End of end of life care in dementia – opportunities for quality improvement

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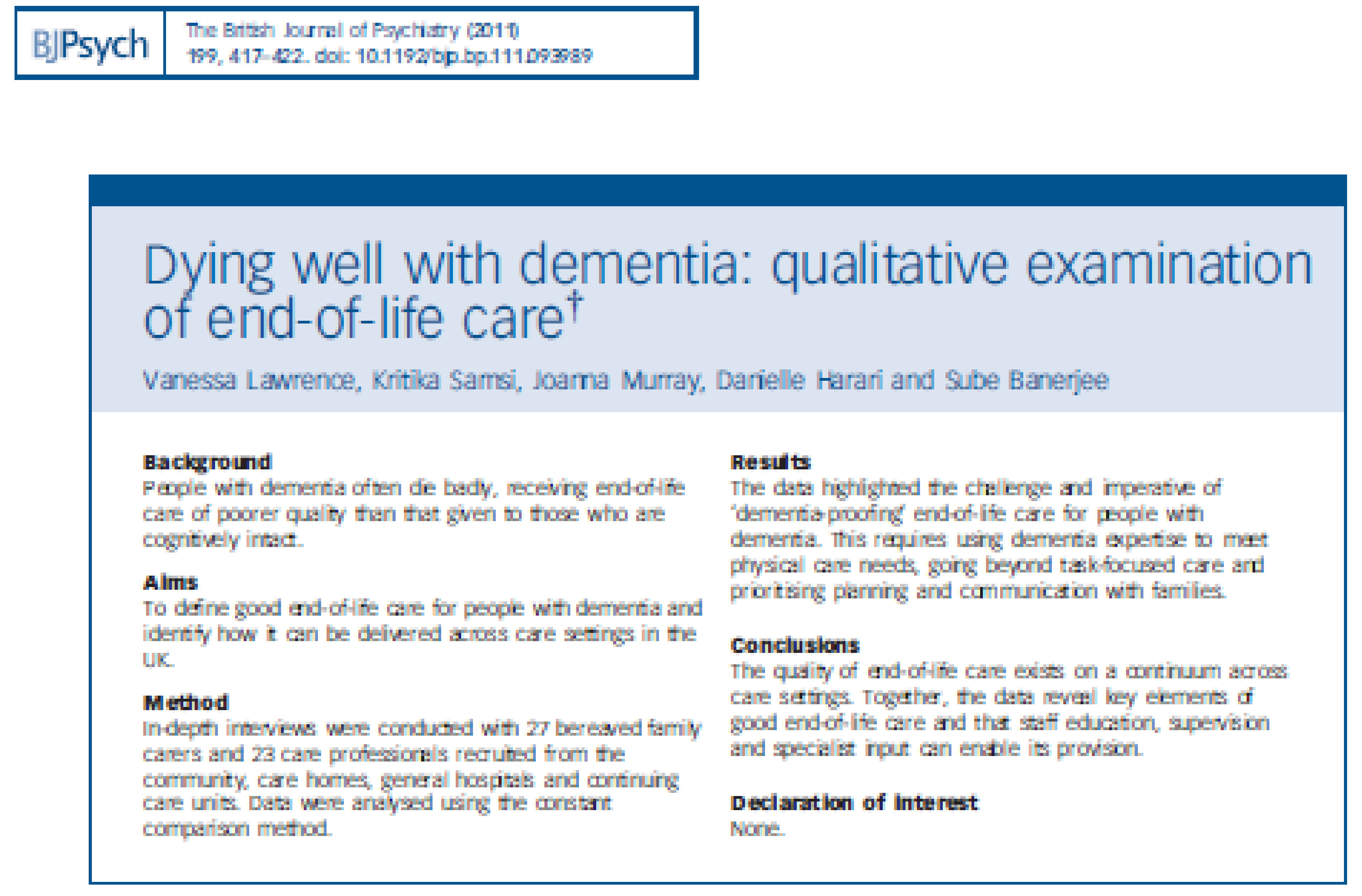
National dementia strategies

- France
- Wales
- Scotland
- Australia
- Germany
- Japan
- South Korea
- India
- England

Theme 3. Improved quality of care from diagnosis to the end of life

Theme 3 - Improving quality of care

- O6. Improved community personal support services
  - generic and specialist – collation of data
- O7. Implementing the Carers’ Strategy for people with dementia
  - make it work for dementia
- O8. Improved quality of care for dementia in general hospitals
  - clinical leads for dementia, specialist liaison teams – collation of data
- O9. Improved intermediate care for people with dementia
  - change in guidance
- O10. Housing support, related services and telecare
  - watching brief
- O11. Living well with dementia in care homes
  - including review of use of antipsychotic medication in dementia
- O12. Improved end of life care for people with dementia
  - making it work for dementia



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199, 417–422. doi: 10.1192/bjp.bp.111.093989

Dying well with dementia: qualitative examination of end-of-life care†

Vanessa Lawrence, Kritika Samsi, Joanna Murray, Danielle Harari and Sube Banerjee

Background
People with dementia often die badly, receiving end-of-life care of poorer quality than that given to those who are cognitively intact.

