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Advance care planning in Dutch primary care: a pre/post-implementation study

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ABSTRACT

Background Despite known advantages of advance care planning (ACP) and a positive attitude towards ACP by older people living in the community and general practitioners (GPs), such conversations are not yet commonplace in GP practices.

Aim To implement ACP as part of routine care in general practice and thereby increasing the number of ACP conversations and advance directives; to investigate characteristics of older people with and without an ACP conversation.

Methods (1) A pre-evaluation and post-evaluation study using questionnaire data from people aged 75 years or older living in the community. (2) A prospective study using data provided by healthcare professionals (people they started an ACP conversation with).

Results After implementation of ACP, significantly more people had spoken to their GP about hospitalisations, intensive care admission and treatment preferences in certain circumstances, compared with before. Advance directives were drawn up more often. People who had an ACP conversation were older, have had a cerebrovascular accident, had a clear idea about future health problems, had a preference to start ACP before they were ill, already had an ACP conversation at pre-measurement and indicated at pre-measurement that their GP knows their preferences.

Conclusion Results in number of ACP conversations and advance directives were modest but positive. ACP was implemented as routine care. GPs select people with whom they have a conversation. This can be an efficient use of time, but there is a risk that certain groups may be underserved (for example, patients with multimorbidity or patients with less health skills).

BACKGROUND

Advance care planning (ACP) enables individuals to define goals and preferences

Key messages

What was already known?

- Systematic reviews have shown that implementation of ACP increases the completion of advance directives and improves consistency of care with patients' goals in various populations.
- Although prevalence of ACP increases with age, percentages remain low.

What are the new findings?

- After implementation of ACP in routine (everyday) GP care, there was a rise in conversations between older people and their GP regarding hospitalisation, IC admission, and treatment preferences, compared with before.
- People who were older, female, and had at least one diagnosis were offered or had a conversation with their GP more often.

What is their significance?

- GPs should assess the readiness to engage in ACP, but ACP can be offered to every person and timely offers of ACP may stimulate people to engage more actively.

for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate.¹ Systematic reviews have shown that implementation of ACP increases the completion of advance directives and improves consistency of care with patients' goals in various populations.^{2 3} Another review showed that 61%–91% of older people are willing to engage in ACP and that healthcare professionals see it as their professional responsibility to conduct ACP conversations.⁴ In the Netherlands, ACP is mentioned in several healthcare standards, guidelines and position papers from professional organisations.^{5–7}

However, despite known advantages of ACP and a positive attitude towards ACP by older people living in the community and healthcare professionals including general practitioners (GPs), conversations are not yet commonplace in GP practices.⁸ It is also known that, although ACP can be initiated at any age and independent of illness/health, ACP is generally initiated late in the disease trajectory of patients and more often involves patients with cancer.⁹ Previous studies suggest differences in rates of ACP by ethnicity, level of education and social economic status.^{10–12} Although prevalence of ACP increases with age, percentages remain low.¹² As people grow older, they are at a higher risk of having to make life-changing healthcare choices, and the balance between pros and cons of treatments may shift.

To improve uptake of ACP among people aged 75 years or older living in the community, primary care providers (PCPs; GPs, community nurses, certified nursing assistants, practice nurses) were trained in ACP and received support during implementation (see [box 1](#)). Primary target of the project was to embed ACP in routine clinical practice. This paper describes results from the study that accompanied implementation. The authors address the following questions:

1. Is there an increase in ACP conversations after implementation, compared with before?
2. Is there an increase in advance directives after implementation, compared with before?
3. With which older people do PCPs start ACP conversations?

METHODS

Design and population

This is a pre-evaluation and post-evaluation using questionnaire data from people aged 75 years or older living in the community enlisted with participating organisations and a prospective study using data provided by PCPs. ACP was implemented in 10 GP practices and 2 care homes (see [box 1](#)). Almost all Dutch residents are registered with a GP, who functions as a gatekeeper for more specialised forms of care. Our target group exists of (1) all older people living in the community enlisted within the participating GP practice who are aged 75 years or older, and (2) all inhabitants of designated wings/divisions of the participating care homes.

Procedure

Before implementation, a list was drawn up of all people aged 75 years or older in the GP practice or care home on 01 January 2017 (see [figure 1](#)). Also, we asked for the age and sex of all people on the list, and some basic information on diagnoses. On this list, the PCP made a note of people with whom they started an ACP conversation until 14 months after start of implementation: the ACP-Monitor. Our initial plan was to monitor both the offer of ACP and the actual conversation separate, but that

Box 1 Content of the advance care planning (ACP) implementation project

Background: In our project, we draw on experiences with ACP in West Friesland. They successfully implemented an ACP project there, and we wanted to broaden the scope of that project to the provinces of North Holland and Flevoland. After literature study and interviews with experts, the materials were adapted.

Recruitment: Participating organisations (10 general practitioner (GP) practices and 2 care homes) reacted to a call within local networks of organisations involved in palliative care to participate in an implementation study on ACP. The two care homes contacted the GP practices involved in the care for their inhabitants, and asked the GP practices to take part in the implementation study.

