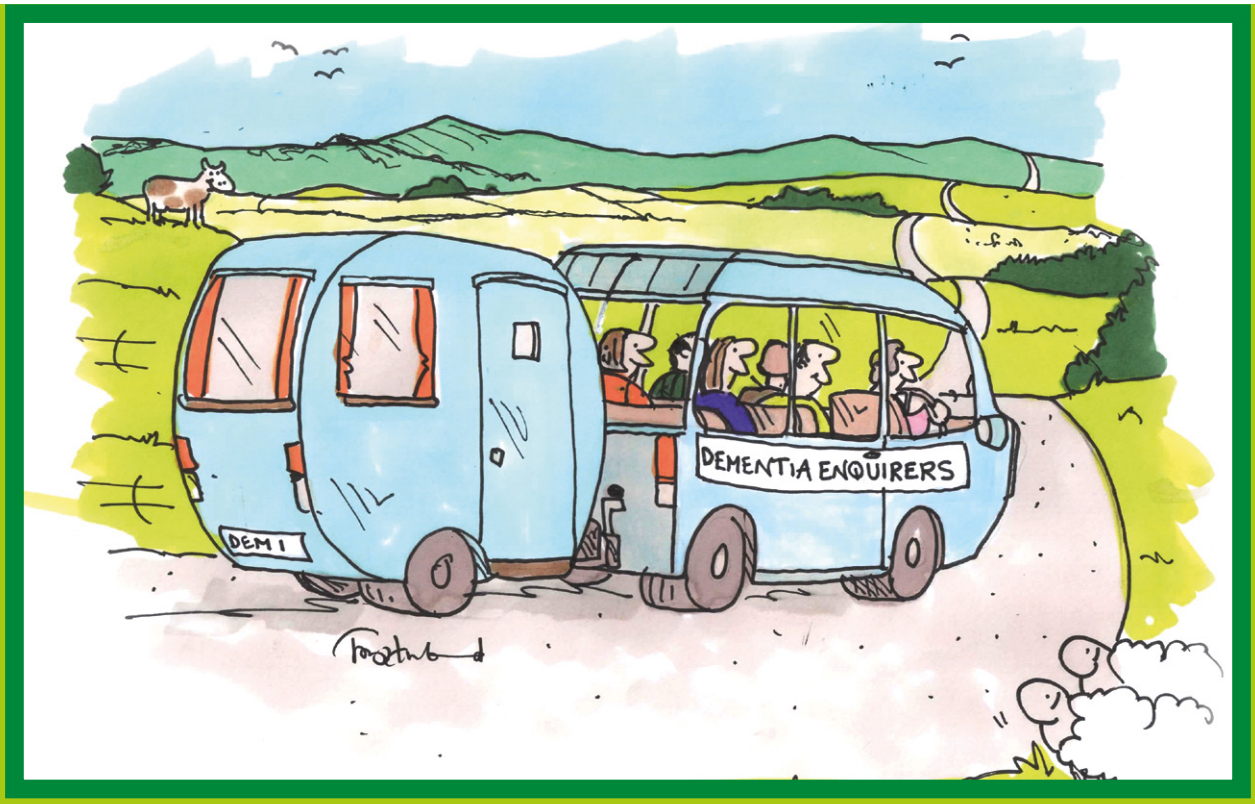
Riversiders

Dementia Enquirers Report



Have you had annual dementia reviews with your general practice since diagnosis?

April 2022

Dementia Enquirers

COMMUNITY FUND

Innovations in Dementia

Key messages from Dementia Enquirers projects

1. People with dementia can lead their own research projects – both drawing on previous life skills and learning new ones to explore the questions that most interest them.

2. The research questions that people with dementia generate can be different from existing research questions. They are based on lived experience – on topics that will make a real difference in people's lives.

3. "Being in the driving seat of research" doesn't mean that you have to do everything yourself. Team work and support can really help. But controlling the research and leading the way gives people with dementia a huge boost in confidence.

4. Making the language and processes of research more accessible helps everyone!

5. Research *between* people with dementia makes communication and engagement more possible, because having something in common increases trust.

Date of publication April 2022

You can download this report here:
https://dementiaenquirers.org.uk/individual-projects/riversiders/

You can read other Dementia Enquirers reports here:
https://dementiaenquirers.org.uk/individual-projects/

To find out more about Dementia Enquirers visit:
https://dementiaenquirers.org.uk

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Annual General Practice Dementia Reviews

Background

People living with a diagnosis of dementia should be reviewed annually by their general practice. This is specified in the General Practice Contract, and reflected in their electronic record system. There are different arrangements in countries of the UK. In England GPs claim a specific amount if they carry out and complete an Annual Review. The minimum requirements of a review are included in the EMIS record system used by many GPs.

Some people living with dementia are reviewed more frequently by their Memory Service, usually if they are being prescribed dementia medication by their service. All people however should be reviewed by their general practice.

The Riversiders DEEP Group is a peer support group for people living with dementia in Shropshire, run by people living with dementia. In addition to being a group where members support each other and chat, we have for several years been advocating locally for improved dementia care and support. Members sit on the Shropshire, Telford and Wrekin Dementia Steering Group. We are one of around 80 DEEP network groups across the UK. The website for further information is: **https://www.dementiavoices.org.uk/about-deep**.

Members of Riversiders DEEP group found that, although almost all general practices were claiming (and being paid) for carrying out annual reviews, few if any people living with dementia could report having had a review. In 2021 it happened that two Riversiders members did receive their first ever review, and the data for these is included in this survey.

But both people found the reviews meaningless, and that they did not follow the EMIS requirements.

Thus the idea to find out more about annual dementia reviews developed.

The group devised survey questions and applied to Innovations in Dementia to carry out a Dementia Enquirers research survey. This was approved.

Ethical Approval was not needed, and all personal data were removed from the returned questionnaires. Names were only provided on consent forms, which were separated from the data returns.

This project was carried out between November 2021 and February 2022.

Research Objectives

a) To find out the proportion of people living with a diagnosis of dementia who have had an annual dementia review at their general practice.

b) To find out the content and quality of the reviews.

c) To find out whether the reviews were felt to be worthwhile by the person living with dementia.

Purpose

To use the findings to campaign for consistent, meaningful annual reviews to be carried out by general practices, and thereby to ensure that general practice staff provided good care and support for patients and were remunerated for so doing.

Method

Questionnaires with ten questions were devised by members of the Riversiders DEEP Group, Shropshire. See Appendix 2.

These were converted into paper format and SurveyMonkey format questionnaires. We ensured that the surveys were totally consistent in both formats.

Copies of paper surveys were sent to every DEEP group facilitator across the UK, and the SurveyMonkey version was publicised on twitter and in the monthly DEEP NEWS magazine. Stamped addressed return envelopes were included with paper copies.

Most of the administrative work was carried out by the group's facilitator, who lives with dementia. The text drafts were sent out to all members for discussion and agreement. The facilitator collated the results and drafted the report, which was checked by another member.

We received paid support for printing and distributing paper copies of the survey from an employee of Innovations in Dementia. This also enabled us to comply with data protection requirements about addresses.

It is important to draw attention to this research being devised and carried out by people living with dementia. It is further evidence that dementia does not as of course prevent a person from carrying out research, nor from wanting to influence change. There is a sea change in attitudes to dementia and research, and many people living with dementia are now working within research project teams, not just as subjects (dyads). Much of the momentum for this has come out of the Dementia Enquirers Research Programme, funded through Innovations in Dementia by the National Lottery Community Fund.

