

Dementia Task Group Report

Report of the County Solicitor

Please note that the following recommendations are subject to consideration and determination by the Committee before taking effect.

Recommendation(s)

To agree the recommendations 1-5 set out in paragraphs 20-24 at the end of this report.

Background

1. In January 2012, the Health & Wellbeing Scrutiny Committee agreed to convene a task group to review the progress against the recommendations of the older people mental health task group (August 2009-March 2010). The group had reviewed dementia services across Devon.

2. In consultation with Cllr Vanessa Newcombe, Chairman of the People's Scrutiny Committee, the view was taken to establish a joint task group between the two committees and Councillors Fry, Newcombe, Sanders, Spence and Westlake (chairman) served on it. The group decided to change its name from older people mental health to dementia task group.

Terms of Reference

3. The original task group report can be accessed on the Council's website at www.devon.gov.uk/devon_county_council_-_opmh_task_group_report.pdf. This task group set itself the following term of reference:

- a) To review the implementations of the recommendations made by the older people mental health task group in March 2010 and to review any relevant new developments.
- b) To identify current service provision, standards, performance and areas of concern.
- c) To identify desired service provision, standards and performance.
- d) To identify and consider in detail any anticipated issues or problems.
- e) To identify and recommend to Devon County Council's Cabinet and/or relevant external organisations suggestions for service developments and/or improvements.

Evidence reviewed

4. The task group received oral evidence from:

- GP Dementia Lead for NHS Devon and the South West Dementia Partnership, NHS South of England
- Joint Strategic Commissioning Manager, Older People Mental Health Services, Devon County Council/NHS Devon
- Joint Commissioning Manager, Older People, Devon County Council/NHS Devon
- Head of Social Care Commissioning, Devon County Council
- Director of Strategic Commissioning, NHS Devon
- Assistant Director Strategic Development, NHS Devon
- Consultant Psychiatrist Older People Mental Health & Co-Medical Director, Devon Partnership NHS Trust
- Managing Partner, Older People Mental Health Services, Devon Partnership NHS Trust

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5. Written evidence:

- Briefings “Dementia in Devon” and “The Dementia Challenge in Devon” (May 2012)
- Devon County Council/NHS Devon: *Older people mental health services recommendations update*. Briefing considered by the Devon scrutiny chairs and vice chairs on 14 March 2012
- Peer reviews by the South West Dementia Partnership relating to memory services as well as the Royal Devon & Exeter NHS Foundation Trust and the Northern Devon Healthcare NHS Trust
- Innovations in Dementia: *Dementia Capable Communities. The views of people with dementia and their supporters*. Exeter: February 2011
- South West Dementia Partnership: *An evaluation of dementia support worker roles*. November 2011
- Draft pathways (Map of Medicine) for dementia management and dementia assessment in primary and secondary care
- Centre for Public Scrutiny: *Ten questions to ask if you are scrutinising services for people with dementia*.
- Responses to a consultation on the implementation of the recommendations by Fusion Gateway (the Gateway was developed in conjunction with the Joint Engagement Board to ensure all involvement activities in Devon follow the same process)
- Responses to a call for information from the Local Involvement Network (LiNK) and comments collated by the LiNK separately during 2011-12

6. The task group would like to thank all those who participated in the process, for their time and effort and continued commitment to helping to shape this review and recommendations for improvement. They would also particularly like to thank our contributors for the detailed evidence they gave to the task group.

Findings

7. Due to the change in demographics, commissioners and providers recognise that dementia care is now a core business for them. For example, 50% of the population in East Devon will be over the age of 65 in 2030 which demonstrates the urgent need to plan and commission appropriate and sustainable services across the sectors but progress is mixed due to Devon’s demography and geography. It is clear that the health and social care system will not be able to cope with the demand if this is not managed and funded properly. Building infrastructure is essential in managing the demand, e.g. further developing virtual wards, improving telecare facilities and aligning patients’ with clinical pathways. Virtual wards play an important role in addressing patients’ acute healthcare needs whilst not exacerbating their mental health.

