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Welsh Government
Consultation – summary of response

CONTINUING NHS HEALTHCARE

The National Framework for Wales

November 2019

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.
This document is also available in Welsh.

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INTRODUCTION

Purpose

1. Continuing NHS Healthcare (CHC) is a package of care and support for people who have complex care issues which are primarily health based. An individual is deemed to be eligible for CHC when their primary need is a health need: 'the primary health need approach'. This is determined by consideration of the four key characteristics of need: nature, intensity, complexity and unpredictability. The NHS in Wales, through local health boards (LHBs), is responsible for the delivery of CHC, though there are roles for others, including local authorities (LAs), in this process. Existing arrangements for the provision of CHC are set out in the National Framework for Continuing NHS Healthcare in Wales which was published in 2014 ('the 2014 Framework').

2. The consultation[1] on a revised national framework was undertaken as part of a long standing commitment to review arrangements within the 2014 Framework. The 2014 Framework, published in June 2014, superseded the 2010 Framework and sought to address a number of issues identified at the time by the Public Service Ombudsman for Wales, the Wales Audit Office and the Public Accounts Committee. These focussed on greater strategic ownership, enhanced support for practitioners and the public, a revised assessment and eligibility process and robust governance arrangements for the management of back-dated, or retrospective claims. The consultation sought stakeholder's views on amendments to the 2014 Framework (revised Framework) and also to the Decision Support Tool (DST), which is used as part of any assessment for eligibility to receive CHC.

3. The consultation, which ran for 12 weeks from 26 May 2019 to 21 August 2019, reports its findings to the Minister for Health and Social Services and will assist in future policy decisions regarding the implementation of CHC in Wales.

4. We will share the revised Framework and DST with all LA and LHB members of staff involved in an individual's assessment or delivery of CHC (practitioners) in December 2019, following any amendments made resulting from the consultation exercise. This will ensure the documents are available during an implementation period, when a comprehensive training package will be delivered to practitioners prior to the publication of the final Framework and DST in April 2020. The publication of the revised Framework will be supported by the publication of a revised CHC Performance Framework and publication of both revised and additional materials for practitioners along with publication of newly developed material for the public, as set out at paragraphs 38 to 39.

[1] https://gov.wales/draft-national-framework-continuing-nhs-healthcare

BACKGROUND

The 2014 Continuing Healthcare Framework

5. CHC is the name given to a package of care and support given by the NHS, through LHBs, to people whose needs are mainly health-based. Given these pressures, CHC was identified as an area of healthcare that would benefit from a nationally coordinated approach and since 2010 has been supported by the National Framework for Implementation in Wales guidance, published by Welsh Ministers. The Framework covers adults aged 18 and over, and sets out the Welsh Government's policy for eligibility for CHC and the responsibilities of LHBs and LAs. It sets out a process for the NHS, working with LA partners, to assess health needs, decide on eligibility for CHC and provide appropriate care. All LHBs and LAs in Wales are required to follow it.

6. An individual may be assessed as having a primary health need and entitlement to receive CHC in a variety of settings outside of hospital, such as at their own home or in a care home. Where the individual is living in a care home, the NHS will have responsibility for funding the full package of health and social care. Where the individual is living at home, the NHS will pay for healthcare (for example, services from a community nurse or specialist therapist) and social care, but this does not include the costs of food, accommodation or general household support.

7. NHS bodies and LAs have responsibilities to ensure that the assessment of eligibility for, and provision of, CHC takes place in a consistent fashion and the process is actively managed to avoid unnecessary delays.

8. If an individual does not meet CHC eligibility, they can still access a range of health and social care services that are likely to be part of mainstream services or individually planned to meet specific need.

9. The Framework was last revised in 2014 and a number of significant changes were made at that time. These included; strengthening of governance issues; stronger provisions for the Welsh Language; the assessment process and how information is recorded through the DST; a strengthened role for carers; reviews of decisions and enhanced arrangements regarding retrospective claims. It also identified and set out linkages with wider policy areas outside CHC, such as mental health, learning disability and Direct Payments.

10. The Framework is designed to provide consistency in practice across Wales and to ensure that adults with complex care issues can receive the appropriate level of care and support for their needs.

General Principles of CHC

11. CHC is just one part of a continuum of services that LAs and NHS bodies need to have in place to support people with health and social care needs. CHC is one aspect of care which people may need as the result of disability, accident or illness to address both physical and mental health needs.

12. The revised Framework makes it clear that the whole process of determining eligibility and planning and delivering services for continuing NHS healthcare should be 'person centred'. This is vital since individuals going through this process will be at a very vulnerable point in their lives. There may well be difficult and significant choices to be made, so empowering individuals at this time is essential.

