**Consultation response form: *Together for a Dementia Friendly Wales* (2017-22)**

1. **Contact Details**

|  |  |
| --- | --- |
| Your name: | Sandra Morgan |
| Organisation (if applicable): |  |
| Email address:  | sandra.morgan2@wales.nhs.uk |
| Contact telephone number:  | 07817409083 |
| Your address:  | Hafan Derwen,St David’s Campus,Job’s Well Road,Carmarthen |

1. **Are you responding as an individual or on behalf of an organisation?**

Please tick box.

|  |  |
| --- | --- |
| **Individual**  | **On behalf of an organisation** (please tell us which organisation) |
|  | West Wales Care Partnership |

The West Wales Care Partnership has been established under Part 9 of the Social Services and Wellbeing (Wales) Act to take forward the integration agenda in the region. Statutory partners comprise Hywel Dda University Health Board, Pembrokeshire County Council, Carmarthenshire County Council, and Ceredigion County Council.

The integration of older people’s services, including for people with dementia, is a key priority of the Regional Partnership Board and a regional dementia strategy is under development within the wider context of the national strategy. This response is submitted on behalf of the Partnership.

**3. Structure of the document**

In the Welsh Government’s Programme for Government ‘Taking Wales Forward 2016-2021’ we confirmed we would take further action to make Wales a dementia friendly country through developing and implementing a national dementia plan. This commitment was also highlighted in the 2016-19 delivery plan supporting the Welsh Government’s 10 year ‘Together for Mental Health’ strategy aimed at improving mental health and well-being for the whole population.

This is the first dementia strategy for Wales but builds on previous work. Engagement with people with dementia, their families and carers has been central to drafting this strategy. Feedback from stakeholders has informed the layout of the strategy, including organising actions as part of a pathway and embedding a ‘rights based approach’ within the document.

**Question 1**

|  |
| --- |
| **The strategy follows the following themes:*** Risk reduction and health promotion.
* Recognition and identification.
* Assessment and diagnosis.
* Living as well as possible for as long as possible with dementia.
* The need for increased support in the community.
* More specialist care and support
* Supporting the plan:
* Training
* Research.

**Do you feel there should be any additional themes included? Please tick the appropriate box below.**  |
| Yes **🗸** | No  | Partly  |
| Where you have ticked ‘Yes’ or ‘Partly’, please explain what the additional themes should be.  |
| 1. The **needs of carers** of people living with dementia should be a defined section of the strategy. This should include the requirement to improve early support and reflect the likelihood that some people may not initially describe themselves as carers or be aware of the benefits of a carers assessment. The benefits of third sector support should be described followed be a recommendation to improve access to this support.
2. West Wales Dementia Steering Group are pleased that Welsh Government supports the Glasgow Declaration, but believe that the Strategy would be improved with a stronger focus on promoting the rights, dignity and autonomy of people living with dementia. Consequently the Group would recommend that this should be an independent theme and include the requirement for demonstrable measures to evidence service accessibility (including commissioned services).
 |

**Question 2**

|  |
| --- |
| **Within each theme we have identified a number of proposed key actions. Do you feel these are the right ones? Please tick the appropriate box below.**  |
| Yes | No  | Partly **🗸** |
| Where you have ticked ‘No’ or ‘Partly’, please provide an explanation and any alternative suggested wording below. Please state **which theme** you are commenting on. |
| **Awareness:** 1. Raising Awareness; should be extended more widely than schools and educational settings and include opportunities to work with businesses.
2. Wording of Key actions for Raising awareness could be improved e.g.
* Increase the number of people in Wales who are able to route people to appropriate support if they suspect they have cognitive impairment through the expansion of dementia friends and dementia supportive communities
* Embed dementia awareness into the core curriculum contextualised through established citizenship programmes.
1. The training should extend to sourcing supporting services at a local level, thus appropriately signposting to support groups and others.
2. For people with young onset of dementia*,* there should be more accessible information regarding the impact that this diagnosis has on younger adults as well as the additional support available to them and their families.
3. Public information campaigns - the approach to raise dementia awareness could be integrated with other health campaigns, such as those for heart conditions, diabetes, smoking, stroke etc. Otherwise the general public will tend to see things separately without understanding appreciating the composite risks. Possibly an integrated ‘look after your brain’ campaign would be helpful.
4. The terminology and language of the consultation is not readily accessible to service users/carers, and we think this could be helpfully addressed further in the final document and/or ‘easy read’ version.

