

# time for action

The report of the Health and Adult Social Care  
Overview and Scrutiny Committee's Care  
Pathways Steering Group





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# Executive Summary

The good news that we're living longer brings with it some very real challenges for us all. Increasing numbers of people living with dementia and the resulting demands upon the health and social care community is perhaps one of the greatest.

Dementia isn't a condition which can be neatly pigeon holed as the responsibility of one or two specialist organisations – every organisation involved in providing services to older people in Cornwall will need to have the skills, knowledge and understanding to care for people with dementia.

This was the reason for the development in 2004 of the Dementia Care Pathway – it aimed to establish a common best practice approach to providing services for people with dementia and their carers. However, getting the Pathway integrated into actual working practice has proven difficult and despite its existence, people receiving the services haven't seen the improvements it had hoped would be achieved.

The Care Pathways Steering Group was established to look at how services could be improved for those people at the receiving end of our services – examining how awareness of the Pathway across health and social care organisations could be increased and the pathway integrated into their working practices; identifying ways of making the Pathway more understandable

and accessible to people with dementia and their carers so that they could understand how services should be helping them; and asking service users and carers what they needed and how the Pathway could be enhanced to make sure their needs weren't forgotten.

Research and consultation undertaken by the Steering Group has included:

- Focus groups of carers across Cornwall
- A survey of 434 carers of people with dementia
- Consultation events with people with dementia and their carers
- Interviews with health and social care organisations across the County
- A stakeholder event which brought together over 80 people representing NHS organisations, Adult Social Care, independent care homes, the voluntary sector, housing providers and carers.

The key findings and recommendations of the Steering Group are summarised on the following pages.

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## Summary of the issues identified and recommended actions

Theme 1		
To establish a mechanism by which organisations and individuals involved in dementia care can work together towards shared goals and standards.	Despite a huge willingness to improve services for people with dementia, organisational boundaries can limit the ability to work together.	✓ The Older People's Partnership Board should receive further information about the work of existing Dementia collaboratives and use this to inform a feasibility study into the development of a dementia collaborative for Cornwall.
		✓ It is vital that the health and social care community in Cornwall collectively agree common aims, objectives, standards and targets for the care of people with dementia and their carers, and develop mechanisms for monitoring and evaluating performance.
		✓ The health and social care community should establish a training programme for all individuals engaged in the care of people with dementia. The development of such a programme should be informed by the Dementia Care Pathway and, where practical, should involve elements of joint training for service providers and carers.
Theme 2		
To ensure that service users and carers are well informed and appropriately engaged.	The pathway was designed for use by clinicians and as such, isn't written in a style or language which makes it accessible or practical as a tool to inform service users and carers	✓ A multi agency team involving carers should be established to look at: <ul style="list-style-type: none"> <li>• Developing a web based version of the Pathway so that it provides a range of information targeted at a variety of audiences - health and social care organisations, other agencies and people with dementia and their carers.</li> <li>• Developing a clear signposting guide for people with dementia and their carers. The guide should reflect the Dementia Care Pathway but be presented in a format and language which makes it accessible and easy to follow.</li> </ul>
		✓ The health and social care community should seek to establish forums for carers and service users to enable their voices to be heard.

### Theme 3

To ensure that the Pathway is embedded into other systems and working practices.

The Pathway is seen as a document rather than a part of working practice.

- ✓ A part of the Single Assessment Process and/or Care Plan should be developed so that it reflects the Dementia Care Pathway and thereby charts an individuals' journey against its various stages.

### Theme 4

To increase recognition of dementia, thus aiding earlier diagnosis and improving care management.

Limited adoption of the pathway at primary care level; difficulties and delays experienced by carers in getting a diagnosis.

- ✓ All agencies involved in the care of people with dementia should be encouraged to formally sign up to the use of the Pathway as a framework for care and ensure its adoption at a primary care level.
- ✓ Further discussion should be carried out with GP surgeries in Cornwall to understand the reasons for the difficulties and delays in making a diagnosis.
- ✓ PCTs should work with GPs to explore the development of a lead professional for dementia within each practice.
- ✓ The establishment of a specialist practice nurse or a dementia care worker attached to a practice should be piloted and evaluated.
- ✓ This stage of the Pathway should be enhanced by:
  - explicitly identifying the steps to be taken at the point of first contact eg. information to be given to the patient/carer and sources of further help and support,
  - including prompts about the kind of information to be provided at the time of diagnosis reflecting on what carers have told us they need – details about the nature of the diagnosis, the implications for them as carer and the longer term impact of the condition, information about how the diagnosis was reached and sources of help and support.
  - specifically triggering the GP to make contact with the Department of Adult Social Care to ensure that an assessment of care needs is offered and that the person with dementia and their carer are contacted by a Dementia Support worker.

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## Theme 5

To ensure that assessments of service users' and carers' needs are carried out promptly and in a way which takes account of their individual needs.

Apparent lack of consistency in the assessment process.

- ✓ There should be clear service standards, shared with service users and carers, for key stages of the Pathway – for example, the timescale within which an assessment of needs should be offered following referral.
- ✓ The assessment process should prompt consideration of non traditional support services - for example walking, art, social outings – and appropriate links should be established with the voluntary sector in order to commission suitable services.
- ✓ Where relevant, other agencies involved in the care of the person with dementia and their carer – such as voluntary sector organisations, housing providers, social landlords – should be involved in discussions around the persons' care needs and ways of addressing these.

## Theme 6

To take a preventative approach.

Services are responsive to immediate needs and are not generally focused on pre-empting problems and taking action early to prevent the need for more serious intervention later.

- ✓ There needs to be a robust process for ensuring that an assessment is offered to all carers. Where a carer declines an assessment, it should be made clear that they are entitled to an assessment at any stage in the future if they feel it is needed and should be given information on how to arrange this.
- ✓ PCTs should work with GPs to look at ways of encouraging routine, regular contact with carers registered with their practice.
- ✓ A system should be introduced whereby carers routinely receive a periodic telephone call simply to make contact and confirm that they are ok. This should include those carers who have declined a carers' assessment and those who currently receive no support services.
- ✓ The resourcing of Dementia Carer Support Workers should be reviewed to ensure that an appropriate level of service is available across the County.
- ✓ Funding put into carer support by agencies in Cornwall should be examined collectively to ensure that resources are being used to greatest effect and that appropriate planning is taking place for future levels of need.

## Theme 6

		<ul style="list-style-type: none"> <li>✓ Other approaches to support carers such as increasing befriending services provided by the voluntary sector, or setting up a mechanism for putting carers in touch with each other on a one to one basis should be examined</li> </ul>
		<ul style="list-style-type: none"> <li>✓ As a part of the Single Assessment Process, carers should be identified and, if they consent, automatically registered as a carer with their GP. PCTs should be active in ensuring that GPs are aware of the ways in which they should be assisting carers upon the register.</li> </ul>
		<ul style="list-style-type: none"> <li>✓ The resourcing of equipment aimed at preventing injuries and potentially saving much greater costs if an injury occurs, such as hip protectors, should be reviewed, calling on the evidence base to support this.</li> </ul>
		<ul style="list-style-type: none"> <li>✓ Clear sign posting needs to be developed so that Service users and carers know who they can contact out of hours. Consideration needs to be given as to how this can be included in an individuals care plan.</li> </ul>
		<ul style="list-style-type: none"> <li>✓ Emotional help and support and/or counselling should be readily available to carers coping with the loss of the people they have cared for – whether as a result of a move to permanent residential care or bereavement.</li> </ul>
		<ul style="list-style-type: none"> <li>✓ The Care Pathway should be extended to address continuing help and support available to carers following the death of the person they have cared for.</li> </ul>

## Theme 7

<p>To ensure a person centred approach to the provision of services.</p>	<p>Carers want to be better equipped to provide care themselves; dissatisfaction with the quality and accessibility of respite; limited awareness of Direct Payments; need for services to better understand their clients as people.</p>	<ul style="list-style-type: none"> <li>✓ Training and practical information should be available to assist carers. Training should take place alongside health and social care staff where appropriate and should cover practical issues like lifting, personal care etc.</li> </ul>
		<ul style="list-style-type: none"> <li>✓ A review of respite provision should be undertaken to ensure that existing services being offered and resourced actually match the needs of carers and can be accessed by those wishing to make a booking.</li> </ul>
		<ul style="list-style-type: none"> <li>✓ Further work should take place to promote awareness of Direct Payments and to provide assistance and support to those carers who choose to use this approach.</li> </ul>

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## Theme 7

		<ul style="list-style-type: none"> <li>✓ Initiatives should be considered to help and encourage carers to work with the person they care for to record information about themselves, their likes, dislikes, interests etc. Together with information such as the Mental Health Foundation’s checklist referred to in section 4.4 of this report, this could provide a valuable source of information for health and social care professionals across both primary and acute sectors which enable services to be centred on the needs and preferences of the individual.</li> </ul>
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## Theme 8

<p>To ensure that services provided continue to appropriately meet the needs of service users and carers.</p>	<p>No clearly defined standard for when a reassessment of needs will take place; Service users and carers unaware of review process; review process doesn’t systematically measure impact and efficiency of services being provided.</p>	<ul style="list-style-type: none"> <li>✓ The Pathway should identify that assessments should be reviewed at least 6 monthly. It should be explicit within the individual’s Care Plan when the next programmed review will take place and what to do if a reassessment is needed earlier.</li> </ul>
		<ul style="list-style-type: none"> <li>✓ The review process should, as a minimum, involve discussion with the service user or carer to prompt their comments on whether the services being received are still the right ones to meet their needs. Service users or their carers should have a record that a review has taken place and be able to understand any changes to the services being received.</li> </ul>
		<ul style="list-style-type: none"> <li>✓ The review process should be outcome focused – it should seek to measure the impact and efficiency of the arrangements put in place to help the service user and carer. A systematic approach such as using the Mental Health Foundation’s Carers’ Checklist (or similar) could help towards achieving this.</li> </ul>

## Theme 9

To ensure that there are longer term drivers to ensure that the Pathway is embedded in services and results in better outcomes for people with dementia and their carers.

Frustration amongst many professionals that these issues have arisen time and time again but that an all systems approach has not been adopted to resolve them.

- ✓ The Older People's Partnership Board be invited to develop an action plan in response to this report, setting out proposed actions and timescales
- ✓ Specific service objectives and performance measures be identified across the health and social care community reflecting key service aims and service user/carer needs. Baseline measures should be established against which to measure progress on an ongoing basis
- ✓ The Health and Adult Social Care Overview and Scrutiny Committee should regularly review progress against the action plan and, in due course, in performance standards.
- ✓ The Health and Adult Social Care Overview and Scrutiny Committee should appoint a Member Champion to take the work of this Panel forward.

“ Dementia isn't a condition which can be neatly pigeon holed as the responsibility of one or two specialist organisations – every organisation involved in providing services to older people in Cornwall will need to have the skills, knowledge and understanding to care for people with dementia. ”

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# 1 Introduction

Dementia affects us all – friends, neighbours, relatives, young and old alike. But especially here in Cornwall, with a growing elderly population, we have a large number of sufferers and their carers.

Now it is Time for Action – to work together in partnership to ensure that all our residents with dementia as well as their carers are receiving the right support at the right time and in the right place. A shared care pathway for people with dementia in Cornwall and the Isles of Scilly was produced in April 2004 by Cornwall County Council and Cornwall Partnership NHS Trust.

The Health and Social Care Overview and Scrutiny Committee set up a Steering Group to evaluate the progress of the Pathway. The task was undertaken as part of an Action Learning project funded by the Centre for Public Scrutiny. The Steering Group consisted of County Councillors, District Councillors and representatives of Cornwall's Patient and Public Involvement Forums. We are very grateful for the support provided by the health and social care practitioners who have worked with us on this project, and also for the research support from our Senior Policy Officer as well as the administrative support from our Committee Services staff.

We aimed to provide recommendations which would lead to improved services for older people with mental health needs

in Cornwall and particularly for those with dementia. Our consultation was varied and included a carers' survey, focus groups, research within organisations and a consultation event which brought together a wide range of stakeholders.

It is due to the dedication and commitment of all involved in this project that we have such a detailed and concise report that is my pleasure to commend to you.

We have received a lot of enthusiasm for this report and by working together we can achieve a lot more and provide more that is needed to improve the wellbeing of our older people with dementia.

**Joyce Mepsted**  
*Care Pathways Steering Group Chair*

“ We have received a lot of enthusiasm for this report and by working together we can achieve a lot more and provide more that is needed to improve the wellbeing of our older people with dementia. ”

## 2 The Project

### 2.1 Background

Our work on the Dementia Care Pathway started back in November 2004 as the government launched its vision for person centred, proactive and seamless adult social care .

The care of older people with dementia and other mental health conditions had long since been highlighted as an issue for Cornwall's health and social care community. A dementia care pathway had already been developed and circulated by Cornwall's health and social care community and had received national acclaim. However there were still some distinct challenges – integrating the pathway into working practices of health and social care organisations throughout Cornwall (GP surgeries, Social Services offices, hospitals etc) has proven difficult and the document's style and content as a professional tool makes it inaccessible to many of the very people who need most to understand what's going on – the service user and carer themselves.

The opportunity to undertake an action learning project supported by the Centre for Public Scrutiny presented the impetus to undertaking a detailed review with a wide range of partners to look at how services for people with dementia and their carers could be improved and better focused upon their needs.

