Yr Adran Iechyd a Gwasanaethau Cymdeithasol
Cyfarwyddwr Cyffredinol a Prif Weithredwr, GIG Cymru

Department for Health and Social Services
Director General and Chief Executive, NHS Wales

Llywodraeth Cymru
Welsh Government

Darren Millar AM
Chair of the Public Accounts Committee
National Assembly for Wales.

Our Ref: AG/LC/TLT

13 February 2015

Dear Darren

Implementation of the Framework for Continuing NHS Healthcare in Wales

I write in response to the queries raised by the members of the Public Accounts Committee on 3rd February 2015. The Clerk of the Committee has set these out as follows and I will address them in turn:

1. Clarify what proportion of the 20 cases from two health boards contained in the sample audit were learning disability or dementia cases and share the outcomes of the review of those cases;
2. Confirm which health board withdrew its involvement in testing the DST;
3. Provide a note on the difficulties Betsi Cadwaladr have had in recruiting to professional roles and confirm whether they're now at full strength; and
4. Provide a note about the size of the tender within each health board with regards to the advocacy services for continuing healthcare.

1. <u>Proportion of Learning Disability and Dementia Cases in the DST pilot and sample audit.</u>

   The proportions of cases are set out in the Table below. The report of the findings of the pilot and.

	Older People (mental health)	Learning Disability
Pilot	20	3
Audit	9	7
Total	**29**	**10**

The ten cases reviewed in each of the health boards who participated in the pilot (i.e. 20 cases in total) related to individuals with dementia.
Their needs were assessed against the 2010 Welsh DST and the proposed DST as issued by the Department of Health in England. In all 20 cases there was no difference in the outcome for CHC eligibility.

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One of the health boards went on to voluntarily test a further 3 cases relating to individuals with a learning disability. Of these 3, one individual which would have been determined as not eligible for CHC using the Welsh tool was found to be eligible using the Department of Health tool.

The report of the pilot study is attached as **Annexe 1**.

The Sample Audit examined 7 recent cases and 3 retrospective claims in each of the seven health boards. Of the 42 recent cases examined, nine related to individuals with dementia. The reviewers agreed that, in taking the totality of need into consideration, the eligibility outcomes for those individuals were appropriate and reflected the evidence in the assessments.

Seven of the 42 cases related to individuals with a learning disability. The reviewers agreed that, in at least two of those seven learning disability cases, the assessed need should have led to an outcome of eligibility for CHC.

The summary of the DST consistency check for the sample audit is attached as **Annexe 2**.

The findings of these small studies indicate to Welsh Government that ongoing monitoring is needed to ensure equity for older people with mental health needs (e.g. dementia) and that closer examination is required of jointly funded cases for individuals with a learning disability. We are currently working with the Local Health Boards to undertake that exercise.

2. <u>The Health Board that withdrew from the pilot study</u>

The Health Boards were approached to volunteer to test the use of the Department of Health DST during the consultation period for the new Framework.
The three health boards that volunteered were:

- Cardiff & Vale UHB;
- Hywel Dda UHB; and
- Betsi Cadwaladr UHB.

The Older People's Mental Health team from Betsi Cadwaladr University Health Board later withdrew from the formal pilot study due to capacity issues. It did discuss the proposed change and forwarded a response in favour of the adoption of the new DST, but was unable to provide data for the study itself.

3. <u>Recruitment in Betsi Cadwaladr University Health Board (UHB)</u>

The UHB has outlined its current staff resource available for CHC as follows:

Corporate	General	Older People's Mental Health	Mental Health and Learning Disability
Band 8=1 wte Band 7=1 wte Band 3= 1wte	Band 8= 2WTE Band 7= 6 WTE Band 6= 9 WTE Band 4= 1WTE Band 3= 3 WTE	Band 8= 2 WTE Band 6 = 8 WTE Band 4 = 1 WTE Band 3= 2 WTE Band 2 = 1 WTE	Band 8= 1 WTE Band 7= 2 WTE Band 6= 5 WTE Band 3= 1 WTE

Bands 6 to 8 are experienced nurses, Bands 2 to 4 are administrative posts.
The UHB reports that they appointed 4 new nurse assessors in 2014 but took the view that work on retrospective claims was best progressed using the well-established skills of the team in Powys.