**Increased diagnosis:** 1. The recommendation of evidence based local referral pathway is welcomed, but the requirement to deliver an integrated care pathway that includes primary care would be more helpful to support the development of services that include primary care led diagnosis in appropriate circumstances.
2. It would be useful to establish an action to improve the reliability of coding dementia in primary care, as there continue to be tensions between GMS and the recommended 5 Read codes. This may be reducing the number of people captured on the primary care register.
3. The requirement to increase the diagnosis rate across the whole of Wales is welcomed, but believe that it would be more productive to articulate more realistic timescales and reflect an achievable rate of improvement.
4. The provision of information to people with new diagnosis should be managed sensitively i.e. a need to build in timeliness, accessibility and effectiveness so that people aren’t overwhelmed with the volume of information provided. This process should be co-designed with people who have dementia as well as carers and delivered in an emotionally supportive manner.

**Reducing use of anti-psychotic medication for people with a dementia diagnosis:** 1. West Wales Dementia Steering Group strongly supports the need to reduce use of anti-psychotic medication which includes persistently up-skilling the residential/care home workforce and the ability to modify the care environment. We would also suggest this action may be enhanced by a pan-agency multi-disciplinary collaborative health and social care team approach, to advise, educate and support alternative management.
2. Additionally there is a requirement to consider the availability of nursing-level longer term placement for people with dementia who have on-going complex needs and challenging behaviours.

**Increased support in the community.** 1. The “‘team around the carer” supportive approach is strongly supported. This should be acknowledged by both health and social care levels.
2. Key actions describe a need to undertake satisfaction surveys. Whilst user experience is important, the adoption of user reported outcomes should also advocated.
3. The action relating to respite care should be expanded to include replacement care as this would deliver a more flexible approach.

**Good care in hospitals**1. The proposed action of increasing the number of hospital settings in Wales that are dementia supportive falls short of ensuring that acute hospitals meet the needs of people with dementia as part of their presentation. All acute wards should be able to provide effective care for people with dementia when it is one of the conditions that make up their multi-pathology. The number of people with dementia who are discharged from hospital to their original place of residence should be monitored.

**Older person’s mental health inpatient units**1. The key action regarding older adult mental health units doesn’t currently reflect the possibility of integrated wards and would recommend that the action be modified to encourage an integrated approach to care pathways and personalised care.

**More specialist care and support**1. When people access more specialist care and support, carer pathways should also be considered. People accessing more specialist support will often have complex presentation which will increase carer strain.

**End of Life care**1. Proposed key actions in “End of Life care” should be modified to recommend “Support people who have been diagnosed with dementia and their families in advanced care planning for their end of life”

**Education and Training**1. The implementation of “Good Work: Learning and Development Framework” would take place more reliably if e-learning modules were available for all three levels. It would be helpful if e-learning was commissioned for all Wales.
2. Explicit recommendation of a pan sector approach to the implementation of the Dementia Learning and Development Framework would strengthen its added value.

