O01

Volunteer-led advance care planning advisory and education services: An evaluation of a new model for Australian service delivery

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Background: Research on utilising volunteers in advance care planning (ACP) is limited. Advance Care Planning Australia delivers initiatives to increase awareness and uptake of ACP among Australians. This study aimed to evaluate the reach and satisfaction with two unique volunteer-led ACP initiatives: a national advisory service and a community education program.

Methods: Volunteers were trained and mentored. Standard operating procedures and presentations guided service delivery, resulting in clearly documented program resources that can be used by other groups. Services were provided to consumers and health professionals. Follow-up measures included satisfaction with the advisory service and awareness, knowledge and confidence regarding ACP and the education program.

Results: During 1 January to 30 September 2018, the national advisory service received 1284 enquiries; 572 from health professionals, 712 from consumers. Fifty percent of calls were responded to by volunteers and 50% by health professionals. Sixty-two enquirers completed an evaluation survey, with 87% of those indicating that they were satisfied or extremely satisfied with the service.

During 30 May to 18 September 2018, volunteers delivered 15 presentations to 247 people. Of those, 149 attendees completed an evaluation survey. Prior to the session, 27% had never heard of ACP whereas 42% had. Post session, 76% of respondents indicated confidence to have ACP conversations with family and friends, 65% indicated confidence to talk to their healthcare professionals.

Conclusion: Volunteer-led models of service delivery can help meet organisational outcomes. Volunteers can deliver high rates of satisfaction and increase community confidence in having advance care planning conversations.

O02

SweACP: a structured conversation-based Advanced Care Planning approach in the ACP-naïve Swedish context

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Background: Sweden has no systematic advance care planning (ACP), nor judicial means of recognizing proxies in end-of-life (EoL) situations. In the SweACP project in the DöBra research program, we focus on engaging stakeholders in active conversations about preferences for future EoL care, rather than using a document-driven approach to ACP. We describe results of feasibility testing a structured conversation-based ACP approach among older adults in the general public as well as exploring their strategies for reasoning about their EoL preferences. **Methods:** After initial testing in pilot focus groups, a Swedish version of GoWish cards, DöBra cards, and Ecomapping were used to catalyze discussions on what and who matters at the EoL. The 65 participants from across Sweden actively contacted the researchers volunteering to participate, after receiving information through national patient-or retiree organizations. Both quantitative and qualitative data were analyzed, using descriptive statistics and inductive analysis.

Results: DöBra cards were positively received by participants; there was great individual variation in card prioritization and formulation of wild cards. Eco-mapping was met with less enthusiasm but was useful in depicting a social context often taken-for-granted. Qualitative analysis revealed several strategies for reasoning about future EoL care.

Conclusions: Having a hands-on tool rather than just talking, and wild cards to open up conversations on possibly taboo subjects were noted strengths of DöBra cards, which also influenced participants' reasoning by shifting focus from hypothetical scenarios to more specific situations. We found the cards to be a feasible tool for stimulating person-centered conversations on EoL preferences.

O03

Knowledge, attitude, and experience of advance care planning among healthcare professionals in Asia: a systematic review

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Background: Despite universal recognition of advance care planning's (ACP) importance, collectivism spirit in Asia may impact its uptake.

Aims

To gain insight into health care professionals' (HCP) knowledge of, attitude towards, and experience with ACP in Asia

Methods: We systematically searched four electronic databases for quantitative and qualitative studies on ACP in East and South East Asian countries. Anticipating unfamiliarity with ACP, we operationalized ACP broadly, covering discussions about future medical care and documentation thereof.

Results: Among 3,358 identified studies, 41 were eligible; 36 applied quantitative and 5 applied qualitative design. Most studies were conducted in high-income countries: Japan (16), South Korea (13), Singapore (4), Hong Kong (4),

and Taiwan (3). While twenty-nine studies addressed documentation of preferences, only six addressed ACP and end-of-life discussion respectively. Ten studies addressing knowledge indicated moderate awareness of ACP. Thirty studies on attitudes showed that although many HCPs considered ACP and involving patient and family in its process important, some found initiating ACP difficult. This hesitation was partly due to fear of conflicts with family members and the legal consequences. Twenty studies on experiences indicated that actual engagement of HCP in ACP is limited, too late, and mostly only involved family without patients.

Conclusion: Although being considered potentially important, ACP did not occur often. HCPs seem to be reluctant to engage in ACP. The role of family in ACP is crucial in Asia. However, evidence was highly heterogeneous and limited to a few high-income countries, which limits its generalizability to other Asian countries.

O04

The concept of ACP: perspectives of palliative care patients living in an urban area in Malaysia. Z.N. Lim

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Background: What are the perspectives of palliative care patients living in an urban area in Malaysia on advance care planning? Exploratory study to shape the concept of advance care planning according to local understanding and needs.

Methods: This is a qualitative study, using semi-structured interviews with a purposive sampling of fifteen participants. All interviews were conducted in participants' homes. Interviews were audio-taped, transcribed verbatim and analysed. Thematic analysis was done through coding, theoretical sampling and finally integrating it into a conceptual framework.

Results: All participants did not know what advance care planning was but was receptive to the idea of planning ahead. The main theme emerged from this exploratory qualitative study was individualised non-medical planning. This was shaped by factors such as participant's spirituality, prior health-related experiences, perceived psychosocial burden and information received on diagnosis, prognosis and availability of resources.

Conclusions: The concept of advance care planning is foreign to palliative care patients living in Malaysia. Advance care planning is not seen as just purely medical-decision planning but it is seen as an interplay between psychosocial and relational factors. Palliative care patients in Malaysia vary considerably with regards to the extent to which they wish to engage in advance care planning discussion, but at the same time, may face barriers from healthcare professionals with poor communication skills. Awareness and education on advance care planning for both healthcare professionals and palliative care patients will eventually lead to improvement in end-of-life care planning.

O05

A conversation card game motivates British Columbians to engage in advance care planning E. Hassan. D. Barwich. K. Kennedy

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Background: Advance care planning (ACP) is an important process that involves reflecting on, discussing and documenting one's values and preferences for future healthcare. A 2016 study in British Columbia (B.C.) showed that public engagement in ACP is low. The BC Centre for Palliative Care (BC-CPC) is leading a provincial initiative, in collaboration with various stakeholders, to promote early public engagement in ACP behaviours through innovative strategies. In 2016, BC-CPC partnered with 15 community-based organizations to assess the acceptability and effectiveness of a conversation card game in engaging the public in ACP conversations. Game questions are designed to stimulate conversations about issues relevant to decision making in the context of a serious illness

Methods: Participants were recruited by convenience sampling using community advertisements. During the game, participants take turns drawing cards, reading the questions on the cards aloud, and writing down their answers before sharing them with the group. Quantitative data was collected using a structured questionnaire to assess the participants' experience and motivation to engage in ACP.

Results: Over 12 months, 547 British Columbian adults participated in 44 game events hosted by community organizations from across B.C. After playing the game, the majority of participants (90%) planned to continue the conversation with family, and 75% agreed that the game made the conversations about the discussed topics safe and meaningful.

Conclusion: Our findings indicate that playing the conversation game in a community setting is a feasible and effective way to motivate British Columbian to engage in ACP.

O06

Primary care clinicians' confidence, willingness and participation in advance care planning discussions: a multi-site survey

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Background: People who engage in advance care planning (ACP) are more likely to receive healthcare that is concordant with their goals and wishes at the end of life. Primary care providers are ideally positioned to facilitate ACP. This study sought to describe the confidence, willingness and participation of primary care clinicians to have

advance care planning discussions.

Methods: We conducted a survey of family physicians and allied health professionals (AHP)in primary care in three Canadian provinces. We asked about willingness and confidence to have ACP discussions and current participation on Likert-type scales (0=not at all, 6=an extreme amount). A modified Dillman approach was used for online survey administration.

Results: The response rate was 72% (n=117) among physicians and 69% (n=62) among allied health professionals. Most physicians (77%) were practicing in an interprofessional practice. The mean willingness to initiate ACP was 5.0 for physicians and 4.8 for AHP. Mean confidence ratings for initiating ACP was 4.8 for physicians and 3.5 for AHP. Current participation in ACP among patients aged 50 years and older was lower; 2.6 for physicians and 1.4 for AHP.

Conclusions: The willingness of family physicians and AHP in primary care to initiate ACP discussions with patients is high. However, confidence is only moderate in AHP and actual activity is low for all clinicians. Efforts to remove barriers in primary care and provide support for AHP to improve their confidence to engage in ACP discussions should be priorities.

O07

Assessing Models of ACP in Primary Care, the Meta-LARC Trial: Part 1 Design and Realization of a US-Canada Study

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Background and aims: Advance care planning (ACP) has the potential to reduce suffering and improve outcomes in serious illness, but its implementation has been limited. A consortium of seven Practice Based Research Networks (PBRNs) in the US and Canada known as Meta-LARC designed a cluster randomized comparative effectiveness trial of two models of ACP in primary care practices.

Methods: Meta-LARC facilitated identification of primary care concerns and topics through collaboration among researchers, PBRN directors, clinicians and patient /family advisors. Over 2 months, we used the PBRNs to quickly assess interest, develop options, assess feasibility, refine ideas and obtain buy-in. Through this iterative process, we identified an existing ACP program to study (the Serious Illness Care Program by Ariadne Labs) and developed a proposal, research protocol and a stakeholder engagement plan.

Results: The trial, agreed to by all seven PBRNs, was funded by the Patient Centered Outcomes Research Institute and began in November 2017. This panel will discuss the key decision steps and drivers for the trial design (Part 1) and the accomplishments to date including engaging stakeholders (Part 2), adapting ACP training for teams (Part 3), obtaining ethics approval in two countries (Part 4), supporting ACP implementation in diverse primary care practices (Part 5) and developing patient-reported measures of goal concordant care (Part 6).

Conclusion: PBRN networks provide an important infrastructure that can facilitate design of a large, complex study of ACP with the potential to influence the spread of ACP in primary care practices in at least two countries.

008

Assessing Models of ACP in Primary Care, the Meta-LARC Trial: Part 2 Engaging Patient and Family Advisors in Research

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Background: Patient and family engagement is essential to community-based pragmatic research. After our study of advance care planning (ACP) in primary care was funded, we expanded the proposal and developed a detailed Engagement Plan (EP) to accompany the study protocol.

Methods: We established a cohort of 11 Patient and Family Advisors (PFA) to guide the project; seven associated with participating PBRNs and four unaffiliated or at-large PFAs (2 US; 2 Canadian). During project initiation, the joint coordinating center established a working committee to develop an EP using the PCORI template. We surveyed PFAs about goals, solicited feedback from PBRNs and engagement experts, distributed planning assignments, and shared drafts with stakeholders.

Results: The EP was developed based on a quality improvement approach in which monitoring, measuring and improving engagement is the focus. Monitoring engagement includes baseline assessment of needs, quarterly surveys and annual check-ins. Engagement measurement tracks stakeholder inputs and resulting impact on the project and establishes processes to support participant recruitment and retention. PFA-identified goals form QI targets and inform strategies to clarify expectations, forms of participation, and documenting and communicating the impact of PFA contributions. The EP will be updated twice annually.

Conclusion: Creating a formal EP allowed operationalization of our commitment to PFA engagement and integration into multiple aspects of the study. Making the plan a living document allows us to identify challenges, address issues, and document our experience. Approaching engagement as a component of trial design and execution facilitates development of best practices and science around engagement.

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O09

Assessing Models of ACP in Primary Care, the Meta-LARC Trial: Part 3 Theory-based Design of an Interprofessional Team Training

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Background and aims: Implementing advance care planning (ACP) in primary care practice has been challenging. An approach incorporating interprofessional (IP) team members has potential to facilitate ACP conversations though teams may lack ACP training. We adapted and pilot tested a program to train IP teams in ACP.

Methods: We developed an ACP conversation training program for primary care teams by adapting the Serious Illness Care Program by Ariadne Labs and incorporating the Interprofessional Approach to Shared Decision Making Model. The training materials were reviewed by eight health professionals and three patient and family advisors for acceptability and feasibility, then pilot tested with six interdisciplinary members of a primary care team. Reviewers' comments and post training interviews were analyzed using qualitative descriptive analysis methods.

Results: The training program consists of a 1.5 hour online module and a 1.5 hour in-person interactive session. Reviewers' comments included: both concerns about and support for non-physician team members discussing prognosis; questions about how to share the responsibility/time for conversations; and need for communication within teams and with patient/families. Post pilot training interviews also revealed barriers to ACP, and lack of clarity about how to share and communicate the conversations across team members. We modified the training and created scenarios showing various team-based approaches for ACP.

Conclusion: Initial assessment indicated the need to adapt ACP approaches for interprofessional team members. In the next step, we are testing the effectiveness of the modified IP ACP conversation training in primary care practices in the US and Canada.

010

Assessing Models of ACP in Primary Care, the Meta-LARC Trial: Part 4 Cross US-Canada Ethics Challenges and Experience

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Background: We designed a collaborative, US-Canadian study to increase generalizability and explicitly consider potential for spread across different systems. Addressing ethical requirements for multiple Institutional Review Boards (IRBs) and Research Ethics Boards (REBs) presents challenges when conducting one trial in two countries. **Methods:** Our trial includes 42 primary care practices from practice-based research networks (PBRNs) in 5 US states and 2 Canadian provinces. A centralized, single IRB process was used in the US with Clinical and Translational Science Award authorization to the PI for the 5 IRBs to rely on one unassociated IRB. In Canada ethics oversight required different approaches in each province. Ontario used a partially centralized and an institutional REB while Quebec used a fully centralized REB. Similar study protocols were submitted to all IRBs/REBs. The joint coordinating center harmonized research workflows and procedures to respond to a variety of concerns and requests.

Results: The number and nature of concerns requiring clarifications and modifications varied across the IRBs and REBs. The IRBs/REBs considered the trial to present different levels of risk and viewed the training, implementation and evaluation of ACP differently. There were differences regarding informed consent, survey language and data sharing. While the process and approvals took longer than expected and posed issues for consistency, addressing them facilitated development of a robust intervention and protocol.

Conclusion: Differences in research ethics perspectives and procedures could be significant barriers to US-Canada research. We demonstrated that variation could be addressed, knowledge-sharing strengthened the project protocol, and future collaborations are possible.

011

Assessing Models of ACP in Primary Care, the Meta-LARC Trial: Part 5: Planning and Supporting Implementation

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Background: Implementation of ACP is challenging, requiring a multi-pronged approach in primary care. We sought to provide a toolkit that would facilitate practices' adoption of the Serious Illness Care Program, as a means of improving the quality of care and engaging patients in serious illness care discussions and planning. **Methods:** The joint coordinating center established a working committee to compile implementation resources. We used an iterative approach to identify key issues, materials, and discussion points necessary to engage practices in

ACP implementation. We involved stakeholder groups representing patients, clinicians, practice facilitators, researchers, and informaticians. The group identified, adapted, and reached consensus on materials and approaches to facilitating ACP in primary care practices.

Results: We identified potential implementation barriers, including knowledge, attitudes, workflow, health information technology constraints, and sensitivity of the topic to engaging practices in ACP. We gathered materials to address

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these barriers including checklists, adaptable templates for dissemination and documentation, and developed a guide to facilitate conversations with practices. The key topics included practice readiness, patient identification, use of prognostic algorithms, workflow enhancement, effective documentation, and sustainability. We are using the TiDier checklist to monitor implementation fidelity to the ACP models in the trial.

Conclusion: We created a toolkit to support implementation of ACP in primary care practice that can be used by practice facilitators. It covers the major topics identified by stakeholders as essential for ACP implementation. We will evaluate and revise this, making an enhanced implementation guide available to the trial practices as well as to others.

012

Assessing Models of ACP in Primary Care, the Meta-LARC Trial: Part 6 Developing Patient-Reported **Measures of Goal Concordant Care**

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Background and Aims: Patient-reported goal concordance in serious illness care is an important primary outcome; however, no validated measure exists. As part of a trial of ACP, we sought to design and validate items for our trial that could form the basis for future measure development.