The project has been managed by a Steering Group including County Council and District Council Members of the Health and Adult Social Care Overview and Scrutiny Committee and representatives of each of Cornwall's five Patient and Public Involvement Forums. This group has worked closely with a team of health and social care professionals representing Cornwall's NHS Trusts, Adult Social Care Services, the Strategic Health Authority and the Independent care home sector.

**We embarked on this project with some clear goals:**

- To identify areas in which the pathway should be further developed so that it more reflects the needs of service users and carers ;
- To explore ways in which the circulated pathway could be adapted to make it understandable and accessible to service users and carers;
- To examine how awareness of the pathway across health and social care organisations could be increased and the pathway integrated into their working practices.

### 2.2 Our Approach

A brief summary of the key stages of the Steering Group's work is set out on the next page.

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# taking the dementia care pathway **forward**

## Understanding Care Pathways event - November 2004

This event effectively launched the Steering Group's work. It brought together the Overview and Scrutiny Committee, Patient and Public Involvement Forums and representatives of health and social care organisations in Cornwall to develop an understanding of the concept of care pathways, the specifics of Cornwall's dementia care pathway and the national picture of care for older people with mental health needs.

## Carer focus groups – May 2005

Three focus group meetings were held with carers of people with dementia. The meetings took place at venues across Cornwall and aimed to identify issues which could be explored more widely in a County-wide survey of carers.

## Consultation with health and social care organisations – May 2005

Patient and Public Involvement members of the Steering Group carried out interviews with key staff within their Trust to find out about services provided for people with dementia and their carers, the degree to which the care pathway is known and used and any barriers which prevent its use. A District Council member of the Steering Group undertook similar research within the Department of Adult Social Care.

## Consultation with service users – June 2005

Dementia Voice, a voluntary sector organisation experienced in working with people with dementia undertook a series of consultation events with service users. Working with Age Concern and the Cascade Theatre Group, three workshop events were organised in different parts of the County. Through the use of comedy and reminiscence, service users and their carers were encouraged to share their experience.

## Carers' Survey – July 2005

The issues raised by the focus groups were used to develop a detailed questionnaire which was sent out to approximately 400 carers of people with dementia in Cornwall.

## Stakeholder conference – September 2005

This event was the culmination of the Steering Group's work - aiming to bring everyone and everything together. Representatives including senior managers, Board members and front line staff from health and social care organisations across Cornwall, housing providers, independent care home operators, district and county councillors, carers and voluntary sector agencies attended and together identified priorities for action. The outcomes of this day form the basis for the recommendations set out in this report.

## Health and social care staff group

Throughout the project, the Steering Group has worked with a health and social care staff group comprising senior managers of Older People's Services from across the Health and Social Care Community. The Group has provided professional advice and expertise to the Steering Group at various stages of the project and served as a link to the Older People's Partnership Board, which has strategic responsibility for services for older people in Cornwall.

## Our report

To reflect that our work was an action learning project, our report is in two parts. The first part focuses upon the issues which our work has identified and our recommendations for action to address these. The second part of the report concentrates on the way in which we have undertaken the work and the lessons we have learnt along the way.

# Part one

Key findings and  
recommendations

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### 3 Building on firm foundations

Whilst the focus of our work has been about ways of developing the Dementia Care Pathway to ensure that it meets the needs of service users and carers, it has become clear that there is an important step which needs to take place first if the Pathway is to ever become something more than a glossy document.

To date, the Pathway has been developed and promoted by the organisations traditionally seen as responsible for the care of people with dementia – Adult Social Care and the specialist mental Health Trust – Cornwall Partnership Trust. However, true responsibility for the care of people with dementia extends well beyond the boundaries of these organisations, and in fact well beyond the boundaries of the health and social care community. The reality of dementia care is that it is everyone's business – public, private and voluntary sectors, local communities and individuals. Real improvements in the lives of people with dementia and those who care for them will only be possible if we all work together with the common goal of achieving this.

We've witnessed two common features in the individuals and organisations we have worked with in carrying out this project. The first has been an overwhelming desire to make things better for people living with

dementia – the dedication and commitment of the carers and those working to provide services for people with dementia is indisputable. The second however, has been frustration that despite this commitment and real efforts to improve things – like the development of the Pathway – not a lot has actually moved forward. The feedback we received from our survey and discussions with service users and carers reflected the same kinds of concerns and difficulties that had been reported by District Audit back in 2000, and those working with people with dementia reflected frustration that their ideas and suggestions had been voiced countless times before and yet nothing on the ground had really changed.

Despite this County wide desire to improve services for people with dementia, there are no specific shared goals or objectives, no processes to ensure that agencies are working to common standards, no effective mechanisms for bringing all agencies together to develop services holistically and no methods of measuring how well services are collectively performing in meeting service users and carers' needs.

It seems therefore, that before looking at the detail of enhancing the Pathway, the most fundamental step needs to be to establish the foundations which will allow a shared

“ Real improvements in the lives of people with dementia and those who care for them will only be possible if we all work together with the common goal of achieving this. ”

understanding and an ability to really work together in improving the lives of people with dementia and their carers. The recommendations in this section therefore focus upon establishing this foundation – ensuring mechanisms are in place which allow organisations to work together to the same goals, to communicate effectively with each other and with those receiving services and critically, to make the Pathway normal, everyday practice.

### 3.1 Dementia Collaborative

Our Stakeholder event brought together representatives from across a broad spectrum – NHS organisations, Adult Social Care, independent care homes, voluntary sector organisations, housing organisations and carers. It was widely acknowledged that one of the real successes of the day was in bringing everyone together to look collectively at ways of improving dementia care in Cornwall. At the end of an exhilarating day of sharing views, experiences and ideas, there was however a sense of frustration that this shouldn't just be a one off event and that there should be a mechanism by which we continue working together on an ongoing basis.

In other parts of the Country, this desire to maintain an ongoing partnership across organisations and involving service users and carers has been addressed through the development of a collaborative. Examples such as Dementia North demonstrate the potential effectiveness of such an arrangement. The strength of a collaborative

is in bringing together all of those people who have a part to play in improving the lives of people with dementia – from front line workers to community organisations to individual service users and carers – and removing boundaries between organisations and professional disciplines.

A collaborative is effectively a network, led by a Steering Group, providing a mechanism for collectively looking at the way in which services work, redesigning services around service users and carers' needs, and coordinating training and sharing good practice.

“ The reality of dementia care is that it is everyone's business – public, private and voluntary sectors, local communities and individuals. ”

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## The Dementia North Collaborative

The Dementia North Collaborative, by way of example, covers an area of four Strategic Health Authorities and involves 29 teams from the North East, Yorkshire and North Lincolnshire. The 29 teams involve people from over 60 Social Services, Primary Care Trusts and Secondary Care Trusts together with representatives from the voluntary and independent sectors and carers. Funding comes from the organisations themselves, the Department of Health regional office, local workforce confederations and sponsorship from pharmaceutical companies.

**The aims of the Dementia North model reflect the same needs and aspirations as Cornwall:**

- Increasing recognition of dementia, thus aiding earlier diagnosis and improving care management
- Improving the provision of information given to people with dementia and their carers
- Helping to ensure that dementia services are person centred
- Improving systems to explore patient and carer experience
- Helping to coordinate services between agencies

**Beneath these aims lie a series of measurable objectives which drive the activity of the Collaborative. These include:**

- % of GPs using an agreed protocol to diagnose, treat and care for people with dementia
- % of people with dementia and their carers to have their views taken into account when planning care and to receive a copy of their care plan
- % of people with dementia participating in activities matched to their needs and preferences
- % social work assessments commenced within 48 hours of referral and completed within 4 weeks
- % of care packages in place within 4 weeks of completion of assessment

**Examples of some of the projects undertaken by the Dementia North Collaborative include:**

- Development of guidelines for the detection, management and referral of dementia in primary care
- Improving the giving of information within memory clinics
- Involving carers in planning and the evaluation of care plans
- Piloting the introduction of life story boxes for clients in care homes
- Raising awareness of roles and promoting integrated working between PCT and Mental Health Trust staff

The Dementia North Collaborative represents a large scale and sophisticated model and its operating costs reflect this. However, with the commitment of Cornwall's health and social care community, it should be possible to develop a network without the need for that degree of expenditure.

The establishment of a collaborative in Cornwall – or potentially for the South West Peninsula - would provide the opportunity to ensure an ongoing dialogue between those people with an interest in dementia care and a mechanism for designing consistent and appropriate services to meet the needs of people in Cornwall and then ensuring that these are mainstreamed across the County's organisations.

### 3.2 Dementia web site

There have been a number of challenges in embedding the dementia care pathway into everyday practice:

- The published document was aimed at a professional health and social care audience – its style, format and language made it mainly inaccessible to other agencies and those at the receiving end of services;
- Its published format meant that it wasn't easy to update;
- Those receiving a copy weren't necessarily signed up to using it;

### Recommendations

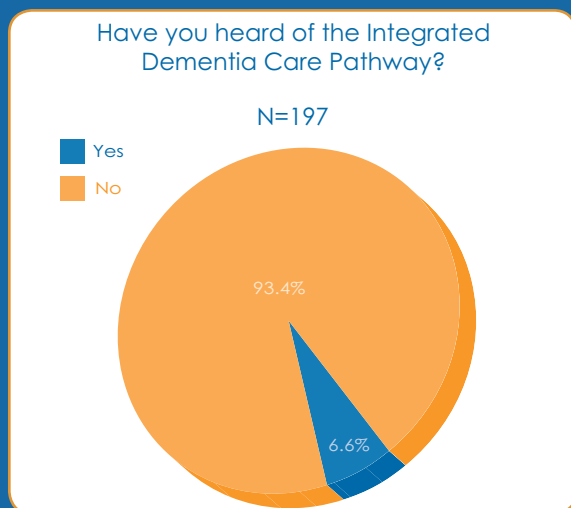
- ✓ The Older People's Partnership Board should receive further information about the work of existing Dementia collaboratives and use this to inform a feasibility study into the development of a dementia collaborative for Cornwall.
- ✓ It is vital that the health and social care community in Cornwall collectively agree common aims, objectives, standards and targets for the care of people with dementia and their carers, and develop mechanisms for monitoring and evaluating performance.
- ✓ All agencies involved in the care of people with dementia should be encouraged to formally sign up to the use of the Pathway as a framework for care and ensure its adoption at a primary care level.

- There was no mechanism for ensuring that the document was used;
- It was all too easy for organisations to shelve the document and forget about it.

Our conversations with health and social care professionals showed a wide disparity in their awareness and use of the Pathway. Staff working in Adult Social Care Services, one of the partner organisations in developing the Pathway, described the Pathway as their bible and considered that it formed the basis for the way in which their

services were delivered. Awareness within NHS organisations was more variable and discussions with GP surgeries suggested that its use here was minimal. Probably unsurprisingly, only a handful of the carers we surveyed had heard of the Pathway.

The possible reasons for the slow adoption of the pathway are explored in the cause and effect diagram on page 20.



Measures need to be taken to embed the pathway into everyday practice. If it is to be useful and usable, the Pathway needs to be “alive” – it needs to be up to date, easily at hand and designed in a way that it provides the right information to the right audience. GPs need to be referring to the Pathway when a person first presents with problems, organisations need to be using the Pathway to inform their decisions about information and services available, and service users and carers should use the Pathway as a signpost to sources of help and information and to

ensure that they too understand the steps which organisations should be taking to help them.

One mechanism for achieving this would be to develop the pathway into a dementia web site. Work has in fact already started to translate the existing Pathway document into an electronic based version that can become web based or a stand alone CD resource. However, it is important that the facility is not limited to simply being an electronic version of the existing pathway. It needs instead to be an interactive resource, designed in a way that the different stages of the Pathway allow access to information tailored to a variety of audiences – GPs, health and social care service providers, people with dementia, their carers and families, and other agencies.

A web site is clearly only one way of communicating the Pathway, and not an appropriate mechanism to make it accessible to everyone. It could however be very effective for those providing services or giving information and advice to service users and carers. It would ensure that all organisations, agencies and individuals could access a consistent, up to date source of information. Furthermore it would be an anchor for the work of the collaborative.

“With the exception of a small minority, carers hadn’t heard of the Pathway and a common issue highlighted was the need to understand “the process.””

### 3.3 Dementia Signposting Guide

Our survey of carers identified a real need for improved information. With the exception of a small minority, carers hadn't heard of the Pathway and a common issue highlighted was the need to understand "the process." Many carers needed much better information in the early stages of consulting their GP, they wanted to know who could provide help and emotional support, practical information about benefits and how to carry out their caring role, and importantly – what next? What action would the GP take? Who would be contacting them and when? What information would they need? What should they do if they couldn't cope?

There is an overwhelming need for a clearly written and designed guide for service users and carers, informing them in everyday language about the different steps of the Pathway and acting as a signpost to the organisations who may be able to provide more detailed information or assistance at each stage. The guide needs to be brief – carers have told us they don't have the time to read lengthy documents – and widely accessible through GP surgeries, agencies and organisations working with older people and through community outlets such as libraries and post offices.

“ Measures need to be taken to embed the pathway into everyday practice. If it is to be useful and usable, the Pathway needs to be “alive” – it needs to be up to date, easily at hand and designed in a way that it provides the right information to the right audience. ”

#### Recommendations

- ✓ A multi agency team involving carers should be established to continue the development of a shared Dementia web site for Cornwall. The web site should be based upon the Dementia Care Pathway and provide a range of information targeted at a variety of audiences - health and social care organisations, other agencies and people with dementia and their carers

One of the problems currently is the plethora of information available to carers. Information aimed at service users and carers is being developed independently by a variety of organisations and agencies in Cornwall. Whilst there may be benefits to organisations in developing literature tailored to their organisation, overall this results in duplication of effort and resources and leaves service users and carers with a bewildering choice of literature and the potential for receiving inconsistent advice.

