NHS
South West

The effective and sustainable development of dementia services in the South West: lessons for commissioning

September 2012

Foreword

This study was commissioned by the South West Dementia Partnership in 2011/12, with a view to understanding better those factors that achieved real change and improvement for people living with dementia, and their carers/families.

Four communities in the South West were identified to participate in the study, in recognition of the pace of change and improvement that had been achieved in those localities: we wanted to capture the learning with a view to this being shared more widely. A case study methodology was selected in order to explore in depth the many factors that have contributed to local, and indeed regional achievements. Our thanks are extended to dementia partnerships in Cornwall and Isles of Scilly, Somerset, Bristol and Gloucestershire for the time and attention they have given to this endeavour. Throughout the report are the voices of people living with dementia, and their carers/families: our thanks are extended to all who have contributed.

This report highlights committed, sustained and ambitious action on the part of local commissioners and their partners to ensure that the needs of people living with dementia, and their carers/families, are understood and addressed. It focuses change in complex systems, approaches to leadership, the relevance of shared values, and in particular on the human factors that have contributed to real success. Most importantly, the study identifies factors that the new NHS commissioning system may build on, and benefit from.

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September 2012

South West Strategic Health Authority

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1. Summary

1.1 This in depth inquiry into four areas in the South West explores a range of innovations and how they were achieved. It highlights the importance of whole systems working, collaboration and flexible partnership working, the importance of a clear and aspirational strategic vision bolstered by top down support and a strong and positive philosophy of care concerned with living well with the diagnosis, seeing people living with dementia as whole people with a history and identity, mainstreaming support (through being as light as possible on specialist input while building capacity in primary care and the wider system) and maximising the contribution of people living with dementia and their carers.

1.2 Success has been achieved through a whole system approach that focuses on relationship as the key to action at all levels, strong and diverse partnership working and being able to lead as a strong and stable team. Sites also support multiple innovations within a clear framework for accountability for outcomes and demonstrate trust in the best of what the voluntary and community sector brings to the agenda.

1.3 Innovation is usually based on strong processes for getting a better understanding of the lived experience of people with dementia while also understanding the lived experience of carers and staff (e.g. in care homes). The role of the lead commissioner as lynchpin is crucial - working alongside providers, facilitating communication and the spread of positive practice. The ways in which their work with clinical leads brings expertise in change management and clinical expertise together is also of paramount importance, as is the role of the GP lead in opening doors and promoting credibility among GPs.

1.4 Successful sites focus on developing leadership capacity and awareness concerning dementia in every corner of their local whole systems. They are also relentlessly focused on recognising and building on strengths and achieving sustainability through embedding commitment through ongoing relationship, highlighting real changes in people's lives, focusing on celebration and affirmation and capturing evidence.

1.5 There is concern that the focus on collaboration and leading as a strong and stable team is at risk in the new commissioning environment.

2. Introduction

2.1 This report has the simple aim of exploring and sharing ways in which care and support for people with a diagnosis of dementia has been achieved in the South West, with a particular focus on commissioning. It also foreshadows the future and explores how improvement can be sustained over the longer term.

2.2 The lessons have been drawn from interviews (both individually and in groups) with a wide range of participants. I have listed, with grateful acknowledgement, their names and affiliations at the end of the document. It is their wisdom and experience that is captured here.

2.3 Four sites in the South West were chosen as the focus for this inquiry: Bristol (B), Cornwall (C), Gloucestershire (G) and Somerset (S). They were selected because each site had made demonstrable progress in implementing the National Dementia Strategy (Department of Health 2009), within differing commissioning and environmental contexts. It should be noted that many of the elements of positive practice identified within this report are also being realised in communities across the South West; their absence is a reflection the limitations of this inquiry alone.

2.4 Rather than write separate “case studies” for each of the four sites, it was less repetitious to collapse the findings into one report while making sure achievements, experience, ideas, and quotations (where permission granted) could be referenced back to their original source. (Some quotations have a reference number indicating its source. The key to finding the source is in the “Participants and Contributors” table at the end).

2.5 The work described here was undertaken with the support of the (then NHS South West) Strategic Health Authority that had the role of establishing leadership and performance managing local plans. It established a multi-agency regional South West Dementia Partnership that served to reinforce and support local partnerships. It had a range of work streams and created many resources/products that reflected or were drawn from local positive practice and expertise. Many were co-produced with people from the field, including some of the commissioners and other key participants highlighted in this report. These resources are highlighted in the “Endnotes and further signposting section” and can be found at www.dementiapartnerships.org.uk.

3. Achievements

3.1 Participants were asked what people with a diagnosis of dementia and the people who support them have now that they did not have before the introduction of the National Dementia Strategy (Department of Health 2009). The following lists some of the achievements highlighted (and of course does not constitute a comprehensive account of all the achievements within those areas).

Whole-system working

- Cornwall's "Changing Lives" framework for service delivery stemmed originally from work on falls that highlighted the need for a whole-systems community based personalised perspective. It was developed by Age UK Cornwall, Volunteer Cornwall, Primary Care Trust and Cornwall Council commissioners. It has sign-up at Board level and a level of clarity that means people can see where they fit into the bigger picture. Rather than just *"plug in a couple of new workers, we needed a wider more integrated view where key statutory and voluntary sector providers are signed up, putting the person at centre of services and decisions, stripping back complexities, signposting to advocacy and reducing layers of intervention."* (13) (C). Changing Lives is not a service, but a description of core principles and values to provide a comprehensive template for needs-led and asset-based commissioning.

- Clear, recognised and accessible pathways was emphasised by all sites. The components are described in more detail below. The clarity of the pathway for primary care is crucial. It has been made public and distributed to primary care both in the form of paper copies to all GPs and electronically on the Map of Medicine (G) and NHS Self Care Web sites (C). The notion of a pathway or a journey creates opportunities for planning at different stages. *"Looking at it as a journey from awareness of memory loss to end of life avoids missed opportunities for perspectives and wishes to be recorded."* (16). It also delivers consistency so that wherever you go you will receive a similar memory assessment service, rationale for attending for memory assessment and post diagnosis counselling, with carers and GPs getting copies of the care plan (S)[1].

- Ensuring that there are people with awareness, knowledge and skill with respect to dementia in every part of the local whole system of care. This was achieved though Dementia Link Worker (DLW) roles although the definition of the role and its coverage varied across the four sites. For example, at the beginning of 2012 Gloucestershire had 387 trained DLW staff in 81% (of 174 care homes) and 75% of accredited domiciliary care agencies had at least one trained DLW. There were also DLWs on each of the wards in community hospitals (C). This had been promoted through the development of dementia champions and a CQUIN (see Glossary) target that meant that core dementia training was applicable and required for all staff in the acute hospital. Bristol and Cornwall has also used CQUINs to make training mandatory across both their acute trusts.

3.2 In Gloucestershire any member of staff can assume the DLW role. It was seen as important that they are people with a passion and an interest rather than those that had been told to go and do it. The role is focused on people with certain levels of responsibility though a wide variety of roles are recognised as important. It was, for example, acknowledged that a porter can be very influential in achieving change. Over a 9-12 month training programme people are supported to understand the basics of dementia. In taking on the DLW role people take that knowledge and understanding into the workplace and cascade it among colleagues creating a form of viral transmission of awareness and expertise. *"People are managing their clients differently and people notice and want to know what is different – they are seeing things demonstrated. People want to change the environment. They want new activities."* The approach has also extended out into the community and into family life, with carers attending the award ceremonies when DLW training is completed. The wide coverage of the DLW programme has created cultural shifts and changing attitudes. For example, DLW in community hospitals were described as "*alight with their energy and their knowledge."*

- In Cornwall, part of the acute hospital DLW role is to collate Key Performance Indicators each quarter at ward level against the eight South West Standards for Dementia Care in Hospital.

- The Bristol model[2] deploys two workers with a strategic function concerned with networking, assessing training needs, training, working with carers and families, sharing good practice and improving awareness. These workers aim to achieve an overview which means that pockets of positive practice can be tested against other approaches elsewhere. This was seen as a means of achieving equality too – particularly for example with respect to race equality. There are many different cultural understandings of dementia and there is a need for cultural competence across the system. These strategic roles are envisaged as having accountability to the local Dementia Board for the delivery of measurable outcomes. They would also be supporting by Community Nurses for Older People (CNOPs) who are employed by and accountable to Bristol Community Health while working with GPs.

- DLWs allow the combining of interests and joint working across parts of the local system. For example, a GP concerned about a care home can work with the DLW there on a given care plan or issue. Similarly, consultants from the local specialist mental health provider can work with DLWs to manage people's behaviours in ways that are less reliant on medication.

- The DLW also facilitates access to a range of tools and resources such as those described below.

- Standardising assessments and other resources that everyone can use to promote quality care, consistency, and improved communication. In Cornwall the dementia resource toolkit includes details of diagnosis and the care pathways as well as more specific items such a pain checklist and mood behaviour charts. Gloucestershire developed an award-winning "Living Well Handbook"[3] as a communication and planning resource. Around a thousand have been distributed.

- Well-designed leaflets get a positive reception, particularly from carers. Further examples concern end of life (C), a directory of services (C) and prevention (C).

- Web-based resources. The materials described above were also developed for GPs as A4 folders. GPs applauded the content but did not want to waste space with a folder. Instead, Cornwall has created a portal on the existing NHS Self Care website[4]. Health care professionals can go in and click on links for diagnosis, assessments, best practice, newsletters, audits, carer leaflets, and also signposting from this one-stop-shop[5].

- In addition to DLWs in Gloucestershire, there are locality-based community dementia nurses who are specialists trained in working with small groups of practices to assist with diagnosis and subsequent support.

- Somerset has invested in a county-wide dementia awareness worker.

- Much whole-system working has been achieved through more effective joint working, particularly with the voluntary and community sector. This has delivered *"More of that long-term sustainable forever support - would not be there if just statutory services"* (13). For example, the dementia advisers offering lower intensity support and signposting are employed by the Alzheimer's Society in Gloucestershire.

Giving a voice to people living with dementia, and their carers

- "We involve people from strategic level through to implementation and in interviewing staff. We also try to get carers or service users on interview panels. Memory assessment services and day services have strong service user involvement." (S). Excellent resources in this area were also developed by the South West Dementia Partnership[6].

- Large events involving the public, people with a diagnosis of dementia and their carers (C). Often these are done in partnership with the voluntary and community sector (e.g. Age UK (C) and Alzheimer's Society (B)) with the involvement of the Local Involvement Network (LINks).

- Bristol now has a carer (Derek Dominey) chairing their Joint Board for Dementia.

- Cornwall has a carer representative on the acute hospital's Dementia Action Group and is developing a Cornwall Leadership Programme for people with dementia (Alzheimer's Society).

Early diagnosis and the focus on primary care

- All sites spoke about how early diagnosis was promoted by creating a sense of the possible range of options to support people post-diagnosis. Acknowledging that GPs want information, advice and early referral, in Somerset they worked to make sure that all this, *"Needs to be not more than three button clicks on the computer*."

- Cornwall has a primary care based integrated service of both health and social care support via an Age UK Cornwall worker based within the surgery, working alongside the GPs and offering a quick, accessible and reliable service. Additional service models being trialled include enhanced and dedicated practice health care assistant time and practice based memory nurses (full description appended) (C). They are testing a different model of work with primary care and have plans to mainstream and embed the work through additional investment and CQUIN payments to the mental health provider.

- In Gloucestershire, they have locality-based community dementia nurses that sit in primary care and are employed by the local specialist mental health provider trust. Their whole focus is to support primary care, and they are seen as an extension of the local memory service. The service is very well received. They are involved in diagnosis, support with developing dementia registers, and active planning and problem-solving along the dementia journey.

- Somerset Dementia Partnership produced "Are you concerned about memory loss?" – A leaflet of advice and guidance for those who feel that they or a family member may be affected by memory loss.

- One step to engage primary care is an annual 'Primary Care Summit' in Gloucestershire. The first summit took place prior to the publication of the National Dementia Strategy (Department of Health 2009). Now on their fourth event, attendance has grown every year. The summits have the function of helping develop priorities for the Primary Care Trust and the local authority, celebrating what has been achieved and getting feedback on how they can collaboratively *"develop the increasing range of support that can sustain people in the community"* (G). Bristol used a similar conference with strong attendance and the involvement of the Primary Care Trust Chief Executive. Cornwall has held GP dementia education 'Academies' and practice-based education seminars.

The memory assessment/clinic function

- Being flexible about location meant that the assessment and intervention functions of memory clinics could be delivered more locally. For example in the dispersed Cornish context there were 22 memory assessment clinics countywide held in a variety of settings including GP practices, community hospitals and mental health services.

- Home visits were offered as well where necessary and following assessment and diagnosis, everyone is offered cognitive stimulation therapy in the form of an eight-week course. If people cannot attend then they can get one-on-one input. The clinics also serve to inform people about maintenance groups and memory cafés (C).

- In Gloucestershire the memory assessment service is run by the specialist mental health provider[7]. A wide range of people are involved in managing memory problems, through education, skills sharing and dissemination. The same processes and paperwork for memory assessment are used across community and acute services. The role of primary care is to promote early awareness and signposting. Those with a more advanced dementia are diagnosed in primary care. Diagnosis by GPs might also happen in care homes, working closely with the dementia liaison nurses (also C).

- Annual joint GP and Pharmacy reviews have also offered an opportunity to diagnose and up-date GP Dementia QOF Registers (C).

Carer support

- Improved carer support based on improved carer assessments,

- Attention to the way information is conveyed to carers. For example, feedback from assessment to GPs and carers needed to be focused differently (S). *"Making it relevant and in language they can understand but without being patronising."* (25).

- Improved carer involvement. For example, in Cornwall they reported more carer involvement in care planning and on the wards with drop-in sessions once a week. People were signposted to these sessions via the memory cafés. Staff reported more carers coming into the ADL (Activities of Daily Living) kitchen on the ward and cooking meals. This created the smell of home cooking, which contributed to making the hospital environment more homely (C).

- Bristol has secured a lot of the local authority funding available for carers' support and achieved joint Primary Care Trust/local authority agreement on how to use it; for example, with respect to carers' support workers in the hospitals and primary care.

- Carer breaks are widely supported and people are signposted to a local carer support worker who can help them negotiate it (B).

- The Dementia Advisor Service in Somerset is particularly valued by carers. People value the opportunity to talk to somebody, talking them through what to expect and giving the right level of information as and when they need it. They are involved at every stage of the journey from early diagnosis. They cover specific areas and will be GP Federation based. Five advisors have so far reached about 700 new people with dementia and have helped them maintain contact with services.

- A review of carers support has lead to a decision that it will be GP practice based and delivered through the local authority (S).

- Carers' education programmes (S) (C).

- New dedicated carer support worker roles based in the third sector (C).

- Carer's leaflets, such as the 'Ten Top Tips' for supporting someone who may be confused or have dementia[8] that fits on one side of A4 paper (S).

Memory cafés

- These have expanded rapidly in some contexts. For example, 24 developed over three years in Cornwall. The low-level intervention and peer support they provide is particularly highlighted as a key part of the pathway. *"People get most value from peer support. It is the living day-to-day stuff - like [famous brand of lager] - reaches parts that clinicians just can't reach"* (13).

- In Bristol their three memory cafés are commissioned by health and social care, one run by the Alzheimer's Society and two by Age UK. Their role was informed by pilot work that highlighted that they were mainly valued as a source of ongoing support rather than early intervention and signposting. Meetings are themed to meet the needs of people as they arise. Very often people attend as couples. They are strongly linked in with other services so are well informed; for example, with respect to other Alzheimer's Society services concerned with wellbeing. They are seen as a key part of the pathway that can be built on.

