



research

searching ways to valuable answers

Dementia Element of NHS Health Check Evaluation Research

**Debrief date:
25th October 2016**

- The NHS Health Check introduced the mandatory dementia awareness-raising component to people aged over 65 years in 2013. People eligible for this are given a leaflet on dementia and provided with information on the signs and symptoms of dementia.
- The purpose of the dementia awareness-raising component of the NHS Health Check is to raise awareness of: The risk factors associated with dementia, the signs and symptoms of dementia, signpost where people can go to get further advice and support.
- The overall aim of this work is to qualitatively evaluate the impact of the current dementia awareness-raising component in the NHS Health Check.
- The findings from this work will be used to help understand the impact of dementia awareness-raising on individuals participating in an NHS Health Check. It will also be used to inform changes to the way the awareness-raising is currently delivered, and the development of training to support professionals and action on the routine collection of data on dementia awareness-raising as part of the check.

- 19 free-found general public interviewed in depth interviews
 - 16 definitely had NHS Health Check; 2-3 may have had a different type of check
 - Mostly conducted at GP (2 in Pharmacy)
- 16 HCPs interviewed in depth interviews
 - Health Trainer/Checker/Lifestyle Specialist x 4
 - Practice Nurse x 8
 - Healthcare Assistant x 1
 - Pharmacists x 5



Objectives - HCP

- To establish awareness and knowledge of the dementia element.
- Explore in detail the frequency of delivering the dementia element.
- Understand the impact they feel that this element is having on patients.
- Understand professionals' experiences of supporting the delivery of the dementia component
- Establish attitudes to training provided and any further training needs to support the delivery of this component
- Explore whether they consider that data should be collected on dementia



Objectives – General Public

- Explore experiences of and awareness of process of NHS Health Check
- Explore awareness of and recall of dementia element of Health Check
- Establish spontaneous recall of content
- Explore perceptions of the impact the dementia element had on their awareness of and attitudes to dementia including
- General dementia awareness
- Attitudes toward dementia
 - Anxiety/worry
 - Knowledge of risk factors
 - Attitude towards the risk of developing dementia
- Lifestyle behaviour Intentions/attitudes/experiences
- Attitudes to concept of referral to lifestyle services and memory services among 64 – 75 year olds

**Contextual attitudes to NHS
Health Check**



Range of patient ages and lifestyles within sample

- Range of ages in general public sample, from 65 to 75
- Variety of different routes to accessing NHS Health Check
 - Most commonly invited by letter
 - Some offered a Health Check by the nurse/their GP
 - Some invited for a check in a leisure centre/drop in opportunity
- Different levels of health consciousness
 - Different attitudes towards own health
 - Some very healthy
 - Others know they could be healthier
 - A few recognise they have an unhealthy lifestyle



Health check appreciated by 65+ patients

- 65+ patients curious to know the state of their health
 - Recognise increased risk of developing health issues in older age
 - Thoughts of aging prompted by change of lifestyle / retirement age
- Curiosity often the motivation
 - Checking “the basics” / checking they’re ‘doing everything right’
 - Others have a specific worry or concern in the back of mind
 - Want to check specific disease heart health/risk of diabetes
- Described as being like a ‘health MOT’
 - Alert to any potential problems in the future
 - Few anxieties reported around attending

‘I was delighted [to have the check], It was free, I had time, it was good to know.’ Female, London

‘I think it’s a good thing to keep a check on things – I wasn’t worried about attending’ Male, London

HCPs feel they conduct fewer 65+ checks than 40-65 checks

- Some HCPs felt more familiar with routine of 40-65 check
 - Some in community health checkers reported experiencing a high proportion of ineligible 65+

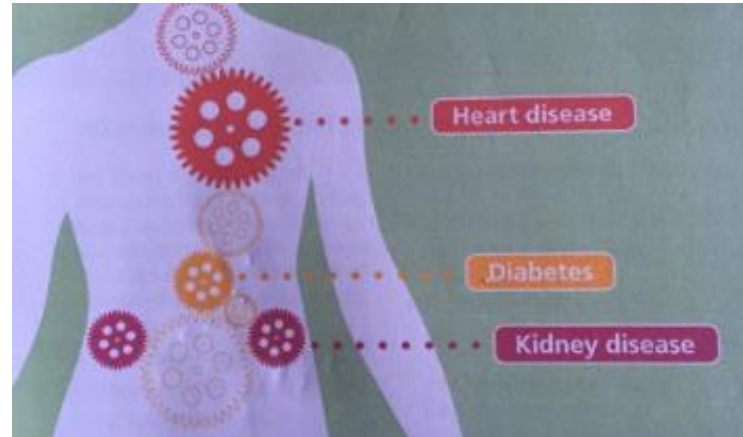


'There's not many that I do that are over 65, most are between 40 and 60' Pharmacist

'I don't see as many 65+ as I do 40 and 50 year olds, so I don't talk dementia that often....' Health Checker

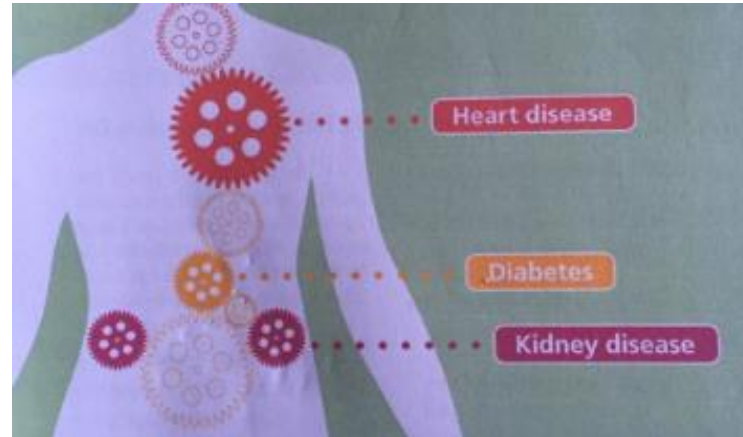
'Those who are 65+ are the lowest [demographic] due to many already having an existing condition. The majority will already be on cardio vascular medication' Pharmacist

Patients: NHS Health Check is a general Health MOT



- NHS Health Check seen as a **general check**
 - Risk of heart attack and stroke and ways to mitigate this (lifestyle/medication)
 - Type II Diabetes top of mind for some
 - Stroke also linked to lifestyle, aging and physical health
- Some patients hoped for more tests
 - E.g. kidney and liver function tests, thyroid
- Dementia unexpected although not unwelcome