**High Level Performance Measures**1. Currently the measurements listed focus on outputs rather than outcomes. West Wales Dementia Steering Group would welcome the inclusion of outcome measures.
2. Page 41 states **“The Welsh Government is developing a learning disabilities action plan which will also consider what support is required in this area”.** The local Learning Disability service we would like to see the following MDT interventions included
* **Person-Centred Approaches to Support -** Person Centred plan; Health Care Plan; Communication Passport; Life Story Book; Advanced Directives & end of life planning.
* **Physical Health -** Health checks leading to a Health Action Plan and any treatment. Tools available e.g. OK Health Check (Matthews, 2006) End of Life support - Gold Standard Framework (Thomas & DH, 2005); Management of weight; Management of pain; Management of sleep; Management of epilepsy; Management of medication
* **Mobility -** Strategies to maintain mobility, promote exercise, address posture especially regarding respiratory function, correct gait and reduce the risk of falls, equipment needed and promote safe manual handling; Control of pain and discomfort; Pressure area care; Treatment of any difficulties of motor function, adaptation and teaching of skills to include compensatory techniques; Equipment (e.g. hoists, profiling beds, etc.).
* **Eating/Drinking -** Eating and drinking, strategies for maintenance of adequate oral intake in a safe manner; Speech and language therapy swallowing assessments, eating programme with dietetic advice and advice regarding posture; Diet to reduce risk of constipation; Dysphagia management.
* **Continence -** Aids/adaptations; Help to maintain continence
* **Communication -** Strategies to improve communication; Use of a ‘communication passport’ i.e. information on how best the person receives information and expresses themselves; Use of objects of reference, pictures; Environmental signposting/signs and symbols; Intensive interaction; Use of hi-tech communication aids to support communication (provided on a loan basis)
 |

**Question 3**

|  |
| --- |
| **The strategy describes what services should be available for people and their families and carers to live well in the community for as long as possible.** **What do you think are the key features of this type of service?** |
| 1. A responsive and flexible respite/replacement care service. Respite should be designed to reflect the abilities and preferences of the individual and also take into consideration the What Matters conversation.
2. A support infrastructure to facilitate effective use of direct payments would reduce dependency on statutory services and provide greater flexibility for people with dementia and their carers/families.
3. A requirement for all social and health care staff to provide information to carers of dementia patients.
4. Community Resilience is embedded into the Preventative model and provides an opportunity to work more closely with the 3rd Sector to develop new ways of working such as use of the Rally Round app (<https://rallyroundme.com/> ) that will be rolled out through Ceredigion.
5. Transport and support in rural areas needs to be considered as part of any flexible support networks. The heavy reliance on the carers ability to drive in rural areas cannot be underestimated.
6. A comprehensive ‘Information, Advice and Assistance’ service allowing people the opportunity to play a key role in managing their own health and well-being.
7. Peer support, involving people sharing knowledge, experience or practical help with each other
8. Housing support, including adaptations and aids
9. Increase use of assistive technology
10. Support for carers
11. Support to maintain and develop social networks, for the carers as well as the individual with dementia.
12. Early co-designed support and advice, utilising the expertise of people with dementia as well as health, social care and third sector.
13. A more robust approach to supporting younger people with dementia in employment to support them to sustain their economic status for as long as possible. This may require providing early employer awareness and engagement.
14. Consideration of the implications of providing equitable services in rural areas (which may result in higher costs in these parts of Wales). The standard economic modelling based on per capita of population may not be adequate and potentially disenfranchise already isolated portions of the population.
15. Ready access to urgent support services for people with challenging behaviour. This would be best developed as a pan-agency multi-disciplinary, health and social care integrated team, to support who support based on need regardless of care setting (including private nursing home).
16. Assessment, care and support should be
* **Asset based** - recognising, using, and drawing on a person’s assets, strengths, and those of their families, friends and community.
* **Proactive**: understanding the person’s current needs, thinking ahead and anticipating change, and planning for the future.
* **Effective**: ensuring that safe, reliable, flexible and responsive services and support are in place.
* **Integrated:** Services and provision to be based around individuals, which essentially includes all elements of support as equal partners.
* **Evidence and outcome based commissioning:** that promotes health and wellbeing, including physical, mental, emotional, social and economic wellbeing. It also includes promoting and maximising people’s capabilities and support within their communities.
 |

**Question 4**

|  |
| --- |
| **Within the final *Together for a Dementia Friendly Wales* we would like to include examples of notable practice. If you have any which you would like to highlight, please do so here.** **Please explain why you think it is an area of notable practice e.g. an evidence base, an achieved accreditation award.**  |
| 1. Tregaron and Cardigan have been identified as two areas in Ceredigion where a research project will be undertaken looking at how communities perceive and understand dementia. With the support of Cynnal Y Cardi, work will be undertaken over a 3 year period with the community, statutory sector, and voluntary sector. This Intergenerational Community Resilience project will establish what works well and vice versa in rural and more urban environments in relation to the development of dementia friendly communities.