Aims
To define good end-of-life care for people with dementia and identify how it can be delivered across care settings in the UK.

Method
In-depth interviews were conducted with 27 bereaved family carers and 23 care professionals recruited from the community, care homes, general hospitals and continuing care units. Data were analysed using the constant comparison method.

Results
The data highlighted the challenge and imperative of 'dementia-proofing' end-of-life care for people with dementia. This requires using dementia expertise to meet physical care needs, going beyond task-focused care and prioritising planning and communication with families.

Conclusions
The quality of end-of-life care exists on a continuum across care settings. Together, the data reveal key elements of good end-of-life care and that staff education, supervision and specialist input can enable its provision.

Declaration of interest
None.

Qualitative design

Grounded Theory Approach using Individual In-depth Interviews:

- 27 bereaved carers of people with dementia:
  - 11 died in continuing care,
  - 5 in care homes,
  - 5 in the community,
  - 6 in general hospital

- 23 care professionals (within continuing care wards, CMHTs, care homes, general hospitals, palliative care and liaison psychiatry)

Summary

- Imperative of “dementia-proofing” end of life care for people with dementia.
- Three elements of end of life care to be delivered:
  - (i) meeting the multiple needs (for basic nursing care, dementia care and palliative care)
  - (ii) going beyond the task, and
  - (iii) prioritising planning and communication

Meeting multiple needs

- basic nursing care
- dementia care
- palliative care

Going beyond the task

- Care professionals sometimes struggled to see that the person was “still there”

We don't know whether someone is still hearing what we are saying. You know, you think only their heartbeat is left. (CP18, Deputy Manager, Care Home)

- Concentrating on practicalities rather than individuals’ emotional needs might allow staff to distance themselves from difficult situations.

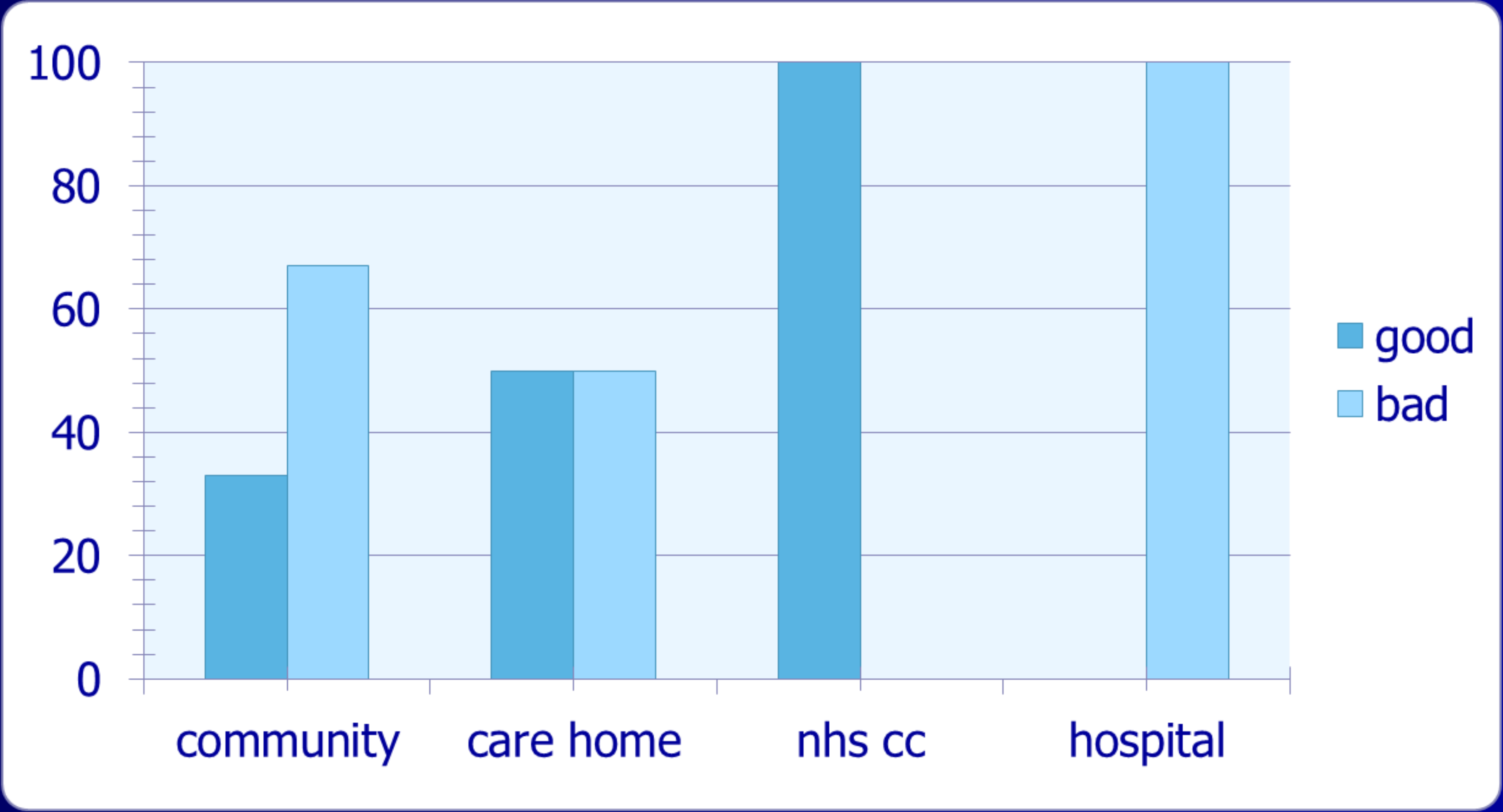
We were just preparing, tidying up, making her clean, her face and then sitting her up. All we can do for someone is make sure the room is clean, tidy. (CP18, Deputy Manager, Care Home).