Methods: To draft items we reviewed the literature for validated measures in goal attainment, shared decisionmaking, and concordance. We engaged stakeholders, including patients, providers, and researchers, to discuss what goal concordant care means, developed draft items, and reviewed these in two focus groups with patient and family advisors as well as with research teams from other funded advance care planning and palliative care projects. **Results:** Our draft instrument consists of 3 parts representing different approaches. The first part asks the patient whether their current care supports what is important to them and if any care received was unwanted. The second part is derived from the Life Preference Scale developed by Ariadne Labs. This asks patients to report on whether health care supports what they identify as their three most important goals. The third part includes process measures based on the content of serious illness conversations and asks patients if each step or activity happened. Conclusion: It is possible to develop a patient-reported measure of goal concordant care that has face validity based on measures of related or similar constructs and the input of a range of stakeholders. Validation and ongoing refinement of the measure will be conducted in parallel with the trial.

Evaluating experiences of Advance Care Planning facilitators: results from the international ACTION study C.A. Christensen^{1,11}, M. Adsersen^{1,11}, A.T. Johnsen^{2,11}, J. Seymour³, F. Bulli⁴, B. Cerv⁵, L. Deliens⁶, A. Van der Heide⁷, I. Korfage⁷, U. Lunder⁵, K. Pollock⁸, N.J. Preston⁹, M.N. Verkissen⁶, M. Zwakman¹⁰, M. Groenvold^{1,11}

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Background: The ACTION trial evaluates the effect of the ACTION Respecting Choices (RC) advance care planning (ACP) intervention in patients with advanced cancer in six European countries. Systematic evaluations of such ACP conversations by facilitators are currently lacking. We developed and applied a 10-item facilitator-reported instrument

Methods: The instrument asked about the facilitator's perception of the patient's and the personal representative's (PR) reactions to and engagement with the intervention and satisfaction with the intervention.

Results: From March 2016 until February 2018, 272 conversations took place. Of these, 265 were evaluated. According to the facilitators, 32% of the patients did not appear to understand all guestions asked (29% understood most, 3% understood about half), and 36% were not able to answer all questions (31% answered most, 4% answered about half, 1% answered fewer). Furthermore, 38% of the patients and 27% of the PRs did not appear to perceive all questions as OK (patients: 33% perceived most as OK. 3% about half, 2% fewer: PR: 24% most, 3% about half). Facilitator perception of patient satisfaction, PR satisfaction and their own satisfaction with ACP conversations ranged 40-54% for 'very much', 41-49% for 'quite a bit' and 5-11% for 'a little'.

Conclusion: To our knowledge, this is the first clinical trial to systematically evaluate the feasibility of ACP conversations from the facilitator perspective. Parts of the ACP intervention appeared to be challenging for patients and PRs. These results, together with qualitative data, will help understand the outcomes of the ACTION trial. Funding: EU's FP7.

014

Effects of implementation of a standardised Palliative Care Pathway for patients with advanced cancer in a **Dutch hospital**

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Background Early integration of oncology and palliative care has been recommended as a major strategy to improve patient outcomes at the end of life. A standardised palliative care pathway(PCP) may be useful to support such integration. We studied whether implementation of a PCP had an effect on place of death, hospitalisations, and documentation of advance care planning.

Methods

In a single centre pre- and post-intervention study, data were collected for adult patients with cancer who had been treated at inpatient or outpatient clinics and died between February 2014 and February 2015 (pre-PCP period) or between November 2015 and November 2016 (post-PCP period).

Results: 852 patients were included, 426 in each study period. The PCP was used for 237 patients (56%) after implementation. The PCP was started 33 days (IQR 12-74days) before death. 76% and 77% of the patients died outside the hospital in the pre- and post-PCP period, respectively (p=0.57). No differences were found for hospitalisations in the last 3 months of life. In the pre-PCP period, bad-news conversations (75% and 62% respectively, p<0.001) and preferred place of death (47% and 32% respectively, p< 0.001) were documented more often, whereas a DNR code was more often documented during the post-PCP period (79% and 89% respectively, p<0.001).

Conclusions: A high percentage of patients died outside the hospital in both groups, not increased by implementation of the PCP. Start of a PCP in the last two months of life may be too late to facilitate ACP.

O15

Patients' Readiness for Advance Care Planning Conversations: a Qualitative Study as part of the ACTION Study

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Background: Patients and healthcare professionals describe patients' readiness for advance care planning (ACP) as an indicator for whether or not to start ACP conversations. Nevertheless, it is unclear how readiness manifests and develops throughout an ACP conversation. This study explores patients' readiness during an ACP conversation. **Methods:** A qualitative study using content analysis of structured ACP conversations between a trained facilitator, a patient with advanced colorectal or lung cancer and a relative. Conversations were conducted in the Netherlands as part of the international ACTION trial. Analysis was supported by NVivo 11.

Results: Transcripts of thirteen ACP conversations were included. All patients expressed both signs of not being ready and being ready within one conversation. Signs of being ready included answering questions on a personal level or demonstrating a realistic understanding of one's disease. Signs of not being ready included limiting one's perspective to the here and now or indicating a preference not to talk about an ACP-related topic. Signs of not being ready were especially seen when future oriented topics such as 'complications' and 'hope' were discussed. Patients could more easily elaborate on less future orientated topics as 'good life' and 'earlier experiences with illness'. Despite signs of not being ready patients were able to continue the conversation.

Conclusion: Patients do not have to be ready for all elements of ACP to be able to participate in an ACP conversation. Healthcare professionals should be aware of patients' ability to alternate in readiness depending on the topic that is discussed.

016

Let's talk about death: Gender effects in cancer patient's preferences for end-of-life

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Background: Males receive more aggressive care near death. End-of-life (EOL) conversations can protect from aggressive care near death and support more consistent EOL care. Therefore, information about gender effects on engagement in and realization of EOL conversations are needed.

Methods: In a cross-sectional study 186 cancer patients from an university and rehab hospital were asked about their preferences for EOL discussions using a semi-structured interview, focusing on a) the importance of six different EOL issues (medical and nursing care, organizational, emotional, social and spiritual/religious aspects), b) the desired time point, c) mode of discussion initiation.

Results: The importance of EOL topics differ significantly by issue (p=.002, η 2=.02) and gender (p<.001, η 2=.11). Females want to speak more about nursing care, emotions, social and religious aspects. Males wish to avoid the engagement in EOL issues and conversations. They prefer to be addressed only about nursing and medical care, whereas females want to be addressed about all EOL topics. Independent of gender, the majority of patients prefer to talk rather late: When the disease is getting worse (58%) or at the end of their palliative therapy or self-sufficiency (27.5%).

Conclusion: Because of distinct gender differences for engagement in and realization of EOL conversations a gender sensitive approach is recommended. Independent of gender, the tendency of patients to talk late about EOL issues should be considered to reduce the risk of delayed or neglected EOL conversations. Therefore, a two-step

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approach of end-of-life conversations is suggested.

017

The Stability of Treatment Preferences among Patients with Advanced Cancer

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Background: Stability of patients' treatment preferences has important implications for advance care planning, among which its timing. We therefore examined the stability of preferences and its predictors of patients with advanced cancer.

Methods: In this cohort, 104 patients with metastatic cancer and an oncologist estimated life-expectancy of ≤ six months participated in interviews following clinical visits in which patients' recent scan results were discussed. Interviews were repeated in three monthly follow-ups. At baseline, patients' age, education, sex, race, marital status, insurance status, and type of cancer were documented. At each assessment, patients reported their treatment preferences (i.e. trade-offs of life-prolonging versus comfort care), quality of life, and illness understanding.

Results: At baseline (n=104), 55 (53%) patients preferred life-prolonging care, 49 (47%) preferred comfort care.

Patients were followed for one (n=104), two (n=74), or three months (n=44). Between baseline and month I, 84 patients (81%) had stable treatment preferences. During follow-up, preferences of 71 patients (68%) remained stable (equally divided between a consistent preference for life-prolonging and comfort care). Treatment preferences of 33 (32%) patients changed at least once during follow-up. Patients' preferences at baseline strongly predicted preferences at month I (OR=17.8; CI=6.7-47.3; p<.001). Patient characteristics, quality of life, and illness understanding at baseline were not significantly associated with stability of preferences at month I.

Conclusion: Two-thirds of patients with advanced cancer had stable preferences regarding life-prolonging versus comfort care. Changes of preferences were often unpredictable. Our findings suggest potential benefits of ongoing communication about preferences, including advance care planning.

O18

Communication issues and challenges of Advance Care Plan in Two African Hospitals.

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Advance care plans (ACP) for patients is an integral part of End of life care services but very challenging in most African clinical settings. Several factors mitigating against its successful implementation include the culture and communication skills. Discussion around death and dying in most African communities is a taboo and an awkward narratives for the majority of the clinicians with little or no skills to facilitate such discourse.

These challenges were explored among patients suffering from life-limiting illnesses in two Nigeria and South Africa hospitals by surveying the clinicians way of handling the issues and the patients and families attitudes towards ACP. **Methodology:** A retrospective evaluation of case notes of cancer patients attending FMCAbeokuta, Nigeria were surveyed. A prospective second phase of the study using a questionnaire tool was administered on patients attending both the FMCA and Victoria Hospital Wynberg, Cape Town, South Africa services to explore their experiences and discussion around the ACP.

Results and Lessons learnt: The FMCA survey revealed none of the reviewed case notes recorded ACP discussion with the patients and if actually done were never documented. The prospective studies further confirmed initiating advance care plan discussion is a big challenge and more daunting process in both African settings. The cultural and incompetent communication skills should be addressed with good public sensitisation and advocacy and also need to empower the clinicians. Mandatory policy that integrates ACP into our routine 'informed consent' for all our clinical activities maybe another good option to initiate such discussion with the patients.

O19

Content analysis of Advance Directives completed by patients as part of Advance Care Planning: insights gained from the ACTION trial

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Background: Writing an Advance Directive (AD) is often seen as a part of Advance Care Planning (ACP). ADs may include specific preferences regarding future care and treatment and information that provides a context for

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healthcare professionals and relatives in case they have to make decisions for the patient. The aim of this study was to get insight into the content of ADs as completed by patients with advanced cancer who participated in ACP conversations.

Methods: A content analysis and descriptive statistics were conducted to describe the content of the completed My Preferences forms, an AD used in the intervention arm of the ACTION trial, testing the effectiveness of the ACTION Respecting Choices ACP intervention.

Results: In total, 33% of 439 patients who received the ACTION RC ACP intervention completed a My Preferences form. Document completion varied per country: 9.6% (United Kingdom), 21% (Denmark), 27.6% (Belgium), 43.8% (the Netherlands), 61.3% (Italy) and 64.3% (Slovenia). Content analysis showed that 'maintaining normal life' and 'experiencing meaningful relationships' were important for patients to live well. Fears and worries mainly concerned disease progression, pain or becoming dependent. Patients hoped for prolongation of life and to be looked after by healthcare professionals. Most patients preferred to be resuscitated and 44% of the patients expressed maximizing comfort as their goal of future care. Most patients preferred 'home' as final place of care.

Conclusions: My Preferences forms provide some insights into patients' perspectives and preferences. However, understanding the reasoning behind preferences requires conversations with patients.

O20

Doctors' perspectives on adhering to advance care directives when making medical decisions for patients with chronic disease:an Australian interview study

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Background: Advance care planning (ACP) assists people to identify their goals, values and treatment preferences for future care. Ideally documentation in an advance care directive (ACD) occurs. ACDs are used when treatment plans are developed for non-competent patients. Limited studies have explored perspectives of doctors regarding adherence to ACDs during medical decision-making for patients.

Aim: To describe the perspectives and attitudes of doctors on adhering to ACDs.

Methods: Doctors were recruited using convenience sampling. Face-to-face semi-structured interviews were conducted, audiotaped, transcribed and analysed using thematic analysis.

Interviews explored 3 case scenarios; doctors were asked to provide treatment plans. They were then given a values-based, followed by a treatment-based ACD. Prompting was used to understand how (if at all) the ACD influences treatment, and reasoning for decisions.

Results: 21 doctors; median: 10 years experience; were included. Interviews lasted 10-60 minutes. Most doctors reported experience with ACP and ACDs. 3 major themes were identified: aligning with patient preferences (alleviating burden of decision-making, returning to baseline health, clarifying with others), questioning validity (distrusting patients' decision-making ability, navigating unrealistic goals, reaching ceiling of care) and navigating decisional conflict (prioritising best interest of the patient and overcoming family opposition).

Conclusion: ACDs provide doctors with opportunities to align patient preferences with treatment; however, doctors sometimes question the validity of ACDs and experience decisional conflict when attempting to adhere to ACDs in practice, especially when family members oppose the plan. These results will assist development of clinical education programs, and resources supporting completion of more specific ACDs.

O21

Prevalence of Advance Care Planning documentation and self-reported uptake in oncology patients: findings from a national Australian survey

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Background: Absence of data on Advanced Care Directive (ACD) completion makes evaluation of Advance Care Planning (ACP) implementation challenging. This study reports the prevalence, accessibility and characteristics of ACDs for people with cancer aged ³ 65 years from Australian hospital, primary care and aged care facilities. **Methods:** Prospective cross-jurisdictional study consisting of health record audit and self-report survey. **Result:** 51 sites and 2285 participants were included; 458 of whom had cancer. Of these, 27% had an ACD located in their record; 3% statutory stated preferences for care, 10% appointed substitute decision-maker, and 19% were non-statutory document. Most (83%) treatment plans were consistent with ACD preferences. More participants with cancer were receiving palliative care (11%) compared to the overall sample (4%). 97 participants with cancer completed the survey, 58% reported they had completed ACP documentation; 30% indicated trusting their children to make medical decisions; 26% trusted their partners, and 19% their doctors.

Conclusion(s): This study is the first to examine ACP documentation prevalence in an Australian cancer population, at the point of care, and across jurisdictions. Whilst 27% of participants had an ACD located during the audit, more people self-reported having completed ACP documentation, which is encouraging as documentation available at point of care is likely to influence care. Only a low percentage of people were recorded as receiving palliative care. Recommendations to improve ACP uptake include: workforce education, care pathway inclusive of ACP and accessibility should be supported by national systems such as "My Health Record".

022

Consideration and Impact of Advance Directives on Therapeutic Decisions in Ten Intensive Care Units in German Speaking Switzerland

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Background: Since 2013 advance directives (AD) are binding in Switzerland. Regularly ICU doctors complain that they are not helpful for making therapeutic choices. But there is no data how often intensive care staff ask for advance directives at all and whether this represents the experience of the majority of intensive care doctors and nurses.

Methods: We performed a survey in 10 Intensive Care Units (ICUs) from the German speaking part of Switzerland. The survey was sent either electronically or in paper format to 1041 professionals. Analysis was descriptive. **Results:** 355 (34% response rate) professionals completed the questions concerning advance directives. Of the respondents 82% were nurses, 18% were ICU specialists or residents working in ICU. The majority of the staff asks always (33%) or regularly (50%) whether their patients have an AD. 6% of the doctors and 3% of the nurses say that an AD is always helpful for treatment decisions, while 29% of the doctors and 33% of the nurses judge it as usually helpful. 60% of doctors and 53% of nurses rated them as sometimes helpful for making therapeutic choices, while 4% of doctors and 11% of nurses estimated ADs did not or hardly ever assisted them.

Conclusions: In our survey, 83% of participants stated that they usually ask their patient or their relatives whether an AD exists. In contrast to the impressions from public media and personal conversations the majority of the respondents indicated that ADs are at least sometimes helpful for therapeutic decisions.

O23

Perceptions of Reasons for Discordance between Current Preferences and Existing Documentation: A Qualitative Study

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Background: Nursing homes throughout the United States use the Physician Orders for Life-Sustaining Treatment (POLST) form to document resident treatment preferences as medical orders. Reasons for discordance between POLST orders and current preferences were explored in the context of a larger study of POLST discordance. **Methods:** Nursing facility residents (n = 25) and surrogate decision-makers (n = 25) were interviewed using Respecting Choices Advanced Steps, a structured, advance care planning facilitation process, to elicit current values-based, informed preferences. Interviews were recorded, transcribed, and coded using qualitative descriptive methods

Results: Reasons for discordance between current preferences and POLST orders included changes in preferences related to new experiences, observations of other residents, new insights, a re-evaluation of goals and values, or a change in condition. Several participants indicated that discordance occurred because they learned new information or developed a better understanding about the treatment options during the interview. A few reported that the decisions recorded on POLST were influenced by others, though this was infrequent. Other participants were unable to explain the discordance because they did not recall the original conversation, or had no insight. Facility process issues including documentation errors and being asked to make decisions hastily during admission to the nursing facility also contributed to discordance.