C:\Users\nerysl\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.Outlook\EZNJ2YMU\t  t9.jpegThe analysis and evaluation of the work will be undertaken through a series of assessments which will be carried out in Tregaron to establish an accurate baseline of attitude, provision and environment prior to undertaking interventions / training etc. This process will be repeated at the end of the 3 year period and will be supplemented with questionnaires with the community to establish the behavioural changes for those individuals, if any, along with changes to services, environment and the experiences of those with dementia and their supporters. It is anticipated that this will help develop a picture regarding which elements are more successful than others, if there is a difference to approaches required in a more urban town setting and those which are more rural, and establish how these can be replicated in other regions. This project may also help to establish why there is a discrepancy regarding the dementia diagnosis rate for Welsh speakers in the County and whether the awareness raising / support / signposting opportunities will have an impact on the referrals being made into the Memory Clinic over the duration of the 3 year project.Two of the key contributors to this work are Bryntirion Resource Centre and Henry Richard School, Tregaron (amongst others). Secondary School pupils routinely join in Day Centre activities when they are required to attend work experience. This inter-generational collaboration generates a lively atmosphere and good humour which is enjoyed by all. Strengthening this work further, three school pupils now attend the Centre on a weekly basis and work with residents on prompting memory recall through recording their history using an IPad which also helps to find information of relevance and interest with those that they work helping to form a basis for discussion.1. Dementia Friends 1These young people have also been trained as dementia friends by staff at Bryntirion Centre who are Dementia Champions with the intention that this will be enhanced with other pupils in the school as part of the project (photograph below of pupils having been awarded their dementia friends certificates).

