



Wessex
Academic Health
Science Network

iSPACE

Dementia Friendly Surgeries Summary Report 2017

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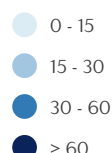
Executive summary



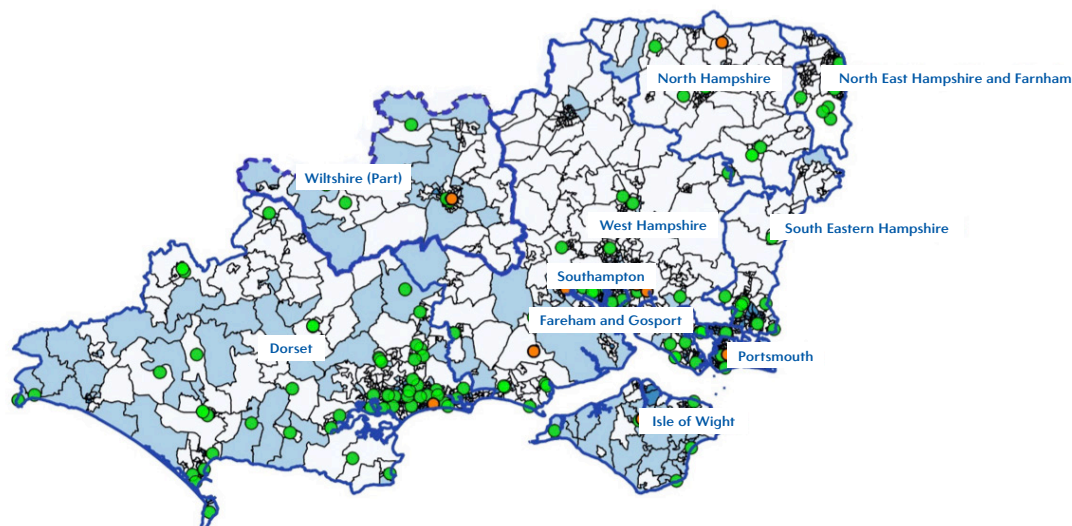
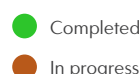
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iSPACE spread in Wessex

Deprivation score
(higher the score
the more deprived)



Wessex GP practices:



*Indices of multiple deprivation are available from: www.gov.uk/government/statistics/english-indices-of-deprivation-2015
**Only one branch id depicted for surgeries with multiple branches

The dementia friendly primary care ‘iSPACE’ project was introduced into GP practices across Wessex as an innovative, cost-effective solution to enhance services in primary care for people with dementia.

During the past three years (2014-17), the project team publicised this project throughout the Wessex region, and at the time of writing this report, 50% have completed the steps to become dementia friendly:

- Over 150 surgeries are dementia friendly
- Nearly 3,000 (2,969) surgery staff have received dementia training at the tier one (awareness level) stage, and a further 244 people have received talks about dementia and the project
- This means the project is impacting over 15,000 people living with dementia across surgeries, which are collectively caring for over 1.4 million people
- Dorset, NE Hants and West Hants CCG are aiming at 100% dementia friendly surgery status – currently they stand at 56%, 70% and 46% respectively

Broadly speaking, the iSPACE work has led to:

- Fewer A&E admissions for patients with dementia
- More patients with personalised care plans
- Fewer appointments needed with GPs, which has freed-up appointments for other patients

Impact summary for participating GP practices 1 year after iSPACE implementation



14% increase in the number of patients diagnosed with dementia



Total number of staff trained is **2.4 times higher**



Approximately 1 carer is identified for every 2 patients – a **43% increase**



Each dementia patient received on average **3.3 consultations**



9% increase in dementia patients with an annual formal review and **26% increase** in dementia patients with a face-to-face review



80% of GP practices have a dementia noticeboard and/or support and provided information through other means, and **83%** of GP practices have a carers' noticeboard and/or support and provided information through other means

The project set out to improve the quality of the patient experience by developing a set of procedures and practices that enhance the patient's relationship with their local primary care team. This focused on people with dementia and their carers but these changes also helped people with other disabilities such as learning disability, cognitive impairment and brain injury.

This project focused on patients and their carers, assessment, staff training, care planning in the surgery, and establishing links with key agencies outside the surgery.