- Authorities recognised the importance of equity of access to this form of support. In Cornwall local communities, Rotary, Age UK, Cornwall Rural Community Council, Volunteer Cornwall, and Arts for Health have been instrumental in achieving the development, sustainability, and quality assurance of cafés. In Gloucestershire, the cafés were reliant on local charitable support but are now commissioned and made available through social care partners and planning teams in local Councils, so that every area now has access to memory cafés. This was a good example of partnership working in that the Primary Care Trust was saying, *"this is not the business we need to be in"* but gave money to social care so that cafés could be commissioned.

Care home focus

- Dementia Care Mapping[9] has provided a powerful foundation for more personalised care and environmental changes in residential homes and hospitals. A full description of the work in Cornwall is appended.

- Gloucestershire has a Home Support Team of mental health nurses working purely with care homes. They connect into the intermediate care team, which includes community mental health nurses. They are not dementia specialists but can access support as required.

- The "Assess Monitor Prevent"[10] toolkit (C) comes with training that develops understanding of what a change in behaviour might mean so steps can be taken to manage the situation at the care home and avoid un-scheduled admissions. Linked to the STAR programme (C) described below, the tool explains effects of events such as transient ischemic attacks (TIAs) and urinary tract infections (UTIs) so that they can be better recognised and managed. The toolkit promotes anticipatory care and has been developed with care home staff, GPs, and consultants in old age medicine. It includes a sheet that describes someone's normal functioning. This follows people into the hospital admissions unit so that their usual behaviour is not misinterpreted; for example, by the ward deciding that they can't send someone home because they are wandering; if the individual usually wanders then there is no reason not to discharge with the right planning and support.

- Investment in care home training from external providers and Primary Care Trust (C).

- In Bristol a pharmaceutical company funded the involvement of a consultancy to evaluate and raise performance in care homes. This work was well received as *"rewarding, proactive and action orientated."* The company had made the approach and were very explicit that they were investing in order to align their brand to dementia. It was seen essentially as *"no strings support"* where all parties benefited.

- The Institute for Healthcare Improvement[11] has been supporting work, including working with care homes, to better manage risk and prevent admission. As one participant observed, *"Why is it that 1am in the morning you send them in an ambulance take them to Accident and Emergency, do every blood test under the sun, x-ray them and move them around the hospital and so their dementia gets worse?"*. Instead they focused on in-reach into the care homes and residential homes using the experience from dementia champions (S). This supported a lot of personalised advance care planning to help reduce admissions with further roll out of the work being undertaken with the support of the Health Foundation.

- Somerset uses specialist residential beds in care homes whereby specialist workers from the local specialist mental health provider 'up skill' the care home workers. To facilitate this a supplement is paid by the NHS to the local authority which then pays independent providers: *"We are joining up all the commissioning bits so that the end product is a joined up service where people happen to be and then those beds are doing their bit by stopping services having to step up a notch... (this) has a preventative element and a joint working element and offers people the help they need at the lowest possible rung of the ladder."*

- The Primary Care Trust clinical lead in Cornwall audits care home admissions routinely to find those who have more than four admissions a month. Without "finger wagging" she goes in to explore why the admissions arise. Care homes have found this approach supportive and have been able to identify for themselves where they need clinical support, or training. It has also promoted the creation of checklists and toolkits that care homes themselves can use (C). See below for how change in care homes has been sustained.

- Sites reported benefiting from working with organisations that represent care homes and domiciliary care on the South West Dementia Quality Mark[12]. Having such organisations (for example, the Gloucestershire Care Providers Association) on partnership boards means that as well as the South West Dementia Quality Mark work they support local leadership programmes and encourage people to do the DLW training (G).

- Bristol has further developed the South West Dementia Quality Mark, drawing on the initiative of an excellent project coordinator and consultation and collaboration with providers and Bristol City Council's own quality assurance staff. They found lots of crossovers with Care Quality Commission standards, which created duplication. Streamlining the process meant that they could explore other topics not hitherto covered, including a range of quality if life questions. These were explored with the help of lay assessors (see below).

- This work is being mainstreamed into the Council's quality assurance (QA) process. The QA team screen homes for suitability to go through the Dementia Quality Mark process and support care homes through it (B).

- This work is conducted with the support of the Retired Senior Volunteer Programme (RSVP, part of CSV). This team of older volunteer lay assessors see themselves as true "quality of life assessors" in that they go in to specifically assess what it is like to live in that home. They absorb what the experience is really like.

- Bristol also emphasised getting care managers involved in the QA process so they that they can experience the care homes in a different way.

- Large conference events involving care home staff with community and acute care staff (C).

- Dedicated specialist in-reach support from dementia liaison nurses (C).

Managing medication

- The STAR (Stop Think Assess Review)[13] project in Cornwall was developed by the Primary Care Trust and acute hospital clinical leads. This is a multiagency training and education programme with toolkits designed to monitor behaviour and reduce prescribing of antipsychotic medications. It talks people through the rationale for good prescribing, reviewing medication and the importance of monitoring and understanding symptoms and behaviours and their potential causes before prescribing (for example, TIAs, UTIs) rather than assuming that changes are symptomatic of dementia. It goes beyond merely taking away or reducing medication by following through with 24-hour observations supported by checklists and tools for charting behaviour. These are laminated and designed so they can fit into nurse's pockets and ward round trolleys. There has also been investment in locality-based training days involving GPs and pharmacists. This was linked to a programme of GPs and pharmacists doing care home visits together, offering a mini-"ward round" going through medications and checking that people with dementia were on the Quality and Outcomes Framework (QOF) register. Very significant benefits were reported with *"huge leaps"* whereby people who were formerly sitting around, disengaged and 'locked in' were talking, more self-aware and able to do more for themselves (C).

- the Medicines Management Team in Bristol was involved in developing the dementia pathway work. Their work in care homes was particularly valued (for example, writing a protocol about monitoring and discontinuing cholinesterase inhibitors). It was helpful that the Head of Medicines Management was fully engaged with the work and part of the Board leading it.

Acute hospital care focus

- Setting up more robust pathways and clinical procedures. (Many of the resources to support this are available on www.dementiapartnerships.org.uk/hospital

- Use of life storybooks and the "This is Me"[14] document. This should accompany people on admission, but if not, it is completed then and supplemented with a more in-depth document (S and C).

- Dementia audits in acute hospitals (B and C).

- Use of the "forget me not" sticker - a reminder for people to consider that someone may have a cognitive impairment (C).

- Dementia wards being accredited with the local university for practice development (S).

- Setting an incentive target (using CQUIN) to develop the range of activities available in acute hospital care (S).

- There is a dementia champion in every community hospital in Somerset. They are not necessarily the experts on dementia there, but they are able to signpost. They are people who have come forward to carry forward ideas and embed them at a local level. They have quarterly meetings where they bring agenda items, develop informal training, and work on linked issues, such as safeguarding and falls. *"It has worked because dementia champions WANT to be dementia champions."*

- Acute care DLWs in Cornwall focus on service improvement, collecting key performance indicators and audits so that positive practice is spread. They also focus on awareness raising for all staff and supporting environmental improvements (for example, big clocks and calendars on wards).

- Linking dementia to the Patient Safety Programme (S).

- DLWs are considered to have improved relationship and communications between management and clinicians (C).

- Hospital Memory Boxes. Rotary (Rotarians Easing Problems of Dementia) developed 30 "memory boxes" for patients with dementia in the acute hospital. These help with reminiscence on the ward and can be topped up with relevant memorabilia. (C, see also their use regarding end of life care.)

- Sign up from 25 GP practices to pursue a new QOF indicator[15] relating to urgent care pathways specifically with respect to their patients diagnosed with dementia (B).

- Somerset has designed a positively received approach to crisis intervention that provides a swift response but does not require involvement of major parts of the service. This flexible approach can include an informal conversation, or input from people attending the individual for other purposes.

- The Somerset Strategic Improvement Fund (SSIF) Dementia project was a collaborative project led by a practice facilitator and project manager seconded from the local specialist mental health trust. It *"really enthused people"* with looking at projects within the ward setting, exploring with health care assistants (HCAs) and staff nurses how they manage challenging behaviours at ward level. Even with only a year's funding there was a strong sense of success and celebration. The work of the project was captured in an evaluation by Bournemouth University[16]. The dementia champions have helped take the work forward, focusing on applications of the tools that the two workers created. They undertake small initiatives to improve the quality of care, for the patient and the carer, often without much funding. Examples include improving signage, creating homely environments, new activities, volunteer involvement, parties, reminiscence, and film matinees. One product was a booklet written by a health care assistant that was very well received and is now in the British Library. The project has developed an on-line platform for staff to exchange ideas and positive practice and a dementia resource. Participants commented *"It really enthused the staff and made them look outside their comfort zones to make their job more positive and meaningful for them as well. Once you do that the caring role becomes easier... it really pushed people's buttons"*, *"The fear factor has gone now - now people have tools and are not afraid to pick up the phone...Housekeeping staff and porters [along with HCAs and nurses] have permission to work with patients in different ways. They have had fantastic ideas. Very quick wins that build confidence*". The dementia champions get together to celebrate good practice and things that have worked well.

Diversity and creativity

3.3 It is not possible to do justice to the broad range of innovations across the four sites. These are just a few that were highlighted:

- Somerset has moved toward a model of time-limited day services, where assessment informs the therapeutic interventions to be received which in turn informs how long people stay with the service. *"We have a clearer sense of what we are achieving for people and have much more throughput."* Bristol is planning a similar approach.

- Using poetry to support their patients, whether in the community or care homes. A poet came to a GP practice and visited dementia patients at home with their carers. He developed poetry drawing on their words and went back for a second visit to share the material. He also had a reading session at the surgery. As a GP from the practice commented,"*… the most moving thing for us (was) because folk we had not known earlier we came to see in a different light. It was incredibly emotional for the individuals involved and their carers. One person said, 'That's me you're talking about, that's me!'... (it was) the best bit of staff training and education we have ever seen".* (16) The patients kept the poems and they were also incorporated into their records.

- Working with arts organisations who work with groups of people living with dementia. This included working with artists themselves on how they can become more dementia-friendly and run their own sessions. They can access dementia training free and it is designed specifically for them (G).

- MindSong[17] is a charity concerned with singing and music in the late stages of dementia with people in care homes (G).

- Work with choirs. Choir members are more likely to have musical skills and may be of an age where dementia is touching their lives (G).

- Work with faith groups. This was also seen as a good way to link into parish councils, which have particular remit concerning the health and wellbeing of their parishioners (G).

- Creative and therapeutic arts, reading aloud, and music therapy being used in care homes and hospitals (C).

- Singing for the Brain ©sessions delivered by the Alzheimer's Society (C).

- A telephone befriending scheme delivered by the Alzheimer's Society (C).

Community involvement

- Gloucestershire has a community time bank schemes in the form of a charity called "Fair Shares"[18]. One issue with time banks is a concern that people cannot make use of the schemes if they are not well placed to put anything back into the time bank as part of a reciprocal process. An investment was therefore made to train facilitators to support communities to look at how people with dementia could be supported to be part of time bank activities and to look at what they could give back. The approach also extends to their carers. This approach is being piloted in the Forest of Dean. Cornwall also has a community time bank scheme.

- Bristol's proposed new Reablement Service (see glossary) has a focus on providing short-term interventions while looking into communities for appropriate support. It is being seen as part of family of services focusing on people with the more challenging needs, including intermediate care. It is a joint in-house service that will not be tendered but will be commissioned within a performance management framework. It will focus on keeping people out of hospital or care and promoting early discharge through home-based care that promotes independence, wellbeing and access to medication reviews.

- In Gloucestershire, the Barnwood Trust has embarked on a 10-year programme of capacity building in communities. The aim is that it will inform commissioning to make better use of the assets within local communities.

End of life care

- In Cornwall, the Primary Care Trust Clinical Lead worked for two years talking to GPs, coroners, ambulance staff and others to develop a pathway for end of life care specifically for people diagnosed with dementia. Initially there was some resistance from people saying that you cannot talk to carers about death when they are already coping with dementia. This myth was dissipated by gathering known carers together to co-design a leaflet that was piloted in one locality. The leaflet helped support carers, family friends, staff and GPs to go through the right legal process for someone who does not have capacity and to explore personal wishes, such as whether the person wanted to die in their care home. Such planning reduced unscheduled and repeated admissions at the end stage of life. The staff who developed and implemented the leaflet also had cheese and wine and curry evenings in care homes on the topic of what to expect at the end of life. This included going into the details of what to expect. These evenings were well attended (around 30 people at each session) and were strongly welcomed by carers. Sensory end of life boxes promoted exploration of what people would like to be sensing at the end stage of their lives; for example, what they would like to be touching and hearing (for instance, preferred music).

- Cornwall has palliative care consultants offering in reach to the hospital from the hospice. This achieved national awards regarding their “Healthy Death” model and “incredible” plaudits from carers. The emphasis is on keeping people pain-free and comfortable but in an environment where they are known.

Workforce development and training

- Gloucestershire recognised the need to develop knowledge and improve skills across the workforce, starting with the community and particularly care homes. They developed a multiagency training strategy lead by a *“visionary training and education lead”* from within the local authority. This training developed the DLW role described above. The aim was for a basic knowledge and understanding of dementia for everyone. Dementia education nurses run the education programme for DLWs and are employed by the local specialist mental health provider.

- This training initiative also developed a pathway linked to academic accreditation and a hierarchy of training for the entire workforce. This was managed through a local Further Education college (G).

- The training prioritised those people who were already most involved with people with the most complex needs (G).

- The training develops a sense of joining an empowered DLW community. The completion of training is marked by an award ceremony, a badge, an annual forum, newsletters and web-based activities. Their event at Shire Hall in Gloucester featured many stories about the positive difference training has made and increasingly involved carers. The DLWs describe greater confidence to challenge themselves and others (G).

- It is seen as a positive marker of partnership working that the workforce, training and development strategy required to deliver this breath of coverage was not owned by any one organisation (G).

- One limitation of the Primary Care Summits in Gloucestershire is that they do not seem to engage many GPs who are not already interested. In addition, therefore, a GP Education Trust is taking on further training and has been commissioned to run locality workshops, taking a member from each practice and following up practices that do not engage, introducing them to the dementia nurses so that a human link or relationship is made (G).

- Bristol undertook some “mapping and gapping” with respect to workforce development opportunities across their whole system. There were many pockets of work going on but coverage, consistency, and access at different levels needed to be developed. A scoping meeting with the voluntary and community sector, training staff, providers, and commissioners explored who was doing what and who was funding it. This also included a private sector representative from their provider forum. They developed a whole-system strategy based on a three level matrix: (1) everyone in touch with people with dementia would get a very basic level input of a couple of hours, some by e-learning; (2) a middle band of staff who may come into contact with people with dementia would get further input, for example, HCAs, nurses; (3) the most intensive input was reserved for dementia champions, Community Nurses in Older People’s Services (CNOPS) and others with a particular roles in dementia. (The Dementia Competencies Framework is a valuable resource for supporting this form of development[19]). The strategy includes ongoing staff development such as supervision, sharing practice and getting linkages across the different sectors as well as exploring the effects of training. There is lively debate about the mix of interventions with recognition of the value of innovations such as action learning, support groups, and joint group supervision.

- Somerset has produced public, private, and voluntary sector Learning and Development Directories which outline courses and resources that are available and how to access them. The information has been presented with four levels of training and provides opportunities for organisations across the sectors to “mix and match.”

