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RESEARCH

Delivering Advance Care Planning Support at Scale: A Qualitative Interview Study in Twelve International Healthcare Organisations

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Context: Globally, populations are ageing, with people increasingly likely to die with chronic progressive illness. In this context, there is widespread interest in advance care planning (ACP), where people are supported to think about and express preferences concerning their future care. However, to date there has been limited systematic implementation.

Objectives: In a purposive sample of 12 international health and care organisations working to provide system-wide ACP support, we examined organisational aims, leaders' perspectives on the economic case and promising approaches for efficiently delivering ACP support at scale.

Methods: In-depth qualitive interviews (average 13 in each organisation) with leaders, ACP specialists and front-line staff.

Findings: Organisational aims for ACP support were multiple and complex; they included optimizing patient and family care, supporting staff and mitigating risks of complaints from bereaved families, reputational damage, poor staff morale and potential legal challenges. The economic case comprised intrinsic benefits for patients, families and staff; averting costs associated with potential risks; and making best use of resources by reducing reactive care and provision of unwanted, low-value treatments. A degree of staff specialism, team-based delivery, use of decision aids, group-based facilitations, public health approaches and supportive parallel system changes and initiatives appear likely to support the efficient and effective delivery of ACP support at scale.

Limitations: We recruited organisations using snowball sampling. Quantitative information was inquired about to complement data from interviews but availability was limited.

Implications: ACP support may be usefully understood as both an individual- and system-level intervention. We identify various approaches for delivering ACP support more efficiently at scale.

Keywords: advance care planning; chronic conditions; chronic illness; multi-morbidity; end of life care; dementia; personalization; population health; cost-effectiveness; health economics

Background

Globally, populations are ageing, with an associated increase in the global chronic illness burden (The Lancet, Global Health Metrics, 2017). This implies longer illness trajectories and more need for medical decision-making across the illness trajectory and at end of life. In this context, there has been growing interest in advance care planning (ACP). ACP is a voluntary process of reflection and discussion, usually undertaken with the support of a health or care professional, concerning goals and preferences for future care (Rietjens et al., 2017). ACP can be undertaken at any time but is especially relevant for those living with chronic and progressive illness and has been widely recommended as an integral part of chronic and long-term care (The Lancet, Global Health Metrics, 2017; Prince et al., 2016; Hall et al., 2011). ACP discussions are generally documented to inform care in the event of loss of capacity. In the United States (US), for example, advance directives (living wills) are used to set out treatment preferences, broader goals and values and to assign Durable Power of Attorney. In England, advance statements set out general preferences, while advance decisions specify treatment refusals. Lasting Power of Attorney for Health and Welfare can also be assigned. While legal frameworks and terminology differ, similar provisions exist in Canada, Australia, New Zealand and numerous other countries.

In research, ACP has been associated with fewer emergency admissions, hospitalizations, burdensome treatments and hospital deaths, as well as reduced hospital costs, greater concordance of treatment with patient preferences and improved carer satisfaction (Dixon et al., 2015; Brinkman-Stoppelenberg et al., 2014). However, provision

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of ACP support, particularly facilitation of ACP conversations, is demanding of staff time, with this widely considered a significant barrier to implementation (Dixon and Knapp, 2018; Fritz et al., 2017; Lund et al., 2015; Hagen et al., 2015; van der Steen, 2013; Sharp et al., 2013; Seymour et al., 2010).

Existing research evidence about implementing ACP is limited and fragmented. It has tended to focus on the identification of barriers (Occhipinti and Ramos, 2018; Lund et al., 2015; Hagen et al., 2015; Lovell and Yates, 2014; van der Steen, 2014; Sharp et al., 2013; Robinson et al., 2013; Seymour et al., 2010). Studies are also commonly small-scale intervention studies in specific settings, usually with ACP facilitators selected and prepared by researchers (Lund et al., 2015) or small-scale focus group studies exploring the views and experiences of health and care professionals (Sharp et al., 2018; Fletcher al, 2016; Robinson et al., 2013; Gott et al., 2009). Research taking an organisational perspective or examining real-world provision of ACP support at scale, such as our study, is currently lacking (Jimenez et al., 2018; Hagen et al., 2015).

This study is an exploratory (contextual), qualitative interview study (Ritchie et al., 2013) conducted with leaders and front-line health and care staff in 12 international healthcare organisations, each aiming to provide system-wide ACP support. The research aims were to

- describe the types of staff and other resources employed in the provision of ACP support;
- understand organisations' aims and objectives for investing in system-wide ACP support, including leaders' perspectives on the economic case;
- identify scope for efficiencies in the delivery of ACP support at scale, particularly facilitation of ACP conversations.

Methods

Study design

A qualitative approach was adopted to elicit provider perspectives and explore first-hand experiences of developing and delivering ACP support. Initial scoping identified limited availability of relevant quantitative (e.g., cost or activity) data.

Sampling and recruitment

A two-stage purposive sampling process was adopted, covering healthcare organisations and staff within these. For the first stage, we sought health and care organisations from any country with 'well-established, system-wide ACP support provision'. In practice, these ranged from a single condition programme to a publicly-funded healthcare region but commonly involved acute care provision alongside primary and community care, as well as engagement with adjoining systems, such as long-term residential care providers and the voluntary sector (**Table 1**). We use the term 'organisation' throughout to refer to the providing or supporting healthcare organisation and 'system' when referring to the wider eco-system of organisations and providers through which patients and families access and engage with ACP support.

For sampling, 'ACP support provision' was defined as helping patients and members of the public find out about ACP, facilitating ACP conversations and assisting with completion of ACP documents. 'Well-established' was defined as provision of 18 months or longer. 'System-wide provision' was defined as providing ACP support widely across all relevant services, sometimes including external partners. We also sought diversity against a range of secondary sampling criteria, including countries, small and large providers, rural and urban areas, care settings and ACP materials and approaches. We estimated that approximately 10 healthcare organisations would provide a sufficient range of experiences, enable diversity against secondary sampling criteria and provide a high level of site triangulation (Shenton, 2004; Cohen and Manion, 2000). This number also allowed for potentially important differences between fieldwork sites to be identified and for similar issues to be explored from a range of perspectives and contexts. It also helped to validate findings such that, where similar results emerged at different sites, findings could be seen as having greater credibility (Shenton, 2004). It additionally enabled us to provide respondents with greater anonymity, with the expectation of promoting more candid, in-depth discussions.