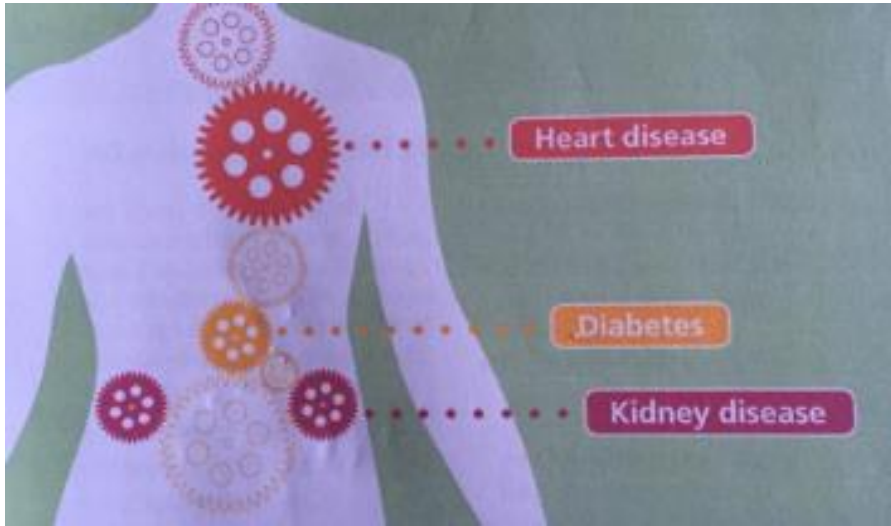
HCPs: NHS Health Check for preventable disease



- Seen as an opportunity to identify those at risk of key preventable disease
- Mainly cardio-Vascular Disease, stroke also mentioned
 - Diabetes recognised as a growing concern
- Change outcomes by motivating lifestyle change / medication
- Health Check seen as having grown/become more comprehensive

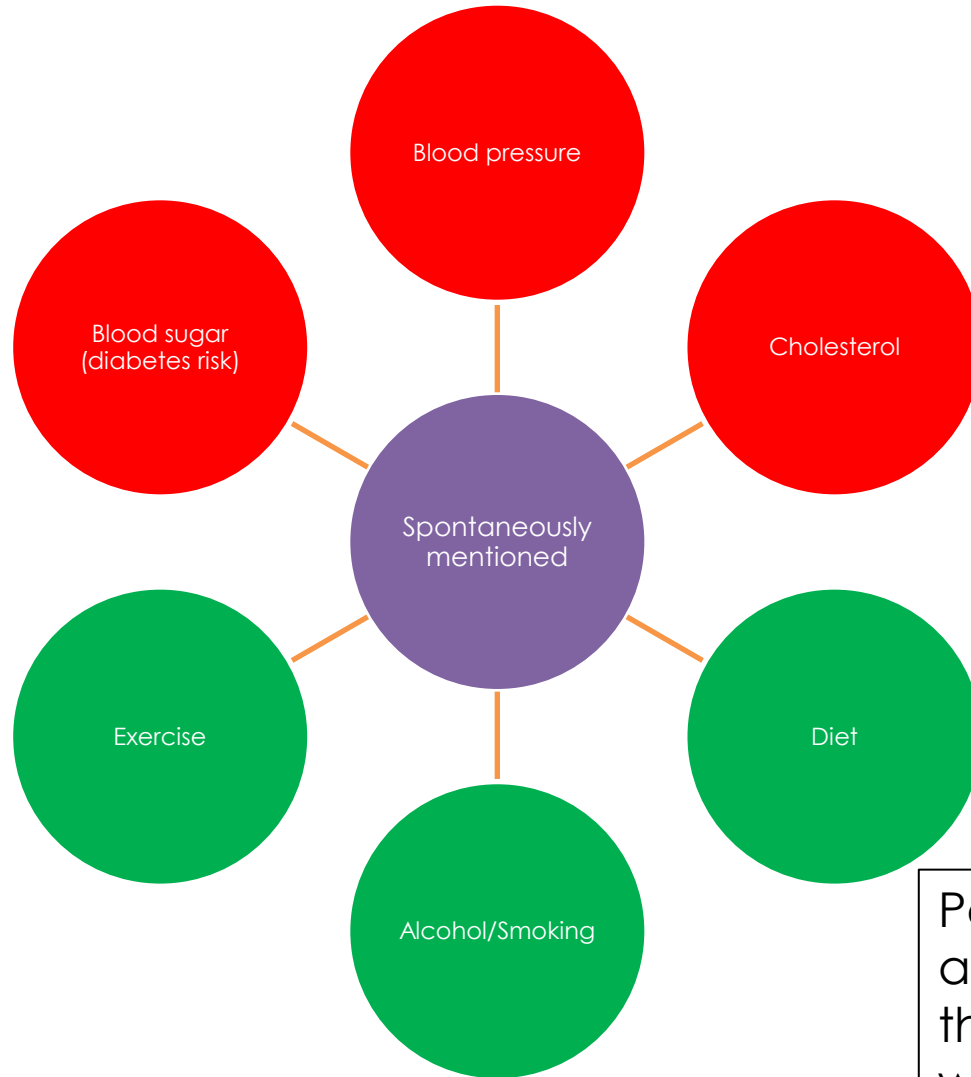
- Assessing risk of developing diseases can be part of the sales pitch
 - Find out your risk of developing diseases like heart disease
 - Used to motivate take up esp. in pharmacy and community Health Checkers who have 'market' the check more than practice nurses

Dementia often viewed as separate and unrelated



- Dementia not top of mind thought of as 'preventable disease'
- Mostly not seen as a key part of the Health Check

Blood tests and advice are prominent feature for all



Patients expected to be asked about and tested for these health issues – there were no surprises

- Patients appreciate the tests e.g. Blood pressure, HDL, LDL, glucose
 - And they trust the data - objective opinion about their health
 - And value it as the information is not easily accessible elsewhere
- Patients can have less interest in the lifestyle advice per se
 - Feel they 'know' what they are supposed to do to be healthy
- However, more motivated to listen / receptive to hearing risk reduction information once they understand their risk of disease



HCPs confident with measureable indicators

- HCPs also depend on and appreciate the measureable indicators of good cardio vascular health
 - e.g. Blood pressure, HDL, LDL, glucose
- Feel like an authority when giving the patient information and advice
 - Know patients are interested
 - And engage with concrete information about their own health
- HCPs also recognise some patients have less interest in the lifestyle advice
 - Aware of barriers to lifestyle change
 - Conscious information given may not be news
 - And this is their opportunity to influence patients



'(parts that generate discussion?) Most concerned with cholesterol and diabetes all they want to know, 9/10 its cholesterol, diabetes and blood pressure' Pharmacist



Q-Risk score is a central feature / key tool for HCPs

- The Q-Risk score is a key feature for HCPs
- The foundation from which HCPs give risk reduction advice
 - Important detail which can increase the relevance of lifestyle advice to patients
 - Your risk of CVD can be reduced with X and Y changes
- HCPs feel very confident with the Q-Risk score
 - Because it's founded on individual patient data



Patients overall report varied experiences of Health Check

Some report positive experiences..