- GP Academy/practice based education seminars and dementia e learning programmes for all health, social care and third sector staff in Cornwall have been accessed by over 4,000 people to date.

4. What made the difference?

Guiding principles of commissioning

Living well with the diagnosis

4.1 This was a recurring theme when sites described their primary purpose. As one put it, “it is being able to help patients live well with dementia. It is not just about the money saved by reducing hospital admissions and delaying moving into care homes. Patients have a better quality of life and carers report feeling more in control of the situation and better supported if there is a crisis” (14). Another commented, “people want things that will help them stay connected to the lifestyle they had before. They are not looking for the expensive specialist things. They want ordinary experiences, where they can say ‘I just happen to come with my dementia as well’”.

Dementia in the mainstream

4.2 One commissioner observed that the fact that dementia touches so many people’s lives makes it easier to take a citizen-based perspective: *“I enjoy working with dementia because it links into our own experience. People have relatives, colleagues dealing with it, for example with their parents - there are interesting situations going on even within the office… you see it as an ordinary citizen. It is brought closer to home than most other areas of service provision. It presents something you cannot ignore; it is in our faces. The ‘no-matter-whatness’ of it is a great leveller. It gets us all thinking in a more ordinary user-focused way.”*

4.3 Bringing a social care perspective was seen as important in seeing dementia in the mainstream, *“linking with dignity and respect so that people are not seen just as an illness.”* In Bristol, there was a strong emphasis on the DLWs operating systemically- creating an environment where “***everyone*** *has a competence and a high level of awareness. It is about the* ***network*** *being competent and understanding.”* There was therefore a strong emphasis on dementia being on everyone’s agenda (for example, from shopkeepers to staff concerned with respiratory illness, stroke, diabetes, and end of life care). This supported the idea of people with dementia as citizens who should not have to go through dementia-specific services to get what they need.

4.4 Hospital staff in Cornwall highlighted the important of seeing dementia as a “normal illness” particularly with respect to the transition to end of life care. *“A lot is about work with frail elderly people not just dementia”.* They stressed *“recognising that you can’t deny dementia - that it is part of life as much as cancer, so people need to get what they need at the right time”.*

People with a past and an identity

4.5 The Dementia Care Mapping (DCM) team in Cornwall highlighted the importance of "men being men" and gave the example of care home residents being able to have sheds where they can potter or fiddle with machine parts without health and safety concerns dictating. In one location an old car in the garden had all the 'dangerous' parts taken off so that *"(the) men [can] go over and tinker - that is real life".*

People with physical as well as mental health needs

4.6 There were many references to a move away from locating dementia within mental health and considering it as a long-term condition. This fits well with primary care mind-sets (for example, with respect to other long-term conditions such as diabetes management) and gives a higher priority to ensuring that people have access to higher skill levels and opportunities regarding physical health assessment and monitoring. This commissioner summarised the position expressed by many: *"We are trying to contextualise it as a long-term condition and dislocate it from mental health because in practical terms it is always the poor relation, suffers from lack of organisational focus, and the stigma is still an issue as you are dealing with older people and they do have a particular view of mental health and mental health services. If someone has a dementia they probably have a range of other physical conditions and so locating them in the world of mental health you put them at risk of just that bit of their needs being addressed and clearly that would be completely illogical. Not because we are against mental health but because most of the interactions people have are with primary care, community care and social care rather than specialist mental health input"* (4).

A balance of models

4.7 Some took an explicitly biosocial and holistic approach – looking at any difficulties in the context of physical, psychological, and social factors. As they said, *"Often a family will report agitated or aggressive behaviour. I am able to look at the social situation and psychological aspects and see how these may be affecting behaviour. It could often be a case of educating carers about possible cause of this behaviour and using social strategies in order to help improve the situation, rather than relying on medication"* (11).

4.8 The DCM team in Cornwall described their person-centred approach as a balance of social and medical model of care where the extremes of each were seen as unhelpful (for example, a neglect of physical aspects but a focus on choice at one pole, and having everything done for individuals rather than with them at the other). Shifts from a medical, risk averse, 'done to' model were symbolised by abandoning uniforms, not allowing health and safety concerns to dictate and creating more homely environments.

A primary care focus

4.9 In Gloucestershire they started by talking with people who were carers or people with lived experience of dementia. It was clear that an important focus for them was that of primary care. It was that part of the local service system that people found consistent – it is known and understood. This challenged them to think of everything from a primary care perspective.

4.10 In achieving a primary care focus, it was felt important not to repeat the problems that arise from shifting responsibilities suddenly from one part of the system to another. The change needs to happen in a way that primary care services and staff *"do not feel like they are suddenly doing a lot of new things. Trying to get them to realise they already have the skills to do it but they can do it in a different smarter way with the right support"* (16).

4.11 Conveying such messages required understanding the GPs' perspective, what is important to them and the pressures they work with. As one participant commented, *"We are all learning to speak GP – they have a different way of looking at the world and you have to translate things. It is all about simplicity. They want it on one page. You groan but actually it is a good discipline."* These issues are explored further under the role of the GP lead, below.

4.12 In many ways primary care is well placed to take a social perspective. For example, when setting up clinical networks in Somerset it was striking that GPs said they didn't want "clinical" in the title, recognising that addressing the issues requires a broader perspective and an understanding that no one party can achieve the change required on their own.

Being lighter on specialist input

4.13 It was recognised that "a lot of the journey does not need specialist input and can be managed by GPs, community and volunteers, as long as they are trained and supported within appropriate infrastructure of supervision" (13). Establishing this principle has been a struggle historically. As one GP lead recalled, "A few years ago with practice based commissioning I came up with a few ideas but as soon as I got round a table with my hospital colleagues it would be "'no no far too dangerous for you clowns to be doing that, think of all the risk, think of all the harm that could happen' We never got anywhere after that so I gave up".

4.14 He went on to describe how the support of a key specialist made all the difference with respect to work in dementia: "Now I do this which is a lot more rewarding - because they are not saying 'We would like you to do these really simple things that you mere mortals can do and all the complicated stuff we will continue to do'. It is the complete opposite approach really, saying that there are still things that we need to do but there is an awful lot more that you can do. We do not have all the answers, the system is not optimal, and we all have to do things differently… [a key high profile specialist[20]] and others recognised that. It was great that the specialist was at least as vocal as everyone else in getting things out of specialist care" (2). "If we had opposition from senior people in our key provider it would have been a real problem for our primary care orientated pathway. Instead we had a pretty unanimous lot of support" (4).

Early and continuous peer support is essential

4.15 This was a recurring theme. It was striking, for example, how in the course of a moving account of coping with dementia from a carer at an event in Cornwall, the local memory café was described as the part of the pathway that had made all the difference. There were seen to be of great value in people turning up at memory cafés before the formal diagnosis so that there was peer support to help see people through.

Carers need just as much support as people with dementia themselves

4.16 How this was achieved is described in more detail below.

People with dementia can contribute too

4.17 Not only to planning their own care but also training, raising awareness and informing services.

Empathic compassion

4.18 One participant highlighted that “person-centred working comes from the heart” (11) and cited the importance of empathy. She observed that whereas we used to use a “shock factor” in training (for example, temporarily removing someone’s sight in order to give them insight into visual impairment) now people are just invited to observe while asking them – “Would be you be happy to have your mum, gran, father in this care home*?”* (11).

The importance of a clear strategic vision

4.19 It was seen as “Very enabling to have an overarching vision for dementia care. When you describe it and the function of different roles, everyone gets it” (13). It helps in serving as a touchstone for promoting positive values and attitudes, as a symbol of partnership working, not setting up false expectations and promises, setting realistic time scales and ensuring everyone gets the same messages. More than anything though it needed to translate into meaningful changes in delivery and in this sense it was sometimes difficult to separate the motive power of the strategy from the people involved in developing and delivering it. “I think it helps thinking of people who lead well having the strategic vision, understanding operationally what’s happening and what's realistic but also being able to translate all that theory about change into practice. That is what is tricky when thinking about the whole system” (13).

4.20 The process of developing strategy is explored further below. The aim was to develop the ownership of such strategic visions so that they become community-led rather than commissioner- led – thereby creating the sense of a ‘*dementia community’.* The Somerset participants highlighted that they had achieved, “*A **Somerset** strategy not an **NHS Somerset** strategy”. “It’s important to know that there is that swell of community support, especially when changing commissioning arrangements”* (13).

4.21 Maintaining fidelity to the vision is an ongoing task. It can be frustrating for commissioners when providers create roles without reference to the wider vision. The tendency sometimes was towards *"A sticking plaster approach when a bit of funding comes up and people understandably are opportunistic"* (13).

Meeting the challenge with aspiration

4.22 It was striking that these localities were highly ambitious with respect to their aspirations for people with a diagnosis of dementia and their carers, and as a result, they tended to downplay the significance of their achievements. *"We have almost just laid the foundations, I feel as if we have just started"* (2).

A whole-system approach

4.23 This was captured well by one participant who remarked, "We all beaver away in our own organisations. It is not often we lift our head up and get a complete panoramic view of everything that is happening with all our patients. And that is what we did and it kind of dawns on you that most people with dementia are not in hospital, they are not seeing specialist services, they are in the community or in residential homes and dotted around all over the place and receiving at best a patchwork of this and that from services. It is about how you join those pieces up so all those services can work better together."

4.24 Ensuring a working level of awareness and skill throughout the system was seen as paramount and was achieved through the approaches to communication, coordination and cascaded training and development described elsewhere in this report. However, a human touch, as for example through widely embedded DLW roles were always seen as crucial to helping translate such innovations into practice.

4.25 Another aspect of working with the whole-system was recognising the interrelatedness of parts: *"We are quite mindful of the need to not push everything into primary care without changing the rest of the system"* (4). This had implications for how commissioners connected with commissioners for other care groups within the commissioning organisations: *"We try to link the work we do around dementia to other work we do and that is a particular strength of our team that we cover those other areas: long-term care, adult mental health, nursing and care homes, safeguarding... raising the profile of dementia wherever you go. I make the point to people that it is in their interest to be more confident about how they interact with people, to focus on prevention and be really mindful that this just isn't [the mental health providers] job"* (4).

Human relationship as the key to action at all levels

4.26 In all aspects of a whole-systems approach, the importance of a human link to support action was a recurring theme. Examples include the Dementia Support Worker (DSW) roles, the importance of being able, as a ward manager to promote carer involvement and the fact that innovations such as STAR and the "Assess-Monitor-Prevent" toolkit were generally more effective when the care home had personal contact with the Primary Care Trust clinical lead (C).

4.27 This human link role was also important at multiple levels simultaneously. For example, taking action at multiple levels was key to achieving improvement in acute hospital care (C) and lead commissioners (whose role is described in more detail later) had a key role in bringing together top-down interest and commitment with bottom-up innovation and lived experience: *"Dissipating the spongy foam between top and bottom"* (13).

A focus on working upstream

4.28 Taking a public health perspective, the projected volume of demand for an effective response to dementia was described as awe-inspiring. The question becomes *"How do we design services and systems that really respond to the volume of the demand and are not just responsive when people get ill enough that they just can't be ignored?"* (3). Pathways need to be designed so that effective interventions are available as soon as possible in the journey. This means both working with people with lower levels of need (for example, the Newquay or Pool model in Cornwall where a health care assistant monitored people with lower levels of need) as well as working from a preventative perspective. It was acknowledged that the evidence in this area needs to build on what is known about healthy ageing; for example, with respect to being active, connected and eating well. The whole emphasis on greater integration and focus on primary care based community services was seen as invaluable in this regard.

Strong and diverse partnership working

4.29 One impetus for partnership working was a "common sense of panic" in light of the demographics regarding demand for an effective response to dementia "and a sense among organisations that on their own they don't stand an earthly of getting to grips with this tidal wave of people."

4.30 Some blurring of boundaries was seen as enabling of partnership working; for example, hanging on in a meeting to contribute to a topic that formerly they might not have been involved in (S). This builds trust and openness.

4.31 The seniority of joint working was also seen as crucial. In Cornwall, they noted that there had been a "Long standing tradition of joint working on the shop floor but that was less so further up the line - but that is beginning to change as well now". Most of the participant sites highlighted how surprisingly easy it had been to engage senior levels across organisations (see below).

4.32 Building on a tradition of partnership working was also helpful. For example, Somerset was described as *"renowned for partnership working"* with for example the countywide housing, health, care and support strategies for older people cross referenced to the dementia strategy, district council housing strategies and highlighting the importance of assistive technology, etc. (20).

4.33 It was recognised that because of different drivers from the Department of Health it *“sometimes feels like we are pulling in different directions.”* The way to avoid this was to *“avoiding splitting off what’s social care and what’s health,”* as far as possible at local level. It also required strong interpersonal skills in bringing people together as described in the next section on team working and when exploring the role of the lead commissioner. Having joint commissioning posts (G) assists with achieving integration at both a practical and symbolic level.

4.34 Often joint working was about creating structures and processes across services and over point of transition within services. For example, the transition into end of life care was crucially important. In Cornwall, the Royal Cornwall Hospital Trust has developed a dementia action group that has representation from executive level to clinicians, commissioners, carers and community groups. This group meets every two months to oversee the implementation of the hospital dementia policy and service improvement plans against the South West Standards for Dementia Care in Hospital. They also have geriatricians liaising with inpatient mental health dementia units and contributing to their ward rounds.

Leading as a strong and stable team

4.35 The importance of countywide steering or project groups for dementia was very evident across the sites: *“The dementia strategy group is completely key. The commitment there is unprecedented.”*

4.36 There were also frequent references to the strong relationships between members of project or steering boards for dementia and with named leads in partner organisations. Friendly, respectful, trusting, and productive relationships had been achieved, as well as a commitment to sharing: “*We have not been afraid to share - to be honest with one another and say ‘I have to write a dementia action plan - what have you already written can you share that with me?”* Another participant commented that, *“We are living evidence that collaboration beats competition every time. We don't waste time scoring points off one another”* (25).

4.37 It was also clear how much people enjoyed working with each other, referring to the “real fun of being involved,” and that this was “one of the most inspiring bits of a career for me -to be involved in something so positive” (16).

4.38 Having **stability** in relationship over a period of time was also seen as important for building trust, sharing knowledge, getting to know each other and *“keeping an eye out for each other”*.

4.39 Sometimes the stability of key elements of the local service system was highlighted. For example, in Somerset the fact that the local specialist mental health provider covered both social care and mental health was seen as promoting continuity (for example, the work of the SSIF project referred to above continuing on a longer-term basis within community hospitals).

4.40 Preserving this level of collaboration through stable relationships was the most frequently cited concern with respect to the future commissioning environment. One commented that it would only take four people within the county to leave for the coordination and promotion of activity to promote better dementia care to come to a halt. Another commented that *"this is very much driven by the group of people around the table. If the balance changes because of GP commissioning I do wonder what will happen without the history that we all have. The membership of the group has been consistent. You see that same person. You need those human champions. There are other strategy groups where without that personal leadership things do not happen"* (S).

Top down influence as a means to engage commitment

4.41 Government policy in the form of national strategy was also seen as very valuable in engaging the interest and commitment of a wide range of stakeholders. *"(the) national strategy was really good because it was a synthesis of what people really wanted to do and wanted to achieve"* (4).

4.42 The fact that Sir Ian Carruthers, Chief Executive of the Strategic Health Authority has personal experience of and commitment to improving the experience for carers and people diagnosed with dementia was also seen as enabling of senior involvement. When it came to engaging "opinion formers," there was a sense that *"We were knocking at an open door"* (B).

4.43 The Care Quality Commission standards were also cited as helping top-down and bottom-up approaches to come together.