Results

65 questionnaires were completed and returned: **37** on paper and **28** on SurveyMonkey.

One paper return included summarised results from **11** members of a DEEP group, and another contained **4**. These were converted into appropriate survey data.

3 SurveyMonkey returns were voided, because the answers were either incomplete or unclear.

Thus the net number of usable questionnaires was **73**.

37 were completed by people living with dementia.

36 were completed by care-givers on behalf of a person living with dementia.

23 people said they had had at least one annual review.

1 of these was in Wales (**4** respondents), the rest in England.

Scotland (**16** respondents) does not appear to do annual dementia reviews, though there is a requirement to do so.

We asked where each person lived, in order to see whether there was any obvious pattern, but there was not, other than by country.

Of those who had not had a review, five people said they thought their GP understood how dementia affects them.

Reviews were carried out by:

GP	**15**
Specialist nurse	**4**
Non specialist clinical staff	**5**
Other non clinical staff	**1**

Did people find these reviews helpful?

Really helpful	**1**
Quite helpful	**6**
Not much help	**8**
No help at all	**8**

Just 2 people were given a copy of their care plan by the practice.

The questionnaire asked whether certain subjects had been discussed during the (23) reviews:

a) your symptoms	**15**
b) anything you are having difficulty with	**14**
c) what matters to you that you want to keep on doing	**7**
d) how you feel	**15**
e) keeping active	**11**
f) eating	**11**
g) your relationship with partner/spouse	**6**
h) plans for future care as your disease progresses	**0**
i) none of the above (please explain)	**0**

The final question asked whether anything had changed as a result of the annual review:

a) medication **4**

b) support **2**

c) benefits **0**

d) living as you wish **0**

e) feeling better about things **3**

Conclusions

The numbers in the survey are small, and firm conclusions can only be made if this is replicated with a much larger sample. However the data are very useful because they suggest that there are problems with the annual review system which need further exploration.

The data suggest that very few people living with dementia get an annual review with their general practice that is in any way meaningful to them, in terms of wellbeing and future planning.

Care plans, insofar as they exist at all, were only given to 2 people, and clearly future care planning was not discussed at all, even though it is specified in the EMIS annual review pages.

Only 5 people said they felt their GP understood how dementia affects them.

In one case, the person said they had had around 9 annual reviews since diagnosis, but that they were ‘not much help’.

The written comments are interesting and informative. See Appendix 1.

One review was carried out briefly over the phone and was found to be unsatisfactory. Another said their GP ‘was really hurried; got the impression he couldn’t care less’.

Almost all people said they got no meaningful support from their general practice.

Only 6 people reported that any change resulted from their review.

Only one third of all respondents had had an annual review with their general practice since diagnosis. Almost all reviews were brief and of little or no help and led to no change in care and support.

The proportion of reviews in England was 22 out of 53, i.e. a little over one third. In Wales it was I out of 4, (with a comment: ‘only because GPs had been told to do reviews’).

The survey suggests that general practices are providing little or no meaningful support and care for people living with dementia, and almost all staff have little understanding of how dementia affects people.

Future care planning is not discussed in general practices, and hardly any patients are given copies of care plans (if these exist).

There are exceptions but these are notable by their tiny number.

Further Research

It would be interesting to know the proportion of general practices in each area of the country represented in this survey claiming funding for carrying out annual dementia reviews, and to compare this with the proportions revealed in this survey.

Our data is not statistically reliable, but it gives a good indication of the likely picture. And the data confirms anecdotal evidence.

Our research (confirming anecdotal evidence) reveals that few face to face, meaningful reviews are undertaken.

We have seen Shropshire data from 2019\20, which showed that almost every practice had claimed to have carried out annual reviews with (all?) their patients, which is not reflected in our data. The Quality Outcomes Framework (QOF) for general practice in England awards a maximum of 44 QOF points for a general practice achieving the requisite percentage level of reviews of its patients. Each QOF point was worth a little less than £200, so in Shropshire around £8,000 was paid to almost every practice in 2019-20, a total of over £320,000.

Similar NHS data across England shows that over 90% of general practices claim the maximum payment for annual dementia reviews. Across England, these figures imply total payments of around £55 million to general practice for annual dementia reviews, many of which may not have happened.

Firstly, this could be fraud, if general practices are being paid for work not done. Secondly, it may leave around seven hundred thousand people living with dementia (out of circa one million across the UK) without the support and care they need and are intended to get.

Requirements for reviews in Scotland and Wales should also be reviewed. It appears from a brief online review, that Wales and Scotland do not have any requirement or even recommendation for an annual face to face review in primary care.

Next Actions

To publish and promote our findings.

To engage with general practitioners and NHS England to improve annual reviews and primary care for people living with dementia generally.

To raise awareness among people with dementia and their families that they have the right to an annual review, and that this should cover specific issues thoroughly.

To encourage further large-scale research on this issue.

Appendix 1

Comments in the questionnaires

Number	Q4 Comment re reviews	Q5 comment on support/care from GP	Q7 comment on discussion	Q9 comment on value of review
3			Talked about tests done	GP listened to me
6				GP was not very good
9		Annual reviews carried out by hospital dementia team		
10		I have no support. Phone surgery when I need to.		Hasn't had any support
11	Diagnosed recently	GPs very supportive		
13	No-one ever asked me	Very little. Constant battle.		
15	Only because GPs were told to. By phone. No good.			Over the phone GP couldn't tell whether I was telling the truth…
16			It was a 10 minute discussion about my wife's progress	Nurse had little knowledge of wife's PCA.
18		Only had phone appointments with GP, so no further forward		

Number	Q4 Comment re reviews	Q5 comment on support/care from GP	Q7 comment on discussion	Q9 comment on value of review
19		One Dr had poor knowledge so changed to another to get referral		
21				Was really hurried. Got impression he couldn't care less.
22		I don't think they have an idea how it affects us.		
23		Husband gets diabetic review not dementia review.		
24	Mostly annually but short	GP is a dementia champion for Alz Soc		
25		Generally good. I need little support but it would be available.	Review was informal.	I'm doing ok at the moment and confident that support would be sorted with help from the practice.
26c			Person living with dementia told you don't look like you've got dementia!	
27			General discussion. GP did not ask about what support we had.	Feels too general an inquiry. Not able to open up as a carer.

Number	Q4 Comment re reviews	Q5 comment on support/care from GP	Q7 comment on discussion	Q9 comment on value of review
28		GP has never discussed how dementia affects me. No special care or support received.		
29		No support whatever	inc toilet (frequency) and POA	Nurse said she was available any time. But then I was told there was no nurse covering dementia.
31				Not told anything we didn't know. But it did make us feel we were in the system.
32		Get telephone support and face to face appointments.		
33		We don't get any support but we can ask to see the doctor who is very caring.		
34		Get no support from General Practice		
36		No idea if GP understands. How can I get the help I need?		