- For those who are healthy, the NHS Health Check confirms good health and validates healthy lifestyle choices
- For those who are less healthy it can provide useful information that would help them improve their lifestyle; provision of medication
- Renewed enthusiasm and engagement in a healthier lifestyle

A few were under-whelmed by the content

- Had high expectations of NHS Health Check, expecting it to be more comprehensive
- May have experienced private medical care checks
- Lack of 'news' perceived by those who are healthy
- Did not find it very thorough; can criticise 'tick box 'approach' / lack of personal touch

'I've had health checks for insurance policies and the sort of things include lung capacity. Blood tests for diabetes, liver and kidney function I would've expected this from the GP too.' Male, London

**Dementia element within Health
Check – actual experiences**



Low patient recall of discussion around memory/dementia

- Dementia component not often spontaneously recalled
- More recall on prompting (approx 1/3 of sample) remembered some mention of memory or dementia during the check
- May not be a recognised component of the Health Check
 - A couple of examples of people recalling dementia discussion but had thought this was because they and the nurse both had parents with Alzheimer's
 - One example of a women who thought a subtext of the check was dementia but without an overt question
 - One woman thought dementia was raised as part of a general mental health discussion - she had a history of depression

'No she didn't ask me any questions [about memory] but I think that was one of the things she was getting at.' Female, Nottingham



Patient experience in their own words

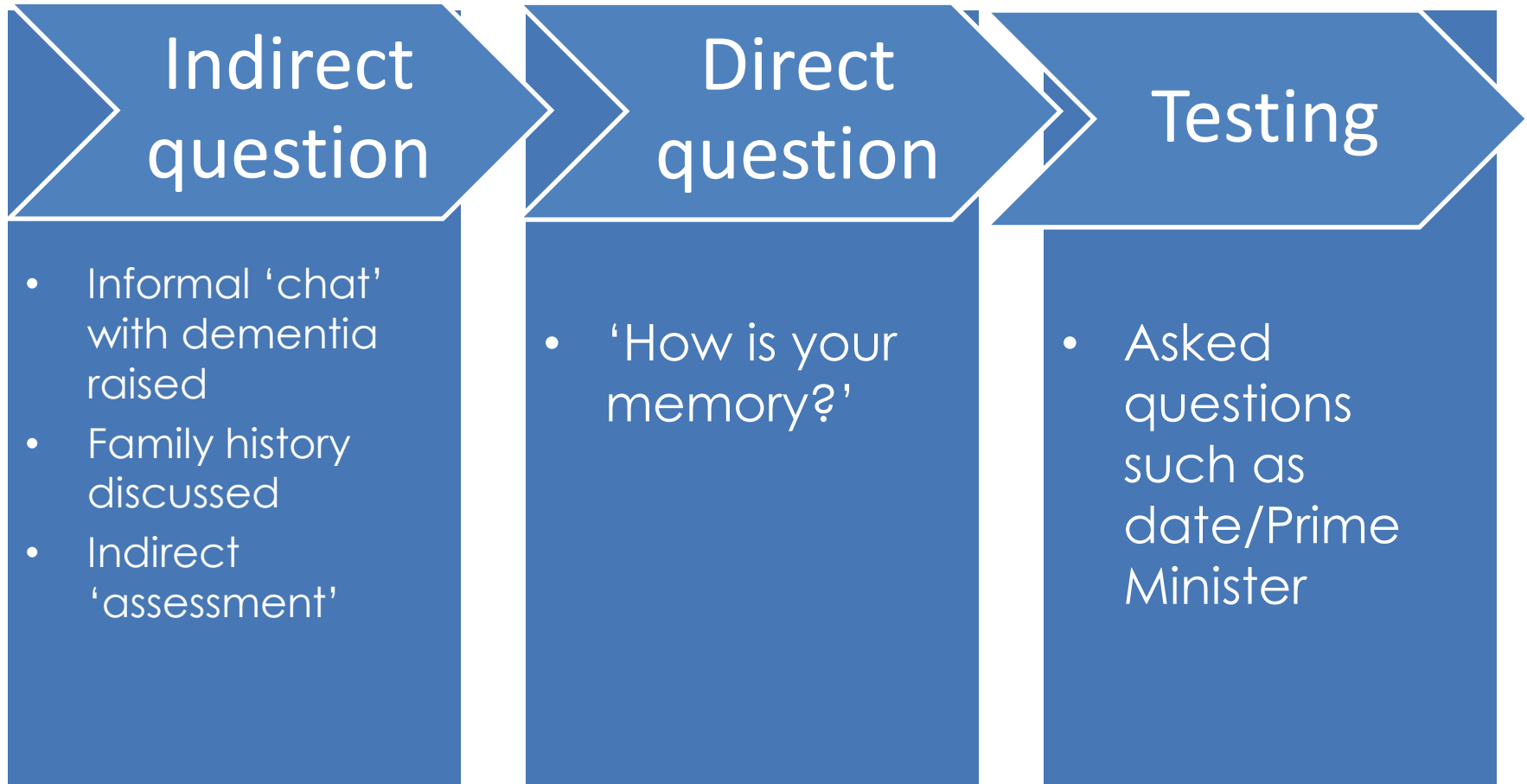
'I think she said, how's your memory, and I said perfectly ok' Male, Leeds

'She asked about my parents, both of them had dementia...it was a very casual conversation, we talked about memory loss, forgetting names...I made a joke about going upstairs and forgetting what I went upstairs for' Male, London

'I don't remember....(and if she did ask about your memory what would you have said?) I'd have said it's alright, though not as good as it used to be. As you get older you get a bit more forgetful, forget people's names. I'm not worried about it' Female, Stockport

'She might have ticked a box on screen she was following a script, I'm quite healthy, so she could've seen I don't have dementia' Male, Stockport