4.44 The senior interest also meant that there were frequently requests for reports to Board-level. "From the Primary Care Trust perspective (and I say this through gritted teeth), it has been really helpful having a directive approach from the Strategic Health Authority. It is in the Operating Framework, what we are being told to do as a Primary Care Trust and therefore all the clunky mechanisms fell into place - 'you will have an action plan'. 'You will report on this' and while we all complain about that and it is horrible at the same time it has kept it up there at the top of everybody's list".

4.45 This high level sponsorship and interest was one of the success factors that people were concerned might be lost in the future: *"The biggest challenge is keeping this on - while you have the high level interest it is OK but as soon as that starts slipping you have problems"* (18).

Supporting multiple innovations

4.46 One authority highlighted the importance of action rather than too much planning. "It's the doing. Really and truly being more proactive. Not doing action plans. Looking at what success looks like. Trying things out. Working with the assumption that the default should be being in an ordinary environment whatever that might be. Going in and seeing what are the constraints."

4.47 One commissioner commented that “sometimes we have used partners to make use of small amounts of money in experimental ways to work with partners saying, ‘Can you help?’”. This is driven by a vision that, although informed by positive practice, is not prescriptive about roles or types of interventions but rather “creating communities that count and care and can do something about living well with dementia. What they need is often not what we [commissioners] think they need.” It is done in a way that is clear on direction but experimental and permissive about how to get there.

4.48 Having support and acknowledgement from the organisation and particularly Board level *“that we can do things differently,”* was seen as crucial and a mark of courage. *“We are allowed to be innovative and to actually be a bit brave or radical. I suspect that is going to change in the Brave New World. But I actually had a sense within our own organisation that you are allowed to do that” (20)*; *“It is a bit brave - particularly when driven by a culture of evidence-based practice - I am afraid I can’t deliver you that!”* This form of pragmatic innovation required some structure, but once again was mainly enabled by effective relationships. Overall, there was a sense that *“You need to formalise things to ensure sustainability but underpinning that is a ‘I know a man who can’ attitude - getting things done despite the regulations*”.

4.49 One wellspring of innovation was *“non-acceptance that what we already have is OK.”* For some there was a clear sense that we *“can’t afford to be doing things as we have always done them,”* with, for example, too many people sitting on waiting lists and teams becoming overwhelmed.

4.50 Innovation is also about challenging assumptions: “There is cultural stuff about what people are and are not allowed to do. What we have been able to do is myth-bust. There will always be people that say, ‘You can’t do that, it is against the law’ so it is question of just pushing those boundaries back a bit and saying, ‘Well, why can’t you do this?’”.

4.51 Diversity and difference was itself a source of innovation. Acute services highlighted the value of a working with a range of staff so that younger staff benefit from the experience of older staff, and younger staff, volunteers and outside agencies bring fresh ideas.

4.52 Effective innovation also required a strong architecture for capturing the learning and the courage to acknowledge when things had not gone as planned. These issues are explored further later.

Trust in the best of what the voluntary and community sector brings

4.53 Thinking creatively with the voluntary and community sector about how things can be done differently was seen as important. “Trust in them that they can support and train volunteers and have quality assurance in place. Take a leap of faith and give them the reins to go ahead and develop” (13).

4.54 It was noted that sometimes promoting innovation was easier within the voluntary and community sector. “[They have] more of an ability to decide something on one day and implement it the next whereas with statutory organisations a decision is made but then the oil tanker starts moving v e r y, v e r y slowly” (13).

Managing for outcomes and accountability

4.55 The enabling management style required to support innovative commissioning is also an advantage at provider level. Person-centeredness was explicitly linked to an enabling management style that is strong on outcomes and accountability but light on prescription. For example, a member of Cornwall’s DCM team said, *“It was like I was given complete ownership of my role. They said, ‘We have given you a job description and the aims of the project but it is up to you to set the agenda’. That said to me that my manager had the confidence in my abilities to fulfil that role. So my role was very bespoke. I set up the agenda. I went to meet the people. I decided some I would need to meet every week, some once a month - it was very person-centred in that with the organisations that need more support I can spend that time with them”* (11).

4.56 This style of management however was far from “laissez-faire” in that it took place in the context of a clear accountability framework. *“I report what I have done every month, what my needs are, what my aims are.”* For this approach to work effectively it was clear that a high level of trust had been established. *“All of us in the department have wide experience; a credit to the managers that have recruited the team. We work with high levels of trust and that makes you feel that you want them to feel that trust is earned, that they made a good decision in recruiting me.”* (11). This devolved and permissive leadership and management style was seen to extend upwards into the higher echelons of the Council. It was also promoted a sense of empathy with people for whom there was far less room for discretion. Specifically they remarked that for staff in care homes with more prescribed roles, *“It makes it so much harder for them to think outside the box”* (11).

Walking in people’s shoes – ways of getting a better understanding of the lived experience of people with dementia

4.57 Participants highlighted the importance of *“Getting into the person with dementia’s bubble.”* This involved really understanding how things are experienced from their perspective, understanding why they would want to make some choices and tolerating that fact that *“some decisions might be unwise but we should go with it because that is their choice,”* and not assuming that people lack capacity.

4.58 In Bristol the Alzheimer’s Society worked with Bristol and South Gloucester Local Involvement Networks (LINks) to find out what it is that people with dementia and their carers want. There were four events exploring people’s experience of diagnosis, community services, home support, and hospital. The questions were positively framed in terms such as *“What would it look like to live well with dementia?”, “What would have helped?”, “What would it have looked like if it had been a good experience?”*

4.59 The events achieved a good attendance and an interim report has been published. This was described as *“A real eye opener in terms of what people’s actual experiences of what we are trying to deliver are.”* The events were seen as successful because people felt comfortable about being very open. There was a very open invitation that attracted a wide range of people including people who had not been involved before. There was also an abundance of facilitators, which meant that participants could have personal “buddies” and there were lots of opportunities for small group conversations. People reported “feeling that we have a voice”[6]

4.60 Consultation was also conducted in Bristol via the PCT and local authority websites and separate consultations. Leads worked with existing partnership meetings to find out what was important to people. The fact that it was often informal and avoided reliance on large and inaccessible documents was seen as important. Instead they were *“Having the conversations that are important to people”.*

4.61 Participants highlighted their conscious attempts to avoid using jargon when relating to carers and people with dementia. A real shift in mind-set was called for. Words to avoid included, “outcomes,” “interventions” and “resources” and as one commissioner remarked, *“To us ‘savings’ means ‘cuts’ but to the outside world ’savings’ is good. It is about thriftiness.”*

4.62 Participants also highlighted the importance of creating a convivial, social environment for involvement including good food in a pleasant venue. They also needed to offer transport and make the event easy for people to get to.

4.63 It was also helpful that the events were specifically and explicitly linked to commissioning. Participants made it clear that they expected changes to occur as a result.

4.64 The fact that the strategy was developed over a long period allowed plenty of scope for consultation. This could be frustrating as the *“world kept moving on”* but the strategy felt more robust as a result.

4.65 At provider level, Cornwall’s DCM project underlines how change of behaviour and attitude among staff comes about through acceptance of the need to change, based on thorough understanding of the individual and the context. DCMs were aware that it is easy to go quickly from identifying a problem to implementing a solution but that this will be ineffective unless the situation is fully understood and explored.

Working from the bottom up to achieve home-grown solutions

4.66 Cornwall’s DCM project highlighted the value of working with the staff from the bottom-up to achieve home-grown solutions - “We put it to the staff to ask what is it that we should do. Because it comes from them they come up with solutions that are sustainable”, “They give us the ideas of what can change, would work and what wouldn’t work,” “it is about ownership of the solution, ownership of the training” (11).

4.67 This value of a bottom-up approach to development was core to the Learning, Training and Development Team in Cornwall County Council. The value of this way of working was demonstrated with the success of the "Time for Change" programme (dating back to 2006) wherein people with learning disabilities provided training. This led the way - showing that if you work with "experts by experience" and staff stand back and let them do the training you get much better results. This ethos in turn attracts people who like to work in this way creating a virtuous cycle and the culture is maintained: "*It grabbed my attention that we would be working with people from the bottom up… this is probably the best job I have ever had"* (11).

Walking in the staff's shoes, too

4.68 The bottom-up ethos described in Cornwall was bolstered by a strong understanding of the experience of care workers and the limits on their authority to make changes. *"It helps that we have done the work ourselves in care homes as direct staff or managers. We can step into their shoes easily"* (11).

Key challenges overcome

4.69 This section goes a little deeper into some of the key challenges facing commissioners.

Early diagnosis

4.70 It was noted that there was now a much younger group of people coming through the memory clinics. Overall though, there was a sense that people should be diagnosed at a time that is right for them and that you *"can't tell people when they want to be diagnosed. Some people are aware very early that they have a problem but choose not to know, while others feel like the really want to know so they can get on with it".* The view was expressed that imposing early diagnosis is not the right way forward but having the resources for those people that want it is crucial. The recurring message was that *"Now we have these things in place and can say 'This and that is available', GPs are less worried about diagnosis. There is less, 'let's not open up a can of worms when we know we cannot do anything about it'".* The roles of dementia nurses and advisors, DLWs (particularly where closely integrated into primary care such as in the Pool Surgery in Cornwall), GP leads supported by clear pathways and advanced care plans were all seen as invaluable. These are explored in more detail below.

Engaging primary care

4.71 The National Strategy (Department of Health 2009) was seen as particularly helpful in promoting closer work with GPs but it was seen as an ongoing challenge. *"We need more voices in GP land and more GPs who are confident in managing dementia*"(13). The innovations described above alongside the need to more GP specific events and practice-based education seminars were highlighted.

Engaging clinicians

4.72 Gloucestershire particularly highlighted the value of having this acknowledged and recognised it as a priority right from the outset within the Primary Care Trust and the Council. There were clear joint allocated resources that allowed them to recruit clinical leadership. Ideas about dealing with difference and opposition were particularly relevant to dealing with clinicians, for example in some contexts approaches to managing medication in care homes were less well received by consultant psychiatrists as they felt it was a challenge to their practice.

Working with difference and opposition

4.73 A number of tips emerged for working with differences of view through to outright opposition.

- Spot and understand, through talking to other commissioners, who the key people are and invite their influence.
- Canvas views widely: *"Make sure that more people are in the loop - not just managers. Who is at the top, who is at the bottom? Identify key individuals at each stage in different organisations. Keep key people in the loop at each stage and involve and engage with people by, asking for help, asking for advice"* (13).
- Recognise your allies. There is value in making sure they are fully on board.
- Recognise your opponents and understand how to get them signed up. They may not have anything to do with dementia services but they have a big voice. Invest time with them and get to understand what is likely to attract them.
- Make sure all communications go through these key people and invest in *"Making sure they have information and an understanding of what we are thinking so they are not put in position that something is a surprise. They need to feel their opinions are being sought at every step of the way"* (13).
- Ensure people's contribution to a given piece of work is properly acknowledged publicly and personally, "*Often all people need is a card to recognise their contribution or an email of thanks"* (13).
- Promote your own credibility. Where applicable, commissioners sometimes found it helpful to *"make people realise I do have a clinical background".*
- Learn from your mistakes: *"If you upset someone you know not to upset that person again"* (13).

Engaging care homes

4.74 Business imperatives served as an incentive for engagement in quality improvement. The sites covered here took a strong line on not using or relying on poor quality homes. Bristol spoke of their *"more assertive commissioning,"* (4) leading to decisions not to use homes unless they make improvements. In Gloucestershire, there were already around 200 empty beds and care homes were closing. Increasingly care homes know they need to be fit for purpose to attract the business and that they need to provide a service that people want.

4.75 Commissioners suggested that care homes are often owned by business people, who may know little about care. As a result, their managers are often unable to get support from above. In many cases people are promoted into management roles on the basis of their length of service; they may therefore not be leaders who can motivate staff, support residents and assume the authority necessary to make the changes. There are many exceptions to this and these usually come to light through the confidence expressed in an individual, particularly by carers. Such people are also often able to plan and budget effectively while also being able to "look outside the box" for innovative solutions.

4.76 The Cornwall County Council Learning Training and Development Team noticed that, "where (care home) management buys in we have huge successes. They support everything we do. They get involved. They get on the floor level, they take part." It was observed that the work progresses well when managers were on first name terms with staff, where staff understand "where the management is coming from and the management know where the staff are coming from". They also noticed that it can take a couple of years to achieve radical change in large homes but in small ones change can happen quickly, particularly where the owner is local.

4.77 They have sought to tackle the issue with specific leadership and management training courses that help to separate out the tasks of leadership and management. They also offer coaching and mentoring courses where half the cost is paid for by the Council if the organisation matches funds. This also includes graduate and postgraduate courses.

Achieving organisational readiness

4.78 The competencies of individuals are important but it is crucial to consider their organisational context. "There is no point thinking about sustainability if you have people with the right skills, attitudes and competencies that are sat within an organisation that doesn't get it" (13). Similarly, in Gloucestershire they recognised that it is "No good to have cohorts of DLWs where managers don't support change." To that end, they have developed a leadership programme for care home managers, which is now broadening out to ward staff and social care team staff.

Working with the shadow system

4.79 One key feature of working well with systems was recognising that much of what happens occurs because of informal relationships between people that are shaped by history and personal interest. This is perhaps inevitable within human systems but has consequences for individuals that need to be self-managed. For example, in local systems people socialise and form relationships across boundaries. Often these relationships exert an implicit influence over decision-making and there was a felt need to *"get into the clique to change service delivery."*

4.80 Another aspect of the shadow system arises from the fact that the provider organisation is often the most stable part of the local service system and Primary Care Trust colleagues may have a personal interest in making sure relationships stay positive for reasons of future employment in turbulent times. This could lead to situations where what is said in public (e.g. with respect to performance of a provider) is different to what had been agreed among commissioners in private, as individuals may have a personal interest in finding work with that provider. Such personal, 'small-p' politics was seen by one commissioner as *"really emotionally draining - the least satisfactory aspect of the work is the internal stuff".* It could form a significant part of the job requiring the investment of a considerable amount of emotion, time and energy. One person described it as *"the thing that causes me most angst."* It was coped with by conscious self-management. For example scheduling meetings where managing internal politics was likely to be an issue late in the day and also ensuring the availability of emotional support. Participants stressed the need to have people around you with shared values who were able to refresh your commitment to the task in hand. *"Part of that is to have enough people around you so that you can say, 'what is our vision again?' so that you can be re-energise … It would be so easy to go along with the masses, which is why we can get stuck in this historical 'oh well we will just keep doing what we have been doing'- it is difficult to be a lone voice- you need a supportive network which you need to realise may not necessarily be in your own organisation".* Specifically people also advocated keeping really close contact with individuals who were on the "front line"- clinicians, carers, families and friends. This *"keeps you energised and helps you to remember what you are in it for."*

The role and qualities of the lead commissioner

The lead as lynchpin

4.81 The role of the lead in having an overview of everything that is happening, including with respect to performance issues such as care homes or practices with very high admission rates, means that sharing positive practice can be focused on where there is most need. As one GP lead said of their lead commissioner, *"[The lead] just knows pretty much everything about pretty much everybody, about all the Board personalities, the issues, the politics, the money - she has a complete overview of absolutely everything. I feel very empowered to do what I do because I know … [the lead] can direct me to what I need to focus on so I don't need to know absolutely everything that goes on with dementia and it's really nice having a focused role"* (2).

4.82 The sense of having a connected overview also meant that the lead was able to take appropriate action. There was clarity and confidence about who to go to; knowing that something useful would result. *"[The lead] doesn't pass the buck to anyone. With managing all the Boards and all the rest of it, people can go to her and figure, because (a) she has the knowledge and skills to do something about it and (b) she WILL do something about it. She won't say 'oh it's not my area, I'll pass it on to somebody else'. [The lead] really is the lynchpin to holding all this together"* (2).