Structure of the intervention: Patients have a first conversation with a home care nurse, a certified nursing assistant or with the practice nurse. This can either be pretty basic, just to introduce ACP and ask the patient to make an appointment with their GP, or more elaborate. Subsequent conversations are with the GP. All the primary care providers (PCPs) involved in our project are regular care providers of the patients, so no new people were introduced with the delivery of ACP.

Implementation: The intervention was partly predefined and partly tailored. Before implementation, the PCPs received training and materials in writing. For nurses and nursing assistants, there was training of three afternoons, for GPs the training was on two evenings. The training consisted of background information on ACP (including timing and target group), aspects of communication and role-play. The materials in writing included among others, a manual with background information on ACP, tips for the conversation (such as questions to ask and ways to react to certain statements), a form to register patient preferences and a roadmap for delivery of ACP (from patient selection to transfer of information and moments to repeat the conversation). The intervention delivered to patients was largely at the discretion of practices, PCPs decided with which patients they wanted to have ACP conversations and which professional would have the ACP conversations with the patient and carers. The implementation process was supported by site visits (face-to-face meeting 1–1.5 hours held in the practice or care home, every 3 months) by an implementation facilitator who was part of the research team. Content of these visits was tailored according to interests and needs. To guide implementation, the Advance Care Planning-Service Evaluation Tool was used.²⁴ This tool identified ACP progress over time across three stages of Establishment, Consolidation and Sustainability within model domains of governance, documentation, practice, education, quality improvement and community engagement.

was not consistently registered, so we chose to combine the information.

Questionnaires were sent to all people aged 75 years or older within the GP practice or care home (the same people as on the ACP-Monitor). The first questionnaire was sent before implementation of ACP (February–March 2017), the second was sent

2 care homes and 10 GP practices

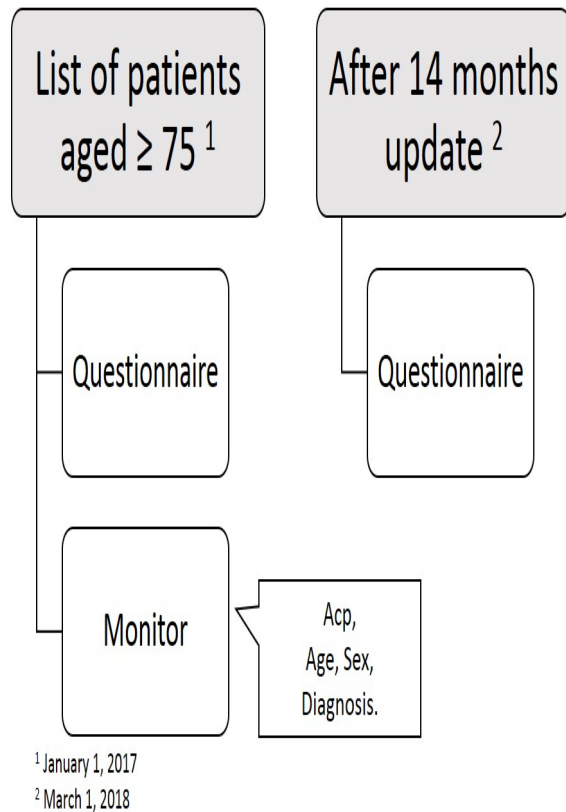


Figure 1 Design of the study. ACP, advance care planning; GP, general practitioner.

approximately 14 months later (April–July 2018). The questionnaire was developed for this study and contained structured questions about experiences with ACP, communication with healthcare providers, relation with proxy, healthcare status and demographics. The questionnaires were piloted on a small sample of respondents to ascertain that the questions were clearly formulated and relevant. The first page of the questionnaire provided information about the study, those responses would be anonymised, and whether or not a questionnaire was returned would not have any impact on the care they receive from their PCP. Also, contact information of the main researcher was included.

Data analyses

Descriptive statistics were used to summarise the characteristics of respondents (older people who filled in both questionnaires). Pre-test and post-test differences in ACP conversations and advance directives were analysed in logistic analyses and logistic multilevel analyses. To assess the difference between the logistic regression model and the logistic multilevel model (which model better

described the data), the X^2 likelihood-ratio test was used.

For research question 3, a new dichotomous variable ‘ACP conversation’ was derived from the following series of questions that were included in both the pre-questionnaire and post-questionnaire:

During the last 12 months, have you thought and/or talked about:

- ▶ Whether or not you would like to go to the hospital under certain circumstances?
- ▶ Whether or not you would like to be admitted to intensive care (IC)?
- ▶ Whether or not you would like to be admitted to a nursing home?
- ▶ Where you would like to die?
- ▶ Which treatments you would and would not like to receive in certain circumstances?

For all topics, seven options were provided: (a) thought about it, (b) talked to my GP about it, (c) talked to a doctor (other than the GP), (d) talked to another healthcare provider, (e) talked to someone else (not a healthcare provider), (f) I have recorded it, (g) none of these answers. Respondents could indicate ‘yes’ or ‘no’ for all of these options. If the person had ‘talked to my GP’ on any of the five topics, an ACP conversation with the GP has taken place (resulting in a dichotomous variable for ‘ACP conversation’). This was done for the pre-measurement and post-measurement.