The UHB is currently in the process of reviewing its approach to managing CHC across the Health Board. This will involve a re-assessment of staffing levels to manage prospective caseload and to ensure that any challenges relating to the new framework are managed in good time so as to avoid the build up of another backlog. They anticipate this work being completed by June 2015.

The UHB is confident that their revised approach will allow them to address the current backlog and ensure that cases are managed in a timely fashion going forward. The performance of all health boards will continue to be monitored by Welsh Government.

4. Health Board resource for advocacy for CHC

The current arrangements for the provision of advocacy by each health board are summarised below. The focus at present is on the provision of statutory advocacy for individuals who lack mental capacity.
Welsh Government is aware that further work is required with the Health Boards to ensure that they implement the requirements of the 2014 Framework.

Health Board	Current Arrangements
Abertawe Bro Morgannwg	Existing Service Level Agreement (SLA) with Age Cymru renewed for 2015/16. Reviewing advocacy provision on a regional basis (Western Bay) as part of the Quality Framework to be published in March 2015.
Aneurin Bevan	Contract with Advocacy Support Cymru to provide Independent Mental Health Advocacy up to March 2017 @ £348,893 per annum. Maintain register of third sector advocacy services in Gwent and signpost individuals.
Betsi Cadwaladr	Contract with IMCA provider @ £135,000 per annum. Contract with IMHA provider @ £421.00 per annum Signposts to Age Cymru/Age Concern for non-statutory advocacy. Intend to work with local authority partners in 2015 to scope advocacy requirements.
Cardiff & Vale	CHC advocacy not tendered for separately. Use existing SLA with Age Connects and IMHA/IMCA services.
Cwm Taf	CHC advocacy not tendered for separately. Use existing SLA with Age Cymru and IMHA/IMCA services.
Hywel Dda	Contract for Mental Health Matters Wales for individuals who lack mental capacity only. £82,000 per annum.
Powys	CHC advocacy not tendered for separately. Use existing SLA with Powys Community Health Council. Prioritise people who do not have mental capacity or are ‘un-befriended’.

As I stated in my evidence to the Public Accounts Committee, this is a complex and growing area of service delivery for NHS Wales. I reaffirm my commitment to securing service improvement and will be happy to provide the Committee with updates on progress going forward.

Yours sincerely,

Dr Andrew Goodall

Annexe 1

Review of the Framework for the Implementation of Continuing NHS Healthcare in Wales 2014

Proposal to adopt the Department of Health (English) Decision Support Tool Report on the Impact Evaluation Exercise

Background and Context

In June 2013 the Wales Audit Office (WAO) published its report on the Implementation of the National Framework for Continuing NHS Healthcare. At the same time Welsh Government began actively engaging with stakeholders to undertake a review of the 2010 Framework, using the WAO report findings as its basis.

In total, 12 Task & Finish Groups were established to address the key themes highlighted. Membership was predominantly drawn from health and social care practitioners and managers, with some representation from the third and independent sectors.

In the course of the work undertaken during summer 2013, a number of groups referred to the Decision Support Tool (DST) produced by the Department of Health in England as being more user-friendly than the version currently used in Wales. It was suggested that adopting the English version would facilitate more efficient cross-border working and could address perceived anomalies in the application of the eligibility criteria to people with cognitive impairment (e.g. through a learning disability or dementia).

These proposals were tested informally across the Task & Finish groups, with the national CHC Advisory Group and at a national 'Tester Workshop' in September 2013.

The consensus that the English DST was an improvement on the current Welsh version was such that Welsh Government submitted the proposal as part of its consultation exercise on the draft 2014 Framework.