Personal skills and qualities

4.83 The personal qualities of the commissioning leads in Primary Care Trust's were highlighted, particularly with respect to their role as a human link and connector: *"She is approachable and she listens… you can pick up the phone and have a conversation with her no matter who you are. From band 5 up, they all know her name. I think she has been quite visible"* (11). Another lead was described thus: *"She has been involved from the word 'go!' There is a great level of respect for her from both within the health and social care community and she is clearly the right person to chair the project management board. She knew how to ... get the right people round the table and get the sign up from above. She is incredibly far forward in her vision and knows how to get the best out of people. She knows how to encourage and enthuse"* (16).

4.84 Acting as a human intermediary between organisations was a crucial role. For example, some providers, (usually large mental health providers) appeared to feel they could deliver the whole pathway with little partnership working and so some voluntary and community sector organisations found it a challenge to work with them. Lead commissioners often had a key role in facilitating dialogue and connection in this context.

Working alongside providers

4.85 The stance that commissioners took with respect to their providers was highlighted: "We are not trying to sell; we are not trying to convince people to do something because it's a target or because the Primary Care Trust wants to. We are acknowledging that there is quite a lot of challenge for people – I think we have got the philosophical and ethical stance and attitude right - we are being open minded about what the challenges are. We are not saying 'if you do this everything will be fine' and then we go away. We are in this with them to change the whole landscape around the pathway and that involves having some quite difficult discussions and us working quite differently as commissioners" (4).

4.86 Working alongside providers also meant offering tangible support and that in itself shifted attitudes. "With commissioning you also need to show people that you can give something back as well … not in a patronising way but rather to demonstrate that you are going to support them and that they have something that they can go back to cynical and sceptical people who will say 'They are bound to say that but what are they going to do?' We have put our money where our mouth is" (4).

Facilitating communication and the spread of positive practice

4.87 Sometimes the support took the form of helping organisations make connections with other sources of ideas and guidance. “I think that the voluntary sector would say that our relationship regarding contract management is supportive and jointly problem solving - maybe in the form of brokering introductions to others who can support with ideas for implementation” (13). The importance of the lead commissioner role in this area was highly valued: “Really helped to build partnership working… really good at linking up everyone, promoting the role, for example through the newsletter and bringing different providers together” (14), “Being alert to things working and then spreading it out. Regular emails and updates - makes my life a lot easier. She is a point of contact.”

4.88 In order to achieve this function well, the role of lead in having an overview was again cited. “Being able to stand back and try to get the overarching picture across providers and sectors and also keeping the ear to the ground to try to pick up best practice to link individuals and providers into one another”. This includes setting up systems for communication such as newsletters and opportunities for people to get together from different sectors and organisations.

4.89 In Cornwall, there is a quarterly Dementia Provider Forum. It initially had the broad aim of promoting two-way communication between commissioners and providers and was high level (director level among providers). Increasingly it was felt that something closer to “ground level” was needed. The Forum has been particularly enthusiastically embraced by the voluntary and community sector. The meetings include an update from the commissioner and feeding through information that providers might not have accessed, (for example, national and local information through the South West Dementia Partnership, web-links and training links). Importantly the Forum members have ownership of the agenda and speakers come from within the membership. There is a lot of sharing and updating and it serves to build the commissioner-provider relationship. It is going from strength to strength in terms of increases in numbers joining, and providers want to own and host it with the prospect that it could become self-sustaining and provider-led.

4.90 The bi-monthly newsletter was also highly valued and was getting out to around 450 people and organisations in Cornwall. It serves to identify highlight positive practice, the experience of carers and lived experience of dementia and gets good feedback. It also served to convey that there is a continuing high focus on dementia.

4.91 Capturing and spreading innovation could be a complex and subtle task in terms of both generating and sharing the material and making sure the right services benefited from hearing about the positive practice. It was noticed that clinician-led innovation sometimes encountered difficulties because they don't have the time to disseminate it, lack the confidence that it is good enough, or feel “I own it and I’m not sure want to share*”.* Here again the interpersonal skill of the lead clinician and their collaborative relationship with clinical leads was of critical importance.

Highlighting mutual benefits to promote partnerships

4.92 Within the Primary Care Trust, the lead has a role in alerting commissioning units to the knock-on effects of more personalised and high quality care on commissioning outcomes such as length of stay in hospital. There were seen as lots of reasons why acute trusts should be interested in improvements in dementia care. Highlighting these was described as the task of aligning self-interest with altruism – *"The only way you can get any traction with organisations that have multiple priorities"* (4). This helps *"Getting folk engaged in different ways on a common agenda."*

Integrating the breadth of commissioning functions

4.93 Effective commissioning required bringing together performance monitoring, service improvement, procurement, contracting and legal skills. Often these do not reside in one person and the commissioner will call on others in the Primary Care Trust (for example, for legal contracting procedures for large block contracts) but as much integration of the functions as possible was desirable. Sometimes local authorities were felt to be at a disadvantage where procurement and contracting is done separately, thereby creating situations where commissioners may not have the depth of clinical insight required.

4.94 The role of the lead commissioner in promoting service improvement was central and sometimes not assumed by providers to be part of the commissioning role. One commissioner remarked: "*My job title does not have the title 'commissioner' in it, so providers and clinicians see me as more to do with service improvement and therefore more friendly and approachable. I am doing the whole cycle, contracts management performance, management and service improvement and innovation"* (13).

Bringing change management and clinical expertise together

4.95 The relationship between clinical leads and lead commissioners was seen as a powerful way of bringing together change management skills and clinical expertise - "*My enabler for service improvement is working very closely with the clinical lead*[10] *– the key focus by which all the major clinical innovations has come out*" (13).

4.96 The close integration of these roles means that innovation can be brought together with the complex task of mainstreaming and embedding. Often there are issues with respect to ownership of ideas and confidence to disseminate as described above. In addition, the lead commissioner may need to ensure the right people are involved in the very early stages of innovation in order to build ownership. Sometimes this may slow things down, creating frustration for innovators but it is "worth it in the end" in terms of ownership.

4.97 Clinical leads also sometimes had a key role in harmonizing processes and paperwork across different parts of the system; for; for example, with respect to memory assessment in the acute hospital in Gloucestershire.

Challenging performance where necessary

4.98 Sometimes the commissioner will test and challenge some of the smaller providers, encouraging them to explore what others are doing and making links and connections. It was remarked that often this is easiest with voluntary and community sector providers because they readily understand the need to work creatively and the need to work with others.

4.99 Big contracts with larger specialist mental health providers were seen as "more complex beasts to manage." Commissioners sometimes encountered frustrations accessing reliable data to inform decisions and having to say, "this is just not good enough". Organisations can then get "defensive and crotchety." Here the need for commissioners to act with integrity, courage, and high levels of interpersonal skill was again highlighted.

Being on the money

4.100 Participants highlighted the value of the lead commissioner's role in being alert to funding opportunities and having a good relationship with the finance department so that the right documentation is in place to be able to capture funding opportunities as they arise. *"Having your finger on the pulse of what's coming and knowing you have to keep asking for it and knowing how to make a really good case for it"* (5). Making sure that the lead commissioner has access to the right intelligence about funding at the earliest point was also seen as helpful (for example, being in receipt of mailings to chief executives).

4.101 Good partnership relations also left organisations in a good place to respond effectively when funding becomes available. As one lead commented, it *"Also really helped having a great relationship with the Council - we are clear about what we want and we support both of our agendas"* (5).

4.102 From the Council perspective, a new formalised process for making business cases across the Council was seen as a great asset. Called "Enabling Commissioning"[21], it promotes a consistent approach across the whole Council, providing a framework for needs analysis and an electronic system for supporting it (B).

4.103 Commissioning is also moving towards outcome-based three-year agreements for the voluntary and community sector (B). This longer-term window gives providers more stability and does not over specify how the outcomes will be achieved. *"Otherwise they only just start working before they need to turn their attention to addressing job instability."*

4.104 Bristol had reviewed all the organisations they were funding and will be decommissioning some of them. That left some that will be purchased through personal budgets and some that are block funded. The aim is to bring all this funding together under the control of commissioners so they are able to generate seed funds that people can bid for with business cases. These business cases need to include plans for achieving sustainability through becoming self-financing. This approach allows commissioners to achieve a good level of control over aspects that have not been prioritised hitherto, such as preventative work.

The role and qualities of the GP lead

A number of key qualities and roles emerged.

- Peer respect: It was very important that the GP was someone to whom peers could relate. In Gloucestershire, they rejoiced in the lead being a *“bog-standard GP”* (in the best sense) and similarly in Bristol the GP lead (2) stressed *“I came into this with no specialist expertise about dementia at all really - - as just a regular GP. I was aware of my considerable shortcoming in knowledge of diagnosis, assessment and treatment and I suspect my knowledge was roughly typical. I knew I did not know as much as I could do and also I came into it feeling frustrated about everybody having to go through a memory clinic with the increasing waiting times that that meant”* (2).

- Knowing and understanding the issues: *“I can be completely honest with him about what the challenges are… it is not ‘I am a GP and I know best’”* (5). *“There is more honesty. People don't necessarily expect you to know everything but they do want people to say ‘I don't know I’ll find out’… This is where the whole heightening of awareness of GPs [is important], giving it credibility, creating a platform for discussion, so they know they have somewhere to come back to”.*

- *“Clinically driven, person-centred, completely recognises the issues from a patient perspective… [and having] an enormous heart for the issues around the person - people living in the best way possible even where their capacity has diminished”.*

- Passion: *“Energy and personal commitment has made such a difference.”*

- *"Knows the complexities of the world of being a GP and keeps us straight and grounded on what is sensible."* The Bristol GP lead gave a vivid description of how important it was to understand how GPs might experience attempts to engage them: "*I guess whenever I speak to my colleagues I am at pains to point out that I am not an expert. I am trying to see everything from their point of view as a GP… just trying to see how we can make it work. Almost it can be too easy to direct work back to primary care because we see it as the right thing to do philosophically but as a GP there are so many interest groups that are trying to expect more from GPs. Every day in your tray there are things saying we need to train more GPs in this and GPs in that then everyone would be better and that is for every disease under the sun. So I am well aware that although dementia is my particular interest it is only a relatively small bit of a GP's working life. I try to fit in with that. I am aware of special interest groups always banging on GPs' doors and so I am trying not to feel like a special interest group that says that my thing is SO important that I expect you to sit up and take notice. I am not taking any of that for granted"*(2). Due to this skilled empathic stance and the peer respect described above the lead was also able to …

- *"challenge their peer group to do things differently,"* and….

- *"Open doors that I could not have opened".* For example, simply having the lead in the room "as a doctor" when meeting with County Councillors was seen as invaluable.

Leadership everywhere

4.105 A dispersed model of leadership but with the very clear support and sponsorship from above was widely advocated. "In terms of leadership it is not just at the top level. Quite often it is a cleaner or cook in a care home. In Cornwall one of our strengths is that we have different leaders at different levels in different organisations but it does go all the way up to Board level. That is also based on policy but also key advocates and leaders. Also recognising those carers and people with dementia who are really helpful and enabling them to be a voice" (13).

4.106 The value of the committed thinking individual was also a recurring theme across sites. "If you get the right care home owner or manager or day centre manager you get significant things happening: staff stop wearing uniforms, they sit down and have dinner with the residents, they don't just have food delivered but always have finger buffets out, or always have pets. When they did it, it was often because of one individual" (13). "We can put all the structures in place but it is ultimately about people that are committed and have some fire for it". (The counter-point was also made however about the need for these people to create systems that support sustainability; see below.)

4.107 This also applied to people in project manager roles. For example, in Bristol the project officer for the Dementia Quality Mark work was particularly lauded as bright, creative, systematic, project-orientated, proactive in talking to lots of people, able to get into the detail of the process, able to get systems in place and has been very thoughtful regarding pressure on other parts of the system.

4.108 As has been noted elsewhere with respect to other roles (for example, GP leads), such qualities are usually more important than dementia-specific expertise: *"As with mental health often people who come with no background knowledge actually come with less baggage in terms of assumptions and expectations. Sometimes, not always, a health and social care background can be a constraint where others might have a more citizen-focused perspective."*

4.109 Participants highlighted the simple fact that *"Thinking is really important,"* when developing new approaches. However, the idea that people need defended time to think was eschewed. Although sometimes there are issues about how to prioritise time (for example, recognising the value of attending South West Dementia Partnership meetings) in general it was felt that *"People that think do it, whether in snatches of time or emails. I don't go along with the idea that people do not have time to think - a bit like equalities; the people that had certain life values and world views would not think about not addressing inequality no matter what the other pressures."*

Mobilising local community participation

4.110 Cornwall is a rural county where services are often sparse and dispersed. There is a strong cultural identification and pride in the county and a tradition of mobilising communities in order to fill gaps in statutory provision. For example, it was estimated by Cornwall County Council that around a third of care is provided by voluntary workers. These people often have experience of care or support themselves or relevant experience as a carer. Often they are people who have had illnesses that have stopped them from going to work but allow them to offer a couple of hours of support in a week. Other examples of community mobilisation include Bristol approach to reablement, Gloucestershire's work on time banks and the longer-term project on community involvement being lead by the Barnwood Trust.

Being relentlessly asset-based

4.111 Being asset-based often concerned being careful to build on what is already there and working well: "With the training stuff you start off very idealistically thinking we can put this in place for everybody, then naively you realise that there are loads of wonderful things already going on and you can't be prescriptive. But equally you want to support people and hence this mix and match approach and being able to support people, the voluntary sector and indeed the County Council" (20).

4.112 Similarly, the proposed new Reablement Service in Bristol is specifically short-term in order to build on the continuous long-term support that is already there. The service will work with the existing provider to promote continuity of care. The team's role is to work alongside, or support existing care packages to "empower and upskill" existing resources, providing guidance and strategies for managing behaviours. This service will also support existing workforce development, offering coaching on a case-by-case basis and building capacity around the individual rather than usurping it (B).

4.113 Cornwall's DCM team stressed the importance of always working from positives, building on whatever strengths they can find in an organisation whether in the staff, the wider organisation, or the location. Their feedback from care staff has highlighted that they are initially scared of external input but when they get a report that includes what they are doing right and what can be built from they are more engaged: *"We always turn things round into a positive. The negative stuff we give them ownership of so they can find their own solutions."*

Avoiding being critical or judgmental

4.114 Around a quarter of the care homes that Cornwall's DCM team worked with came through the service improvement branch of the Council because they were seen to be in need of support with their learning needs and training transfer. They are always care homes that have already approached by the Learning, Training and Development Team. The team highlighted that they consciously avoiding saying *'We told you so!'* and instead stayed true to their commitment to build confidence and ownership of the changes needed. Since their focus is so strongly on improving care for residents, they work hard to have staff on their side and take on board everything that people say rather than inculcate resistance through appearing critical or judgemental. Being enabling is felt to be more important than seeming to have been right. Even where they don't agree with staff views, they skilfully reframe how issues are described so that positive practice emerges.

Achieving and communicating clarity of role and practice

4.115 Part of the strength of a clear framework for delivery is that people can see how their involvement and commitment can contribute to the greater good. Cornwall's "Changing Lives" is a good example. The value of clarity of role and practice is also evident at a local level. For example, in their work with care homes it was crucial that the Learning Training and Development Team in Cornwall were clear about their terms of engagement, clarifying for example what would need to occur if a safeguarding issue is highlighted. The team meets once a month to clarify roles and reinforce their code of conduct. Care homes are part of an open dialogue concerning the code of conduct, so expectations are clear with everyone.