Using ‘ACP conversation’ at post-measurement as an outcome variable, a regression model was fitted. First, variables were tested bivariately. All significant variables were then entered in a backward logistic multilevel regression procedure to investigate which items would remain significant (removal at $p > 0.10$). All analyses were conducted with Stata SE V.16.

RESULTS

Non-response analyses and characteristics of respondents

A total of 2292 persons were included on the Monitor list (online supplemental file 1). The mean age was 82 years and 59% were women. The people who filled in both questionnaires ($n=458$; 20%) were younger, more often had (an offer of) an ACP conversation, and more often were community dwelling (as opposed to living in a care home) compared with the people who did not fill in both questionnaires. Conversations were offered to or started with 26% ($n=597$) of people on the Monitor list. Compared with people with no conversations, conversations were more often offered or started with women (64% vs 57%), with older people (83 years vs 81 years) and with people who had at least one diagnosis (95% vs 88%) (online supplemental file 2). There was no difference in home-dwelling people and people living in a care home with regard to (the offer of) an ACP conversation.

Table 1 Characteristics of respondents who filled in both questionnaires (2017–2018), n (%)

	Patients' characteristics (as measured before implementation) N=458
Setting of inclusion	
Care home	14 (3.1)
GP practice	444 (96.9)
Country of birth, NL*	
	429 (93.7)
Marital status, married*	
	184 (41.1)
Level of education*	
Lower secondary education or lower	239 (52.2)
Higher secondary education	103 (22.5)
Tertiary education	116 (25.3)
Religious affiliation*	
No specific religious affiliation or atheist	256 (55.9)
Protestant	92 (20.1)
Catholic	57 (12.5)
Other	21 (4.6)
Do not want to answer this question	32 (7.0)
Diagnosis (more than one answer possible)*	
Cancer	31 (7.0)
Rheumatism/arthritis	126 (28.6)
COPD	44 (10.0)
Diabetes	57 (12.9)
Heart condition	115 (26.1)
Stroke/cerebrovascular accident	27 (6.1)
Dementia	7 (1.6)
Depression	21 (4.8)
Other	101 (22.9)
None	110 (24.9)
Do you have a clear idea about future health problems that you might face?	
Don't know/no	277 (61.6)
Yes	173 (38.4)
Preferred timing of ACP, never (vs ever)	
	18 (4.4)
If ever, preferred timing of ACP is	
Before someone is ill	89 (23.0)
At time of diagnosis of a possible life-threatening illness	129 (33.3)
When it is clear that it is no longer possible to cure from the illness	169 (43.7)
Reasons not to engage in ACP	
My next of kin know what I want	175 (38.2)
I see no reason not to talk about it	186 (40.6)
I don't want to think about the future or about getting (more) ill	60 (13.1)
My GP knows what I want	40 (8.7)
I am healthy, there is no reason to do so	11 (2.4)
I am afraid I don't get the opportunity to change preferences later	4 (0.9)
I don't know what the future will bring	9 (2.0)
Other reasons	13 (2.8)

*Characteristics at pre-measurement are reported, if missing in pre-measurement then answer at post-measurement was used in country of birth, education and religion. Missing data: marital status n=10; diagnosis n=17.

ACP, advance care planning; COPD, chronic obstructive pulmonary disease; GP, general practitioner; NL, the Netherlands.

Table 1 shows background characteristics of the respondents who filled in both questionnaires. A majority (61.6%) of people did not have a clear idea about future health problems that they might face. When asked about the preferred timing of ACP conversations, a very small portion of people answered 'never' (4.4%). The preferred timing showed a gradual incline from before illness (23.0%), to the time of diagnosis of a potentially life-threatening illness (33.3%), to the moment that a cure was no longer possible (43.7%).

ACP conversations and advance directives

After implementation of ACP, more people had spoken to their GP about hospitalisations (OR 1.66 (1.18 to 2.32)), IC admission (OR 2.12 (1.40 to 3.22)) and treatment preferences in certain circumstances (OR 2.01 (1.42 to 2.84)), compared with before (online supplemental file 3). Written statements saw a rise after implementation compared with before with regard to hospitalisation (OR 1.84 (1.33 to 2.55)), IC admission (OR 1.89 (1.30 to 2.73)), preferred place of death (OR 2.15 (1.20 to 3.84)) and treatment preferences (OR 1.58 (1.14 to 2.20)). People spoke to other healthcare professionals more often about admission to a nursing home (OR 4.11 (1.36 to 12.38)) and treatment preferences (OR 1.81 (1.03 to 2.77)). There was a decline in people who thought about IC admission (OR 0.59 (0.44 to 0.79)) or treatment preferences (OR 0.64 (0.47 to 0.87)) after implementation compared with before. With regard to nursing home admission, there was a rise in people who answered 'none of the above' (they had neither thought about it, spoken about or made a written statement about it) (OR 1.45 (1.10 to 1.92)) after implementation compared with before. On none of the five topics, there was a difference in the number of people who had spoken to someone else (not the GP or other healthcare professional) after implementation compared with before.