Suitable healthcare organisations were identified, drawing upon our own knowledge and through expert, network and snowball sampling (appropriate where sample units are rare, hidden or where there is no available sample frame). While these approaches can generate sample units within closed systems, we deliberately approached experts with a wide view of international practice, attempted to create different start points, took an iterative approach, adopted multiple sampling strategies and sampled until no more cases likely to add sufficiently new information were identified (Cresswell and Plano Clark, 2017; Miles and Huberman, 1994). Experts included four members of the International Society of Advance Care Planning and End of Life Care (ACPEL, recently re-named ACP-international). We also conducted eight scoping interviews with end of life care experts in the UK, including representatives from the National Council of Palliative Care, Care England and the Association of Directors of Adult Social Services. Potentially, we may have missed relevant organisations outside of our networks. In particular, we may have identified organisations most active in ACP knowledge-exchange networks. However, arguably, these are likely to be organisations with the most developed ACP support. In total, we recruited 12 healthcare organisations (**Table 1**).

Each organisation was approached directly, usually by email, through an appropriate senior staff member. This was followed with one or more telephone conversations with senior staff to explore eligibility and to discuss what participation would involve. All organisations received written information about the study. Once organisational and local ethical approvals were secured, we undertook the second stage of sampling.

Stage 2 involved sampling staff within each organisation, with a view to including a wide range of perspectives and achieving role triangulation (Tan et al., 2019; Shenton, 2004; Cohen and Manion, 2000). A key contact in each

Table 1: Participating healthcare organisations.

	Description of organisation	How organisation was identified
United States		
Gundersen Health	A physician-led, not-for-profit healthcare system; birthplace of Respecting Choices, an evidence-based ACP model for person-centered decision making.	Snowball sampling via Wisconsin Medical Society and known to the authors through the literature
Dartmouth-Hitchcock	A non-profit, academic health system, providing ACP support using the Honoring Care Decisions ACP programme (based on the Respecting Choices model).	Snowball sampling via *Gundersen Health*
Wisconsin Medical Society	A physician member association supporting 32 participating health organisations to implement the Honoring Choices ACP programme (based on the Respecting Choices model).	Known to the authors through an earlier study they led into the economics of ACP
Sharp Healthcare	A not-for-profit, integrated regional health care system, providing ACP support in collaboration with the Coalition for Compassionate Care of California.	An academic expert identified through ACPEL* made an introduction to a regional coalition organisation that, in turn, made an onward introduction to *Sharp Healthcare*. *Sharp Healthcare* and its Transitions program were also known to the authors through the literature
Canada		
Northern Alberta Renal Program (NARP)	Renal programme in Edmonton, Alberta, providing integrated ACP support using an approach based on Conversations Matter.	Identified directly through a clinician, academic and member of ACPEL*
Fraser Health	One of six publicly funded health care regions in British Columbia, providing ACP support in community, acute and residential care based on materials developed provincially and at Fraser Health Authority.	*Northern Alberta Renal Program* (NARP) made an introduction to an academic expert in Alberta who, in turn, made an onward introduction to *Fraser Health*
Australia		
Austin Health	A publicly-funded health service in Melbourne, providing acute, sub-acute, mental health and ambulatory services, providing ACP support using materials developed locally and as part of Advance Care Planning Australia.	Identified directly through a clinician and member of ACPEL*
Northern Health	A publicly-funded provider of acute, sub-acute and ambulatory specialist services in Melbourne, providing ACP support using the 'A-C-P in three steps' approach developed within Northern Health.	Identified through snowball sampling via *Austin Health*
Barwon Health	A publicly-funded, large regional health service, providing acute, sub-acute, elderly care, community health and mental health services, with ACP support delivered across secondary and primary care using materials, including MyValues, developed in Barwon Health.	Identified through snowball sampling via *Austin Health*
Albany Health	A regional primary and secondary healthcare system, providing ACP support using forms developed by the Western Australian government and piloting systems for communication and access of ACP documents.	Identified through an academic and member of ACPEL* and through a contact identified by the authors in an earlier study they led into the economics of ACP
New Zealand		
The Canterbury Initiative	A District Health Board initiative, delivering change and quality improvement initiatives across community, primary and secondary care and providing ACP support using materials developed by the Canterbury Initiative and by the National ACP Cooperative, New Zealand.	A clinician and member of ACPEL* made an introduction to the National ACP Cooperative who, in turn, made an onward introduction to the *Canterbury Initiative*
Auckland District Health Board	A regional health authority overseeing community, primary and secondary care, providing ACP support using material developed by the National ACP Cooperative, New Zealand.	Identified through a clinician and member of ACPEL*

organisation compiled a list of personnel with in-depth experience of developing or delivering ACP support and a range of others with routine experience. These included senior managers, dedicated ACP staff, physicians, nurses, social workers, volunteer staff and others. These lists were then narrowed, in consultation, with a view to balancing staff with different roles and for reasons of manageability or availability.

All identified staff were sent an introductory letter describing the study and what participation would involve. They were informed of the voluntary nature of participation and given the opportunity to opt out of further contact by emailing the key contact person in the organisation or the research team. If they did not opt out, they were invited to interview. These were scheduled, for logistic reasons, by the key contact. Participants were informed that they could withdraw at any time and were provided contact details for an independent person responsible for research ethics at LSE if they had concerns or queries about the conduct of recruitment or interviews.

Conduct of interviews

We conducted between 3–25 (average 13) interviews in each organisation during fieldwork visits undertaken November 2015 to May 2017 (**Table 2**). Most were individual (n = 112), although, for practicality, 18 group interviews involving between 3–12 people were also conducted. Interviews lasted 20–180 minutes. Fully informed verbal consent was obtained at the beginning of each interview. Topic coverage was adapted to reflect the role and expertise of interviewees, with people asked about their own role and experiences as well as their wider perspectives on the provision of ACP support in their organisations. Information provided in early interviews was cumulatively tested and further explored in later interviews. Interviews were audio-recorded with permission.