Achieving sustainability

4.116 As we have highlighted above, achieving sustainability is a key concern for participants, particularly with respect to maintaining steering groups or project boards as stable groups and continuing to benefit from senior sponsorship and support. There was a felt need to continue to *“Carry the message together”.* What follows are some factors that were felt to help.

Embedding commitment through ongoing relationship

4.117 The power of the committed individual described above was also cited as key to sustainability – *“Sustainability is founded on individuals”* (13). The importance of sustained personal commitment from any direction was highlighted. For example, from the outset, the Gloucestershire Steering Group had “*a serious passion there and that has been sustained”* (16), and it was particularly noted that the chair of the PCT would come and sit in on meetings.

4.118 Cornwall’s DCM team highlighted how some care home cultures tend to revert but that monthly one-to-one proactive informal contact helped keep things on track. They also found that increasing communication between care homes has been important. Care homes are also part of provider forums (C) (G) and whole-system innovations such as DLW roles help them stay connected.

Seeing changes in people’s lives

4.119 Changing people’s experience and bringing about positive outcomes was seen as crucial to promoting motivation and commitment. This is a key consideration with respect to the way that work is designed.

Celebration and affirmation

4.120 Positive feedback, for example from carers, was seen as incredibly important. As one person commented, *“Thanks is more important than absolutely anything”.* All sites highlighted the importance of celebration to mark successes (for example, the achievement of a ‘green’ traffic light rating): “*We have events where people get awards and some recognition. It is important. Most people in public service want to make a difference*” (25). There were many examples of practices such as the DLW role or particular materials, such as leaflets, gaining formal award or recognition, both from local sources and national bodies (for example, Ward Accreditation through the Royal College of Psychiatrists, nomination for a Nursing Times award).

Capturing the evidence

4.121 As was pointed out in Bristol, “We need to evidence that this is making a difference to achieve ongoing sustainability. It is too tempting to do lots of things that then can’t be sustained.”

4.122 Participants highlighted the importance of being honest about whether a service was working or not and also the changes that need to be made to achieve affordability. *"People often assume you are putting something there forever and though it might work for them, it might not work in terms of the bigger picture".* Often the bigger picture involved consideration of affordability and equity and involved learning about how the best of a given model that can be taken forward in different ways. For example, the Newquay integrated care pilot was Department of Health-funded and looked at services in and around GPs. It generated a lot of learning regarding principles of integrated care and the functions and roles that are needed to deliver good dementia care in the community. The challenge, as with most pilots, was to pull out the positive elements but also to acknowledge what did not go well and refine the model using experience from other pilots (in this case, for example, the work described in this report from the Pool Surgery and Lostwithiel). Importantly the learning *"Builds on a vision that many clinicians had already but it reinforces it with evidence and experience"* (13). (C)

5. Looking to the future

Respondents were invited to voice their hopes for the future.

5.1 "We will not hear 'I was diagnosed and then left'. We will hear - 'I was diagnosed in a way that met my needs and I am still in the system. I know who to go to for help and they routinely check on us. I know who my contact is and I know what to do. I know who my peers are and I have a range of activities that are meaningful" (13).

5.2 "We should not be frightened about saying – 'I am worried about my memory'- I am going to know who's out there when I have worries."

5.3 "Seen as a person rather than a diagnosis. People know who they are, their hopes and aspirations, personal plans and ambitions. A truly person-centred service" (16).

Even more attention to the voice of carers and people with dementia and their carers

5.4 As with the Cornwall's memory cafés, increasing the role of people diagnosed with dementia and their carers was a recurring theme and of real significance in, for example, developing a more outcomes-based approach to dementia. Telling stories of lived experience were seen as *"the most impactful messages"* informing future work.

More outcome-based commissioning

5.5 This went hand-in-hand with the hopes expressed above. For example, in Gloucestershire they are doing more work on their focus on outcomes working with the Alzheimer's Society and dementia advisers. They are developing a simple tool that they hope to be able to use with people who have different degrees of impairment.

More focus on key groups

5.6 Some groups were highlighted as particularly difficult to serve currently. For example it was sometimes unclear where in the system people with alcohol-related memory problems are best served. Such clients can be quite young and for someone with alcohol-related problems in their forties, a dementia care home or acute ward was judged to be the wrong environment. Also it was particularly uncertain whether they would be diagnosed with dementia later on and become more dependent, the emergence of disability and whether they will be able to live independently. Often they did not fit within complex care, nor within adult community services.

5.7 Younger people with a diagnosis of dementia were also seen as being served with varying degrees of success, and often innovations had occurred (for example, the positively evaluated younger person's carers group in Caradon, Cornwall) because of the motivation of a particular team or individual rather than as part of a clear local strategy.

Implementing, embedding and evolving local pathways

5.8 Bristol was realistic about the challenge of fully implementing the pathway and learning from their experience. "The pathway is innovative, so it's bound not to be perfect - there will be things that don't work well, or aren't appropriate. Unless you specifically try to find out about these things you won't know [complexity]… it will be iterative. We will keep on improving it as time goes on" (2).

Increasing confidence of support post diagnosis

5.9 This was seen as key to promoting early diagnosis. One ambition was extending the DSW role so that everyone diagnosed with dementia is supported, they have a main contact and maintain contact with the service.

More home-based care

5.10 Providing more specialised home-based support was seen as desirable and even more sharing of knowledge, skills and experience between agencies was seen as a way forward.

More joint working

5.11 This was the most frequently cited way forward across sites. For example:

- The Learning and Development Team at Cornwall County Council advocates more joint training as part of their ambition to balance properly social and medical models of care. This is proposed for 2012.
- Bringing carer education together with cognitive stimulation therapy - this would involve social care and health staff co-leading the training.

- Access to social workers and Deprivation of Liberty Safeguards assessors was often reported as good but more was often sought. From the acute wards perspective, getting a social worker on the ward to complete assessment and financial assessments was seen as a source of delay. Having an attached social worker/AMHP would result in fewer delayed discharges and delayed transfers. There was a proposal to implement this in Cornwall for two days per week within the next six months.

- Staff in acute inpatient settings advocated multiagency integrated teams for assessment and complex care as the way forward. In order to promote personalized care *"shared experience and specialist skills right on hand and [the staff] being able to dip in and dip out as necessary is what is needed"*.

- Some advocated a single assessment process through one delivery organisation.

- Integrated service hubs were seen as one way to promote further joint working.

Seamless and integrated support

5.12 Cornwall has a proposed model of support that offers integrated and seamless care of varying intensity through a relationship between GP practices, Age UK Cornwall and the Primary Care Trust. Specifically, the proposal is to have trained volunteers who would add value to the work of the team by adding capacity to enable continued support to promote independence. They would be supported by people in DSW roles as described at Pool Health Centre in Cornwall. The DSWs would remain the main worker (from Age UK Cornwall) involved with individuals. As now, they proactively contact people with dementia to provide support, rather than wait for a referral. They also proactively seek out people who can be assisted pre-diagnosis. The plan is for practices to have two or three volunteers, ideally with relevant experience of caring roles. One DSW could oversee two or three surgeries, providing the link between the surgery and the volunteers. The proposed model has a memory nurse who in turn provides clinical support to the DSW. The memory nurse would work closely with the community matron and district nursing services to provide comprehensive case management to individuals with more complex health needs and long-term conditions. As well as regular contact with the volunteers, individuals and their carers would also be made aware that they are able to contact any of the workers described above or their GP should they need to. One advantage for the workers is that they feel as if they are part of the same 'team' supporting people with dementia.

Funding and the implications of constraints

5.13 Resource constraints also had an upside but the right context needed to be created: "There being less money will have an upside in that it will sort out the men from the boys. Those that have good business practices will survive but it does put huge pressure on them to operate collaboratively. That is why we need the legacy" (20).

5.14 It was recognised that “When times are tough organisations tend to retrench when actually that is when you need to collaborate more. There is a real danger that all the good relationships and collaboration that we have built up over the years will disappear as organisations say ‘no no we need to make a saving we can’t to do this anymore’”. There was some concern expressed that the new commissioning environment may inhibit some of the innovative funding solutions described in this report (for example, the NHS Somerset Home Improvement Agency contract with the local authority).

Sustaining compassion and relationship

5.15 Although “Delivering Dignity”[22] saw the *“the myth of the over-qualified nurse as an irrelevant distraction to the debate on securing dignified care for older people,”* (33) there was nonetheless the view that we need to go right back to student nurse training so that people get the right kind of practical experience. They felt that training should inculcate the right values and experience and allow staff to hold onto them. Rather than a degree education, lived experience was seen as the key - *“A degree does not actually help you to speak to people, to relate to people.”*

Less bureaucracy

5.16 Staff lamented some of the seemingly unnecessarily labour-intensive bureaucracy, such as the 32-page Decision Support Tool document with respect to assessing social care eligibility. It was recognised that much of this was determined by national requirements and more local control over design was sought.

5.17 Managing the transition to the new commissioning world

5.18 As highlighted above, the two most frequently raised concerns were the threat to the continued existence of county/authority-wide steering groups or boards in their present form and a decline in support and impetus from above. This meant there had to be some strategic thinking about how the current momentum is to be maintained. One participant commented, *“Let’s face it, the likelihood of any of us on the commissioning side being in the same role in a year’s time is pretty remote, so there is something about a legacy here. I think it may be up to providers to hold this baby for a while. While the rest of the world chases its tail it is the most stable part of the system.”*

Using the learning to inform

5.19 In Cornwall, from April there will be a shadow Payment by Results contract running with the mental health provider that will provide better understanding of unit costs and scheduled activity costs. In parallel, a tiered model of care will be piloted in the east of the county. Both will provide useful information and evidence for Clinical Commissioning Groups so that by April 2013 the community will be well positioned and informed to meet the demands of new contracting and commissioning practice.

6. Discussion

6.1 This report has analysed how the remarkable achievements within the four sites came about. This final discussion summarises key themes in the context of published research and commentary on service improvement, leadership and change management. It aims to use pertinent research and theorising to contextualise the learning.

The importance of clarity of purpose

As understood by the end user

6.2 Being clear and strong on purpose as understood by end users of services and their supports is key to effective service design[23]. Sites devoted considerable energy to understanding this perspective; for example, through skilled consultation at local level and innovations such as Dementia Care Mapping and the deployment of the Retired Senior Volunteer Programme lay assessors in Bristol.

Aligning goals through moral leadership

6.3 Ganz defined leadership as "*taking responsibility for enabling others to achieve shared purpose in the face of uncertainty*"[24]. The work described here is characterised by remarkable alignment of goals from top to bottom across partnership organisations. This was clearly partly due to a strong national and regional lead, the fact that national strategy chimed with purpose as expressed by people with dementia and their carers and the *"fierce urgency of now"*[25] associated with the huge demand for an effective response to dementia due to demographic trends. More personally though, there was also a sense of alignment arising from the fact that dementia was already impacting on the personal lives of participants in commissioning and providing roles.

6.4 Perhaps the most fundamental moral principle is the Golden Rule of only doing to others that which you would have done to yourself. Karen Armstrong expresses it thus: *"Look into your own heart, discover what it is that gives you pain and then refuse, under any circumstance whatsoever, to inflict that pain on anybody else"*[26]. When dementia is already impacting on your life or the lives of those you love and you can realistically expect to experience it for yourself, then the Golden Rule becomes all the more salient. Enacted every hour of every day, it is a fine guiding principle for the empathic compassion revealed in this analysis. It is also a useful principle for service delivery and improvement[27]. It provides the perfect context for true "transformational" leadership[28] - that which turns followers into leaders and leaders into moral agents; releasing leadership capacity to act on the basis of strong moral values. As "Delivering Dignity"[22] states, *"It is individual decisions to* ***do the right thing*** *that ultimately change an organisation's culture*" (p.25). This is often much more than just ***doing things right*** in procedural terms. This principle extended to commissioner-provider relationships, where it was clear that commissioners were not merely enacting a policy, but rather working alongside providers for the whole journey towards improved outcomes.

Ambitious shared vision

6.5 It has been said that “from the perspective of human action, there is no better clue to a system’s overall well-being than its guiding image of the future”[29]. Clarity of vision and objectives is the starting point for service improvement. Yet how that vision is articulated and subsequently internalised by those responsible for delivering care is critical. The Pursuing Perfection[30] (P2) programme stressed developing transformational goals that connect with the values that brought people into health and social care in the first place, with externally imposed targets assuming only a secondary significance and leaders being seen personally to commit to these aims. This is well reflected in the four sites. They of course remained very conscious of the performance management context. In fact they often reported feeling enabled by it. However, they went beyond it to create ambitious and meaningful objectives, such as achieving a workable level of universal awareness of dementia through DLW programmes.

6.6 The ambition of local leads was also reflected in their non-acceptance of the status quo. Einstein is said to have stated that a definition of insanity was doing the same thing over and over again and expecting different results. Leaders in improving dementia are prepared to challenge fundamental assumptions about how care should be delivered. Examples include the reduced role of specialists, the increasing use of volunteers in direct provision of complex care (albeit often coordinated by trained professionals) and the sort of *“assertive commissioning”* that took a zero tolerance approach to poor quality residential care.

The power of senior sponsorship.

6.7 Another theme of P2 was that *“the currency of leadership is attention”*[31]. This attention needs to be channelled into structures and processes for system-level improvement and in this case, county or authority-wide project or steering groups were a key vehicle. P2 also stressed the value of reporting on performance to the highest levels of governance within the participating organisations, the role of top teams as giving formal permission for people to operate outside their normal roles and selecting local project areas as learning opportunities for the whole system. These were all important features of this work.

6.8 However, channelling leadership attention also requires high levels of organisational, project management and interpersonal skills and here the role of commissioning leads as “lynchpins” was of crucial importance. Improvement work needs to be organised so that everyone knows their contribution to the overall system aims. Processes such as meeting agendas, performance measurement, sharing of positive practice and small-scale innovations and pilots all need to be aligned to the system goals and the work of commissioning and clinical leads in the South West exemplified this.

Working effectively with complex systems

The wisdom of messy interconnection

6.9 Many commentators are underlining how understanding the ways in which complex natural systems work informs the task of leading improvement[32,33,34.] Participants in this process appeared to recognise the inherently messy and uncontrollable nature of human systems, wherein everything is interdependent on everything else and the only way you can find out where you stand is by trying something out and seeing what happens - albeit within frameworks that promote clarity of direction, capture learning and promote the exercise of the right level of risk. Systems thinking also helped in promoting understanding of the importance of not over-burdening parts of the system (for example, primary care) and the fact that changes in one part of the system will have implications for many other parts. This in itself is a driver for integration and a shift away from control-orientated practices toward creating contexts for creativity and self-organisation.

Bringing people together

6.10 "Whole-systems thinking" has been defined as, "develop[ing] shared values, purposes and practices within and between organisations and [using] large group interventions to bring together the perspectives of a wide range of stakeholders across a wider system"[35]. The imperative is therefore to be ambitious in bringing together those participants who have some significant interdependence on each other in the task of achieving valued outcomes, using interventions that promote clarity of purpose and effective participation. This is precisely what the leads did in bringing together their project or steering groups and creating other processes for connecting people and sharing positive practice (for example, through forums and newsletters).

6.11 Another P2 finding was that that "The most common reason for failure of large systems to change is the failure of the senior leadership team to function as an effective team with the right balance of skills, healthy relationships and deep personal commitment to the achievement of the goals"[31] (p.3). The achievement of effective boards and steering groups was pivotal to success in the South West.