Patients report varied approaches in delivery of element



'She asked me who the prime minister was and what day/month it was' Female, London



Questions about memory function can be hard to answer

- Closed questions such as 'are you having problems with your memory' can on consideration be hard to answer...
 - Hard to distinguish normal cognitive decline due to aging
 - Can be normalised to an extent (senior moments)
 - Not able to judge what is and is not normal memory loss
- Also relies on honest self reporting
- HCPs and patients report that memory loss can be trivialised
 - Patients 'make light of' problems experienced
 - Not comfortable acknowledging problems

'It's a taboo subject. It's linked to being mad, they laugh and titter "I'm demented". People can be quite flippant, which undermines the conversation a bit' Practice Nurse

'She said what about Dementia, I told her my father had it before he passed away, I know the signs and I haven't got any of the signs yet, hang on....where am I?' Male, London

Dementia risk reduction message not recalled by patients

- Most who recalled discussion around memory/dementia reasoned it was...
 - Judging if any early signs exist or if person has own concerns
 - Giving advice on what signs to watch out for in the future
 - Or just a general ‘chat’ about dementia
- No recall of advice around ways to reduce risk of developing dementia
- Very low recall of link between cardio vascular health and dementia - 1 on prompting recalled ‘what is good for the heart is good for the brain’



‘I think she said ‘how’s your memory and I said perfectly ok.... I think if I had been worried I had an opportunity to say something, but I wasn’t worried so we moved on’ Female, Stockport



HCP perception of dementia in Health Check

- Attitudes towards dementia awareness and early intervention is mostly positive
 - N.B. early intervention assumed
- Dementia seen as a worthwhile condition for the NHS to address within Health Check
 - Growing issue, awful outcomes
 - In the news
- Although some can question how effective the NHS Health Check is as a forum for addressing issue (more later...)

'I don't quite get why dementia is in the health check. I ask the question, sometimes I'll ask do you know where you are, how to get home? I feel the patients are too young to be diagnosed with dementia at 65 years of age, it can be good to screen early but I feel it's not quite relevant at 65' Practice nurse



HCPs interviewed covered dementia element

- Dementia element covered by most of the HCPs in our sample
 - Recognised relatively new feature within 65+ health check
 - Cover defined as “raised” to patients in some shape or form
 - Could be as simple as ‘any problems with memory?’
- A small number did not discuss dementia with every over 65
 - Aware of inclusion of element for over 65s
 - More selective approach - those who they observed as having concerns, early signs / more at risk
 - Two appeared to be using another or the 40-65 template irrespective of patient age, and therefore were not prompted to do so
- None had experienced anyone who had been concerned about their memory and needed referral



Different approaches evident

- Health checkers more likely to cover every time, even if briefly
 - Address subject in an impersonal and direct way
 - Covering all the bases, working off script
- Some examples of practice nurses who tailored the approach
 - Had access to patient records or knowledge
 - Could base approach on knowledge of the patient - weave dementia in
 - Others more open to going further – deliver a memory test
 - A more personal, thoughtful strategy – with view of prompting lifestyle change maybe
- A couple of practice nurses and a pharmacist judged it – did not discuss dementia with every over 65



Differences in tone and style of delivery

- Many had developed their own approach or way of handling dementia
 - Potentially linked to confidence in subject matter?
- Different ways of approaching the subject apparent
 - Short and quick to longer/ more diagnostic
- Style of delivery varies...
 - May ask simply and directly
 - May be slightly apologetic, make light of it (to diffuse awkwardness)
 - Or excuse topic... introduce as 'as you are over 65...'

'I can feel embarrassed asking people about dementia as a lot of people are very well at 60-65 so I tend to make a bit of a joke of it' Practice Nurse

'I always explain...that I'm bringing it up because of their age, so they don't feel it's personal' Practice Nurse

Different approaches taken by HCPs – direct, but superficial?

- Have you any problems with memory?' Have you heard about dementia?

No...

Yes...

Danger of quick closure

May just move onto next part of check having 'ticked the box' – no further discussion needed

Or may choose to have brief conversation about signs/symptoms

Light awareness raising and signposting (to justify raising the subject)

'If you do become concerned book an appointment with your GP...

Trying to identify at risk patients

Focus on today

Relevant to a few



Example of more effective approach framing as risk reduction

Small number in our sample

Dementia has been in the news a lot recently....Do you think there's anything that YOU do can do to reduce YOUR risk of developing dementia?



"I feel satisfied they will at least go away and think about it"

Risk reduction framing
Focus on the future
Relevant to everybody



For some a more detailed diagnostic approach

- Minority, with some other experience of doing cognitive checks with elderly patients e.g.. in homes for elderly or hospital
- Recognise patients may not be able or ready to recognise signs of unusual forgetfulness
- Feel the memory question is an inadequate way to identify those to target most in need of signposting and advice
- Try to make it light-hearted fun with games and activities
 - Give an address and asked to remember it at end of health-check
 - Ask question like name of patient's Doctor / patient address
 - What's the current year
 - Common knowledge questions e.g.. WWII dates / who the Prime Minister is
 - Draw a clock e.g... 'ten to three'

Trying to identify at risk patients by adding more thorough 'tests'



Overall the approach can feel overly diagnostic or simplistic

Diagnostic...

- 'Any problems with memory' can feel like an assessment tool
- But one that is insufficient as it is subjective and relies on patient self-identification
- And if no risk assessed then discussion may not develop about risks

Simplistic...

- Have you heard of dementia' if yes CLOSE
- Have you any problems with your memory if no CLOSE

Little follow up discussion evident

'If they answer "yes" to 'are you aware of dementia' then we don't ask much further apart from "are you aware of where to source information if needed"? Or "is everything ok at the moment?"' HCA



Dementia element overall feels less of a priority

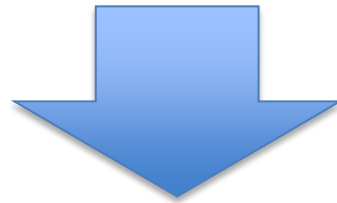
- In context of the main purpose of Health Check, dementia can seem a “niche” issue
- Few HCPs had experienced identifying 65+ patients with memory concerns through the NHS Health checks conducted so far
- Discovering early stages of other diseases like CVD and diabetes feels more likely
 - HCP experience suggests these diseases are more prevalent
- Perception of dementia component as important, but lower priority

'It's such a small part of the Health Check. The check is focused on CVD' Health Checker