Data analysis and reporting

Audio-recordings were listened back to in full as soon as possible after the interview and a comprehensive, descriptive written summary produced. Time-stamps were used to reference the audio-recordings, and potential quotes were included verbatim. Longer and more complex interviews were listened to on two or three occasions. Analytic notes were taken simultaneously. This process of data reduction is appropriate for analyzing large volumes of interview data in thematic analysis and supports comprehensive and systematic data handling (Ritchie et al., 2013). Data management thus also involved several stages, allowing for considerable familiarization.

Data were then analyzed thematically using NVivo software (Ritchie et al., 2013). The theoretical orientation employed was pragmatic (Cresswell, 2018). Given the requirements of fieldwork, interviews and analysis were conducted primarily by a senior qualitative specialist (JD). A second senior researcher (MK) read a sample of interview summaries, commented on coding frames and provided regular critical input into evolving and final analyses, with any differences resolved through discussion and consensus. Feedback on coding frames and evolving analyses was also obtained in face-to-face meetings with a project advisory group. Descriptive analyses reported in this paper were checked for accuracy by the key contacts in each organisation; no substantive changes were proposed. Quotes are identified throughout by country and professional role, differing slightly from categories in **Table 2**, to provide appropriate context while protecting respondent anonymity.

Results

Results are presented in three sections:

1. *Resources for delivering system-wide support* provides context by describing the types of staff and other resources employed by organisations to provide system-wide ACP support.
2. *Organisational aims and objectives for providing system-wide ACP support* explores organisational rationales for providing system-wide ACP support; sub sections consider 2.1) *Patient and family care*, 2.2) *Health and care staff* and 2.3) *The Economic case*.
3. *Delivering system-wide ACP support efficiently* examines factors associated with variation in the time taken to facilitate ACP conversations and identifies promising approaches for efficient and equitable provision of ACP support at scale; sub-sections consider 3.1.) *Staff skills and experience*, 3.2) *Materials, guides and approaches* and 3.3) *Informational and educational needs of patients and families*.

1. Resources for delivering system-wide ACP support

The primary resource used to deliver ACP support was staff time, covering strategic, specialist and generalist roles. While senior involvement varied between systems and over time, it was generally high, particularly during development and implementation stages. In one US system, for example, an executive-level leader had devoted around 30 hours over several months to oversee a review of ACP support provision, including several pilot studies. Internal performance improvement teams and externally commissioned consultants also provided strategic support. Most organisations additionally employed full-time ACP leads (in two systems, senior academic physicians took this on as an adjunct role). Responsibilities included the development of ACP resources, staff training and support, quality control, process improvements, external liaison and community outreach. ACP leads, particularly in larger systems, sometimes also oversaw community volunteers or worked with local community groups. In four of the larger healthcare systems in the US and Australia, between 2–4 dedicated ACP facilitators were also employed, part-time, to facilitate ACP conversations and to coach other staff.

Across all organisations, within their existing roles, physicians, nurses, social workers, care coordinators, occupational therapists, spiritual advisors and others provided day-to-day ACP support directly to patients and their families and, sometimes, to others in the community. ACP conversations of sufficient quality and scope were thought, depending on complexity, to take 30–90 minutes, either in one or multiple sessions. ACP staff were supported, in some instances,

Table 2: Interviews by healthcare system and respondent role.

	Gundersen	Dartmouth-Hitchcock	Wisconsin Medical	Sharp	NARP	Fraser	Austin	Northern	Barwon	Albany	Canterbury	Auckland	TOTAL
Senior managers/leaders	4	1	2	2	0	1	1	0	2	0	2	2	17
Dedicated ACP staff	2	3	3	3	0	1	4	1	3	0	3	1	27
Physicians	2	2	1	2	1	2	3	2	2	4	3	0	21
Nurses	3	2	5	1	8	6	0	0	1	3	5	3	37
Social workers	4	0	5	2	2	1	0	0	1	0	1	1	17
Other	10	6	1	2	1	5	4	0	2	2	3	2	38
TOTAL	**25**	**14**	**17**	**12**	**12**	**16**	**12**	**3**	**12**	**9**	**16**	**9**	**157**
Individual	19	1	7	12	12	16	12	1	6	9	10	7	112
Group	3	5	3	0	0	0	0	1	2	0	3	1	18

Notes:

- Respondents sometimes filled more than one role. In these cases, we have selected the primary role. For example, physicians with a full-time clinical position are categorized as physicians even if they are an ACP lead or hold other leadership roles.
- The category of physicians includes hospital physicians (including palliative care physicians, geriatricians and other specialists) and general practitioners.
- Dedicated ACP staff are those whose positions are exclusively or predominantly ACP-related.
- Other includes spiritual care advisors, volunteers, care home staff, speech therapists and occupational therapists.

by administrators who scheduled appointments and checked and scanned completed ACP documents. Because ACP support was provided by different staff groups, often delivered with other care and broken into multiple shorter conversations and not separately recorded, no organisation was able to quantify the time spent by health and care staff delivering ACP support. While some of this work was potentially absorbed into existing care, much was widely thought to be additional work. A companion article explores the different approaches taken by health and care staff to accommodate this work in their day-to-day roles, noting the significant challenges presented by time constraints (Dixon and Knapp, 2018). Total staff time spent receiving training could also be substantial, particularly where large numbers of staff were trained, with courses ranging in duration from one or twohours to two or three days.

Non-staff resources included training resources; these were provided nationally online, developed and delivered in-house, directly commissioned from external providers or delivered within existing continuing professional development provision. Materials such as conversation guides and forms varied in cost to the organisation delivering ACP. These were sometimes available from national or regional initiatives, usually free of charge; others were purchased, sometimes as part of wider support packages, or were developed or adapted internally. Where ACP support was provided as part of routine care, this took place in usual appointment rooms but otherwise took place in vacant consulting rooms and offices, at the hospital bedside, in people's homes and in community settings. Adaptations and updates to existing electronic patient information systems were sometimes implemented to allow ACP conversations to be more readily recorded and documents retrieved. Respondents also identified variable costs associated with external promotion and outreach activities.