8. Partnership working is also fundamental to future service planning and provision, especially with third sector and local voluntary organisations which will carry on beyond the transition to clinical commissioning groups but many such organisations were affected by public sector budget reductions.

Strategic direction of travel

9. In order to design future-proof services, one of the key objectives of the local and national dementia strategy (published February 2009) is to improve public and professional awareness and understanding of dementia, and to address the stigma associated with it. This should inform individuals of the benefits of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should encourage behavioural change to facilitate appropriate help-seeking and help provision, positive community responses, as well as furthering the preventative agenda. The aspiration is to achieve more early diagnoses and although no formal eligibility for services exist at this early stage, patients can start contingency

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planning. Memory cafés, the development of dementia-friendly communities, as well as the new dementia support workers will accompany patients along their journeys.

Dementia-friendly communities

10. The aim of dementia-friendly communities is to build capacity within localities to cope with an increasing demand by improving the physical environment, local facilities, support services and social networks in order to support people with dementia. This would enable the development of a toolkit for e.g. local businesses, cultural and leisure facilities to raise awareness of the needs of people with dementia and promote initiatives which are inclusive, welcoming and supportive of people with cognitive problems. This will reduce isolation and the stigma associated with dementia.

Dementia support workers

11. The roles of dementia support workers are anticipated to provide crucial community-based support for all people who suffer from dementia and their carers as soon as possible after receiving a diagnosis. It is anticipated that they help navigate through the complexity of services from housing and benefits through to health, social and voluntary sector care. Anticipated benefits include improved services and yet reduced health and social care costs per patient, visible post-diagnosis care, helping people who use services access what they need at the right time and offering patients and carers the support they need to remain in their chosen environment for longer.

12. The roles will be tendered for during 2012 after funding arrangements have been finalised through a section 256 arrangement covering £575,000 to support the service for the first year, during which sustainable funding will need to be sought based on the effectiveness of the service particularly in reducing premature admission to long term care and avoidable admission to hospital. This service should be jointly funded by Devon County Council and the NHS. The aspiration is to recruit one dementia support worker per complex care team area which total 23.

Social care commissioning

13. In adult social care, priorities centre around promoting independence, wellbeing and choice. This includes care being provided close to or in people's homes and promoting their quality of life which can be missing if a person is isolated in their own home. This gap can be addressed by e.g. a befriending service provided by a voluntary organisation and could lead to a reduction in professionalised services and a reinvestment in local voluntary activities where people receive professional care when what they might actually need is company and people who need care might not receive it because of capacity issues.

Social care Provision

14. Meanwhile, an £11.2 million investment programme has recently been agreed to remodel and refurbish in-house residential care homes with the aim to create up to ten centres of excellence providing dementia-specific care. The redesign of the homes will be undertaken in conjunction with Stirling University, given their expertise and extensive research in the built environment for people with dementia. The first three "demonstrator sites" will be announced in September 2012. It is envisaged that each centre will be the focal point of a dementia-friendly community, providing on a flexible basis a range of long stay care facilities, short stay and respite care facilities as well as support for carers. They will also provide a shop window for telecare and assistive technology to support people with dementia living in their own homes.

Devon Partnership NHS Trust

15. The reconfiguration in older people mental health services within the Devon Partnership NHS Trust resulted in a modernisation of inpatient services and a shift towards community care

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following extensive community engagement. 60 beds are now provided across units in Barnstaple, Exeter and Torbay and following a £4.6m investment, the facilities are fit for purpose and have seen a decrease in inpatient incidents. The average inpatient stay also decreased from 90 days to 40-50 days. The community team were able to recruit more staff which resulted in referrals to the teams quadrupling. The Devon Partnership NHS trust liaison service in acute hospitals is speeding up discharges. Improved services meant that GPs can now successfully refer patients for treatment and support, whereas before early diagnoses might not have resulted in comprehensive care.

Challenges

16. Care pathways have to be adjusted in order to prevent disjointed services between sectors and to improve communications between organisations as well as simplifying the access to care services and understanding where and how people access information and where they might fail to achieve progress. The pathways under development will be designed to increase early diagnoses which means that patients will not present with advanced dementia and that primary care rather than secondary care professionals will deal with mild dementia and that the burden would be shared between the primary and secondary as well as the statutory and third sectors. Other pathways, e.g. falls and promoting bone health, also have to be “dementia-proofed”.

