Oxford COVID-19 Evidence Service

What enables or hinders people in the community to make or update advance care plans in the context of Covid-19, and how can those working in health and social care best support this process?

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SUMMARY

- In the context of COVID-19, some known barriers to advance care planning (ACP) in community settings have worsened, while others have improved. The same is true for known enablers of ACP (Table 1).
- COVID-19 has raised public awareness of ACP, increased the importance of and attention to IT systems, motivated the development of new guidelines and templates, and rapidly shifted 'business as usual' processes and protocols. This presents opportunities to improve ACP in the community.
- However, existing guidelines and resources are to a major extent clinician-focused; there are few video- and web-based ACP resources for the public and those that exist are scattered and piecemeal. This is a concern given good quality evidence that online and video ACP interventions are beneficial, particularly among people with limited English proficiency, poor health literacy and/or from otherwise disadvantaged communities.
- In the context of COVID-19, and to reduce inequalities in access to ACP, we recommend national investment in evidence-based, public-facing resources and integrated systems to support ACP, building on existing resources.
- Alongside this investment, simultaneous, interconnected strategies are needed, underpinned by healthcare policy: training for those working in health and social care, better coordination of electronic medical record systems, and public education and awareness raising.

KEY IMPLICATIONS

The COVID-19 pandemic highlights the importance of advance care planning (ACP), and presents opportunities to widen access to its benefits, in the context of raised public awareness of how health can deteriorate suddenly and unexpectedly. This rapid review synthesises recent evidence regarding ACP in community settings, considering its implications with respect to COVID-19, and highlights existing guidelines and resources.

On the basis of this evidence synthesis, those working in health and social care can support ACP in the community in the context of COVID-19 by:

1. Informing the public about the processes and legal status of ACP and dispelling fears and misperceptions, e.g. that ACP is related to rationing healthcare resources.
2. Creating opportunities for ACP conversations among patients and residents early, particularly among older people and those at increased risk, discussing ACP over several sessions and revisiting decisions.
3. Sign-posting to appropriate written, web-based and audio-visual ACP resources.
4. Adapting ACP to the individual and, if appropriate, including the opportunity to complete ACP documentation, without focusing on this.
5. Using remote consultations for ACP discussions where needed and appropriate, drawing on best practice guidelines.
6. Helping to cultivate a culture of openness around ACP in nursing home settings and having ongoing ACP conversations with residents (including those with cognitive impairment) and their family members.
7. Ensuring ACP discussions are fully and promptly recorded in patient records which are accessible to those who need them.

Health and social care policy can support ACP in the community by:

1. Targeting multiple levels of influence (individual, interpersonal, provider, system) to ensure ACP interventions are effective, sustainable and have maximum reach during the pandemic. At present most ACP guidelines focus on clinicians.
2. Introducing coordinated and consistent public health messaging that reframes ACP as routine and normal for anyone interested in considering and influencing their future care, making ACP driven by the public and supported (rather than owned) by health and social care professionals.
3. Creating a robust, nationally coordinated and public-facing web portal for ACP resources to facilitate this shift and increase awareness and uptake, harnessing the increased use of technological approaches to care and communication during the pandemic. It is essential that resources are diverse, use audio-visual as well as written formats, and are designed to support disadvantaged communities.

4. Ensuring each country in the UK has a comprehensive policy to support ACP and aid its implementation, monitoring and evaluation.
5. Prioritising research into an integrated web-based system for ACP in which members of the public could create an advance care plan which links to their medical record.

These strategies could reduce the input required by professionals and increase the uptake and documentation of ACP, leading to cost-savings for the NHS as well as more person-centred care, and better outcomes and experiences for patient and families.

CONTENTS

BACKGROUND

Advance care planning (ACP) is a process that supports people "at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care", with the goal of helping to "ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness" (Sudore et al. 2017). Documented benefits of ACP include improvements in patient and family satisfaction and well-being (Detering et al. 2010), improved concordance between preferences for care and delivered care (Silveira et al. 2010; Houben et al. 2014), and healthcare savings (Dixon et al. 2015). However, there are inequalities in ACP, with barriers associated with being from an ethnic minority group, lower educational attainment and a non-cancer diagnosis, among others (Lovell and Yates 2014).

Undertaking ACP in community rather than hospital settings plays an essential role in helping patients and families plan preferred care, agree ceilings of treatment and, where appropriate, make decisions to refuse treatment prior to a crisis situation. In the UK, the importance of ACP in the community is recognised in NICE guidance for managers of care homes and home care services, the Royal College of General Practitioners and Marie Curie UK's General Practice Core Standards for Advanced Serious Illness and End of Life Care (Daffodil Standards), and the Gold Standards Framework for best practice in end of life care. However, ACP does not necessarily take place in health care settings or contexts; it can also be initiated by people from home, e.g. via online portals such as mywishes.co.uk or, in London, myCMC.

An ACP process will often result in an Advance Care Plan document (also denoted as ACP)[1]. It can also, but does not have to, include formal documentation of a patient's wish to refuse treatment. In the UK, an Advance Decision to Refuse Treatment (ADRT, also called Advance Directive or Living Will) allows a person to document any treatments they don't want to have in the future, including cardio-pulmonary resuscitation (CPR), in case they later become unable to make or communicate decisions (Compassion in Dying 2020). An ADRT is only used if the person loses capacity to make the treatment decision in question. If it meets certain requirements it is legally binding and healthcare professionals must follow it.

ACP and COVID

While ACP discussions about ceilings of treatment, resuscitation and end of life care preferences, and documenting and sharing these discussions, are always important, they are even more crucial during the COVID-19 pandemic (see below). Open, honest discussions regarding ceilings of treatment and overall goals of care are not only essential to ensure that those with significant potential to recover receive appropriate care, but also that those who are very unlikely to survive receive appropriate end of life care (APM 2020).

Undertaking ACP in community settings such as primary care and care homes can play a crucial role during the pandemic, as professionals in these settings often have the opportunity to get to know patients much better than hospital clinicians, facilitating appropriate opportunities for sensitive conversations that might be difficult to achieve in busy inpatient settings. Given the speed at which patients with COVID-19 can deteriorate, undertaking ACP in the community is important to prevent unwanted hospital admissions, as well as to help ensure appropriate care on hospital admission; it may be too late for ACP conversations on an intensive care unit if the patient is unconscious and family are not present.

Despite the important role of ACP in community settings, there is also the potential for ACP to be poorly managed. During the COVID-19 pandemic in the UK, there have been high-profile cases reported in the media of Clinical Commissioning Groups or individual GP practices posting letters regarding blanket DNACPR (Do not attempt cardio-pulmonary resuscitation) to certain demographic groups (Iacobucci 2020). Given anecdotal evidence of inconsistent and at times problematic practice regarding ACP in community settings, there is a need to synthesise the evidence in this area to inform health and social care practice in the community, both during the pandemic and in the future.

RESEARCH QUESTIONS AND OBJECTIVES

The research questions for this review are:

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[1] We will usually denote ACP to mean the process of advance care planning, but will specify if referring to the documentation.