Number	Q4 Comment re reviews	Q5 comment on support/care from GP	Q7 comment on discussion	Q9 comment on value of review
4sm		He fully understands the affects of dementia but the support isn't obvious. You need to be very proactive to find out what is available.		
5sm		GP does not listen , always talked over	No review in 3 years	
6sm		Understands somewhat but not the complexities of Lewy Body Dementia		
10sm		Gp has no idea about how dementia affects my mother in law or us as carers. Repeat prescriptions are about all they know about us. Once referred to memory clinic have had no input from gp at all. Pandemic made everything worse and we rely on local dementia support services for help		
13sm		Can’t do can they if you don’t see and talk face to face		
14sm				

Number	Q4 Comment re reviews	Q5 comment on support/care from GP	Q7 comment on discussion	Q9 comment on value of review
16sm		I don't think the G.P. totally understand the problems with the person with dementia, they would be able to see if the person is deteriorating and need drugs charging.		
17sm		No. Gp input is minimal.		
18sm		I feel our GP Surgery do not understand how dementia affects people, especially the staff on the reception desk!		
20sm		just checked whether his list of medication was correct (and he had me as his wife)		
24sm		Hasn't got a clue		Didn't ask me enough questions to make changes
26sm		Only asked if I felt I was getting worse and if I thought my medication helped		Nothing was discussed other than asking if I thought my medication made a difference

SM refers to a SurveyMonkey respondee.

Appendix 2

The full survey text

Dementia Enquirers Research Project
Shrewsbury Riversiders

A project led by and carried out by DEEP group members living with dementia

“Have YOU had a meaningful Annual Dementia Review?”

Information for DEEP members and group facilitators/leads

Thank you for taking part in this Dementia Enquirers Research Project.

It has been designed, and is being carried out, by people living with dementia, who are members of the DEEP Riversiders group Shrewsbury.

We want to find out how many members of DEEP groups across the UK (people living with dementia) have had one or more meaningful Annual Dementia Review with their local General Practice. (Not your memory service).

The findings will enable us all to work locally and nationally with GPs and Healthcare Commissioners to ensure that every person living with dementia is reviewed annually in a meaningful face to face meeting.

The results of this project will be published in 2022, and will be circulated to all DEEP groups, and to people who request a copy.

We are asking each member to complete the questionnaire individually, stating their own views and knowledge. But of course your group may wish to talk about the questions and complete the questionnaire together.

It is entirely ok for a family or friend carer/supporter to complete the survey with you, on your behalf.

There is also an online survey you can complete, if you prefer. The link to this is below:

https://www.surveymonkey.com/r/HB9YNMX

We have enclosed a stamped addressed envelope for your group to return your questionnaires. Please remember to complete and return the enclosed consent form as well for each survey.

The address to send questionnaires is:

George Rook

Lyneal Mill Farm
Lyneal
Ellesmere
Shropshire
SY12 0LE

We hope to have all questionnaires (and consent forms) returned to us by X

Christmas 2021.

Thank you so much for taking part.

If you would like more information or would like to discuss this project please contact me by email.

George Rook, Lead at Riversiders DEEP

georgerook51@gmail.com

07976 189641

The **DEEP Riversiders** group in Shrewsbury want to find out whether people living with a diagnosis of dementia are having meaningful annual dementia reviews with their general practice.

This is a Dementia Enquirers project, using funds from the National Lottery funding grant to Innovations in Dementia.

We will ask DEEP group members across the UK to complete a survey questionnaire, either on paper or on Survey Monkey.

We hope then to interview those who say they have had one or more Annual Dementia Reviews, to find out more about what was included in the reviews, and how they were conducted.

Surveys can be completed by either the person living with dementia or their family/friend carer on their behalf.

Please note that what we mean by a meaningful Annual Dementia Review is a face to face meeting or appointment to talk about:

a) how you are,

b) what is important to you,

c) your medication(s),

d) what you might need support with,

e) advance care planning, and

f) anything else that you want to raise.

The Annual Review could be conducted by a GP or a suitably trained other member of the practice staff. What you discuss and agree should be recorded in your Care Plan. A copy of your Care Plan should be given to you, then or soon after.

Every person living with a diagnosis of dementia should have an Annual Dementia Review with their General Practice.

This General Practice Annual Review is different from any meetings you have with your Memory Service staff.

For office use: Survey Number

1. Are you living with a diagnosis of dementia?

Y / N

2. Are you the family or friend carer for a person living with dementia?

Y / N

3. Which area or county in the UK do you live in? …….

4. Have you (or the person you care for) ever had an Annual Dementia Review with someone at your General Practice?

Y / N

Comment Box: Please tell us how many?

5. If no, please tell us whether you think your GP understands how dementia affects you.

Y / N

If you answered no to **Question 4** there are no more questions for you. But please tell us about the support and care you receive from your general practice, regarding living with dementia.

6. If you think you have had an Annual Dementia Review, was it carried out with:

(please circle those that apply)

a) GP/Doctor

b) Specialist Nurse

c) Practice Nurse (non-specialist)

d) Non-medical staff

7. Did the Review include talking about:

(please circle)

a) your symptoms

b) anything you are having difficulty with

c) what matters to you that you want to keep on doing

d) how you feel

e) keeping active

f) eating

g) your relationship with your partner or spouse (if you have one)

h) plans for future care as your disease progresses

i) none of the above…please explain below what was discussed!

8. Were you given, then or some time later, a copy of your Care Plan, wwhich included what you had talked about and agreed at the Annual Review? Y / N

9. Do you think your Annual Dementia Review was:

(please circle)

a) really helpful

b) quite helpful

c) not much help

d) no help at all

e) None of the above

Please explain your answer to question 9 if you can.

10. Did your Annual Dementia Review result in any changes in:

(please circle)

a) medication

b) support

c) benefits

d) living as you wish

e) feeling better about things?

Would you be willing to speak to us over zoom or telephone about your experiences in your Annual Dementia Reviews?

If so, please enter your contact email address, postal address or phone number and your first name.

Thank you for taking part. If you have completed the paper version, please give it to your group facilitator to return to us. If you have used the Survey Monkey version, please go to the end and complete the final step to finish.

We will publish our findings in a report online and on social media, with a summary in the DEEP newsletter.

We will also send you a copy if you would like to receive one. Please add your name and address (for a paper copy), or your email address, below.

If you want your responses above to remain anonymous, please tell us here, and we will separate your name and address from your other responses.

Your name and address

Dementia Enquirers Research Project

Shrewsbury Riversiders

A project led by and carried out by DEEP group members living with dementia

Consent Form

This form is to make sure you are happy to take part in this research project, and to assure you that your information will be used anonymously and stored securely.

To comply with data protection requirements, please sign and date the form and return it with your completed survey. By signing it, you are only consenting to your information being used anonymously for this research project.

The form will be detached and stored separately from your survey, and the two are not cross referenced, so your survey remains anonymous.

Data Protection

All data collected will be anonymous. No names or addresses or contact details are asked for.

Questionnaires will be returned by post to the Project Lead, George Rook, and will be stored securely.

Data will be collated and analysed and used solely for the purposes of this research project.

I hereby consent to the data in my completed questionnaire being stored and used for this Dementia Enquirers Research Project.

I understand that my completed questionnaire will remain anonymous.

I understand that the information I have provided in this survey will remain confidential.