Discussion: Reasons for discordance are varied, but suggest a need for increased education, more frequent reevaluation of treatment preferences, and improved practices in order to ensure nursing home documentation is concordant with the current, values-based informed preferences of residents. "

O24

Usage of Do-not-attempt-to resuscitate-orders in a Swedish community hospital - patient involvement, documentation and compliance

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Background: The purpose of the study was to characterize patients dying in a community hospital with or without attempting cardiopulmonary resuscitation (CPR) and to describe patient involvement in, documentation of, and compliance with decisions on resuscitation (Do not attempt to resuscitate orders; DNAR). Material and methods

All patients who died in Kalmar County Hospital during January 1, 2016 until December 31, 2016 were included. All information from the patients' electronic chart was analyzed. Approved by the Regional Ethic review Board in Linköping, Sweden.

Results: Of 660 patients (mean age 77.7 \pm 12.1 years; range 21-101; median 79; 321 (48.6%) female), a DNAR order had been documented in 563 patients (85.3%). In 66 of 94 (70.2%) patients without DNAR, CPR was unsuccessfully attempted. 28 of 94 (29.8%) patients died without attempt at CPR and without a DNAR order in place. In 4 of 563 (0.7%) patients CPR was attempted despite a DNAR order in place. In 416 patients (73.9%) the DNAR order had not been discussed with neither patient nor family/friends. Moreover, in 84 cases (14.9%) neither patient nor family/friends were even informed about the decision on code status.

Conclusions: In general, a large percentage of patients in our study had a DNAR order in place (85.3%). However, 28 patients (4.2%) died without CPR attempt or DNAR order and DNAR orders had not been discussed with the patient/surrogate in almost three fourths of the patients. Further work has to be done to implement ethical CPR guidelines to insure patient autonomy.

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O25

A Randomized Trial of a 'Goals of Care' Decision Support Intervention (PlanWell™) in Primary Care in Alberta, Canada

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Background: We aimed to determine the efficacy of a recently developed decision support intervention, PlanWell™, which was designed to improve the quality of Goals of Care Determinations (GCD) in primary care settings

Methods: We conducted a multicenter randomized trial of patients considered by the primary care doctor to require establishment or review of GCD. Enrolled patients were randomized to receive the study intervention by a trained facilitator or usual care. Outcomes included preferences for life-sustaining treatments, a modified decisional conflict score (DCS), and the proportion of patients who with completed GCD form 8-12 weeks post intervention. Physician ratings of DCS and amount of time spent with patient obtaining GCD were also compared.

Preliminary Results: 123 were consented and randomized, 115 completed the trial. Of enrolled patients, 52% were male and the average age was 74 years. Post intervention, fewer intervention patients preferred CPR and ICU care (15 % vs. 30%, p=0.25). Patients in the intervention group were better informed (p=0.03) and feeling more support from the physician (p=0.03). The completion rate of GCD forms was similar in both groups (96.7% intervention vs. 94.0% usual care, p=0.71). Physicians considered intervention patients to be better informed (p=0.07) and to have a clear sense of their values (p=0.04) and spent less time with them (9.7 vs 13.0 mins, p<0.001) compared to usual care patients.

Conclusions: The PlanWell™ intervention seems to help clarify values, better inform patients and may reduce preference for resuscitation, while reducing the physician's time to accomplish GCD decisions.

O26

Effects of a Late Life Supportive Care Innovation that Focuses on What Matters Most

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Background: Whole person care is a new paradigm for serious illness beyond disease specific practice guidelines and lacks robust evaluation. The purpose of this presentation is to describe the effects of LifeCourse(LC), a personcentered program for patients living with serious illness, utilization of healthcare, care experience and quality of life. **Methods:** This quasi-experimental intervention study with a Usual Care (UC) comparison group was conducted between 2012-2017. Enrolled patients (N=903) were estimated to be within 3 years of end of life and diagnosed with 1+ serious illness. Community health workers (CHWs) delivered standardized monthly 1-hour home visits based on palliative care guidelines to assist patients in identifying self-defined goals, support ongoing person-centered advance care planning, and promote physical, psychosocial and financial wellbeing. Primary outcomes included healthcare utilization measured by electronic health records and patient and caregiver-reported experience and quality of life measured every 3 months.

Results: Patients were elderly (LC 74, UC 78 years) and primarily non-Hispanic, white, living at home, and had a cardiovascular primary diagnosis (LC 69%, UC 57%). A higher proportion of LC patients completed advance directives during the study (N=173, 38%) than did UC patients (N=66, 15%; p<0.001). LC patients who died spent more days in hospice (88±191 days) compared to UC patients (44±71 days; p=0.018). LC patients reported greater improvements than UC in communication as part of the care experience (p=0.016).

Conclusions: The implementation of person-centered programs delivered by CHWs is feasible. Inexpensive upstream expansion of palliative care models can yield benefits for patients and caregivers.

O27

Implementation of the Serious Illness Care Program in the hospital setting: emerging results of a multi-site quality improvement collaborative.

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Background: Seriously ill, hospitalized patients often receive treatment that is not aligned with their values and goals. The Serious Illness Care Program (SICP) is a multi-faceted health system intervention aimed at enabling more person-centered conversations about goals-of-care (GoC) with patients who have serious, life-limiting illness. **Methods:** We conducted a multi-site quality improvement study to adapt and implement the SICP on the medical wards of 3 Canadian hospitals. Our primary outcome measure was the change in patient or family member responses to the validated question: "Over the past 2 days, how much have you felt heard and understood?" (1=not at all; 5=completely) before versus after a conversation about GoC with a clinician trained in the use of the Serious Illness Conversation Guide (SICG). At one site, we also examined health resource use before and after implementation.

Results: With phased implementation across sites, we trained 57 clinicians in use of the SICG, delivered conversations using the SICG to 205 patients (mean age 76 years), or their family members. Of these

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conversations, 139 were documented in the electronic medical record. After these guided conversations, participants felt more heard and understood (increase of 0.4 ± 1.1 points; P=0.005). Compared to historical controls, conversations using the SICG were associated with a reduction in length of stay as an acute care patient (5 vs. 19 days. P=0.001).

Conclusion: The SICP was associated with improvement in patients' and family members' perception of being heard and understood by their healthcare team and a reduction in health resource use.

O28

How do Dutch primary care providers overcome barriers to advance care planning with older people? A qualitative study

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Background: Few older people benefit from advance care planning (ACP), due to several barriers related to primary care professionals, such as insufficient knowledge, negative beliefs and a lack of time. Information on overcoming these barriers is limited. We assumed primary care professionals experienced in ACP with older patients are likely to have learned how to overcome these barriers. Therefore we investigated how primary care professionals, experienced in ACP with older patients, overcome these barriers.

Methods: A qualitative study, based on semi-structured interviews, among a purposive sample of 14 Dutch primary care professionals experienced in ACP with older people. Transcripts were thematically analysed.

Results: We interviewed eight general practitioners (GPs), three nurses and three elderly care physicians, experienced in ACP with older people. Respondents overcame their own insufficient knowledge and skills, as well as their negative attitudes and beliefs by gaining experience through practicing ACP in their daily practices, exchanging and reflecting on those experiences with peers, pursuing continuing education, teaching and participating in research. To overcome patients' and families' lack of initiative and openness to ACP, respondents prepared them for further steps in ACP. To overcome a lack of time, respondents used tools and information communication technology, delegated parts of ACP to other primary care professionals, acquired financing and systematized documentation of ACP.

Conclusions: Primary care professionals can overcome barriers to ACP with older patients by practicing, reflecting on experiences and pursuing continuing education, by preparing patients and involving family and by investing in support to approach ACP more efficiently.

O29

'While my thinking is clear': Outcomes from a feasibility pilot of a multidisciplinary, step-wise pathway for ACP in Family Medicine

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Background: Advance care planning (ACP) and goals of care (GCD) discussions with patients align with the tenets of patient-centred shared decision-making central to family medicine (FM). We sought to determine whether a multidisciplinary pathway is feasible in family medicine to enable effective ACP conversations. This pathway reorders Ariadne Lab's Serious Illness Conversation Guide (SICG) with a values clarification tool in a step-wise approach to ACP.

Methods: Mixed-methods feasibility pilot study of pathway implementation in an urban FM clinic in Alberta, Canada. We recruited community-dwelling patients age 60 or older with indications of frailty (multi-morbidity, unplanned hospitalizations), and their surrogate decision-maker (SDM). An allied health professional initiated the ACP pathway, which preceded an appointment with the family physician (FP) to complete the SICG discussion. We conducted a survey of patients and SDMs, and a focus group with clinicians to evaluate feasibility, acceptability and perceived impact.

Results: Nine patients, seven SDMs, and four clinicians participated in the pilot. All patients and SDMs rated the process as "very good" or "excellent". Eight patients and two SDMs reflected that discussing and documenting their preferences helped them feel more prepared for future illness, and that involving SDMs was essential. Clinicians found the pathway and SICG improved their skills and empowered them to facilitate these conversations more effectively.

Conclusions: This pathway that adapts use of the SICG was acceptable and effective for all participants. The pathway fits well into FM as the trusting relationship between the patient and FP provides the foundation for these meaningful conversations.

O30

Scoping Review about Web-based Advance Care Planning Programs

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Background: Advance Care Planning (ACP) enables persons to define goals and preferences for future medical treatments and care, to discuss, record and review these. Potentially, web-based programs can support patients in

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ACP. However, an overview of their effectiveness and feasibility is lacking.

Methods: To provide an overview of the content, feasibility and effectiveness of web-based, interactive and patient-centered ACP programs, we systematically searched in 7 databases. We extracted data using the EAPC consensus concept of ACP as our framework.

Results: The search identified 3434 records; 21 studies were included. Three additional studies were identified by hand search. The 24 studies evaluated 11 web-based ACP programs, developed in the USA (10) and Ireland (1). Most programs addressed exploration of goals, values and preferences, and ACP communication. Users considered programs as easy to use (7/7 studies) and not burdensome (7/8 studies). Users were satisfied with the programs (10/10 studies). ACP communication (11/11 studies) and ACP documentation (14/16 studies) increased. Two studies evaluated concordance between preferred and provided care. Designs of 10 studies allowed comparison before/after completing ACP programs or between study groups.

Conclusion(s): Most web-based ACP programs contain the important elements of ACP. Studies reported that programs tended to be effective and feasible. Evaluations of concordance between preferred and provided care are scarce. Web-based programs have potential to support patients, and scale up ACP. However, since many studies did not assess differences before/after or between groups, outcomes should be interpreted with caution.

Funding: The Netherlands Organisation for Health Research and Development (ZonMw).

O31

Developing and improving a web-based tool for clients in long-term care: a user-centred design <u>C. van Leersu</u>¹, A. Moser, B. van Steenkiste, E. Stoffers, M. Reinartz, J. Wolf, T. van der Weijden *Maastricht University, Maastricht, Netherlands*

Background: The decision-making process for clients in need of long-term care is challenging and clients need to make choices about the care they prefer. A tool to assist the clients and caregivers with the decision-making and elicitation on preferences could be beneficial. The aim is to investigate user-requirements of a tool for the decision-making.

Methods: We applied a user-centred design to develop this tool. This was an interactive process of collecting data with end-users and improving the prototypes. The end-users included clients, relatives, and caregivers. Four end-users participated in a development team and 22 end-users were interviewed individually. We collected data during three phases of iteration: look and feel, navigation, and content. We analysed the data using thematic analysis and adjusted the prototype after each phase.

Results: The lay-out was approved by all participants during the look and feel phase, but there was a need for different/neutral pictures. During the navigation phase, participants experienced easy navigation, but text-blocks had to be shortened. Considering the content, participants missed questions about well-being/happiness. After the third phase, the tool was finalized.

Conclusion:The user-centred design was necessary to move from the prototypes to the finalized tool fitting usability-requirements of end-users. The tool 'What matters to me' (http://www.watikbelangrijkvind.nl) is currently in the feasibility-testing phase.

O32

Using Twitter to Explore Advance Care Planning Among Brain Tumor Stakeholders

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Background: Advance care planning (ACP) often occurs too late in the disease course of patients affected by brain tumors. Furthermore, the perspectives of brain tumor stakeholders on ACP are not well described. This study uses a social media tweet chat to understand perspectives on ACP among brain tumor stakeholders.

Methods: This qualitative descriptive study analyzed a tweet chat (real-time virtual group discussion on the social media platform Twitter) of brain tumor stakeholders. The 1-hour tweet chat was organized by the patient-run Twitter community referred to with the hashtag #BTSM, which stands for Brain Tumor Social Media. Participants reflected on four questions about ACP by including #BTSM in tweets. Unique tweets and stakeholder type (i.e. patient, caregiver, advocate or organization member, clinical provider and researcher, leader) were categorized. The tweet chat transcript was analyzed to identify key themes.

Results: Fifty-two participants from four countries contributed 336 unique Tweets. Most participants were patients, clinical providers or researchers, and advocates or organizations. There were four key themes regarding brain tumor stakeholder perspectives about ACP: 1) cultural barriers prevent discussions of death; 2) ensuring one's voice is heard; 3) Goldilocks' approach to timing – fearing ACP is too early or too late; and 4) crowdsourcing ACP resources. **Conclusions:** A multi-national group of brain tumor stakeholders engaged in ACP discussions via a social media tweet chat and highlighted important challenges and opportunities. Social media is a new avenue in which clinicians and patients may engage with to better understand each other's perspectives related to ACP.

O33

Nationwide Multicenter Evaluation to Determine Whether Patient Video Testimonials Can Safely Help Ensure Appropriate Critical Versus End-of-Life Care

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Background: End-of-life interventions should be predicated on consensus understanding of patient wishes. Written documents are not always understood; adding a video testimonial/message (VM) might improve clarity. Study goals were to (1) determine baseline rates of consensus in assigning code status and resuscitation decisions in critically ill scenarios and (2) determine whether adding a VM increased consensus.

Methods: We randomly assigned 2 web-based survey links to 1366 faculty and resident physicians at institutions with graduate medical education programs in emergency medicine, family practice, and internal medicine. Each survey asked for code status interpretation of stand-alone Physician Orders for Life-Sustaining Treatment (POLST) and living will (LW) documents in 9 scenarios. Respondents assigned code status and resuscitation decisions to each scenario. For 1 of 2 surveys, a VM was included to help clarify patient wishes.

Results: Response rate was 54%, and most were male emergency physicians who lacked formal advanced planning, document interpretation training. Consensus was not achievable for stand-alone POLST or LW documents (68%–78%noted "DNR"). Two of 9 scenarios attained consensus for code status (97%–98% responses) and treatment decisions (96%–99%). Adding a VM significantly changed code status responses by 9% to 62% ($P \le 0.026$) in 7 of 9 scenarios with 4 achieving consensus. Resuscitation responses changed by 7% to 57%($P \le 0.005$) with 4 of 9 achieving consensus with VMs.

Conclusions: For most scenarios, consensus was not attained for code status and resuscitation decisions with stand-alone LW and POLST documents. Adding VMs produced significant impacts toward achieving interpretive consensus.

O34

Finding What Matters: Using Natural Language Processing to Identify Patient Care Preferences within Clinical Notes

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Background: Delivering care that is consistent with patient preferences is considered the outcome of successful advance care planning interventions. However, patient preferences are often difficult to ascertain within clinical notes, and thus difficult to extract and utilize in clinical or evaluative settings. The objective of this study is to show the efficiency and accuracy of two natural language processing (NLP) methods in identifying documentation within the free-text of clinical notes.

Methods: Rule-based and machine learning NLP methods were developed and trained on a dataset of 449 clinical notes derived from Multi Parameter Intelligent Monitoring of Intensive Care (MIMIC) III database. Human annotators identified instances of code status limitation and patient care preference documentation in a second validation dataset of 192 clinical notes. We then assessed the performance of the rule-based and machine learning NLP mathods in identifying code status limitation and patient care preference documentation in the validation dataset. **Results:** Machine learning NLP identified documentation with a sensitivity ranging from 85.1-98.3% and a specificity ranging from 91.0%-97.0%. Performance of rule-based NLP was comparable, identifying documentation of code status limitation with a sensitivity of 98.3% and a specificity of 97.7% and patient care preferences with a sensitivity of 81.5% and a specificity of 83.0%.