There is still societal stigma associated with dementia, and many primary care teams have never received any formal training or education on this subject. Education, understanding and training can all help to address the fear that exists around dementia. For patient-facing staff in primary care it is helpful for them to have a set of tools that they can use to connect with patients with diminished communication and comprehension skills.

The project ran from April 2014 to May 2017, and was led by Wessex AHSN. During the duration of the project, over **200 GP surgeries in Wessex** were contacted and by the end of July 2017, over 150 surgeries had completed the steps to become dementia friendly.

A further **25 surgeries** have undertaken many of the actions necessary to become dementia friendly.

This project has now been mainstreamed into the primary care teams in CCGs across the region, and the resources (toolkits, videos, check lists) are publicly accessible, and free to use, via the Wessex AHSN website: www.wessexahsn.net/ispace

This work was grounded in the work on dementia friendly communities, and as such, will continue to succeed if communities come together to address the stigma and the exclusion that often occurs after a diagnosis. The work of the Alzheimer's Society to make dementia friendly communities and to create Dementia Friends has helped to raise the profile of dementia and to normalise this illness. See www.dementiafriends.org.uk and www.dementiaaction.org.uk

Overview

iSPACE is a quality improvement and innovation programme delivered in GP surgeries

The aim of iSPACE is to improve the pathway of patients with dementia and their carers through primary care.

The key to the spread of iSPACE is the engagement of staff teams and a recognition that people with dementia need a more personalised care plan and access to resources to help them and their carers better manage the pathway

Ultimately it is about keeping more people at home in dementia friendly communities and preventing a move to residential or nursing care



1 year before iSPACE
implementation each
dementia patient received
on average
4 consultations



1 year after iSPACE
implementation each
dementia patient received
on average
3.3 consultations

Background

The innovative iSPACE model of dementia friendly primary care was developed from a hospital-based dementia care model. Dr Nicola Decker, hosted by Wessex Academic Health Science Network (AHSN), planned and piloted the iSPACE model in her surgery, Oakley and Overton Partnership practice in North Hampshire. This was then evaluated by the AHSN's Centre for Implementation Science (CIS), Anstee et al (2015).

The evaluation demonstrated that the model provided a number of benefits for staff, patients and carers. As a result of this positive evaluation, it was decided to spread this work across Wessex, which was undertaken between April 2014 and May 2017.

The project has now been mainstreamed to CCGs and all resources are available on the Wessex AHSN website to help surgeries that want to become dementia friendly.

How was engagement achieved?

A range of methods were used to inform people about this project, its benefits and outcomes, and to engage staff teams to sign up.

1

Clinical Commissioning Groups (CCG) and dementia leads in Public Health England (PHE), Health Education England (HEE), Strategic Clinical Networks (SCN) and Collaboration for Leadership in Applied Health Research and Care (CLAHRC)

Initially all CCG leads for dementia and other key stakeholders were approached and notified about this project and the other work being undertaken, i.e. the dementia acute care development programme in the eight acute hospitals in Wessex.

See wessexahsn.org.uk/projects/47/working-with-acute-hospital-dementia-leads-to-improve-care-in-their-hospitals

2

Communications materials

Wessex AHSN created a set of resources describing the project, a brochure and a leaflet which outlined the benefits of the work and invited surgeries to get involved.

3

Dementia events

A number of dementia focussed events were held across the region, where this project featured, or had a stall to inform delegates about the project.

Examples of these events were:

- Portsmouth TARGET meeting - September 2015 and April 2016
- Southampton TARGET meeting - March and September 2015
- Better Local Care – West Hants primary care meeting - March 2016
- Local Medical Committee dementia training session, Dorchester - February 2015
- Practice Manager meetings in Bournemouth, Southampton, SE Hants

Wessex AHSN team
working on iSPACE Joanna
Bazalgette, Sarita Chavda,
Sue Sparkes, Jane Ward,
Katherine Barbour, Melissa
Richards and Claire Fleming
(not pictured)





4

Clinical spread

Dr Nicola Decker, who is a GP, was approached by a number of GPs and practice teams who had previously heard her speak about the project; and Dr Michele Legg, the clinical lead for Wessex AHSN's dementia programme, trained colleagues on Isle of Wight and led events in Hampshire.

5

Voluntary sector

The voluntary sector has helped with the spread and adoption of iSPACE.