17. Further challenges presented themselves in the most appropriate commissioning of services from the Devon Partnership NHS Trust and furthering the GP education programme. Following the shift from inpatient to community services, the resulting cultural changes still need to be embedded and managed.

Health & Wellbeing Board and clinical commissioning

18. From April 2013, the Health & Wellbeing Board and the clinical commissioning groups will oversee health and social care commissioning. It is hoped that the Health & Wellbeing Board will ensure sustainability and funding stability for providers and address differences in health and social care provision across localities. But high-level developments in the health and social care sector added further complexities. For example, the boundaries of the two new clinical commissioning groups in Devon are not coterminous with local authority boundaries which might make joint commissioning difficult.

Developments in end of life care

19. NHS Cornwall and Isles of Scilly are piloting an end of life pathway which aims to improve care for people with dementia who need coordinated care when approaching their end of life. Early evidence suggested that the pilot saw acute admissions halved after care plans had been established for patients which determined whether they should be admitted to hospital and/or resuscitated. Work is currently being undertaken in Devon on end of live advanced care plans which would include capacity assessments and/or best interest decisions but these might prove complicated and time consuming due to the involvement of a number of professionals including doctors and lawyers.

Refresh of recommendations

20. The task group acknowledges the progress which has been achieved against the original recommendations which is set out in Appendix 1 but it also recognises that further improvements are required if services are to be able to cope with the projected future demand. The group has identified a number of specific areas where it considers further work is required. These are represented in the following five recommendations which replace those made in March 2010:

Recommendation 1:

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To recommend that the Devon Health & Wellbeing Board and the clinical commissioning groups covering the Devon local authority area make the development of dementia services a priority and work with partners to secure sufficient and long-term funding.

21. The task group recognises the uncertainties, challenges and risks related to the establishment of Health & Wellbeing Boards and clinical commissioning groups from 1 April 2013, especially with regard to clinical commissioning groups covering different local authority areas (Devon, Plymouth and Torbay) and the potential impact of this on joint commissioning with different local authorities, continuous and consistent service provision as well as the further development of pathways/maps of medicine.

Recommendation 2:

To further improve early diagnoses by rolling out the GP education programme to all practices in Devon by the end of 2012-13.

22. The Devon GP education programme commenced in March 2011 whereby one-hour dementia awareness courses have been carried out in 61% practices in Devon so far. The original target was to reach 75% of practices by March 2012. Diagnosis rates in Devon have significantly improved and currently stand at 44% compared a UK average of 43.3%.

Recommendation 3:

To provide relevant and timely information and support to people who suffer from dementia and their carers, whilst recognising the specific needs of patients who live on their own, by:

- a) supporting the long-term development of dementia support worker roles.
- b) appropriately training all those staff involved in the direct care of people suffering from dementia.
- c) identifying more coordinated, creative, tailor-made, local and need-led solutions.
- d) achieving joint decision making between health professionals and patients/carers.

23. The task group views the impact of the new dementia support workers on the further implementation of recommendations as crucial. As this is an untried approach in Devon, the first year will be used to evaluate the service in order to determine its longer term future by assessing its impact in a number of areas.

Recommendation 4:

To commit to productive partnership working with the voluntary sector whilst considering the sustainability and funding implications the voluntary sector faces.

24. The task group recognises the invaluable and indispensable services provided by voluntary organisations and is concerned about the pressures on some services.

Recommendation 5:

To recommend a revisit of these recommendations in 12-18 months.

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County Solicitor

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Electoral Divisions: All

Cabinet Member: Cllr Stuart Barker, Adult Social Care, Families & Post 16

Local Government Act 1972: list of Background Papers: None.