A natural role for the Dementia Collaborative could be to review the information available about dementia and to rationalise this into a commonly branded set of information produced by the Collaborative rather than individual organisations. This would have the benefit of giving clear, consistent advice

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to carers and service users and saving the time and resources being expended by organisations across Cornwall in producing organisation focused literature.

The first step signposting guide referred to above should follow this approach. It needs to be a shared document, not attributable to any one organisation, used and promoted by all organisations and agencies involved in the care of people with dementia.

### Recommendations

- ✓ A multi agency team involving carers should develop a clear signposting guide for people with dementia and their carers. The guide should reflect the Dementia Care Pathway but be presented in a format and language which makes it accessible and easy to follow.

### 3.4 Single Assessment Process

Many carers shared with us their frustration at being visited by countless organisations, all asking for the same information from them. This duplication has been identified by organisations in Cornwall and work is in progress to develop a single assessment process.

This could provide another way of bringing the Dementia Care Pathway into practical day to day use. By reflecting the Pathway within the Single Assessment Process or Care Plan, it would be possible to chart the

individual's journey through its various stages – for example showing personalised information about details of other agencies, carers and family members involved in their care, timescales for reviews etc. This document could serve as a synopsis of the care arrangements for that individual, providing common information across agencies and to the individual and the carer themselves.

“ Many carers shared with us their frustration at being visited by countless organisations, all asking for the same information from them. This duplication has been identified by organisations in Cornwall and work is in progress to develop a single assessment process. ”

### Recommendations

- ✓ A part of the Single Assessment Process and/or Care Plan should be developed so that it reflects the Dementia Care Pathway and thereby charts an individuals' journey against its various stages.

### 3.5 Training

It's clear from the views expressed by carers that the standard of service received depends greatly on the motivation, skills and training of the staff providing care. This standard has been described as variable across the county. The consultation process has led us to believe that significant improvements will be seen in service provision if a standard level of training could be provided, across all agencies, to all people engaged in the care of people with dementia. A training strategy will need to consider the training needs of the large unqualified work force, and the professionally qualified workforce. The Truro College, nationally accredited care staff qualifications for working with people suffering from dementia is a local example of good practice. Additionally an organised training approach will need to be formulated to meet the needs of carers and wherever possible, joint training for carers and service providers should be offered to enable shared understanding. Building on the success of a number of service user focused groups across the county the training needs of people with dementia needs to be considered to enable them to adjust their lives to their changed health, ability and circumstances.

#### Recommendations

- ✓ The health and social care community should establish a training programme for all individuals engaged in the care of people with dementia. The development of such a programme should be informed by the Dementia Care Pathway and, where practical, should involve elements of joint training for service providers and carers.

we spoke to felt that decisions about their lives were being made by people they didn't know and without their involvement. There isn't currently any real consistent forum in Cornwall which enables carers and service users to voice their views as true stakeholders in service provision and to play an active role in the development and improvement of those services.

#### Recommendations

- ✓ The health and social care community should seek to establish forums for carers and service users to enable their voices to be heard

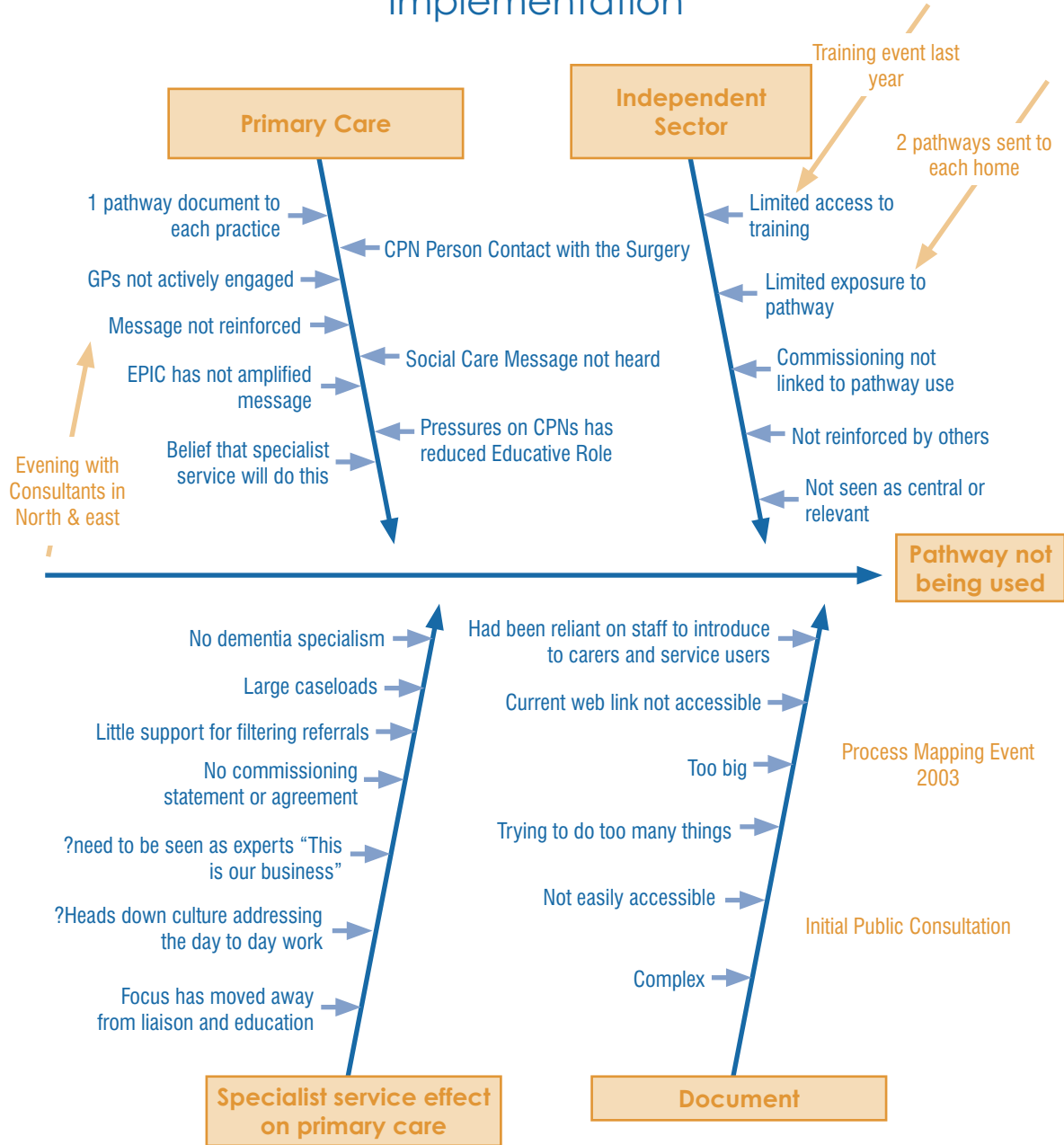
### 3.6 Forums for carers and people with dementia to be heard

Throughout our consultation with carers and people with dementia – we heard the same message time and time again – listen to us and what we want. Many of those

“ A natural role for the Dementia Collaborative could be to review the information available about dementia and to rationalise this into a commonly branded set of information produced by the Collaborative rather than individual organisations. ”

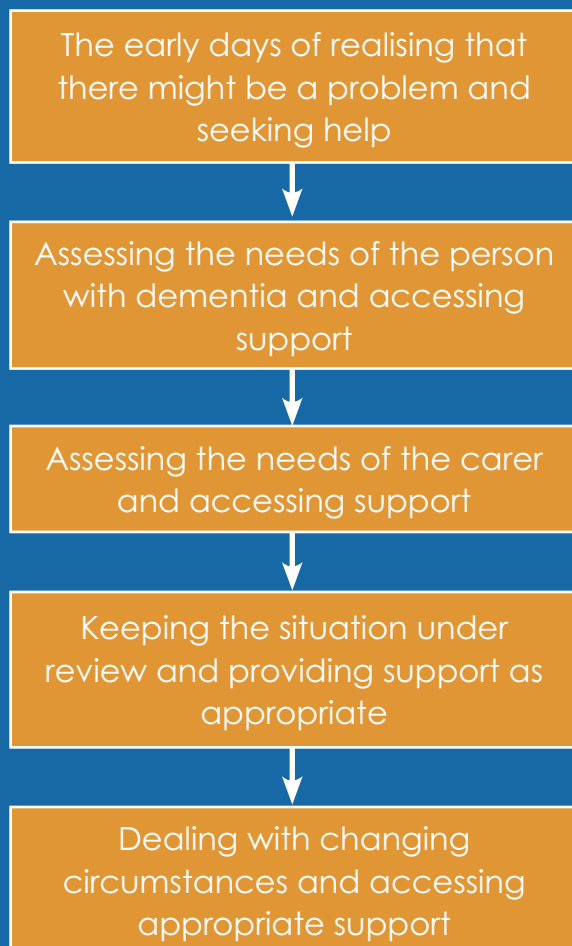
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## Dementia Pathway Cause and Effect of Challenges to Implementation



## 4 Aligning the Pathway to carers' & service users' needs

The Dementia Care Pathway incorporates the following key stages.



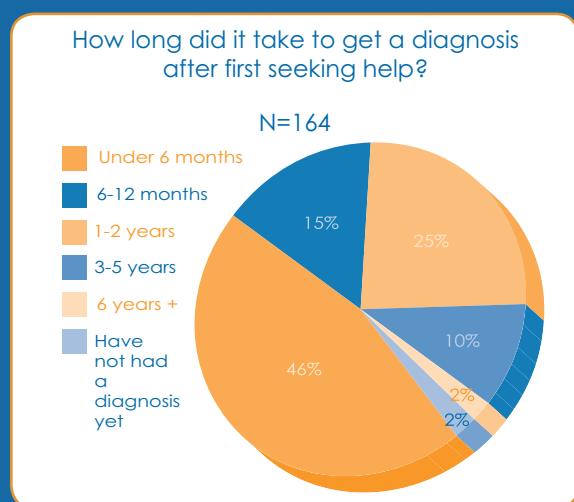
Our consultation with carers and service users has focused upon each of these stages, exploring their experiences, what was good and where things could have been improved. The following section of this report takes each stage in turn and reflects upon what carers and service users have told us and identifies ways in which the pathway could be enhanced to take better account of their needs.

### 4.1 Diagnosis and seeking help

A positive outcome from the survey of carers was that carers are generally seeking help as soon as they realise that there may be a problem - in the majority of cases via their GP. Carers' experience of approaching their GP differed greatly amongst those we spoke to - some had received an exemplary service - finding their GP receptive and quick to act in determining a diagnosis and referral to agencies who would be able to provide support. In other cases, carers' experiences had been very different - GPs unwilling to take action, long delays in getting a diagnosis (or never receiving one) and an absence of information about sources of help and support.

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The Audit Commission's report *Forget me Not*, published in 2002, reported that nationally two fifths of GPs were reluctant to diagnose dementia and that fewer than half used specific tests to help them diagnose dementia. The results of the carers survey suggest that getting a diagnosis may still be difficult - in 46% of cases a diagnosis was received within 6 months, however in a quarter of cases diagnosis had taken 1-2 years and for a further 10% the diagnosis took between 3 and 5 years. However, where a diagnosis had been made, it appears that the use of memory tests and/or scans was in place.



Some carers, usually where they were not the spouse of the patient, felt that they had been excluded from conversations with the GP. This was a particular problem where the patient presented well and the GP was not able to get a realistic picture of the difficulties being experienced. These carers told us

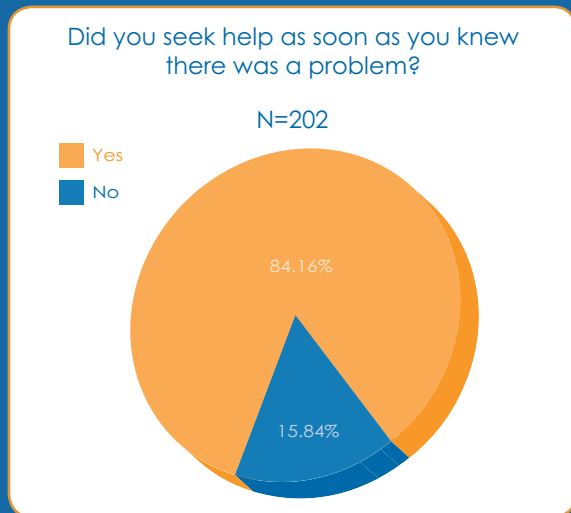
about the strain that this had caused them in having to cope with a situation which had not been recognised and for which help was not made available.

Access to information at the time of diagnosis also seems to be something of a lottery. GPs were generally considered to be the preferred source of information followed by Community Psychiatric Nurses and Social Workers. Some carers received good information and signposting to services, but a number told us that they had left their GP surgery without any idea of what would happen next or where they could go for help. Carers highlighted the following areas in which they felt they needed more information at the time of diagnosis:

- The nature of the diagnosis and the implications for themselves as carer
- How the diagnosis had been made and what other alternatives had been considered
- Help and advice available to the carer, especially any financial assistance which may be available
- The long term impact of the condition

Recently published guidance by the National Institute for Clinical Effectiveness (NICE) concerning the funding of certain Alzheimers drugs only when patients reach a moderate stage of the condition is likely to add additional concern and uncertainty for many people at the early stages of diagnosis.