In its December 2013 report the National Assembly for Wales Public Accounts Committee welcomed the proposal but recommended that the Welsh Government assess the impact of amending the decision support tool upon those people scored under the previous decision support tool.

The formal consultation on the draft 2014 Framework closed on 13th March 2014. Early analysis indicates overwhelming support for the adoption of the English DST, with caveats regarding the avoidance of a 'tick box approach' to determining eligibility.

This paper describes the exercise undertaken to test any potential impact of the use of the English DST on the eligibility outcome for those previously assessed using the current Welsh version.

Purpose of a Decision Support Tool.

Continuing NHS Healthcare is defined as a package of care arranged and funded solely by the NHS, where it has been assessed that the individual's primary need is a health need.

The determination of whether an individual's primary need is a health need is based on the following characteristics and their impact on the care required to1 manage them:

• **Nature**: This describes the particular characteristics of an individual's needs (which can include physical, mental health or psychological needs) and the type of those needs. This also describes the overall effect of those needs on the individual, including the type ('quality') of interventions required to manage them.

• **Intensity**: This relates both to the extent ('quantity') and severity ('degree') of the needs and to the support required to meet them, including the need for sustained/ongoing care ('continuity').

• **Complexity**: This is concerned with how the needs present and interact to increase the skill required to monitor the symptoms, treat the condition(s) and/ or manage the care. This may arise with a single condition, or it could include the presence of multiple conditions or the interaction between two or more conditions. It may also include situations where an individual's response to their own condition has an impact on their overall needs, such as where a physical health need results in the individual developing a mental health need.

• **Unpredictability**: This describes the degree to which needs fluctuate and thereby create challenges in managing them. It also relates to the level of risk to the person's health if adequate and timely care is not provided. Someone with an unpredictable healthcare need is likely to have either a fluctuating, unstable or rapidly deteriorating condition.

In determining whether an individual has a primary health need multidisciplinary teams must, following comprehensive assessment, consider the totality of the person's overall needs and the interaction between them.

This decision-making process can be complex and emotive. The purpose of the DST is to provide a mechanism that gives confidence that a rational and evidence-based decision has been made. It does not replace robust assessment or professional judgement.

Differences between the English and Welsh DSTs

Members of the Task & Finish Group examining the application of the Framework to people with dementia worked through the domains of both DSTs and identified the following differences:

Behaviour: the domain in the English DST makes reference to a risk to property as well as self or others. The group felt that this would be a positive addition.

Cognition: the English DST introduces a 'severe' level of need and adds emphasis to the words "could" and may" in the high and severe categories. Reference to short term memory is deleted from 'low needs' box.

Psychological/Emotional: Referred to as 'Mental Health (Psychological and Emotional needs)' in the current Welsh version. The English DST removes the 'severe' level of need and makes reference to psychological and emotional state in moderate and high boxes. The previous severe level of risk in relation to mental health (e.g. risk of suicide) is now sits within the Behaviour domain.

Communication: No difference between English and Welsh DSTs.

Mobility: Extra "OR", moderate risk of falls added in moderate box in the English version.

Nutrition: No significant change, although the description in the English version is less 'wordy'.

Continence: The English version removes the 'severe' level of need and reference to constipation in the 'low need' box. Helpful examples are given in 'high need' box.

Skin: No significant change, although the description in the English version is less 'wordy'.

Breathing: - The English version does not specify frequent chest infections or pneumonia in the 'High' level of need. There is an additional "OR" in the 'severe need' box.

Drug Therapies – The English DST makes additional reference to the role of a registered nurse, carer or care worker in 'moderate need' box. Having a physical or mental state or cognition impairment requiring support to take medication has been removed from the 'low need' box. Also the reference to liquid medication has been deleted from the 'moderate need' box.

Altered States of Consciousness – The English version makes reference to "monthly or less frequently" in moderate box, which is felt to be an improvement on the previous 'occasional'.