Looking at specific treatments and interventions, the following were discussed with the GP more often after implementation: resuscitation (OR 1.96 (1.44 to 2.65)); mechanical ventilation (OR 2.72 (1.59 to 4.66)); artificial hydration or nutrition (OR 3.97 (2.11 to 7.46)); euthanasia (OR 1.81 (1.36 to 2.41)), and the answer 'none of the above' was given less often (OR 0.56 (0.43 to 0.73)) compared with before implementation. Advance directives were drawn up more often (OR 1.54 (1.18 to 2.00)), more specific the form that was part of the implementation toolkit (OR 3.88 (2.39 to 6.31)), do-not-resuscitate orders (OR 1.48 (1.05 to 2.07)) and appointment of a proxy (OR 1.48 (1.12 to 1.96)). The partner was more often appointed as proxy after implementation (OR 1.48 (1.12 to 1.96)), compared with before.

Table 2 Characteristics of respondents who did or did not have an ACP conversation after implementation of ACP

	No ACP (n=308)*	ACP (n=150)*	OR (95% CI) Unadjusted (bivariate)	OR (95% CI) Model†
Age, mean (SD)	80.2 (4.3)	82.3 (5.5)	1.09 (1.05 to 1.14)	1.10 (1.04 to 1.16)
Sex, female	190 (63.1)	96 (64.8)	1.08 (0.72 to 1.63)	
Country of birth, NL	284 (92.2)	145 (96.7)	2.45 (0.92 to 6.56)	
Marital status, married	134 (44.7)	50 (33.8)	0.63 (0.42 to 0.95)	
Level of education				
Lower secondary education or lower	160 (52.0)	79 (52.7)	Reference	
Higher secondary education	68 (22.1)	35 (23.3)	1.04 (0.64 to 1.70)	
Tertiary education	80 (26.0)	36 (24.0)	0.91 (0.57 to 1.46)	
Religious affiliation				
No specific religious affiliation or atheist	168 (54.6)	88 (58.7)	Reference	
Protestant	63 (20.5)	29 (19.3)	0.88 (0.53 to 1.46)	
Catholic	42 (13.6)	15 (10.0)	0.68 (0.36 to 1.30)	
Other	15 (4.9)	6 (4.0)	0.76 (0.29 to 2.04)	
Do not want to answer this question	20 (6.5)	12 (8.0)	1.15 (0.54 to 2.45)	
Diagnosis (more than one answer possible)				
Cancer	17 (5.7)	14 (9.7)	1.77 (0.85 to 3.71)	
Rheumatism/arthrosis	84 (28.3)	42 (29.2)	1.04 (0.67 to 1.62)	
COPD	32 (10.8)	12 (8.3)	0.75 (0.38 to 1.51)	
Diabetes	39 (13.1)	18 (12.5)	0.95 (0.52 to 1.72)	
Heart condition	79 (26.6)	36 (25.0)	0.92 (0.58 to 1.45)	
Stroke/cerebrovascular accident	13 (4.4)	14 (9.7)	2.35 (1.08 to 5.15)	2.51 (0.92 to 6.83)
Dementia	4 (1.4)	3 (2.1)	1.56 (0.34 to 7.06)	
Depression	16 (5.4)	5 (3.5)	0.63 (0.23 to 1.76)	
Multiple sclerosis	0	0		
Amyotrophic lateral sclerosis	0	0		
Other	63 (21.2)	38 (26.4)	1.33 (0.84 to 2.12)	
None	83 (28.0)	27 (18.8)	0.59 (0.36 to 0.97)	
Do you have a clear idea about future health problems that you might face?				
Don't know/no	197 (65.0)	80 (54.4)	Reference	Reference
Yes	106 (35.0)	67 (45.6)	1.56 (1.04 to 2.33)	1.25 (0.75 to 2.11)
Preferred timing of ACP, never (vs ever)	17 (6.1)	1 (0.8)	0.12 (0.02 to 0.93)	
If ever, preferred timing is				
Before someone is ill	46 (17.6)	43 (34.1)	Reference	Reference
At time of diagnosis of a possible life-threatening illness	90 (34.5)	39 (31.0)	0.46 (0.26 to 0.81)	0.63 (0.32 to 1.22)
When it is clear that it is no longer possible to cure from the illness	125 (47.9)	44 (34.9)	0.38 (0.22 to 0.65)	0.52 (0.28 to 0.99)
Having had an ACP conversation at first measurement (before implementation), yes	38 (12.3)	63 (42.0)	5.15 (3.22 to 8.23)	3.85 (2.07 to 7.15)
Reasons not to engage in ACP				
My next of kin know what I want	114 (37.0)	61 (40.7)	1.17 (0.78 to 1.74)	
I see no reason not to talk about it	127 (41.2)	59 (39.3)	0.92 (0.62 to 1.38)	
I don't want to think about the future or about getting (more) ill	49 (15.9)	11 (7.3)	0.42 (0.21 to 0.83)	
My GP knows what I want	12 (3.9)	28 (18.7)	5.67 (2.79 to 11.50)	3.27 (1.17 to 9.12)
I am healthy, there is no reason to do so	10 (3.3)	1 (0.7)	0.20 (0.03 to 1.58)	
I am afraid I don't get the opportunity to change preferences later	3 (1.0)	1 (0.7)	0.68 (0.07 to 6.62)	
I don't know what the future will bring	8 (2.6)	1 (0.7)	0.25 (0.03 to 2.03)	
Other reasons	7 (2.3)	6 (4.0)	1.79 (0.59 to 5.43)	

Bold indicates a p-value < 0.05.