“ A positive outcome from the survey of carers was that carers are generally seeking help as soon as they realise that there may be a problem - in the majority of cases via their GP. ”

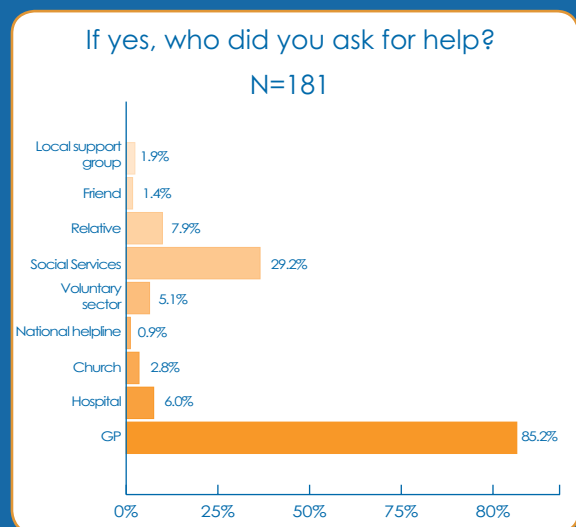


The role of the GP as the general first point of contact for people seeking help is key. They effectively serve as the “gatekeeper” to the dementia care pathway and it’s therefore essential that this first stage is working effectively.

Research by the Dementia North Collaborative suggests that difficulty in getting a diagnosis isn’t limited to Cornwall. This research found that concerns amongst GPs in making an early diagnosis included:

- The fear that giving a diagnosis will lead to distress
- A belief that there is no purpose in diagnosing dementia as there are no effective treatments available

- A concern that starting to diagnose everyone with dementia will “open the floodgates”
- Concerns about the length of time it takes in a consultation to carry out cognitive tests
- Uncertainty about the difference between memory impairment as part of normal aging and dementia as a disease



People seeking help at this early stage should be entitled to receive a consistent level of service. It has been difficult to engage with GPs in carrying out this work, but feedback from a small sample of GP practices contacted suggested that there was relatively low awareness of the Dementia Care Pathway and that it isn’t currently

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being widely used. Experience from those responsible for the development of the Pathway has shown that attempts to embed the Pathway within practices have been challenging.

Possible ways to address the difficulties being experienced in getting a diagnosis could include:

- Reinforcing awareness of the Pathway amongst GPs through training;
- Making the Pathway a more accessible and interactive tool by presenting it via a website;
- Introducing rewards via the GP Contract as a means of encouraging good practice in dementia diagnosis;
- Seeking alternative arrangements, such as referring possible dementia cases to a specialist Practice Nurse who would have more time to be able to carry out a thorough diagnosis and provide the information that service users and carers need;
- Linking Dementia Support workers to GP practices to provide information, liaise with other agencies and organisations in arranging support, and as a source of emotional support.
- Reconfiguration of specialist mental health services to enable memory clinics to be developed to support GPs in making a diagnosis and advising on future treatment, support and care.

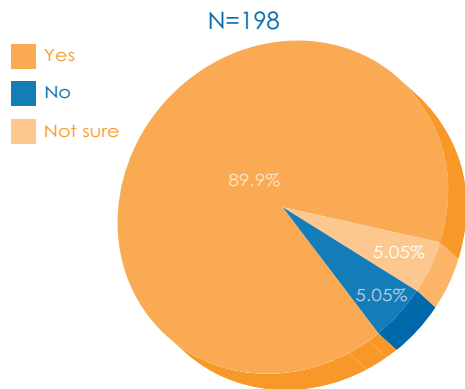
### Recommendations

- ✓ Further discussion should be carried out with GP surgeries in Cornwall to understand the reasons for the difficulties and delays in making a diagnosis.
- ✓ PCTs should work with GPs to explore the development of a lead professional for dementia within each practice.
- ✓ The establishment of a specialist practice nurse or a dementia care worker attached to a practice should be piloted and evaluated.
- ✓ This stage of the Pathway should be enhanced by:
  - explicitly identifying the steps to be taken at the point of first contact eg. information to be given to the patient/carer and sources of further help and support;
  - including prompts about the kind of information to be provided at the time of diagnosis reflecting on what carers have told us they need – details about the nature of the diagnosis, the implications for them as carer and the longer term impact of the condition, information about how the diagnosis was reached and sources of help and support.
  - Specifically triggering the GP to make contact with the Department of Adult Social Care to ensure that an assessment of care needs is offered and that the person with dementia and their carer are contacted by a Dementia Support worker.

## 4.2 Assessing the needs of the person with dementia and their carer

It seems that for the person with dementia, once a diagnosis has been made, the process of receiving an assessment to identify their care needs is working relatively well. In most cases this assessment is offered without the person or their carer having to ask and it is generally carried out by a Social Worker or Community Psychiatric Nurse (CPN).

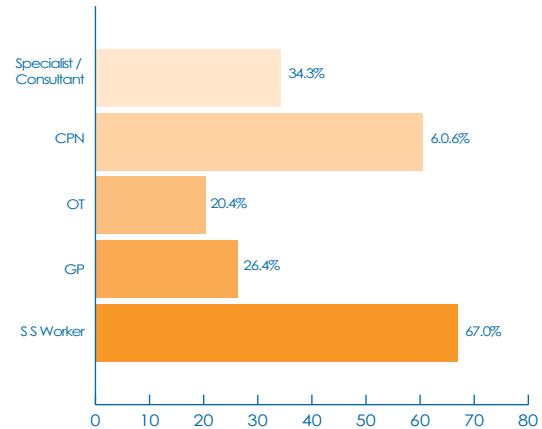
Has a formal assessment been undertaken to identify the needs of the person you care for?



The time taken between diagnosis and the assessment, however, seems to vary considerably. In a third of cases, an assessment had taken place within a month of diagnosis, another third had taken between two and six months. In 10% of cases, the assessment had taken more than 6 months. There does not appear to be a service standard determining the period within which the assessment should be offered.

If yes, by which professional?

N=194



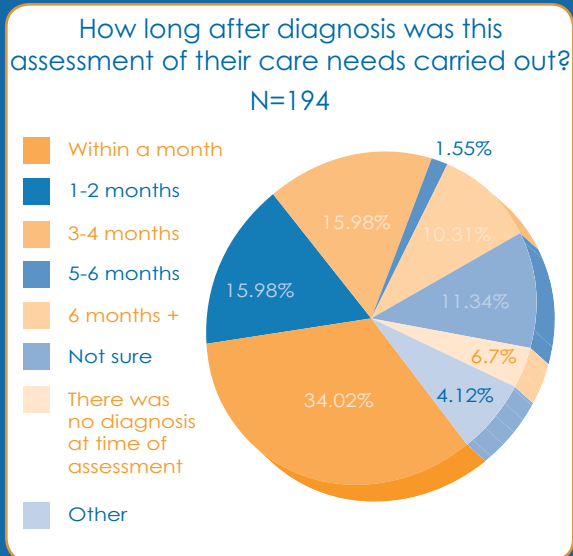
Feedback was positive about the clarity of the process and the extent to which the person undertaking the assessment had listened and explained the kind of services which may be available to help.

Carers are entitled to an assessment of their own needs too. This process doesn't appear to be working as well. Many carers don't realise that they are entitled to an assessment, many are not receiving an assessment, and some are only receiving one once they have specifically requested one. The role of carers is so important in maintaining the health and wellbeing of the service user that failing to look after their needs is short-sighted.

What is not clear from the consultation work is whether carers have in fact been offered an assessment at an early stage and turned the

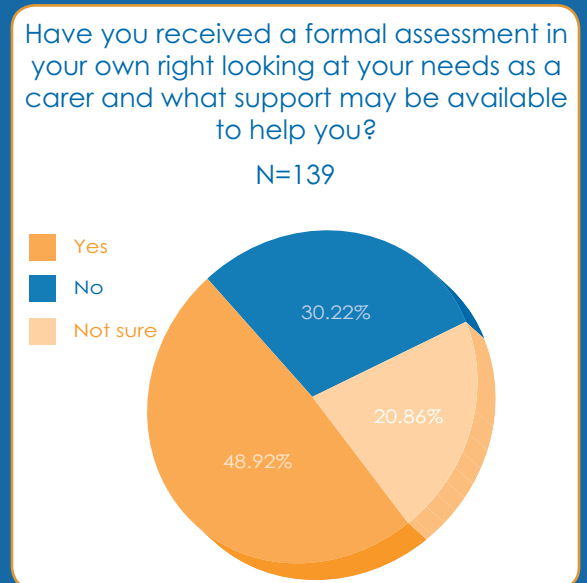
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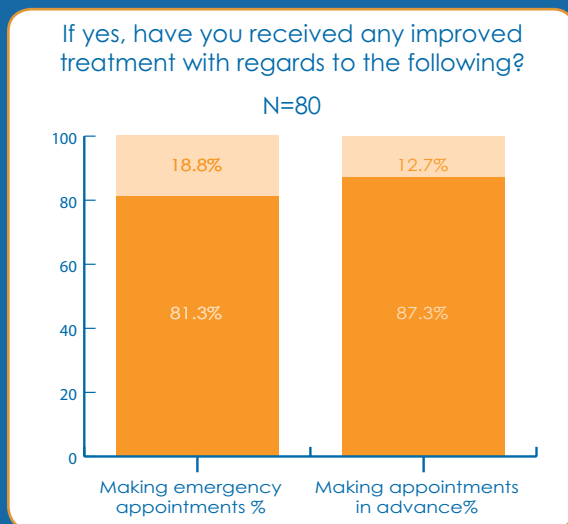
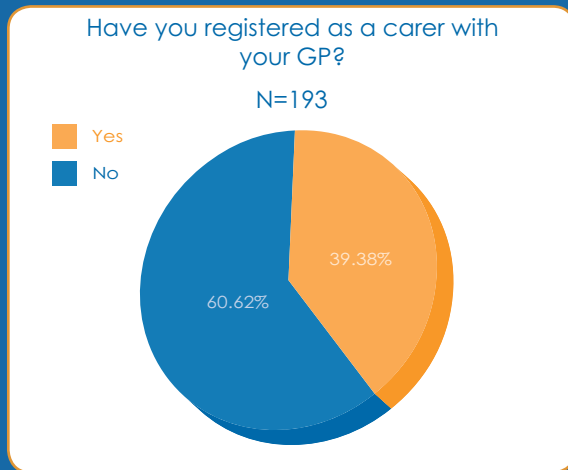
opportunity down. A number of the carers we spoke to had done so, coped well for a while but, as circumstances changed, found things more difficult and eventually reached crisis point. Carers like these can find themselves feeling “locked out” of the system – there is no process for periodically following up to make sure that they are still managing and still don’t feel they need an assessment. Time invested at this stage could help to stop such cases ever reaching a crisis situation.



Carers are generally also not aware that they should register with their GP as a carer and that this should ensure that the practice takes account of their circumstances when making appointments. Of those carers who were registered as a carer only a small number felt that they had received improved treatment with regards to making emergency or advance appointments.

The one need identified repeatedly by the carers we have spoken to which is not being met is “just someone to talk to”. Most carers are not keen to take part in support groups but many find themselves in need of emotional support. There is an appreciation that health and social care professionals are busy people and that they don’t have the time that carers may need. The Dementia Carer Support Workers are extremely valued by carers, but at the time of this work, there were only two posts covering the County meaning that their time is spread very thinly too. We have also learnt that in other areas of the county schemes exist to provide Community Psychiatric Nurses to work with carers, one example being the use of Admiral Nurses (<http://www.fordementia.org.uk/admiral.htm>).





An important part of the assessment process should be about seeking ways in which the service user and carer can be helped to maintain their independence for as long as possible. Traditional domiciliary services – help with washing, cooking etc – may be only part of the equation. Activities focused upon improving lifestyle and well being – for example, painting, walking, socialising could have a positive effect upon a person’s ability to prolong their independence,

and may prove to be a more cost effective option. An example which we heard of which demonstrated this was a case where a gentleman had been regularly receiving night sitting services because he was active throughout the night. By organising for the gentleman and his wife to take an accompanied walk each afternoon, it was found that he was no longer active overnight and the need for the sitting service was eliminated. Practical measures including the use of assistive technology within peoples’ homes also have a tremendous part to play in supporting safety and independence. Talking to the person with dementia and their carer to understand more about them as people, their likes and dislikes, lifestyle, hobbies and interests should form part of the assessment process. Care packages shouldn’t simply be focused on “traditional” methods of support and procurement arrangements should allow for the provision of a range of activities which can help the person and their carer retain their independence and their enjoyment of life.

It’s important that assessments take a rounded view of the person’s life and enable health and social care professionals to understand who else is involved in the person’s support and care. In talking to agencies outside of the health and social care community, we sensed a concern that often these agencies, although often significantly involved in the life of the person, were excluded from the picture and therefore found themselves unable to contribute to arrangements for the person’s care. Examples included Housing Wardens in sheltered housing accommodation who felt that they could have provided useful information or assistance in the assessment of needs, but had been excluded from the process.