Whilst the English version of the DST has been welcomed as being more user-friendly, questions have been raised from a number of stakeholder perspectives, namely:

> Does the difference in DSTs mean that people assessed under the 2010 Framework in Wales, NB those with a cognitive impairment, have been disadvantaged compared with those in England?

Informal discussion with practitioners in Bristol (via the Clinical Commissioning Group) and officials at the Department of Health has indicated that, as long as Welsh practitioners have made robust decisions based on the totality of need, the adoption of the updated English DST should make little or no difference to the outcomes.

Groups representing the user groups most likely to be affected e.g. Alzheimer's Society, argue however, that the process in Wales has become 'too tick-box focussed' and therefore there cannot be confidence that robust decisions based on totality of need have indeed been consistently made.

The full impact of the change will need to be carefully monitored via the performance framework. The purpose of the exercise described below was to 'double-run' the two versions of the DST during February 2014 and assess whether the outcomes would be different.

Methodology

The methodology for the evaluation was developed with the Dementia Task & Finish Group, which included academic input from Cardiff University. As this was a service development/evaluation exercise, ethical approval was not required.

A pragmatic approach was adopted in order to balance the needs of the evaluation against the potential impact of additional workload on already stretched multi-disciplinary teams.

Three Local Health Boards initially volunteered to take part in the exercise but one later withdrew as it did not have the capacity to participate.

Hywel Dda University Health Board and Cardiff and Vale University Health Board agreed to:

- Undertake the exercise on a minimum of 10 cases during February 2014;
- Complete their usual assessment and decision making process using the Welsh DST.
- In addition apply the matrix from the English DST.
- Record the result on a standard template which asked the following questions:
    1. Was the outcome (eligibility decision) different when the new matrix was applied?
    2. If so, what was the difference? Which domains were affected and why?
    3. Are there any practical issues in applying the new tool that we need to consider?

The Task & Finish group was reconvened on 14th March 2014 to consider the results.

Findings

- **Hywel Dda University Health Board.**

  Question 1: Was the outcome different?

  The team compared 10 cases categorised as 'Elderly Frail' and/or 'EMI' (Elderly Mentally Infirm).

  In all of these cases the eligibility outcome was the same using both DSTs. Although the content and scoring in some domains was different, the assessment of the presence of a primary health need remained the same.

  In addition to the ten Frail/EMI cases, the Hywel Dda team tested the DSTs with 3 cases involving individuals with a learning disability (LD). Of the three cases, two decisions on eligibility were the same. One case that was not eligible using the Welsh DST would have been eligible using the English version.

  Question 2: What was the difference?

  For both client groups, the scoring was often higher in the Behaviour and Cognition domains (in 6 of the 10 Frail/EMI clients and in 2 of the three Learning Disability cases).

  For the LD cases, the team felt that there was some overlap with the Psychological and Emotional Needs and the Behaviour domains NB re 'severe fluctuations in mental state'.

  In the light of a recent article, the team had applied Emerson's definition of challenging behaviour and this may also have impacted on the scoring.
  "culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities" (Emerson, 1995)[1]

  There was considerable debate regarding the scoring of cognition for people with a learning disability and this is detailed later in this report.

  Drug Therapies and Medication: 'Risk of non concordance with medication, placing them at risk of relapse' has moved from high to severe level of need, which the team felt could be an issue in relation to anticonvulsant therapy (significant numbers of people with LD take anticonvulsants).

  In addition it was noted that issues of non-compliance score as 'severe need' in the English DST and the team felt this would impact on many individuals with LD.

  Altered States of Consciousness: 'Occasional ASCs that require skilled intervention to reduce the risk of harm' moves from moderate to high level of need which could impact on LD clients with epilepsy.

[1] Emerson, E. (1995) *Challenging Behaviour. Analysis and Intervention in People with Learning Difficulties*. Cambridge: Cambridge University Press

Question 3: Are there any practical issues in applying the new tool that we need to consider?

