

LIVING WELL WITH DEMENTIA - BRIEF

An introduction to SBRI

SBRI competitions are open to all companies and designed to stimulate new technology either as a standalone solution or underpinning a service solution for specific public sector needs. Small Business Research Initiative (SBRI) is a mechanism which enables public sector bodies to connect with innovative ideas and technology businesses to provide innovative solutions to specific Public Sector challenges and needs.

The Public sector is able to find innovative solutions by reaching out to companies from different sectors including small and emerging businesses. New technical solutions are created through accelerated technology development, whilst risk is reduced through a phased development programme. SBRI also provides business with a transparent competitive and a reliable source of early-stage funding.

The SBRI scheme is particularly suited to small and medium-sized business, as the contracts are of, relatively, small value and operate on short timescales. Developments are 100% funded and focused on specific identified needs, increasing the chance of exploitation. Suppliers for each project will be selected by an open competition process and retain the intellectual property generated from the project, with certain rights of use retained by the contracting Department. This is an excellent opportunity to establish an early customer for a new technology and to fund its development.

SUMMARY

NHS South East Coast

NHS South East Coast is the regional headquarters of the NHS in Kent, Surrey and Sussex. It is the name given to the strategic health authority working on behalf of patients and communities in this region. Our core aim is to ensure that the people living and working in Kent, Surrey and Sussex have access to high quality, safe, effective and personal healthcare; and to maintain and improve the health of the population, reducing unacceptable health inequalities across the region.

Strategic health authorities (there are ten across the country) have three main roles:

- To lead and set the strategic direction for the local NHS
- To develop and support local NHS organisations – ensuring they are fit for purpose and have the right people working in the right way at the right time in the right place

- To performance manage and hold the local NHS to account for delivering on promises to local people.

NHS South East Coast also has a duty to innovate (and to spread that innovation across our region) and we champion quality and innovation in all that we do.

NHS South East Coast covers a geographical area of 3,600 square miles and a residential population of some 4.2 million. We manage a budget of approximately £6.5 billion in conjunction with 25 local NHS organisations. NHS South East Coast leads the health system for Kent, Surrey and Sussex, working closely with commissioners, providers, local government and increasingly with industry through our new relationship with the South East Health Technology Alliance (SEHTA).

As a high priority for the region, the key overarching outcome of this SBRI will be focused on using technology to improve the quality of life for people with dementia, their carers and improve equity of access.

NATIONAL EMPHASIS ON DEMENTIA

Revision to the Operating Framework for the NHS in England 2010/11

(Published 21 June 2010)

“During the recent sign-off of SHA plans, two areas stood out as not being given sufficient emphasis. [One of these areas] is dementia. NHS organisations should be working with partners on implementing the National Dementia Strategy.”

Living well with dementia: A National Dementia Strategy

(Published 3 February 2009)

“Full implementation of the Strategy will mean that all people with dementia and those who care for them would have the best possible healthcare and support. We know that early diagnosis, effective intervention and support from diagnosis through the course of the illness can enable people to live well with dementia. We also know that improving health and social care outcomes in dementia in the short and medium term can have significant benefits for society both now and in the future.

Our vision is for the positive transformation of dementia services. It would be a system where all people with dementia have access to the care and support they need. It would be a system where the public and professionals alike are well informed; where the fear and stigma associated with dementia have been allayed; and where the false beliefs that dementia is a normal part of ageing and nothing can be done have been corrected. It would be a system where families affected by dementia know where to go for help, what services to expect, and where the quality of care is high and equal wherever they might live.”