1. What enables or hinders people in the community to make or update advance care plans in the context of Covid-19?

2. How can staff working in health and social care best support this process?

The objectives are to:

- present what is known about ACP in community settings, considering relevance to people with COVID-19
- report on the feasibility, acceptability, challenges/barriers and facilitators/enablers of ACP in the context of COVID-19, where the need for infection control measures can prevent face-to-face ACP discussions
- summarise emerging evidence and clinical guidelines relevant to ACP in the community during the COVID-19 pandemic

METHODS

We conducted a rapid evidence review with narrative synthesis of the published literature.

Search strategy

We searched for English language publications on PubMed, Embase (OvidSP) [1974-present], LitCOVID, medRxiv, Google Scholar and Google up to 7th July 2020. We broke down the topic to four main searches:

- Advance Care Planning/End of Life Communication during COVID-19
- Interventions to improve Advance Care Planning or End of Life Communication – Systematic Reviews [2010 onwards]
- Telehealth and mobile technologies for Advance Care Planning or End of Life Communication [2010 onwards]
- Advance Care Planning or End of Life Communication and Personal Protective Equipment and

The searches for Embase are listed in Appendix 1 and were adapted for the other databases and web-sites (available if required). We sought to identify works containing the information most relevant to the review objectives, of high quality and most likely to be impactful on practice. These included, where available, systematic reviews and clinical guidelines as well as original research of any study design relevant to the review objectives.

Screening and data extraction

We included systematic reviews and UK guidelines of relevance to ACP in primary and community care settings. We also included original research on ACP conducted with patients in primary/community care settings, with no restrictions on patient age; we excluded research not

conducted in these settings or conducted with patients in a specific disease group. We included communication-focused and narrative interventions as well as formal/documented ACP interventions, and interventions in which ACP occurs outside a professional health/social care setting, e.g. peer-to-peer or online ACP. We excluded studies of interventions focused solely on identifying patients for ACP, and studies of communication practices rather than interventions. In line with the review objectives, we did not exclude studies on the basis of outcome.

For systematic reviews and studies, standardised data extraction was conducted in Excel. Relevance of the included records in answering the review objectives was judged as low, medium or high. Included guidelines are summarised in the text.

Critical appraisal of research

Quality appraisal was conducted of original research studies and systematic reviews categorised as 'highly relevant'. We used Amstar II (Shea et al. 2017) to appraise systematic reviews and the following tools for primary studies, dependent on study design: CASP checklists (RCTs, qualitative studies), Checklist for reporting Theory of Change (Breuer et al. 2016), Quality Assessment Tool for Before-After (Pre-Post) Studies With No Control Group, GUIDED (Duncan et al. 2020) (intervention development).

FINDINGS

CURRENT EVIDENCE

We screened 203 records and identified 21 research studies and 10 systematic reviews that met our inclusion criteria and were classed as highly relevant (see Appendix 2 for data extracted; quality appraisal results available on request). We also identified 12 guidelines related to ACP in the UK during COVID-19.

Barriers and enablers in the context of COVID-19

In 2019 Risk et al. conducted a highly relevant review, Barriers, enablers and initiatives for uptake of advance care planning in general practice: a systematic review and critical interpretive synthesis. A total of 54 studies were included in the critical interpretive synthesis: 8 systematic reviews, 8 randomised control trials, 14 analytical cross-sectional studies, 3 cohort studies, 9 quasi-experimental studies and 12 qualitative studies. The review synthesises the published literature to understand how the knowledge, attitudes and practices of clinicians and consumers in general practice are understood as barriers and or enablers to achieving uptake of ACP, and consider transferability to the Australian context. The authors used a socioecological framework to interpret and map the literature across four contextual levels of influence:
- individual: consumer/patient attitudes, beliefs, knowledge, behaviour
- interpersonal: families, friends, relationships
- provider: provider practice, knowledge, attitudes

- system: linkages, processes, models of care

Another relevant review by Hemsley et al. 2019, not focussed on community settings, identified barriers to and facilitators of ACP and Advance Care Directives and categorised these as applicable to the initiation, documentation or implementation of ACP. The integrative synthesis included 74 original research papers, 12 discussion articles, 1 instructional paper, and 6 review papers; from 14 countries.

We summarise findings from Risk et al. 2019 regarding enablers and barriers in Table 1, using the socioecological framework defined above. Additional findings from Hemsley et al. 2019 and others were integrated as referenced, alongside our assessment of how COVID-19 might have affected these barriers and enablers, based on published literature and reflection on clinical practice during COVID-19.

Table 1: Key barriers and enablers to ACP in primary care, adapted from Risk et al. 2019 and considered in light of COVID-19

Level identified	Barrier		Enabler	
Individual level	Lack of (consumer) knowledge about ACP – including poor health literacy and lack of access to tools (Hemsley et al. 2019)	↓	Demographic likelihood (increased age)	↑
	Attitudes – perceived irrelevance	↓	Education and public awareness	↑
	Trust/questions of efficacy	↑	Stage of change - readiness	=
	Denial/emotions/reluctance	=	Timing	↑
Interpersonal level	Role ambiguity – GP expectation patient will initiate discussion about ACP	=	Doctor-patient relationship (strength, length of, trust, familiarity)	=
	Role ambiguity – patient expectation GP will initiate discussion about ACP	=	Nurse-patient relationship	=
	GP-patient relationship	=	Conversation and deliberation – agreeing on scope/content of discussions, clarification of professional roles, sensitivity to emotions (Hemsley et al. 2019)	=
	Concerns with family relationships	↑	Group interaction	↓
	Preference for informal discussion with family	=	Previous experience with ACP	=
Provider level	Lack of (GP) knowledge/ skills/ confidence – and concern initiating ACP too early might deprive patients of hope/create anxiety (Vleminck et al. 2016)	=	GP and practice nurse education and communication training	=
	Lack of time	↑	GP or practice nurse initiating the ACP discussion	↑
	Misc. concerns including legal uncertainty, prognosis, best time	↑	GP with philosophical agreement to ACP	=
	Doubts about efficacy of ACP	=	GP engagement in team approach	=

System level	Lack of linkages and mechanism for sharing ACP	=	IT systems – portals, prompts, decision aids	↓ ↑
	Lack of funding mechanisms	=	Templates – high quality, personalised content (Hemsley et al. 2019)	↓ ↑
	Lack of standard templates, tools, documents, IT systems	↑	Business as usual processes and protocols	↓ ↑
	Accountability	=	Models of care – group appointments, nurse-led clinics, ACP facilitators	↓

ACP = advance care planning; IT = Information technology

Key - relevance in COVID-19 context:

↑	possible increase in COVID-19 context
↓	possible decrease in COVID-19 context
=	unknown/no effect
↓ ↑	opportunity areas

As indicated in Table 1, in the context of COVID-19 some of these barriers are likely to worsen:
- issues of trust (given fears of rationing of healthcare resources, particularly relevant in some Black and minority ethnic (BAME) groups (Elbaum 2020) but also other communities with experience of discrimination, such as Lesbian, Gay, Bisexual and Transgender (LGBT) older adults (Beringer et al. 2017));
- concerns with family relationships and the physical distance of family members (Miller et al. 2019), particularly given social distancing;
- lack of time among staff, concerns related to prognostication and the best time for ACP, given clinical uncertainty in COVID-19 (Koffman et al. 2020); and
- a lack of appropriate templates, tools and systems in the context of an unprecedented pandemic.