Prioritising planning and communication

He was imminently dying, yet the GP phoned the family and I think the way it was put to the family well the family then said let's send him to hospital, I don't know if the family actually realised that he was imminently dying or what they thought hospital would achieve. So it was quite distressing for me and the staff to see this man who was imminently dying being shipped off to hospital. (S22, Palliative Care, Nurse Specialist)

- Critically, achieving a good death also involved enabling family members to be present at the time of death.

Quality of death

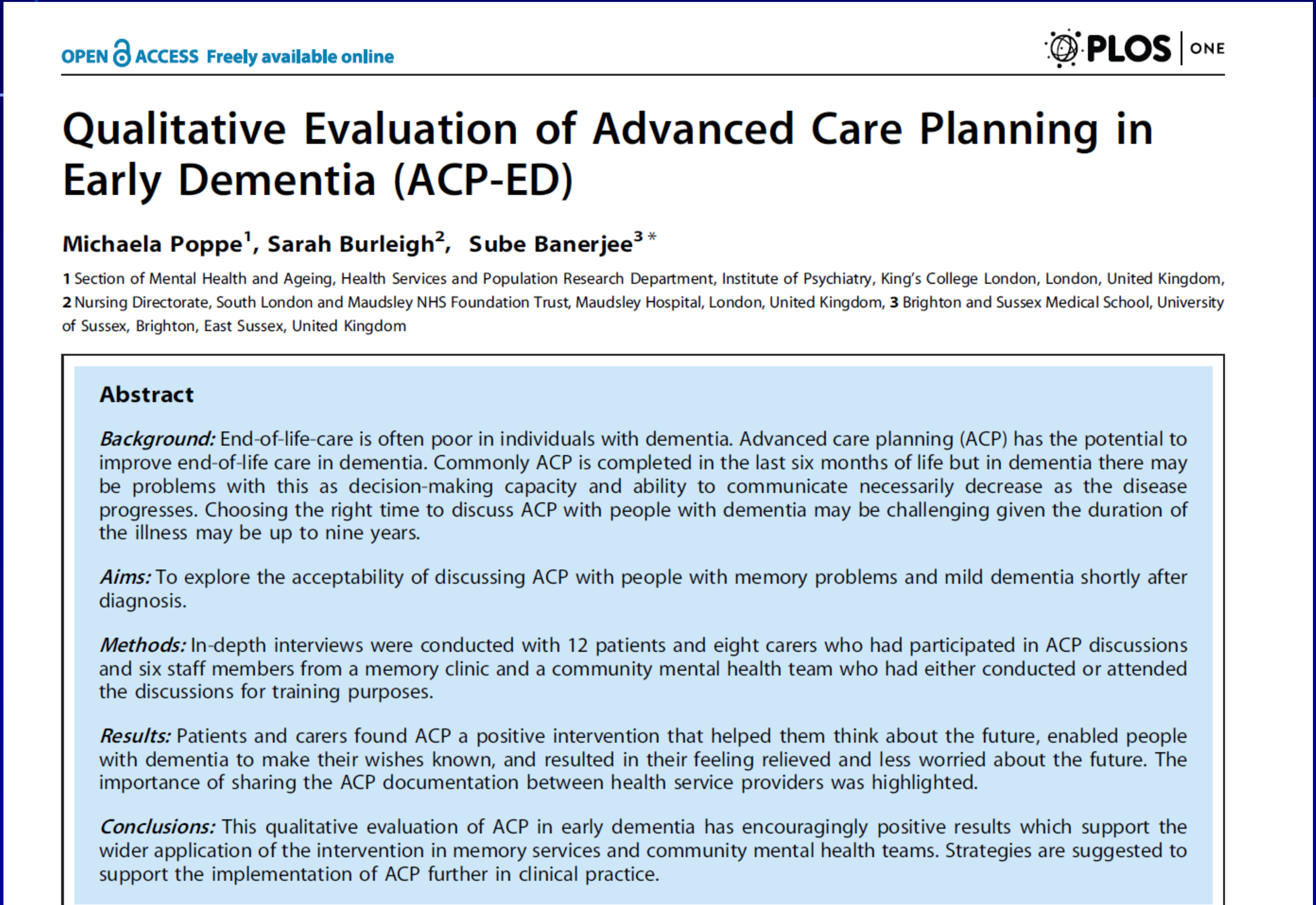


Conclusions

- All about planning
- All about carer involvement
- All about communication
- Need to know the person has dementia
- Need to modify care to allow for this

CAN ACP BE INCORPORATED INTO ASSESSMENT?

The Advanced Care Planning in Early Dementia tool (ACP-ED) evaluation [Poppe et al (2013) PLOS One]



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PLOS | ONE