### Recommendations

- ✓ There should be clear service standards, shared with service users and carers, for key stages of the Pathway – for example, the timescale within which an assessment of needs should be offered following referral.
  - ✓ The assessment process should prompt consideration of non traditional support services - for example walking, art, social outings – and appropriate links should be established with the voluntary sector in order to commission suitable services.
  - ✓ There needs to be a robust process for ensuring that an assessment is offered to all carers. Where a carer declines an assessment, it should be made clear that they are entitled to an assessment at any stage in the future if they feel it is needed and should be given information on how to arrange this.
  - ✓ PCTs should work with GPs to look at ways of encouraging routine, regular contact with carers registered with their practice.
  - ✓ A system should be introduced whereby carers routinely receive a periodic telephone call simply to make contact and confirm that they are ok. This should include those carers who have declined a carers' assessment and those who currently receive no support services.
- ✓ The resourcing of Dementia Carer Support Workers should be reviewed to ensure that an appropriate level of service is available across the County.
  - ✓ Funding put into carer support by agencies in Cornwall should be examined collectively to ensure that resources are being used to greatest effect and that appropriate planning is taking place for future levels of need.
  - ✓ Other approaches to support carers such as increasing befriending services provided by the voluntary sector, or setting up a mechanism for putting carers in touch with each other on a one to one basis should be examined.
  - ✓ As a part of the Single Assessment Process, carers should be identified and, if they consent, automatically registered as a carer with their GP. PCTs should be active in ensuring that GPs are aware of the ways in which they should be assisting carers upon the register.
  - ✓ Where relevant, other agencies involved in the care of the person with dementia and their carer – such as voluntary sector organisations, housing providers, social landlords – should be involved in discussions around the persons' care needs and ways of addressing these.

“ An important part of the assessment process should be about seeking ways in which the service user and carer can be helped to maintain their independence for as long as possible. ”

### 4.3 Provision of Services

Satisfaction was found to be generally high with services provided to help people with dementia and their carers, although again satisfaction with services provided for the person with dementia was higher than with those provided for the carer.

Many carers called for more practical guidance to help them to care effectively themselves. Most commonly, this was in the areas of advice as to how to lift a person safely and how to administer personal care. Investing in proactive advice of this nature will help to preserve the health and independence of service users and carers.

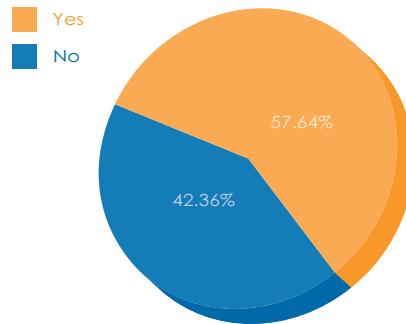
Respite services stand out as an area in which many carers feel dissatisfied. Feedback from the focus groups was reinforced by the survey results which show that whilst people are aware of respite available, uptake is relatively low. A number of carers told us that short term residential respite services was virtually impossible to access – they had found that they were unable to book places far in advance and that arrangements were subject to change – this made it impossible for them to book a holiday or to rely on a period of planned respite. The survey highlights concerns too about the quality of respite and the location/accessibility of establishments providing respite.

**29% of carers in our survey had never had a break from their caring role.**

It's essential that good respite services are there to give carers a chance to relax and have

Have you ever tried to arrange respite services?

N=203



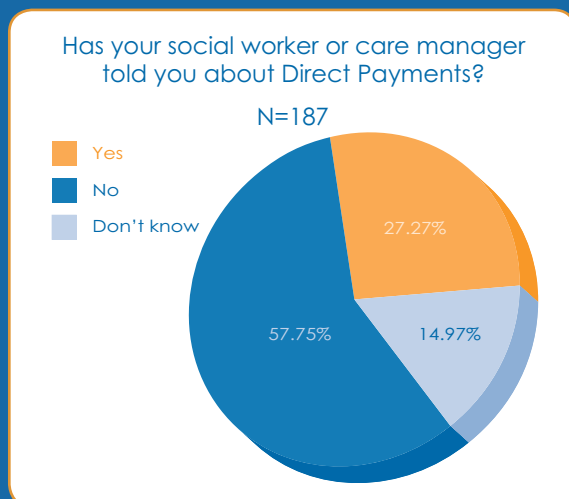
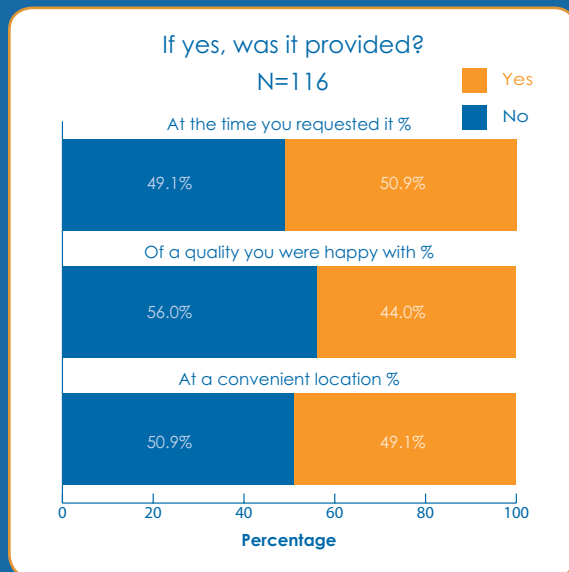
some time to themselves, and ultimately stay well and healthy and able to continue caring. Outside of residential respite, carers told us that the most useful services would be short (2 hour or so) breaks giving them an opportunity to do shopping or catch up on other jobs.

Paradoxically our conversations with health and social care organisations show frustration on their part that residential respite services are available, being resourced but not being used. There is a clear mismatch here and more work is needed to understand the reasons why respite beds are empty whilst carers are struggling to book them.

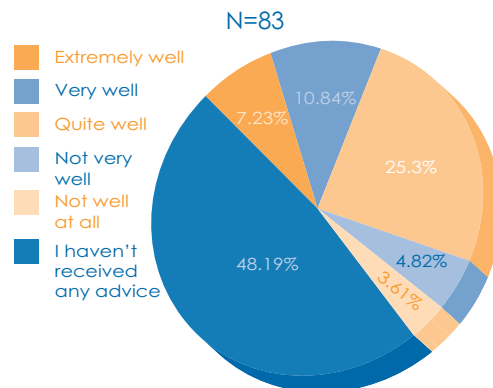
Awareness of Direct Payments as a means of independently purchasing services direct using money provided by Adult Social Care Services, appears to be relatively low amongst most carers. There were also concerns about the extent to which carers had received advice or support to help them in the use of Direct Payments. If the vision for use of

time for action

Direct Payments set out in the recent white paper Independence, Well Being and Choice, is to be achieved, the survey results suggest that further work is needed in this area.



Overall how well do you think you have been advised and supported in using Direct Payments?



## Recommendations

- ✓ Training and practical information should be available to assist carers. Training should take place alongside health and social care staff where appropriate and should cover practical issues like lifting, personal care etc.
- ✓ A review of respite provision should be undertaken to ensure that existing services being offered and resourced actually match the needs of carers and can be accessed by those wishing to make a booking.
- ✓ Further work should take place to promote awareness of Direct Payments and to provide assistance and support to those carers who choose to use this approach.

## 4.4 Keeping the situation under review

The Pathway reflects the importance of ongoing review of the care needs of people with dementia and their carers. Indeed, for the carers we spoke to, one of the most important needs highlighted was for routine, regular contact with someone who wanted to check that they were ok and coping. For many there was a feeling that they shouldn't "trouble" their Social Worker or Community Psychiatric Nurse because they were busy and a tendency therefore to just carry on alone. A number of carers also told us that, through pride, they didn't like to ask for help but that they wished someone would offer it.

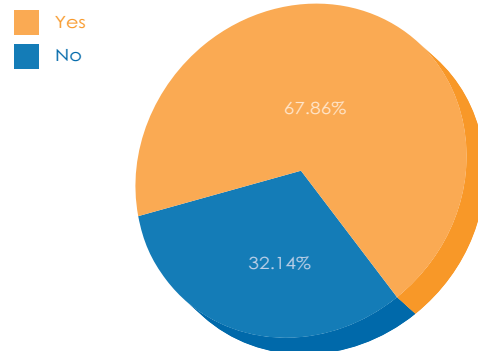
Most service users are however receiving a regular review – although a concerning 32% of carers responding to our survey told us that no review had taken place for the person they care for. For carers, the picture was less satisfactory with over half of the carers surveyed reporting that the assessment of their needs had never been repeated.

It is concerning that in so many cases, service users and carers are not aware that there has been any periodic review of their care needs. Feedback from those working in the health and social care community suggested that the reviews probably were happening but that these may be undertaken in some circumstances as a desktop exercise based on file notes or the caseworker's knowledge of the case. In such cases it may not be explicit to the service user and carer that a review has actually taken place. Knowing that a review

is happening and that there is an opportunity to highlight any concerns or changing needs is important to carers and the process should be clear and transparent to them.

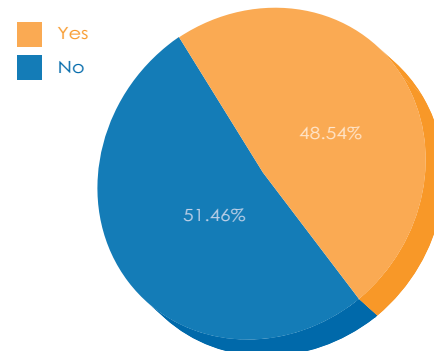
Are regular reviews of changes of circumstances carried out for the person you care for?

N=196



Has your carer assessment been repeated on a periodic basis to look at any changing circumstances or additional support needs?

N=171

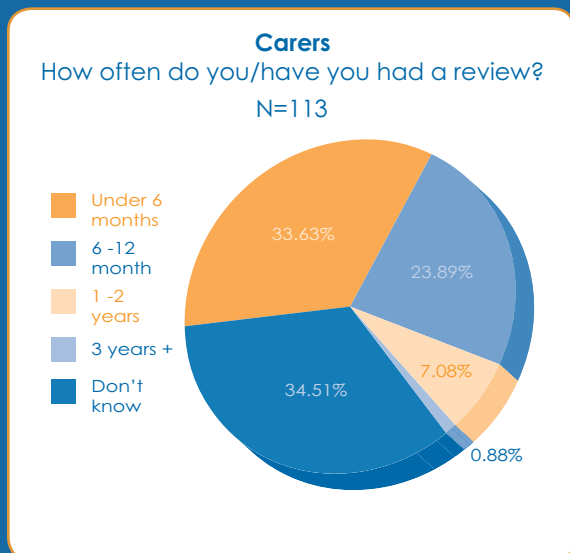
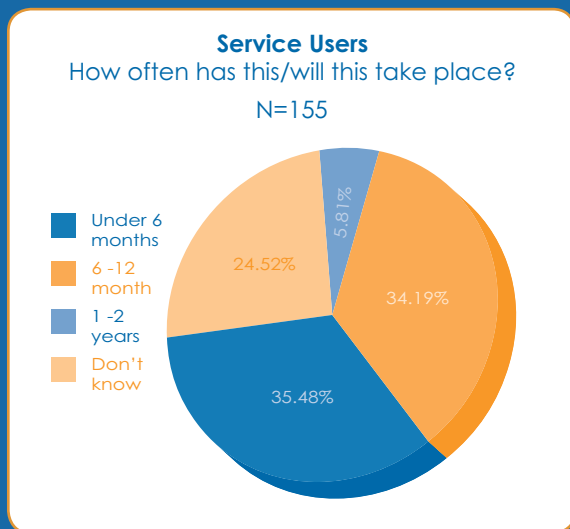


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Although routine reviews are a clear element of the Pathway, the frequency of these and responsibility for undertaking them isn't specific and this may contribute to the uncertainty amongst carers.

There will always be a need to take account of individuals' circumstances, but the Pathway should provide an indication of the appropriate minimum frequency for reviews. Individuals' care plans should provide more information tailored to the person's own circumstances identifying specific review dates.

The review process, whilst assessing any changes in needs currently doesn't provide a basis for measuring the effectiveness of the services put in place. The Mental Health Foundation has published a carers' checklist which encourages carers to identify features in the behaviour of the person they care for, the frequency of this behaviour and the degree to which they find dealing with each aspect stressful. Completed as part of the initial assessment and then periodically during reviews, this would serve to benchmark the areas which the carer was finding difficult to deal with, enable health and social care workers to identify help to tackle these specific areas and then to subsequently measure whether the services put in place had made a positive effect in helping the carer. The review process could also be a useful mechanism in surveying performance in achieving service standards.



## Recommendations

- ✓ The Pathway should identify that assessments should be reviewed at least 6 monthly. It should be explicit within the individual's Care Plan when the next programmed review will take place and what to do if a reassessment is needed earlier.
- ✓ The review process should as a minimum involve discussion with the service user or carer to prompt their comments on whether the services being received are still the right ones to meet their needs. Service users or their carers should have a record that a review has taken place and be able to understand any changes to the services being received.
- ✓ The review process should be outcome focused – it should seek to measure the impact and efficiency of the arrangements put in place to help the service user and carer. A systematic approach such as using the Mental Health Foundation's Carers' Checklist or could help towards achieving this.

### 4.5 Dealing with changing circumstances and accessing appropriate support

It's likely that at some stage of the caring process, circumstances will change – whether this be a short term admittance to hospital for another health matter, a crisis situation where the carer is not able to continue to provide care, a move into residential care or the death of the person with dementia.

Carers were generally positive about short term admittance to hospital although there was a common feeling that such a move can be disorientating and heighten confusion in the person with dementia and that stays should not be prolonged unnecessarily. There were concerns about what would happen to the person they care for if they, as full time carer, required a period in hospital.

Looking after a person with dementia on an acute hospital ward brings with it many challenges for the hospital staff. Training in the care of people with dementia is essential for a wide range of health professionals across the health community, not simply those working in organisations which specialise in mental health.