*Characteristics at pre-measurement are reported, if missing in pre-measurement then answer at post-measurement was used in country of birth, education and religion. Missing data: age no ACP n=9, ACP n=4; sex no ACP n=7, ACP n=2; marital status no ACP n=8, ACP n=2; diagnosis no ACP n=11, ACP n=6; idea about future health problems no ACP n=5, ACP n=3; preferred timing no ACP n=30, ACP n=23; reasons not to engage in ACP: missing answers were coded as 'no'.

†Backward logistic multilevel regression procedure (to adjust for organisation), model with random intercept is reported, removal at p>0.10.

ACP, advance care planning; COPD, chronic obstructive pulmonary disease; GP, general practitioner; NL, the Netherlands.

In 26 out of 50 variables, the model better described the data if GP practice was taken into account, indicating that there was variation in implementation of ACP between participating organisations (in statistical terms; the model with random intercept performed better compared with the model without, according to the likelihood-ratio test). This was the case especially in models concerning the communication between the GP and the older person and communication between the older person and others.

Table 2 shows with which older people PCPs had ACP conversations (research question 3).

DISCUSSION

After implementation of ACP, there was a rise in conversations between older people and their GP regarding hospitalisation, IC admission and treatment preferences, compared with before. Resuscitation, mechanical ventilation, artificial hydration or nutrition, and euthanasia were discussed with the GP more often after implementation, compared with before. In addition, treatment preferences and admission to a nursing home were discussed more often with other professionals after implementation, compared with before. Advance directives were drawn up more often. Older people more often had an ACP conversation after implementation when they were older, have had a cerebrovascular accident, had a clear idea about future health problems at the pre-measurement, had a preference to start with ACP before illness, already had an ACP conversation before implementation and indicated at pre-measurement that their GP already knew what their preferences were. There was variation in implementation of ACP between participating organisations.

The good news is that it is possible to implement ACP in routine primary care. The implementation efforts lead to a higher number of conversations on care preferences between older people and their GP. In the review by Glaudemans *et al*,⁸ the prevalence of conversations in GP practices ranged from 21% of PCPs having ACP discussions with the general elderly population to 69% having ACP discussions with terminal patients and 81% with patients with mild to moderate Alzheimer's disease. Compared with the percentages related to specific patient groups, the percentage of 26% is rather modest. However, in our study all patients aged 75 years or older were included. In older populations, the prevalence of advance directives and/or ACP is generally lower; we found rates between 3.2% for people aged 65 years or older in primary care in Australia, 12.6% for people aged 90 years or older who came to UK hospitals with a medical emergency, and 10% for Dutch people aged 61 years

or older.^{12–14} In a meta-analysis on interventions targeting advance directive completion in primary care, completion rates in the intervention groups ranged from 1% to 70%, with 10 studies showing rates lower than 25% and 8 studies showing higher rates than 25%.¹⁵

However, the intervention appeared to have limited success in encouraging people to discuss preferences with other healthcare professionals and others (such as family). Also, the topics of ACP were highly medicalised, with a high rise in mechanical ventilation and artificial hydration or nutrition being discussed after implementation (compared with before). Topics like nursing home admission and preferred place of death were less likely to be discussed. This was probably due to the form that PCPs received as part of the implementation toolkit, which prominently featured medical topics and interventions. This form was an adaptation of the forms used in the precursor of this project which mainly involved people in the care home. However, the population in care homes show more signs of frailty and are in lesser health than patients in the community. In line with comments we received from participating PCPs, we thoroughly revised the form. The current version starts with questions on what is important to the patient, relation with family and living situation. This is also in line with the suggestion by Combes *et al* that ACP should be reframed as something that promotes living well now as well as planning for the future, since this relates more readily to older people's daily lives.¹⁶

GPs make a selection in people they have conversations with. From the ACP-Monitor it became clear that people who were older, female, and had at least one diagnosis were offered or had a conversation more often. This selection makes sense in view of readiness to engage in ACP.^{17 18} Research has shown that the most common reason people give for not discussing end-of-life preferences is not that they feel uncomfortable about it, but that death is something far into the future.^{13 19 20} From the questionnaires it was seen that people who already had an ACP conversation before implementation and indicated at the pre-measurement that the GP knew their preferences were also more likely to have an ACP conversation after implementation. This is in line with ACP as a process instead of a single conversation, and it may also be seen as a time-efficient way to spend limited GP time; to (first) start a conversation with those in your GP practice who seem open to ACP or have already had past experience with ACP. However, a point of attention may be to encourage GPs to engage 'less likely' people as well since 60% of their patients are open to ACP. We are about to implement a community-based intervention to promote

end-of-life preparation and discussion among older people by organising presentations by healthcare professionals. We hope this will raise awareness and stimulate attendees to talk to family and their GP about their preferences, as has happened in another community intervention.¹⁹