There is a strong professional working relationship with the local GP Surgery, District Nurses and Tregaron Hospital which assists in enhancing the level of care provided. This professional respect and trust established supports the development of new ways of working which will be core in delivering the Cylch Caron Project.1. It is also acknowledged that a consultant specialising in dementia from Bronglais Hospital (Aberystwyth) regularly attends a Cardigan setting, along with a welsh speaking dementia nurse. Approaches such as this significantly enhances the equity of services provided, which are often challenging in a large rural county such as Ceredigion.
2. **Dementia Friendly City:** In 2014St David's in Pembrokeshire become the first dementia friendly city in Wales. The unique project aimed at making the community a welcoming place for those with the condition was organised by Pembrokeshire County Council, St David's City Council, St David’s Community Forum, Hywel Dda University Health Board, and the Alzheimer's Society. Voluntary organisations such as the Alzheimer's Society, Care & Repair, Pembrokeshire Access Group, PAVS, Age Concern, PCC Good Neighbours and Carer's Strategy Coordinator - as well as Health Board and Local Authority dementia services - were present at the launch and provided information on how they can help/support members of the local community.
3. **Establishment of a Memory Café in St David’s, Pembrokeshire**. The café provides support for people living with dementia and their carers. A variety of activities are run as well as being a hub of information and support.
4. **Dementia awareness training.** The staff and pupils at St David’s Secondary School undertook dementia awareness training. Schools provide children with a wide-ranging and broad education, helping them to become well-rounded individuals. It is right that as part of their education they learn about issues such as dementia and learn the skills needed to best take care of and help family members and friends who have the condition."
5. **The ‘One Stop Shop’ Held on the 1st and 3rd Fridays of every month in Llandybie Community Hall.** A collaborative venture endorsed by HDUHB, Carmarthenshire County Council, and the Alzheimer’s society. Clinics are held by a G.P. but people who attend also have access to support and information, from nurses, social workers and the third sector, as well as a cup of tea, and the company of others who are facing the same challenges.
6. **St Nons ward,** have trailed the use of luncheon vouchers for patients on the ward who believe that they do not have the money to pay for meals. This has proved very successful.St Nons has also introduced conical chip holders for patients that eat on the move. The chip holders are a lot easier to hold than plates and bowls and are able to contain a meaningful amount of food without spillage that the patient can dip into as they walk around.
7. **The psychology staff in Pembrokeshire has introduced the ‘START’ project for carers of patients on the ward.** This ten session intervention is aimed at promoting the development of coping strategies for carers of people with dementia including the wider family. Research has shown that this intervention reduces stress and incidence of depression amongst this group of people.
8. **Investors in Carers:** West Wales has a scheme for GP surgeries which aims to encourage carers to register themselves as a carer with their GP surgery and to have a referral for further help and support. Investors in Carers is a framework of good practice, which was designed initially for GP surgeries. It is a scheme which develops Carer Awareness and ways of working to support all ages of Carers across the region. Through this scheme Carers of people with dementia are visited by a Carer Lead and receive advice and support that is specific to their personal needs.
9. **Fulfilled Lives**: Llanelli locality has developed a holistic dementia pilot to improve care and support for those living with dementia and their carers.
* The first phase of this project was to concentrate on developing a dementia friendly community. This has involved making Llanelli Market the first dementia friendly market in Wales as well as working with private shops and businesses and front line workers receiving dementia awareness sessions. Dementia Friendly Llanelli group also worked with a local theatre to develop a dementia specific performance that also involved workshops and interactive sessions.
* The next phase of the project has been to deliver an outcome based model of commissioned support. This is a stratified approach that aims to provide holistic care and support that will enable people to continue to live well with personalised support as their dementia progresses. The focus will be on the individual directing the support that they need – in partnership with a specifically trained domiciliary care provider that will provide consistent and flexible support which will increase in intensity based on need.
 |

**Question 5**

|  |
| --- |
| **Within the document we have highlighted the advantages of using telehealth, telecare and assistive technologies to help people live more independently and safely within their own home.** **What do you think the challenges and barriers are in making this happen and how could you overcome these?** |
| 1. There are still significant areas of rural West Wales where limited access to sufficiently fast enough broadband will prevent or deter individuals from accessing telehealth. Key locations in communities could be provided to help overcome this, providing access to telehealth etc however connectivity in Wales must be supported by WG.
2. Fear of the complexity of new technology continues to be a barrier in the use of telehealth, telecare or assistive technologies. The value of telecare, telehealth and assistive technologies is recognised and welcomed however, when this is provided, there is a need to ensure that sufficient support, and where necessary, training is provided for both the carer and the individual living with dementia and sufficient resources need to be allocated to enable and maximise the effectiveness of this provision.To overcome these barriers more needs to be done to raise awareness and encourage its use by developing links with local neighbourhood and social groups. Awareness needs to be raised at an earlier stage to embed understanding of its uses and benefits.
3. A need to build public and professional awareness and confidence in the different ways technology can make a positive impact to our lives. To ensure that information on new technology and advancements in equipment are appropriately cascaded to support the integration of services and resources.
4. There is also a need to resource ‘response’ services where emergency support is required for people to maintain independent living arrangements. Without additional capacity response relies on family / carers.
5. Knowledge of what’s available, the full range, keeping abreast of innovations e.g. affordability, Endorsed Brands, Broadband speeds & mobile reception in rural areas, IT savvy/skills
6. Greater development of its utility, sharing of solutions, bespoken application e.g. one person couldn’t recall how to make a cup of tea but could still use a Tablet. So bar-codes were attached to/near appliances and the scanner was used to bring up instructions for respective tasks. This may generate more and more creative application...
7. People are often referred too late for technology to make an impact and benefits to be achieved.
 |