Name:

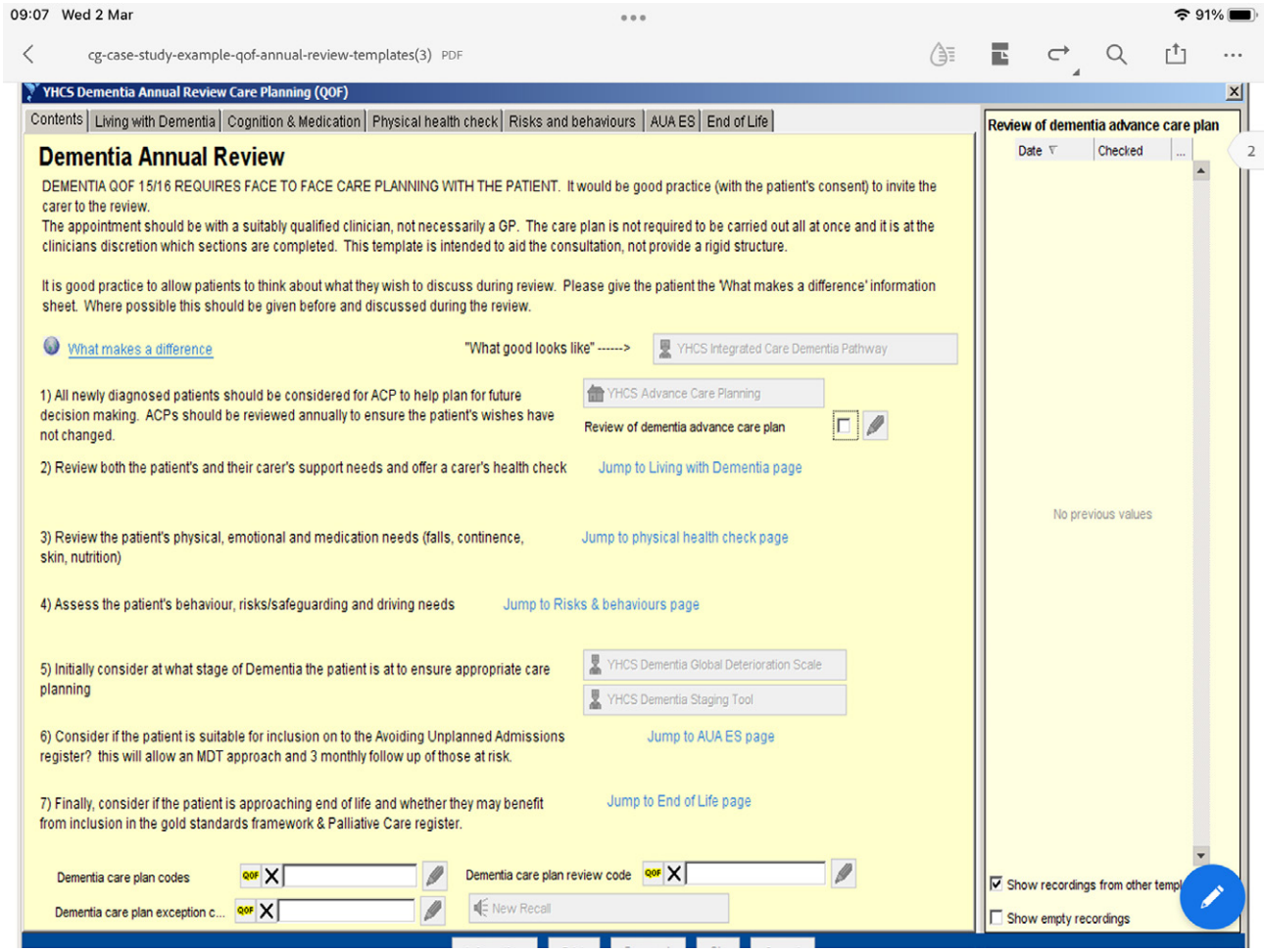
Signature:

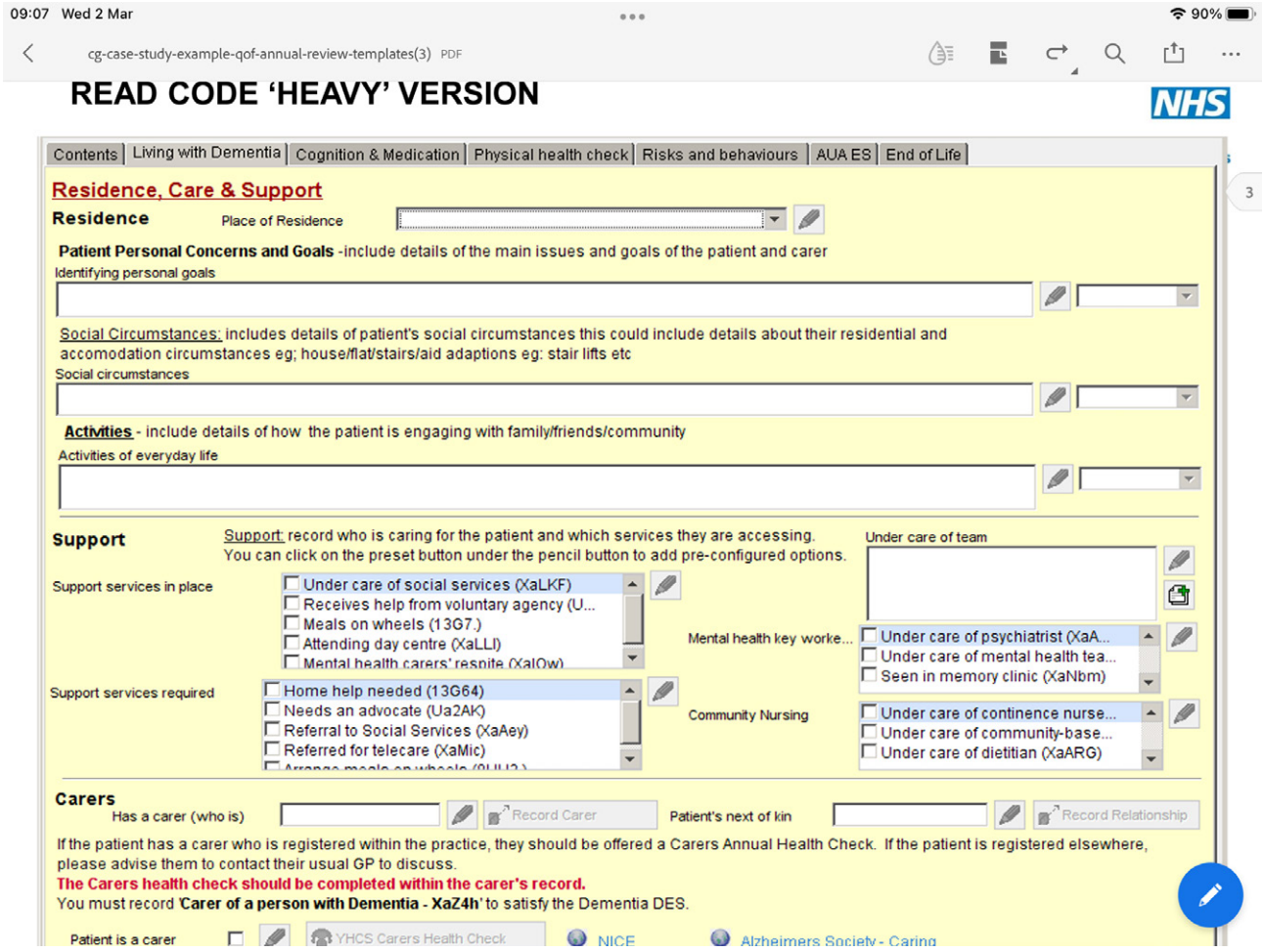
Date:

Appendix 3

EMIS GP record system pages re annual dementia reviews (YHCS refers to Yorkshire and Humberside)

circa 2016

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NHS
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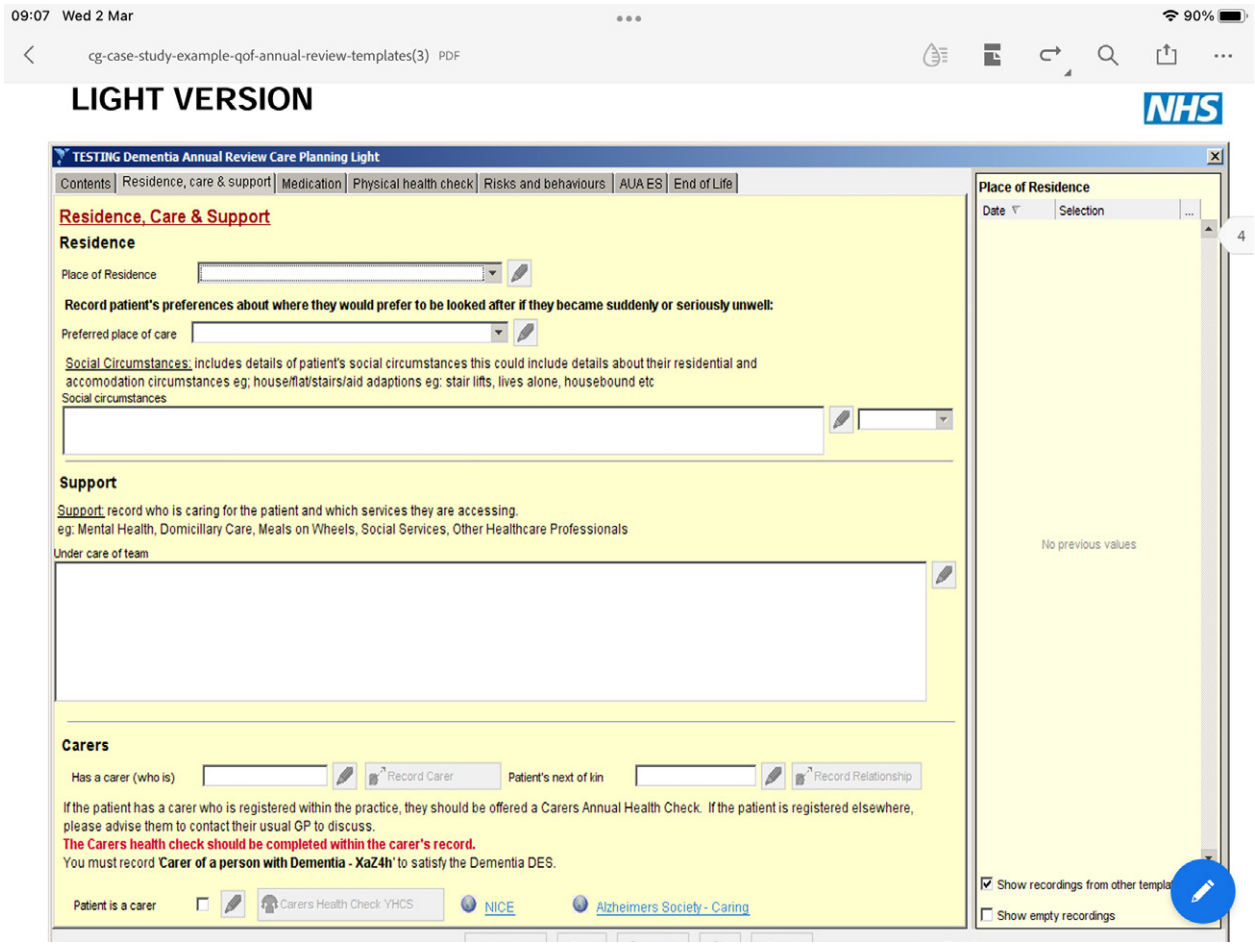
Living with Dementia
Cognition & Medication
Physical health check
Risks and behaviours
AUA ES
End of Life
Residence, Care & Support
Residence
Place of Residence
Patient Personal Concerns and Goals -include details of the main issues and goals of the patient and carer
Identifying personal goals
Social Circumstances: includes details of patient's social circumstances this could include details about their residential and accomodation circumstances eg; house/flat/stairs/aid adaptions eg: stair lifts etc
Social circumstances
Activities - include details of how the patient is engaging with family/friends/community
Activities of everyday life
Support
Support: record who is caring for the patient and which services they are accessing.
You can click on the preset button under the pencil button to add pre-configured options.
Under care of team
Support services in place
Under care of social services (XaLKF)
Receives help from voluntary agency (U...
Meals on wheels (13G7.)
Attending day centre (XaLLI)
Mental health carers' respite (XaIOw)
Mental health key worke...
Under care of psychiatrist (XaA...
Under care of mental health tea...
Seen in memory clinic (XaNbm)
Support services required
Home help needed (13G64)
Needs an advocate (Ua2AK)
Referral to Social Services (XaAey)
Referred for telecare (XaMic)
Community Nursing
Under care of continence nurse...
Under care of community-base...
Under care of dietitian (XaARG)
Carers
Has a carer (who is)
Record Carer
Patient's next of kin
Record Relationship
If the patient has a carer who is registered within the practice, they should be offered a Carers Annual Health Check. If the patient is registered elsewhere, please advise them to contact their usual GP to discuss.