Human scale connections

6.12 It has been suggested that "The role of professionals has shifted from managing transactions, to building and sustaining relationships between people and services"[36]. Indeed some go so far as to describe organisations as living networks of conversation, wherein "We are creating the organisation anew in each moment by what we are saying about it and how we are relating to each other as we carry out its work" [32]. It is certainly true that the importance of high quality human interaction or people receiving services cannot be over-stated: "The way staff interact with an older person has a profound effect on that person's life… Older people describe how their skills, self-help and self-confidence can deteriorate as a direct result of the way they are treated, such as being spoken to as if they are a child or having things done to them rather than with them" [22] (p11).

6.13 It is notable that ways of interacting that are helpful at one level of a system, tend also to be helpful at other layers of the system. So for example, a manager showing authentic personal concern for staff as individuals, giving voice to the value of their work and their aspirations and assiduously working to stay conscious of the need to build on their existing strengths and assets, leads to better outcomes for both staff and the people they serve[37, 38]. This considered and thoughtful attention was a repeating theme, for example with respect to work done by the DCM team and the Primary Care Trust clinical lead in Cornwall's care homes. In short, attention needs to be paid to the quality and effectiveness of relationship and inter-connectedness at every level[39].

Engaging sources of power and influence

6.14 Successful engagement also required strategic thinking and high levels of local intelligence (again based on relationship and familiarity) about who needs to be involved, how and at what level of commitment[40]. Commissioners were skilled in demonstrating to partners how their involvement would also serve their own local concerns (for example, the acute hospitals with respect to their performance indicators).

6.15 Leaders are not likely to achieve system-level improvement without the enthusiasm, knowledge, cultural clout and personal leadership of practitioners. This work has exemplified another P2 lesson, in that success in this area often came not through engaging practitioners in the quality improvement work of the organisations but rather involving the organisation in the quality improvement work of the practitioners[31]. Often practice staff were keen and able to innovate. They just needed support in developing, sharing and spreading innovation. Once again, high levels of interpersonal skill, for example on the part of commissioning and clinical leads, were needed.

Being grounded in lived experience

6.16 The Department of Health has advocated 'subsidiarity' as a key change principle[41] - ensuring that decisions are made at the right level and as close to the individual and their supports as possible. This serves to enact the clarity of purpose as understood by end users of services as described above. It also bears on all the innovations described above concerning supporting people with dementia to be as involved as possible in planning and choosing their own care, including at transitions such as end-of-life. It also concerns the ongoing quest for local innovation based on the experience of people who are closest to the lived experience of people with dementia. This underlines the wisdom of authorities that prioritised staff working with people with the most complex needs when rolling out DLW programmes and assiduously exploring what is already working well in any given environment[42].

Integration at every level

6.17 Integration across providers was constantly highlighted, for example avoiding splitting health and social care at the individual level. However, integration of functions within roles was also key. One participant expressed concern about *"technical expertise being split off"* based on the faulty *"assumption that commissioning is a technical objective exercise".* While it includes some technical skill, this analysis has highlighted that on the contrary, commissioning is a highly skilled interpersonal process requiring an overview of the whole local system and an integration of different functions (for example, service improvement, performance monitoring, facilitation and influencing) into roles occupied by people with whom stakeholders can interact personally and effectively.

Promoting effective communication across boundaries

6.18 Another key aspect of integration is the removal of constraints on communication and "boundary busting." The whole process of getting people talking to each other also serves to promote new partnerships and mainstreaming. It also promotes the sort of spontaneous self-organisation that is the bedrock of effective innovation.

Promoting self-organisation and innovation

6.19 One participant commented that "Organisational change now is vast and profound. This is my ninth reorganisation but this is completely unprecedented. It is even more profound for the local authorities. I do not think there is an answer but it does not mean you sit down and whinge about it. You get on and be flexible, surviving and hopefully getting the job done." (20). Such pragmatic calls to action were frequent. Participants highlighted the value of taking action, rather than becoming consumed in planning and analysis.

6.20 It may seem paradoxical that the clearer the vision and purpose the more experimental participants could be. One aspect of working well with complex systems is being strong on outcomes (ends) but light on how they are achieved (means). This often arose as a theme concerning outcome-based commissioning. Complex systems will self-organise to find the optimal way of being if they are clear on direction and constraints are removed as far as possible. Another aspect of working well with complexity demonstrated by participants was undertaking multiple innovations at different levels of local systems simultaneously. Examples at commissioning level were the large array of often-small scale innovations that were commissioned and supported and at provider level in ward-based innovations. In both cases leaders were instrumental in creating an enabling context.

Leading at every level to host creativity

6.21 We have already referenced the importance of senior sponsorship. It was particularly enabling where it helped create a culture of positive risk taking where people are supported to innovate at the edges of their comfort zones. Winston Churchill was quoted as saying, *"Success is the ability to go from one failure to another with no loss of enthusiasm,"* and this spirit was evident across the sites. Inviting innovation and experimentation requires acknowledgement that mistakes will be made. Without this there is no scope to learn and people are constrained to simply play out the patterns of the past.

6.22 The recent Good Work Commission report[43] highlighted that staff stay motivated when they are able to operate with appropriate levels of autonomy, develop competence and feel personally supported and connected. Leadership is the task of unleashing the capacity of everyone to work at their best in all corners and levels of the organisation. Rather than thinking of leaders as just heroes or servants, it is useful to consider the metaphor of leaders as host-creating spaces where people can find or reclaim meaning and purpose and give the best of themselves[44].

6.23 The emphasis was therefore on creating opportunities for creativity by creating spaces for meaningful collaboration, not over-specifying means and valuing experimentation and risk-taking. Successful innovators took time to reflect on and develop their experience: *"These days, what managers desperately need is to stop and think, to step back, and reflect thoughtfully on their experience…. events or 'happenings', become experience only after they have been reflected on thoughtfully"*[45]. They also understood the value of their work: "*Great leaders often inspire their followers to high levels of achievement by showing them their work contributes to worthwhile ends. It is an emotional appeal to some of the most fundamental human needs – the need to be important, to make a difference, to feel useful, to be part of a successful and worthwhile enterprise"*[46].

Positive, affirming, strengths-based work

6.24 A key principle of asset-based approaches to change such as using a "Solution Focus"[47] or "Appreciative Inquiry"[48] is that human systems move in the direction of that which they study. For this reason, it is important to study what works and framing objectives as the achievement of positive improvements (what people want and would help) rather than just rectifying deficits. The way the sites framed their consultation questions was a good example. Such an approach also invites an asset-based approach where all participants can consider how the resources they can access, including their own knowledge, skills and experience, can contribute to a preferred future.

6.25 It was also striking how personally appreciative participants were of the contributions of other stakeholders and the attention paid to affirming and celebrating achievement; often dignifying it with public ritual and ceremonies in the form of awards and events. This creates a virtuous cycle. As the founder of Appreciative Inquiry observed, *"The Power of Appreciation ... rests with its self-reinforcing and self-generative capacity"*[29]. One example was how the ethos of the Learning and Development Team appeared to attract people with the sort of values and attitudes that allowed the culture to flourish and sustain over many years. In contrast to deficit-based approaches such as inquiries and root-cause analysis, working appreciatively builds relationships, thereby developing collective intelligence and improvement capacity. It also serves to create more positive and sustainable work cultures.

6.26 The Good Work Commission[43] has highlighted the importance of purpose and meaning in creating effective environments and there is mounting evidence that people learn, perform better and achieve improved outcomes in a positive emotional climate[38, 49]. Social capital is also developed, where people feel cared for and valued. The co-production movement demonstrates that people are better able to offer care and support to other citizens when they feel valued and where there are opportunities to make meaningful contributions[50].

Working with the wider system: the co-production mind-set

6.27 Sites were all actively engaged in working more closely with their host communities, building on existing traditions of partnership working, community activism, and volunteering. Some were explicitly highlighting principles of co-production and stressing local mutuality and reciprocity, for example through time banks. Releasing capacity within communities also makes economic sense, though this did not appear to be the primary driver. "Delivering Dignity" advocated the everyday involvement of family, friends, carers and volunteers in line with the wishes of the individual concerned and suggested, for example, that care homes should be increasingly seen as part of the wider community through fostering links with local schools, community groups and the voluntary and community sector. Other commentators on aging[51] have particularly highlighted the importance of wider involvement of a greater diversity of people in the lives of older people, particular where this spans generations. They also stress the enormous value of older people continuing to offer us gifts of wisdom and life experience. Infirmity or illness, for example in the form of dementia, in no way disqualifies us from giving something back.

6.28 'Delivering Dignity"[22] also highlighted the importance of every environment offering older people a sense of security, belonging, continuity, purpose, achievement and significance[52]. It is striking how this list could equally well apply to staff or indeed any other stakeholder involved in taking forward this crucial agenda. Sites were already working towards a new mind-set - a shift from care "delivery" to the co-creation or co-production of care through creating and sustaining productive and affirming relationships at every level.

7. Specific Projects

Dementia Care Mapping in Cornwall

7.1 Dementia Care Mapping (DCM) is a powerful technique for improving care by helping staff to truly understand the experience of people with dementia. It begins with intensive observation of staff interactions with residents. For example, with the best of intentions, a care worker may offer a resident in a care home a cup of tea, which the resident refuses but which keeps being offered. Working to understand the experience from the resident's perspective may reveal, for example, that they have concerns that they will wet themselves. Understanding this dynamic provides the basis for a programme of care that includes effective hydration and use of the toilet. DCM generates a report covering the individual's wellbeing, ill-being and needs. This promotes a holistic view that allows a bespoke programme of care and support to be pulled together.

7.2 DCM provides a baseline from which is it possible to demonstrate measurable change and particularly what has changed from the perspective of the individual. It looks at the quality of care, general wellbeing and aspects of the environment. For example, does the person have their personal belongings in their room; does it look like a home; can people come and go? Is the behaviour of staff task-based or based around the needs of individuals?

7.3 There are four people delivering DCM from Cornwall County Council. The practice is spreading with some care home providers doing their own care maps. There is no cost to care homes. All they need to do is make staff available. Where DCM is delivered in hospital setting there is some cost to health budgets.

7.4 At the beginning of the DCM project, 300 care homes were approached. Thirty expressed an interest in being involved. Of these 17 committed. Six of these have *"huge changes which everyone talks about."* Sometimes change after six months can be transformational. As a DCM facilitator noted, *"it was like walking into another place"* (11). Now that 17 has spread to the east of the county and by December 2011, 27 homes were involved and a waiting list established. The project is now engaging new owners as well as those that originally expressed interest but did not commit at the time.

7.5 As well as the positive rumours spreading about the effect of the mapping, another lever for change is the fact that the regulator (the Care Qualities Commission) uses a reduced version of DCM (SOFI). DCM therefore provides a framework and bespoke support that meets the concerns of the regulator.

7.6 Many of the key factors that promoted the success of this work are described elsewhere in this report. In addition, specific success factors were:

- Strong values concerning individualised care.
- A bespoke programme of training and support that follows the mapping process.

- Different interventions operating at different levels within the same care home (for example, communication workshops, leadership and management workshops, reminiscence work, Arts for Health, person centred working, Appreciative Inquiries, coaching and/or mentoring).

- Working with the organisation for six months. Given the age of the group served, sometimes the individual concerned may not still be alive at the end of six months *"but even if it is just for two months, we have worked to increase their wellbeing over that time."*

- A sophisticated understanding of how learning is achieved. They cited the observation that where 50% of the input is straight training, people do not take away more than 10% of the learning. In contrast, if the intervention is 50% preparation, 25% training and 25% implementation within a learning cycle completed with managers, learning and improvement is properly embedded. As a result, their training is *"very much NOT, talk and chalk - we always say to them 90% is going to come from you."* With the emphasis on preparation people come to the training knowing what it is they are going to focus on in changing their practice and what they hope the outcomes are going to be.

- The Learning and Development Team used a multiagency pool of trainers, voluntary organisations and other teams in the Council to provide a comprehensive service. They particularly valued working with people with expertise by experience, whom they saw as people well placed to help articulate the needs of residents. They had links with other key local staff such as patch-based Dementia Liaison Nurses but ensured strong boundaries around shared information. They worked to the principle that the care home owns its Dementia Care Map and that it remains confidential to them, although they can choose to share it.

A primary care-based Dementia Support Worker role

7.7 This is an integrated service offering both health and social care support via an Age UK Cornwall worker based within the surgery. They work alongside GPs offering a quick, accessible, and reliable service through ongoing support and offering one main contact for the range of people involved. The DSW role in Cornwall is different to workers with the same description in other contexts in that it is a specifically designed and funded role, rather than an unpaid role that is assumed alongside other duties.

The achievements

- Carers have the support of the DSW who is trained with specialist knowledge and so able to support forward planning (for example, developing contingency plans with respect to suspected urinary tract infection), while providing emotional support and advice on managing ongoing challenges (for instance, support with "difficult behaviour").

- The service has seen increased referrals from GPs as they have realised the benefits for their patients.

- GPs diagnose earlier because they now know that they are able to offer their patients effective support.

- The service has also supported independent living, as demonstrated in reduced hospital admissions and delayed moves into care homes.

- The service contacts people with dementia to provide support, rather than waiting for a referral. It also proactively seeks out people pre-diagnosis to offer support.

- The service has also been able to support people that are often missed, for example, people living alone with little support from family (if they have family), or people that decline involvement in social groups. The service therefore fills a gap that might otherwise be filled by a carer or family member. There was an inherent challenge in these contexts concerning knowing “where to draw the line” regarding practical hands-on support. The first imperative is often to mobilise whatever other support is available. However, there are some contexts where no matter what you do the family support is simply not there and so the service has to fill a gap.

What made the difference?

- Very strong integration with the primary health care team while at the same time having the support of Age UK Cornwall - ”The surgery feel I ‘belong’ to them and am part of the team. Also Age UK feel that I ‘belong’ them, so am part of their team also” (14).

- People knowing that a professional, well-trained and effective resource is easily contactable. Previously GPs had been reluctant to diagnose due to the felt lack of support available.

- The strong integration and close joint working with the other members of the primary care team was clearly valued by patients, who appreciated the combined support of GP and the DSW. For example, they could see the GP with concerns and then be followed up at home within a few days by the DSW. This is also an opportunity to make sure the individual and their carers understand the situation and are following GP advice.

- Close joint working built confidence among GPs concerning the reliability, accessibility, and effectiveness of the service.

- An integrated electronic information system means that GPs can access notes and see records of visits and what was done. This feeds integration. It also makes tasks such as helping individuals to get to diabetic care appointments easier.

- The strong integration with the surgery is also helpful with respect to getting referrals on to other services (for example, for scans).

- The ease of contact and continuous support means it is possible to pre-empt possible issues, meaning that the service can intervene preventatively, in some cases staving off a crisis.

- The strong integration with the practice systems also allows the proactive engagement with people rather than waiting for them to contact the service.

- A focus on helping individuals and their carers live well with the diagnosis. There was an emphasis on quality of life and coping well with difficulty and crises.

- The close integration with the primary care team also means that the service is involved in annual reviews to support surgery QOF figures

- Building effective partnerships with various organisations. The role is dependent on there being a wide variety of services available to offer patients (examples cited included memory cafés, Outlook SW information sessions for carers, Cognitive Stimulation Therapy groups, Arts for Health and “Reading Allowed”[53], etc.). It was seen as important that Age UK Cornwall has always had a philosophy of not only promoting its own work, but also all the other services available.