13. The ongoing assessment and review process should therefore be explained to the individual, their family, carer or representative from the outset and confirmed in writing. Communication tools and template letters for various stages of the process can be accessed by all agencies and practitioners via the Complex Care Information & Support website (CCISS website). This was set up for practitioners as part of the implementation of the 2014 Framework.

14. Where an individual lacks capacity to make informed choices, under the Mental Capacity Act Code of Practice, staff may disclose information about the individual, providing it is in the best interests of the person concerned, or there is a lawful reason to do so.

15. CHC should not be viewed as a permanent arrangement. Care provision should be needs-led and designed to maximise ability and independence. Any care package, regardless of the funding source, should be regularly reviewed in partnership with the individual and/or their representative to ensure that it continues to meet their needs.

REVIEW OF THE 2014 FRAMEWORK

Scope of the Review

16. The National Complex Care Board (NCCB) set the scope of this review. It had strategic oversight for CHC and comprised senior representatives from each of the seven health boards in Wales, alongside Welsh Government officials. The NCCB's view was that the principles supporting the existing Framework were sound and therefore the review should only aim to clarify, refine or add to the existing Framework as appropriate. The NCCB has now ceased and responsibility for the governance and strategic oversight of CHC now lies with the National Commissioning Board (NCB). This board includes senior representatives from the NHS, LAs, care providers, the third sector and the Welsh Government.

17. The Welsh Government established a small working group to assist in the review of the Framework. The group met on a number of occasions during 2017 and 2018 to discuss potential changes to the Framework. The group comprised of representatives from:

- LHBs
- LAs
- the Public Services Ombudsman for Wales
- third sector representatives

CONSULTATION

Summary of consultation responses

18. We published the consultation online and circulated it to a wide range of stakeholders including representatives from health, local government and social care sectors, as well as patient representative groups, and the public. All those consulted were, to varying degrees, stakeholders in the health and social care sector.

19. We received responses to the consultation from the following categories:

- Members of the public
- LHBs
- LAs
- Public service bodies
- Patient representative groups
- Inspectorates

20. We received 58 responses. Some of the responses were a collation of sector-specific stakeholder comments and not all of the respondents commented on every question that was posed in the consultation document. Furthermore, some respondents did not provide direct 'yes' or 'no' answers to each question. In these circumstances, every effort has been made to interpret and include the respondent's intended viewpoint in the figures quoted in this summary.

21. A small number of respondents chose to respond by letter and not via the consultation form, in these circumstances, where possible their responses have been included in the relevant consultation question. Where this has not been possible their response has been included at question 11, which provided for responses outside of the set consultation questions.

22. All quotations from consultation responses are in the original language unless specified otherwise.

Key Findings

23. In general, the revised Framework was well received and many respondents agreed the document provided additional clarification and detail in some key areas which has been welcomed. A few felt that some areas still fell short of providing the clarity required for the successful implementation of CHC. A number of key findings were highlighted as follows:

Roles and responsibilities

24. Some respondents highlighted that the specific roles and responsibilities of LHBs and LAs throughout the CHC assessment process could be clearer.

Decision Support Tool (DST)

25. A number of concerns were raised regarding the proposed changes to the DST which respondents felt amounted to a change in the eligibility threshold, which has not been mandated.

Pooled Budgets

26. The Social Services and Well-being (Wales) Act 2014 (the SSWB Act) and associated regulations required LHBs and LAs to work together and deliver seamless services, including through pooled budgets. Some respondents felt that the revised Framework could provide more clarity on how this could be achieved in practice in relation to CHC.

Direct Payments

27. Direct payments are monetary amounts made available by local authorities to individuals, or their representative, to enable them to meet their eligible care and support needs, or support needs in the case of a carer. Direct payments allow people to exercise, voice and control to decide how, when and who supports them to meet their eligible care and support needs. Some respondents have stressed that the transition to CHC can result in people losing control of the way that care and support services are provided which can be detrimental to the individual and their well-being. The revised Framework sets out what LAs and LHBs should do in these circumstances, including setting up joint packages of care to ensure individuals do not lose their voice and control. Some respondents felt that in reality, this was very rarely delivered. Further, some felt the revised Framework was contradictory and therefore open to interpretation on this subject.

Independent User Trusts

28. Some respondents suggested that the Welsh Government should consider trialling Independent User Trusts as a potential solution to allow CHC recipients to receive funding for their health and social care needs. This could enable an individual, who

had previously been eligible to receive direct payments, to maintain continuity of the personnel delivering their care, where the individual wishes this to be the case. There was a suggestion of a trial for a restricted group – such as learning disability.

Funded Nursing Care (FNC)

29. A number of respondents requested an urgent review the current FNC Policy and guidance as they were 15 years old and possibly did not reflect current policy or statutory positions.

CONSULTATION RESPONSES

Implementation

Question 1: In addition to revising the Framework we are placing a strong emphasis on its effective implementation. Are there particular areas you would wish to see addressed in materials developed to support implementation?