Qualitative Evaluation of Advanced Care Planning in Early Dementia (ACP-ED)

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Abstract

Background: End-of-life-care is often poor in individuals with dementia. Advanced care planning (ACP) has the potential to improve end-of-life care in dementia. Commonly ACP is completed in the last six months of life but in dementia there may be problems with this as decision-making capacity and ability to communicate necessarily decrease as the disease progresses. Choosing the right time to discuss ACP with people with dementia may be challenging given the duration of the illness may be up to nine years.

Aims: To explore the acceptability of discussing ACP with people with memory problems and mild dementia shortly after diagnosis.

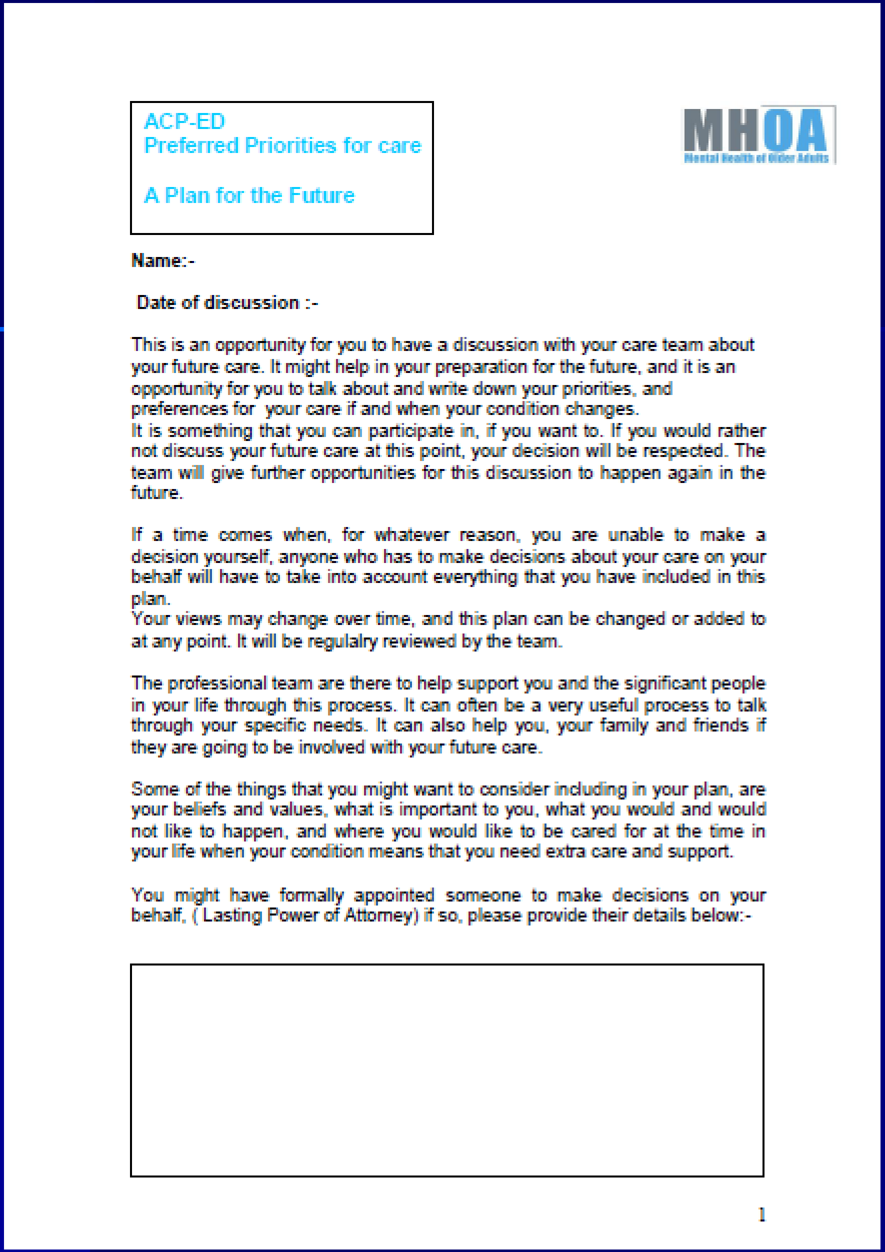
Methods: In-depth interviews were conducted with 12 patients and eight carers who had participated in ACP discussions and six staff members from a memory clinic and a community mental health team who had either conducted or attended the discussions for training purposes.