Dementia not prominent part of check for either audience

- Emphasis of the check feels dominated by lifestyle and common routine checks (blood pressure, cholesterol etc)
- Focus more around heart attacks/stroke
- Little evidence of much follow up discussion around the memory question if patient has no concerns
- No play back of significant impact of being asked about memory for those who recall this element



Consequently dementia element can feel like an 'add on'

**What may influence HCP
delivery?**

HCP approach feels influenced by other parts of check

- HCP approach elsewhere focuses on assessment and this can feel mirrored in dementia element
 - Assess patient for **signs** or **knowledge of signs/symptoms**
 - Give advice to those ‘in need’ or advise on signs to look out for
 - Provide leaflet as information if required
 - Refer to GP for further investigation if required
- Only a few HCPs talked to patients about reducing the risk of dementia or framed dementia as having similar risk factors as CVD



‘They’re coming in for a quick health check to talk about their blood pressure, their cholesterol and their diabetes. The last thing they want to talk about is dementia’ Pharmacist

‘Because we are only asking 65+ patients, It seems its (purpose is) to ‘screen’ for dementia, but many are too young...I don’t get why it is in the Health Check for the 65s...’Practice nurse



Some HCPs feel awkward raising dementia

- Some HCPs are concerned that patients are not anticipating dementia discussion and can be concerned that topic is not something patients want addressed
 - At odds with other parts of check
 - And potentially more frightening
- Some openly admit to softening the approach...
 - Apologetic approach/blame the computer system/government
 - May refer to age 'because you are now 65 I have to ask you this'
 - Find a place to drop it in alongside other questions e.g... family history
- Others address it efficiently and pragmatically - sat side by side looking at computer so it's clear the question is non-judgmental

'I keep it brief, 30 seconds, any problems with your memory? Sometimes people get embarrassed. It's the thing I'm least comfortable with. It's not an area of expertise...I haven't dealt with the area of treatment for dementia, not enough to talk about it anyway'
Practice Nurse



Some HCPs conscious of stigma and upset

- Concerned about upsetting or causing unnecessary worry in the patient
 - In cognitively/physically healthy patients low perceived relevance
 - In suspected dementia sufferers - can feel concern if they are unaware, in denial, or concerned about a loved one
- HCPs aware of the high level of fear around the disease...
 - Devastating consequences/untreatable/ Prejudice

'Patients won't want to go there, they won't want to talk about it, there's shame associated' Health Checker

'I judge it....it depends. It's difficult because I don't want to make people paranoid...I don't like to bring dementia into sharp focus. I start off talking about the risk factors being the same as for CVD. I raise awareness of the symptoms. If they live alone I think twice before worrying them. I tag it on...something like You're more at risk of heart attack, stroke, Alzheimer's, dementia too. All of this lifestyle advice I'm about to give you will help with that' Pharmacist



HCP delivery potentially influenced by own confidence

- Varying degrees of confidence in talking about dementia evident...
 - Some do admit to lack in confidence – leave conversation to patient interest
 - Less experience and knowledge of dementia than other diseases
- Dementia training completed online a long time ago and some had not completed any training at all
- They can also feel they do not have sufficient tools to assess unlike alcohol questionnaire, bloods which give clear indicators
- Can feel they do not know enough about dementia to initiate more of a conversation with patients
 - Or be equipped to answer questions E.g. how to differentiate unusual and usual forgetfulness/subtle signs

'I don't feel equipped to give advice on dementia' Practice nurse



Delivery also influenced by time pressure

- Skirting over also due to time pressure
- HCPs report being short on time/under pressure
 - “A lot to cover and 20-30 mins for whole check”
 - Health checkers often have targets
- Some using judgment - minimal conversation for those not at risk of dementia (the very young looking/healthy)
- And limited awareness raising or default to reassurance and encouraging worried patients to see the GP (few encountered)

‘About dementia I’m probably 5/10 confidence but I feel more confident asking the actual question [about dementia]...if they asked any questions I’d ask for advice anyway’ HCA



Patients mostly open to dementia element

- All patients in our sample appeared happy to have dementia raised in this context even if not expected
 - NHS Health Check is a good opportunity to discuss any aspect of your health including dementia
 - Dementia relevant to age group
- Although may be fearful of diagnosis and signposting to memory services...
 - In principle sounds like a good idea
 - However the reality may be frightening as dementia is a life changing diagnosis

'I would have welcomed a dementia discussion... I would be happy to talk about those things. What's normal and what's problematic. For a guy pushing 69, am i were I should be. If not, where am I and what do we do about it' Male, Stockport

Approach is important

- Patients do appreciate a sensitive approach on the topic therefore
- However occasionally a question can be raised over how it would feel to be assessed and discussed if you had genuine concerns about yourself

'If I was worried about dementia I wouldn't want to talk about it as part of a general check, I'd expect a separate meeting. it's an emotive issue, It's losing who you are, very frightening' Female, Stockport.

'I have questions in relation to my wife. Actually it would have been quite useful to have had the opportunity to talk to someone about it. I'm absolutely positive that my wife has problems with sort term memory. But if you ask her she would say there is no problem is wouldn't been a good moment for me to discuss it. If there was a way I could almost trick her into going to a session at the NHS over 40s Check I would do..... I like the direct approach, but my wife with her it would have to be done with great tact and diplomacy... It needs to be explored with empathy and understanding' Male, London

**Knowledge about dementia –
patients and HCPs**

Dementia is frightening

- Overall, dementia is a condition that generates much concern
 - Disease that has grown in significance
 - Where cancer was 5-10 years ago – next to be tackled
 - Growing problem with aging population
- Many patients and HCPs knew someone who had been affected
 - Some had had parents/grandparents with dementia
 - Some were at the time of research living with someone/close to someone with dementia

'I would fear dementia more than cancer as it's not curable as many cancers are these days' Male, Nottingham



Patients and HCPs feel they don't know enough about dementia



'I think cancer and dementia are probably the luck of the draw as to whether you get it or not, it's a bit of a lottery when it comes to these two illnesses.' Female, Nottingham

'I couldn't really give a customer advice on dementia because I don't really know myself' Pharmacist



Superficial understanding evident across both audiences

- Some awareness of different types e.g.. Alzheimer's / Senile Dementia / Vascular Dementia, v Korsakoff's
- However, types are not well understood - Alzheimer's and dementia term used interchangeably, even by some HCPs
- Sense of more superficial awareness than true understanding of condition
 - Many questions arise when both HCPs and patients think about it
 - Difference between types?
 - Causes - whether hereditary or not, genetic-links?
 - Types of treatment?
 - Ability to slow progression?