Strengths and limitations of this study

This was a pragmatic implementation study, and participating organisations were self-selected and motivated to implement ACP. ACP is a complex intervention, and results of the implementation process will be ‘interwoven’ with characteristics of the participating organisations²¹ as was highlighted by the results of the multilevel analyses. Attention to practice-differences and ‘couleur locale’ will improve implementation.^{22 23}

The response rate made it possible to select patients who answered both the pre-implementation and post-implementation questionnaire, making our analyses more robust. It is likely that our results were biased: (1) selection bias because those who were less comfortable talking about future health problems may have been less likely to engage in ACP (as mentioned above in light of GP selection of patients), and (2) response bias as the same people may be less likely to complete the questionnaire.

CONCLUSION

Implementation of ACP is possible in everyday GP care. PCPs make a selection in people with whom they have a conversation. Although some aspects of selection such as attention to the readiness to engage in ACP may be good, a point of attention should be that ACP can be offered to every person and timely offers of ACP may stimulate people to engage more actively.

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Contributors BO-P and AvdP made the study design. AvdP did the analyses of data. BO-P and AvdP interpreted the results. AvdP drafted the manuscript, which was discussed with and critically revised by BO-P and JG. All authors read and approved the final manuscript.

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Patient consent for publication Not required.

Ethics approval The Medical Ethics Review Committee of VU University Medical Centre has judged that the Medical Research Involving Human Subjects Act (WMO) does not

apply to this study and that an official approval of the study by our committee is not required. The participants choosing to respond to the questionnaires implied their consent to participate in the study.

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Implementation of Advance Care Planning in Dutch primary care. a pre- post evaluation study.**Supplementary File 1****Table A.1. Non response analyses with regard to the questionnaires (based on data from the ACP-Monitor)**

	Total (n=2292)	Filled in no questionnaire or filled in questionnaire but not the ACP- questions (n=1375)	Filled in pre questionnaire only (n=363)	Filled in post questionnaire only (n=96)	Filled in both questionnaires (n=458)	p-value ^a
Age, mean (SD)	81.6 (5.3)	81.6 (5.9)	82.6 (5.5)	81.9 (5.2)	80.6 (4.8)	<0.000
Sex, female	1352 (59.0)	789 (57.4)	218 (60.1)	55 (57.3)	291 (63.5)	0.129
At least one diagnosis, yes	2056 (89.7)	1223 (89.0)	336 (92.6)	88 (91.7)	409 (89.3)	0.208
Setting of inclusion is general practice	2168 (94.6)	1289 (93.8)	340 (93.7)	95 (99.0)	444 (96.9)	0.011
Offer of ACP- conversation, yes	597 (26.1)	267 (19.4)	132 (36.4)	27 (28.1)	171 (37.3)	<0.000
If yes, then conversation with:						0.240
- Unknown (GP or nurse)	102 (17.1)	45 (16.9)	22 (16.7)	4 (14.8)	31 (18.1)	
- Nurse only	128 (21.4)	70 (26.2)	24 (18.2)	4 (14.8)	30 (17.5)	
- GP only	241 (40.4)	100 (37.5)	55 (41.7)	9 (33.3)	77 (45.0)	
- Both	126 (21.1)	52 (19.5)	31 (23.5)	10 (37.0)	33 (19.3)	

^a For the non response analyses we used ANOVA for age, and for sex, diagnosis and ACP conversation (whether there was a conversation and who the conversation was with) a chi-square test was used.

Implementation of Advance Care Planning in Dutch primary care. a pre- post evaluation study.**Supplementary File 2.****Table A.2. Characteristics of patients on the ACP-Monitor and comparison of characteristics of patients who got offered ACP according to the ACP-Monitor or not**

	All patients (n=2292)	No ACP offered (n=1695)	ACP offered (n=597)	OR (95% CI) ^a	OR (95% CI) Adjusted for organisation ^a
Age, mean (SD)	81.6 (5.6)	81.1 (5.2)	83.0 (6.5)	1.07 (1.05 – 1.09)	1.09 (1.07 – 1.11)
Sex, female	1353 (59.0)	973 (57.4)	380 (63.7)	1.30 (1.07 – 1.57)	1.28 (1.04 – 1.57)
At least one diagnosis, yes	2056 (89.7)	1490 (87.9%)	566 (94.8)	2.51 (1.70 – 3.71)	2.47 (1.63 – 3.74)
Setting of inclusion:				1.03 (0.68 – 1.55)	0.83 (0.25 – 2.80)
- General practice	2168 (94.6)	1604 (94.6)	564 (94.5)		
- Care home	124 (5.4)	91 (5.4)	33 (5.5)		
Conversation with:		Not applicable		Not applicable	Not applicable
- Unknown (GP or nurse)	102 (4.5)		102 (17.1)		
- Nurse only	128 (5.6)		128 (21.4)		
- GP only	241 (10.5)		241 (40.4)		
- Both	126 (5.5)		126 (21.1)		

^a Differences were analysed in unadjusted logistic analyses and logistic multilevel analyses (whether or not there was a ACP conversation registered on the Monitor was the outcome variable). We report the model with random intercept.