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APPENDIX 1

The scope of this task group was to revisit the recommendations made by the former older people mental health task group and the group's findings can be summarised as follows:

Recommendation		Progress
<p>1 To further scope the deliverability of the National Dementia Strategy in Devon, including</p> <p>a) developing a strong and accountable leadership within the National Dementia Strategy Programme in Devon to coordinate the work streams and future service provision.</p> <p>b) undertaking a financial exercise on current spending levels for dementia services and compare this to other local authorities and PCTs, with a view to inform current and future service provision.</p>	<p>✓</p> <p>✓</p>	<p>Achieved; an Older People Mental Health Steering Group meets monthly chaired by Dr Nick Cartmell, GP Dementia Lead for NHS Devon and the South West Dementia Partnership, NHS South of England. Officers from NHS and County Council commissioning, GP commissioners and provider organisations are represented on the group.</p> <p>Achieved; Although comparison of spend is problematic due to the numerous ways in which services are described and commissioned, in relation to the redesign work undertaken with the Devon Partnership NHS Trust, national benchmarking across this type of provider organisation has been helpful in determining future directions. Some mapping and peer review work undertaken by the South West Dementia Partnership has been helpful in identifying good practice models.</p>
<p>2 To suggest to the Local Medical Committee to raise awareness with their members.</p>	<p>✓</p>	<p>Achieved; Copy of the report sent to Local Medical Committee on 16 March 2010 and level of awareness among GPs raised (see recommendation 3 below).</p>
<p>3 To identify one dementia lead in every GP practice in order to ensure referral for diagnoses and appropriate support.</p>	<p>-</p>	<p>Work in progress; A GP education programme commenced in March 2011 whereby one-hour dementia awareness courses were carried out in so far 61% practices in Devon. The original target was to reach 75% of practices by March 2012. Nevertheless, the early diagnosis rate rose from 33% to 45% and referrals to secondary care quadrupled. The target is to provide training in 90% of practices and to continue to review performance in the remaining 10% of practices. As a result of the GP education programme, the majority of practices now have named dementia leads. The GP education programme will continue to be rolled out during 2012/13. The task group acknowledges the work undertaken so far but recommends that, as a target, by the end of 2012-13 all GP practices should have received training.</p>

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4 To promote approaches to diagnosing dementia which strengthens the role of those close to the patient, e.g. through improved family and carer involvement and confidentiality at the point of diagnosis.	-	Work in progress; Carer involvement is now considered crucial. Patients undergoing memory clinics are supported in conjunction with their spouses or carers by default and a six-week structured training programme for carers has been developed with the capacity to roll this out across the county. The task group recognised that carer involvement is crucial from the onset and is pleased to record that this recognition is filtering through to frontline services.
5 To provide support and advice to patients on how to appoint a welfare attorney at the point of receiving a diagnosis of dementia.	X	Further improvements required; The redesign of Devon Partnership NHS Trust services is allowing greater access to memory assessment services and early interventions following diagnosis. This includes carer training which provides advice on all aspects of on-going care including financial and decision making issues. A tender will be launched for the provision of a dementia support service, including dementia support workers, which would provide people newly diagnosed with dementia access to a support worker for signposting and advice across a range of matters.
6 To review and strengthen existing peer support and learning networks such as memory cafés by maintaining professional commitment and enhancing partnership working with the voluntary sector.	-	Work in progress; There are now 37 memory cafés in Devon aligned to the market and coastal towns. These are mostly held monthly but a number are considering a fortnightly service due to demand. The library service has established really positive links with the memory cafés, providing reminiscence material and local information to stimulate discussion. A bid for the European Interreg programme is also being developed to promote dementia-friendly communities. In the Yealm estuary, dementia-friendly parishes are already being developed. An intergenerational project has been piloted with a Honiton school and a further community project with a large supermarket in Torridge. The task group commends the positive developments but remains concerned about on-going funding uncertainties.
7 To provide support, advice and guidance to patients when choosing their treatment and care and to consider how to improve advocacy services in order to offer increased numbers of face to face callers a better response.	-	Work in progress; The redesign of Devon Partnership NHS Trust services is allowing greater access to memory assessment services and early interventions following diagnosis. This includes carer training which provides advice on all aspects of on-going care including financial and decision making issues. A tender will be launched for the provision of a dementia support service, including dementia support workers, which would provide people newly diagnosed with dementia access to a support worker for signposting and advice across a range of matters.
8 To scope opportunities to follow up cases and to provide continuity of support.	-	