I didn't realise Alzheimer's was a type. I thought it was just another name for dementia. I didn't realise it was a type, a classification. I thought quite strongly that it was inherited' Male, Nottingham



Perceptions of symptoms consistent between patient and HCP

The better known symptoms

Memory loss top of mind

Struggling for words

Repeating conversations and anecdotes

Becoming easily confused



Less top of mind but make sense on thought

Getting lost in familiar places

Trouble making plans



Least well known and less connected

Depression, agitation, irritation

But hard to distinguish between 'getting old' until too late

Not easy to (self) identify

- Not easy to identify during early stages, from both HCP and patient perspectives – confusion with normal ‘aging’
- HCPs recognise difficulties in identifying early signs/symptoms of dementia
 - In part, because it relies on patient self awareness/self identification
 - Potential for patients to ‘play down’ anxiety over symptoms
 - Use of humour and flippancy
 - Patients may not be objective enough to recognise a concerning decline in cognitive function
- By the time memory loss is a significant and ‘a problem’, patients may not be able to recognise it themselves anyway





Common assumptions made about outlook across audiences

Attitudes are often fatalistic - 'What will be will be'

Cannot be prevented

Inevitable, matter of time

Untreatable - medication can slow it down but nothing can reverse it

'I think I had the assumption that it just happens. Random chance. I had assumed that it just arrived and that there was nothing you could do about it. Like a lottery.' Male, Leeds

'I find...people have a heart attack, they get treatment, and they get better. They fall and break a hip, they get treatment, they get better. But once they have dementia,. Alzheimer's, and of these sorts of things, that's the end.' Male, Leeds

- Both HCPs and patients feel dementia is linked to age
 - HCPs believe public more at risk when older
 - 65-70 year old patients expect it to effect people older than themselves
- It can affect you regardless of you / condition of your health
 - Potentially hereditary
 - Something that some people 'just develop'
 - 'Luck of the draw' / unavoidable
- And some HCPs link dementia other conditions e.g. stroke



'You either get it or you don't. It's a beast. It strips you of who you are.'
Practice Nurse

'I don't think you have that much control over it you can do games, crossword. I do those, I'm sure they help....but I know you do get it from your parents' Female, Stockport

Most patients have not considered prevention before

- Mental 'exercise' and stimulation most often raised on consideration of prevention - keeping an active mind 'keeps you sharp' – e.g. suduko
 - Although some uncertainty as to whether this really would make enough of a difference to prevent it



- On prompting they acknowledge that taking care of your health and having a healthy lifestyle is good for you and therefore potentially therefore also good for your brain

'You need to keep your mind active. Read the newspaper. I didn't get this from the doctor, it's from general knowledge. Listen to the news. Keep your brain going' Male



HCPs firm believers in healthy living

- Prevention approaches do not feel top of mind for most HCPs
- Only a few discriminated between vascular and other types of dementia
 - Those thinking ‘vascular dementia’ tend to think of potential to avoid the disease developing
 - Distinction between vascular and other types seems key for HCPs who can more easily associate vascular problems with lifestyle choices
- All firm believers in benefits of positive healthy lifestyle
 - That living well results in better quality of life
 - All sorts of illness can be avoided generally (rather than specific types)
- Can believe that healthy lifestyle and keeping brain active may slow onset or slow down progression of dementia
- But they can also believe dementia is inherited or ‘luck of the draw’

**Linking vascular health and
dementia**



Link between vascular health and dementia not known by most patients

- Dementia is seen as distinct disease of the brain
- Vascular dementia is not commonly known
- The link between vascular health and dementia is not well known
 - Heart, vascular system, cholesterol and blood pressure prompt thought primarily of heart attack and stroke
 - No spontaneous thought of the relationship between vascular system, heart, oxygen and brain
- But linking vascular health to brain health makes sense to patients on thought and explanation

'Its not true that you can only inherit Alzheimer's. And its not true that you don't need to do physical exercise as long as you were doing crosswords. You need to do both, keep your mind active and your body active... I knew exercise was a good idea generally but not specifically for dementia' Female, Stockport

Ways to address risk levels is new information

- That there are lifestyle choices that could reduce risk of developing dementia is interesting news
- Suggests dementia could be preventable which in itself can be motivational



'We all know that smoking and drinking can cause a lot of illness. I don't think you're aware that it can cause dementia as well. Normally you'd associate that with a stroke or heart attack, you don't think about dementia with that' Female, Stockport

'I'm not surprised by it, but I wasn't aware of it and I think its very good.. I think people should be made much more aware of it. Maybe younger, before they get to 65+' Male, Nottingham

Can now become a very credible element for patients

- Explaining that ways to help prevent cardio vascular problems/heart attack and stroke are the same as those that help prevent dementia gives credibility to its inclusion within the Health Check and is welcomed by patients
- This is not just 'a test as you get older'
- Reframing maintaining good vascular health



'maybe having a huge emphasis as they do with heart attack and stroke, on dementia. Say maybe make this the third thing'
Male, Nottingham

'What's good for the heart is good for the head. That's right . I would welcome that message being banged home like don't drink and drive' Male Stockport



Some HCPs familiar with vascular health risk/dementia message

- A small number of HCPs in our sample already delivering information about dementia in context of risk reduction and behaviours that influence cardio vascular health (2: 1 nurse and 1 pharmacist)

'Dementia is a personal issue as my mum has it. It needs to be talked about as a separate item. It's a massive health issue. I want to make it feel significant, I link it to the smoking, alcohol, cholesterol, diabetes. It needs to be more than a 'by the way, you'll be improving your risk of dementia' Practice Nurse



But not all HCPs appear familiar with this information

- For others linking vascular health and dementia and exploring idea of risk reduction in this context felt like new information
- Or latent knowledge that needed refreshing and made more prominent

'I did learn that...the link between CVD and Dementia, but I've forgotten it!, The Health Check itself is so focused on blood pressure and cholesterol' Health Checker

'Mild strokes can lead to dementia.... I've not been trained on how to approach people and what to say so there should be more training on it' Pharmacist

'On the screen it says please give a patient an information leaflet if they are over 65. That's all it tells us to do it doesn't tell us to have a discussion' Pharmacist



This can reframe the purpose of dementia component for them

- A proper examination and exploration of the dementia information via leaflet and training can pull HCPs away from the assumed purpose of the dementia component
- Reframed as risk reduction rather than just about raising awareness around signs is well received
 - Feels relevant for a wider audience
 - Positive focus of the element is also thought to make it less socially awkward for HCPs to raise and discuss