Conclusions: NLP methods are reliable tools for identifying information related to patient care preferences within clinical notes. Machine learning NLP may be better suited to identify documentation of conversations that vary in the way they are recorded, such as conversations related to goals of care.

O35

A national framework for anticipation in health care: the Swiss proposal

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Background: Anticipatory planning including advance care planning has become one of the megatrends in health care. As in many countries, terminology and understanding of anticipatory planning varies significantly. Aim: for a common understanding of anticipation and guidance in clinical practice, we aimed to develop a national framework for anticipation in health care in Switzerland.

Method: we undertook a national consensus project with representatives from all cultural regions in Switzerland. After review of the literature and existing guidelines and/ or recommendations we performed a three Delphi process including additional national expert review.

Results: we propose a three level model of anticipatory planning in health care. Level one aims to initiate general anticipatory planning including discussion on individual values, preferences and expectations; experts from various professional background (e.g. pastoral care, social care, psychology) may offer support on this level. Level two focuses on disease specific anticipatory care planning; expertise in regard of potential complication of specific diagnosis/ disease trajectory is necessary to provide assistance while planning. Level three finally is dedicated to advance care planning (ACP) for clinical situations without capacity for judgement; guidance by professionals with a background in intensive and emergency care may be needed.

Conclusions: a national consensus process on definitions of various levels for a participatory approach in anticipatory planning helps to create a solid basis for common understanding of anticipation in health care, to highlight professional roles and expertise for counselling on each level, and to prevent low quality in written documentation.

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O36

Prevalence of advance care directives among older Australians accessing health and residential aged care services: multi-centre audit study

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Background: Advance care planning (ACP) is a priority in Australian health policy, legislation and accreditation standards. ACP supports people to consider and communicate their future treatment preferences and document them in an advance care directive (ACD). However, the availability of ACDs at the point of care amongst Australians is unknown. The aim of this study was to describe the prevalence of ACDs in those aged ≥65 years accessing general practice (GP), hospitals and residential aged care facilities (RACF).

Methods: A prospective multi-centre health record audit. Literature review informed the methodology. Auditors received education and jurisdictional-specific audit manuals. Recruitment of organisations was via expression of interest. The primary outcome was presence of an ACD.

Results: Fifty-one sites participated (13 GPs, 12 hospitals, 26 RACFs), representing six jurisdictions. 2,285 health records were audited; 503 attending GPs, 574 in hospitals, and 1,208 in RACFs. 30% of people had at least one ACD. Most (21%) were non-statutory documents. The prevalence of statutory ACD-preferences for care was 3%; the prevalence of statutory ACD-substitute decision-maker was 11%. ACD prevalence in GP was low (3%) compared to hospitals (16%) and RACFs (48%).

Conclusions: Approximately 30% of older Australians had at least one ACD in their health record, and the majority of these were non-statutory ACDs. Priorities to increase accessibility of documentation may include improved policy, promotion of ACD uptake amongst older persons, storage within health record systems, workforce education and training, information resources, and ongoing prevalence monitoring. These initiatives are required across all sectors, especially GP.

O37

The Alberta ACCEPT Study: The impact of a system-wide advance care policy on communication, care planning and documentation

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Background: The ACCEPT survey (Audit of Communication, CarE Planning, and DocumenTation) evaluates the quality of Advance Care Planning (ACP) practice through patient-reported experience measures and ACP documentation audit. We evaluated practice three years post system-wide policy for ACP implementation and patient awareness of their "Goals of Care Designation" (GCD) medical order.

Method: Consecutive, consenting patients over 55 years with serious, chronic illness or age >80 years with any acute admission were prospectively enrolled from acute medical units in seven hospitals across Alberta, Canada. Research assistants administered the ACCEPT survey within 5 days of admission and reviewed participant charts for ACP and GCD documentation.

Results: Of 502 patients (mean age 81 years, 53% female) 93% had a GCD order in their chart but only 30% were aware of this. 33% reported having discussed none of the five key elements of goals of care conversations (patients' values and beliefs, prognosis, patients' fears and concerns, treatment preferences and prior ACP documentation or conversations) with a hospital clinician. Raw agreement between patients' expressed preferences for EOL care and documentation in patient charts was 56% (concordance kappa=0.273). Multivariate regression analysis found that awareness of GCD order was associated with health region, patient frailty, quality of goals of care conversations in hospital and whether ACP conversations were considered important to the patient.

Conclusions: Despite a system-wide policy, we found evidence of serious concerns about the quality of ACP and GCD practice. Intentional quality improvement interventions are likely needed to enhance practice and achieve patient-centred care.

038

With which patients do primary care providers start ACP conversations and does this lead to an increase in advance directives?

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Background: To improve uptake of ACP, primary care providers (PCP; general practitioners (GPs), community nurses, certified nursing assistants, practice nurses) were trained in ACP and received support during implementation.

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Methods: ACP was implemented in 10 GP-practices and 2 care homes. Before implementation a list was drawn up of all patients of 75 years or older in the GP practice or care home on 01-01-2017. On this list, PCP made a note of patients with whom they started a ACP conversation until 14 months after start of implementation. Also, questionnaires were sent to the patients before and 14 months after start of implementation. Now we present interim analyses, at the conference the final data will be available.

Results: A total of 2292 older patients were enrolled with the GP practices or living in the nursing homes. Of those, 596 (26%) received an offer of ACP and/or had an ACP conversation. The conversation was started more often with older patients (mean age 81 versus 83 years); female patients (57% versus 64%), and patients with at least one diagnosis (88% versus 95%). Questionnaires show an increase in advance directives (31.1% versus 41.0%) after implementation, compared to before implementation.

Conclusions: With a quarter of older patients an ACP conversation was started (ACP was offered and/or an ACP conversation was held). Advance directives are drawn up more often after implementation of ACP. Care providers make a selection in patients with whom they start the conversation.

O39

Evaluation of the Living Matters ACP training course for health professionals through a multi-centre study E.J. Koh¹, C.C. Yu¹, J.A. Low¹, R. Ng²

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Background: The Living Matters ACP course trains healthcare professionals in Singapore to engage patients and families in ACP conversations. The assumption is that with more effective training, the knowledge, skills, attitude and confidence of participants in undertaking ACP conversations will improve.

Methods: This mixed method study recruited a total of 223 healthcare professionals who attended the one-day course over a span of 1 year. Quantitative data were collected using pre and post-course questionnaires (immediate and 6-months) in domains on knowledge, skills, attitude, satisfaction, confidence and practice of the participants. Qualitative data from participants is currently being collected (3 to 12 months post-course) to determine their opinions and experiences on the training course and effects on practice.

Results: Preliminary findings from the quantitative data suggest the course was efficacious in advancing participants' knowledge and self-reported skills and confidence. This was shown by the significant and practically large changes in matched *t* test scores. Conversely, the course may have limited impact on attitudes since similar tests did not show changes of such magnitude and were largely trivial. Views suggest ACP conversations can be improved through means to enhance the emotional resilience of ACP facilitators and also means to navigate shared decision making and conflict resolution.

Conclusion: Coupled with the qualitative data, current findings from this study can guide changes to the current ACP training in Singapore to make it more relevant and effective for healthcare providers.

O40

Advance care planning in medical training in the Netherlands

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Our abstract is for a themed session and describes the workshop we want to give. In this workshop we will highlight the need to integrate ACP in the education of medical students and offer some examples of how to do this. Firstly, Judith Westen provides an introduction on the training needs of medical students and the current place of palliative care and ACP in the Dutch medical curricula. Then, Roeline Pasman discusses the outline of a minor on palliative care. She will illustrate the basic ingredients of the minor and show how ACP is integrated in the minor. Thirdly, in small groups, the participants of the workshop will experience different work forms that can be used to stimulate awareness of the need for ACP and train patient – physician communication regarding ACP (e.g discussion of a movie, role play, discussion on different communication styles). Afterwards the participants discuss their experiences and share ideas on how to integrate ACP in local training and education.

Target audience: Educators, healthcare professionals, researchers, policy makers.

Content:

Introduction and background: palliative care and ACP in the curriculum of Dutch medical students

Example: Outline of a minor on palliative care

Interactive: working with training materials and role play **Group discussion:** take home messages of participants

O41

Advance care planning and palliative care for homeless people in medical respite shelters: a retrospective record review

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Background: To improve advance care planning and palliative care for severely ill homeless people, insight into current practice is required. Therefore, the present study aims to describe the characteristics of people who deceased after having been homeless, the care preferred and received at the end of life, and difficulties in medical

decision-making at medical respite shelters.

Methods: We conducted a quantitative and qualitative retrospective record review at two Dutch medical respite shelters. Included were the medical and nursing records of 61 homeless clients who were known to be deceased between 2009 and 2016 and had resided in one of both shelters for at least one night in the three months before death.

Results: The large majority of patients had a combination of somatic (98%), psychiatric (85%) and substance use problems (93%). Discussions about imminent death were reported for 75% of the patients for whom it was recognized. Twenty-six percent of records provided information about patients' preferred place of death, which mostly was the shelter. For 36% of patients, hospital admissions had been considered undesirable by their clinician(s). In the three months before death, 75% of patients had at least one such admission. Documented difficulties in medical decision-making mainly concerned impaired decisional capacity of patients, language barriers, and fragmentation and discontinuity of care.

Conclusion:At the end of life, homeless people suffer from multiple health-related problems that require specific expertise. They experience multiple, often undesired hospital admissions. This could be avoided by more comprehensive collaboration between psychosocial, medical, and palliative care.

042

Confronting versus Comfortable: two approaches to the recruitment of people with learning disability in an Advance Care Planning study

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Background: Supporting people with learning disability to complete Advance Care Plans is relatively new and there is a lot to learn. This presentation discusses the recruitment processes and outcomes of two New Zealand based studies on this topic. The learnings from this may help us to increase the uptake of Advance Care Planning with people who have learning disabilities.

Methods: Both studies are qualitative action research projects, both attempted to recruit 10 people with learning disability. A key difference is that the initial study recruited participants who were dying (and aware of that), while the current study recruited participants who were well. Recruitment data from both projects was analysed thematically to identify commonalities and differences in processes and outcomes.

Results: Recruitment for the initial study was difficult, resulting in four participants. In contrast, recruitment for the current study was over-subscribed. Removing the need for participants to have a life-limiting condition contributed to this. In part this was because disability service staff, who sought expressions of interest for the study, were more comfortable to talking about Advance Care Planning within a pro-active context.

Conclusion: Pro-active approaches to Advance Care Planning appear to be less confronting and more comfortable for disability staff. Taking a pro-active approach could increase uptake of Advance Care Planning for people with learning disability, who are clear that it is their right to plan for the end of their lives.

O43

The Application of SDM Regarding People with Intellectual Disabilities as part of the ACP process: a Scoping Review.

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Background: Shared decision making (SDM) is the process in which the professional caregiver and patient (or the representative) both provide input and jointly discuss and decide which treatment policy will be followed. SDM is seen as an important component of the ACP process. Little is known about SDM in people with intellectual disabilities (ID).

Aims: To provide an overview of the application of SDM in people with ID in the palliative care phase.

Methods: In this scoping review, we systematically searched in the Embase, Medline and PsychINFO databases for studies that evaluated the SDM process in people with ID in the palliative phase.

Results: Of 402 titles and abstracts, 14 full studies were included. 10 were empirical studies, 3 were opinion papers and 1 was a legal report. Papers show an increasing focus on the importance of involvement of people with ID themselves, or - if applicable - their loved ones, in making medical decisions around the end of their lives. None of the papers described SDM in the palliative care phase, and no best practices, guidelines or definitions were shown for SDM in the palliative care phase.

Conclusion:This study shows that there is no consensus-based model about what SDM regarding people with an ID should look like. General recommendations indicate that we should involve people with an ID more in the decision-making process by providing them an appropriate environment full of support.

044

'Like pearls on a string': Developing a pediatric advance care planning intervention with a step-by-step modular design

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Background: Advance care planning concepts for adults are not directly applicable to the pediatric setting. Aim of

the study was to develop a specific pediatric advance care planning (pACP) intervention using a participatory approach.

Methods: Bereaved parents and healthcare professionals selected by purposeful sampling participated in two transdisciplinary workshops. In the first workshop, discussion groups identified key elements of pACP. In the second, participants organized the key elements and visualized the pACP process on a timeline. Results were systematized, translated into a modular program, and sent back to participants for validation.

Results: The structured intervention organizes pACP elements in a modular design. First steps include 1) *Preparation:* building up trustful relationships; 2) *Opening discussions*: framing the process, making participants' expectations and aims explicit.

The next modules can be arranged in accordance with participants' priorities: 3) Focusing on the child: quality of life, wishes and hopes; 4) Medical topics: emergency situations and disease-specific crises discussed in hypothetical scenarios; 5) End of life issues: optional.

Final steps: 6) Concluding discussions: validation of written documents (e.g. parental advance directives), discussion on their implementation; 7) Implementation: informing all relevant stakeholders.

Timing (initiation, appropriate intervals, actualization), *communication*, *documentation* (emergency and care plans, advance directives, discussion protocols), and *age-appropriate participation of children and adolescents* are transversal aspects pertaining to the whole process.

Conclusion: The developed pACP program exhibits a modular design ensuring a structured step-by-step approach as well as a personalized process aimed at meeting the highly individual needs of the child and the family.

045

Pediatricians' experiences and attitudes regarding Advance Care Planning

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Background: Advance Care Planning (ACP) enables individuals together with their relatives and health care professionals to discover, discuss and document their values, preferences and goals for care.

Objective: To evaluate the involvement of pediatricians taking care of children with life-limiting conditions in ACP. **Methods:** All pediatricians from six Dutch pediatric hospitals completed a survey about experiences with ACP in their most recent case of a deceased child.

Results: Of the 207 participating pediatricians (response 36%), 168 completed the questionnaire (81%), of which 86% described a case. Of these children, 53% died before the age of 5 years. ACP conversations always took place with parents, mostly about diagnosis, life expectancy, goals of care, fears and worries and code status. In 23%, ACP conversations occurred with children (age: range 2.2-17.3 years, median 11.5 years), discussing mostly joy of life, hope, diagnosis and fears and worries. 94% of pediatricians were satisfied with their conversations skills. The occurrence rate of ACP conversations was indicated as insufficient by 49%. Pediatricians stated in 60% that ACP conversations have to result in a documented code status. 37% said ACP conversations intend mainly to provide information to families. Reported barriers to ACP conversations were mostly parent-related, while facilitators concerned continuity of care and a multidisciplinary approach.

Conclusion: Pediatricians reported to have ACP conversations mainly with parents with a focus on medical issues. Insight in the perspective of the child is limited. Education on the holistic approach of ACP and on involvement of children in ACP is needed.

O46

Talking about life and death - using films in intercultural palliative care

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Background: The number of first generation migrants needing care in the final phase of life is growing. However, they make little use of care facilities and support, while they do need it. Care providers feel insufficiently capable to provide good care to this group.

Method: Based on research by Roukayya Oueslati (LUMC, publication pending) the Pharos short films 'Conversations about life and death' show situations from the last phase of life of a patient with a migration background and their immediate family members. The films are available in four languages at https://www.eventure-online.com/eventure/www.pharos.nl/ingesprek

The films show multiple perspectives and therefore every family member, including the patient can identify. Watching the films in a migrant gathering or information meeting, in a family setting, or possibly together with a care provider, provides a good opening for a conversation about the needs, fears, and wishes of a patient. The films can be viewed as a whole, or in fragments (of just a few minutes), e.g. the fragment about disclosure or about pain relief. **Results:** We see that the films are conversation starters for both migrants and care providers. People are informed about supportive care and realize they can make choices.

Conclusions: Pharos wants these films to be seen by many more people and 'spreads the word'. We would love to show the films at the congress, provide translation in English on the spot, and discuss their usefulness with the public.

047

Experiences, knowledge and attitudes of informal caregivers regarding Advance Care Planning. A systematic review and meta synthesis of qualitative studies

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Background: Advance Care Planning (ACP) is a communication process about a person's preferences for treatment and care in case of physical or mental deterioration, when the person is unable to express these wishes. Trained health professionals act as facilitators and relatives may be involved. The aim of our review is to explore the experiences and attitudes of informal caregivers, and their knowledge regarding ACP.