30. There were 49 responses to this question. 30 (61%) agreed there were additional materials they would like to see developed to support implementation, 17 (35%) partly agreed and 2 (4%) did not agree.

Summary of responses

31. Comments received from respondents who agreed or partly agreed are summarised as follows:

- A majority of respondents agreed the implementation of the revised Framework should be supported by LHB and LA joint training sessions, with learning events being held across Wales prior to implementation of the revised Framework. Also, that a rolling programme of training should be developed for new staff and refresher training for current staff on all aspects of the CHC process.

- A majority of respondents welcomed an implementation period although some stated the implementation period during the introduction of the 2014 Framework, did not succeed in ensuring the Framework was effectively and consistently implemented across all LHBs and LAs. Some considered that this could only be achieved through a strengthened and transparent CHC audit process.

- Some suggested the CCISS website should include materials available to the breadth of practitioners and organisations dealing with CHC. This should include best practice protocols to avoid inconsistency in relation to Section 117 (of the Mental Health Act 1983). Some felt that the revised Framework provided clarity in

terms of CHC and Section 117, but further clarity on the interface between Section 117 and FNC was required.

- Some respondents welcomed the checklist, which is a CHC screening tool to help practitioners identify individuals who may need a full assessment of eligibility for CHC. Some considered training should be provided to all staff to ensure it is consistently delivered. It was also considered that use of the checklist should be included in the audit process to evaluate its use. Some requested further clarity on which practitioners should complete a checklist assessment as well as the process to follow when the outcome of the checklist assessment is disputed.

Welsh Government response

32. The Welsh Government will work with LHBs and LAs to produce a comprehensive training package to be delivered to all LHB and LA staff involved in the CHC process during the implementation period, to ensure the effective, consistent and equitable implementation of the revised Framework. We will also be working with stakeholders to revise the performance framework to ensure effective delivery of CHC.

33. During the implementation period, we will overhaul the existing CCISS website to ensure all practitioners have access to the right materials to enable effective delivery of CHC. We will also add a section to include materials relating to the transition from Children and Young People's Continuing Care (CYP) to Adult CHC. We will monitor the website and keep it up to date.

34. In relation to clarity on the interface between S117 of the Mental Health Act 1983 and FNC, we intend to address this in the review of the FNC policy, as set out at paragraph 76. In terms of the checklist, we will reconsider the wording in the framework to ensure it is implemented appropriately.

Question 2: The CHC Framework as it stands is a technical document aimed at specialist professionals who oversee assessment and care provision. We would welcome your thoughts on the potential publication of a simplified Framework aimed at both practitioners and service users. Comments on its appropriateness, including suggested format, content and style are welcome.

35. There were 45 responses to this question. 37 (82%) agreed a simplified Framework aimed at both practitioners and service users should be developed for the following reasons:

Summary of responses

- A number of practitioners agreed a simplified version would be useful for multiple reasons, however, they acknowledged that to produce this would be a significant piece of work as CHC is a complex area. Further, because the current technical document is complex (for both practitioners and individuals) it is challenging for CHC staff when advising and supporting individuals, particularly when having to interpret and explain the nuances of the Framework.

- A mixture of professionals, public and patient representative groups agreed a simplified version of the framework would be very useful for the public. It would ensure they are aware of their rights, and what they are legally entitled to, so that they are not reliant on practitioners' knowledge, awareness and ability to explain the CHC process to them. A number of respondents agreed it would be essential to co-produce this with patient representative groups, individuals and their families, carers and representatives.

- Respondents welcomed the new content on carers in the revised framework. Some suggested CHC documents should include a prompt to inform the carer of their right to a carer's assessment by the LA or LHB, as set out in the SSWB Act.

- Some respondents felt that awareness of CHC was limited amongst the general public and a public awareness campaign should be launched in line with the publication of the revised Framework.

36. The following reasons were provided from those that didn't agree a simplified version of the revised Framework should be produced:

- Information for members of the public already exists in CHC public information leaflets. Given that the revised Framework is a technical document, a simplified version for practitioners or the public could risk diluting complex information, presenting an inaccurate picture of the process and inconsistent delivery.

Welsh Government Response

37. The Welsh Government considers that on balance, the production of additional materials would be more beneficial than a simplified version of the framework for practitioners. This could include best practice protocols and frequently asked questions relating to the more contentious areas of the CHC process. This would negate the risk of diluting highly complex information which could result in an inconsistent delivery of the revised Framework.

38. The Welsh Government agrees that members of the public should be able to access a comprehensive CHC guide so that they are fully informed of what to

expect from the start of the CHC assessment process. Therefore, we will work with people who have been through the CHC assessment process and patient

representative groups to develop a one-stop CHC booklet. This will set out the step by step journey an individual will take in the CHC assessment and delivery process. We expect this would include a flowchart, information on the individuals' rights at each stage of the process and information on the responsible organisations at each stage. It could also include information on organisations providing advocacy and support and advice services. This comprehensive guide, which will also be available bilingually and in an Easy Read format, will empower the individual and their carer to play a full role in the assessment process and in the decisions about the support they receive.