The Carers health check should be completed within the carer's record.
You must record 'Carer of a person with Dementia - XaZ4h' to satisfy the Dementia DES.
Patient is a carer
YHCS Carers Health Check
NICE
Alzheimers Society - Caring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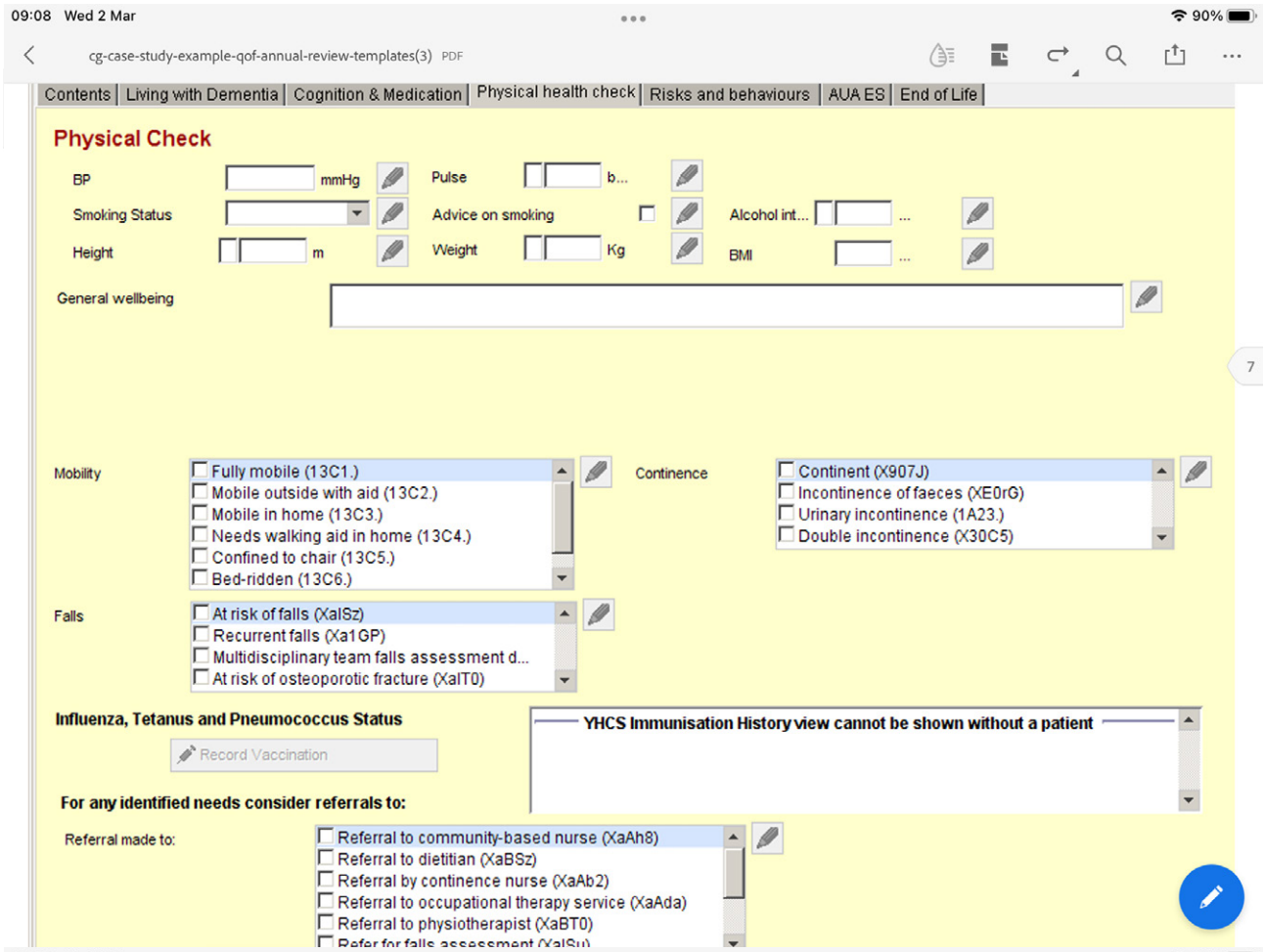
LIGHT VERSION
NHS
TESTING Dementia Annual Review Care Planning Light
Contents
Residence, care & support
Medication
Physical health check
Risks and behaviours
AUA ES
End of Life
Residence, Care & Support
Residence
Place of Residence
Record patient's preferences about where they would prefer to be looked after if they became suddenly or seriously unwell:
Preferred place of care
Social Circumstances: includes details of patient's social circumstances this could include details about their residential and accomodation circumstances eg; house/flat/stairs/aid adaptions eg: stair lifts, lives alone, housebound etc
Social circumstances
Support
Support: record who is caring for the patient and which services they are accessing.
eg: Mental Health, Domicillary Care, Meals on Wheels, Social Services, Other Healthcare Professionals
Under care of team
Carers
Has a carer (who is)
Record Carer
Patient's next of kin
Record Relationship
If the patient has a carer who is registered within the practice, they should be offered a Carers Annual Health Check. If the patient is registered elsewhere, please advise them to contact their usual GP to discuss.
The Carers health check should be completed within the carer's record.
You must record 'Carer of a person with Dementia - XaZ4h' to satisfy the Dementia DES.
Patient is a carer
Carers Health Check YHCS
NICE
Alzheimers Society - Caring
Place of Residence
Date
Selection
No previous values
Show recordings from other templa
Show empty recordings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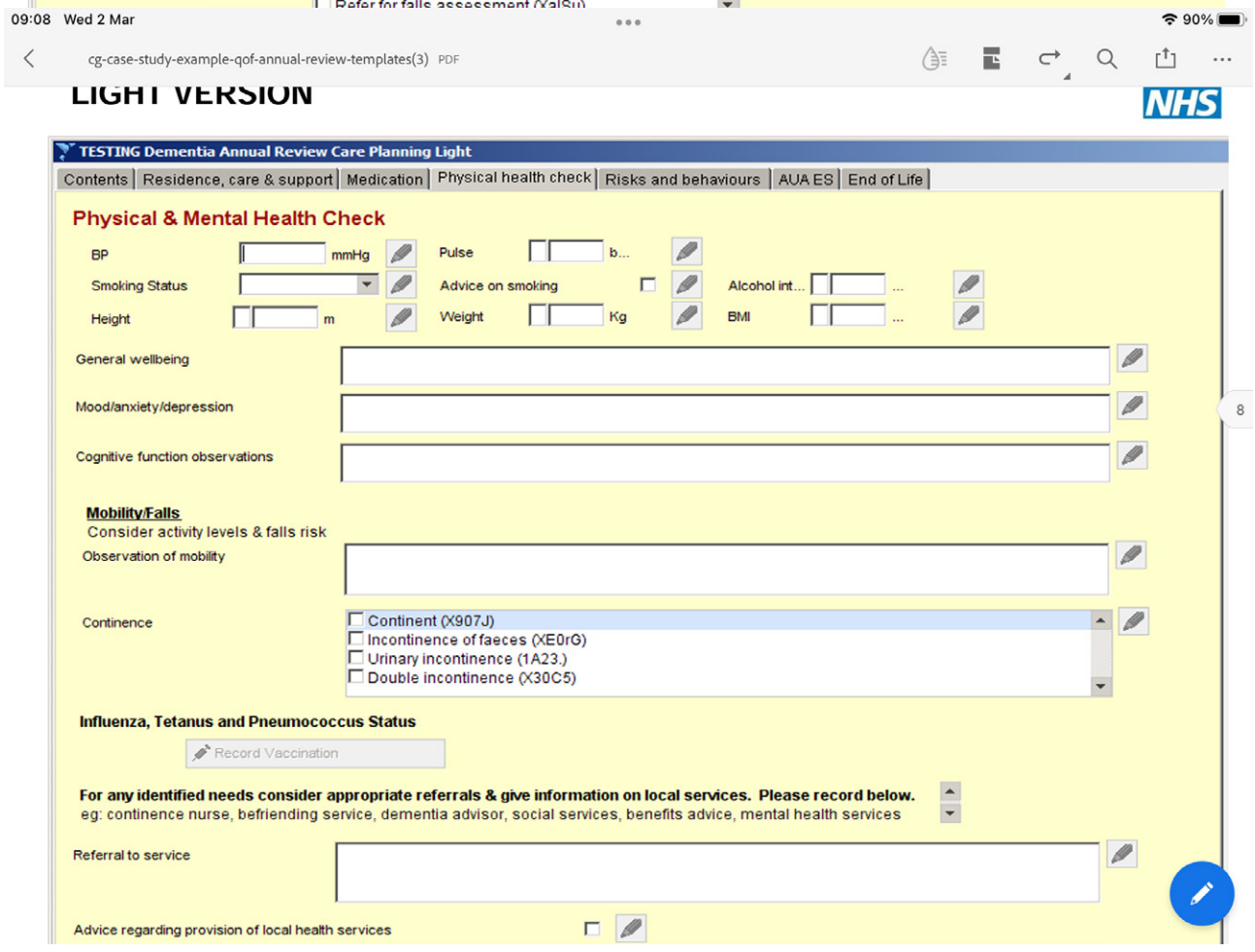
Physical Check
BP mmHg