Methods: A systematic literature search was conducted (participants: informal caregivers, intervention: advance care planning; databases: MEDLINE, PsycINFO, CINAHL, Cochrane Library). Eligible studies were assessed by two independent reviewers. Quality appraisal was conducted using the Critical Appraisal Skills Programme (CASP) checklists. Thematic synthesis was applied for qualitative studies. Results from quantitative studies were associated to the meta categories of the thematic synthesis.

Results: 41 studies met the inclusion criteria, of which 37 qualitative studies were included in the thematic synthesis. Major themes found were: "ACP-structures", "Roles and Relationships", "Perceptions of ACP", "Caregivers' Knowledge", "Attitudes". Barriers to and facilitators for ACP from the viewpoint of caregivers were described following the structure of the major themes. The importance of caregivers' role perceptions and the mutual influence of ACP and family relationships were highlighted.

Conclusion: It is widely accepted, that ACP interventions have to take caregivers' points of view into account. Our review provides a rich description of caregivers' experiences, knowledge, attitudes, and needs regarding ACP. The results will support the development of patient- and family-centred ACP interventions and of instruments that measure effects of these interventions in caregivers.

O48

Planning ahead with healthcare: proxies' needs and experts' recommendations to support advance care planning in Switzerland

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Background: When there is no advance care planning (ACP), relatives feel uncomfortable and ambivalent when deciding on behalf of someone who has lost decision-making capacity. The aim of this study was to understand proxies' needs and gather experts' views on how to improve ACP in Switzerland.

Methods: We conducted 20 interviews with proxies and four with experts in the three linguistic regions of Switzerland.

Results: Half of the proxies were not familiar with ACP and spoke about living wills, testaments, and financial and organizational challenges of daily care. Only four people had the opportunity to advance decisions about healthcare with their kin when s/he was diagnosed with a neurocognitive disease. Most interviewees became proxies by the circumstances and did not discuss their role further with the patient or other relatives. For most people, ACP was made difficult by caregivers not being explicit about disease progression and potential complications and proxies' role in future decision-making. When patients were very sick but still competent, professionals tended to exclude proxies albeit decisions had huge impact not only on the patient but also on their families. Communication and coordination with professionals and money are major concerns for most interviewees, in particular parents of disabled children. Experts' views are consistent with interviewees' experiences.

Conclusions: Recommendations to improve ACP in Switzerland include increasing awareness in both professionals and the public, improving communication and coordination between professionals, patients and their proxies, better supporting relatives in their most urgent needs, and broaching ACP when discussing ongoing care plans.

O49

Wellbeing of family carers of people who died of cancer: preliminary results of the ACTION Advanced Care Planning (ACP) trial

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Background: Previous studies showed that family carers (FCs) who engaged in formal ACP had fewer adverse outcomes in wellbeing compared with FCs who did not. The ACTION trial is the first multicentre randomized

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controlled trial of ACP in six European countries. This study will report on the effect of ACP on the wellbeing of bereaved FCs.

Methods: 451 questionnaires were sent to bereaved FCs 3 months after the patient participating in the trial had died; 163 were returned (response rate: 36.1%; N control= 93, N intervention= 70). Wellbeing was measured with the Hospital Anxiety and Depression Scale (HADS) and Impact Event Scale (IES).

Results: No significant differences were found in wellbeing of FCs between groups. The mean scores for the HADS show no significant differences between groups for anxiety (mean score control 7,09 vs. mean score intervention 8,29) and depression (mean score control 6,72 vs. mean score intervention 7,17). No significant differences are found between groups in the mean scores for the IES. Intrusion had a mean score of 21,27 for control vs. 21,38 for intervention; Avoidance had a mean score of 10,34 for control vs. 12,72 for intervention.

Conclusion: Despite previous evidence about improved outcomes for wellbeing in FCs in ACP programs, our ACP intervention did not show differences between groups. Possibly the non-response or cultural discrepancies between the different countries have a part in this. More research is needed to explain what mechanisms are present. *This study is supported by a grant from the FWO (nr. G034717N)*

O50

Influencing factors on engagement in Advance Care Planning (ACP) from the caregiver's perspective S.Herzog, M. Koch, C. Seifart

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Background: One important aspect of successful ACP is the engagement of caregivers during the process. However, sometimes the engagement of patients and their caregivers in ACP is known to be difficult. Therefore barriers and facilitators of participation in ACP from the caregiver's point of view are explored.

Methods: 12 relatives (caregivers) of palliative-oncologic patients were questioned in guideline-based interviews. 5 caregivers were children and 7 were spouses of patients. The analysis was conducted by Qualitative Content Analysis by Ma Recruiting patients

yring. Two code trees were built: one posing a two-dimensional axis system made of plus and minus poles, the other one operating in the shape of clusters ("clouds") considering overlappings and connections of the six main themes ("stardust model").

Results: Six result clusters were evaluated influencing the willingness of both patients and caregivers.

- 1) Skills Of ACP-Initiators (general and social expectations on the initiator and conductor of ACP-intervention)
- 2) "Omnipresent Electivity" (setting of daily-life impulses for ACP bearing a non-binding nature)
- 3) Importance of Relationship Between Spouses (understanding of symmetrical needs)
- 4) Relative Differences Of Perception Of Children And Spouses of patients
- 5) Maintenance of Objective Necessities (non-emotional structural circumstances such as resources of time, finances and legal responsibilities)

All empowering relatives to be 6) A Participative Caregiver (including experiences and desired role in ACP setting) **Conclusions:** Acknowledging the importance of caregivers and their essential role in ACP further interventions should consider incorporating these factors to improve the implementation of such.

O5'

Experiences with and outcomes of Advance Care Planning in bereaved relatives of frail older patients: a mixed methods study

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Background: Advance Care Planning (ACP) may prepare relatives of frail older patients for future decision-making. **Objective:** To investigate (1) how bereaved relatives of frail older patients experience ACP conversations and (2) whether ACP has an effect on relatives' preparation for decision-making and on their levels of anxiety and depression.

Design: Cluster randomised controlled trial.

Setting: Residential care homes in the Netherlands.

Subjects: Bereaved relatives of care home residents and community-dwelling frail older patients.

Methods: We randomised 16 residential care homes to either the intervention group, where participants (frail older patients) were offered facilitated ACP, or the control group (n=201), where they received 'care as usual'. If participants died, we approached relatives for an interview. We asked relatives who had attended ACP conversations for their experience with ACP (open-ended questions). Furthermore, we compared relatives' preparation levels for decision-making and levels of anxiety and depression (HADS) between groups. This trial was registered (NTR4454).

Results: We conducted interviews with 39/51 (76%) bereaved relatives (intervention group: n=20, control group: n=19). Relatives appreciated the ACP conversations. A few considered ACP redundant since they were already aware of the patient's preferences. Nine of 10 relatives in the intervention group felt adequately prepared for decision-making as compared to five of 11 relatives in the control group (p=.03). Relatives' levels of anxiety and depression did not differ significantly between groups.

Conclusions: In our study, bereaved relatives of frail older patients appreciated ACP. ACP positively affected preparedness for decision-making. It did not significantly affect levels of anxiety or depression.

To what extent do online resources meet the needs of substitute decision-makers in Australia? Part 2

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Background: We aimed to examine Australians' knowledge, attitudes and experiences regarding the role of substitute decision-makers (SDMs). SDMs may also be known as 'surrogate' or 'proxy' decision-makers. **Methods:** A national survey was distributed via an online panel in September 2018 to 1,484 adults aged 18 years and over. Quotas on age, gender and jurisdiction (based on 2017 Australian Census data) aimed to maximise representativeness.

Results: Of the 1,058 survey completers (response rate=71.3%), the majority (67%) did not know there were laws about substitute decision-making and 12% had previously made medical decisions on behalf of someone else. Seventy-four percent of those with SDM experience (n=97) agreed that making medical decisions on someone's behalf can be a difficult and stressful experience compared to 56% of those without SDM experience (n=589). Moreover, only 38% of those without SDM experience indicated they would feel confident in the role of SDM. When asked their preferred source for receiving SDM information, 59% of all respondents ranked health professional as their first preference, followed by discussion with family or friends (23%), traditional media (7%), new media (6%) or an event (3%). Only 16% indicated that appointing a SDM was a priority at the time of completing the survey. **Conclusion(s):** Among a representative sample of Australians it was relatively common to have acted in the role of SDM and most who had perceived the role as challenging. Further education and support is needed to clarify roles, relevance and benefits in appointing and preparing SDMs.

053

A systematic review of economic evaluations of Advance Care Planning: data limitations and ethical considerations

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Background: Evidence regarding the degree and direction of economic impacts of implementing Advance Care Planning (ACP) is inconsistent. Also, available reviews have not systematically assessed the quality of the costing data in the primary studies. We aimed to synthesize current evidence on the economic impacts of implementing ACP and explore implications for policy and practice.

Methods: We conducted a comprehensive search of online bibliographic databases. Reference lists of included articles were also reviewed. We assessed the quality of costing in studies using the Consensus on Health Economics Criteria Checklist (CHEC).

Results: We included 33 studies; the majority were from the USA (78.8 %). Studies were conducted in various settings, mostly hospitals (60%). Almost 64% of studies reported cost savings from the healthcare systems' perspectives; no study included patients' perspectives (out-of-pocket-costs). Assessing quality of costing using CHEC revealed weaknesses in studies including: flaws with costs identification (37.9%), measurement (39.3%), and valuation (44.8%); no consideration of intervention costs (87.9%); not including all relevant variables in sensitivity analyses (34.5%); and not discounting the costs (55.6%).

Discussion: We detected substantial methodological issues with current economic evaluations of ACP that compromise the validity of evidence. To inform policy makers about ACP, which is a multifaceted process, methodologically robust studies are needed that capture costs of the program from all major payers. A comprehensive report on cost evaluations is highly recommended. Meanwhile, respecting patient choice remains a valid clinical basis for promoting use of ACP.

O54

Delivering system-wide advance care planning support in real-world settings: economic considerations. An exploratory, qualitative study in twelve international healthcare organisations <u>J. Dixon</u>, M. Knapp

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Background: Facilitation of ACP conversations is time consuming, whether undertaken in one or multiple shorter discussions. Our exploratory, qualitative study in twelve healthcare systems (US, Canada, New Zealand, Australia) providing system-wide ACP support explored:

- -organizational rationales for provision, including perspectives on the economic case
- -type and organization of staffing
- -ways of providing high-quality, system-wide support cost-efficiently.

Methods: Interviews with leaders, ACP specialists, physicians, nurses, social workers and others (average n=13) were conducted in twelve purposively-sampled healthcare systems. Data were transcribed and thematically analysed using NVivo software.

Results: System-wide ACP support was primarily a strategic response to risks associated with increased availability and use of life-prolonging interventions in serious illness and frailty. Overall cost-savings were not expected. Staffing ACP support was challenging. While professionals often needed more protected time, promising approaches included team-based provision, especially physicians working with nurses and social workers, and

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systematic incorporation into chronic and routine care.

Skilled and experienced staff underpinned cost-effective provision. While dedicated facilitators were not scalable or sustainable, some level of specialism and voluntarism, with plentiful opportunities to develop skills in practice, was indicated

ACP support was provided equally efficiently by experienced staff regardless of guides or approach used. Serious illness conversations could build on earlier ACP support. Community- and group-based approaches were thought cost-efficient, increasing reach and supporting later planning and decision-making.

Conclusions: Investments in ACP support were justified by management of organizational risk and high-quality patient care. Our findings identify areas where cost-efficiencies in provision of system-wide ACP support may be found

O55

Evaluating costs of Advance Care Planning; results from the international ACTION study

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Background: Systematic evaluation of health care use and costs is important to identify the impact of advance care planning (ACP) programs. Such evaluations are currently scarce in Europe.

Methods: Our study was performed in the context of the ACTION trial, a randomized controlled study to evaluate effects of the ACTION Respecting Choices (RC) ACP intervention in patients with advanced cancer in six European countries. We applied a healthcare perspective and identified hospital care use from hospital medical records for 1 year after study inclusion. Unit prices were calculated for all six countries separately. The unit price of the 'Respecting Choices' ACP intervention was determined with the micro-costing method, which is based on detailed assessments of all resources used.

Results: Most intervention patients had one ACP conversation, one third had two. The average length was 90 minutes (standard deviation 45 minutes). Unit costs were comparable between countries for most interventions, with the exception of cancer-specific treatment. Most patients received chemotherapy, with a minority receiving surgery. Preliminary analyses showed similar patterns of health care use in both ACP and control groups: numbers of diagnostic procedures such as scans and biopsies were comparable; mean (range) length of hospital stay was 9 days (0 - 63) and 8 days (0 - 75) in intervention and control patients, respectively.

Conclusion: Unit costs of health care interventions were remarkably comparable between countries. The ACTION RC ACP intervention, consisting of conversations by patiens, relatives, and facilitators, did not appear to affect hospital care use.

Funding: EU FP7.

O56

The cost-effectiveness of advance care planning for older adults with end-stage kidney disease.

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Background: We aimed to examine hospital costs and outcomes of a nurse-led ACP intervention compared with usual care in the last 12 months of life for older people with end-stage kidney disease (ESKD) managed with haemodialysis.

Methods: A case-control study of ACP in adults with ESKD from a major tertiary hospital and a simulation of the natural history of decedents on dialysis, using hospital data, to model the effect of ACP on end-of-life care preferences. Outcomes were assessed in terms of patients' end-of-life treatment preferences being met or not, and costs included all hospital-based care. The cost-effectiveness of ACP was assessed by calculating an incremental cost-effectiveness ratio (ICER), expressed in dollars per additional case of end-of-life preferences being met. Robustness of model results was tested through sensitivity analyses.

Results: The mean cost of ACP was AUD\$519 per patient. The mean hospital costs of care in last 12 months of life were \$100,579 for those who received ACP versus \$87,282 for those who did not. The proportion of patients in the model who received end-of-life care according to their preferences was higher in the ACP group compared with usual care (68% vs. 24%). The incremental cost per additional case of end-of-life preferences being met was \$28,421. The greatest influence on the cost-effectiveness of ACP was the probability of dying in hospital following dialysis withdrawal, and costs of acute care.

Conclusions: Our model suggests nurse-led ACP leads to receipt of patient preferences for end-of-life care, and may represent good value for money.

O57

Advance Care Planning for frail older adults: Findings on costs in a cluster randomised controlled trial A. Overbeek¹, S. Polinder¹, J. Haagsma¹, P. Billekens², K. De Nooijer¹, B. Hammes³, D. Muliaditan¹, A. van der Heide¹, J. Rietjens¹, I. Korfage¹,

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Background: Advance Care Planning aims at improving alignment of care with patients' preferences. This may

affect costs of medical care.

Aim: To determine the costs of an Advance Care Planning programme and its effects on the costs of medical care and on concordance of care with patients' preferences.

Design/settings/participants: In a cluster randomised trial, 16 residential care homes were randomly allocated to the intervention group, where frail, older participants were offered facilitated Advance Care Planning conversations or to the control group. We calculated variable costs of Advance Care Planning per participant including personnel and travel costs of facilitators. Furthermore, we assessed participants' healthcare use during 12 months applying a broad perspective (including medical care, inpatient days in residential care homes, home care) and calculated costs of care per participant. Finally, we investigated whether treatment goals were in accordance with preferences. Analyses were conducted for 97 participants per group. Trial registration number: NTR4454.

Results: Average variable Advance Care Planning costs were €76 per participant. The average costs of medical care were not significantly different between the intervention and control group (€2360 vs €2235, respectively, p=0.36). Costs of inpatient days in residential care homes (€41,551 vs €46,533) and of home care (€14,091 vs €17,361) were not significantly different either. Concordance of care with preferences could not be assessed since treatment goals were often not recorded.

Conclusions:The costs of an Advance Care Planning programme were limited. Advance Care Planning did not significantly affect the costs of medical care for frail older adults.

O58

New US advance care planning billing codes - Who's using it and for whom?

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Background: In the US, new reimbursement for advance care planning (ACP) started on January 1, 2016. This study aims to describe patient and practitioner characteristics related to use of the new billing codes, including documentation of the ACP process and advance directives.