The Department's goal is for people with dementia and their family carers to be helped to live well with dementia, no matter what the stage of their illness or where they are in the health and social care system. The vision to achieve this is a simple one, in three parts, to:

- *encourage help-seeking and help-offering (referral for diagnosis) by changing public and professional attitudes, understanding and behaviour;*
- *make early diagnosis and treatment the rule rather than the exception; and achieve this by locating the responsibility for the diagnosis of mild and moderate dementia in a specifically commissioned part of the system that can, first, make the diagnoses well, second, break those diagnoses sensitively and well to those affected, and third, provide individuals with immediate treatment, care and peer and professional support as needed; and*
- *enable people with dementia and their carers to live well with dementia by the provision of good-quality care for all with dementia from diagnosis to the end of life, in the community, in hospitals and in care homes.*

BACKGROUND AND CHALLENGE

About dementia

There are approximately 700,000 people in the UK living with dementia, only about one third of whom currently receive a formal diagnosis. Dementia is a terminal condition that someone can live with for seven to twelve years. It is characterised by a progressive decline in functioning, including memory loss and the ability to carry out every-day activities. It is also associated with behavioural and psychological symptoms, such as anxiety, depression, aggression and wandering. Dementia is predominately a disease of old age; generally, onset of dementia is during a person's late 70s and 80s. One in five people aged over 80 has a dementia and are likely to have co-morbidities.

Stigma

Research shows there is a widespread vague knowledge of dementia. In principle, people are sympathetic towards people with dementia and their families. However, because there is a fear about dementia and a lack of understanding, in practice people avoid those with dementia and their families. (Alzheimer's Society findings, 2009)

The nationwide awareness campaign in March 2010 focused on the message of: "the more we understand, the more we can help". The advertising featured people with dementia saying, "I have dementia, I also have a life" and provided examples of simple, practical ways that the public can help people who are living with dementia.

Accommodation

As more people aged over 65 live alone and families are more dispersed across the country, people with dementia often do not have a family member to call on in an emergency.

A range of housing options are required for people as they age, which are flexible enough to respond to the needs of people affected by dementia. More information on the range of housing options can be found at:

<http://www.direct.gov.uk/en/DisabledPeople/HomeAndHousingOptions/index.htm>

Telecare is being used to support people with long term conditions, including dementia, and trial approaches are being tested and evaluated by a number of local authorities. Community alarm services can be viewed as expensive by the people who use them and by their potential market (reported at South East Regional Forum on Ageing housing conference, held in March 2010).

Health and social care needs

People affected by dementia require health and social care and support at all stages of the pathway – from encouraging well-being and access to information, diagnosis and care in the community, to hospital and care homes and end of life care. This brings challenges for providers to deliver integrated, personalised care.

Dementia is one of a number of long term conditions (such as Parkinson’s disease, COPD, stroke, arthritis, MS and heart disease) and, as such, it shares a number of common characteristics, e.g. risk of falls, isolation, difficulties with continence.

Local population profile

In 2007 the Alzheimer’s Society identified approximately 55,330 people (including those without a formal diagnosis) in Kent, Surrey and Sussex living with dementia (Dementia UK report, Alzheimer Society, 2007). By 2021, it is expected that this number will have increased to over 77,000.

Local Authority Area	Population size diagnosed with dementia, 2007
Brighton and Hove	3,100
East Sussex	9,800
Kent	17,500
Medway	2,200
Surrey	13,200
West Sussex	12,600
	55,330 TOTAL

Scope

The desired outcomes of the proposed technology development must cover at least one or more of the following areas:-

- **Ensuring people with dementia are able to maintain independence**
- **Supporting carers by reducing the burden of care placed upon them**
- **Ensuring equality of healthcare and access to healthcare for people with dementia.**

Topic 1: Ensuring people with dementia are able to maintain independence

Supports objective 6 of the national dementia strategy: Improved community personal support services

Provision of an appropriate range of services to support people with dementia living at home and their carers. Access to flexible and reliable services, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of their broader family circumstances. Accessible to people living alone or with carers, and people who pay for their care privately, through personal budgets or through local authority-arranged services.

People wish to remain in their own homes for as long as possible with a range of support services. Some of the issues that affect people in the early stages of dementia are around:

- Understanding
- Financial planning
- Social support
- Health support
- What to expect in the future.
- Benefits
- Working
- Driving
- Legal and financial advice

There are a number of models of service provision being developed to support people with dementia and their carers: peer support groups, internet networks, face to face or other ways of communicating, Alzheimer's Cafés, craft, drama, arts and poetry groups and many others.