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<p>9 To develop a coordinated service directory which provides information on all statutory and voluntary older people mental health services across Devon and which can assist the Care Direct service to identify more coordinated, creative, tailor-made, local and need-led solutions.</p>	<p>X</p>	<p>Further improvements required; The Community Directory is now live and gives access to the information described. It is an important part of the move to personal budgets and direct payments, giving people greater choice and flexibility about how they arrange their support. The further plan was to establish a way of monitoring the take-up of direct payments by people with dementia to ensure they are accessing the full benefit that this approach can offer.</p> <p>The task group anticipates that the dementia support worker roles will be helpful in providing a local insight which will help solutions become more focused, tailor made and coordinated. However, commissioners and providers also need to continue to improve awareness of dementia both in provision and care management across health and social care.</p>
<p>10 To emphasise the importance of good communications and supportive relationships with families and to encourage joint decision making between health professionals and carers wherever appropriate.</p>	<p>X</p>	<p>Further improvements required; Evidence of better access to liaison services, effective joint working through complex care teams and closer working with primary care are all aimed at supporting people to live well with dementia. Services now need to ensure that the good practice is maintained in relation to information sharing and this continues to be built on.</p> <p>It is also envisaged that the dementia support workers will be standing members of local core groups and this will be the vehicle for ensuring a joined up approach across organisations and with carers and families</p>
<p>11 To increase and secure carer support arrangements and keeping carer support separate from patient support.</p>	<p>✓</p>	<p>Achieved; The new “Virtual Carers Centre” is now operational, giving people clearer access to advice and support. When this is combined with the new dementia support service about to be launched there should be enhanced opportunities to ensure both carers and people with dementia get the support they need. The consultation regarding respite and day care is also seeking to establish good carer support alongside good experiences of support for the cared for person. The Devon Partnership NHS Trust, as part of their service redesign, are introducing carer training programmes and the Expert Patients Programme has developed a ‘Looking after me’ course specifically for carers which is held in Devon. On-going monitoring of the Carers Centre will ensure it is delivering an effective service.</p>
<p>12 To improve in-patient facilities for older people with mental health problems in order to provide suitable environments for recovery.</p>	<p>✓</p>	<p>Achieved; The new inpatient units managed by the Devon Partnership NHS Trust are now fully operational ensuring optimum care within tailor made environments. The four units now ensure that there is separation of functional and organic treatment; gender separation and meeting of privacy and dignity standards. Community support now need to be further strengthened, standards of inpatient care needed to be maintained and lengths of stay needed to be kept to a minimum so that beds are used as effectively as possible and only when necessary for an individual’s treatment.</p> <p>The task group is also aware of a separate scrutiny task group review into the future of community hospitals</p>

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		which will be published during 2012.
<p>13 To establish how all those staff involved in the direct care of people suffering from dementia can access appropriate education and support.</p>	X	<p>Further improvements required; The GP education programme is underway and will be completed during 2012 covering primary care sector. The general hospital standards developed by the South West Dementia Partnership are in place and organisations have been peer reviewed against these standards. These include expectations regarding staff training in dementia. The South West Dementia Partnership has produced a range of support materials for organisations to use to develop their workforce and these have been presented to relevant provider and learning and development organisations. Both the Royal Devon & Exeter NHS Foundation Trust and the Northern Devon Healthcare NHS Trust had embarked on dementia awareness programmes. Dementia-related training was also being carried out in in-house care homes.</p> <p>There is further work to be done to improve training within independent sector care homes. Devon County Council care homes have been involved in a programme of learning regarding dementia.</p> <p>All organisations involved in the care of older people have a responsibility to ensure they are building a workforce which understands the needs of people with dementia.</p>
<p>14 To enter negotiations with “for dementia” about the future provision of Admiral Nurses in Devon.</p>	X	<p>Recommendation not adopted; Increased community mental health team staff following the reconfiguration of Devon Partnership NHS Trust services has meant improved access to specialist support in the community. This, combined with the imminent launch of the dementia support service, should ensure that people are getting a good level of support and that the functions provided by admiral nurses are covered in other ways. Dementia support workers to be in post in the latter part of 2012.</p>
<p>15 To scope the following areas for improvement in the care for people with a learning disability and dementia:</p> <p>a) increase capacity for baseline screening, reactive and proactive monitoring</p> <p>b) improve awareness training for frontline staff</p> <p>c) consider the complex needs of people with a learning disability in residential, nursing and inpatient settings when redeveloping services.</p>	X	<p>Recommendation not adopted; Initial discussions have taken place but further consideration is needed in all these areas. Dedicated learning disability commissioner time has been limited for a period of time although steps are in place to resolve this.</p>