Methods: Retrospective, cross-sectional analysis of the billing code 99497 from January 1, 2016 thru June 30, 2018 in outpatient visits in a large healthcare system. We describe patient-level and practitioner-level characteristics. We reviewed clinical documentation elements from a sample of patient visits from high- and low-utilizing practitioners. **Results:** Seventy-six practitioners used the ACP billing code in 3421 outpatient visits for 2884 patients. Patients were mean age 73 (range 20-104 years), 57% female, and 2% rural residing. 35% of patients had an advance directive on file. Mean number of billing encounters per practitioner was 45 (range 1–704). Visits occurred in primary care settings (family medicine, internal medicine, geriatric medicine) and two subspecialty clinics (neurology, cardiology). ACP was billed multiple times for 150 patients (5.2%), with a range of two to four visits. The average time between unique visits was 330 days. The most commonly documented topics were code status, POLST/MOST form, and surrogate decision maker. 28% of ACP documents on file were completed within seven days of the ACP billing visit.

Conclusions: This is the first study to describe use of ACP billing codes in outpatient settings. Practitioners are using the ACP billing code mostly in primary care settings, among older adults, and occasionally multiple times.

O59

Complex interventions guiding Advance Care Planning conversations: A Systematic Review J. Fahner¹, A. Beunders², J. van Delden¹, A. Van der Heide³, M. Vanderschuren¹, J. Rietjens³, M. Kars¹ **University Medical Center Utrecht, Utrecht, Netherlands **3Erasmus MC, Rotterdam, Netherlands

Background: Conversation guides support professionals to conduct ACP-conversations, yet insight in essential components is limited. This systematic review aims to evaluate the content, rationale and empirical evidence on the effect of ACP interventions based on conversation guides.

Methods: Medline, Embase, PsychINFO and CINAHL were searched from January 1, 1998 to February 23, 2018 to identify peer-reviewed articles describing or evaluating scripted ACP-conversation guides. A thematic analysis of the guides was performed. Data on intervention characteristics, underlying rationale and empirical evidence was extracted.

Results: Eighty-two articles reporting on thirty-four unique interventions met the inclusion criteria. Analysis of the conversation guides revealed a framework for ACP-conversations consisting of four phases: preparation, initiation, exploration and action. Exploration of patient's perspectives on illness, living well, end-of-life (EOL) issues and decision making formed the core part of the guides. Their design was often expert-based, without an underlying theoretical background. Empirical evidence on the effect of the interventions was based on heterogeneous outcome measures. Dyad congruence and preference documentation rates increased among intervention subjects in most studies. The studies showed varying effects on knowledge of ACP, decisional conflict, quality of communication and preferences-concordant care. Qualitative research showed that participants appreciate the importance and benefits of ACP-conversations, yet perceive them as difficult and emotional.

Conclusion: ACP-conversation guides address a diversity of themes regarding illness, EOL and decision making, with a focus on the exploration of patient's perspectives and preferences. Evidence on translation of explorative information into specific treatment preferences and consequences for care as provided is limited.

O60

Evaluation and further development of a Dutch question prompt list on palliative care from the perspective

of patients and family.

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Background: Patients and family often do not know what to expect of an advance care planning (ACP) consultation. Question prompt lists (QPL) help them to gain insight into and express their wishes and questions. We developed the 'Leiden Guide for Palliative care' (LGP), combining an adapted Edmonton Symptom Assessment Scale and a translated QPL on palliative care¹, to hand out before the ACP consultation with palliative care specialists. The goals of this study were to evaluate personal experiences of patients and family with the LGP, and to further develop the LGP.

Methods: In this qualitative study semi-structured interviews with six patients and seven family members were conducted. Manual coding and thematic analysis were done by two researchers.

Results: Three main themes for optimal use of the LGP were identified: 1. Prerequisites: early in disease trajectory; adequate introduction by the healthcare professional (HCP); positive first impression. 2. Benefits: provides complete overview of ACP topics and relevant questions; facilitates end of life discussions, also between family members. 3. Practical use: preferably the LGP is reviewed with family 1-2 days before the consultation. With detailed suggestions on content and format we constructed an improved LGP.

Conclusion: Patients and family consider the LGP as helpful and useful in preparation and during ACP consultations with palliative care specialists, provided that the prerequisites are met. The usefulness of the LGP in ACP discussions with generalist HCPs and in different settings is subject of further study.

Reference: 1 Clayton J et al Br J Cancer 2003

O61

Development and Certification of Quality Patient Decision Aids

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Background: Individuals with serious illness face complex healthcare decisions which have important and lasting consequences. Person-centered care can be achieved when personal values, goals, and beliefs are aligned with the actual care provided.

Person-centered decision-making requires a) clear, accurate and unbiased information about **all** options, including risks versus benefits; b) clinician investment and expertise in engaging and communicating with patients; and c) the effective integration of personal values, goals, and beliefs into choices. Person-centered decision aids (PDAs) are tools designed to help patients and providers in the process of shared decision-making. Research shows, high quality PDAs lead to increased knowledge, more accurate risk perception, reduced indecision about care, and improved patient engagement.

Methods: Based on criteria developed by the International Patient Decision Aids Standards Collaboration (IPDAS), *Healthier Washington Initiative*, Washington State, USA, developed and implemented a process of certifying PDAs to assure they are effective, accurate, unbiased tools to use in the shared decision-making process. Implementation of quality PDAs can be standardized using the fundamentals described in the National Quality Forum's(NQF) National Quality Partners(NQP) Playbook—Shared Decision-Making in HealthCare.

Results: This presentation will review certification criteria for developing high-quality PDAs. A four-phased approach will be discussed that describes the process of developing and certifying three serious illness decision aids and their integration within Respecting Choices® person-centered decision-making programs.

Conclusion: Development and certification of quality PDAs in healthcare organizations using a standard approach to the decision-making process can support a culture of person-centered care.

O62

Sustainable implementation of Advance Care Planning in Asia: An Interpretive-Systemic Framework for National Development

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Background: To examine the underpinnings of Asia's first national Advance Care Planning (ACP) programme, and to identify the dynamics, mechanisms and systemic factors that influence the implementation of ACP in Singapore. **Methods:** A qualitative interpretive-systemic focus group study with 4 professional stakeholder groups who played critical roles in the ACP programme. Study included 63 physicians, nurses, medical social worker and allied health workers from 7 public hospitals and specialist center that incorporated ACP into clinical practice.

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Results: Framework analysis revealed 19 themes, organized into 5 categories including: (1) Life and Death Culture (social perception of death, biomedical model, health system hierarchy, health seeking behaviors), (2) ACP Coordination (institutional leadership, programme receptiveness, interdisciplinary trust, preparatory training), (3) ACP Administration (practice diversity, work flow, operation clarity), (4) ACP Outcomes (care preferences, medical-social dissonance, performance measures, intrinsic values), and (5) Sustainability Shift (public life and death education, holistic end-of-life care training, governance and service alignment, empowered citizenry). These further formed an interpretive-systemic framework of sustainable ACP, reflecting the social, cultural, political, operational and spiritual contexts that support national ACP development.

Conclusion: This research provides insights on developmental and implementation challenges of Asia's first national ACP programme. ACP should be supported by public health strategy for enhancing individual, professional, and institutional readiness for end-of-life conversation before programme commencement. It emphasizes the importance of health policy, organizational structure, social discourse, and shared meaning in planning and delivery of ACP to aid care decision making among Asian patients and their families facing terminal illness and mortality.

O63

Estimating and communicating prognosis in palliative care: a cross-sectional survey among physicians in the Southwest region of the Netherlands

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Background: Advance care planning is important for patients with an advanced illness and a limited life expectancy. We explored experiences from physicians from different settings with estimating and communicating patients' poor prognosis.

Methods: A survey study was performed in 2017 in the Southwest region of the Netherlands among a random sample of physicians working in primary care, hospitals and nursing homes (n=2212).

Results: 547 physicians participated: 259 general practitioners (GP's), 205 hospital physicians (HP's) en 83 nursing home physicians (NHP's). In total, 61.1% stated that they can adequately estimate if a patient will die within a year; 66.7% stated that they can adequately estimate a life expectancy of less than three months and 76.1% a life expectancy of less than a week. When a patient is estimated to have a prognosis of less than one year, 75.0% of all physicians indicate that they always/often discuss their wishes for treatment and care. For patients with an estimated prognosis of less than three months, 85.9% of HP's discuss patients' wishes, compared to 96.1% of GP's and 91.6% of NHP's. After hospital admission of patients with a limited life expectancy, 29.0% of GP's and 16.9% of NHP's indicate that they always/often receive adequate information from HP's about patients' wishes.

Conclusion: The majority of physicians indicate that they can adequately estimate a patient's limited life expectancy and that they tend to discuss patients' wishes if they have a poor prognosis. Information transfer concerning patients' wishes for treatment and care can be improved.

O64

Examining patient-reported barriers to talking about Advance Care Planning (ACP) with Family Physicians: a Multi-Site Survey

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Background: Advance care planning (ACP) can improve satisfaction with end-of-life care among patients and families and reduce unwanted treatments. Primary care is an ideal setting in which to facilitate ACP. This study analyzed the reasons why patients find it difficult to discuss ACP with their family physicians.

Methods A self-completed, validated questionnaire about four ACP engagement behaviours and barriers was administered to patients aged 50 and older in 20 family practices in Canada. The questionnaire included an openended question about what makes it difficult to talk about ACP with the family physician. Four authors analysed the open-ended comments using thematic content analysis.

Results: 810 patients (mean age=66, 55.6% female) participated. Of the 53% (n=428) of patients who had talked to someone about end-of-life medical treatments, only 18% (n=75) had talked with their family physician. Patients identified the following barriers to ACP conversations: 1) They feel too young, healthy and well; 2) They abdicate responsibility to their physician; 3) They worry about a negative impact of ACP on the physician relationship; 4) Inadequate time during appointments; 5) They feel ACP is emotionally difficult to discuss with their physician. **Conclusions:** Our findings suggest that patients need help preparing for ACP conversations, both to change the perception that ACP conversations only occur at the end-of-life and to normalize these discussions between patients and physicians. There is an opportunity for family physicians, who have longstanding relationships and frequent visits with patients, to have ACP conversations.

O65

Framing Advance Care Planning in Parkinson's Disease: Patient and Care Partner Perspectives

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Background: Advance care planning (ACP) is a new core quality measure in caring for individuals with Parkinson's disease (PD) and there are no best practice standards for how to incorporate the ACP process into PD care. This study describes patient and care partner perspectives on ACP to inform a patient and care partner-centered framework for clinical care.

Methods: Qualitative descriptive study of 30 patients and 30 care partners affected by PD within a multi-site, randomized clinical trial of neuropalliative care compared to standard care. Participants were individually interviewed about perspectives on ACP, including prior and current experiences, barriers to ACP, and suggestions for integration into care. Interviews were analyzed using theme analysis to identify key themes.

Results: Four themes illustrate how ACP is perceived and integrated into clinical care: 1) variation in personal definitions of ACP in the context of PD; 2) barriers to engaging in ACP with PD; 3) role of care partners as active participants in ACP; and 4) influence of a palliative care approach on ACP. Taken together, the themes support clinician initiation of ACP discussions and interdisciplinary approaches to help patients and care partners overcome barriers to ACP.

Conclusions: ACP in PD may be influenced by patient and care partner perceptions and misperceptions, symptoms of PD (e.g. apathy, cognitive dysfunction, disease severity), and models of clinical care. Optimal engagement of PD patients and care partners in ACP should proactively address misperceptions of ACP and utilize clinic teams and workflow routines to incorporate ACP into regular care.

066

How do patients with life limiting diseases experience patient-physician communication about life expectancy? - an interview study

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Background: The Dutch Framework for Palliative Care advises physicians to timely start advance care planning (ACP) in patients with life limiting diseases. Such communication requires disclosure and discussion of patients' limited life expectancy. We explored patients' experiences with such discussions.

Methods: Medical specialists from three different hospitals included patients with incurable cancer or late-stage chronic obstructive pulmonary disease (COPD), with whom they had spoken about their limited life expectancy. All 14 patients (7 cancer and 7 COPD) had a semi-structured interview with one researcher about their experiences on those conversations. The interviews were audiotaped, transcribed, coded, and analysed by two researchers. **Results:** All patients were aware of their limited life expectancy. They were often shocked when their physician had indicated prognosis rather concrete. However, such indications also enabled them to reflect certain treatments and led to conversations about ACP sometimes. Most patients agreed that the physician should initiate conversations about life expectancy, but that the patient should have control of the continuation of that topic. Some patients with COPD who disagreed with this also believed that the pulmonologist lacked the ability to indicate their life expectancy. Factors that facilitated agreeable conversations for the patients were: clear explanations and messages about the disease, prognosis and treatment options, feeling of being heard, sufficient time, and adequate preparation by the physician, an open attitude, and sensitive non-verbal communication.

Conclusion: Overall, patients appreciate honest, personalized and attentive communication on a limited life expectancy enabling reflections and communications about ACP.

O67

Patient perspectives on information provision and advance care planning regarding implantable cardioverter defibrillator deactivation at the end of life.

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Background: Implantable Cardioverter Defibrillator (ICD) shocks can negatively influence the last phase of life. Advance care planning, timely and frequently discussing ICD deactivation with the patient, can help patients to make a well-informed decision about future ICD deactivation. Perspectives of patients on ICD deactivation are however largely unknown.

Methods: Focus groups with ICD patients were conducted using a predefined topic list and were audiotaped and transcribed. Transcripts were analyzed using the constant comparative method.

Results: Forty-one patients participated in a total of five focus groups. Average age was 64 years and 56% of patients were male. Many patients expressed a need for more information about ICD deactivation. Although most patients agreed that it would be appropriate to deactivate the ICD on a certain point in the disease trajectory, they had difficulties deciding on the right moment to do so, indicating the need to frequently re-assess their preferences. Possible circumstances in which patients would consider deactivating their ICD in order to avoid shocks were: a terminal stage of their disease, and a diminished quality of life. Arguments *against* deactivation were also mentioned, and mainly concerned not wanting to give up on life, both for themselves and for their family.

Conclusion(s): There is room for improvement in informing patients about ICD deactivation in the last phase of life. We found that patients' perspectives towards ICD deactivation were highly personal and sometimes ambivalent. This emphasizes the importance of early and recurring discussions on this topic.

O68

A cluster-randomized trial of a nurse-led advance care planning session in patients with COPD and their

loved ones

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Background: Advance Care Planning (ACP) is uncommon in patients with COPD.

Aims: To assess whether a nurse-led ACP-intervention can improve quality of patient-physician end-of-life care communication in patients with COPD. Furthermore, the influence of an ACP-intervention on symptoms of anxiety and depression in patients and loved ones was studied.

Methods: A multicenter cluster randomized-controlled trial (RCT) in patients with advanced COPD was performed. The intervention group received an 1.5-hours structured nurse-led ACP-session. Outcomes were: quality of patient-physician end-of-life care communication, prevalence of ACP-discussions six months after baseline, and symptoms of anxiety and depression in patients and loved ones.

Results: 165 patients were enrolled (89 intervention: mean age 65.7 (9.2) years; 49.4% male; 76 control: mean age 69.5 (9.0) years; 57.9% male). The improvement of quality of patient-physician end-of-life care communication was significantly higher in the intervention group compared to the control group (<.001). The ACP-intervention was significantly associated with the occurrence of an ACP-discussion with physicians within 6 months (p=.003). At follow-up, symptoms of anxiety were significantly lower in loved ones in the intervention group compared to the control group (p=.02). Symptoms of anxiety in patients, and symptoms of depression in both patients and loved ones were comparable at follow-up (p>.05).

Conclusion: One nurse-led ACP-intervention session improves patient-physician end-of-life care communication without causing psychosocial distress in both patients and loved ones.

The Advance Care Planning study is supported by Lung Foundation Netherlands.

O69

Effectiveness of advance care planning in improving end of life care for patients with advanced heart failure <u>C. Malhotra</u>, D. Sim, F. Jaufeerally, N. Nadkarni, H. Meibo, E. Finkelstein <u>Duke-NUS Medical School, Singapore</u>, <u>Singapore</u>

Background: Our primary aim was to assess, among advanced heart failure patients, effectiveness of Advance care planning (ACP) in ensuring end of life (EOL) care consistent with patient wishes. Secondary aims were to assess its impact on patients' decisional conflict, discussion of care preferences with surrogates, illness understanding, anxiety, depression and quality of life.