However, other barriers (lack of consumer knowledge about ACP and perceiving ACP as irrelevant) are likely to be alleviated in a context of increased public and media discussion of ACP (Auriemma et al. 2020; Compassion in Dying 2020), with raised awareness and the urgency of COVID-19 acting as a "trigger" to initiate ACP conversations (Combes et al 2019).

With respect to enablers, at the individual level COVID-19 has raised awareness of ACP and its importance at this time, and healthcare staff may be more motivated to initiate ACP discussions. However, other enablers have decreased as group interaction is not possible and certain models of care known to facilitate ACP are therefore ruled out. Other possible system-level enablers have been disrupted during the pandemic, yet may also present an opportunity to enhance ACP on an ongoing basis: COVID-19 has increased the importance of and attention to IT systems, motivated the development of new templates (see *Guidelines*) and rapidly shifted 'business as usual' processes and protocols.

While not a focus in Risk et al.'s review, cultural factors can play an important role in enabling or hindering ACP, as discussed in a systematic review by McDermott & Selman 2018. The authors found culture-related barriers to ACP, including mistrust between patients and

clinicians and cultural variation in willingness to discuss death, evident in lower levels of formal ACP uptake in 14/15 studies in this area. The concept of an advance care plan is not universally accepted and may be seen as intrusive or unnecessary (Calanzani et al. 2013). Attention to these cultural factors are particularly relevant in a pandemic which disproportionately effects BAME communities and has thrown into stark relief existing health inequalities (Elbaum 2020).

Supporting ACP in the context of COVID-19

We identified no systematic reviews of ACP related to COVID-19 and only one paper reporting original research: a small pilot study of an ACP tool for COVID-19. In A Structured Tool for Communication and Care Planning in the Era of the COVID-19 Pandemic, Gaur et al. report on the development and piloting of a tool to facilitate ACP in long-term residential care settings in the US. The tool is intended to guide the discussion between a clinician and a resident and/or their family members about COVID-19 infections, including responding to symptoms and to end-of-life considerations. It includes actions for clinical staff, discussion points, and additional language that may help the discussion and can be modified to suit the context. Headings are: **c**ourse of illness, **o**utcomes in older adults, pro**v**isions we have made, **i**nformed consent, **d**ocumentation. The authors developed the tool based on evidence from a review on communication about serious illness care goals (Bernacki et al. 2014) and in conjunction with palliative and end of life care experts. The tool was piloted with 17 residents; staff evaluated the tool positively but no feedback from residents or families is given.

In all, we identified 10 systematic reviews of studies of ACP either conducted in or relevant to community settings. Interventions were single or multi-component and were compared with usual care or an alternative form of ACP, e.g. written ACP versus online. Despite heterogeneity in components and study quality, there are clear areas of consensus.

The most effective interventions to support ACP in community settings involve mitigating known barriers to ACP uptake and leveraging facilitators. But they also consider the relationships and causal mechanisms between barriers and enablers at different levels of influence (Risk et al. 2019). In this respect they are highly complex interventions: ACP is not a single action to be achieved or documented but a series of steps in a complex process (Sudore et al. 2008). Optimising ACP processes in community settings during COVID-19 therefore involves considering (a) which known barriers and enablers to ACP are particularly crucial to attend to in COVID-19, and (b) which existing ACP interventions with evidence of benefit are relevant and feasible in the pandemic context. Of use in this regard is a systematic review focused on ACP in community-dwelling frail elders, which applied the COM-B behaviour change model to help identify necessary ACP behaviours (Combes et al. 2019).

Drawing on the existing evidence base, the state of the science for ACP interventions in primary and community care settings can be summarised as follows. The most promising and sustainable interventions:

- target multiple levels of influence (individual, interpersonal, provider, system), with each component reinforcing each other, and take into account known barriers to and facilitators of uptake (Risk et al. 2019)
- use a consistent process to identify eligible patients for ACP discussion (Vleminck et al. 2016)
- introduce ACP earlier in the trajectory of a serious illness (Yue-Lai Chan et al. 2018) and engage older people early to provide the greatest chance of being able to engage physically and cognitively with ACP (Combes et al. 2019)
- involve direct, person-to-person interaction with experienced and trained facilitators (Vleminck et al. 2016; e.g. nurses Miller et al. 2019, Yue-Lai Chan et al. 2018) and/or group education (Risk et al. 2019)
- include a structured, patient-centred discussion (Vleminck et al. 2016, Yue-Lai Chan et al. 2018)
- take place over multiple sessions and as part of everyday practice (Vleminck et al. 2016, Miller et al. 2019, Yue-Lai Chan et al. 2018, Combes et al. 2019).
- include the opportunity to complete ACP documents but are not focussed on this (Vleminck et al. 2016)
- use written resources and ACP forms which are understandable, acceptable, sensitive, honest and reliably capture patient wishes (Wickersham et al. 2019; Xafis et al. 2015)
- document ACP conversations in patent records in a timely manner (Wickersham et al. 2019) and ensure patient records can be accessed as needed
- Motivate older people by emphasising maintaining current quality of life rather than future planning (Combes et al. 2019)

The best tested ACP intervention we identified was PREPARE, a patient-facing, online ACP programme, evaluated in two high-quality RCTs in the USA, among veterans and English- and Spanish-speaking older adults (Sudore et al. 2017; Sudore et al. 2018). The PREPARE website included video stories, modelling of behaviours, and a 5-step process to motivate and prepare individuals to discuss their values and care preferences with family, friends and clinicians. Materials were designed with and for diverse communities. In conjunction with an easy-to-read advance directive, PREPARE increased rates of ACP documentation and engagement among veterans (Sudore et al. 2017) and ethnically diverse primary care patients in San Francisco, USA, without clinician-level or system-level interventions (Sudore et al. 2018). Both tools were rated highly in terms of ease-of-use, satisfaction, and helpfulness. These tools may improve the ACP process and mitigate literacy and language barriers to ACP, allowing patients to begin planning on their own (Sudore et al. 2018). The authors highlight that some patients may always require a facilitator in order to begin engagement with ACP.

In a systematic review McDermott & Selman 2018 found discussion-based, informal ACP interventions in which ACP is part of a broader strategy of communicating with patients about end of life care may be more culturally appropriate than a formal process focused on documentation. Peer mentoring interventions (Perry et al. 2005) and patient-led question prompt lists (Walczak et al. 2013) may also be helpful, although studies in this area are beyond the remit of this review. Assumptions on the basis of culture should be avoided; selecting the

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most appropriate form of ACP process should be individualised to the particular patient and in discussion with them.

An individualised approach is also essential when supporting people with intellectual disabilities [ID] with ACP (Voss et al. 2017). A systematic review in this area concluded that ACP for people with ID must take different forms depending on the degree and complexity of the disability and vulnerability of the person with ID. While more research in this area is crucial to understand best practice in ACP for people with ID, the authors recommend that professionals adopt a flexible ACP process depending on the needs and preferences of the individual and their relatives. Particular barriers to be aware of include difficulties in recognising palliative care needs, and uncertainties among relatives and professionals about their roles and tasks in ACP.