Results: Patients and carers found ACP a positive intervention that helped them think about the future, enabled people with dementia to make their wishes known, and resulted in their feeling relieved and less worried about the future. The importance of sharing the ACP documentation between health service providers was highlighted.

Conclusions: This qualitative evaluation of ACP in early dementia has encouragingly positive results which support the wider application of the intervention in memory services and community mental health teams. Strategies are suggested to support the implementation of ACP further in clinical practice.

The Advanced Care Planning in Early Dementia tool (ACP-ED) evaluation [Poppe et al (2013) PLOS One]

- No ACP tool to structure discussions about EOLC and records of discussions in early dementia
- We developed the Advanced Care Planning in Early Dementia tool (ACP-ED)
- An initial draft devised and iteratively revised:
  - 18 patients
  - 25 carers
  - 150 members of staff



ACP-ED
Preferred Priorities for care

A Plan for the Future

MHOA
Mental Health of Older Adults

Name:-

Date of discussion :-

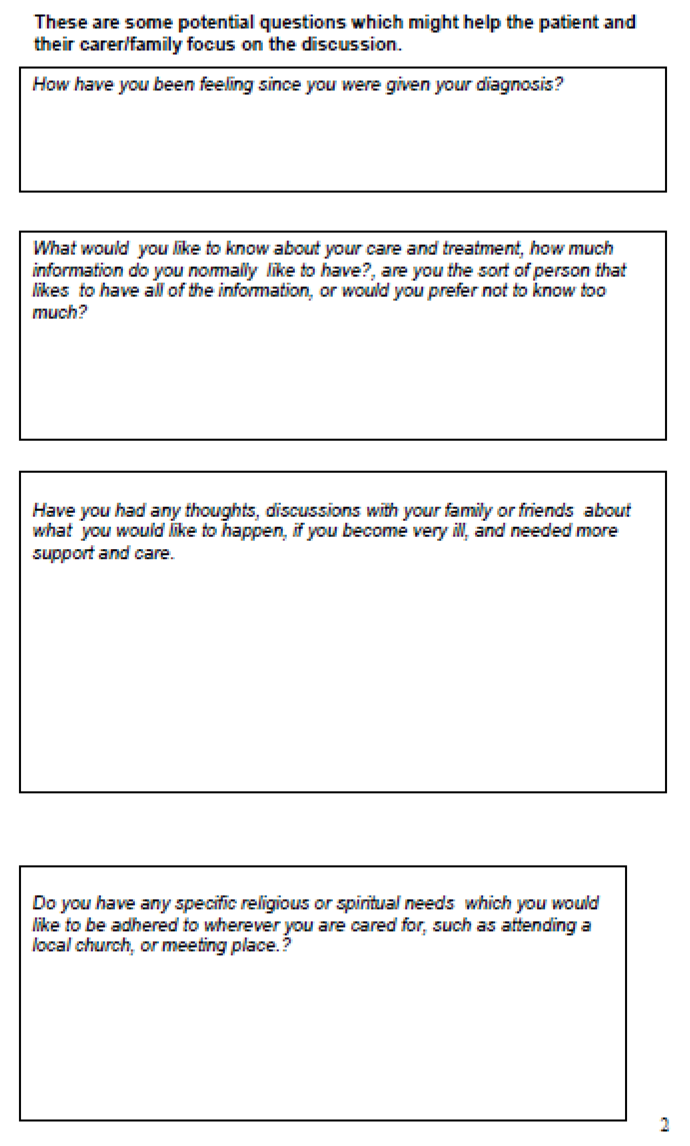
This is an opportunity for you to have a discussion with your care team about your future care. It might help in your preparation for the future, and it is an opportunity for you to talk about and write down your priorities, and preferences for your care if and when your condition changes.
It is something that you can participate in, if you want to. If you would rather not discuss your future care at this point, your decision will be respected. The team will give further opportunities for this discussion to happen again in the future.