Methods: We conducted a randomized controlled trial of ACP (based on Respecting Choices Model) versus usual care in Singapore. 282 patients hospitalized with heart failure and NYHA III and IV symptoms were randomized to ACP (93) or control (189) arm. They answered up to 6 follow-up surveys conducted every 4 months. Primary outcome was assessed in the deceased sample (89; 23 in ACP, 66 in control arm). Both intention-to-treat and perprotocol analyses were done.

Results: 63% of ACP arm received intervention. Deceased patients in ACP arm were no more likely to have their wishes followed for EOL treatments (35% in ACP vs 44% in control; p=0.47) but were more likely to have their wishes followed for cardiopulmonary resuscitation (83% in ACP vs 62% in control, p=0.12) though the difference was not statistically significant. At first follow-up, ACP patients had lower decisional conflict (β =-10.8, p <0.01) and were more likely to discuss preferences with their surrogate decision maker (β =1.3, p=0.04). Both arms did not differ on other patient outcomes. Per-protocol analyses showed similar results.

Conclusion: ACP has benefits in improving decision making. More needs to be done to improve implementation of ACP for patients with heart failure.

O70

Normative principles of Advance Care Planning: a systematic literature review

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Background: Since the introduction of the concept of advance care planning (ACP), many studies have been conducted exploring beneficial effects. These studies show a heterogeneity in clinical endpoints, which reflects diversity of goals connected to ACP. Clarification of underlying normative principles of ACP is crucial in understanding both motivation and hesitation to initiate ACP among health care professionals and patients. This study aims to clarify normative principles of ACP and to get insight in the range of normative principles that comprise the legitimacy of ACP.

Methods: Systematic literature search in PubMed, EMBASE, PsychInfo, CINAHL and Cochrane Library, using various search terms for 'ACP' and 'ethics'. Articles on normative aspects of ACP were included, based on title and abstract. Due to the quantity of inclusions, of which many had similar content, purposive sampling was used to select articles for full text document analysis. Analysis stopped once saturation was reached. Sensitivity analysis was performed to guarantee that unfrequently mentioned goals and objections were found as well.

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Results: In total, 6497 unique articles were found of which 183 were included. Saturation was reached after document analysis of 55 articles (30%); this yielded 211 codes concerning normative principles of ACP. We identified 5 main normative principles for ACP: respecting individual patient autonomy, improving quality of care, strengthening relationships, improving quality of life, and reducing overtreatment.

Conclusion: Defining normative principles of ACP should serve as a starting point when developing ACP interventions and selecting outcome measures to evaluate ACP interventions.

071

ACP Alberta: Collaborative Action of Health Care, Legal, Government, Community and Academic Sectors to Increase Participation in Advance Care Planning

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Background: In 2014, Alberta's health service providers implemented a province-wide Advance Care Planning (ACP) and Goals of Care Designation policy. Despite significant efforts, barriers to full implementation remain including lack of public comprehension across health, legal and other public systems. A World Café consultation revealed multi jurisdictional recommendations to 'normalize ACP.'

Methods: Through the ACP Collaborative Research Innovation Opportunities program, we formed a collaboration with lawyers, Legal Education Society of Alberta, Canadian Bar Association, Law Society of Alberta, palliative care physicians, patient advocates, academics, provincial health care providers and other stakeholders. A community of practice propagated spontaneously. Surveys and focus groups identified barriers, knowledge and resource gaps, and novel solutions, including joint health-legal education.

Results: Traditional approaches to ACP have been siloed. We expand on the innovative medico-legal framework to include other stakeholders including community agencies, faith groups, health advocacy agencies, national ACP projects, and the financial planning and insurance industries. Ongoing collaborative activities include community engagement, education, policy and practice innovation, which bundles activities relating to health care planning with those relating to personal and financial planning. Our business case addresses the identified gaps and adopts public recommendations through activities to coordinate, integrate and/or support development/implementation of a community volunteer program, an electronic registry for ACP and Goals of Care documentation, and a legal toolkit. **Conclusion**: In practice, ACP spans medical, legal, social and personal domains. Multi-disciplinary and multi-sector approaches are posited to improve knowledge and uptake of ACP while improving the quality of life of Albertans.

072

Who is in control? Cultural and institutional barriers to EOL decision in Japan and the United States A. Morita

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Japanese and American healthcare providers enjoy abundant medical resources at their disposal, yet both systems often fail to adequately address a patient's end-of-life (EOL) wishes for vastly different reasons.

In a society as highly structured in hierarchical and patriarchal dimensions as Japan's, a terminal patient's wishes are often superseded by the treating physician's suggestions in deference to the doctor's education and social status. In addition, a family member who has cultural authority tends to speak and make decisions on behalf of the dying person and the family.

Similarly, American healthcare providers often avoid the topic of EOL decision-making to deflect away from the realization that in spite of their formidable arsenal of available medical treatments, they are powerless to help. The American system of medical training also encourages physicians to advise their patients to fight an incurable disease to the end because the hope of prolonging life is never lost.

These cultural versus institutional factors have the same result. Oftentimes, the EOL wishes of a terminal patient is either not heard or lost at best. In either case, these factors have a major detrimental impact on the quality of a patient's end-of-life experience as their wishes fall prey to more dominant cultural or social factors. This theoretical study discusses the importance of EOL conversation in providing quality care, and discusses how the medical professions in both countries can approach EOL discussions with the cultural sensitivity and understanding to improve the quality of living and dying.

O73

Differences between advance directives and advance care planning in the Italian Law 219/2017

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Background: The Law 219/2017, entered into force on January 31, 2018, regulated for the first time advance directives (ADs) and advance care planning (ACP) in Italy. We aimed to examine main legal differences between ADs and ACP according to this law.

Methods: The Law 2019/2017 was analyzed, and relevant differences between ADs and ACP were described. **Results:** ADs and ACP differed mainly with regard to subjects involved, legal formalities required, and the

healthcare professionals' duty to respect the patient's will. ADs may be made by mentally competent adults through notarization or delivery to a municipal office or to a health facility with electronic health record database structure; ADs are, in principle, binding for physicians, but the physician, in agreement with the healthcare proxy, may go against the patient's will in some circumstances. On the other hand, ACP may be carried out by the patient and the physician with regard to the expected trajectory of a chronic disabling disease or a progressive illness with a poor prognosis; there are no particular legal formalities for establishing the ACP, which should be included in the patient record; ACP is always binding for both the physician and the healthcare staff members.

Conclusion(s): The Italian Law 219/2017 set up a binary approach to guaranteeing patient self-determination in the case of lack of decision-making capacity, establishing the primacy of the ACP carried out with the physician when patients' outcomes are already predictable.

074

Advance care planning by proxy: an analysis of the ethico-legal foundation

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Background: Advance care planning (ACP) in practice often includes conversations with family caregivers of those patientes who have already lost decision-making capacity. This approach has been defined as ACP by proxy and rightly been pointed out as a distict activity, but it blatantly lacks an ethico-legal foundation.

Method: Theoretical analysis, drawing from bioethics, philosophical ethics, and international medical law. **Results:** In contrast to ACP by the patient, ACP by proxy has its core roots not on direct, but indirect patient autonomy. While the patient with his or her autonomous preferences is also at the heart of the process, the epistemological approach to assess these preferences has to pass via surrogates and others close to the patient. As the patient commonly cannot participate in the conversation, his or her preferences cannot be jointly developed by a kind of maieutic process, but have to be approximated by substituted judgment. Another key difference is the ethicolegal responsibility placed on the surrogate decision maker as well as on the health care team and ACP facilitator linked to this substituted judgment.

Conclusion: Irrespective of shared values, ACP by the patient and ACP by proxy have distinct ethico-legal features that warrant particular consideration in the practical process of ACP, the qualification of ACP facilitators, and the documents used.

O75

The decision making capacity in Amyotrophic Lateral Sclerosis (ALS)

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Background: From the beginning and during the disease the ALS patients have to take difficult decisions about care and end of life. A sensible and open communication among patient and clinicians is an indispensable tool to ensure the freedom of choice and the recognition of the responsibility for everyone. Any intervention by the health professionals cannot forget the clinical complexity and the subjectivity of the patients who exercises their rights to know and to choose among technology opportunities. The aim of the study is to identify those elements that influence the patient's choices.

Methods: We examined 200 ALS patients taking care by palliative multidisciplinary team for 18 months about: withholding and withdrawing vital supports, mobility and communication aids, rehabilitation care and dying setting. We registered the respect for advance directives, the changing's patients minds, the making informed choices, the clinicians attitudes about care planning and communication disability.

Results: For every choice the decision making involves scientific aspects, patient's quality of life, and community resources too. We showed that the choices are often not real free but depending on the clinicians' point of view, the availability of high technology aids and the clinician-patient communication skills.

Conclusion: The negotiation is the new aspect of the physician-patient relationship founded on empathy, respect and recognition of different competences.. The clinician' ethical-clinical reasoning could be a useful tool to improve the patient ability to choose on difficult clinical situations.

O76

Advance care planning: core competency of elderly care medicine in the Netherlands

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Target audience: professional caregivers, including physicians, nurses and allied healthcare professionals, researchers, policy makers.

Description: The Dutch elderly care physician is a physician who specializes in long-term care for frail elderly people and patients with complex chronic health problems. Advance care planning (ACP) is a corner stone of elderly care medicine. The current session shows the importance of ACP for frail elderly and patients with complex chronic health problems as well as evidence for ACP interventions in this population. ACP education of Dutch elderly care physicians will be highlighted. The specific challenge for elderly care physicians in ACP for persons with decision-making disabilities will be discussed. Finally, the collaboration between elderly care physicians and general practitioners will be illustrated.

Content: Introduction ACP in elderly care medicine – by dr. Daisy J.A. Janssen

Specific challenges for elderly care physicians: ACP and decision-making disabilities – by prof. Cees Hertogh Collaboration between elderly care physician and general practitioner – by general practitioner invited by dr. Annicka van der Plas

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The Advance Project: an Australian national program to support nurses to initiate advance care planning in General Practice

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Background: Primary care has been advocated as an ideal setting to initiate advance care planning (ACP). Few studies have examined the role of general practice nurses (GPNs) in promoting/initiating ACP. The Advance Project evaluated initiatives to address this gap.

Methods:

This Australian Government-funded program aims to increase GPNs' confidence in initiating conversations with patients/carers about ACP during routine health assessments with older and/or chronically ill patients using a structured interview. This is part of a broader program enabling GPNs to identify patients at risk of deteriorating and dying and to assess these patients' palliative/supportive care needs. Identified needs are then addressed in consultation with General Practitioners. The program includes a suite of resources and multi-component training (online, face-to-face and individual tele-mentoring). Pre/post/follow-up surveys and qualitative interviews collected GPNs' perspectives about the training/resources and barriers to implementation in clinical practice.

Results: As of 31 December 2017, 823 GPNs enrolled in training and 536 completed one or more training components. 27 workshops were held across Australia, including 182 regional/rural participants. 585 pre-training, 384 post-training, and 125 follow-up surveys were received. 20 GPNs were interviewed. There were significant improvements in GPNs' confidence, comfort, knowledge and attitudes towards initiating ACP post-training that was sustained at follow-up. Participants were significantly more likely to have had ACP discussions with their patients at follow-up (81%) compared to baseline (55%, p<0.001).

Discussion/conclusion: GPNs can have an important role in initiating ACP. The evaluation informed refinement/expansion of the resources/training to support team-based initiation of ACP in general practice http://www.theadvanceproject.com.au

O78

Regional (central) versus institutional: Competing strategies for nationwide ACP implementation J. In der Schmitten¹, G. Marckmann²

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Background: Implementing ACP in nursing homes is often essentially done by educating selected n/h staff as ACP facilitators. Recent German legislation covers ACP offered to nursing home residents, and offers an alternative strategy for implementation, i.e. cooperation of participating n/hs with a regional (central) partner that employs a team of facilitators. Which of these two strategies should be preferred?

Methods: 1. Follow-up of facilitator training effectivity in Germany in 2015-2017, 2. review of the literature, 3. theoretical analysis of the competing rationales.

Results: Of some 270 facilitator trainees attending our ACP courses, only few report ongoing practice as an ACP facilitator. A number of important publications describe facilitators and barriers, or essential elements, of successful ACP implementation, but few if any compare regional versus institutional implementation strategies of ACP yet. Similarly, while regional ACP coordination is described as an important precondition for sustainable ACP implementation, it requires significant resources on top of institutional implementation. A comparative analysis yields a number of strong reasons why regional may well beat institutional implementation strategies, referring to staff aptitude, team building, regional coordination, economic efficiency, and both sustainability and expandibility. Arguments that have been raised against qualifying external staff can be shown not to consider sufficiently the potential of creating regional (central) facilitator teams.

Conclusion: Regional implementation of ACP, characterised by regional (central) facilitator teams cooperating with nursing homes and other institutions, has yet rarely been described, but poses a substantial potential when compared to conventional institutional implementation strategies that deserves scientific evaluation.

O79

Creating momentum and consistency with a national five year strategy in New Zealand L. Manson, L. Price

Background: The development of ACP in New Zealand was driven by the ACP Cooperative, a grass roots organisation of clinicians. The Cooperative's aim was to drive consistency and address the barriers to ACP implementation. Over time, the lack of an official mandate and funding threatened the sustainability of the work of the Cooperative.

Method: In 2017 the Cooperative partnered with the Health Quality & Safety Commission – a crown agency tasked with supporting the public health sector to improve the quality and safety of services. Together they presented a business case to the district health boards (DHBs) to agree to a national programme with a clear mandate and funding. The DHBs agreed to a five-year strategy and roadmap of national and local actions aimed at increasing ACP activity and addressing sustainability. The key strategy workstreams and their aims are:

- -promotion: that future health care planning and end of life discussions are normalised in society
- -resources: ACP is accessible to all regardless of language, literacy level or cultural beliefs
- -education and training: we have workforce and community prepared to have conversations and use ACPs
- -monitoring and evaluation: we know care is based on what matters to consumers
- -implementation: we are maximising value for DHBs

Result: a national mandate, strategy and specified actions have resulted in an increase in ACP activity; increased governance with decision-making being supported by a representative Steering Group; wider national stakeholder engagement and buy in from agencies in and outside of the health sector.

Ω 80

Shared Care Planning: A new model to integrate Advance Care Planning into community. The Basque Country experience

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In the Basque Country, a project has been implemented based on community education, the training of health and social workers. It tries to elicit the individual's preferences and encourages them to take part in planning their care. Writing down advance directives is not the main aim.

The target population is chronic patients, elderly people and anyone at the end of life. The project also includes everyone who wants to think about the process of dying and needs to have a conversation related to this topic. The project started in 2014 as a bottom-up project and it has grown into a top-down project performed in the whole Basque Health Service.

Results: More than one hundred conferences and debates have been taking place in neighborhood associations, cultural centers, libraries or educational centers. More than five thousand people have attended these activities. One thousand workers have attended a basic training course, more than 500 workers have been trained as SCP facilitators and more than 700 doctors and nurses have participated in conversations with patients and families helped by an SCP facilitator. In 75% of cases, the citizens asked to be included after attending a conference; only 25% of participants were included because of a doctor or nurse's invitation. Many support documents have been created in order to explain the project and to make it easier to understand.

The keystone is the training of health and social workers in order to answer citizens' requests and to integrate the conversations into everyday care.

O81

Implementation of advance care planning in aged care: what do you want and how can we help? H. Kelly¹, L. Nolte¹, M. Fearn², F. Batchelor², B. Haralambous², P. Mackell², K. Hwang², K. Detering¹¹Advance Care Planning Australia, Melbourne, Australia²National Ageing Research Institute Inc, Melbourne, Australia

Introduction: The goal of advance care planning (acp) is to ensure that individuals receive future care consistent with their expressed preferences. Benefits of acp include: increased adherence to a person's preferences, higher staff satisfaction, reductions in unwanted hospitalisations and medical treatments, and reduced stress and anxiety for family. Despite clear benefits, uptake of acp has been limited in Australian aged care settings. This research explored barriers and enablers to implementing acp in residential and community aged care settings, from the perspectives of aged care staff and older people.

Method: Focus groups and interviews with aged care staff and older people were conducted in four Australian states. Sixty staff from 15 residential and community aged care organisations and 24 older people participated. A thematic analysis was undertaken to identify facilitators and barriers.

Results: Factors identified as impacting on the experiences and implementation of acp included: knowledge and understanding access to education/training understanding of relevant legislation having defined roles/responsibilities cognitive capacity of the older person timing of initiating the conversation availability of clear policies/procedures

engaging older people and their families diversity within the workforce and older people.