'It's such a small part of the Health Check. The check is focused on CVD. Doing this research has made me think WOW! That link (between heart and head) is strong. You've made me think we should be flagging up, educating people. I always say this Health Check is to look at your heart and your arterial health' Health Checker



A small number feel element could even be more in depth

- A few HCPs felt that the dementia element could be even more in depth and further integrated..
 - Visual representation of risk like CDV Q-Risk
 - To show link between lifestyle and risk
 - (NB – potentially frightening for people however)
- And they can suggest repositioning Health Check as a comprehensive brain and body check

'To give weight to the subject, I think there should be separate personal risk score for Dementia alongside the Q-risk for CVD. We don't want to scare people though, so we need to be able to show them they can change that score by giving up smoking, exercising more or cutting down on alcohol' Practice Nurse



'What's good for the heart is good for the brain' simple and memorable

- Appreciated by both audiences
- 'What's good for the heart is good for the brain' is a catchy statement that fits well...
 - Makes sense
 - Is easy to get
 - Feels easy to remember
 - Powerful

'It's catchy, it's sharp, I like that' Practice Nurse

'That makes sense, I can understand that now. Keep yourself mentally and physically/socially active' Female Stockport

Attitudes to leaflet

- A few HCPs report providing a leaflet, although few patients interviewed received one
 - Typically the 'cog' leaflet – new leaflet mostly not seen before
- Distribution to patients varied from setting to setting
 - Small number had never seen any leaflets
 - Some had not had a leaflet 'in stock' recently
 - Some were cynical about benefits of leaflets (thrown away/dropped)
- A small number of HCPs report handing leaflet out consistently at the end of every check with the over 65s
 - Others more selective handing it out to those the HCP judged as being at risk
 - Or who were interested in having a conversation
 - Or on request if patient did not know much



Not used as a prompt at moment

- None of the HCPs were using it as a prompt for dementia risk reduction
- Some were concerned about handing a leaflet with dementia on the cover to a healthy patient in case it suggested a problem had been observed
- Patients report appreciation for leaflet on this subject
 - Ability to read information at home, in own time
 - Particularly for a subject which could be emotionally awkward
 - As much for the family who may be better able to spot and signpost

New leaflet well received by patients

- New leaflet shown in all depths
- Overall seen as providing new, relevant and interesting information and advice
- Executed in a logical clear structure
 - Answers questions which follow on from earlier questions
 - Chunked information, 'just enough'
- Positive tone of voice seen – not judgemental and patronising
- Focused on risk reduction



*'I realise from this I absolutely didn't understand dementia'
Male, Leeds*



Content works well with particular elements stand out

- Information about symptoms mostly already known although some new detail
- Distinction of Alzheimer's as a type of dementia can stand out as interesting
- Great appreciation of myth-busting sections - particularly around issue of heredity
 - challenges preconceptions about dementia and prevention
- Clear, new information on how to reduce risks very interesting
 - Explains link between lifestyle choices and dementia
- Encourages self-referral and signposting

Give up smoking

Smoking almost doubles your chance of getting dementia. Smoking is very harmful to the heart, lungs and circulation of your blood. This can affect the blood vessels in the brain. By giving up smoking you can reduce the risk of dementia.

*'I didn't have a sense of whether it was inherited or not
– I like being reassured it's not' Male, Stockport*



Leaflet can open eyes to own risk and prevention steps

- Section on myths feels particularly relevant and can increase personal relevance
- Healthy lifestyle messages not new in their own right but reframing as dementia risk reduction messages is new and interesting
- Small tips in context of dementia prevention can therefore gain relevance
- Direct link between cardio-vascular health and brain health could be another 'carrot' to adopt changes

Myth 2: Dementia is inherited from your parents.

Fact: Dementia is only inherited in a very small number of cases. Most dementia is not inherited.

'I like the de-mything' Male, Stockport



'Helping your brain stay healthy' is liked

- Simple, easy to understand
- Straight to the point
- About maintaining good function - relevant to everybody

'It goes without saying you should have a healthy body and if you have a healthy body you should have a healthy brain'
Male, London



HCP attitudes reflect patient views on leaflet

- Positive response to the leaflet overall
 - Seen as a useful hand out
- And for HCPs it helps by legitimising raising subject
 - Informational, not personal
- Some positive about it as a tool to prompt discussion
 - Could work as a guide for least confident HCPs

'I'd put more pictures in but content wise, it's solid'
Practice Nurse

Attitudes to training



Overall HCPs report Health Check training felt brief

- NHS Health Check training felt to be very brief; and focused on CVD
- Some sense that training may have been a while ago on generic 'Health Check' and may not have been topped up recently or when dementia element introduced
- Some had knowledge of dementia from other training E.g. Pharmacist learned about dementia as part of his professional training, elective module as part of a course specialising in mental health; others had learned through personal experience of disease amongst family members

*'Maybe I wasn't listening or hearing properly (when I did my training) but I don't remember hearing much about dementia. The whole conversation was focused on CVD, and even now when I think about it, all the questions are about CVD. Have you experienced any problems with your memory sounds diagnostic'
Health checker*



Little exposure to dementia training noted

- Majority of the sample had not seen any dementia related training with some not being aware of its existence
 - Most would want to complete the training
 - Prevention objective in context of Health Check feels new and could motivate engagement

'I know more about the cholesterol, diabetes, heart disease, weight management but I've not been trained on dementia and I would love to be' Pharmacist

'The health checks are fantastic, but they've put this new thing and we've never really had an update on dementia awareness' Pharmacist



Online training not recognised by most

- Only a minority (1-2) had seen the online training on dementia
- Online training can be good for the time poor, but also can be treated as a task to get done
- Many preferred face to face training, seeing it as more engaging
 - Some wanted the opportunity to ask questions

'We are so time limited and most practice nurses are part time so you've got to try and keep your skill level up so something like that where you don't actually have to go on a training course, I think that would be really good' Practice Nurse



Great interest in more dementia training

- All HCPs felt they would benefit from further training around the subject
- Open and interested in the online tools
- Particularly with regards to:
 - Understanding the different types of dementia;
 - How to identify and address the subject with appropriate sensitivity
 - Being able to answer any potential questions patients may ask
- Pharmacists and Health Care Assistants in particular welcomed training as typically they felt the least clinically prepared to answer dementia related questions

'You are giving me some educational training with the leaflet and the e-learning you just showed. I'm not comfortable giving information on dementia. Four years ago when I did my training they didn't even mention dementia' Practice nurse

What next...