39. It is our intention to publish the CHC booklet for members of the public in April 2020 to coincide with the publication of the revised Framework. We will share these publications widely to the public and practitioners to raise public awareness.

Question 3: Does the proposed Framework provide sufficient assurance about the responsibility, ownership and governance of CHC by Welsh Government, LHBs and their partners?

40. There were 46 responses to this question. 12 (26 %) agreed the revised Framework provided sufficient assurance about the responsibility, ownership and governance of CHC by Welsh Government, LHBs and their partners and 17 (37%) partly agreed and 17 (37%) did not agree at all.

Summary of responses

41. Generally respondents thought the Framework provided or partly provided sufficient assurance about the responsibility, ownership and governance of CHC by Welsh Government, LHBs and their partners. Suggestions received on what changes or additions should be made are summarised as follows:

- Some respondents suggested the revised framework was confusing in relation to the roles and responsibilities of LAs and LHBs for areas such as the checklist, pooled budgets and direct payments.

- Some stakeholders suggested that an adjacent accountability framework (detailing organisations' responsibility and accountability) would provide both clarity and transparency to the CHC process. Some responses stated that when an assessment for or provision of CHC is delayed, the individual should know

who is responsible for that delay and what implications it has to them, and the responsible organisations.

- LAs suggested a desire to input into revisions to the CHC performance framework. They would also like the opportunity to view LHBs quarterly reports. They further suggest the quality assurance process that LHBs follow should include all CHC decisions and not just those that are eligible, to gain a true picture on how CHC is being delivered in Wales. They also suggested that the LHB quality assurance mechanisms should be included as an annex of the revised Framework.

Welsh Government Response

42. The Welsh Government will consult further with LHBs and LAs, to provide further clarity in the areas highlighted, prior to the publication of the revised Framework.

43. We developed the current CHC Performance Framework to set out governance and accountability arrangements for CHC. It provides assurance that health boards are compliant with the 2014 Framework. We have already begun a review of the current performance framework, to ensure it is fit for purpose. We have agreed a revised approach with the NCCB to capture performance that would standardise requirements across health boards and provide a more comprehensive assurance mechanism for the Welsh Government. We will work with LHBs and LAs during the implementation period to finalise the performance framework, taking account of consultation responses and audit reports. We intend to introduce this in April 2020 alongside the revised CHC Framework.

Question 4: What approaches could be put in place nationally, regionally and locally to further develop partnership working between LHBs, LAs and other partners in relation to CHC?

Summary of responses

44. There were 45 responses to this question which are summarised below:

- A number of respondents agreed that joint working in the production of protocols for joint care packages, pooled budgets, etc. would assist in further developing partnership working between LHBs, LAs and other partners on a local level. Some felt that regional partnership boards taking responsibility for the development and ongoing delivery of joint training of LHB and LA staff involved in delivering CHC would promote closer partnership working. Some considered there needs to be an increased focus, at both a regional and national level, on accurate reporting of the CHC assessment process, eligibility decisions, common health needs, and ‘user’ experiences.

- LAs considered they should be involved in the multi-disciplinary team (MDT) recommendation on eligibility as well as the MDT meeting where the DST is completed. Currently, this recommendation is made separately from any discussions with the individual and/or their representative and submitted to the quality assurance panel for agreement. LAs consider this is necessary for the purposes of ensuring there are no delays due to disputes concerning which body is responsible for funding. They also considered they should have mandatory attendance at all key national CHC meetings.

Welsh Government Response

45. The Welsh Government will discuss the benefits of LA attendance at the MDT recommendation meeting with LAs and LHBs. We agree it would be beneficial for LAs to attend key meetings and groups relating to the provision of CHC. Since the NCCB ceased, its functions have transferred to the NCB whose membership includes LA **representatives. This will** allow both parties to work collaboratively on national approaches, e.g. in relation to joint packages of care and pooled funds. We will also consider LA attendance at CHC Leads meetings.

Greater clarity and presentational style

Question 5:	It was felt that some aspects of the Framework lacked clarity. Have we identified and addressed the right areas in the Framework and improved clarity?

46. There were 39 responses to this question, 10 (26%) agreed there was improved clarity in the Framework and 20 (51%) partly agreed and 9 (23%) disagreed.

Summary of responses

- A majority of respondents were concerned that some areas of the revised Framework still lacked clarity. They suggested amendments either did not go far enough to clarify the issue, or entirely overlooked particular issues. Examples included the purpose of the checklist, when and by who it should be completed and circumstances where the decision could be challenged.