7 out of the 10 comparisons made identified that the new tool was less onerous or repetitive, and that completing the narrative was easier. When reading the completed DSTs as a panel, they were perceived as flowing well, made for easier reading and gave a good picture of the patients in question.

3 out of the 10 completed felt that they still required the prompts to complete and to ensure that all the information is inserted. However, managers felt it fair to point out that these 3 all dealt with areas in which there was a shortage of supporting evidence, i.e. robust care plans, risk assessments and assessments on the whole and that the teams tended to use the DST as an assessment rather than the purpose for which it is intended. This will need to be addressed in training and in the monitoring of implementation.

- **Cardiff & Vale University Health Board**

Question 1: Was the outcome different?
All of the recommendations regarding CHC eligibility were unchanged by the application of the English DST.

Question 2: What was the difference?
Reflecting on the exercise, the team involved felt that:

  - The introduction of a 'severe' level of need within Domain 2 - Cognition could strengthen the recommendation of CHC eligibility for many patients.

  - The description of frequent conditions (e.g. chest infections, pneumonia, etc) in the 'High' level of Domain 9 Breathing has previously proved useful yet has been omitted (although we accept that this is covered within the "breathlessness due to a condition which is not responding to treatment ... " it is not as descriptive and the MDT sometimes require it to be). This could be addressed within the 'crib notes' section in the Toolkit.

  - The introduction of moderate risk of falls added in the moderate level of need for Domain 5 Mobility is useful. The MDT often perceives any falls history to indicate a high level of need.

Discussion re the scoring of cognition for individuals with a learning disability.

Members of Task & Finish Group reported that in some Health Boards the Multi-Disciplinary Teams (MDTs) routinely omit to give any score for Cognition in the DST ('no needs'), arguing that cognitive impairment is 'a given' in individuals with a learning disability.

The ensuing debate highlighted the importance of avoiding the tick box approach and using rounded, evidence-based professional judgement, referencing the four characteristics of a primary health need.

It was concluded that the following will need to be included in the Toolkit and the training to ensure that a consistent approach is adopted:

1. As already detailed in Welsh Government Guidance and the current DST, managed need is still a need. The cognitive impairment present in an individual with LD can impact on the complexity and risk in their presentation as whole, and needs to be considered in this context.

2. It is acknowledged that when considering CHC eligibility, it is however often a change in cognitive function that can 'tip the balance'. The updated guidance emphasises the need to understand and evidence change in need. In completing the DST the MDT also needs to consider the impact of cognition on other domains (this is already clearly stated in the current Welsh DST and repeated in the English version).

Conclusion

The sample size of the evaluation was smaller than anticipated and the findings do not replace the need for the ongoing monitoring of implementation from an equalities perspective.

It does provide some assurance to Welsh Government that it does not appear likely that significant numbers of people with a dementia have been disadvantaged by the application of the Welsh DST issued with the 2010 Framework.

The exercise has raised some query regarding the application of the DST to individuals with a learning disability, and this requires further exploration with the relevant expert groups.

Comparison Table: DST Scores and Outcomes							
Case 1 (General)		**Case 2 (LD Transition)**		**Case 3 (LD)**		**Case 4**	
Domain Scores	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**
Low x 9 No Needs x 3	FNC	High x 1 Moderate x 2 Low x 4 No Needs x 4	Continue Joint Package	High x 1 Moderate x 1 Low x 4 No Needs x 5 (Reviewers did not agree with these low scores and would have found eligibility)	Continue Joint Package	High x 1 Moderate x 5 Low x 2 No Needs x 5	Not Eligible
Case 5		**Case 6 (General)**		**Case 7 (General)**		**Case 8 (LD/MH)**	
Domain Scores	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**
High x 1 Moderate x 3 Low x 6 No Needs x 1	Eligible (on totality of need)	High x 2 Moderate x 4 Low x 3 No Needs x 2	FNC	High x 2 Moderate x 3 Low x 4 No Needs x 3	FNC	High x 2 Moderate x 3 Low x 4 No Needs x 3	Additional NHS input into Joint Package
Case 9 (LD)		**Case 10 (OPMH)**		**Case 11 (General)**		**Case 12 (LD)**	
Domain Scores	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**
High x 2 Moderate x 1 Low x 3 No Needs x 5	Continue Joint Package	High x 2 Moderate x 3 Low x 3 No Needs x 4	FNC	High x 3 Moderate x 2 Low x 3 No Needs x 2	Eligible	High x 3 Moderate x 2 Low x 2 No Needs x 4 (Reviewers did not agree with these low scores and would have found eligibility)	Continue Joint Package