Finally, ensuring the effectiveness of ACP interventions also involves considering their effective implementation as well as initiation and documentation (Hemsley et al. 2019). Healthcare policy is crucial to support healthcare providers in having the knowledge and confidence to raise ACP discussions regularly during routine clinical interactions. Policy development on the storage, retrieval, and implementation of documented ACP (include advance decisions) is also required to strengthen the procedures around the development and management of advance decisions in the wider healthcare system.

ACP in nursing homes

Five studies (2 RCTs, a pilot study, a survey and a Theory of Change study) described ACP in nursing home settings. In the COSMOS trial, an ACP education programme for nursing home staff followed by monthly conversations between the primary nurse, patent and family increased nurse and family satisfaction and reduced staff distress (Aasmul et al. 2018). In a cluster RCT in Norway, a whole-ward approach with regular staff performing ACP and inviting all patients and next of kin to participate resulted in more end of life treatment conversations, improved documentation of patient preferences, hopes and worries, and increased concordance between provided treatment and patient preferences and next of kin participation in ACP (Sævareid et al. 2019).

In a US pilot study of 'Me and My Wishes', nursing home residents created videos discussing their preferences for daily and end of life care (Towsley et al 2020). The intervention was feasible and acceptable to residents, including for people with mild-moderate cognitive impairment and serious mental illness, and rated positively by family and staff, although some were concerned about what to do if residents' preferences changed. There is low quality evidence that viewing a decision support video about ACP in healthy adults prompts proxies and residents to engage in ACP discussions with health care providers earlier and make changes to Advance Directives (Loomer et al. 2019). Barriers in nursing home settings include a concern that ACP might be used to persuade a patient to accept less treatment, thus reducing costs (Sævareid et al. 2019), and a lack of support for staff (Aasmul et al. 2018).

Summary of recommendations for ACP in nursing homes:
- Build a culture where knowledge of ACP is widespread within the organisation and regular nursing home staff are responsible (Sævareid et al. 2019)
- Build a culture supportive of ACP so people feel free to reflect on and talk about death, dying and end-of-life issue; everyone is committed; and professionals invest in ACP despite the lack of financial incentives, staff shortages or staff turnover (Gilissen et al. 2018)
- Involve residents with cognitive impairment and be open to what they want to discuss (Sævareid et al. 2019; Towsley et al 2020)
- Involve next of kin in ACP process, particularly for patients with cognitive impairment (Sævareid et al. 2019)
- Initiate the ACP process early, aiming to build up relationships by carefully considering timing and receptiveness (Aasmul et al. 2018)
- Ensure staff are supported to maintain a good routine of ACP (Aasmul et al. 2018)
- Provide sufficient resources (including funding, time and human capacity) and a quiet private space where ACP conversations can be held (Gilissen et al. 2018)

Use of decision aids in ACP

Decision aids (DAs) are used to educate patients so that they can make informed decisions about their future care, but they have known limitations. A systematic review of the effectiveness of DAs in assisting older patients at the end of life concluded that although there is a multitude of DAs for screening and disease treatment, there is a scarcity of comprehensive DAs for either generic end of life issues or specific end of life management approaches (Cardona-Morell et al. 2016). The review found low quality evidence that DAs at the end of life are generally acceptable to users, and appear to increase knowledge and reduce decisional conflict. The authors recommend that DAs are administered with clinicians' input early in the trajectory of a serious illness, but caution that additional human resources may make them less suitable for routine care in busy clinical environments. They also highlight that use of DAs should not be seen as a single episode; their repeat use as disease progresses should be encouraged so that there are opportunities to change decisions as the disease progresses. Problems with DAs include gaps in the instruments (e.g. lack of focus on patient values) prohibiting genuine informed decision-making, the difficulty of basing decisions on hypothetical scenarios rather than the patient's state of health, and a lack of non-English DAs (Barwise et al. 2020).

Systematic reviews suggest that video decision aids are generally acceptable to participants, perceived as supportive and result in greater knowledge related to ACP (Jain et al. 2015; Cruz-Oliver et al. 2020). There is low-quality evidence that videos led to preferences for less aggressive care at end of life and reduced costs (e.g. Volandes et al. 2016); it remains unknown whether these tools can increase congruence of end of life care with patient wishes (also see *Use of technology for ACP* below). ACP completion rate does not appear to be significantly different after video DAs compared to other forms of educational information (e.g. written). Cruz-Oliver et al. 2020 found that videos clarified messages better than verbal communication,

and conclude that they may be especially suitable for non-native English speakers and those with low literacy levels. Using video resources may help overcome communication and health literacy barriers irrespective of education level (Volandes et al. 2008). Research is needed to establish when face-to-face video delivery versus remote delivery will achieve comparable results.

Use of technology for ACP

Technology and telemedicine, including ACP via remote, virtual consultations, could play an important role in the COVID-19 pandemic, reducing the risk of exposure to the virus for both patients and care providers (Calton et al. 2020). Here we review existing evidence in these areas.

Video- and internet-based ACP

Light-touch interventions e.g. video, DVD and web-based tools can help support shared decision making and provide a platform for ACP discussions (Baik et al. 2019). Evidence suggests that video- and web-based ACP may be of particularly benefit among people with limited English proficiency (LEP), poor health literacy and/or from otherwise disadvantaged communities. A systematic review of interventions addressing disparities in end of life decision-making and ACP for patients with LEP (Barwise et al. 2020) found that while resource-intensive interventions (e.g. home visits, counselling, specifically trained personnel) were effective, so too were video images and web-based programmes. The latter interventions were found to be generally feasible and acceptable and of benefit to people with low health literacy. The authors recommend interventions that address both LEP and poor health literacy concurrently.

Online ACP may be particularly effective at supporting ACP when integrated into existing systems used by patients. A US study found integrating ACP tools into an existing patient portal which documented patient decisions in their medical record was convenient for patients and easier to complete than on paper (Jordan et al. 2019). However, web-based information is only valuable if credible, accurate and user-oriented (easy to use and understand). An assessment of internet advance directives information found most sites were unsuitable in terms of learning and informing (Stuart 2017). The author highlights the need for health information to empower and enable valid healthcare decisions and recommends a quality indicator or code of health information ethics for website-based information. An evaluation of two online advance directive programmes in the US which integrate web and mobile applications, guided interviews, storage, and retrieval in multiple languages highlighted the need for resources to be free of charge and easy to use, and use locally appropriate terminology (Klugman and Usatine 2013). Web-based platforms have also been developed for and with LGBT people to ensure resources and content are LGBT-appropriate; this is essential given evidence that older LGBT adults often delay seeking formal care and are less likely to have conversations about their care (Beringer et al. 2017).

A US report of early experiences in building a systematic, population-based ACP initiative described health system-wide deployment of an internet-based tool as an adjunct to a

facilitator-based model (Reidy et al. 2017).The tech-based tool worked only within a broader context of culture change and education about ACP and alongside other tools to overcome tech barriers among older people. Authors recommend simultaneous interconnected strategies targeting patient education, clinician training, electronic medical record documentation and community awareness.