Approaches were made to all the agencies providing support to patients who had recently been given a diagnosis of dementia, and to the charities engaged, including the Alzheimer's Society (Hampshire and Dorset), Andover Mind, Carers Together, Dementia Friendly Hampshire, Alzheimer's Society Wiltshire, Princess Royal Trust for Carers, Remind Portsmouth and Age UK IOW.

Staff from the local dementia advisory service were invited to many of the training sessions to facilitate introductions to the staff team and to share the referral process.

6

Funding incentives

In November 2015, 30 surgeries were engaged in the project, and a small underspend in Wessex AHSN budget was identified.

This was used to incentivise surgeries to undertake iSPACE and to collect data about the impact of the project. Awards of up to £1,000 per surgery were made. **This resulted in the engagement of a further 50 surgeries.**

7

Clinical Commissioning Group (CCG) support and engagement

Two CCGs contacted Wessex AHSN offering support for the project, and made funding available to all surgeries that undertook iSPACE. North East Hampshire and Farnham established this in June 2016, and offered £2,750 per surgery on completion. **This resulted in 70% of their surgeries completing iSPACE.**

West Hampshire CCG also offered support to 17 surgeries in the New Forest - Totton and Waterside. **This resulted in all surgeries in the area implementing iSPACE, and being paid £750 per surgery. This incentive is being extended to all the surgeries in West Hampshire CCG in the hope of achieving 100% uptake.**

Dorset CCG has recognised the impact of iSPACE on its primary care service and has appointed a member of staff to take this work forward. This person had a handover from Wessex AHSN and attended training to learn more about the project and to be able to deliver training. Dorset has a target to achieve greater take up of iSPACE.

8

Posters and papers

Wessex AHSN submitted posters and papers to a number of conferences, National Dementia Congress 2015, Public Health England 2015 and 2016, University of Southampton Dementia conference in 2015.

Dr Decker submitted this project for an HSJ Compassionate Care Award in 2016, and finished a runner-up.

How was engagement achieved?

9

Targeting surgeries

Direct approaches were made to surgeries with high numbers of registered patients living with dementia. In Dorset, all surgeries were written to and asked if they wished to get involved. This was also done in Wiltshire. All surgeries on the Isle of Wight - where prevalence is high - were approached, and Dr Michele Legg delivered a training session to nurses from every surgery on the island.

10

Eli Lilly

A consultant from Eli Lilly has been part of the adoption and spread team since October 2016.

11

Evaluation

Four evaluation exercises have been completed. In autumn 2014, the first two surgeries to participate in the iSPACE project were evaluated. This was reported back in January 2015. In May 2016 and May 2017, a second and third round of data collection was undertaken by Wessex AHSN and their Centre for Implementation Science.

In Spring 2017, focus groups were held with three surgeries that had undertaken the project in 2015/16 to gain feedback from patients living with dementia and their carers on the impact of the changes.



"Very client focussed and relevant to practice."

Administrator,
Park & St Frances
Surgery

"Fantastic resources, tailored to our organisation. Very helpful."

Manager,
Crondell Surgery

"I found it very useful and thought provoking."

Receptionist,
Southwood Surgery,
NE Hants

"Best dementia training I've ever had - thank you."

Practice Nurse,
Forestside Surgery

"Will be cascading to all admin team."

Manager,
Badgerswood
Surgery

"Really helpful in understanding what the person with dementia is feeling."

Receptionist,
Rowner Surgery

"Very informative, not too long but full of valuable information."

Receptionist,
The Vine Group
Waterlooville

"Thank you for providing such a good overview."

GP,
Heatherview Surgery

Evaluation of iSPACE

Report by the Wessex AHSN Centre for Implementation Science, February 2015

In Autumn 2014 Syd Anstee evaluated the first two surgeries to undertake iSPACE and other steps to become dementia friendly. The evaluation used a mixed-methods study to describe experiences over six months in two case-study practices within Wessex, namely Oakley & Overton Partnership, North Hampshire, where the iSPACE initiative was implemented fully in April 2014, and Tower House Surgery, Isle of Wight, where a collection of dementia initiatives had been implemented through uptake of national schemes and lead GP ideas.