On a practical level, staff working in hospitals in Cornwall told us that they needed much better information about the person with dementia when they enter hospital so that their care needs can be understood. The introduction of an initiative to help the person with dementia and their carer to maintain some kind of log or diary of their life, maybe as a component of their care plan, could be useful in tackling this issue and could also have a number of other tangible benefits for the individuals and the organisations responsible for their care. In the work carried out by Dementia Voice on our behalf, people with dementia and their carers were encouraged through activities to record key milestones in their lives, the things they have enjoyed doing and the things they have liked and disliked along the way. The exercise had so many positive aspects – stimulation of memories, working

together as husband and wife or mother and daughter, laughter and fun and a product which provided an excellent basis upon which to plan services based on them as an individual.

Falls were highlighted as another common difficulty when a person with dementia enters a hospital environment. Staff have the difficult job of making a judgement about the safety of allowing an individual to wander around the ward, and we were told about the number of cases where individuals had subsequently fallen, broken their hip and then endured a lengthy stay in an unfamiliar environment resulting in a longer term deterioration in their condition. We were told that whilst relatively low cost preventative measures such as hip protectors exist and would help the situation, they are in short supply.

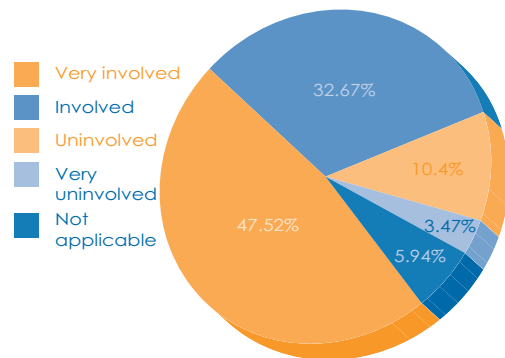
Worryingly, nearly half of the carers responding to our survey told us that they wouldn't know what to do in a crisis situation where they are, for whatever reason, unable to provide care.

We understand that Adult Social Care provide on call officers who can be contacted in a care crisis, likewise there is an on call psychiatrist who can advise GPs out of hours if needed. Enabling service users and carers to understand the services that are available and how to contact them is a much needed measure. It is essential that information is readily available to carers advising them of what action to take in a crisis situation.

Most carers felt that they were involved and included in decisions being made about the future care needs of the person they care for, however some felt excluded from case conferences and wished to have greater involvement in that process.

To what extent do you feel involved and included in decisions being made about the future care needs of the person you care for?

N=202



Involvement in case conferences was also raised as a concern by other agencies. There was a concern amongst a number of those working in the voluntary sector and other agencies outside of mainstream health and social care services that they were viewed as “amateur” organisations and therefore not involved in processes such as case conferences. This is a source of frustration to those agencies who feel that they could make a meaningful contribution to the process and assist the statutory service providers in their role.

A permanent move by the person with dementia into residential care can be an immensely traumatic experience for the carer. Those we spoke to described their feelings as a bewildering mixture of relief, devastation and guilt. At this stage they needed emotional support, honest advice and someone to talk to. Many however, felt that this need wasn't met and that once the person they had cared for had entered residential care, their needs as carer were no longer seen as anyone's business. Health and Social Care organisations need to be proactive in working with the voluntary sector to ensure that emotional support and, if appropriate, counselling is made available to carers in this situation, if needed.

We met some carers through the focus groups whose partners had died. Their needs were particularly acute – feelings of remorse, loss and having let their partner down. The Care Pathway does not currently address the issue of bereavement and role of organisations in caring for the carer during, and following, this time. This should be added to the Pathway and should again involve close working with the voluntary sector. Proactive help and support at this stage will ensure that the carer can re-establish an independent lifestyle and keep well and healthy.

“Most carers felt that they were involved and included in decisions being made about the future care needs of the person they care for, however some felt excluded from case conferences and wished to have greater involvement in that process.”

## Recommendations

- ✓ Initiatives should be considered to help and encourage carers to work with the person they care for to record information about themselves, their likes, dislikes, interests etc. Together with information such as the Mental Health Foundation's checklist referred to in section 4.4 of this report, this could provide a valuable source of information for health and social care professionals across both primary and acute sectors which enable services to be centred on the needs and preferences of the individual.
- ✓ The resourcing of equipment aimed at preventing injuries and potentially saving much greater costs if an injury occurs, such as hip protectors, should be reviewed, calling on the evidence base to support this.
- ✓ Clear sign posting needs to be developed so that service users and carers know who they can contact out of hours. Consideration needs to be given as to how this can be included in an individual's care plan.
- ✓ Emotional help and support and/or counselling should be readily available to carers coping with the loss of the people they have cared for – whether as a result of a move to permanent residential care or bereavement.
- ✓ The Care Pathway should be extended to address continuing help and support available to carers following the death of the person they have cared for.

## 5 Keeping the Pathway alive

Many of the recommendations within this report have the aim of mainstreaming the Dementia Pathway into normal practice and establishing mechanisms which allow the Pathway to be shared and collectively developed by all of those agencies and individuals involved in dementia care.

The Health and Adult Social Care Overview and Scrutiny Committee and the Older People's Partnership Board have an important part to play in ensuring that the Dementia Pathway is kept alive – by directing the action required in response to the recommendations in this report, monitoring the performance of services in achieving service standards and targets and in reviewing outcome measures to see the impact of the services being provided.

The time to act on these recommendations could not be better as many of the concepts put forward by the group are encapsulated in "Every Body's Business", (Care Services Improvement Partnership, 2005) the most recent central guidance on multi-agency approaches to the care of people with dementia.

### Recommendations

- ✓ The Older People's Partnership Board be invited to develop an action plan in response to this report, setting out proposed actions, timescales and lead organisations.
- ✓ Specific service objectives and performance measures be identified across the health and social care community reflecting key service aims and service user/carer needs. Baseline measures should be established against which to measure progress on an ongoing basis.
- ✓ The Health and Adult Social Care Overview and Scrutiny Committee should regularly review progress against the action plan and, in due course, in performance standards.
- ✓ The Health and Adult Social Care Overview and Scrutiny Committee should appoint a Member Champion to take the work of this Panel forward.



# Part two

## Action Learning

time for action

## 6 What we have learnt along the way

This health scrutiny project has been unusual in that it has involved two distinct activities – firstly the substantive review of services for people with dementia and their carers, and secondly a review of the scrutiny process itself, reflecting, as it has progressed, upon what has worked well and what we'd do differently given another opportunity.

As one of nine national action learning projects, we were fortunate in being awarded funding for this work by the Centre for Public Scrutiny. They will be using the experience from our project to help inform other Councils with responsibility for scrutinising local health services.

This part of the report looks at each stage of our project – our approach and what we have learned.

### 6.1 The Care Pathways Steering Group – December 2004 to December 2005

Cornwall's Health and Adult Social Care Overview and Scrutiny Committee includes County Councillors and District Council Members representing each of the six districts in the County. Usually, projects such as this one would be undertaken by a Single Issue Panel – effectively a sub

group of the main Committee – involving 5-10 County Councillors and 2 District Councillors.

We used the Action Learning Project to try something different. The Steering Group was set up to include the usual mix of County and District Members, but additionally, one representative of each of the six Patient and Public Involvement Forums (PPIFs) in Cornwall was co-opted. The County Council's Constitution dictated that only the County and District Members could have voting rights at meetings and that the Chair and Vice Chair of the Group must be a County Councillor. The Group met formally on seven occasions at the County Council's headquarters in Truro and members of the Group were actively involved in the various consultation events and informal meetings which took place at venues around the County.

The Group worked to a Terms of Reference (Appendix 1) set by the Committee and developed a project plan mapping out the timetable for the various elements of the project (Appendix 2).

During May 2005, at the mid point of the Steering Group's work, County Council elections took place resulting in a complete change in the County Council membership of the Steering Group.

## Our reflections and learning points

<p>✓ When the project was originally scoped, the aim had been to review care pathways for older people. We quickly realised that this brief was much too broad and we needed to focus on a particular area of older people's care. Through discussions with staff working in the health and social care community, it was evident that there were many concerns about organisations' having difficulty managing the care needs of people with dementia and the project was therefore re-scoped accordingly.</p>	<p>✓ One of the biggest challenges to the project was the lack of continuity in membership of the Steering Group. The County Council membership of the Steering Group changed completely following the County Council elections and PPIF representation had changed following the resignation of two Forum members. This presented a steep learning curve for new members joining the project at its mid point, and meant that different members of the group had varying degrees of knowledge and experience of the work undertaken.</p>
<p>✓ The philosophy of pooling resources has been positive – the OSC could bring to the partnership a level of resources and staffing support not available to the PPIFs and its powers to call upon information from NHS managers, whilst the PPIFs could contribute their knowledge of Trust activity and their rights of access to GPs.</p>	<p>✓ Although the membership was different, the approach of the Steering Group was largely the same as one of the Council's Single Issue Panels. PPIF members found this approach to be more formalised than they expected or were used to. The structure of reports and notes of meetings were also seen as more formal than within Forum meetings.</p>
<p>✓ The project has provided an excellent opportunity for Members of the Overview and Scrutiny Committee (OSC) to work alongside representatives of the Patient and Public Involvement Forums (PPIFs) – the experience of joint working has been rewarding.</p>	<p>✓ The level of involvement of the five PPIFs varied – some Forums were able to attend all meetings and were actively involved in the Steering group's work. Some however, found the time and work commitment too great and participated to a lesser degree.</p>
<p>✓ Despite the cultural differences, both OSC and PPIF members considered themselves to be part of a single Group. Additionally, Forum members felt that joint working with the OSC gave them greater legitimacy.</p>	<p>✓ The Steering Group felt that it should have met more frequently. The absence of meetings over the period of the County Council elections and the appointment of new membership was not ideal.</p>

## Our reflections and learning points

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| <ul style="list-style-type: none"> <li>✓ It would be fair to say that the joint working has led to some culture clashes reflecting the different approaches of the County Council and the PPIFs. PPIF members found the restrictions of the Council's Constitution bureaucratic and an obstacle to true partnership in the disparity of voting rights and opportunities to chair the Group.</li> </ul> | <ul style="list-style-type: none"> <li>✓ Relationships between County Councillors and their officer support was observed to be different from that of the PPIF members and their support staff. It was perceived that the Councillors made decisions and officers offered advice when requested and then actioned decisions, whereas PPIF members had an informal relationship with their support staff</li> </ul> |
| <ul style="list-style-type: none"> <li>✓ A positive impact of the change in membership was that it gave the Group a wider perspective and different ideas.</li> </ul>  |  |

## What we would do differently

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| <ul style="list-style-type: none"> <li>★ Some form of informal team building event at the start of the process might have been useful in breaking down boundaries between OSC and PPIF members.</li> </ul>  | <ul style="list-style-type: none"> <li>★ Establishing ground rules at the beginning so that everyone had a shared understanding of what was expected and a consensus about the approach to be taken.</li> </ul> |
| <ul style="list-style-type: none"> <li>★ Holding the meetings on neutral territory. Using the County Council's meeting rooms brought with it a culture associated with council meetings – agendas, minutes, speaking through the Chair etc – which stifled the opportunity to take a more informal approach.</li> </ul> | <ul style="list-style-type: none"> <li>★ Involving all members of the Group in the development of the terms of reference rather than imposing a remit already established by the parent Committee.</li> </ul>   |
| <ul style="list-style-type: none"> <li>★ Look at ways of making meetings less formal and building flexibility into the Council's constitution to allow us to be more innovative in the way our Committees operate.</li> </ul>   | <ul style="list-style-type: none"> <li>★ Meet more frequently – not just at key stages of the project.</li> </ul>   |

## 6.2 Health and social care staff group – December 2004 – December 2005

A group of health and social care staff was established as a source of ongoing technical assistance and expertise. It included:

- Sid Deeble - Older People's Lead Officer – West of Cornwall PCT
- Julie Green – Older People's Lead Officer – Central Cornwall PCT
- Tim Jones – Service Manager for Older People's Services – Cornwall Partnership Trust
- Mike Langshaw - Commissioning & Partnership Officer – Cornwall County Council Department of Adult Social Care
- Tracie North – Director of Operations and Quality – Cornwall Care
- Laura Wheeler – Older People's Services Workforce Development Manager - South West Strategic Health Authority (for part of the project)

The group met periodically with members of the Steering Group and maintained a regular dialogue with the County Council's Senior Policy Officer who was supporting the Steering Group. The group played a key role in assisting in the development of the carers' survey and in the planning and execution of the Stakeholder Event.

### Our reflections and learning points

✓ Working with the health and social care staff was invaluable – their involvement assisting in ensuring that the project focused on relevant issues and provided insight and understanding of the challenges being faced.

✓ The staff members reflected that this approach was a welcome opportunity to discuss important issues of service delivery without the constraints of organisational boundaries. The neutrality of chairmanship of the meetings prevented any one agency from dominating the discussion process.

✓ The informal meetings with the group achieved a much greater degree of productivity than formal meetings allowed.

## What we would do differently

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| <ul style="list-style-type: none"><li>★ Engage with health and social care staff at the earliest opportunity. At first there were concerns amongst some health and social care professionals that a duplication of effort was to be expended, that the challenges of creating a pathway for people with dementia was to be repeated. When it became clear that this was to be a process of honest reflection, learning and an opportunity to enhance the work already done the group came together with a clear aim to improve the experience for service users, carers and all those involved in the care and support of people with dementia.</li></ul> | <ul style="list-style-type: none"><li>★ The group would have benefited from including representatives from the acute and voluntary sectors and the involvement of GPs.</li></ul> |
| <ul style="list-style-type: none"><li>★ More informal meetings between the two groups to allow more discussion and a more productive environment.</li></ul>   |  |

### 6.3 Understanding Care Pathways Event – November 2004

This event effectively served as the “launch” for the project. It was aimed at all members of the Overview and Scrutiny Committee and the five Patient and Public Involvement Forums for Cornwall.