- A number of respondents raised concerns regarding the proposal in the revised Framework that when an LHB does not agree with the recommendation made by the MDT, the LHB should seek further evidence from the MDT. Some considered this revision should be removed and the framework should state recommendations made by the MDT should be accepted by the LHBs unless in exceptional circumstances, as set out in the 2014 Framework.

- A majority of responses considered the revised Framework did not provide further clarity regarding the process to be used by LHBs and LAs where an individual who has received direct payments becomes eligible for CHC. The revised Framework sets out responsibilities of LAs and LHBs to ensure individuals do not lose their voice and control including where they wish to retain the personnel providing their care. However, some suggested best practice guidance on how to achieve this would be useful.

Welsh Government response

47. Although a majority of responses welcomed the additional clarity the revised Framework provided in a number of areas, there remain a few areas where requests for further clarity have been received. The Welsh Government will review these requests and amend the revised Framework where appropriate to achieve this further clarity. Including the proposal in the revised Framework that an LHB may seek further evidence from the MDT.

48. The Welsh Government will work with LHBs, LAs and other agencies as required to explore options to enable people to retain voice and control over their care when transitioning between social care and CHC. A confident, empowered and informed workforce is key to the delivery of integrated health and social care. We will review and address any remaining legislative barriers preventing local health boards and local authorities' use of pooled funds to deliver integrated person-centred health and social care. We will look at the feasibility of introducing independent user trusts in Wales as one mechanism to support individuals to manage their health and social care needs. The clear, unambiguous expectation in Wales must be personalised, seamless integrated health and social care that enables an individual to maintain continuity of their voice and control, including the personnel delivering their care, where the individual wishes this to be the case.

The Assessment Process

Question 6: The following aspects have been considerably revised, do you agree these areas, as they are proposed, are fit for purpose?

- Assessment process,
- Consideration of eligibility
- Use of toolkits, notably the Checklist and the DST

49. There were 48 responses to this question, 10 (21%) agreed these areas, were fit for purpose, 28 (58%) agreed partly and 10 (21%) did not agree these areas, as proposed were fit for purpose.

Summary of responses

50. Generally respondents welcomed the redesigned layout and ordering of the Framework, which now mirrors the CHC process itself from start to finish. Some LHBs supported the re-ordered DST. Some welcomed the requirement that LHBs should inform individuals in writing of their CHC eligibility outcome, including a copy of their DST. Some also suggested that this should be monitored and reported in the CHC audit process. A patient representative group welcomed the inclusion of the underpinning principles as they helped to illustrate the spirit in which practitioners are expected to conduct the CHC process and suggested integrating these throughout the Framework.

51. Those respondents who thought further revision in these areas was required offered the following reasons:

- A number of respondents requested a CHC process flowchart and timescales to be included in the Framework. Some also requested further guidance on the circumstances in which an individual who had a positive checklist assessment would receive support prior to having a full DST assessment.

- Some respondents raised concerns regarding the statement in the revised Framework that MDT members involved in completing a DST should have been involved in the assessment and treatment of the individual, 'where possible'. They considered this should be a compulsory requirement to assure individuals and their families, carers or representatives that the MDT understand, and have accurately assessed, the needs of the individual.

- A variety of respondents raised concerns regarding the revision of the DST, especially in relation to uniformity between Wales and England. Many considered that the proposed changes to the domains and amendments to descriptors in the DST represented significant changes which amounted to the CHC threshold being changed. This could potentially increase the burden on individuals to establish a primary health need. LAs considered these changes could result in a number of care packages that are currently funded by the LHBs or jointly funded between the LHBs and LAs, no longer being eligible for CHC.

- Some LAs and LHBs considered that as the eligibility discussion is a needs led and evidence based process, the heading 'Scoring domains – levels of need' should be amended to say 'assessing levels of need'.

Welsh Government Response

52. The Welsh Government agrees the addition of a CHC process flowchart to the revised Framework would be a useful guidance tool for practitioners. As set out in paragraphs 38, the Welsh Government also intends to provide this in the CHC booklet to be produced for members of the public.

53. In relation to the checklist, the Welsh Government will have further discussions with stakeholders during the implementation period, to ensure the wording in the revised Framework is clear. We will also consider further training on the use of the checklist to ensure it is consistently and fairly implemented across Wales.

54. The Welsh Government considers the framework should still state MDT staff members should have had involvement in the assessment and treatment of the individual 'where possible', but this would only occur in exceptional circumstances to ensure an individual's assessment was not delayed. We will amend the text to reflect this.

55. We note the concerns about changes to the domains and descriptors in the DST. To ensure that the eligibility threshold is not changed, we will retain the current domains in the 2014 Framework and re-consider the wording in the descriptors.

56. The Welsh Government agrees that the reference to the term 'scoring' in the DST, and any other CHC documentation, shall be replaced with 'levels of need' to reflect that the CHC eligibility process is a person-centred needs-based assessment.