The costs of staff time and other resources for providing ACP support were met primarily from existing internal budgets. Governmental and other external sources of funding were sometimes available but largely for developing ACP infrastructure and for public engagement, rather than direct provision of ACP support. However, during the course of our study, new funding for facilitating ACP conversations was identified, including a new Medicare charging code in the US and flexible use of existing Medicare codes in Australia. In one New Zealand system, the District Health Board also incentivized general practitioners (GPs) to complete plans for people in their last year of life. Initial take-up was slower than anticipated, largely due to GP time pressures. However, a change allowing nurses and social workers to facilitate conversations under GP supervision led to a steady increase in use of the incentive. Most leaders expected their organisations to sustain their commitment to providing system-wide ACP support with, occasionally, additional investments envisaged. Only exceptionally, in the context of budget cuts or less supportive funding contexts (e.g., fee for service) were investments in ACP support considered vulnerable.

2. Organisational aims and objectives for providing system-wide ACP support

The aims and objectives described by leaders for providing system-wide ACP support were complex and multiple. Overall, leaders discussed the provision of ACP support as a strategic response to a range of emerging challenges associated with an ageing population, higher levels of chronic illness and frailty and greater availability and use of potentially life-prolonging treatments in advanced illness. These challenges, and the role of ACP in helping to mitigate them, are discussed in the following sections: (2.1) Patient and family care, (2.2) Health and care staff and (2.3) The economic case.

2.1. Patient and family care

The provision of system-wide ACP support was commonly discussed as a way of systematically improving patient and family care in the context of growing levels of chronic, progressive disease. In the absence of ACP support, such patients and families were often thought insufficiently prepared for eventual deterioration in their health condition and the medical decision-making likely to be associated with this.

> Many patients are in a stable chronic state, but they need to understand that this stability will end. (Physician, Canada)

People could have unrealistic expectations concerning the care they were likely to receive in the future. Some assumed, for example, that they wouldn't be offered or provided with aggressive treatments.

> People don't always understand that they are going to be treated, and possibly quite extensively, even as they get older and frail. (Physician, Australia)

Others expected to be provided with all and any available life-prolonging treatments, potentially overestimating the likely benefits while underestimating associated burdens and risks.

> People's expectations of healthcare are very high. People have come to see medicine as being the fix-it for all sorts of things. (Physician, Australia)

Without appropriate knowledge and preparation, families may also, particularly in the context of health crises, request everything is done for their relative.

> Guilt and panic can lead people to opt for the default of wanting more and potentially inappropriate interventions; 'I can't let mom go without feeling I've done everything possible' (Physician, Australia)

In the face of uncertainty, hospital physicians too were thought to err towards providing life-prolonging treatments. They were thought to underestimate treatment burdens, had limited training in palliative and end of life care and could be unsure about their legal responsibilities to treat. As a result, marginal, and potentially unwanted, treatments were sometimes provided, with some respondents specifically identifying this as a medical consent issue.

> It {ACP} is really important as we're potentially talking about very burdensome treatments or treatments with a risk of poor outcomes. For example, resus[citation] is such a bad treatment, so few people do well, so I think you need consent for this. (Physician, Australia)

Importantly, without ACP support, people were generally unaware of their right to express preferences about how health and care decisions are taken or to refuse certain medical treatments.

> People don't know they can choose not to have treatment. They think they don't and that's euthanasia. (ACP specialist, New Zealand).

In this context, systematic and routinised provision of ACP support was thought to help prepare patients and families, clarify patients' preferences and support professionals to personalize care and limit the use of low-value or potentially futile treatments.

> Empowering doctors to say, you know, I am not going to insert a feeding tube in your 92-year-old grandma who has end-stage Alzheimer's and multiple comorbidities. (ACP specialist, US)

It was also thought to help avert a range of associated organisational-level risks, including increases in the level of formal complaints, particularly from bereaved families dis-satisfied with their relative's end of life care, and reputational risks, politically and in the media. One respondent in the US also saw potential for new legal challenges associated with the provision of unwanted treatments.

> There was a recent article in the New York Times, 'The patient lived and the family sued.' I think we will be seeing an increase in this. (ACP specialist, US).

2.2. Health and care staff

As a result of an increase in chronic progressive illness and greater need for medical decision-making at points of health crisis, health and care staff were thought to be increasingly at risk of conflictual and/or crisis-driven conversations with families.

> As a tertiary provider, we have serious long-term and acute cases transferred, so we have that perspective and see what happens when people are unprepared; conflict between family members and between them and clinicians, residential care staff etc. (Leader, New Zealand)

Staff were also thought to be increasingly exposed to the risk of moral distress, particularly with regard to aggressive medical treatments in advanced illness.

> The default is always to provide aggressive care, so I was asked to do things I thought were ethically wrong and medically wrong. (Physician, US)

> They think doctors are not stopping; nurses are thinking, 'why is this treatment happening? (Physician, Australia)

At an organisational level, these pressures could lead to poor staff morale and related workforce management challenges. System-wide provision of ACP support was seen to mitigate these risks by promoting improved and more timely communication between professionals, patients and families and by reducing the pressure on physicians to provide marginal, low-value or potentially futile treatments.

2.3. The economic case

Organisational risks, such as complaints from families, reputational damage and poor staff morale, were also associated with unpredictable but potentially significant economic costs, which the systematic provision of ACP support was thought to help manage. It was also considered a way to make best use of resources, by redirecting staff time towards timely, rather than crisis-driven, interactions with patients and families and by providing fewer unwanted, low-value medical interventions.

> For a long while it's about maintaining quality of life and living with illness, but then there is a time when it is about dying and diminishing returns and there are huge costs to get to tiny benefit … Most people have a threshold and we're not identifying that point reliably. (Leader, Canada)

Consequently, some respondents thought that ACP support could help to reduce spending on end of life care in acute settings.

> If just one person is not stuck in ICU [intensive care unit] for three months as a result, it's easily paid for itself. (ACP specialist, US)

> If you do it properly, suitably efficiently, it seems likely that there will be savings. There is evidence of oversupply, treatments people don't want. People are able to have a conversation and potentially withdraw from active treatment, will not be hospitalised; there must be savings attached. So, some of the challenge is establishing the quality indicators determining that this is also better for people. (Leader, Australia)

It was widely understood, however, that any savings needed to be set against the costs of making ACP support widely available and that costs were also likely to be incurred in providing alternative, community-based support. Some respondents also thought acute savings could be limited, with people preferring or needing, particularly where appropriate community-based care was lacking, to be admitted to hospital.