Web-based interventions directed at clinicians may also be useful. Evaluation of the ACPTalk website to support health professionals in conducting ACP conversations within diverse religious and cultural populations interviewed multiple stakeholders regarding the website design and content (Pereira-Salgado et al. 2018). While highlighting areas for refinement, findings indicated overall positivity in relation to accessibility, functionality, usefulness, design, and increased knowledge of ACP.

Finally, *video* has also been used as a way of documenting ACP discussions (see *Nursing Homes).*

ACP via remote consultation

While there is evidence from systematic reviews that remote consultations via videoconferencing, use of tablets or telephones are feasible and useful in the care of older adults (Ramprasad et al. 2019), we found no studies or reviews specifically related to ACP via remote consultations or telemedicine. This is an important area for future research as remote consultations are potentially the best way of replicating the face-to-face and group education sessions known to be successful in ACP. Research should include identifying barriers to ACP via remote consultations to help ensure their use doesn't exacerbate inequalities in accessing ACP.

The UK's General Medical Council (GMC) has produced guidance and a flowchart to help doctors manage patient safety risks and decide when it's safe to treat patients remotely during the pandemic. Of relevance to ACP, it states that face-to-face treatment may be preferable if it's hard to ensure by remote means that patients have all the information they want and need about treatment options, or if you are unsure of the patient's capacity to decide about treatment. However, based on the evidence above it is clear that online resources could play an important role in ensuring people have the information and resources they need for ACP.

Greenhalgh et al. 2020 and Calton et al. 2020 provide useful guiding principles for remote consultations (see Box 1 for key points). Remote consultations can be achieved by telephone, but video may provide additional visual cues and therapeutic presence. Video may be appropriate for sicker patients, those with comorbidities, those whose social circumstances have a bearing on the illness, and those who are very anxious. Patients who are hard of hearing may prefer video to telephone; some platforms offer subtitles when using video links. In many countries there has been formal relaxation of privacy and data protection regulations for video and other communications technologies during the COVID-19 pandemic; the General Data Protection Regulations in the UK and European Union already include a clause excepting work in the overwhelming public interest. Greenhalgh et al. 2020 also recommend that, in the case of patients with a very poor prognosis, a "ceiling of treatment" conversation is considered during

the remote consultation. They go on to state: *'If the patient is very sick and death almost inevitable whether ventilated or not, some people may prefer to stay home and opt for palliative management. Many such patients will already have an advance care plan and DNACPR flag, and in those who do not, urgent efforts should be made to put these in place to avert unwanted emergency intervention.'*

Box 1: Guidelines for successful remote consultations (adapted from <u>Greenhalgh et al. 2020</u> and <u>Calton et al. 2020</u>)

- Include instructions for patients/families on how to download and operate the telemedicine platform/software application;
- Ensure in advance a point of contact within the household (key family member if possible) to enable a workable electronic connection;
- Attend to call etiquette including the free consent of participants and a quiet confidential environment;
- Include documentation of discussions and decisions made;
- Pay careful attention to body language (on video calls), subtle comments and tone of voice;
- Attend to key communication principles e.g. asking for permission and attending to

ACP AND COVID-19: UK GUIDELINES

Since the start of the COVID-19 pandemic, a number of guidelines and resources relevant to ACP have been produced; a useful list of resources from the UK and elsewhere is found at the end this report. We focus here on relevant UK guidelines, as legislation and recommendations differ across countries and an international guideline review is beyond the scope of this work. The following guidelines are summarised below:
- National Institute for Health and Care Excellence (NICE)
  - <u>COVID-19 rapid guideline: managing symptoms (including at the end of life) in the community</u>
  - <u>COVID-19 rapid guideline: managing suspected or confirmed pneumonia in adults in the community</u>
  - <u>COVID-19 rapid guideline: community-based care of patients with chronic obstructive pulmonary disease</u>
- Health Improvement Scotland <u>Essential Anticipatory Care Planning Guidance and Template</u>
- Association for Palliative Medicine <u>COVID-19 and Palliative, End of Life and Bereavement Care in Secondary Care. Role of the specialty and guidance to aid care</u>
- British Geriatrics Society Good Practice Guide <u>COVID-19: Managing the COVID-19 pandemic in care homes for older people</u>
- National Centre for Post-Qualifying Social Work and Professional Practice Guide <u>Advance Care Planning</u>
- Compassion in Dying framework <u>Advance Care Planning by phone or video</u>

- Resuscitation Council UK statement on the ReSPECT process in COVID-19
- Public-facing guidance:
    - NHS England and NHS Improvement ACP template and guidance: My COVID-19 Advance Care Plan
    - NHS Inform (Scotland) guidance: Talking about your care and Making a plan for your care during the COVID-19 pandemic

National Institute for Health and Care Excellence (NICE)

In the UK, NICE has produced two relevant general guidelines related to care planning in the context of COVID-19: COVID-19 rapid guideline: managing symptoms (including at the end of life) in the community and COVID-19 rapid guideline: managing suspected or confirmed pneumonia in adults in the community. These guidelines recommend discussing the risks, benefits and likely outcomes of treatment options with patients with COVID-19 and their families and carers 'where possible', so that they can express their preferences about their treatment and escalation plans. Decision support tools are recommended when available and the need for these discussions to take place remotely is recognised, with reference to guidance on communicating with patients and minimising risk (Box 2). Staff are advised to put treatment escalation plans in place due the risk of rapid deterioration and urgent hospital admission. Staff are also advised to 'find out' if patients with pre-existing advanced comorbidities have ACPs or advance decisions to refuse treatment, including DNAR decisions, to document this clearly and take account of these in planning care. However, neither guideline goes so far as to recommend that staff complete formal ACP documentation with patients and their families, even when patients have confirmed or suspected COVID-19 infection.

Box 2: NICE guidance on communicating with patients and minimising risk

Minimise face-to-face contact to reduce the risk of infection by:

- using telephone, video or email consultations whenever possible (see BMJ guidance on COVID-19: a remote assessment in primary care for a useful guide, including a visual summary for remote consultations)
- cutting non-essential face-to-face appointments
- contacting patients via text message, telephone or email
- using electronic prescriptions rather than paper
- using different methods to deliver prescriptions and medicines to patients, for example pharmacy deliveries, postal services, NHS Volunteer Responders or introducing drive-through pick-up points for medicines.

If patients are having a face-to-face appointment, on the day of the appointment, first screen them by telephone to make sure they have not developed symptoms of COVID-19. Document ACP discussions and decisions clearly and take account of these in planning care.

In contrast, the NICE [COVID-19 rapid guideline: community-based care of patients with chronic obstructive pulmonary disease](#) advises care providers not only to find out if patients have advance care plans or advance decisions around ceilings of care, including DNACPR decisions, but also to encourage patients with 'more severe' COPD who do not have an advance care plan to develop one. Decision support tools are recommended (where available) and staff are referred to the Mental Capacity Act for patients who lack capacity. The fact that these discussions may need to take place remotely is flagged, with sign-posting to the guidance in Box 2.

Health Improvement Scotland

In Scotland, the [Essential Anticipatory Care Planning Guidance and Template](#) recommends that people at a [much higher risk](#) of becoming seriously ill from COVID-19 are prioritised for Anticipatory Care Planning. The guidance also states that many of those at [increased risk](#) of severe illness from coronavirus will also benefit from Anticipatory Care Planning. The [RED-MAP framework](#) and [resources](#) are highlighted as helpful to guide discussions about ACP (Box 3).