If a time comes when, for whatever reason, you are unable to make a decision yourself, anyone who has to make decisions about your care on your behalf will have to take into account everything that you have included in this plan.
Your views may change over time, and this plan can be changed or added to at any point. It will be regulalry reviewed by the team.

The professional team are there to help support you and the significant people in your life through this process. It can often be a very useful process to talk through your specific needs. It can also help you, your family and friends if they are going to be involved with your future care.

Some of the things that you might want to consider including in your plan, are your beliefs and values, what is important to you, what you would and would not like to happen, and where you would like to be cared for at the time in your life when your condition means that you need extra care and support.

You might have formally appointed someone to make decisions on your behalf, (Lasting Power of Attorney) if so, please provide their details below:-



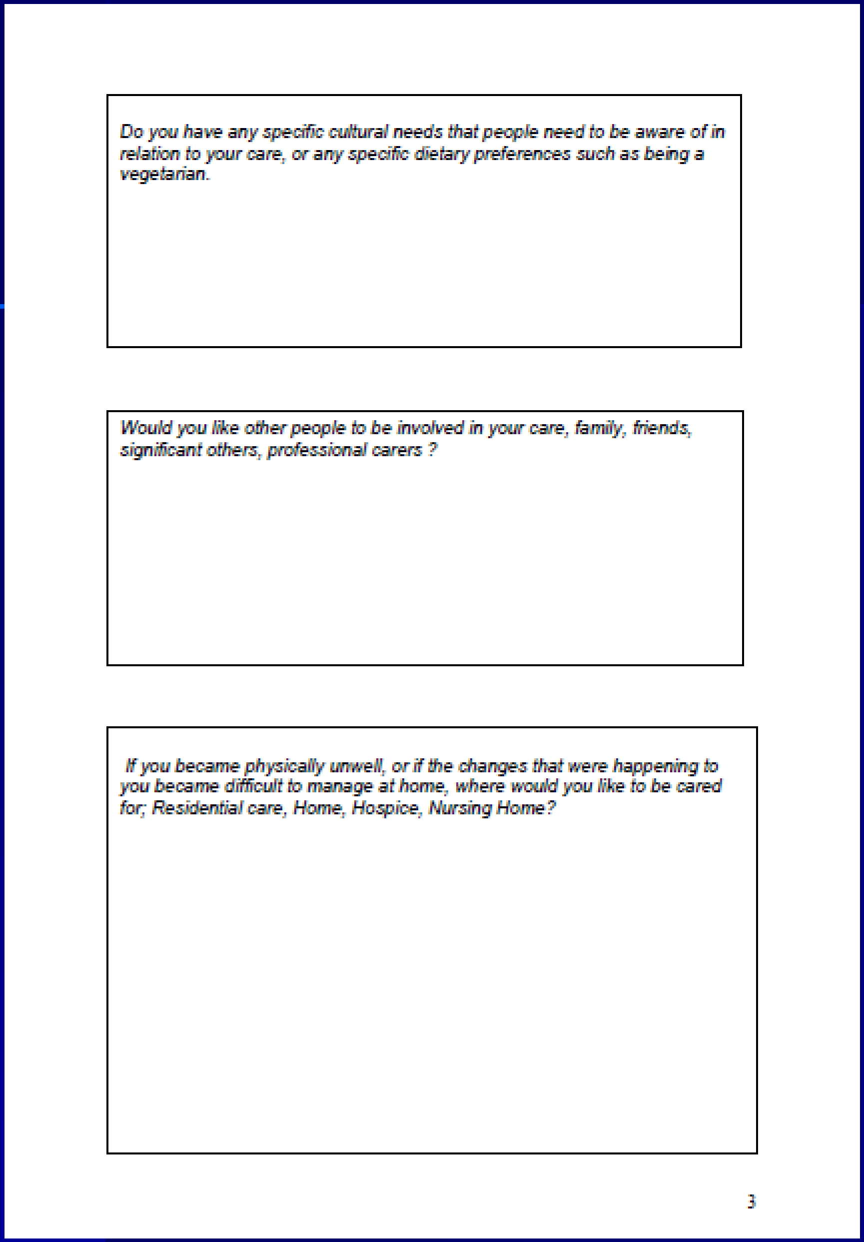
These are some potential questions which might help the patient and their carer/family focus on the discussion.