> A lot of people want to die in hospital, that's okay. It won't necessarily save resources. (Physician, New Zealand)

> The trouble we had was that we did try to measure costs, but if you opted out of aggressive care it wasn't as though there was somewhere else you could go to, you still had come to hospital. (Leader, Australia)

Overall, there was no widespread expectation of overall cost savings and no organisation had identified economic outcomes or targets for its ACP support provision.

> There is an economic argument but we aren't interested in any financial outcomes. (ACP specialist, New Zealand)

ACP was also widely understood by leaders to be a complex intervention, the full economic implications of which were necessarily difficult to measure. Leaders noted particular challenges in gathering accurate and comprehensive cost and activity data, placing economic value on quality improvements and determining causal associations.

> It's too cumbersome to get accurate costs figures because people would need to charge to the code and it's more work than it's worth, particularly because it cuts across departments and overlaps with other work. (Leader, US)

> The health economics people we've worked with say what's hardest is linking cause-and-effect in practice in a complex intervention like ACP. (Physician, Australia)

Scope for media and public misunderstandings could also limit discussion about the potential economic implications of ACP. To sustain investments, leaders wanted research evidence that demonstrated economic value (rather than cost-savings), including showing positive impacts for patients and families and reassurance concerning potential harms. Leaders also wanted evidence about how ACP support could be delivered optimally, with an indication of the level of resource needed.

> It would be good from my perspective, in order to ask for more resources, to validate the amount of resource that is required. (Leader, Australia)

> The aim is to improve quality and efficiency, to make it leaner. It's part of the culture. You know you need to do it. The hard part is knowing how much resource to put into it and how to put that resource into it. (Leader, US).

3. Delivering system-wide ACP support efficiently

Finally, we explored factors associated with variation, within and between systems, in the level of resource, notably staff time, used to provide ACP support. Through this, we were able to meet our third research objective of identifying scope for efficiencies in the delivery of ACP support at scale. In particular, we generated evidence around three main themes: (3.1) staff skills and experience, (3.2) materials, guides and approaches and (3.3) informational and educational needs of patients and families

3.1. Staff skills and experience

The experience and abilities of staff were widely considered key to the efficient, as well as effective, facilitation of ACP conversations.

> If you're good, it may only take about 45 minutes. There are other people who take two hours and come out just with medical power of attorney. (ACP specialist, Australia)

> There are two parish nurses who do advance care planning with people in their homes. They're efficient; their ones are shorter, about 30 minutes. (Volunteer, US)

Leaders, however, described challenges in developing these competencies in their workforces. Existing medical training for physicians, for example, was identified as lacking adequate coverage of communication skills or end of life care.

> It does seem extraordinary that people who are dealing with really serious illness do not get too much education around end of life. Most people are currently learning on the job. If they've not had that really fully in their early education, and if you're learning from someone who does it poorly, then that's not good. (Leader, Australia)

To develop workforce skills, some organisations had previously provided in-depth training to substantial numbers of physicians, nurses and social workers, with the intention of embedding ACP widely in practice. However, many staff failed to apply and develop their skills in practice because of time constraints, perceptions that this work was not sufficiently acknowledged or supported in their departments or due to staff turnover.

> We trained thirty-one, but only ten are active. The rest changed position or decided they couldn't do it on top of their work. (Nurse, Canada)

> They trained everyone but sitting down and talking to patients wasn't always recognised. You might get people championing it for a while, but they would get tired or would move on. (Physician, Australia)

In some cases, staff were reluctant or lacked confidence and, once trained, either didn't facilitate ACP conversations or did so less effectively and efficiently.

> People were put forward and volunteered for training. We trained people for two days and never heard any more from them. People turned up not knowing what they were there for. (ACP specialist, New Zealand)

> It was pushed onto people who weren't that competent. It took ages and they struggled to do it. (Leader, Australia)

Staff could also find it hard to get enough practice, following their training, to develop and maintain their skills.

> It was so was hard to get their skills up. They needed more experience. (Physician, Canada)

At the same time, there was wide agreement that reliance on a select group of dedicated ACP facilitators was neither scalable nor sustainable. In organisations that employed them, dedicated ACP facilitators could demonstrate ACP was acceptable and feasible in a clinical context and could provide support to other professionals. They were also independent of physicians, who patients might feel a need to please. However, they tended to take longer to facilitate a conversation, and ACP could be insufficiently integrated with the rest of a person's care. They could also give physicians, nurses and others the impression that providing ACP support was not their responsibility. Organisations sometimes aimed to find a middle way. In one well-established organisation, most staff were expected to introduce ACP and refer while a pool of 30–40 staff, primarily nurses and social workers, were trained to undertake ACP conversations. These staff worked with their managers to find the additional time needed to accommodate this work alongside their day-to-day roles.

Views concerning the amount of initial training needed also varied. Longer training sessions, of two to three days, ensured sufficient topic coverage and skills development, including opportunities to practice facilitation. However, some respondents thought shorter sessions, from two hours to a day, were sufficient, as well as more realistic and less off-putting for those with no previous experience of ACP. It was suggested follow-up training could be provided to those who would go on to conduct ACP conversations regularly or who wanted to develop specialisms, such as working with people with specific diagnoses.

3.2. Materials, guides and approaches

A wide range of ACP approaches and guides were employed in the organisations engaged in this study (see Appendix 1). A range of government and state forms were also in use. None of these specifies the length of an ACP conversation, while materials and guides range from comprehensive and structured to short and flexible. The benefits of more comprehensive and structured guides were they included tried and tested questions and processes, encouraged consistency and were thorough.

> We need to do enough at the front end to work out what they really mean and what they understand. (Leader, US)

However, others found such approaches to be complicated, inflexible or unhelpfully inclusive.

> Some of the questions can be patronizing, repetitive and unnecessary. They didn't know why we were going through the same things again. (Social worker, US)

> We want to ensure we are not saturating the document with so much information it becomes too much and paralyses us. (ACP specialist, US)

They were also considered less amenable to being broken down into shorter, more opportunistic conversations.