The aim of the event was to establish a common understanding amongst all those attending about:

- terminology – care pathways, patient pathways, patient journeys

- what care pathways are in practice
- the wider context of services for older people with mental health needs
- the direction of the Steering Group’s work

Speakers included the Health Community’s Modernisation Manager, a Modern Matron, Adult Social Care’s Contracts and Service Development Manager and the Policy Lead for Older People from the Strategic Health Authority.

### Our reflections and learning points

✓	The event set the scene well and provided an effective knowledge base in preparation for the work of the Steering Group.	✓	A shared event for OSC and PPIF members gave the organisations a chance to meet prior to formally commencing work together.
✓	The event prompted ideas which were subsequently built into the Steering Group's work.	✓	The evaluation of the event showed that 85% of those attending felt that the event had helped their understanding and that 80% felt that it had helped them in preparing for the scrutiny project. 90% said that the event had made them enthusiastic about the work.

### What we would do differently

★	Use a different venue. The event was held in the Council Chamber – a large and rather daunting room which fails to lend itself to an informal atmosphere. This wasn't helpful in encouraging discussion and questions around the presentations.
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## 6.4 Carer Focus Groups – May 2005

Three focus groups were held in locations around the County. Transport was made available and we covered the cost of any sitting services needed to enable the carers to go out. Three venues were chosen based on their accessibility and we aimed to use community meeting rooms which would provide an informal atmosphere. The focus groups were intended to assist us in identifying the issues and concerns which needed further exploration through a County-wide carers' survey.

Carers were identified by the Dementia Support Workers and contacted by the Council's Adult Social Care Consultation

Manager. We had aimed to have about 10-12 carers at each of the meetings, however at two of the meetings a number of carers had to pull out of the meetings at the last minute.

A topic guide was developed in advance of the meetings setting out the issues which we wanted to get the carers' views upon. This broadly reflected the different stages of the Dementia Care Pathway and prompted the carers to share their experiences of each stage. The meetings were facilitated by the Council's Adult Social Care Consultation Manager.

## Our reflections and learning points

<p>✓ Working with carers was humbling – many had made a tremendous effort to attend the focus group meetings and were willing to share their experiences in the hope that services could be improved for others.</p>	<p>✓ A member of the Steering Group attended each of the focus group meetings – mainly as an observer – the members found this invaluable in understanding the poignant needs and concerns of carers first hand.</p>
<p>✓ We learnt that in working with carers, you need to understand that their first priority will naturally be to the person they care for and they may have to pull out of other commitments at short notice as a result.</p>	<p>✓ There were pros and cons of using a Council employee to facilitate the meetings – her knowledge of social care services allowed issues to be pursued in a good level of detail, but despite her impartial approach there were some concerns that the meetings should have been facilitated by someone completely independent of the health and social care community.</p>

## What we would do differently

<p>★ We would have invited more carers to attend the focus groups in the knowledge that it was likely that some may have to pull out due to commitments to the person they care for.</p>
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## 6.5 Consultation with Health and Social Care Organisations – May 2005

This piece of work was predominantly carried out by the Patient and Public Involvement Forums. The plan was that each Forum representative on the Steering Group would undertake a consistent process within their respective Trust, asking a series of detailed questions about the services provided for people with dementia and their carers, the extent to which the Care Pathway was known and used within their organisation, barriers which stopped them using the Pathway and details of the literature and information they produce

relating to dementia care. One of the District Councillors on the Steering Group carried out a parallel piece of work within the Department of Adult Social Care.

The work was programmed to take place over the period of the Council elections when the County Councillors were withdrawing from the Steering Group and to feed into the “new” Steering Group’s first meeting in July once new County Council members had been appointed.

### Our reflections and learning points

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| <p>✓ Although both OSC and PPIF members had worked to a common template of questions, their approach was entirely different. The OSC member responsible for interviewing Adult Social Care staff organised interviews through her local Social Services offices and produced a written report setting out her findings and conclusions. The PPIF members took a variety of approaches – all much less formal and less structured. The PPIF members generally provided oral feedback to the Steering Group. This exercise highlighted the cultural differences between the OSC and the PPIFs and the contrast between OSC members expectation of structured reports identifying results and the PPIFs' expectation of simply discussing what they had found.</p> | <p>✓ For the PPIF members, trying to gather information from GPs was found to be challenging – the fact that GPs are independent practitioners meant that they could choose to cooperate or not as they liked. As a result, very little information was forthcoming.</p> |
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### What we would do differently

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| <p>★ In considering ground rules for joint working, we would collectively discuss and agree the approach to tasks of this nature and not presume that all organisations will work in the same way.</p> | <p>★ We would be mindful of the difficulties in engaging with GPs and would look at different ways to secure their involvement and get their feedback.</p> |
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## 6.6 Consultation with Service Users – June 2005

We worked with Dementia Voice, a voluntary sector organisation with expertise in working with people with dementia, for this aspect of the project. We commissioned Dementia Voice to run three workshops (one in each PCT area) with groups of people consisting of people with dementia

and where relevant their family member or carer. We aimed to involve approximately 10 households at each workshop, up to 20 individuals.

The workshops were designed to be informal and friendly, based around a shared café-style

meal. Age Concern assisted Dementia Voice in the identification of attendees and a local educational theatre Group, Cascade, were contracted to take part.

The intention was that during the day, participants would be encouraged to have conversations together and with facilitators, helped by specially produced visual prompts, and to share their experiences as service users/carers and their ideas for where things could have been improved.

As with the focus groups, the number of participants was significantly less than the number who had accepted invitations and indicated they would be attending. One or two representatives of the Steering Group attended each event and actively participated.

Cascade Theatre led the morning session and used a combination of activities linked to memory loss – a name game, music, reminiscence and drawing up a visual life history. This included a great deal of humour with the actors playing the roles of teacher and (very out of control) schoolboy. In this way discussion of memory loss was brought out into the open and participants began to share present and past experience combining serious conversation with much laughter.

Conversation over lunch led into the afternoon session which consisted of discussion between the facilitators in pairs or groups, to look in more detail at their life stories drawn in the morning and their experiences and understanding of the support process.

### Our reflections and learning points

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| ✓ Commissioning services from the voluntary sector can have very different dynamics to contracting with the private sector and needs a different approach and expectations.  | ✓ The workshops ran from about 10.30 to about 3.00 – this may have been too long for some of the participants. |
| ✓ Dementia Voice shared their learning from the process with us:   |  |
| <ul style="list-style-type: none"><li>• The process of inviting people to attend an event of this kind can be lengthy and highly dependent on individual contact</li><li>• Any similar ventures should anticipate some fall-out, for sound reasons, between the numbers who accept and those who actually attend</li><li>• It may be significant that the majority of carers attending were female, and that all the people with dementia attending were male. There may be a need to develop new ways of involving male carers and females with dementia.</li></ul> |  |

✓ Members of the Steering Group found their involvement with the workshops particularly rewarding. It was an honour to spend time with people so unselfishly committed to the care of their loved one. The workshops provided an incredible insight into the dramatic challenges of living with dementia.

✓ The format of the day worked very well. The activities and exercises were tremendously effective in involving and engaging with those attending with dementia. It brought home the value of using such techniques as part of a care package.

### Feedback from the participants

✓ “A very relaxing and friendly day from start to finish. Good company and excellent food. Transport good, setting good. We need more information days”

✓ “Good to meet other people in the same situation as me. Very friendly. Good to go somewhere safe with my husband, where people understand. So good to see my husband laughing”

✓ “All aspects have been positive. It has been good to be able to discuss freely all aspects that were of concern to us as individuals with others in the same position and people within the service who have the ability to influence change. Lovely lunch, very well facilitated”

✓ “This day was a marvellous surprise! I don’t know what I expected, but as soon as we were there we were all involved with a most amusing but relevant entertainment which subtly involved everyone, and for my part I was back in my childhood. My husband took a lively interest in everything and talked more than I have heard for ages”

### What we would do differently

★ Very little – the workshops were one of the real successes of the project. Our experience of seeing how carers often have to drop out from plans at short notice would lead us to invite more people to a similar event in the future.

## 6.7 Carers' Survey – July 2005

After holding focus groups with carers of people with dementia, a questionnaire was designed from their comments with questions reflecting the issues which they felt were important.

A total of 434 questionnaires were sent out to all carers of people with dementia that we were able to locate within the County. Cornwall Partnership Trust and Cornwall Care, an independent care home provider, assisted in promoting awareness of the

survey and the survey was promoted on local radio and in local newspapers.

A draft copy of the survey was sent out to the carers who had attended the focus groups to ensure questions were clear and addressing issues in the way they had intended.

The questionnaire ended up as a lengthy document – 25 pages – however, carers told us that they didn't feel this would deter people from completing it because the issues it addressed were so important.

We received replies from 249 carers (57.4%). A number were accompanied by letters and detailed accounts of carers' experiences. There was an overwhelming appreciation amongst carers that their views were being sought.

The results were analysed and reported to the Steering Group. The key findings from the survey were also used as the basis for discussions at the later Stakeholder Conference.

## Our reflections and learning points

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| <ul style="list-style-type: none"> <li>✓ Attempting to involve the whole Steering Group in the development of the survey wasn't practical.</li> </ul>  | <ul style="list-style-type: none"> <li>✓ Despite sending a draft copy to a sample of carers, it was clear from the results of some questions that carers had interpreted them differently – avoiding ambiguity is an essential skill in survey design.</li> </ul> |
| <ul style="list-style-type: none"> <li>✓ The length of the survey didn't seem to deter people – we felt that it was important to ensure that carers were kept informed of the outcomes of our work and we have promised those taking part a copy of this report if they would like one.</li> </ul> |   |

## What we would do differently

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| <ul style="list-style-type: none"> <li>★ Work informally with a small group of members to design the survey before bringing it to the wider Steering Group.</li> </ul> | <ul style="list-style-type: none"> <li>★ Pilot the survey with a small group of carers initially to test that the questions are being interpreted correctly</li> </ul> |
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## 6.8 Stakeholder Conference – September 2005

The Stakeholder Conference was the culmination of our project. It aimed to bring together all that we had learnt from our consultation with carers, service users and service providers. The health and social care staff group was closely involved

in the planning of the day and assisted in identifying appropriate people to invite.

Over 80 people attended the day – representing local NHS organisations, Adult Social Care, the independent sector,

voluntary sector, housing providers and carers. Those attending represented a wide range of levels and professional backgrounds – including Senior Managers, Board Members, clinicians, social workers, Community Psychiatric Nurses, housing wardens, care home managers and so on.

The day was a mixture of sharing information from our project, speakers from the local health and social care community, the National Institute of Mental Health Excellence and the Social Care Inspectorate, videos showing carers in Cornwall talking about their experiences of caring, and workshop discussions involving a cross section of organisations, professions and viewpoints.

The event was made possible by the funding provided for this project by the Centre for Public Scrutiny and financial support from the South West Peninsula Strategic Health Authority.

Each of the discussion groups were based around different themes – information and communication; securing services that work; maintaining well being; workforce and training; person centred care and embedding best practice within organisations. Each group was facilitated by a member of the health and social care staff group and worked towards developing a key actions which needed to be taken in respect of the discussion theme. The outcomes from these discussions have formed the basis for the recommendations included in this report.

### Our reflections and learning points

✓ The event was well attended by a wide range of organisations but the one group of professionals we failed to get involved was GPs – their input to the day, and the wider project, would have been invaluable.	✓ Getting the support of the Older People's Partnership Board – responsible for the strategic development of older people's services in Cornwall – was an important step. Their support gave validation to the importance of the event and encouraged input from their organisations.
✓ Organisation of an event like this takes a huge amount of planning and needs plenty of time and resources.	✓ The event also brought real benefits in facilitating networking across organisations.

### Feedback from participants

✓ "GPs continue to be a missing link. Primary care needs to be the target of the next event"	✓ "Everyone is working to the one goal of achieving an understanding of dementia and now by working TOGETHER we can achieve this"
✓ "A frustrating day as I feel all this information has been discussed before and gone nowhere"	✓ "We need action as a result of today"

time for action

## What we would do differently

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| ★ Take more steps at an early stage to engage with GPs and find ways to encourage them to attend – for example, getting the day registered as an approved training event. | ★ Ensure that there are adequate numbers of OSC and PPIF members present by asking members to nominate substitutes to attend on their behalf if they were unable to be there. |
| ★ More actively involve OSC and PPIF members in the practical aspects of planning of the event.   |   |

## 6.9 General action learning conclusions

The Project itself has been stimulating, sometimes fun, sometimes traumatic, but extremely rewarding. The rewards of joint working, with the Patient and Public Involvement Forums, the health and social care community and carers have been great. It has brought organisations together and allowed working relationships to develop which would never have otherwise happened.

It has highlighted the differences in history, approach and way of working of the Overview and Scrutiny Committee and the Patient and Public Involvement Forums, but reinforced the commitment of both to getting the best out of health and social care

services for people with dementia and their carers.

The work has focused on a really important issue and all of those involved in the project have been humbled by the way in which the carers we have met continue to provide love and care in what are sometimes incredibly difficult circumstances.