Box 3: RED-MAP Framework

R eady:	Can we talk about how coronavirus might affect you?	
E xpect:	What do you know? What do you want to ask?	
D iagnosis:	We know that coronavirus.... We don't know.....	
M atters:	What matters to you if you were to become unwell?	
A ctions:	What we can do to help is....	
P lan:	Let's plan ahead for 'just in case'	

A template is provided entitled [An essential ACP for those most vulnerable to coronavirus](#) for health and social care professionals to complete with patients. The template notes that specific care options e.g. ventilation in intensive care may not be available/appropriate and it may help to explore this further, but no guidance is given on how to have this conversation. The template domains include the things you would like; the things you do not want; any other information around preferences for care; discussions and decisions about CPR; the people you would like to be involved in decisions about your care; power of attorney/welfare guardianship; important contacts; key worker; responsible clinician; consent to share in [key information summary](#).

Association for Palliative Medicine

The UK's [Association for Palliative Medicine Guidance](#), while focused on secondary care, contains relevant guidance on ACP for community settings. Its section entitled *Discussion about goals of care*, adapted from [RCP 2018](#), highlights the importance of timely honest conversations about the person's preferences and priorities for anybody who has a progressive life-limiting illness. In the context of people who have severe COVID-19 disease, it states, *"honest conversations about goals of care and treatment escalation planning should be initiated as early as is practicable so that a personalised care and support plan can be developed and documented. This will need to*

be revisited and revised as the situation changes. Families and those close to the person should be involved in these discussions as far as possible and in line with the person's wishes." In treating a patient with COVID-19 and respiratory failure who lacks capacity, clinicians are instructed to refer to ACP documentation, e.g. Advance Decision to Refuse Treatment, Statement of Wishes.

Specific challenges discussed in the guidance regarding the context of COVID-19 include the speed of deterioration limiting the opportunity for discussion with patients and involving them in decision making; the shock for family members who may themselves be ill/self-isolating; multiple members of a family being ill; and health professionals needing to triage patients, often in emergency or urgent situations, and prioritise certain interventions and ceilings of treatment. However, health professionals are encouraged to have these conversations and keep families informed, even if conversations need to occur via PPE, telephone or technological solutions. The latter options are acknowledged as 'less than ideal' ([DoH, 2015](); [NPEoLCP, 2015]()), however the guidance emphasises that honest conversations are often what patients and those close to them actually want ([Choice in End of Life Care Programme Board, 2015]()). The SPIKES mnemonic is recommended to guide care planning conversations (Box 4).

Box 4: SPIKES framework ([Baile et al. 2000]())

o	**S**etting / situation:	read clinical records, ensure privacy, no interruptions
o	**P**erception:	what do they know already?; no assumptions
o	**I**nvitation:	how much do they want to know?
o	**K**nowledge:	explain the situation; avoid jargon; take it slow
o	**E**mpathy:	even if busy, show that you care
o	**S**ummary / strategy:	summarise what you've said; explain next steps

The guidance highlights the possibility of anger/upset/questions when ceilings of treatment conversations include ethical issues, for example where escalation to Level 3 care is thought not to be appropriate due to frailty, comorbidity or other reasons, and gives advice on responding appropriately in such situations. Finally, the guidance states: *"While palliative, end of life and bereavement care professionals cannot take over responsibility for this aspect of care and have the conversations for you, they should be able to support, advise and provide follow up care."*

British Geriatrics Society (BGS)

BGS have produced the Good Practice Guide [COVID-19: Managing the COVID-19 pandemic in care homes for older people](). Key recommendations include:
- Care homes staff, General Practitioners, community healthcare staff and community geriatricians should work to review Advance Care Plans with care home residents. This should include discussions about how COVID-19 may cause residents to become critically unwell and what they and their families would wish if their health deteriorates.
- Advance Care Plans must be recorded in a way that is useful for healthcare professionals called in an emergency situation. A paper copy should be filed in the care home records

and, where the facility already exists, an electronic version used which can be shared with relevant services.

The COVID-19 pandemic is presented as an important opportunity for care home staff to revisit, or visit for the first time, ACP for all residents and their families. Care home staff should be supported in this by GPs and primary care teams as well as specialists in geriatric medicine, mental health and/or palliative care when needed. Having discussions via phone or videoconferencing is described as 'not ideal', with staff advised to plan conversations in advance and referred to resources available through the Royal College of General Practitioners' Palliative Care Toolkit. Guidance states that advance care plans should include decisions about whether hospital transfer would be considered (for oxygen therapy, intravenous fluid and antibiotics) for COVID-19-related illness, and that advance care plans should be shared with the primary care out-of-hours service.

National Centre for Post-Qualifying Social Work and Professional Practice

The guide Advance Care Planning, published in April 2020, provides a comprehensive overview of the purpose and importance of ACP, referring to NICE guidance on decision making and mental capacity and Advance Care Planning – A quick guide for registered managers of care homes and home care services. In particular, guidance outlines the NICE recommendation that ACP should start as early as possible after a diagnosis of any life-limiting condition and the need to revisit ACP throughout an illness. Although the relevance of ACP during the COVID-19 pandemic is flagged at the start, there is no other reference to the pandemic or its implications for ACP. Following the Gold Standards Framework 2018, the guide describes the process of ACP as providing the means for individuals to clarify 'what is important to me', 'what I want to refuse' and 'who will speak for me'. A checklist for supporting people through ACP is provided (Box 5). The guide goes on to discuss ACP to inform Best Interest decisions, ACP to identify refusal of medical treatments and ACP for decision about emergency care (referencing ReSPECT).

Box 5: Checklist for supporting people through ACP (from National Centre for Post-Qualifying Social Work and Professional Practice 2020)

> **Check** - has the person already made provision for future decisions?
> **Think** - some people may not want to talk about future care or planning for this.
> **Remember** - everyone is different – their wish for knowledge, autonomy and control.
> **Be prepared** - to explain the purpose and process of Advance Care Planning.
> **Respect** - people may make choices that seem unwise; this does not mean that they are unable to make decisions or their decisions are wrong.

Compassion in Dying

The charity Compassion in Dying has produced a framework, Advance Care Planning by phone or video, to support GPs to have open and honest ACP conversations with patients by phone of video in the context of COVID-19. It suggests using existing appointment of 'touchpoints', such as wellbeing calls, to initiate ACP, and offers guidelines for communicating in the following

areas: Starting the conversation; understanding what matters to the person; explaining treatments including CPR; recording wishes (preferences about their care, CPR decisions, patient's wish to refuse treatment); sharing a completed ADRT; and giving a trusted person authority to make health decisions. The guidance states that if someone wants to refuse CPR or the GP believes CPR is likely to be futile or not in the person's best interests, the GP should complete a DNACPR form or the ReSPECT process. Resources referenced include the Royal College of Physicians patient-facing information on critical care, the Compassion in Dying's factsheet explaining CPR/DNACPR and Advance Statement form, Coordinate my Care public portal, the My Decisions website to generate an Advance Decision/Advance Statement .