> The kinds of things that came back are 'it's too complicated', 'they didn't have the time'. And there was a sense that if you start you have to go the whole way. People were daunted by that. (Physician, Australia)

However, in practice, we found more comprehensive and structured guides were often used flexibly or selectively and conversations using these, particularly when led by experienced staff, generally took no longer than those undertaken with shorter, more flexible guides. Shorter and more flexible guides were also not intended to, nor did they, necessarily result in significantly shorter conversations.

Two new approaches were mentioned, however, as potentially having cost-efficiency benefits: Ariadne Lab's Serious Illness Conversation Guide and a group facilitation model based on Respecting Choices®. The Serious Illness Conversation Guide was designed to help non-palliative physicians integrate basic elements of palliative care, including ACP, into their practice.

> It is discrete, do-able. The training is two and a half hours. Most people can manage that. The conversation is 20-minutes. Most people can think about doing that. (Leader, Canada)

While considered highly valuable for engaging clinicians, particularly busy consultant physicians, the guide is, however, intended for advanced illness. There was, consequently, concern that, unless built upon earlier ACP-style discussions, patients and carers may be poorly positioned to participate meaningfully in them.

> If you've just got a diagnosis, serious illness conversations may not apply yet. (ACP specialist, Canada)

> Some say this is 20 mins. I don't think a 20-minute conversation is realistic. They're not meant to be yes, no answers. (Physician, Canada)

> It is helpful if they've done advance care planning beforehand as then there is more to hang your hat on. (Physician, New Zealand)

Group facilitations based on Respecting Choices® were described as lasting around an hour, with 4–12 attendees, sometimes including family members. One, sometimes two, trained facilitators led the groups, with time for questions and discussion. In the two organisations using this approach, the groups were popular. Participants were reported as feeling less obliged to complete ACP documents than in one-to-one discussions and to value the peer sharing aspect.

> The group works well for some people because they hear what other people say and it enriches their experience of the discussion. (Social worker, US)

Facilitators ran groups on a regular basis and developed expertise in this approach. In one US-based system, for example, eight nurse health coaches from primary care clinics each led a monthly group. Participants could complete documents immediately afterwards, assisted by a facilitator, or book a one-to-one ACP conversation. Providers estimated that 25–50% of participants completed documents and around 5% booked a follow-up ACP conversation. We found examples of groups involving the general public, people just having received diagnoses and disease-specific groups.

> Disease-specific groups are a really good model; they're all facing similar issues. I don't find people are reluctant to discuss their issues in the group. Those who don't want to talk about themselves will just sit and listen. (ACP specialist, US)

The approach was thought to increase reach and to be a cost effective and equitable means of providing ACP support.

> Our groups have been fabulous so far. They have allowed us to serve more people with less resources. (ACP specialist, US)

3.3. Informational and educational needs of patients and families

Finally, respondents repeatedly described the informational and educational needs of patients and families as being a significant influence on the amount of time needed for an ACP conversation. ACP was often a new concept for people, and it could take time to explain its purpose and scope.

> What can make it take a long time is their ability to understand what it's all about. (Nurse, New Zealand)

Patients and families often needed clarification and reassurance about the legal and formal aspects of ACP. They sometimes also had a poor understanding of their condition, necessitating more conversation time and/or physician referral. Considerable time could also be spent explaining the implications of specific treatments, such as cardio-pulmonary resuscitation (CPR), assisted ventilation, clinically-assisted nutrition and clinically-assisted hydration.

> Can get into circular, murky CPR conversations. They don't believe you. They want to have it first so they aren't dead. It's hard to get people to understand only 4% will be alive. This takes time. (Social worker, US)

> ACP raises a lot of questions, things like, 'what if I faint, will I not be helped if I've said no to CPR?' sort of thing. This takes explaining. (Nurse, Australia)

> People have a lot of questions about nutrition and it can take up a lot of the conversation. (ACP specialist, US)

Some staff, particularly social workers and others with limited clinical backgrounds, found using decision aids useful to help simplify and standardise these conversations.

> It's a pictorial decision aid; gives you information that's hard to explain otherwise. (Social worker, Canada)

> We may well end up going down the road of using decision aids; there is a company that have some really sleek and useful health decision aids. Also, you don't know what information physicians are giving. You like to believe that they are giving standardised, credible information, but you don't know. (Leader/physician, US)

People also often had questions about the process of dying that had not been addressed elsewhere and often had only limited awareness of palliative treatments.

> People want to know if they'll be in pain, worried they won't be conscious and in control. Issues around difficulties breathing and feeding are not well understood, and they don't know about the things that can be done palliatively; there's been lots of progress. (GP, Australia)

Some participants needed support across many or all of these areas, and these conversations could be particularly lengthy.

> They may have poor understanding, say, of CPR. May not know what they want or who should be the agent. It can be a lengthy discussion just trying to explain things, an hour to an hour and a half. At that stage I suggest they go home and reflect. Repeated appointments are not unusual. (Nurse, US)

Where people, and their families, had attended community-based education or events or undertaken other preparation, particularly earlier on in the disease trajectory, ACP conversations could be much shorter.

> If they are prepared it can be quick. We will have sent information; some will read it and some won't. (ACP specialist, Australia)

> The good thing about drawing people in through education, outreach and community presentations is that they will have already thought through some of the questions and discussions. It will, therefore, be less protracted. (Social worker, US)
>
> It's really hard getting people to think about this stuff. The first time is often when they are acutely unwell. They need to start educating people along the journey, along the way. (Physician, Australia)

While it was thought important that people had sufficient and equitable access to high-quality ACP support, some thought it an inappropriate use of resources for staff to spend considerable time in individual ACP conversations attempting to elicit clear preferences from those who remained indifferent, undecided or wished professionals to make these choices.

Discussion

ACP is emphasised in national policy in many countries within the context of rapid population ageing and increasing chronic illness burden (Prince et al., 2016; Institute of Medicine, 2014). However, the demands on staff time of providing ACP, particularly at scale, are widely understood to be a significant barrier to implementation (Dixon and Knapp, 2018; Fritz et al., 2017; Lund et al., 2015; Hagen et al., 2015; van der Steen, 2013; Sharp et al., 2013; Seymour et al., 2010). The resourcing of ACP support provision at scale remains, therefore, an important evidence gap. In particular, our study directly responds to calls in the literature to move beyond small-scale pilots and to consider how ACP support may be provided and resourced at a whole organisation and/or system level (Jimenez et al., 2018; Hagen et al., 2015). In particular, we set out to understand how leaders working to provide ACP support across their organisations, and commonly also into adjoining systems, justified their investments, as well as to explore their perspectives on the economic case. We also aimed to gain insights from leaders and practitioners into ways of delivering ACP support efficiently and equitably at scale. We found many common challenges and experiences with some limited differences associated with the relative size of the organisation and population served, the maturity of ACP support provision, availability of different types of staff and, occasionally, specific or innovative approaches. We discuss the implications of our findings in two parts: organisational aims and objectives and the economic case and delivering system-wide ACP efficiently at scale.