Question 7: Do you think that individuals and their families are involved enough in the updated assessment process?

57. There were 43 responses to this question, 14 (33%) agreed that individuals and their families were involved enough in the updated assessment process, 15 (34%) agreed partly and 14 (33%) did not agree.

Summary of responses

58. Those who felt families were not sufficiently involved in this process provided these comments:

- A few patient representative groups stated they were pleased to see the involvement of individuals and their families as a key message in the revised framework. However, they felt this needed to be put into practice consistently

across Wales, with staff undertaking CHC assessments trained to listen to family, friends, carers and advocates who are supporting the person being assessed. They reported individuals and families who describe the assessment meetings held as “scary’” due to the number of people involved, the language used which included professional jargon and acronyms. They also reported a seeming lack of consideration that individuals, carers and advocates may not be familiar with the process and the absence of people with knowledge of the individual or the condition, present in the MDT meeting.

Welsh Government response

59. The Welsh Government wants to ensure all assessments for CHC fully involve the individual, their family, carers or their representatives and are conducted in the spirit set out in the underpinning principles of the Framework. We consider the appropriate guidelines for this are already set out in the revised Framework but further work is required to ensure these guidelines are implemented in a consistent manner across health boards. We agree improved communication between the individual or their representative and the MDT team along with awareness training for MDT staff is essential to ensure the individual receives a person-centred CHC assessment. Where an LA recognises an individual or their family requires advocacy and support, the LA must arrange for an Independent Professional Advocate to assist the individual to participate fully in all assessments and processes.

60. Our introduction of a new CHC booklet for members of the public (outlined in paragraph 38 to 39) will help. This will provide individuals and their families, carers and representatives with information on what to expect, timescales, rights and how to access advocacy, information, advice and assistance services.

Links to wider policy areas

Question 8: In your view, does the revised Framework link well with other health and social services policy and guidance? If you have answered partly or no can you tell us what feel is missing and what you recommend we add?

61. There were 44 responses to this question, 15 (34%) agreed the proposed Framework linked well with other health and social services policy and guidance, 18 (41%) agreed partly and 11 (25%) did not agree.

Summary of responses

62. The following information was provided from respondents who thought there should be stronger or additional links to policies and guidance:

- Some comments asked how the revised Framework aligned with policies such as the Welsh Government's Code of Practice on the Delivery of Autism Services, the Additional Learning Needs and Education Tribunal Act and Loneliness and Isolation. Some also commented that although the revised Framework linked with the ideals in the National Dementia Action Plan, implementation would be key. It was highlighted that the revised Framework should specifically mention that where appropriate, assessments are coordinated in line with other assessments and reviews being undertaken for the individual. This will ensure the Framework is in line with guidance to public bodies outlined in other policies and that all agencies and professionals are engaged.

- Other comments included disappointment that the Framework places a heavy emphasis on Health as a medical intervention and fails to recognise the cross over and the importance of social model themes within current various legislation, such as the National Outcomes Framework.

- A number of respondents commented that although revisions had been made to the revised Framework regarding the transition from CYP CHC to Adult CHC, concerns remained that the transition process did not adequately support young people in regard to issues such as clear guidance on the process of identifying young individuals with potential CHC triggers and timescales. Some requested assurances that both sets of guidance are considered jointly to ensure efficient cooperation between children and adult continuing healthcare, some thought there should be an equitable system of support based on need, and not age.

Welsh Government response

63. Our continued work with policy areas across Welsh Goverment is an essential part of our development and delivery of the CHC policy and National Framework. The Dementia Oversight Implementation and Impact Group oversees the implementation of the Dementia Action Plan and brings together the stakeholders who will be key in ensuring effective implementation. The forthcoming autism code of practice will make reference to the CHC policy and framework as it applies to autistic people. We will give further consideration as to how other policies and frameworks align with the Framework and whether these need to be specifically referenced in the Framework.

64. The transition from CYP CHC to adult CHC can be a stressful time for families which is why it is important for LAs and LHBs to talk to families about possible implications at the start of the transition planning process. We have included additional information in the revised Framework which sets out this process which will be assessed via the Performance Framework to ensure consistent

implementation. The CCISS website contains a comprehensive Transition Pack for young people moving into adulthood which includes a guide for young people, parents, video stories, transition plans in various formats and also includes a multi-agency Transition Protocol for Young People with Disabilities and Additional Learning Needs. We will work with LHBs, LAs and patient representative groups to review these materials to ensure young people and their parents, carers or representatives are fully aware of the CHC transition process.

Disputes and Appeals

Question 9: Is the proposed two-stage process for retrospective reviews appropriate and sufficiently comprehensive?

65. There were 43 responses to this question. 24 (56%) agreed the proposed two-stage process for retrospective reviews appropriate and sufficiently comprehensive, 9 (21%) agreed partly and 10 (23%) did not agree.