Patients and carers at Oakley and Overton provided positive feedback on:

- Consistency of dedicated GP
- Having a GP as dementia champion
- Staff who have good understanding of dementia issues
- Being treated with respect
- Feeling listened to
- Carers feel included and valued
- Better awareness of medicines adherence issues

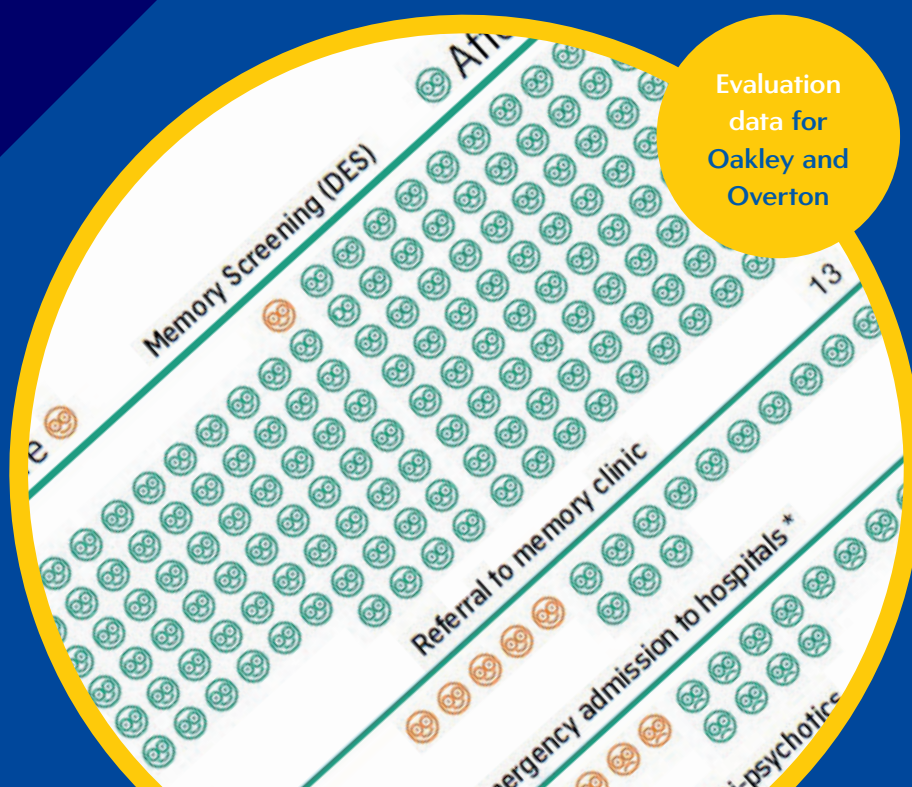


Patients and carers at Tower House provided positive feedback:

- Staff having a good understanding of dementia issues
- Big improvements from a few years ago when there were no dementia services after diagnosis – significant improvements on follow-up support
- Excellent care from GP for both patient and carer

Quantitative data showed increases in memory screening, diagnosis rates, care planning, referrals to memory clinics, use of the 'This is Me' care document and recording of resuscitation status.

The published summary report, dated April 2015, can be found on the Wessex AHSN iSPACE resources page. See wessexahsn.org.uk/projects/166/ispace-resources



Data collection May 2016

Methodology

- A data collection template was developed to ensure a standardised data collection process
- The template was tested in five practices and feedback has been incorporated into the final version
- The questionnaire was sent out to 49 practices across Wessex
- 33 practices returned the questionnaire (return rate of 67%) with data for
 - 1 year before iSPACE implementation: 28
 - Year of iSPACE implementation: 25
 - 1 year after iSPACE implementation: 1
- The differences in responses are mainly due to the different stages of implementation among the practices
- Due to the variation in practice characteristics and to ensure comparability of results, the following analysis focuses on the practices which submitted data for data points (n= 20)
 - 1 year before starting iSPACE
 - Year of iSPACE implementation
- Data collection issues: it appeared to be very difficult for some practices to extract hospitalisation data from their systems e.g. number of emergency admissions, length of stay. Therefore, the section was not analysed

Findings



Dementia diagnosis rates **increased by 15.9%** for people aged over 65



The number of patients with dementia for whom a carer has been identified **increased by 26%**



The number of staff trained more than **doubled**



There was a **reduction in clinical consultations of 6%** for people living with dementia

Patient and carer feedback during project

Patient and carer feedback was built into the design of the project.