The real value of this project can only be measured by what it achieves. The will is certainly evident in organisations and individuals throughout Cornwall – as one of the delegates of the stakeholder conference concluded “now it’s time for action”.

“ The Project itself has been stimulating, sometimes fun, sometimes traumatic, but extremely rewarding. ”

# Appendix 1

## Cornwall County Council

### Care Pathways Action Learning Project Steering Group Terms Of Reference

Purpose of this panel / anticipated value of its work:

Recommendations which would lead to improved services for older people with mental health needs in Cornwall – in particular:

- ❖ Care which links more closely with the wishes of patients and carers;
- ❖ Quicker and more effective access to care for more patients and carers;
- ❖ Clearer understanding of the pathways to care for patients and carers leading to greater reassurance and confidence in patients and carers in understanding the services and choices available;
- ❖ Improved ways of working for health and social care professionals
- ❖ Clear, efficient, effective, accessible and consistent pathways for the care of older people with mental health needs

#### Key objectives:

1. To examine the ways in which older people with mental health needs gain access to the range of health and social care services and supports using a “whole system” approach.
2. To examine the care pathways of these people through their care and support (including voluntary, community and independent as well as public service sectors) and to review the extent to which these focus upon the needs of patients and carers.
3. To examine the information made available to both patients and carers to make informed decisions.
4. To examine how carers may be able to give advice and reassurance to patients.
5. To examine the ways in which the range of health and social care services can be more effectively integrated at local levels to ensure consistency in quality and response.
6. To recommend changes in organisation models for delivery, contracts and quality standards.
7. To recommend changes in the access to and dissemination of information to patients, carers, voluntary and community sectors.
8. To explore the financial consequences and opportunities of the above recommendations.

# Appendix 2

## Project Plan

Identify key officers from Health and Social Care services and other partners who will be involved in project – initial discussions about their possible input	August/ September 2004
Research into most appropriate methods of engaging with older people and any existing data which can inform project. Identify any patient confidentiality issues in terms of identifying consultees	August/ September 2004
Arrangements put in place with Treasurers for separate financial accounting arrangements	September 2004
Establish membership of Steering Group	September/ October 2004
Awareness raising event for HSCOSC Members and PPIF members	November 2004
<b>1st Steering Group meeting to develop draft terms of reference, detailed project plan and agree roles</b>	<b>November 2004</b>
Develop arrangements for consultation exercises	November 2004
Terms of reference and project plan considered by HSCOSC	December 2004
Submit plans for consultation work to Research Governance Board for approval	December 2004
<b>Steering Group meeting to review progress</b>	<b>January 2005</b>
Finalise schedule of issues for examination by PPIFs with PPIF members	January - February 2005
Focus groups of carers to identify: <ul style="list-style-type: none"> <li>• Problems of access to care and difficulties experienced in finding their way through “the system”</li> <li>• Whether the dementia care pathway is happening in practice</li> <li>• Satisfaction with information for patients/carers</li> <li>• Issues to be pursued further via survey of wider carers consultation panel</li> </ul>	February 2005

Eldercare Partnership Board informed about Steering Group's work and their role in supporting Members	February 2005
<b>Steering Group meeting to agree carer survey and issues to be explored with NHS Trusts and Social Services</b>	<b>March 2005</b>
Research within organisations by PPIFs	March- June 2005
Elections – identify new County Council membership of Steering Group	May 2005
Survey of carers	June 2005
Consultation with service users via Dementia Voice	June 2005
<b>Steering group meeting to review work to date, proposals for planning for real event, and agree next steps</b>	<b>July 2005</b>
Carer survey response deadline	July 2005
Action learning session	July 2005
Preliminary Carer survey results available	August 2005
<b>Steering Group meeting to finalise arrangements for Planning for Real event</b>	<b>Early September 2005</b>
Planning for real event – bringing together professional partners, patients and carers	29 September 2005
<b>Steering Group meeting to review outcomes from Planning for Real event + action learning discussion</b>	<b>October 2005</b>
Work with partners on outcomes of planning for real event, resource implications, delivery options etc	November 2005
Report and recommendations produced	December 2005
<b>Steering Group meeting to approve report + action learning discussion</b>	<b>December 2005</b>
Manchester University evaluation report	December 2005
Draft report to Older People's Partnership Board	January 2006
Report to HASCOSC	31 January 2006
Publicity and Dissemination of learning from project – for example to health community, other councils, carers' newsletter etc	January 2006

# Appendix 3

## Care Pathways Steering Group

### County Councillors

#### January 2005 to June 2005\*:

- David Whalley (Chair)
- Ken Yeo (Vice Chair)
- Colin Brewer
- James Currie
- Rachel Ewer
- Terry Lello
- Shirley Oliver

#### July 2005 to December 2005\*:

- Joyce Mepsted (Chair)
- Bob Emuss (Vice Chair)
- Sally Bain
- Mike Nicholls
- Carolyn Rule

### District Councillors

- Maureen Emus (Caradon District Council)
- Chris Goninan (Penwith District Council)

### Patient and Public Involvement Forum (PPIF) representatives

- John Bernard\*\* and Mildren Curtice\*\*  
(*Cornwall Partnership Trust PPIF*)

- Barbara Hewett-Silk  
(*Central Cornwall PCT PPIF*)
- Gordon Swindell  
(*Royal Cornwall Hospitals Trust PPIF*)
- Cynthia Watmore  
(*West of Cornwall PCT PPIF*)
- John Pennington-Hare\*\*  
(*North and East Cornwall PCT PPIF*)

### Health And Social Care Staff Group

- Sid Deeble - Older People's Lead Officer  
*West of Cornwall PCT*
- Julie Green – Older People's Lead Officer  
*Central Cornwall PCT*
- Tim Jones – Service Manager for Older People's Services  
*Cornwall Partnership Trust*
- Mike Langshaw - Commissioning & Partnership Officer – *Cornwall County Council Department of Adult Social Care*
- Tracie North – Director of Operations and Quality – *Cornwall Care*
- Laura Wheeler\*\* – Older People's Services Workforce Development Manager  
*South West Strategic Health Authority*

\* Change in County Council membership due to local elections

\*\* For part of the project

# Appendix 4

## Contributors

The Steering Group would like to express their sincere thanks to all those who provided information, views, advice and participated in the stakeholder event:

- **Steve Abbot**, *Social Worker, Adult Social Care*
- **Aidan Ackerman**, *Lifeline and Supported Housing Services, Carrick District Council*
- **Dr Adie**, *Senior Registrar Geriatrics, Royal Cornwall Hospitals Trust*
- **Peter Ashby**, *Elderworld Ltd*
- **Andrew Baker**, *Education and Training Manager, Cornwall Care*
- **Lesley Beresford**, *Community Team Leader, Cornwall Partnership Trust*
- **Naomi Blackmore**, *Manager, TrewCare Ltd, Nurses and Domiciliary Care Agency*
- **Dr Richard Bowers**, *Specialist Registrar, Cornwall Partnership Trust*
- **Carol Bransgrove**, *Cornwall County Council*
- **Dr. Philip Bringham**, *Associate Development Manager, West Cornwall Primary Care Trust*
- **Beverley Chapman**, *Psychiatric Liaison Nurse, Royal Cornwall Hospitals Trust*
- **Jean Chipperfield**, *Carer*
- **Gilly Constantine**, *Occupational Therapist, Cornwall Partnership Trust*
- **Will Crocker**, *Independent Complaints Advocacy, Liskeard Citizens' Advice Bureau*
- **Nick Datlen**, *Information and Data Collection Administrator, Cornwall County Council*
- **Sid Deeble**, *West of Cornwall Primary Care Trust*
- **Alice De Wilson**, *Kerrier Homes*
- **Philippa Dowling**, *Senior Policy Officer, Cornwall County Council*
- **Diane Dyckhoff**, *TrewCare Ltd, Nurses and Domiciliary Care Agency*
- **Bob Emuss**, *Cornwall County Council*
- **Maureen Emuss**, *Caradon District Council*
- **Michele Fisher**, *Clinical Specialist Occupational Therapist, Royal Cornwall Hospitals Trust*
- **Margaret Ford**, *Head of Care, Age Concern*
- **Mike Faulds**, *Adult Social Care*
- **David Francis**, *Commission for Social Care Inspectorate*
- **Judy Gardener**, *Social Worker, Adult Social Care*
- **Chris Goninan**, *Penwith District Council*

- **Tim Gornouvel**, *Carer*
- **Helen Gough**, *Geevor Ward, Royal Cornwall Hospitals Trust*
- **Julie Green**, *Older People's Lead, Central Cornwall Primary Care Trust*
- **Margaret Green**, *Social Worker, Adult Social Care*
- **Jackie Greenbrook**, *Head of information, Age Concern Cornwall and the Isles of Scilly*
- **Eve Greenwood**, *Social Worker, Adult Social Care*
- **Sally Guffick**, *Geevor Ward, Royal Cornwall Hospitals Trust*
- **Melanie Hambly**, *Social Worker, Adult Social Care*
- **Sue Harrison**, *Social Worker, Adult Social Care*
- **Maria Haycock**, *Kerrier Homes*
- **Barbara Hewitt Silk**, *Central Cornwall Patient and Public Involvement Forum*
- **Mr Hill**, *Carer*
- **Nick Hudson**, *Clinical Specialist Physiotherapist, Royal Cornwall Hospitals Trust*
- **Ann Hughes**, *Housing Department, North Cornwall District Council*
- **Linda Hurst**, *Kerrier Homes*
- **Tim Jones**, *Service Manager, Cornwall Partnership Trust*
- **Brian Kennedy**, *Director, Cornwall Care*
- **Helen Lally**, *Support Worker in the Sheltered Service, Penwith District Council*
- **Mike Langshaw**, *Cornwall County Council*
- **Helen Lewis**, *Assistant Director of Nursing - Medical Group, Royal Cornwall Hospitals Trust*
- **Tarina Luscombe**, *Cornwall Partnership Trust*
- **Mary Mallet**, *Modern Matron, West of Cornwall Primary Care Trust*
- **Lyn Manuell**, *Chief Executive, Central Primary Care Trust*
- **Bryn Martyn**, *Social Worker, Adult Social Care*
- **Jon Meech**, *Patient and Public Involvement Forum Support, Scout Enterprises*
- **Joyce Mepsted**, *Cornwall County Council*
- **Helen Minton**, *National Institute of Mental Health Excellence*
- **Fiona Monk**, *Independent Complaints Advocacy, Liskeard Citizens' Advice Bureau*
- **Kate Morgan**, *Carer*
- **Jennifer Nancarrow**, *Peace of Mind – Domestic Agency*
- **Jennifer Nias**, *Falmouth Citizens' Advice Bureau*
- **Mike Nicholls**, *Cornwall County Council*
- **Tracey North**, *Director, Cornwall Care*

- *Magi Omlo-Coad, Research and Consultation Officer, Cornwall County Council*
- *Lindsay Panton, Social Worker, Adult Social Care*
- *Barbara Pendleton, Non Executive Director, North and East Primary Care Trust*
- *Viv Perry, Carer*
- *Linda Rodder, Kerrier Homes*
- *Tracey Roose, Chief Executive, Age Concern*
- *Angela Rowe, Senior Carers Support Worker, Cornwall Rural Community Council*
- *Andy Rust, Assistant Director, Adult Social Care*
- *Chris Sherratt, Dementia Voice*
- *Heather Skillington, Elderworld Ltd*
- *Annette Swiggs, Penwith Housing Association*
- *Gordon Swindell, Royal Cornwall Hospitals Trust Patient and Public Involvement Forum*
- *Ali Thompson, Support Worker in the Sheltered Service, Penwith District Council*
- *Kerry Trenwith, Penwith District Council Housing Association*
- *Tony Wainwright, Consultant Clinical Psychologist, Cornwall Partnership Trust*
- *Mr Watkins, Carer*
- *Cynthia Watmore, West Cornwall Patient and Public Involvement Forum*
- *Lorna Watt, Commissioning Lead for Mental Health, Health Community*
- *Laura Wheeler, Workforce Development Manager, South West Strategic Health Authority*
- *Carol Williams, Director of Operations, Central Cornwall Primary Care Trust*
- *Jo Woosey, Community team leader, Cornwall Partnership Trust*
- *Jo Yelland, Older People's Policy Lead, South West Strategic Health Authority*

And all of the carers who so generously shared their experiences with us through focus groups and the carers' survey.

time for action

# Appendix 5

## Reference Materials

A shared care pathway for people with dementia in Cornwall and the Isles of Scilly

*Cornwall County Council and Cornwall Partnership Trust*

Better care, higher standards

*Cornwall Health Community and Local Authorities*

Carers checklist

*The mental Health Foundation*

Carers information pack

*Department of Adult Social Care, Cornwall County Council*

Changing times – improving services for older people

*Department of Health*

Continuing NHS healthcare

*South West Peninsula Strategic Health Authority*

Dementia carers consultation survey 2005

*Care Pathways Steering Group, Cornwall County Council*

Discharge from hospital – getting it right for older people with dementia

*Department of Health*

Everybody's business

*Change Agent, Care Services Improvement Partnership*

Forget me not

*Audit Commission*

Independence, wellbeing and choice

*Department of Health*

Mental health services for older people in Cornwall and the Isles of Scilly

*District Audit*

Much done, more to do

*Dementia North Collaborative*

Older people independence and wellbeing

*Audit Commission*

Older persons mental health service review

*Cornwall Partnership Trust*

Provision of services to older people in Penwith

*Penwith District Council*