Organisational aims and objectives and the economic case

Leaders identified multiple, inter-related organisational aims and objectives, raising questions about how ACP support is most usefully conceived and about the research outcomes that are most relevant (Jimenez et al., 2018; Gilissen et al., 2018; Sudore et al., 2018; Dixon et al., 2015). Researchers, to date, have primarily conceived of ACP as a means of promoting patient autonomy, with some research focused also on how ACP impacts the utilisation of acute healthcare (as a proxy for reductions in unwanted treatments) (Brinkman-Stoppelenburg et al., 2014; Dixon et al., 2015). Leaders and other respondents in our study emphasised the role of ACP in supporting patient choice and control over the type of care received in advanced illness, with many seeing ACP as key to ensuring people did not receive unwanted treatments, and this was identified specifically as a medical consent issue. However, improved communication with family members was also identified as an important objective, with a view to improving families' experiences, reducing moral distress for families and, at an organisational level, mitigating risks of formal complaints from family members, reputational damage and potential legal challenge. In the ACP literature, there is some focus on the role of family members in end of life decision-making, particularly in dementia (Brazil et al., 2018; Harrison-Dening et al., 2016; Davies et al., 2014) and some theoretical literature, for example, around ACP and relational autonomy (Johnson et al., 2018; Ikonomidis and Singer, 1999). However, there is undoubtedly greater scope for developing these areas of research and for considering how to better support the families of people with serious illness and frailty in the context of increasingly complex decision-making about treatment and care. In addition, leaders intended for the systematic provision of ACP support to help create a more supportive culture and environment for health and care staff. As well as enabling them to limit the provision of low-value or potentially futile interventions, it was expected that ACP could help to reduce experiences of conflict in interactions with families, workplace stress and the potential for moral distress (Oliver, 2018; Pauly et al., 2012). This, in turn, was seen to contribute to more effective workforce management at an organisational level. So far, research into the provision of ACP support has tended to focus on the challenges for staff of implementing ACP (Dixon and Knapp, 2018; Lund et al., 2015). However, there is likely scope for researchers to explore the potential benefits of ACP, both for individual staff members and at a workforce level.

Leaders in our study saw an economic case for systematically offering ACP support, with this an important aspect of retaining organisational support for investments. However, the economic case primarily focused on realising economic value rather than cost-savings. This included the intrinsic benefits to patients, family and staff discussed above, with this particularly important to those working within population health systems, who needed to demonstrate value in terms of prevention and improvements in population well-being (Buck et al., 2018; Alderwick et al., 2016). The economic case also included making better use of resources by reducing reactive use of staff time and limiting low-value treatments. It also included mitigating potentially significant economic risks associated with increased complaints, reputational damage, legal challenges associated with perceived over- and under-treatment, workforce stress and low staff morale.

Some saw the potential for cost savings in acute settings, which is a view supported by a small number of existing outcome studies (Dixon et al., 2015). However, overall cost savings were generally not expected and no organisation had economic targets. Leaders also commonly thought that, even if there was the potential for modest savings, these would be difficult to identify, measure, attribute and, in the short to medium term, operationally realize or redirect. Although not directly mentioned by respondents, we also know there are complex, dynamic and longer-term economic (and quality of life) impacts associated with medical decision-making in serious illness, some of which will fall to health and care providers in future, further complicating the economic case (Gross et al., 2018). In light of this complex picture, while leaders had some interest in research illuminating the economic case, they were more immediately interested in research demonstrating ACP support is good for patients and their families and for clarifying and offering ways to minimise possible harms. They also wanted evidenced-based assessments of how to deliver ACP optimally, an area in which there are currently significant gaps in our understanding, and for these assessments to include an indication of the resources required (Jimenez et al., 2018).

Overall, our findings emphasised complexity (Gilissen et al., 2018), a multiplicity of desired outcomes and stakeholders (Jimenez et al., 2018) and ACP support as a system- as well as individual-level intervention (Jimenez et al., 2018; Hargreaves, 2010). In this context, the provision of system-wide ACP support is also just one of a range of, potentially inter-dependent, strategic actions and structural changes that may be needed to address the same underlying pressures, brought about by an ageing population and the increasing prevalence of chronic progressive illnesses (Johnson et al., 2017). These may include greater personalization, the implementation of public health approaches and more focus on intermediate and community-based care; new funding and delivery models, such as population health approaches, which incentivise prevention and improvements in well-being for a target population over volume of care (Buck et al., 2018; Alderwick et al., 2016); and improved awareness and availability of supportive and palliative care (Campbell and English, 2016; Dixon et al., 2015). Changes in medical training and culture are also likely to be important, including improved coverage of communication skills and end of life care in basic medical training (Head et al., 2016; Gibbins et al., 2011), improved physician skills in assessing and communicating the respective benefits and harms of treatments (Hoffmann et al., 2017) and improved end of life care skills within nursing homes (Anstey et al., 2016). The Serious Illness Conversations training and guide, referred to by some of our respondents, is also pertinent here (Bernacki et al., 2015). Additionally, further development of initiatives designed to minimize burden and harm from over-investigation and overtreatment, such as Choose Wisely (US), Speak Up, (Canada), Rethinking Medicine (UK) and Realistic Medicine (Scotland), are relevant (Gross et al., 2018). At the same time, while the provision of ACP support may be one element in a wider series of related structural interventions and developments, it retains a unique role, providing a means for individuals to consider and express preferences concerning their future care in a context in which high-risk, high burden treatments are increasingly available and provided in the late stages of illness.