This took a number of forms:

- Focus groups with people living with dementia and their carers living in Hants and Dorset – autumn 2016
- Study site meetings in surgeries that had implemented iSPACE – spring 2017
- Patient participation groups (PPG) attached to a surgery undertaking the Kings Fund tool – is your health centre dementia friendly?
- Patient surveys about whether the surgery is “dementia friendly”
- Unscheduled walkabouts of the surgery by carers, people with dementia and WAHSN staff

This aspect of the project helped to ensure the voice of the person living with dementia and their carer was heard and was extensively used in training sessions with staff teams in surgeries.

A template walkabout sheet was used to provide feedback on the surgery and this was undertaken in over 20% of surgeries. A few surgeries requested a template to communicate with the virtual PPG with a number of questions about whether the surgery was already dementia friendly, questions such as...

Can you give us an example of a time when you have felt the care you have received has been unhelpful or lacked understanding?

Do you feel involved in making decisions about your care or treatment?

The surgeries that undertook these surveys used the data received to address issues raised by patients.

Wessex AHSN led qualitative evaluation through patient and carer focus groups in autumn 2016 and through three study site visits in spring 2017.



Patient and carer focus groups Autumn 2016

These were held in south Hampshire and north Dorset with groups of people living with dementia and their carers – participants were not all registered with surgeries that were working to become dementia friendly. They contributed useful information on their experiences of primary care, diagnosis and of care in the community post diagnosis.

Below are a number of quotes from carers and people living with dementia:

"I write a letter to the GP a couple of days before the appointment – lets him know how it is and it saves time at the appointment. My husband isn't aware, but it helps."

"This project is good – it's what's needed."

"We saw the memory nurse every six months, and she spent time with you, and you got a report. Once we moved to the GP – she's very nice, but she hadn't looked at his notes – he's been diagnosed for eight years and she asked if he wanted a memory test! It felt as if we'd lost all support. She didn't really talk to either of us, or ask about my, or his, issues."

"He's losing weight, but the doctor just says, 'Oh keep an eye on him'. I'm worried."

"Really each surgery needs a lead dementia GP in each practice – someone who's really committed."

"You need to know the little things about people – 'How's your grandson?'. It all helps break the ice, and staff should use it more."

"They've completed [iSPACE] – dementia's mentioned more, posters are up – and we see the same doctor every time."

Key findings

There is limited follow up after diagnosis by the GP and team. The surgery has some understanding of the pressures on the carer but does not always effectively acknowledge the illness and the impact on the family of this long term condition. However there is some very good practice and in surgeries that had implemented iSPACE patients were starting to see improvements.

iSPACE study site meetings with patients and carers at three surgeries Spring 2017

Invitations were sent out to all the patients with a diagnosis of dementia at each surgery. This elicited 23 patients and carers from one surgery and 15 from the other. A third surgery site meeting was held in June 2017 with 31 participants. The meetings were facilitated by Wessex AHSN staff, and staff from the surgery initially attended to introduce people and then left. A discussion was held and then each couple or individual was given a questionnaire to complete about their experiences in a number of areas of dementia care.

Numbers of people getting annual reviews

Annual reviews	Yes	%	No	%	Not sure	Under a year
Surgery one	4	36	7	64		
Surgery two	5	55	4	45		
Surgery three	2	14	7	50	3	2

Q. Have you been offered an annual review?

"Yes, this covered progression of disease, social contacts, physical health, carer (spouse) consulted regarding concerns"

"Blood tests, blood pressure, height, weight, discussion with carer, care plan drawn up/revised memory tests"

"No. Annual review for diabetes but Alzheimer's has never been mentioned"

Q. How is your carer being supported – health checks, flu jabs, regular check ups?

"Carer is registered on system – priority appointments, offered flu jabs"

"Health checks, flu jabs, regular check ups"

"No health checks being offered"

Q. What are your overall views of the surgery?

"Very positive over general care and compassion shown"

"Excellent, Dr is very supportive and always appears to have time for discussion. They are concerned about the welfare of patient and carers."