Summary of response

66. A majority of respondents agreed that the proposed two-stage process for retrospective reviews appropriate and sufficiently comprehensive. Many added the process is clear and will prove effective in efficiently managing retrospective claims in a timely and comprehensive manner, while maintaining fairness.

67. Those respondents who didn't agree provided the following information:

- Some respondents considered further clarification was required regarding the rolling cut-off of 12 months, e.g. could individuals make several applications covering different 12-month periods dating back to 1 October 2014, or would claims only cover the 12 months immediately preceding the application date?

- Some expressed concerns about the introduction of a 28 day appeal period following notification an individual's eligibility to receive CHC. Some welcomed the introduction as it provides a consistent timeframe across LHBs but considered 28 days was insufficient time for the individual or their representative to process the information, seek guidance and advice and develop a case outlining their eligibility for funding. It was suggested that 6 months would be more appropriate. One LA highlighted that an individual who wanted to appeal an eligibility decision from a local authority, had up to 12 months to do so under the Social Services (Complaints) (Wales) Regulations 2014.

- A number of LHBs considered the 3 month period for providers to submit records was too long in the overall 6 month period to complete a review, and requested template letters and protocols to be provided on the CCISS website to assist in this process.

Welsh Government response

68. The Welsh Government will work with the LHBs and LAs regarding requests to clarify wording in the disputes and appeals sections of the revised Framework. We agree with comments received about the proposed 28 day appeal period. We want to make it clear in the Framework that the timescale of 28 days is simply for an individual to inform the LHB that they are appealing the LHBs decision.

69. We note the current Department of Health Guidance for Strategic Health Authorities and Primary Care Trusts on the time limits for individuals to request a CHC review of their eligibility decision is no later than 6 months from the date they received their eligibility decision. In light of these considerations we will work with stakeholders to determine the most appropriate timescale to submit an appeal (potentially either 6 months or 12 months). We do not propose these timeframes are applied retrospectively - they will apply only to eligibility decisions notified after the date of introduction of the revised Framework. We will also ensure protocols and template letters relating to the appeals process will be included on the on CCISS website, accessible to all practitioners, to ensure a consistent expedient appeals process is implemented.

Welsh language

70. We would like to know your views on the effects of the revised Framework on Welsh language, specifically on opportunities for people to use Welsh and on treating the Welsh language no less favourably than English.

Question 10: What effects do you think there would be? How positive effects could be increased, or negative effects be mitigated?

- A majority of comments agreed the revised Framework should be as inclusive as possible, including being available in Welsh. One LHB welcomed the reference to the Welsh language in the documentation but requested references to Welsh language should be embedded throughout the Framework. One example was a reminder in the MDT section, to give members of the public that speak Welsh, especially the elderly, or those suffering from dementia, or those who are autistic, the opportunity to speak freely in the a language they feel more comfortable using.

- Some patient representative groups commented that when a bilingual person has a diagnosis of dementia, it is often proficiency in a second language that is lost first. It is therefore essential to ensure people living with dementia are able to access services in the language of their choice. Other comments stated the Welsh language provision stops short of the expectations within ‘More than Just Words’ and specifically short of the ‘Active Offer’, which is to provide a service in Welsh without someone having to ask for it. The Welsh language should be as visible as the English language.

- Comments from some LHBs confirm they have introduced an active offer to their processes. Other LHBs state sourcing Welsh speakers to attend assessment meetings could cause delays for individuals to receive their assessment, but every effort would be made to access staff who could accommodate this if required.

- The Welsh Language Commissioner commented it would be beneficial to incorporate the Welsh Language Standards further in the revised Framework. This could include requirements to plan CHC services in Welsh as well as plan and develop the workforce in order to provide those services.

Welsh Government response

71. The Welsh Government agrees with the importance of meeting people’s health needs in their language of choice, this is key for groups such as dementia sufferers and is therefore factored into the Dementia Action Plan.

72. We will confirm in the framework that both the checklist and CHC eligibility assessment should lead with an active offer to meet the expectations of ‘More than Just Words’.

73. The Welsh Government would not expect a request for assessment in Welsh to delay an individual’s CHC eligibility as there are specific Standards which require both LAs and LHBs to develop the Welsh language skills of their workforce through planning and training. We will strengthen the wording in the revised Framework to include the requirements of the Welsh Language Standards and ‘More than Just Words’, including the active offer. It is our intention that all publications intended for members of the public will be available in easy read and bilingual.

RELATED ISSUES

Question 11: We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, please use this space to report them:

74. A majority of the comments received to this question related to the implementation of the Framework which has been addressed in question 1. There were also a number of suggestions made on the text of the revised Framework which the Welsh Government will consider as part of the consultation exercise.