Delivering system-wide ACP efficiently at scale

Delivering ACP support efficiently was identified by leaders in our study as important for viability and equity and important for justifying additional investments. Although offering ACP support was seen to be inherently resource-intensive, we identified several areas in which meaningful efficiencies may be sought. Firstly, we found that staff who were skilled and experienced at facilitating ACP conversations were most efficient, while those who undertook ACP irregularly, were reluctant or lacked confidence were widely thought to take much longer and to achieve less. This finding adds to existing debates in the literature about whether ACP should be facilitated by dedicated facilitators or by health and care staff within their existing roles (Pollock and Wilson, 2015; Lund et al., 2015; Hammes et al., 2012). Having professionals incorporate ACP into usual care has been a common policy preference for reasons of perceived efficiency and continuity of care. However, we (in a companion paper) and others have found, using this approach, ACP can get squeezed out or become unhelpfully fragmented, roles and responsibilities can be unclear and sufficient physician input can be lacking (Dixon and Knapp, 2018; Lund 2015; Robinson et al., 2013; Sampson et al., 2010). Findings from the current study further suggest even when professionals do deliver ACP support within their existing roles, they are likely to facilitate conversations infrequently and less efficiently. In-depth training is also harder to target where facilitating ACP conversations is a general responsibility. Our findings, therefore, point to the need for a degree of specialism (Pollock and Wilson, 2015). At the same time, existing research (including our own, in a companion paper) suggests that a cadre of dedicated ACP facilitators is not sustainable, not likely to optimize efficiency or effectiveness and may lead to ACP being unintegrated with other care (Dixon and Knapp, 2018; Occhipinti and Ramos, 2018; Lund et al., 2015). Overall, then, the evidence suggests models that balance continuity of care with skilled, efficient delivery are required. In one US-based organisation, for example, a pool of specially trained nurses and social workers were available for referrals, usually from physicians, with time set aside in their schedules for this work. In other organisations, this balance was achieved by GPs and other physicians working closely with specially trained nurses and social workers in their own teams (Dixon and Knapp, 2018). Such team-based approaches are also consistent with many new models of care, including patient-centred medical homes and primary care homes (NHS England, 2019; Kumpunen et al., 2017; RACGP, 2016; Collins, 2016).

There were varied views about whether longer and more structured guides or shorter, simpler guides were more efficient. Comprehensive and structured conversation guides could initially be experienced as cumbersome. However, some appreciated the greater guidance they provided, and it was generally thought that, used flexibly by experienced staff, they did not necessarily lead to longer ACP conversations than shorter guides. Two specific approaches, however, were mentioned specifically as having efficiency implications. The Serious Illness Conversation guide from Ariadne Labs was praised for its ability to engage time-pressured clinicians, particularly in acute settings, and for its simplicity and brevity (Bernacki et al., 2015). However, because it is short and intended for advanced illness, it was seen as important it build on earlier ACP conversations. Therefore, while the approach may have other positive effects, it would not necessarily save staff time. Where they were used, group facilitations were thought a cost-efficient way of extending reach. They were generally run by staff with expertise in this approach, were suitable for all stages of illness and, while rates of document completion were lower than in one-to-one conversations, they could help to prepare people and simplify later conversations and/or decision-making (Lin et al., 2019; Sudore and Fried, 2010). It seems likely there is scope for group approaches to be more widely developed, building on public health approaches to end of life care locally (Karapliagkou and Kellehear, 2013; NHS England/LGA, 2017).

Existing research shows lack of public awareness of ACP and poor understanding of the limitations of medical interventions and of palliative and end of life care are significant barriers to the uptake of ACP (Hagen et al., 2015; Lovell and Yates, 2014; Seymour et al., 2010). Our research adds a new dimension to this literature, suggesting, even where people take up ACP support, their informational and educational needs, and those of family who accompany them, can dominate ACP conversation time, with this potentially contributing to persisting inequalities in end of life care (Roberts, 2015).

We found only limited use of decision aids, but where used, they were thought to help simplify conversations, increase equity and support non-physicians to facilitate ACP conversations effectively (Gross et al., 2018). They were thought especially useful for commonly misunderstood interventions (e.g., clinically-assisted nutrition and hydration, assisted ventilation and cardio-pulmonary resuscitation) and for where facilitators may lack specialist clinical knowledge (Gross et al., 2018). This, therefore, seems a useful area for further development (Jimenez et al., 2018; Jain et al., 2015; Aslakson et al., 2015; Butler et al., 2014). However, it is also the case relying solely on individual ACP conversations to address these informational gaps and misunderstandings may not be the most efficient approach, suggesting a need for a strengthened public health approach to end of life care, with investments in well-designed, locally relevant public education initiatives (Jimenez et al., 2018; Sallnow et al., 2016; Karapliagkou and Kellehear, 2013).

Finally, as earlier noted, the provision of ACP support may be most usefully understood as a complex intervention, with multiple desired outcomes for different stakeholders and inter-connections with a range of other structural developments. It is probable that, as these wider system changes, designed to reduce dependence on acute medical care, are progressed, ACP as a process and the issues covered by ACP conversations will become better understood by health and care staff, patients and families. As a result, ACP conversations may well become somewhat less challenging and time-consuming to facilitate in future.

Further systematic research into these promising approaches is needed to determine how they can be delivered optimally and to determine their potential impacts on efficiency and effectiveness of delivery of ACP support. Such research should include the perspectives of all stakeholders, including individuals and their families.

Conclusion

System-wide ACP support was understood as a complex intervention, with leaders seeking outcomes at a system and individual level and for different stakeholders simultaneously. The economic case was based primarily on achieving value for patients and families, management of organisational risk and making best use of resources, rather than identifying cost savings. A degree of staff specialism, team-based delivery, use of decision aids, group-based facilitations, public health approaches and wider system change all offer promising ways of delivering ACP support efficiently and effectively at scale.

Additional File

The additional file for this article can be found as follows:

- **Appendix 1.** Materials and guides in use across the organisations involved in the study. https://s3-eu-west-1.amazonaws.com/ubiquity-partner-network/up/journal/jltc/jltc-7_dixon-s1.pdf.

Ethics and Consent

Ethical approval was obtained from the UK National Social Care Research Ethics Committee (Ref: 15/IEC08/0044) and approved locally. All participating organisations and staff have provided fully informed consent to participate in this study.

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Competing Interests

The authors have no competing interests to declare.

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