Implementation of Advance Care Planning in Dutch primary care. a pre- post evaluation study.**Supplementary File 3****Table A.3. Conversations on care preferences and Advance Directives before and after implementation of ACP**

	Pre measurement (n=458), n (%) ^a	Post measurement (n=458), n (%) ^a	OR (95% CI) Unadjusted (bivariate)	OR (95% CI) Adjusted for organisation; random intercept	Log likelihood test; chi2 (p-value) ^b
With regard to the following topics, have you thought about or spoken about care at the end of life?					
Hospitalisation in certain circumstances. Have you in the past 12 months...					
- Thought about it only (no further action)	136 (29.7)	118 (25.8)	0.82 (0.61 – 1.10)	0.82 (0.61 – 1.10)	1.41 (0.12)
- Spoken to GP about it	74 (16.2)	109 (23.0)	1.62 (1.17 – 2.25)	1.66 (1.18 – 2.32)	23.16 (<0.00)
- Spoken to other professional about it	22 (4.8)	27 (5.9)	1.24 (0.70 – 2.21)	1.24 (0.70 – 2.22)	0.57 (0.22)
- Spoken to someone else about it	158 (34.5)	131 (28.6)	0.76 (0.58 – 1.01)	0.76 (0.57 – 1.00)	5.23 (0.01)
- Written statement	76 (16.6)	122 (26.6)	1.83 (1.32 – 2.52)	1.84 (1.33 – 2.55)	6.84 (<0.00)
- None of the above	90 (19.7)	91 (19.9)	1.01 (0.73 – 1.40)	1.01 (0.73 – 1.41)	9.62 (<0.00)

IC admission. Have you in the past 12 months...					
- Thought about it only (no further action)	150 (32.8)	102 (22.3)	0.59 (0.44 – 0.79)	0.59 (0.44 – 0.79)	1.20 (0.14)
- Spoken to GP about it	40 (8.7)	75 (16.4)	2.05 (1.36 – 3.08)	2.12 (1.40 – 3.22)	25.13 (<0.00)
- Spoken to other professional about it	15 (3.3)	20 (4.4)	1.35 (0.68 – 2.67)	1.35 (0.68 – 2.67)	0.00
- Spoken to someone else about it	97 (21.2)	93 (20.3)	0.95 (0.69 – 1.31)	0.95 (0.68 – 1.31)	8.44 (<0.00)
- Written statement	52 (11.4)	89 (19.4)	1.88 (1.30 – 2.73)	1.89 (1.30 – 2.73)	0.42 (0.26)
- None of the above	149 (32.5)	161 (35.2)	1.12 (0.85 – 1.48)	1.12 (0.85 – 1.48)	0.42 (0.26)
Nursing home admission. Have you in the past 12 months...					
- Thought about it only (no further action)	153 (33.4)	127 (27.7)	0.76 (0.58 – 1.01)	0.76 (0.58 – 1.01)	0.35 (0.28)
- Spoken to GP about it	36 (7.9)	42 (9.2)	1.18 (0.74 – 1.88)	1.19 (0.74 – 1.90)	7.46 (<0.00)
- Spoken to other professional about it	4 (0.9)	16 (3.5)	4.11 (1.36 – 12.39)	4.11 (1.36 – 12.38)	0.00
- Spoken to someone else about it	145 (31.7)	123 (26.9)	0.79 (0.60 – 1.05)	0.79 (0.59 – 1.05)	5.92 (0.01)
- Written statement	37 (8.1)	47 (10.3)	1.30 (0.83 – 2.04)	1.30 (0.83 – 2.05)	0.91 (0.17)
- None of the above	127 (27.7)	164 (35.8)	1.45 (1.10 – 1.92)	1.45 (1.10 – 1.92)	0.00
Your preferred place of death. Have you in the past 12 months...					