"There is very little time for discussion of issues"

"The dementia noticeboard is tucked out of the way and needs to be more prominent"



Summary

The evaluations present a mixed picture; there is some evidence of a real transformation in relationships between clinicians and patients with noticeboards and information supporting carers and people with dementia. This was as a result of iSPACE and of individual doctors recognising the impact of the illness through personal and work experiences. There is still work to be done and for surgeries that were part of the study sites the numbers receiving annual reviews needs to be addressed.

Carers identified in iSPACE practices that submitted data



1 year before iSPACE
implementation
approximately **1 carer** was
identified for every
3 patients



1 year after iSPACE
implementation
approximately **1 carer** was
identified for every
2 patients

Report by the Wessex AHSN Centre for Implementation Science, May 2017

39 surgeries supplied data in May 2017 and these surgeries are representative of the surgeries in Wessex. The same methodology was followed as in the earlier round of data collection. Many of the tables in this document come from Dr Argyropoulos' report.

Findings



Dementia diagnosis rates
increased by 10% for
people aged over 65



The number of patients
with dementia for whom
a carer has been identified
increased by 43%



The number of staff
trained more than **doubled**



There was a **reduction in
clinical consultations by
16%** by people living with
dementia

1 year after iSPACE implementation across Wessex: How does it feel?

"Eight months later, I'd just like to say how useful the staff felt that their dementia training was. They have certainly put it to use by helping patients on a day to day basis, and looking out for 'signs' without drawing attention to the situation."

Dorchester practice manager

"It has revolutionised the (patient's) annual review. We used to just do blood pressure, weight, and it felt like a tick box exercise. Now we have This is Me, take details of the carer and give information about local services. Doing iSPACE has improved our care."

Southampton practice manager

"It's a god send. Since we've been part of the dementia programme, we're not so isolated. We're not so stuck at home. We are able to get out more and feel part of the village."

North Hampshire carer

"This work will give us a good basis on which to provide ongoing support to people living with dementia in our community."

Sherborne practice manager

Impact summary for participating GP practices 1 year after iSPACE implementation



14% increase in the number of patients diagnosed with dementia



Total number of staff trained is **2.4 times higher**



Approximately 1 carer is identified for every 2 patients – a **43% increase**



Each dementia patient received on average **3.3 consultations**



9% increase in dementia patients with an annual formal review and **26% increase** in dementia patients with a face-to-face review



80% of GP practices have a dementia noticeboard and/or support and provided information through other means, and **83%** of GP practices have a carers noticeboard and/or support and provided information through other means



Sustaining momentum

12

Sustaining momentum

In two parts of Dorset (West Dorset with Weymouth and Portland, and North Dorset with Mid Dorset) Dementia Champions Networks have been formed.

Dementia Champions from surgeries across the localities meet four times a year to share best practice, keep up the momentum of being dementia friendly, support each other and to hear from dementia related services offered in these areas.

So far there have been guest talks by Age UK in Dorchester, Future Roots in Sherborne and Dorset Advocacy. All the speakers have been excellent and very engaging, and have brought information which can be shared with people who are diagnosed with dementia at the various surgeries. The staff attending value these meetings, and the opportunity to share best practice, to learn from each other and to have a presentation on a related topic. The resources needed to facilitate these meetings are a person willing to host a meeting, to invite a speaker and to communicate this to the network.



Dementia Champions have created new Networks to share best practice **four times a year**



Over **33 iSPACE resources and templates** available on the Wessex AHSN website



10% increase in the number of patients over 65 diagnosed with dementia



7% increase in the number of patients with Memory Screening (DES)

Lessons learnt:

- Engagement of GPs and clinicians in the work is crucial – they can facilitate the process at surgery level and know what is feasible to implement. They have been strong advocates for the work
- Having training sessions for all the staff team together is better than training admin staff away from clinicians. All staff need to be trained
- Persistence with the practice managers (PM) and champions is needed to achieve engagement and completion
- Training and completion dates should be communicated at first meeting
- Resources on the Wessex AHSN website allow people to find out about the project independently, and have helped facilitate conversations with teams across the country
- Bold set of marketing tools helped with early recognition
- The evaluation by the Centre for Implementation Science helped with getting sign up to the project, convincing busy and sceptical people that this work was beneficial
- Having a set of tools on a memory stick to give to the team to download saves paper and is easier to find
- It is recommended that all surgeries invite an external facilitator to the surgery to do pre and post surveys with their patients. During the focus groups with patients and carers, feedback indicated that surgeries had not communicated about iSPACE and seeing an invitation to the focus group had caused distress as dementia was mentioned.