Resuscitation Council UK

Resuscitation Council UK has released a document clarifying the role of the ReSPECT process in COVID-19. The statement defines ReSPECT as a process which creates personalised recommendations for a person's clinical care and treatment in an emergency when they might be unable to communicate this for themselves. It centres around having conversations between a person, their family, and a clinician, and produces a clinical document which belongs to the patient. It also states that ReSPECT is not just a form but a process, it should not be completed in isolation, must be individualised, and is not legally binding or an ADRT.

Public-facing guidance

NHS England and NHS Improvement have produced a public-facing ACP template and guidance, My COVID-19 Advance Care Plan. The document is designed to record quickly and in one place, the thoughts and wishes a person has on the care and support they would like if they develop severe COVID-19 symptoms. Importantly, it is meant to complement but not replace any pre-existing ACP and is to be kept by the patient and shared by them with others supporting them, e.g. their GP. Readers are signposted to government and NHS information regarding creating a Lasting Power of Attorney, Advance Decisions to Refuse Treatment and DNACPR. The template includes the following fields: name; NHS number; I like to be known as; summary of health condition; Who am I?; Three important things I want you to know; Medication I take and how it is administered; How I communicate; My emergency contacts. There are no references to other guidance or evidence regarding ACP.

In Scotland, NHS Inform has produced helpful and more detailed guidance and advice for the public on the webpages Talking about your care and Making a plan for your care during the COVID-19 pandemic. A video on coronavirus and care planning conversations is also available. Talking about your care introduces the concept of discussing your wishes with those around you and the need to consider how COVID-19 could affect your care. It also contains guidance on having enough information; starting conversations about care; what to talk about; challenges when talking about care; and next steps. Links are provided to further information, e.g. regarding CPR decisions, deciding whether or not to be cared for in hospital (not COVID-19-specific) and palliative care.

Making a plan for your care during the COVID-19 pandemic recommends that if you are at extremely high risk of severe illness you start having conversations about ACP and your wishes if you fell ill. It states that you may also benefit from an ACP if aged 70 or older or if under 70 with an underlying health condition, and discusses the personal benefits of having an ACP in place. Importantly, it also tells you that if you have received a letter from the government advising that you're at risk of severe illness from COVID-19, then someone from your care team will be in touch as soon as possible to make sure you've understood the information, and discuss your options for creating an ACP or making changes to an existing one. Specific advice is provided for those who don't have an ACP and those who do. Throughout, the guidance emphasises the importance of talking to those close to you about your wishes for future care and decisions you'd want to be made if you feel ill.

International guidance

- A comprehensive list of international guidance on palliative care in general in the context of COVID-19 is available from the European Association for Palliative Care.
- National Institute on Aging (USA) guidance on ACP

IMPLICATIONS FOR PRACTICE

COVID-19 provides an impetus for members of the public, confronted with the possibility of their own death, to initiate ACP (Auriemma et al. 2020; Compassion in Dying 2020). Those working in health and social care play a vital role in informing and supporting everyone who wants to plan their future care, and helping to ensure their wishes are documented and available should they become seriously ill. Those working in health and social care should be prepared for enquiries about the processes and legal status of ACP and able to signpost to suitable written and audio-visual resources and documentation. This will often require investment in staff education and training, drawing on existing resources.

As well as supporting people who initiate ACP themselves, professionals play a key role in creating opportunities for ACP discussions among patients and residents, raising awareness of ACP and dispelling fears and misperceptions. Among older people and those with existing health conditions, staff working in health and social care should use the pandemic as an opportunity to initiate ACP conversations or as a trigger to revisit ACP. ACP is ideally initiated early, and consists of a person-centred, structured discussion which takes place over several sessions, and is repeated as needed during the course of an illness. It should be adapted to the individual and should include the opportunity to complete ACP documents, but not be focussed on this. The need to be sensitive and patient-centred in these discussions should not prevent their occurrence.

In nursing home settings, a culture of openness around ACP is needed, alongside organisational support for staff to enable an ongoing conversation with residents (including those with cognitive impairment) and their family members. It may be helpful to motivate older people to

engage in ACP during COVID-19 by emphasising its role in maintaining current quality of life rather than focussing only on future planning.

To enable ACP, people need access to information and resources to help support informed decision-making about their future care. Video decisions aids and video and web-based ACP resources are particularly valuable in this regard. An important benefit is that these kinds of resources are effective among people with limited English proficiency, poor health literacy or from otherwise disadvantaged groups, potentially addressing disparities in end of life decision-making. Information resources need to be understandable, acceptable, sensitive, honest and appropriate to the target population. They should ideally also take into account the context of COVID-19, when certain barriers (e.g. fears of rationing healthcare) might be particularly relevant. The guidelines and resources referenced here can help inform sign-posting.

In the context of COVID-19, when face-to-face individual or group discussions need to be minimised, ACP discussions may take place remotely, recognising, however, that this format will not be appropriate for all patients and in all circumstances. Where remote consultations are used for ACP, we recommend evaluating or auditing this practice as evidence regarding its acceptability, utility and outcomes is currently lacking. ACP forms, when used, need to be able to reliably capture patient wishes and should be documented promptly in patient records which are accessible to all those who need them.

IMPLICATIONS FOR POLICY

The COVID-19 pandemic presents opportunities to reframe ACP as routine, every day and normal; to shift its emphasis from harm reduction to a broader conversation about what matters most to people; and to dispel public fears and misperceptions (O'Riordan et al. 2020; Abel et al. 2020). Current clinician-directed guidance understandably emphasises the importance of ACP to older and clinically vulnerable people, yet ACP is relevant to any of us who want to consider and influence the care we will receive should we become seriously ill. Shifting public awareness in this way would have major benefits: increasing public-initiated ACP would reduce the need for health and social care workers to lead the process, and is likely to increase engagement, uptake and completion of ACP, as well as improving patient and family experiences of end of life care. It would also potentially reduce NHS costs by helping to reduce unwanted and unnecessary hospital admissions, in line with patient preferences. Transforming ACP in this way requires consistent and coordinated public health messaging.

The most promising and sustainable ACP interventions target multiple levels of influence (individual, interpersonal, provider, system), with each component reinforcing the other, and take into account known barriers to and facilitators of uptake. Interventions that focus on only one component, e.g. raising awareness of ACP among patients or staff, or that omit key contextual factors, e.g. the effects of the pandemic, are unlikely to be effective. Current guidance does not adequately reflect this multidimensional approach to ACP, tending to focus solely on provider, individual and, to a lesser extent, interpersonal levels of influence.

Simultaneous interconnected strategies are needed, targeting public education and awareness, training for health and social care workers, and electronic medical record documentation. Healthcare policy plays a crucial role in supporting all these domains. As health provision is devolved within the UK, each country should aim for a comprehensive policy to support ACP across these areas and aid the implementation, monitoring and evaluation of ACP.

While there are UK websites providing ACP information and resources, there is no national NHS portal for information and resources (written and audio-visual) on ACP. Existing websites are not nationally coordinated or accredited, and the quality varies. The acceptability and utility of ACP resources depend on their comprehensibility and content. To meet the country's needs and reduce known inequalities in care planning, it is essential that resources are diverse and co-produced with specific community groups (e.g. people from BAME communities, with intellectual disabilities or limited English proficiency, and the LGBT community). We recommend a review of existing resources and websites, investment in public-facing resources where there are known gaps, and creation of a national portal to facilitate community-based ACP, widen access to ACP and support those working in health and social care. Focused efforts in this area are likely to pay dividends by reducing the input required from clinicians and increasing the uptake and documentation of ACP.

