers, professionals and other frontline staff receive better training.

**2.32** Clarification was requested on a range of issues including matters such as defining the term 'hospital'; what elements of health and social care are available; and whether the current weekly £100 payment to meet the nursing care needs for individuals in a nursing home is sufficient.

**2.33** Comments were received stating that packages of care should be needs driven, not based on financial considerations and it was suggested that the Department should look at adjusting budgets accordingly in order to support continuing healthcare packages. Some respondents took the opportunity to reaffirm that continuing healthcare should be available to individuals in all care settings.

## SECTION 3 - Equality and Human Rights

Respondents were referred to the Department's Equality Screening, Disability Duties and Human Rights Assessment Template and asked the following questions:

### **QUESTION 7**

Is the preferred option set out in the consultation document likely to have an adverse impact on any of the nine equality groups identified under Section 75 of the 1998 Act?

Table 4

<b>Q7 (Adverse impact on the nine equality groups)</b>	
Yes	7
No	17
Did not answer	19

**2.34** Seven respondents believed that the Department's preferred option would have an adverse impact, whilst 17 respondents believed it would not and the remaining 19 respondents did not answer this question.

**2.35** Two respondents suggested that a full EQIA be completed to determine the implications of the proposed revisions to the Department's continuing healthcare policy. Concerns were also expressed that the proposed policy revisions would seriously impact the elderly more than any other age group in society.

## **QUESTION 8**

**Are you aware of any indication or evidence – qualitative or quantitative – that the preferred option set out in the consultation document may have an adverse impact on equality of opportunity or on good relations?**

Table 5

<b>Q8 (Adverse impact on equality of opportunity/good relations)</b>	
Yes	5
No	18
Did not answer	20

**2.36** Five respondents answered ‘yes’ to this question, with most believing that good relations would be adversely affected by the Department’s proposed option. Some respondents commented that individuals in Northern Ireland were not being treated equally with their counterparts on the mainland and therefore public opinion would be affected.

## **QUESTION 9**

**Is there an opportunity to better promote equality of opportunity or good relations?**

Table 6

<b>Q9 (Opportunity to better promote equality)</b>	
Yes	6
No	16
Did not answer	21

**2.37** Of the 6 respondents who answered ‘yes’ to this question, 2 respondents suggested that a process similar to that in England would better promote equality. Other comments received covered issues including free healthcare and training for social services staff in the legal healthcare rights of Northern Ireland citizens. It was



also suggested that further consideration given to the differential in costs between residential care and domiciliary care would be useful.

### **QUESTION 10**

**Are there any aspects of the proposals in the consultation where potential human rights violations may occur?**

Table 7

<b>Q10 (Potential human rights violations)</b>	
Yes	8
No	14
Did not answer	21

**2.38** In relation to the 8 respondents who answered 'yes', comments were made alluding to the potential impact of the Department's preferred option on the human rights of older people, in particular Article 5 'Right to liberty and security' and Article 8 'Right to respect for private and family life'.

### **3. Departmental Response and Next Steps**

**3.1** The Department is grateful to all those individuals and organisations who took the time to respond to the public consultation exercise on continuing healthcare in Northern Ireland.

**3.2** It is evident from the broad range of comments submitted that there continues to be much uncertainty and confusion about continuing healthcare and its applicability in Northern Ireland.

**3.3** The outcome of the consultation revealed that, by a very small margin, more respondents considered the Department's preferred solution, Option 3 (the introduction of a single eligibility criteria question), to be the most suitable option for the Department to implement. This was closely followed by Option 4 recommending the development of standalone guidance and an assessment checklist specific to the HSC system in Northern Ireland.

**3.4** The Department has taken consideration of and analysed the points raised by respondents. With the population of older people continuing to increase year on year and advancements in technology and medicine, individuals are now able to live much longer with complex and long-term care needs. Acknowledging a commitment to improving how the health and social care needs of those requiring support are met, this must be achieved within an environment where there are well documented increasing financial pressures on the wider health and social care system.

**3.5** Therefore, on balance, officials still consider Option 3 to be the most workable solution, providing a clear and easily understood test, avoiding the difficulties of the system in England and Wales which appears to be overly complex and burdensome. One of the main advantages with implementing this option is that it would ensure regional consistency in continuing healthcare outcomes across HSC Trusts, importantly addressing any existing inequality issues for individuals. This option would create a fairer system where individuals needing to avail of residential or nursing home care services would be subject to the same charging policies and

would contribute to the costs of their care depending on their financial circumstances. By adopting a similar stance to Scotland, those individuals already in receipt of continuing healthcare, would continue to receive it so long as they remained eligible to do so and therefore would not be disadvantaged as a result of introducing the new arrangements.

**3.6** Equality and Human Rights have been considered and the Department is of the view that a full EQIA is not needed because no evidence has been identified to show that the proposal will have a differential impact on any of the Section 75 groups. The Human Rights impact was deemed neutral. The policy will be based on assessed need and will be applied equally across all Section 75 categories.

**3.7** It is important to note that there will be instances where it may not be appropriate to financially assess an individual placed in a residential or nursing home, for example, if a person is discharged from hospital for end of life care. It is proposed that Departmental guidance developed will address such exceptions.

**3.8** The Department accepts that any revision to the current continuing healthcare policy must be underpinned by guidance which is fit for purpose. This will require the Department to engage with the HSC Board, HSC Trusts and other key stakeholders as required. Further, the Department is committed to ensuring that any guidance developed will be done so utilising the principles of co-production.

### Consultation Responses

Age NI
Caldwell Robinson Solicitors
Citizens Advice
Commissioner for Older People (COPNI)
Fermanagh & Omagh District Council
Home-Start UK
Law Centre NI
Macmillan Cancer Support
Marie Curie
Mid and East Antrim Borough Council
Northern Health and Social Care Trust (NHSCT)
Parkinson's UK
Patient and Client Council (PCC)
Positive Futures
Presbyterian Church in Ireland
Royal College of General Practitioners NI (RCGPNI)
Royal College of Nursing (RCN)
Royal College of Occupational Therapists (RCOT)
Royal College of Psychiatrists
Sinn Fein
Social Democratic and Labour Party (SDLP)
South Eastern Health & Social Care Trust (SEHSCT)
Southern Health & Social Care Trust (SHSCT)
Western Health & Social Care Trust (WHSCT)
19 Individuals