A number of third sector organisations in the south east are providing services for people living with dementia, e.g. Alzheimer's Society, Age UK, Dementia UK, Friends of the Elderly, MIND, Princess Royal trust for carers, pr and others.

In the later stages in the pathway there may be a need for:

- Medicines management
- Contenance support
- Distance monitoring
- Respite care
- Environmental support
- Housing with extra care input
- Safety in the home
- Money management
- Protection from financial abuse
- Reablement following a physical illness
- Falls prevention
- Health and social care input.

Topic 2: Supporting carers by reducing the burden of care placed upon them

Supports objective 7 of the national dementia strategy: Implementing the Carers' Strategy

Family carers are the most important resource available for people with dementia. Active work is needed to ensure that the provisions of the Carers' Strategy are available for carers of people with dementia. Carers have a right to an assessment of their needs and can be supported through an agreed plan to support the important role they play in the care of the person with dementia. This will include good-quality, personalised breaks. Action should also be taken to strengthen support for children who are in caring roles, ensuring that their particular needs as children are protected.

It has been estimated that informal carers save the NHS and care sector over £87 billion per year (Valuing Carers: Carers UK report 2007). Informal carers are a very vital part of the support system for people with dementia and they consistently highlight a need for access to flexible and regular respite, either in the home or away from it. This may take the form of:

- Day care
- Respite care breaks – emergency, urgent and planned
- Support services
- Time for themselves
- Distance tracking.

Distance tracking may be a way of supporting more people in the community and using systems that are less cumbersome than the community alarm system, which can be negatively viewed by consumers (reported at South East Regional Forum on Ageing housing conference held in March 2010).

Topic 3: Ensuring equality of healthcare and access to healthcare for people with dementia

Supports objective 8 of the national dementia strategy: Improved quality of care for people with dementia in general hospitals.

Identifying leadership for dementia in general hospitals, defining the care pathway for dementia there, and the commissioning of specialist liaison older people's mental health teams to work in general hospitals.

The experience of many people affected by dementia in acute hospital care is very poor and over a third of people with dementia are admitted to residential care once they have been in this setting for 2 weeks or more. Stays in acute care are much longer for people with dementia and their outcomes are worse (Royal College of Psychiatrists – Who Cares Wins, 2005). Some of the issues that carers have raised about care in general hospitals:

1. Feeding and drinking does not always happen and so the person with dementia becomes dehydrated and takes longer to get better as they are not getting nutrition;
2. People with dementia not being treated with respect;
3. Things not being explained properly to the person with dementia;
4. People with dementia being moved from ward to ward and becoming disoriented in the process;
5. The hospital saying that the dementia is not their business, only the physical illness and being dismissive of the person with dementia;
6. Person-centred care not being delivered, advice and guidance not being sought from the family and carers of the person with dementia;
7. Intermediate care not being available for people with dementia; and
8. Staff not understanding dementia.

People with dementia can access health care and support at all stages of the pathway as the condition progresses. Therefore similar considerations will apply for people receiving care in intermediate care settings (o9), in care homes (Objective11) and in end of life care (objective10.)

For further information on dementia

There are a number of websites:

www.dementia.dh.gov.uk

www.alzheimers.org.uk

www.dhcarenetworks.org.uk/IndependentLivingChoices/Telecare/

The National Dementia Strategy can be found on the first website above.

Also see;

www.sehta.co.uk

APPLICATION PROCESS

Directions on how to enter this competition can be found in the Invitation to Tender (SBRI_NHS_41_001_ITT).

More information on this and other competitions may be obtained at www.innovateuk.org/SBRI

There is an expectation that all bid proposers will have made contact with a clinician in dementia, relevant to the topics above. For more information, please see invitation to tender.