- Flexibility and being able to offer a wide range of support. The role has adapted so that it provides the optimal response to presenting needs and wants. Each person is unique and so different types of support are needed at different times. This can vary from seeing someone several times a week to once every six months. The nature of the support can also vary, for example, with respect to telephone, email support or direct personal contact. Support also varies depending on what other assistance has been put in place.

- The post-holder works in a health setting but has a social care background.

- The post-holder also highlighted the value of being able to manage their own caseload.

- Some key stakeholders had important roles in helping the service get off the ground and become an effective and valued local asset. Staff at the health centre (for example, the nurse practitioner, dementia lead and the practice manager) were key to supporting implementation. The community matron provided invaluable mentoring based on her experience of supporting people within the community and so was able to provide clinical support and advice from a community perspective. The dementia lead within the Primary Care Trust provided training, clinical leadership and helped link the role to other sources of support groups (for example, DLWs). She was also instrumental in promoting the role to other surgeries. The Primary Care Trust commissioning lead for dementia also helped to connect the role to all the other services available, through personal support, regular newsletters and emails of events. All these individuals also had a key role in promoting the role to people within statutory organisations and producing a report on the service that obtained funding for the role.

- The reciprocal relationship with the Age UK team was also seen as a key asset. They helped pass on information and specialist input concerning developments related to older people and the DSW feedback dementia-specific expertise back into Age UK.

- Recognising and responding to the emotional labour involved in getting to know people well and seeing them get worse and approach and arrive at the end of their lives. The team and support from Age UK was seen as helpful in managing the emotions that arise effectively.

7.8 For more details please contact: Rosie Stokes. Dementia Support Coordinator, Age UK Cornwall/Pool Health Centre, Rosie.Stokes@ciospct.cornwall.nhs.uk, 01872 266388Rosie.Stokes@ciospct.cornwall.nhs.uk, 01872 266388.

Memory cafés in Cornwall

The achievements

7.9 This is a story of rapid expansion of a resource for people with dementia and their families that offers informal support, opportunities for sharing of information and experience and involvement in enjoyable activities in a safe and friendly environment. The cafés are strongly owned at local level and supported by local volunteers. People attending are referred to as “guests.” This captures the importance of events being well hosted and for those attending to be involved in helping to create a positive experience together. As one carer remarked, *“I bring a stranger to the memory café and take home my husband.”*

7.10 “Ageing Artfully” was an event (jointly funded by the Memory Café Network and REPoD) that brought guests and volunteers together to explore what would make their experience of cafés even more worthwhile. A survey of 54 guests and 54 carers highlighted the value of memory-based activity, including quizzes and reminiscence work, as well as playing games and days out. Inevitably, cafés develop their own sense of what they want and need. For example some cafés are ambivalent about too much specialist health input and some guests have set their own ground rules, for instance, banning discussion of “The three Ds”: Dementia, Depression and Death; preferring an emphasis on engaging people in the groups through focused and enjoyable activities rather than “problem talk”. For some carers however, facilitated discussion on these difficult topics is helpful.

What made the difference?

7.11 The Wadebridge Rotary Club was early pioneer of memory cafés. They established their steering group four years ago and were asked to look for models supporting people with dementia and raising community awareness. At this time the only memory café in Cornwall was Launceston, which had been in existence for over a year. A newsletter article on cafés gave a sense of what could be achieved. The Primary Care Trust and council supported by Rotary and others, made an ambitious bid for National Demonstrator site status and funds to support the development of 19 cafés when at the time of the bid there were only around five. In the event even these ambitions have been exceeded.

7.12 The development of the memory cafés was described as *“Almost a synchronicity of ideas coming together,””* though on the back of “*a lot of hard work aimed at inspiring.”* In some areas Rotary Clubs contacted local groups and asked them if they would like to get involved but usually it took the personal advocacy and energy of a couple of key individuals who had lots of contacts to ignite change at a local level. A number of Rotarians created “Rotarians Easing Problems of Dementia” (REPoD) to provide support to Rotarians around the country (and internationally) in their projects to people living with dementia.

7.13 The key tipping point and their top tip for change is the formation of an effective local steering group. These local steering groups involved the key people who might contribute to the development and running of local cafés. A core group of people from the steering group would go out and try to engage local GP practices and memory clinics who could signpost people to the cafés. They would help the local community to recognise the need and then engage as many people as possible to come up with a solution. The pioneers of the Cornish memory cafés particularly advocated linking to local organisations such as the Lions Club, Rotary, Round Table and the Freemasons as well as the local faith communities and always looking for connections and overlaps in intention. REPoD has also approached the local Bishop to explore closer links with the diocese. It is also important to ensure that local statutory providers from health and social care are invited to participate. The aim is to build local ownership to create something that is part of your local community.

7.14 Cafés then need to establish their own processes for funding and governance, For example the Rotary Club sponsored the Wadebridge Memory Café for the first three years but on the basis that at end of three years it would be self-sustaining. The café created a constitution and governance through the steering group of a new association (in its own right separate from the Rotary Club) with its own bank account. In this way it was able to receive bequests and the profit of raffles to cover costs such as the rental of space. The current situation is that the association is self-sustaining with Rotary funding there as a “cushion” if needed. In other parts of the country, there is statutory funding with full-time fundraisers employed to achieve secure and sustainable operation.

7.15 Other success factors included:

- Giving ownership to carers and people living with dementia, for example with people with dementia doing ordinary but important tasks such as wiping down tables and washing up the crockery. There are also plans to get more people with dementia leading café activities with the right levels of support, for example giving talks on their own lives or an abiding passion.

- The role of the Memory Café Network Project Manager was seen as crucial. It was recognised that volunteering can be a “big ask” for community members. *“Some volunteers are keen and like what they are doing but are finding it slightly more than they had envisaged to take on. Our role is to support them with something they want to do well.”* The project manager’s role is to provide training and information for volunteers and ongoing ‘up skilling’ of volunteers. They also send out details of activities a couple of times a month, providing ideas and materials (for example, a reminiscence newspaper) that are age appropriate, stimulating and relevant to the time of year. This takes some of the pressure off of volunteers to be creative in isolation.

- A network of cafés has been established with an independent “Memory Café Forum” for people involved in establishing and running cafés that aims to meet quarterly.

- The network has been able to help with key practical issues such as organising shared public liability assurance for the network as a whole (this would be prohibitively expensive on a café by café basis) and helping with CRB checks, complaints, etc. Support is also provided through training and advice sessions on developing appropriate governance arrangements and how to make the memory café self-funding (for example, through writing applications, fund raising, etc.). The network pools experience and through this what is needed becomes clarified.

- Local financial support and support with running the cafés makes a significant difference. For example the Lostwithiel Memory Café is funded by the Rotary Club and members and their partners ensure the smooth running of the café, which is overseen by someone from a voluntary organisation (Outlook SW). Having one or two skilled professionals providing input (for example, a nurse running cognitive stimulation groups) really benefits the café. In practice they noticed that *“A lot comes down to the individual worker or volunteer going the extra mile when it comes to statutory services and cafés being properly enmeshed.””* (15). Where it was achieved there were significant benefits in supporting and publicising the café and being involved early on, for example in providing training to volunteers.

- Effectively involving GPs. GPs are the key gatekeepers to the cafés and are also adopting new commissioning relationships. There was felt to be an ongoing need to support GPs in better understanding of dementia and particularly from the perspective of the carers.

- The support of key local organisations such as Age UK Cornwall or Cornwall Care was seen as very helpful but most often change came about because of the commitment of specific energetic individuals. Bude was cited as an example of where they had *“Contacted the club and they just ran with it”* (15).

Challenges to overcome

7.16 A pioneer of memory cafés remarked that when they started, “It was not our expectation that we would be such a big part but rather more of a part of a bigger local jigsaw. It is disappointing that some cafés that really want and need specialist support from local statutory services have difficulty getting it – it would be nice to know that they are there”. As described above, where it is in place the blending of statutory and voluntary support is extremely effective. For example, Falmouth Memory Café got NHS Choices to help them make a high quality DVD.

7.17 Often Rotarians assume that statutory support for cafés will be there. They found that part of the process of getting cafés going is to highlight that often it isn’t and there is a job to be done in mobilising the local community. Cornwall has strengths here in being characterised by small but tightly knit communities where there is a culture of volunteering but the scale of need raises concern for the future. With around 8000 people living with dementia in Cornwall it is perhaps unsurprising that memory cafés can become victims of their own success with cafés going from four guests in a session to around forty. At this point the level of noise affects people’s ability to hear. There is a fear that increasing the frequency of sessions may not impact on attendance numbers. Some people use the cafés for something to do every day of the week, travelling all around Cornwall. They felt that what is really needed is more volunteers and more sessions. Inevitably, there is concern over the limited pool of volunteers that can be drawn from any locality. Many carers value giving something back by subsequently volunteering but there is concern that “*not too much weight should fall on their shoulders”* (15).

Looking to the future

7.18 Ideas included:

- Further reflection on what could be done differently to stop people going into residential care or hospital. Developing further supportive links in communities (for example, specific dementia friendly local shops) was being considered as a way forward. It was hoped that such initiatives might also help to support bids for further statutory funding.

- Increasing the choice of activities to engage in can reduce pressure at home and can also delay admission to residential care. Some concrete plans for activities included an art project and dining nights out where people gain confidence by going *en masse* somewhere to eat.

8. Participants and contributors

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4	Richard Lyle	Associate Director of Community, Partnerships and PPI NHS Bristol	Bristol
5	Emma Moody	Commissioning Manager for Older People, NHS Bristol	Bristol
6	Paula Shears	Alzheimer's Society, Bristol	Bristol
7	Liz Sutton	Strategic Commissioning Manager, Bristol City Council, Health and Social Care	Bristol
8	Ian Popperwell	Commissioning manager. Bristol City Council, Health and Social Care	Bristol
9	Alison Morris	Ward Manager, Cove Ward. Clinical lead for inpatient services; Psychiatric Liaison services at Treliske, CPT Cornwall Partnership Trust (CFT)	Cornwall
10	Julie Anderson	Team manager CFT, leading on Trust's memory assessment service Dementia Liaison	Cornwall
11	Carol Griffiths	Learning, Training and Development Team, Cornwall County Council	Cornwall
12	Sue McDermott	Memory Cafe Network Project Manager	Cornwall
13	Kate Mitchell	Joint Dementia Programme Manager, NHS Cornwall & Isles of Scilly PCT and Cornwall Council	Cornwall
14	Rosie Stokes	Dementia Support Coordinator, Age UK Cornwall	Cornwall
15	Tim Jones	Rotarians Easing Problems of Dementia (in Cornwall)	Cornwall
16	Martin Freeman	GP Clinical Lead – Dementia, NHS Gloucestershire and GP lead for dementia SW Dementia Partnership	Gloucestershire
17	Helen Bown	Joint Commissioning Manager Older People and Physical Disability, NHS Gloucestershire	Gloucestershire
18	Alison Rowswell	Programme Manager, Strategic Development NHS Somerset. Lead manager for Dementia	Somerset
19	Derek Dodd	Locality Manager, Alzheimer's Society, Dorset and Somerset	Somerset
20	Penny Guppy	Public Health Specialist, NHS Somerset. Chair of Workforce and Training Subgroup on Dementia.	Somerset
21	Tracy Evans	Head of Community Services Programme, Somerset Partnership Foundation Trust. Operational Lead for Adult Community Services Directorate	Somerset
22	Wayne Lewis	Associate Director Joint Commissioning, NHS Somerset	Somerset
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24	Rob Conway	Matron COOP/Stroke/Neurosciences, Emergency & Urgent Care), Musgrove Park Hospital, Taunton and Somerset Hospital NHS Foundation Trust.	Somerset
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9. Glossary

AMHP	Approved Mental Health Professional. Their role under the Mental Health Act 2007 is to assess and decide whether there are grounds to detain people, who meet the statutory criteria, without their consent. They can be social workers, clinical psychologists, occupational therapists or community psychiatric nurses.
AQP	Any Qualified Provider
CQC	Care Qualities Commission
CQUIN	Commissioning for Quality and Innovation. CQUINs are local quality improvement goals that are linking a proportion of the providers' income. They are designed as a way for commissioners to reward excellence.
CRB	Criminal Records Bureau
CVS	Council for Voluntary Service
DLW	Dementia Link Worker
DSW	Dementia Support Worker – often this and the role above may seem different to differentiate. See the Dementia Support Worker Competency framework for further clarity[19].
DOLS	Deprivation of Liberty Safeguards
HCA	Health Care Assistant
Intermediate Care	Short-term intervention to preserve the independence of people who might otherwise face unnecessarily prolonged hospital stays or inappropriate admission to hospital or residential care. (Kings Fund definition)
LINks	Local Involvement Networks. These will become the basis for local HealthWatch groups under new arrangements.
PBR	Payment By Results
PCT	Primary Care Trust
POPP	Partnerships for Older People Projects – a programme of local authority led pilots exploring approaches to promoting health, well-being and independence of older people and preventing or delaying the need for higher intensity or institutional care.
QA	Quality Assurance
QIPP	Quality, Innovation, Productivity and Prevention.
QOF	Quality and Outcomes Framework for GP contracts
RAG-rating	Assessment using a Red-Amber-Green colour code
Re-ablement	Home based care focusing on skills for daily living. It aims to complement intermediate care.
SHA	Strategic Health Authority
SOFI	Short Observational Framework for Inspection. Used by the CQC
SWDP	South West Dementia Partnership
TIA	Transient Ischemic Attack
UTI	Urinary Tract Infection
VOLUNTARY	Voluntary and community sector

AND
COMMUNITY
SECTOR

10. Endnotes and further signposting

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[1] See the Transforming Models of Care for People with a Diagnosis of Dementia report at http://www.dementiapartnerships.org.uk/commissioning/models-of-care/defining-a-model-of-care/

[2] At time of writing although funding for the link worker proposals has been established implementation is still in the planning stage. Please see http://www.bristol.nhs.uk/your-health/dementia.aspx for further developments or contact Emma.Moody@bristol.nhs.uk

[3] www.nhsglos.nhs.uk/?wpfb_dl=1656

[4] http://www.cornwallandislesofscilly.nhs.uk/CornwallAndIslesOfScillyPCT/InformationForPatients/SelfCareinCornwall/HealthCareProfessionals/HealthCareProfessionals.aspx

[5] See also the work on 10 Key Steps to Improving Diagnosis as http://www.dementiapartnerships.org.uk/diagnosis/10keysteps/ and the resources page at http://www.dementiapartnerships.org.uk/resources/

[6] For example, http://www.dementiapartnerships.org.uk/communities/involvement/

[7] http://www.2gether.nhs.uk/managing-memory-2gether

[8] http://carefocussomerset.org/documents/TenTopTipsforsupportingsomeonewithDementia.pdf

[9] See the work of the University of Bradford for the origins of this approach and also SOFI, the the produce of their collaboration with the Care Quality Commission http://www.brad.ac.uk/health/dementia/dcm/

[10] See Beverley.Chapman@Cornwall.nhs.uk

[11] http://www.ihi.org/Pages/default.aspx

[12] http://www.southwestdementiapartnership.org.uk/2010/11/dementia-quality-mark/

[13] http://www.cornwallandislesofscilly.nhs.uk/CornwallAndIslesOfScillyPCT/InformationForPatients/SelfCareinCornwall/HealthCareProfessionals/Dementia/STARmedicationsInDementia.aspx

[14] http://alzheimers.org.uk/site/scripts/download_info.php?downloadID=399

[15] QOF. QP11. The practice engages with the development of and follows three agreed care pathways (unless in individual cases they justify clinical

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reasons for not doing this) in the management and treatment of patients in aiming to avoid emergency admissions and produces a report of the action taken to the PCT.

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