**Question 6**

|  |
| --- |
| **Do you think the key actions will provide a positive impact for people based on the following protected characteristics:-*** Disability
* Race
* Gender and gender reassignment
* Age
* Religion and belief and non-belief
* Sexual orientation
* Human Rights
* Children and young people
 |
| Yes ` **🗸** | No  | Partly  |
| **Where you have ticked ‘No’ or ‘Partly’, please explain why.**  |
| The key action appears to advocate the positive discrimination of individuals with protected characteristics. The action should be amended to reflect that people with protected characteristics may require an adapted approach that reflects their personal needs and that this should be reflected in service planning and delivery. This would result in people with protected characteristics accessing services equitably. |

**Question 7**

|  |
| --- |
| **Do you think the key actions will provide a positive impact on the opportunities for use of the Welsh language?** |
| Yes | No  | Partly **🗸** |
| Where you have ticked ‘No’ or ‘Partly’, please explain how you feel the opportunities for using Welsh could be strengthened to ensure it is treated no less favourably than English.  |
| 1. We must ensure that language and cultural needs and preferences of people with dementia and their carers are catered for, especially as their illness progresses. While the actions are well intended, there is a fundamental issue with recruitment of Welsh speaking health and social care staff to deliver on these actions – there should be Welsh Government actions and strategy to address this recruitment issue/skills gap.
2. Support services may require additional resource to develop use of Welsh language in their services.
3. There are concerns that the needs of people of other nationalities aren’t highlighted and suggest that the key action should refer to language of choice.
 |

**8. Additional Comments**

We have asked a number of specific questions. If you have any related issues which we have not addressed, please use the space below to comment.

|  |
| --- |
| 1. West Wales Dementia Steering Group are pleased that monitoring implementation of the strategy is described. Older Persons’ Delivery Assurance Group membership should reflect the scope of the Strategy
2. Given the need to integrate further as a requirement of the SSWBA it would be helpful to draw out the links of the SSWBA more in the Strategy.
3. It was pleasing to see that the action plan is aligned with the ambitions of the Wellbeing of Future Generation (Wales) Act 2015 as well as the principles of prudent healthcare as these are crucial messages in engaging our population
4. West Wales Dementia Steering Group is concerned that provision of a presumptive/working diagnosis is advocated. When people receive a diagnosis in error, this causes significant anxiety and distress. Pressure to increase diagnostic rates in England has triggered an increase in incorrect diagnosis and patient experience has alerted to the impact of receiving a diagnosis of dementia in error.
5. A number of sections would be more informed if the issues were covered in more detail i.e.
	* ‘Risk reduction and health promotion’ should include information and advice relating to theses themes as well as referencing the significance of preventative services in delaying the onset of the illness.
	* Specific reference should be made to the relevance of an integrated approach to the delivery of person centred assessment, care and support which would include commissioned services. People with dementia and their carers often describe the challenge of being a recipient of fragmented care. Integrated and coordinated working and care delivery should include making explicit the advantage of limiting the number of staff supporting people with dementia and their families in order to avoid duplication and confusion for the person and their family.
	* The management of risk is often the most prevalent concern for families, carers and professionals involved in care and support. This theme should be expanded to discuss the benefits of a Positive Approach to Risk & Personalisation.
	* Whilst living as well as possible is a reasonable theme, a person with dementia continues to have the ability to achieve a good quality of life and have fulfilment within the constraints of the condition. It would be helpful if this was reflected in the narrative.
	* Many people with dementia are likely to have multiple health conditions. Consequently, the relationship between dementia and frailty should be described more explicitly, as well as the opportunity to develop integrated frailty/dementia models of assessment and care
6. Greater focus needed through the document on the contribution of carers
7. ‘Recognising the needs of carers’ section page 25: the current description in this section could be misinterpreted to mean that only social care have a responsibility to support carers. While the principal duty lies with social care to provide Carers Assessments, it is essential that healthcare staff are equally as carer aware and involve carers in the conversation and information provision at the various stages of diagnosis, treatment etc. Carers are everyone’s business.
8. E-learning should be explored as a flexible option for understanding dementia which can be provided for those who have recently been diagnosed, for unpaid carers, professionals and those working in communities. This can also be supported by the Dementia Friends sessions.
9. The value of support groups and advocacy provided by organisations from the third sector for those with dementia and their carers cannot be underestimated.
10. Could there be potential for NERS (National Exercise Referral Scheme) be extended (subject to funding), to support and to deliver interventions for those who have been diagnosed with dementia, not only offering a support group but a social opportunity too.
11. West Wales is a significantly rural area. There are many Welsh families/communities who do not ask for help as the family believe they have a duty of care to support. How to support farming communities effectively should be a consideration reflected in the Strategy as part of Section 4 – Living as well as possible for as long as possible with dementia.
12. West Wales Dementia Steering Group believes that the added value of the key worker role in coordinating the wide range of health and social care services should be described.
13. “Support to stay safe and secure in the home and community” should include reference to housing services and their role in adaptation of housing as well as identifying and addressing environmental hazards and providing accommodation.
14. Clearer description of approaches that enable people with dementia to maintain life skills would be helpful, including strategies to support people to retain skills if they have episodes of care in residential/hospital care.
15. West Wales Dementia Steering Group would value more explicit recommendations regarding the responsibilities of different sectors of health and social care in delivering the strategy, underpinned by the philosophy that supporting people with dementia is everybody’s business.
16. A number of key actions will have a cost implication to implement and may require Welsh Government funding to implement.
17. The examples of supportive communities and active citizenship are welcomed as this provides balance between informal, third sector and statutory provision.
18. West Wales Dementia Steering Group welcomes the requirement to increase early recognition, diagnosis and treatment of dementia so that people with a diagnosis can have maximum benefit from effective management.
19. An integrated Health and Social Care training plan would support integrated teams in developing a shared approached to skills development. It would be helpful if this was reflected in the recommendations.
20. The section relating to acute hospital care could make reference to the Butterfly scheme and John’s Campaign as two examples of good practice.
21. Older Peoples Community Mental Health Teams (and Services) should be predominantly focussed on care and treatment of people with both
	* complex higher risk presentations of people with serious and enduring mental health problems and
	* people with complex high risk advanced behavioural and psychological symptoms of dementia.