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16 To continue to work towards providing mental health services to people on the basis of need and not age.	✓	Achieved; Devon Partnership NHS Trust services are now delivered on the basis of need not age. One example is the Crisis Resolution service which now supports people with a functional illness regardless of age.
17 To develop specialist mental health services to specifically meet the different needs of older people while ensuring that people can access the full range of services regardless of age.	✓	
18 To establish condition-specific care pathways for older people mental health services.	-	Work in progress; The dementia care pathway map has been developed using Map of Medicine and this provides access to localised information about services available, evidence based interventions and decision making support. The pathway now has to be adjusted and access to the Map of Medicine be made available to a wider range of stakeholders including voluntary and community sector partners.
19 To develop processes which allow the follow up of referrals and/or concerns raised with professional staff from third sector providers.	✓	Achieved; Voluntary sector representatives have been established in complex care teams for some time now and provide a conduit for local voluntary and community organisations to connect with local complex care teams. The new dementia support service should also assist in communicating across agencies to support responsiveness and the dementia support workers should enhance this relationship.
20 To recognise the invaluable and indispensable services provided by voluntary organisations and to commit to productive partnership working, better engagement and communication between all NHS trusts in Devon, the County Council and community and voluntary providers.	X	<p>Further work required; The establishment of service such as Memory Cafes have highlighted the important role which voluntary and community sector organisations can fulfil but many such organisations were affected by public sector budget reductions. As changes to the way health and social care services are commissioned and delivered it is an expectation that local groups have a voice. The redesign of Devon Partnership NHS Trust services has been characterised by the establishment of local community-led stakeholder groups and these are influencing local community services development and delivery. In addition the Devon Dementia Partnership brings together people from across the county to influence services. The clinical commissioning groups will have to ensure support for local community and voluntary sector engagement and influence.</p> <p>It is anticipated that the dementia support workers should “glue” a range of services together to help navigate through the complexity of services from housing and benefits through to health, social and voluntary sector care. Commissioners will gather the views of people receiving the services of a support worker to ensure that</p>

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		improved outcomes are being experienced.
<p>21 To undertake further research to develop better support for older people with mental health issues and their carers in the following areas:</p> <ul style="list-style-type: none"> a) how people with dementia and their carers can best be supported to live well b) how mainstream services can best be adapted to their needs c) how good practice can more readily be implemented d) how those working in health and social care can best be supported in providing care which genuinely respects the personhood of everyone with dementia e) meaningful measures for assessing the effect of particular services f) preventative strategies, including support for isolated people. 	✓	<p>Achieved; The establishment of the Older People Mental Health Steering Group and a clear work plan for delivery of the dementia strategy are established. A GP lead for Devon has access and is sharing latest thinking on older people mental health care and support. Devon Annual Public Health Report and Devon Prevention Strategy both address the importance of support and development in relation to dementia. A Peninsula Dementia Research Network is about to be launched, led by the newly appointed Professor of Old Age Psychiatry to the Mental Health Research Group at Peninsula College of Medicine & Dentistry.</p> <p>The task group recognises the importance of continued academic and medical research, especially within the South West region with its challenging demographic profile.</p>
<p>22 To recommend to the Health & Adults' Services Scrutiny Committee to request a report on the implementation of the recommendations of the older people mental health task group in November 2010 and in 2011.</p>	✓	<p>Achieved</p>