Next Steps

75. We will work in partnership with LAs and LHBs to develop a comprehensive training package to support the effective, consistent and equitable implementation of the revised Framework and we will overhaul the CCISS website to ensure its materials are fit for purpose. We will also work with patient representative groups and members of the public to co-produce a CHC public information booklet. This publication, which will set out an individual's journey through the CHC process, as detailed at paragraphs 38 to 39, will be published in April 2020 to coincide with the publication of the revised Framework.

76. The Welsh Government recognises there is a need to review FNC policy and we will work with stakeholders to do this in 2020 with the intention of holding a consultation on a new FNC Framework in 2021.

77. We will work with relevant stakeholders in the coming months to explore options to ensure an individual transitioning from direct payments to CHC can exercise voice and control to decide how, when and who supports them to meet their eligible care and support needs. We will look at the feasibility of introducing independent user trusts in Wales as one mechanism to support individuals to manage their health and social care needs.

ANNEX 1

GLOSSARY OF TERMS

Active Offer Providing a service in Welsh without someone having to ask for it. The Welsh language should be as visible as the English language.
Advocacy The act of speaking on the behalf of or in support of another person, place, or thing.
Carer The Social Services and Well-being (Wales) Act 2014 defines a carer as a person who provides or intends to provide care for an adult or disabled child. The definition excludes those who provide or intend to provide care under, or by virtue of, a contract or as voluntary work.
Checklist The Checklist is a CHC screening tool to help practitioners identify individuals who may need a full assessment of eligibility for CHC.
Children and Young People's Continuing Care Guidance The Guidance is designed for use by all those planning and providing children's continuing care services in LHBs and LAs.
Continuing Healthcare (CHC) A package of care arranged and funded solely by the NHS to meet physical and/or mental health needs that have arisen because of disability, accident or illness. It can be provided in any setting including, but not limited to, a care home, a hospice or your own home.
Complex Care Information & Support site www.CCISS.org.uk This is a web-based resource hosted by Welsh Government to support implementation of this Framework.
Decision Support Tool (DST) A tool designed to support the decision-making process. It is not an assessment in itself and it does not replace professional judgement in determining eligibility. It is simply a means of recording the rationale and facilitating logical and consistent decision-making.
Domain One of 12 key areas of consideration within the integrated assessment and the Decision Support Tool. These are breathing, nutrition, continence skin integrity, mobility, communication, psychological & emotional needs, cognition, behaviour, drug therapies and medication, altered states of consciousness and other significant care needs.
Funded Nursing Care (FNC) Funded Nursing Care applies to all those persons currently assessed as requiring care by a registered nurse in a care home.
Multi-disciplinary Team (MDT) This refers to a team of professionals across health and social care and the third sector who work together to address the holistic needs of their patients/clients in order to improve delivery of care and reduce fragmentation. As a minimum requirement an MDT can comprise two professionals from different healthcare professions, the MDT should include both health and social care professionals (unless there are exceptional circumstances), who are knowledgeable about the individual's health and social care needs and, where possible, have recently been involved in the assessment, treatment or care of the individual.

Independent User Trusts This is where the patient or relative of a patient sets up a trust which becomes the provider of care for the individual. The LHB then contracts with the trust to provide specified health care services for the individual.
Pooled Budgets Pooled budgets are when two or more organisations pool their resources into one shared budget. Regulations under Part 9 of the Social Services and Well-being (Wales) Act 2014 require LHBs and LAs to maintain pooled budgets in relation to care home places for older people. They also require regional partnership boards to promote pooled budgets and to consider the use of pooled budgets for anything they do jointly.
Practitioner All local authority or local health board member of staff involved in an individual's assessment or delivery of CHC.
Primary Health Need An individual is deemed to be eligible for CHC when their primary need is a health need: 'the primary health need approach'. This is determined by consideration of the four key characteristics of need: nature, intensity, complexity and unpredictability.
Retrospective NHS CHC claims Where someone has paid for care in the past, but believes that they should have been eligible for CHC.
Section 117 Under Section 117 of the Mental Health Act 1983, health and social services authorities have a duty to provide or arrange after care services for individuals who have been detained under certain provisions of the 1983 Act, until they are satisfied that the person is no longer in need of such services.
Social Care Social care is care provided to support an individual's social needs. It refers to the wide range of services designed to support people to maintain their independence, enable them to play a fuller part in society, protect them in vulnerable situations and manage complex relationships.
Social Care Services For people who need help/assistance to live their lives as independently as possible in the community (either at home or in a care setting), people who are vulnerable and people who may need protection. Local authorities, the voluntary sector and the independent sector can provide social care.
Social Services and Wellbeing (Wales) Act 2014 The Social Services and Well-being (Wales) Act came into force on 6 April 2016. It provides the legal framework for improving the well-being of people who need care and support, and carers who need support, and for transforming social services in Wales. It transforms the way social services are delivered, promoting people's independence to give them stronger voice and control.