How have you been feeling since you were given your diagnosis?

What would you like to know about your care and treatment, how much information do you normally like to have?, are you the sort of person that likes to have all of the information, or would you prefer not to know too much?

Have you had any thoughts, discussions with your family or friends about what you would like to happen, if you become very ill, and needed more support and care.

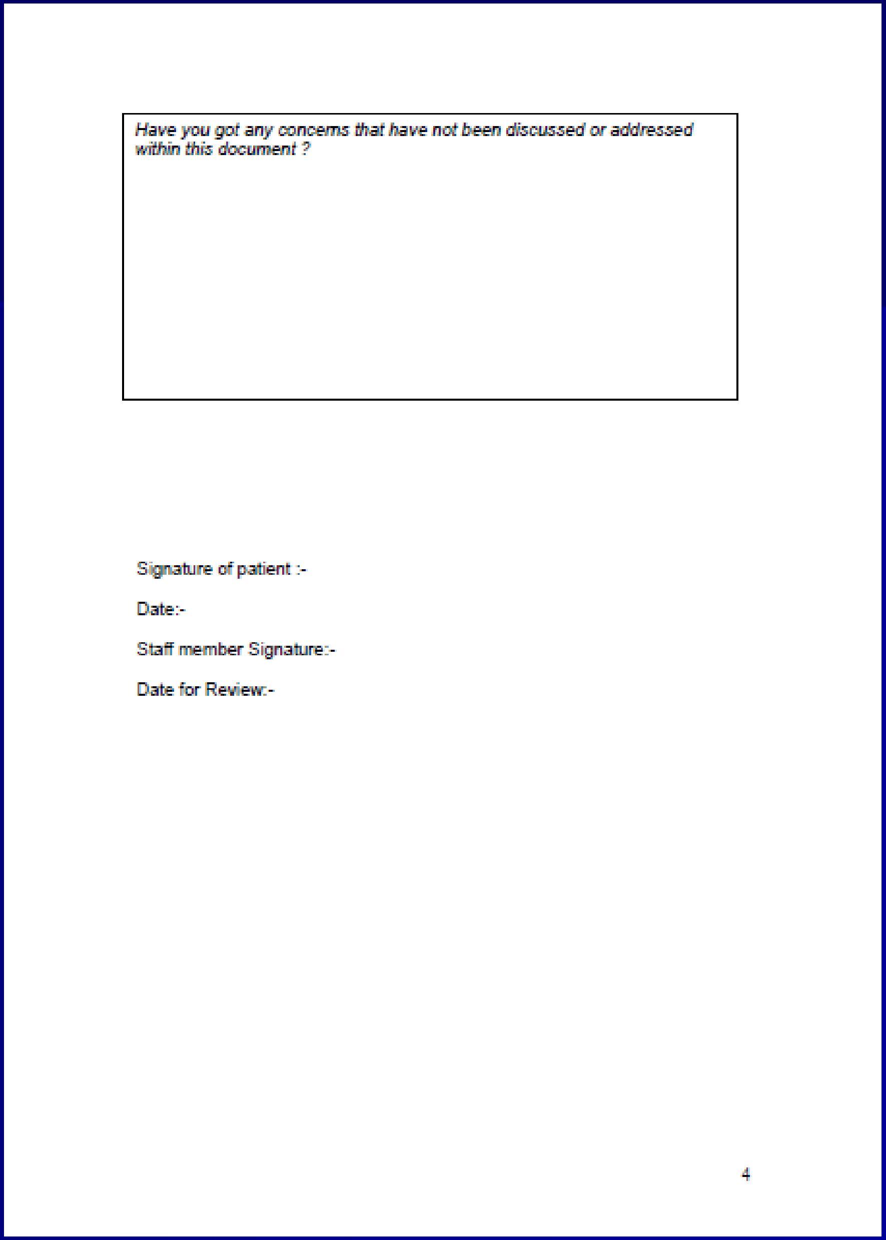
Do you have any specific religious or spiritual needs which you would like to be adhered to wherever you are cared for, such as attending a local church, or meeting place.?



Do you have any specific cultural needs that people need to be aware of in relation to your care, or any specific dietary preferences such as being a vegetarian.

Would you like other people to be involved in your care, family, friends, significant others, professional carers ?

If you became physically unwell, or if the changes that were happening to you became difficult to manage at home, where would you like to be cared for; Residential care, Home, Hospice, Nursing Home?