Comparison Table: DST Scores and Outcomes							
Case 13 (General)		**Case 14 (OPMH)**		**Case 15 (General)**		**Case 16 (General)**	
Domain Scores	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**
High x 3 Moderate x 3 Low x 2 No Needs x 4	Eligible	High x 3 Moderate x 4 Low x 4 No Needs x 1	FNC	High x 4 Moderate x 4 Low x 1 No Needs x 2	Eligible	High x 4 Moderate x 2 Low x 4 No Needs x 4	Eligible
Case 17		**Case 18**		**Case 19 (General)**		**Case 20 (General)**	
Domain Scores	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**
High x 4 Moderate x 5 Low x 1 No Needs x 1	Eligible	High x 4 Moderate x 5 Low x 1 No Needs x 1	Eligible	High x 5 Moderate x 5 Low x 1 No Needs x 1	Eligible	High x 5 Moderate x 3 Low x 1 No Needs x 3	Eligible
Case 21 (General)		**Case 22**		**Case 23 (OPMH)**		**Case 24 (LD)**	
Domain Scores	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**
High x 5 Moderate x 2 No Needs x 4	Eligible	High x 5 Moderate x 2 Low x 1	Eligible	High x 5 Moderate x 4 Low x 1 No Needs x 2	Eligible	High x 5 Moderate x 4 Low x 1 No Needs x 1	Continue Joint Package
Case 25 (MH)		**Case 26 (OPMH)**		**Case 27 (LD)**		**Case 28 (Gen + Dementia)**	
Domain Scores	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**
High x 6 Moderate x 1 Low x 1 No Needs x 5	Eligible	High x 6 Moderate x 2 Low x 1 No Needs x 2	Eligible	High x 6 Moderate x 4 Low x 1	Eligible	High x 6 Moderate x 3 Low x 2 No Needs x 2	Eligible

Comparison Table: DST Scores and Outcomes							
Case 29 (OPMH)		**Case 30 (OPMH)**		**Case 31**		**Case 32 (OPMH)**	
Domain Scores	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**
High x 6 Moderate x 2 Low x 2 No Needs x 2	Eligible	High x 6 Moderate x 3 No Needs x 3	Eligible	High x 6 Moderate x 3 No Needs x 2	Eligible	High x 7 Moderate x 2 Low x 2 No Needs x 2	Eligible
Case 33		**Case 34 (General)**		**Case 35 (OPMH)**		**Case 36 (MH)**	
Domain Scores	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**
High x 7 Moderate x 2 Low x 1 No Needs x 1	Eligible	Severe x 1 High x 3 Moderate x 1 Low x 2 No Needs x 5	Eligible	Severe x 1 High x 3 Moderate x 4 Low x 1 No Needs x 3	Eligible	Severe x 2 High x 2 Low x 2 No Needs x 6	Eligible
Case 37		**Case 38**		**Case 39**		**Case 40**	
Domain Scores	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**	**Domain Scores**	**Outcome**
Priority x 2 Severe x 1 High x 3 Low x 1 No Needs x 5	Eligible	No DST completed as Section 117	Eligible	No DST completed as Fast Track end of life care	Eligible	No DST completed for annual review in care home.	FNC

Reviewers omitted to record the DST scores in two cases.