13

Spread and adoption beyond Wessex:

There has been a lot of national interest in this work:



9 AHSNs, SCNs and Universities

have approached Wessex AHSN to learn more about iSPACE and 12 Clinical Commissioning Groups have contacted Wessex AHSN



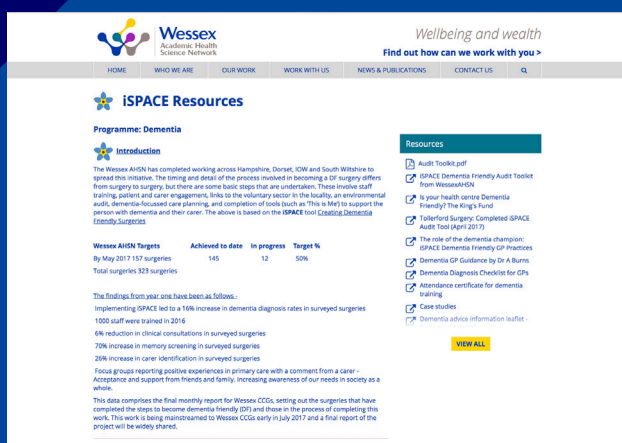
8 GP surgeries

outside the region have contacted Wessex AHSN, and one surgery attended a training session to learn more about the project



iSPACE is featured on 6 national websites

including the Royal College of Nursing and The Academy of Fabulous Stuff



Creating dementia friendly GP surgeries and iSPACE resources

Wessex AHSN training session and our work towards making GP surgeries dementia friendly

Current situation

iSPACE has been an extremely successful project with over 50% of surgeries in Wessex engaging with this work. This is in large part due to the energy and endeavours of the staff who have worked tirelessly with teams in surgeries, sometimes in the face of reluctance to engage and difficulties in following up on initial contact.

The project is now being mainstreamed into standard practice for GP surgeries and will be overseen by the CCGs. Dorset, North East Hampshire, and West Hampshire CCGs are each working towards 100% Dementia Friendly surgery status. In Dorset the primary care quality team has picked up this work.

A network of dementia champions is now in place across the region. Each CCG has been given a list of these leads and their contact details to enable new surgeries keen to undertake the work to be linked to local experts.

Manchester CCG will be piloting iSPACE and, following successful evaluation, spreading the initiative to 105 surgeries in inner Manchester. Practices will receive a charter mark and financial incentives to undertake iSPACE as part of a package of quality improvements.

It is heartening to see that the Alzheimer's Society has picked up this work and is spreading this across the UK.

See www.alzheimers.org.uk/info/20136/resources_for_gps/515/resources_for_gps/4

As a result of implementing iSPACE, surgeries now have:

- dementia friendly signage
- bespoke leaflets listing local services
- care planning documents that focus on dementia and carers
- trained staff
- reduced numbers of consultations
- increased diagnosis rates
- better engagement with carers
- noticeboards
- more annual reviews being undertaken.

If you are interested in implementing this in your area

Working in Wessex:

Please contact your CCG primary care or dementia team for support with implementing this work.

If you are from outside Wessex:

Please look at the webpage in the first instance: See www.wessexahsn.org.uk/ispace

If you have particular questions about this work please contact Katherine Barbour, programme manager, enquiries@wessexahsn.net



Special thanks

Special thanks must go to Dr Nicola Decker of Oakley and Overton Partnership in North Hampshire, who had the vision and energy to adapt dementia friendly settings to primary care and to drive this forward in her surgery before its spread across Wessex and beyond.

Our thanks also go to:

- the iSPACE project team for their dedicated delivery of improvement to dementia care
- national clinical experts for their input and accreditation of iSPACE
- patients, carers and voluntary sector representatives who have all generously given their time to attend our focus groups and provide feedback
- the CCGs and primary care teams across the region for their enthusiasm in implementing these improvements, and
- AHSN staff for all their support to spread this work and improve the lives of patients with dementia and their carers.

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Dr Nicola Decker and
Professor Alistair Burns
(National Clinical Director
for Dementia, NHS England)
opening Oakley and Overton
Partnership as a dementia
friendly practice





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