Pulse b...
Smoking Status
Advice on smoking
Alcohol int... ...
Height m
Weight Kg
BMI ...
General wellbeing
7
Mobility
Fully mobile (13C1.)
Mobile outside with aid (13C2.)
Mobile in home (13C3.)
Needs walking aid in home (13C4.)
Confined to chair (13C5.)
Bed-ridden (13C6.)
Continence
Continent (X907J)
Incontinence of faeces (XE0rG)
Urinary incontinence (1A23.)
Double incontinence (X30C5)
Falls
At risk of falls (XaISz)
Recurrent falls (Xa1GP)
Multidisciplinary team falls assessment d...
At risk of osteoporotic fracture (XaIT0)
Influenza, Tetanus and Pneumococcus Status
Record Vaccination
YHCS Immunisation History view cannot be shown without a patient
For any identified needs consider referrals to:
Referral made to:
Referral to community-based nurse (XaAh8)
Referral to dietitian (XaBSz)
Referral by continence nurse (XaAb2)
Referral to occupational therapy service (XaAda)
Referral to physiotherapist (XaBT0)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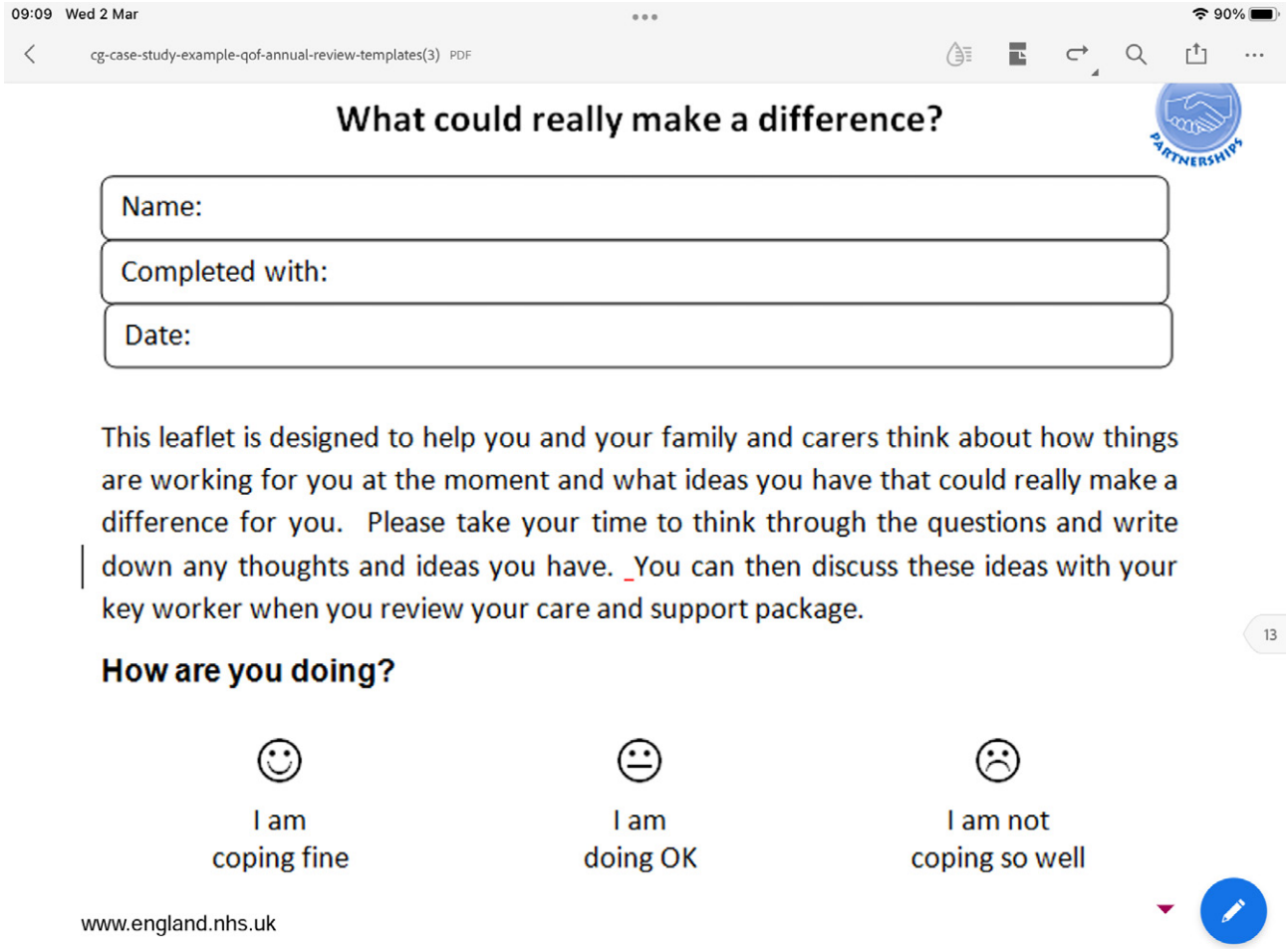
LIGHT VERSION
NHS
TESTING Dementia Annual Review Care Planning Light
Contents | Residence, care & support | Medication | Physical health check | Risks and behaviours | AUA ES | End of Life
Physical & Mental Health Check
BP mmHg
Pulse b...
Smoking Status
Advice on smoking
Alcohol int... ...
Height m
Weight Kg
BMI ...
General wellbeing
Mood/anxiety/depression
Cognitive function observations
8
Mobility/Falls
Consider activity levels & falls risk
Observation of mobility
Continence
Continent (X907J)
Incontinence of faeces (XE0rG)
Urinary incontinence (1A23.)
Double incontinence (X30C5)
Influenza, Tetanus and Pneumococcus Status
Record Vaccination
For any identified needs consider appropriate referrals & give information on local services. Please record below.
eg: continence nurse, befriending service, dementia advisor, social services, benefits advice, mental health services
Referral to service
Advice regarding provision of local health services