So evidence from our sample suggests...

Impact of element is more limited than it could be currently



Delivery feels more around assessment than education on risks and link to cardio vascular health



More around signs or awareness of signs



Little discussion around risks or framing in terms of risk reduction which could generate discussion



There are challenges around delivery of element due to knowledge, confidence and stigma



But great scope for it to have greater impact

Patients open to inclusion within Health Check

Patients do not consider a sensitive question around dementia or memory within Health Check out of place due to their age



It is a condition that raises concern and is topical



Strong interest in risk reduction information which is new and motivating



Makes sense since when linked to vascular health - clear fit with current Health Check questions



Ability to signpost to memory services also beneficial ... Although could be slightly scary for those concerned about their memory



Potential for much greater impact

HCPs engaged by information about prevention steps and link to vascular health



Element could have more impact if a more educational approach dementia risk reduction steps? vascular health and dementia?



Leading to discussion of risk reduction and prevention



Allowing opportunity for individual to raise any concerns



May help negate sensitivities around own memory or presence of signs



More integrated in the flow of discussion about CVD?

- Dementia might feel more important to both HCP and patient if it is raised within the key part of the check when patients are most engaged
 - More related to CVD, and the risk factors for CVD
 - Not small and separate part of the check
- Naturally flows into the risk reduction advice discussion
 - ...And you'll be improving your risk of developing dementia too
 - “In effect, what’s good for your heart is good for your head”
 - 2 for 1 benefits
- Although care needed in delivery due to how frightening dementia is and could be even more so when linked to risk



Collecting more data could address some of the challenges

- Idea of collecting 'more data' was explored conceptually
- Some HCPs liked the idea feeling more questions should be asked
 - More questions would increase the presence of the dementia component within the check
 - This could lead to a more objective risk assessment
 - Identify whether a person has/could be a risk of getting dementia, based on the questions asked
 - Remove the subjectivity around assessing dementia
 - Address the difficulty of self-identification
- Potential to make the conversation less awkward / impersonal
 - Data collection is process oriented
 - Appealing for a conversation they found challenging



But raises question about tools and training

- Is there a tool sophisticated enough for this complex area?
 - might it be very detailed?
 - and time-consuming to complete
- In increasing the presence and conversations around dementia, there'd be even more need for knowledge and training



Both audiences agree relevance for 40 + age group

- Some spontaneously suggested that the element should be incorporated into checks for under 65s, most agree on prompting
- A focus on reducing risk naturally feels relevant to a younger target who have more to gain by reducing risks earlier
 - Many HCPs and patients spontaneously mention it would make sense to get in earlier to talk to 40+ about risk reduction
 - Also would help in spotting signs in self or other relatives

'If we know there's a link between vascular dementia and heart health we should be talking to people earlier...It would be very relevant to people in their 40s, they can make more of a difference to their mental health earlier. The fear of dementia is so strong!' Health Checker

'If we asked everyone it wouldn't be about screening. It's important to start earlier if you want to highlight that you can change your risk factor' Practice nurse

- Somewhere between mid 50s and mid 60s can feel optimal from HCP perspective
 - Patients parents may have had dementia so they may have it on their radar / be receptive
 - Beginning to experience longer term / chronic problems so may be open to ways to preserve future health
 - Starting to look forward to retirement and have some thoughts about quality of life in older life
 - Less likely to be the case with younger 40-50 year olds

'Younger patients 40-somethings haven't yet begun feeling unwell, or experienced loss of vitality. They think by the time they get to 80 they won't care!' Practice Nurse

Conclusions

- From the HCP and patient perspective, the subject of dementia is recognised as a topical and a significant health concern for over 65s. Dementia is feared and seen to be a growing problem with an ageing population.
- The patients in our sample and even many of the HCPs did not feel they have a good understanding of dementia and there are lots of myths that need addressing. Although there is basic knowledge of common signs and symptoms, there is not a good understanding of different types of dementia, why it develops, if it can be prevented and outlook.
- Dementia is seen as a very frightening condition of the brain, but there are few top of mind links to vascular health in either the HCP or patient samples.

- In our sample of patients approximately a third recalled some discussion about dementia or memory during their Health Check. All the HCPs were aware of the element and most were delivering it to all 65 + participants. However at the moment the element can feel like an add on, included and relevant to the 65+ population because dementia mainly affects the elderly. It does not seem to be having as much impact with patients as it could have.
- Coverage of this component can feel brief and limited to either providing an opportunity for patients to say if they have any concerns with memory or to check they know the signs of dementia. HCPs may lightly raise awareness of the risk after 65 and encourage patients to see a GP should they experience problems in the future.
- Prevention and risk reduction is not often seen as the goal of the dementia component amongst HCPs and dementia risk reduction messages were mostly not being given as a matter of course in this sample. Only a small number in our sample were framing dementia in terms of risk reduction.
- Although the element is felt to be relevant, some HCPs did also express some concern about upsetting patients by raising dementia in the context of the Health Check, and were also concerned about their own knowledge of dementia and ability to answer questions. However feedback from patients in the sample suggests that it is appropriate to mention dementia if it is raised sensitively.

- The link between vascular health and dementia, and that some of the risk factors for dementia are the same as the risk factors for CVD is interesting news for patients. The take out is that they can make lifestyle changes to reduce the chance of developing one type of dementia. Both HCPs and patients feel this information may motivate patients.
- It seems important to explicitly challenge the many assumptions about dementia, one of which is the strong assumption/perception that dementia is largely unpreventable and caused mainly by genetic factors rather than influenced by lifestyle factors. The new leaflet currently does this well.
- HCPs are also engaged in this information and feel better equipped to talk about dementia when framed as a risk reduction exercise, however this needs to be a clearer part of the Health Check brief for them.
- Most HCPs in this sample had not seen the online training and were open to the concept of more training on the dementia element.

- Consideration could be given to the style of question used in the element which perhaps could be more of a conversation opener that challenges perceptions of prevention/risk reduction and is less just about a patients current memory/cognitive function or knowledge?
- The leaflet is effective at dispelling myths and reframing dementia as a partially preventable disease and both HCPs and patients were interested in its content. In addition 'what's good for the heart is good for the brain' is a strong line.
- The presence of the dementia component only in the 65+ NHS Health Check and not the 40-64 check, can reinforce the perceived goal of encouraging self referral amongst patients with early symptoms / worried about memory loss. Most patients and HCPs in our sample thought it would be an interesting and useful component in the younger age Health Check.