- Thought about it only (no further action)	125 (27.3)	110 (24.0)	0.84 (0.63 – 1.13)	0.84 (0.63 – 1.13)	0.08 (0.39)
- Spoken to GP about it	25 (5.5)	37 (8.1)	1.52 (0.90 – 2.57)	1.54 (0.90 – 2.63)	11.50 (<0.00)
- Spoken to other professional about it	4 (0.9)	10 (2.2)	2.53 (0.79 – 8.14)	2.53 (0.79 – 8.14)	0.00
- Spoken to someone else about it	105 (22.9)	100 (21.8)	0.94 (0.69 – 1.28)	0.94 (0.69 – 1.28)	4.54 (0.02)
- Written statement	18 (3.9)	37 (8.1)	2.15 (1.20 – 3.83)	2.15 (1.20 – 3.84)	0.06 (0.40)
- None of the above	202 (44.1)	209 (45.6)	1.06 (0.82 – 1.38)	1.06 (0.82 – 1.38)	1.79 (0.09)
Treatment preferences in certain circumstances. Have you in the past 12 months...					
- Thought about it only (no further action)	136 (29.7)	98 (21.4)	0.64 (0.48 – 0.87)	0.64 (0.47 – 0.87)	3.49 (0.03)
- Spoken to GP about it	64 (14.0)	111 (24.2)	1.97 (1.40 – 2.77)	2.01 (1.42 – 2.84)	12.44 (<0.00)
- Spoken to other professional about it	20 (4.4)	35 (7.6)	1.81 (1.03 – 3.19)	1.81 (1.03 – 3.19)	0.00
- Spoken to someone else about it	135 (29.5)	123 (26.9)	0.88 (0.66 – 1.17)	0.88 (0.66 – 1.17)	4.57 (0.02)
- Written statement	74 (16.2)	107 (23.4)	1.58 (1.14 – 2.20)	1.58 (1.14 – 2.20)	0.01 (0.46)
- None of the above	108 (23.6)	108 (23.6)	1.00 (0.74 – 1.36)	1.00 (0.74 – 1.36)	0.19 (0.33)
Did you discuss the following interventions with your GP, before					

the intervention was necessary?					
- Resuscitation	95 (21.0)	152 (33.9)	1.92 (1.43 – 2.59)	1.96 (1.44 – 2.65)	11.01 (<0.00)
- Mechanical ventilation	20 (4.4)	50 (11.1)	2.71 (1.58 – 4.63)	2.72 (1.59 – 4.66)	2.60 (0.05)
- Artificial hydration or nutrition	13 (2.9)	47 (10.5)	3.95 (2.11 – 7.41)	3.97 (2.11 – 7.46)	0.69 (0.20)
- Heart-pacing machine	22 (4.9)	32 (7.1)	1.50 (0.86 – 2.62)	1.50 (0.86 – 2.64)	4.71 (0.02)
- Treatment with antibiotics	17 (3.8)	25 (5.6)	1.51 (0.80 – 2.83)	1.51 (0.80 – 2.83)	4.80 (0.01)
- Euthanasia	113 (25.0)	168 (37.4)	1.79 (1.35 – 2.39)	1.81 (1.36 – 2.41)	4.63 (0.02)
- other	28 (6.2)	41 (9.1)	1.52 (0.92 – 2.51)	1.52 (0.92 – 2.51)	0.00
- None of the above	263 (58.2)	198 (44.1)	0.57 (0.44 - 0.74)	0.56 (0.43 – 0.73)	14.88 (<0.00)
Advance Directive					
- Refusal of life sustaining treatment document	33 (7.3)	24 (5.5)	0.74 (0.43 – 1.28)	0.74 (0.43 – 1.28)	0.00
- Form from the GP ^c	24 (5.3)	76 (17.6)	3.79 (2.34 – 6.12)	3.88 (2.39 – 6.31)	7.29 (<0.00)
- Do not resuscitate orders	77 (17.1)	100 (23.1)	1.46 (1.05 – 2.03)	1.48 (1.05 – 2.07)	12.14 (<0.00)
- Advance euthanasia directive	110 (24.4)	120 (27.7)	1.19 (0.88 – 1.61)	1.19 (0.88 – 1.62)	9.63 (<0.00)
- Wish to live statement	15 (3.3)	25 (5.8)	1.78 (0.93 – 3.43)	1.78 (0.93 – 3.43)	0.00
- Other	11 (2.4)	12 (2.8)	1.14 (0.50 – 2.61)	1.14 (0.50 – 2.61)	0.36 (0.28)

- None of the above	281 (61.4)	233 (50.9)	1.53 (1.18 - 1.99)	1.54 (1.18 - 2.00)	1.64 (0.10)
Appointed a proxy, yes	129 (29.3)	169 (38.0)	1.48 (1.12 - 1.96)	1.48 (1.12 - 1.96)	0.00
If so, who?					
- Partner	21 (16.8)	36 (21.6)	1.78 (1.02 - 3.09)	1.78 (1.02 - 3.10)	0.09 (0.38)
- Son or daughter	76 (60.8)	92 (55.1)	1.26 (0.90 - 1.77)	1.27 (0.90 - 1.78)	7.38 (<0.00)
- Other family	16 (12.8)	21 (12.6)	1.33 (0.68 - 2.58)	1.34 (0.68 - 2.63)	12.20 (0.00)
- Other person(s)	12 (9.6)	18 (10.8)	1.52 (0.72 - 3.19)	1.52 (0.72 - 3.20)	0.06 (0.41)

^a Missing data: Idea future problems: pre 8, post 7; Preferred timing: pre 53, post 42; Reasons not to engage in ACP: missing answers were coded as 'no'; ACP topics: missing answers were coded as 'no'; Discussion of treatments with GP: pre 6, post 9; Advance Directive: pre 7, post 25; appointed proxy: pre 4, post 2.

^b test to determine which model best describes the data; the model without vs with random intercept

^c This form was provided as tool in the ACP implementation toolkit.