Appendix 4

Example from Humberside of a prompt for plwd and care partner to make notes before attending an Annual Dementia Review.



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What could really make a difference?

Name:

Completed with:

Date:

This leaflet is designed to help you and your family and carers think about how things are working for you at the moment and what ideas you have that could really make a difference for you. Please take your time to think through the questions and write down any thoughts and ideas you have. You can then discuss these ideas with your key worker when you review your care and support package.

How are you doing?

I am coping fine	I am doing OK	I am not coping so well

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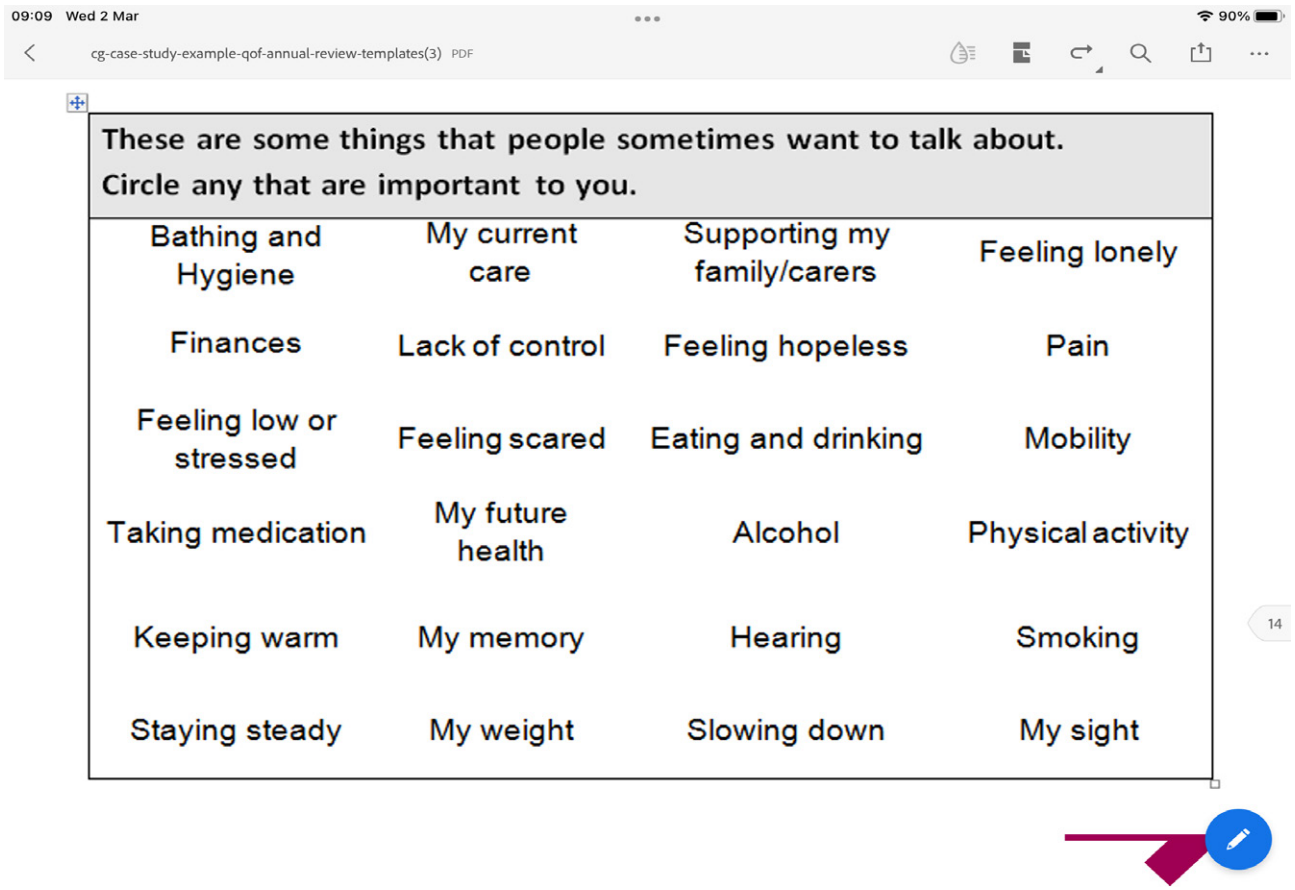
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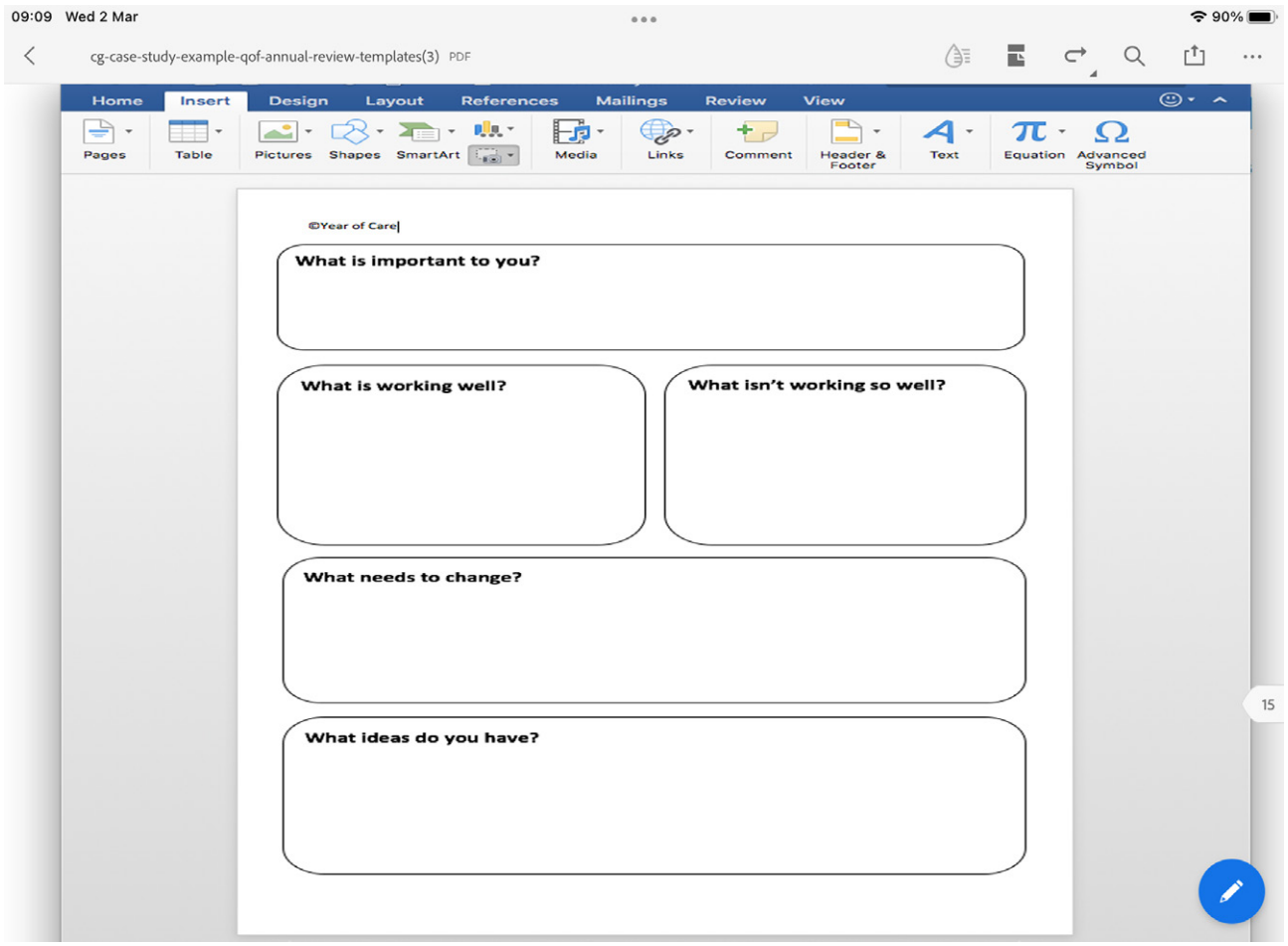
These are some things that people sometimes want to talk about.
Circle any that are important to you.
Bathing and Hygiene
My current care
Supporting my family/carers
Feeling lonely
Finances
Lack of control
Feeling hopeless
Pain
Feeling low or stressed
Feeling scared
Eating and drinking
Mobility
Taking medication
My future health
Alcohol
Physical activity
Keeping warm
My memory
Hearing
Smoking
Staying steady
My weight
Slowing down
My sight
14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Home
Insert
Design
Layout
References
Mailings
Review
View
Pages
Table
Pictures
Shapes
SmartArt
Media
Links
Comment
Header & Footer
Text
Equation
Advanced Symbol
©Year of Care
What is important to you?
What is working well?
What isn't working so well?
What needs to change?
What ideas do you have?
15

Notes

Notes

Dementia
Enquirers

COMMUNITY
FUND

iD
Innovations
in Dementia