Secondary Specialist Mental Health Services play a part in the pathway for people with dementia and are not the sole provider of services; it would help if this is made explicit to clarify their roles in an integrated health and social care collaborative pathway. 1. It would be helpful guidance was developed regarding best practice for generic older people’s mental health wards i.e. mix of people with functional serious and enduring mental health problems and advanced dementia or managed within bespoke separate units.
2. West Wales Dementia Steering Group would welcome a stronger focus on the relationship between dementia and frailty, as for many people the need will be for support from a single service able to robustly meet the needs of people with both frailty and dementia. Specialist Older Peoples Mental Health Service aligns more closely with frailty services than Adult Mental Health, and local clinicians have found Frailty assessment documentation more relevant than CTP assessment documentation.
3. There is the need for the recognition that some people at times may require a form of Psychiatric Intensive Care (PICU), dedicated to people with dementia whom have acute high risk episodes of care, where it is not safe to manage their needs within standard older people’s psychiatric wards. Standard adult treatment modalities for managing behavioural risks associated with acute mental illness (rapid tranquilisation & de-escalation) would not be clinically suitable. There seems to be a small but possibly growing need for a service provision to offer people with significant cognitive impairment, a separate ‘safe-soft’ segregated environment, with modified de-escalation approaches, and sustained high intensity risk management.
 |

**9. Sources of information**

The final document will include a list of useful sources of information. If there is anything you feel should be included, please state in the space below:

|  |
| --- |
| Women and Dementia, A Marginalised Majority, Alzheimer’s Research UK Letter to all NHS Mental Health Providers from Royal College of Psychiatrists on the development of Older Adults servicesInvestors in carers scheme annual report 2015/16 can be found at:<http://www.wales.nhs.uk/sitesplus/862/page/66977> |