Have you got any concerns that have not been discussed or addressed within this document ?

Signature of patient :-

Date:-

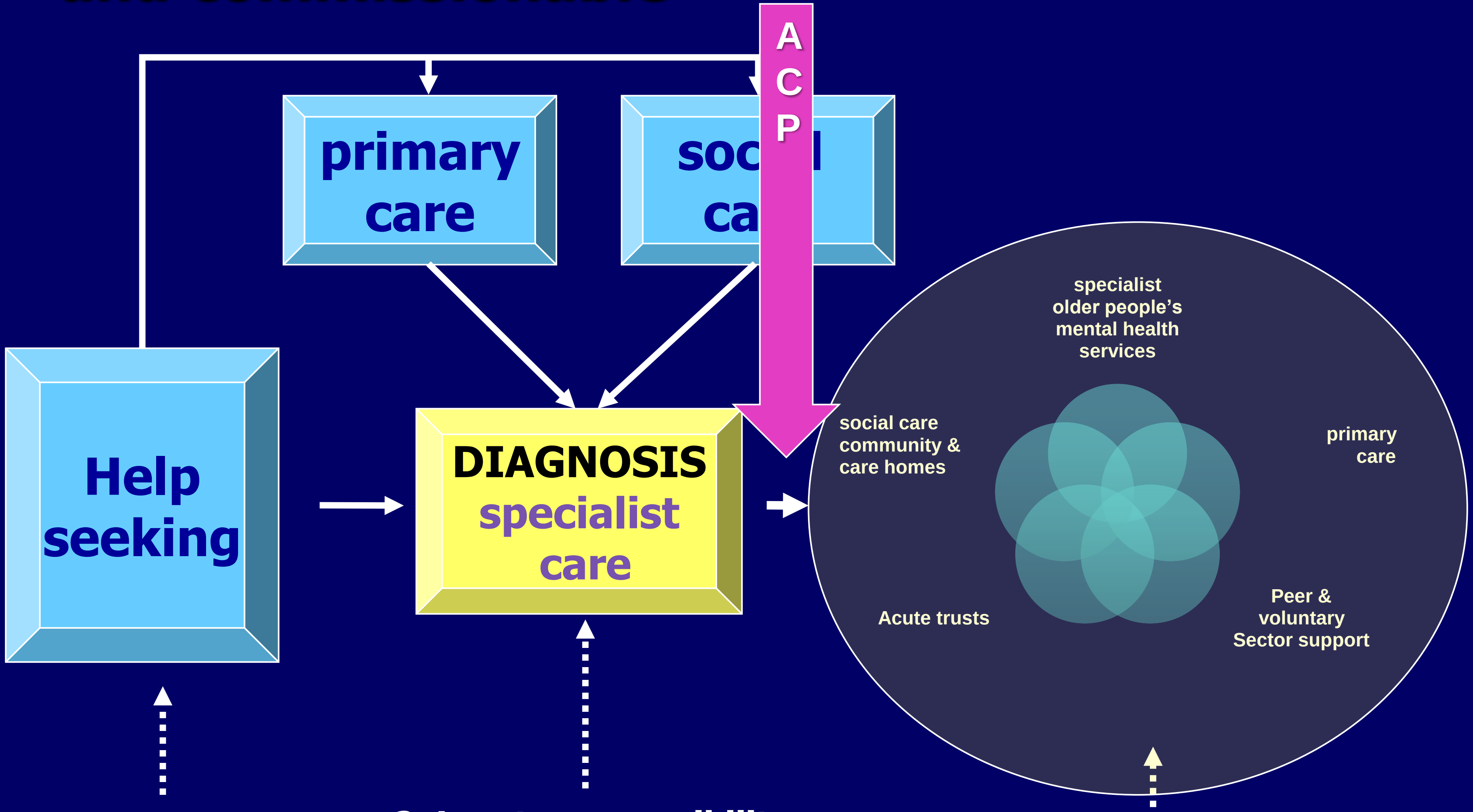
Staff member Signature:-

Date for Review:-

ACP-ED results

- Patients and carers found ACP a positive intervention
- It helped them think about the future
- It enabled people with dementia to make their wishes known
- It resulted in their feeling relieved and less worried about the future
- Importance of sharing ACP document with health service providers

Dementia care pathway – simple, navigable and commissionable



1. Encourage help seeking and referral

2. Locate responsibility for early diagnosis and care… and ACP

3. Enable good quality care tailored to dementia

Final thoughts

- We can do this so much better
- Tough to do but real potential value
- People with dementia and their family carers are brave, we need to be brave too

Thank you and good luck!