Conclusions: Aged care staff indicated there are a range of factors that can impact on acp implementation. All these factors may need to be considered when implementing acp within Australian aged care organisations. The findings informed the development of a new national resource titled *Advance care planning in aged care: a guide to support implementation in community and residential settings.*

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Identification, Implementation and Evaluation of Indicators to Monitor Successful Uptake of Advance Care Planning in Alberta

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Background: In 2014, a province-wide policy for advance care planning (ACP) and Goals of Care Designation (GCD) was implemented in Alberta, Canada; nevertheless, few quality indicators have been rigorously developed or evaluated for measuring the uptake of ACP/GCD.

Methods: In phase I, we performed a systematic literature review and environmental scan to identify potential ACP/GCD indicators. A Delphi consensus-based approach, consisting of 3 rounds of face-to-face meetings and/or online surveys, was used to develop a short list of indicators. In phase II, the panelists met face-to-face to operationalize and implement the indicators. In phase III, two validated questionnaires and semi-structured interviews of 60 individuals (stratified by manager/practitioner and physician/nurse) are being used to evaluate the usability and acceptability of the implemented indicators on a dashboard interface.

Results: A total of 132 potential indicators were identified in phase I. The indicators were reduced and refined to 18 after 3 Delphi rounds. Phase II resulted in 9 valid and feasible indicators in a measurable format (i.e. numerator, denominator, data source defined). The Phase III protocol is under ethical review and potential participants' recruitment is underway.

Conclusions: Of 132 quality indicators for ACP/GCD, 9 are feasible, valid, usable and acceptable for monitoring performance in the rollout of ACP/GCD. This set of indicators shows promise for describing and evaluating ACP/GCD uptake throughout a complex, multi-sector healthcare system.

O83

The challenge of finding the 'right' outcome to measure the effects of ACP - Part I

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Background: Advance care planning (ACP) is increasingly implemented in oncology and beyond, but a definition of ACP and recommendations concerning its use are lacking. This hinders the development of ACP programmes and the evaluation of ACP's effectiveness.

Methods: We used a formal Delphi consensus process to help develop a definition of ACP and provide recommendations for its application in healthcare, policy and research.

Results: Of the 109 experts (82 from Europe, 16 from North America, and 11 from Australia) who rated the ACP definitions and its 41 recommendations, agreement for each definition or recommendation was between 68-100%. ACP was defined as the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate. Recommendations included the adaptation of ACP based on the readiness of the individual; targeting ACP content as the individual's health condition worsens; and, using trained non-physician facilitators to support the ACP process. A list of outcome measures is also presented to enable the pooling and comparison of results of ACP studies.

Conclusion: This large international Delphi panel was able to come to a consensus on an ACP definition and recommendations. This represents an important first step in providing clarity with a view to further policy and research in this field. We believe that our recommendations can provide guidance for clinical practice, ACP policy, and research.

O84

The challenge of finding the 'right' outcome to measure the effects of ACP - Part II

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Background: Standardized outcomes that define successful advance care planning (ACP) are lacking. The objective of this study was to create an Organizing Framework of ACP outcome constructs and rate the importance

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of these outcomes.

Methods: This study convened a Delphi panel consisting of 52 multidisciplinary, international ACP experts including clinicians, researchers, and policy leaders from four countries. We conducted literature reviews and solicited attendee input from five international ACP conferences to identify initial ACP outcome constructs. In five Delphi rounds, we asked panelists to rate patient-centered outcomes on a seven-point "not-at-all" to "extremely important" scale. We calculated means and analyzed panelists' input to finalize an Organizing Framework and outcome rankings.

Results: Organizing Framework outcome domains included process (e.g., attitudes), actions (e.g., discussions), quality of care (e.g., satisfaction), and health care (e.g., utilization). The top five outcomes included 1) care consistent with goals, mean 6.71 (±SD 0.04); 2) surrogate designation, 6.55 (0.45); 3) surrogate documentation, 6.50 (0.11); 4) discussions with surrogates, 6.40 (0.19); and 5) documents and recorded wishes are accessible when needed 6.27 (0.11). Advance directive documentation was ranked 10th, 6.01 (0.21). Panelists raised caution about whether "care consistent with goals" can be reliably measured.

Conclusion: A large, multidisciplinary Delphi panel developed an Organizing Framework and rated the importance of ACP outcome constructs. Top rated outcomes should be used to evaluate the success of ACP initiatives. More research is needed to create reliable and valid measurement tools for the highest rated outcomes, particularly "care consistent with goals".

O85

The challenge of finding the 'right' outcome to measure the effects of ACP: Part III

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Background: A key outcome of successful advance care planning is consistency between patient goals of care and the care provided. However, assessing consistency is methodologically challenging due to conceptual and logistical barriers as well as practice limitations.

Methods: The team reviewed the literature and identified key methodological barriers to measuring care consistency with patient preferences and goals of care. Strategies to overcome these barriers are proposed. **Results:** Key methodological barriers include: 1) the specificity and relevance of documentation about preferences and goals of care; 2) the availability of documentation about preferences and goals of care; 3) the stability of documented preferences and goals of care; 4) the timing of treatments provided and identifying decisions not to treat ("non- events"); and 5) calculating rates of consistency. Strategies to address these methodological barriers include using tools to document specific preferences, incorporation into electronic health records, period reassessment of preferences, prospective data collection, and using percent agreement to report consistency.

Discussion: There are clear challenges to assessing care consistency with preferences and goals of care. The ability to assess and report on this important outcome of successful advance care planning requires focused efforts to improve practice.

086

The challenge of finding the 'right' outcome to measure the effects of ACP - Part IV

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Background: There is little agreement about which outcomes are the most important outcomes to use in ACP trials. Previous studies have taken the first important steps to address this challenge by developing a consensus definition of ACP, a list of outcome measures for ACP studies and an organizing framework regarding outcomes that would define successful ACP in research. The extensive work they undertook included consulting multidisciplinary, international experts in Delphi panels. However, these expert panelist mainly consisted by healthcare professionals, lawyers, and researchers. Patients and family caregivers might rate the importance of outcomes for ACP differently. However, little is known about the most important and desired outcomes of ACP from patients' and family caregivers' perspective.

Methods/Design: In this presentation, we will present the results of 1) a scoping review of the literature to identify desired outcomes of ACP from patients' and families' perspective, and 2) expert panels and/or interviews with patients, family caregivers, patient representatives, etc. to define in ranking in the outcomes according to their importance to achieve when engaging in the process ACP.

Conclusion: The results of this study will provide an overview and ranking of outcomes that are considered as (most) important when engaging in ACP from patients' and family caregivers' perspectives. These results will add to the knowledge base regarding outcomes to measure successful ACP and might help researchers who are considering to perform evaluation studies of ACP interventions to reflect upon appropriate outcomes that are relevant to patients and family caregivers.

O87

Understanding advance care planning for people living with dementia: a review of reviews

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Background: Worldwide, every three seconds someone develops dementia. Dementia is a terminal condition. Therefore, communication about future care preferences (advance care planning, ACP) is important for people with

dementia (PwD) and their network. This review of reviews aims to synthesize the evidence on ACP for PwD and their carers

Methods: PubMed, CINAHL Plus, SCOPUS, SocialCareOnline and Cochrane Library, were systematically searched for systematic reviews in July 2018. After tabulation of primary research, PubMed, CINAHL Plus and SCOPUS were searched for additional recent primary research articles in September. Methodological quality was assessed using AMSTAR-2 and the Joanna Briggs Institute instruments. Overarching themes were identified. **Results:** 19 reviews and 10 primary research articles met the inclusion criteria. Methodological quality was variable. Preliminary analysis suggests that ACP interventions led to increased ACP documentation, an increase in PwD dying in their preferred place and a decrease in hospitalisations. Qualitative data showed that the ACP process can be experienced as stressful, but is also perceived as relevant by PwD and carers. Lack of knowledge about ACP and dementia were barriers to ACP use for all parties involved. Facilitators for ACP were; education to improve healthcare professionals' communication skills and legal and ethical knowledge; education for PwD and carers about the ACP process, the differences between palliative and terminal care and the dementia disease trajectory. **Conclusion:** ACP interventions have shown to be effective on health utilization outcomes, however education for all parties involved is key to optimize the ACP process for PwD and their carers.

OSS

Advance Care Planning and Spousal Couples Affected by Dementia: A constructivist grounded theory <u>T. Ryan</u>, J. McKeown

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Background: Global policy and clinical guidelines place emphasis on the implementation and use of advance care planning (ACP) to inform decision making about care and treatment at the end of life. For people with dementia, where its use is encouraged at the point of diagnosis, utilisation of ACP is relatively low, raising concerns about the challenges present in the context of the condition. This study explores the ways in which co-residing couples considered ACP in the light of a recent diagnosis of dementia.

Method: Using face-to-face interviews as part of a constructivist grounded theory methodology the study sought to understand how people with dementia and their long-term co-residing partners consider and plan, or do not plan, for future medical and social care.

Results: Sixteen participants were interviewed. They identified the importance of relationships in the process of planning alongside an absence of formal service support. As a result few engaged in ACP. Findings recognise the fundamental challenges faced by couples when considering end-of-life decisions whilst making efforts to 'live well'. Importantly, the paper identifies features of the ACP experience of a relational and biographical nature.

Conclusion: The study challenges the relevance of current global policy and practice, concluding that what is evident is a process of 'emergent planning' through which couples build upon their knowledge of dementia, their networks and relationships, and a series of 'tipping points' in the process of considering future care options. The relational and collective nature of future planning is also emphasised.

089

Use of Advance care directives for individuals with dementia living in residential accommodation: A descriptive survey

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Background: End-of-life decision-making for individuals with dementia needs to be addressed because as dementia progresses, their capacity to make decisions about their health care, living arrangements and end-of-life care changes. Advance care directives (ACDs) provide an opportunity for individuals with dementia to communicate their wishes, about these important issues.

Aim: The aim of this study was to understand how Australian registered nurses (RNs) use ACDs for individuals with dementia living in residential aged accommodation.

Methods: Two hundred and thirty eight RNs working in Australian residential aged care accommodation were recruited via social media, professional organisations and organisations providing residential accommodation. Respondents completed an online survey delivered via Survey Monkey.

Findings: 59.7% of respondents reported commencing discussions around ACDs within the first month of individuals living with a dementia relocating to residential accommodation. However, 42.4% never or rarely completed ACDs. Only 59.3% stated that ACDs for individuals with dementia were always or often regularly reviewed. 53.8% identified that ACDs were always adhered to when an individual's circumstances changed. 62.6% felt that understanding amongst families about ACDs was sometimes, or often, a barrier to using ACDs.

Conclusion: The implementation of ACDs in Australian residential accommodation for those living with dementia remains sub-optimal. The study has demonstrated that ACD documentation and policies describing how they should be used exist; but gaps remain around the practical implementation of ACDs. Strategies to promote communication and collaboration between residential facilities, general practitioners and carers/families could also assist in providing cohesive, high quality care.

O90

Trials and tribulations of implementing ACP in dementia care

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Background: Although loss of decision-making capacity forms part of the expected trajectory of dementia progression, advance care planning (ACP) is not routine in dementia care.

Methods: Dementia-specific ACP intervention piloted with 20-30 patient-relative dyads in the context of a university memory clinic in French-speaking Switzerland. Recruiting patients with early dementia and preserved decisional capacity and piloting this intervention unveiled unforeseen obstacles. We want to present these obstacles and discuss potential strategies in order to advance ACP research internationally.

Results: Concern that ACP may cause distress to patients and their families was evidenced by the fact that the research ethics committee required formal consent of the patients' primary care physicians as well as an emergency response plan to address distress emerging during ACP. Care professionals in the memory clinic showed substantial gatekeeping, based on a reluctance to inform patients and families about the dementia course and complications and on skepticism about the ethical justification of ACP. The distinction between ACP and traditional advance directives is also unclear to many health professionals who therefore do not see the benefit of ACP. Despite these barriers, people with dementia and their relatives report relief after ACP conversations they had and were satisfied with the tool.

Conclusion: Paternalism and misconceptions among healthcare providers have the power to impede research and implementation of ACP. There is an urgent need to increase healthcare providers' awareness and knowledge of ACP in French-speaking Switzerland. Working with patient advocacy groups offers opportunities to promote ACP in dementia care.

O91

Advance care planning by proxy for elderly people without decision-making capacity

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Background: Advance care planning (ACP) as commonly understood requires decision-making capacity (DMC). When people lose DMC proxies are called upon to make surrogate decisions. ACP by proxy is an extension of classic ACP that specifically promotes patient autonomy in this context. Little research focuses on how ACP by proxy is best conducted, and most ACP research in nursing homes has excluded residents without DMC. Our project aims to identify current proxy planning practices, difficulties and needs, and to explore how ACP by proxy can be implemented in nursing homes in Switzerland.

Methods: We present the results of five focus groups; one with physicians of nursing home residents and four with health professionals involved in planning processes in nursing homes in French-speaking Switzerland. Focus groups were audio-recorded and transcribed verbatim. Themes important to the concepts of 'current practice', 'difficulties' and 'future needs' were identified through thematic analysis.

Results: Current practices: communication between health professionals, residents, and family, use of advance directives for documentation and as conversation starters, and a variety of systems for recording information. Difficulties: 'timing' of communication with families, interpersonal conflicts, roles of family members, hesitancy talking about end of life care and transfer of information. Future needs: documentation, conversation guides and decision aids specifically adapted for ACP by proxy.

Conclusions: The identification of specific needs for ACP by proxy can inform the adaptation of existent tools to facilitate ACP by proxy in nursing homes and therefore promote care in accordance with the presumed wishes of residents without DMC.

O92

The challenges around localisation of ACP training - New Zealand train-the-trainer programme

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Bacground: In the very early days of ACP implementation in New Zealand it was identified that one of the greatest barriers was clinicians feeling unprepared to initiate and facilitate ACP conversations. The National ACP Cooperative developed and delivered a programme of training. One component of the programme, the one-day ACP workshop (Understanding more about ACP and having the conversations), were delivered by a small national group of national trainers. 63 workshops (907 participants) were delivered in 2017. These workshops reported a statistically significant increase in clinician confidence to have ACP conversations. The District Health Boards (DHBs) wanted to increase the number of workshops being delivered and to take greater local control of the training. Method: the national ACP team worked with a team of trainers to develop a train-the-trainer course to train local DHB trainers to deliver the L1A workshops. 41 local DHB trainers have been trained. There was concern that delegation of training delivery to local trainers might impact the quality of the workshops. To mitigate against this risk, trainee trainers are required to go through a rigorous 6 step training and accreditation process before being accredited as trainers of the L1A workshop.

Results: The preliminary evaluation of the train-the-trainer programme finds that it meets the expectations of trainee trainers and leaves them feeling prepared to deliver the workshops locally. Initial assessment indicates that the increase between pre-and post- workshop confidence scores of participants remains statistically significant.

O94

Standardized patients for the ACP-facilitator qualification: Enhance your training

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Summary of workshop: In 2017, after delivering some 14 ACPacilitator workshops in 3 years, we redesigned our facilitator workshop to a 72h-training incl. 24h of a standardized patient (SP) – supported role-play training that allows to teach ACP-specific attitudes and skills, with a focus on identifying and adequately responding to emotional barriers.

In an interactive workshop approach, we will first share and discuss the process and lessons of developing SP roles, training the SP, working with the SP-supported facilitator training, caring for SP in the field, and developing a transferrable SP-trainer-trainer system to support ACP-facilitator-qualification at six German-speaking facilitator training sites. Secondly, the participants will work in small groups on developing criteria for meaningful rolescripts and practice writing one. Thirdly, we will present a role-play and thereby demonstrate the interactive training technique that we developed for our workshops.

Learning objectives:

Think about standard and challenging ACP-Situations

Appreciate what SP need in order to do a good job

Write small sequences of a SP role-script

Identify the required steps and depth a SP-training needs to really make a change in teaching complex conversations

Experience interactive SP-Training

Anticipated outcome of the workshop:

After the workshop, the participants will ...

- ... understand the SP-training that needs to be done in order to qualify them for their role in ACP workshops
- ... be aware of interactive trainer techniques that allow effective learning
- ... be inspired to include SP-supported training elements in their facilitator training, or enhance existing trainings.