A national, integrated web-based system for ACP in which members of the UK public can create an advance care plan which links to their medical record is currently not available in the UK. Since 2008, over 80 Electronic Palliative Care Coordination Systems (EPaCCS) in England and the electronic Palliative Care Summary (ePCS) in Scotland have been introduced with the aim of improving care coordination by recording and sharing information about patients' clinical condition and treatment decisions (Petrova et al. 2015). While these systems present opportunities, there are also significant challenges to their implementation and little published evidence on benefits and/or harms (Sleeman & Higginson 2016). There is evidence from the US that integrated web-based systems are feasible and acceptable (Jordan et al. 2019) and could mitigate literacy and language barriers to ACP, if implemented alongside tools to overcome technological barriers among older people and other group (Sudore et al. 2017; 2018). However, given the complex contextual factors which influence ACP, UK-specific research in this area is urgently needed. While an integrated national system could revolutionise ACP in the UK, it must be designed on the basis of robust research. Given the technological and clinical practice shifts COVID-19 has prompted, and the urgency of ACP in the context of the pandemic, this research is even more vital.

CONCLUSIONS

- COVID-19 has worsened some known barriers to ACP in community settings; however the increase in public awareness of ACP and its potential benefits, and the shift towards technological approaches to care, also provide opportunities to transform ACP.

- Video- and web-based ACP may be of particular benefit among people with limited English proficiency, poor health literacy and/or from otherwise disadvantaged communities, but there is no national coordinated provision of such resources in the UK.
- In the context of COVID-19, and to reduce inequalities in access to ACP, we recommend national investment in evidence-based, public-facing resources and systems to support ACP.
- Alongside this investment, simultaneous, interconnected strategies are needed to support ACP, underpinned by healthcare policy. This should include training for those working in health and social care, better coordination of electronic medical record systems, and public education and awareness raising.

ADDITIONAL RESOURCES

A pre-print, Communicating with patients and families about difficult matters: A rapid review in the context of the COVID-19 pandemic, synthesises evidence regarding communication practices relevant to the pandemic and identifies 11 relevant communication practices.

UK:
- The Advance Care Plan resource for England & Wales – a selection of videos and FAQs about ACP developed by Byw Nawr (Dying Matters in Wales) in collaboration with Hospice UK, NHS Wales and others.
- Health in Wales resources on Advance and Future Care Plans
- National Institute for Health and Care Excellence Guidance on Advance Care Planning and ACP A quick guide for registered managers of care homes and home care services
- NHS Ambitions Preferred Priorities of Care (public-facing template) and Resources currently available to support rollout of electronic sharing of End of Life Care records
- MyWishes website provides a range of online tools that generate both legally and non-legally binding forms. Once completed, documents can be downloaded, printed, emailed and shared with loved ones, healthcare professionals and funeral directors.
- Coordinate my Care – a patient and clinician portal for formulating and sharing urgent care plans, available in London. Also contains video and written resources.
- Cardmedic communication flashcards on Living Will/Advance Decision/Advance Statement, Power of Attorney, DNACPR and End of Life Care.
- CPR and COVID-19 (coronavirus) conversations with patients - RCGP blog post
- Anticipatory Care Planning in a COVID landscape – RGCP blog post
- Royal College of Physicians of Edinburgh COVID-19 Online Update: Anticipatory Care Plans
- MacMillan Cancer Support advice and resources on ACP and coronavirus
- Real Talk resources on clinical communication during COVID-19

USA/international:
- Vital Talk's [REMAP framework for goals of care discussions](#) (Reframe, Expect emotion, Map out patient goals, Align with goals, Propose a plan) and [COVID-19 communication skills guide](#)
- Ariadne Lab's [Serious Illness Conversation Guide](#) for ACP and [COVID-19 Telehealth communication](#)
- [Palliative Care Toolkit](#) developed by Dana-Faber Cancer Institute and Brigham and Women's Hospital, includes physical, online and real-time support with difficult conversations and ACP
- [Prioritizing Advance Care Planning in the Time of COVID-19](#) is a free webinar offered by Johns Hopkins Medicine
- The [GOOD framework](#) (Goals, Options, Opinions, Documentation), developed at the Stanford University School of Medicine to clarify uncertainties in working with older patients or those with serious illness.
- International Association for Hospice and Palliative Care's COVID-19 [resources list](#)

End.

Disclaimer: the article has not been peer-reviewed; it should not replace individual clinical judgement and the sources cited should be checked. The views expressed in this commentary represent the views of the authors and not necessarily those of the host institution, the NHS, the NIHR, or the Department of Health and Social Care. The views are not a substitute for professional medical advice.

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APPENDIX 1: Embase search terms

	ACP/End of life communication and Coronavirus
# ▲	Searches
1	Coronavirus infections/
2	(coronavirus or COVID-19 or 2019nCoV or 2019-nCoV or WN-CoV or nCoV or SARS-CoV-2 or HCoV-19).ti,ab,kw.
3	1 or 2
4	living will/
5	(advance* adj2 (directive? or care plan* or decision*)).ti,ab,kw.
6	(treatment escalation plan* or living will?).ti,ab,kw.
7	terminal care/ or palliative therapy/ or conservative treatment/
8	exp professional-patient relationship/
9	family decision making/ or patient decision making/ or shared decision making/
10	8 or 9
11	7 and 10
12	(("end of life" or palliative or terminal) adj5 (decision making or talk* or conversation? or communicat*)).ti,ab,kw.
13	(difficult adj3 (conversation? or communication?)).ti,ab,kw.
14	4 or 5 or 6 or 11 or 12 or 13
15	3 and 14
	ACP/End of life communication and Systematic Reviews
# ▲	Searches
1	living will/
2	(advance* adj2 (directive? or care plan* or decision*)).ti,ab,kw.
3	(treatment escalation plan* or living will?).ti,ab,kw.
4	terminal care/ or palliative therapy/ or conservative treatment/
5	exp professional-patient relationship/
6	family decision making/ or patient decision making/ or shared decision making/
7	5 or 6
8	4 and 7

9	(("end of life" or palliative or terminal) adj5 (decision making or talk* or conversation? or communicat*)).ti,ab,kw.
10	(difficult adj3 (conversation? or communication?)).ti,ab,kw.
11	1 or 2 or 3 or 8 or 9 or 10
12	limit 11 to ("systematic review" and "reviews (maximizes specificity)")
13	limit 12 to (english language and yr="2010 -Current")
14	conference*.pt.
15	13 not 14

ACP/End of life communication and Telemedicine

#▲	Searches
1	living will/
2	(advance* adj2 (directive? or care plan* or decision*)).ti,ab,kw.
3	(treatment escalation plan* or living will?).ti,ab,kw.
4	terminal care/ or palliative therapy/ or conservative treatment/
5	exp professional-patient relationship/
6	family decision making/ or patient decision making/ or shared decision making/
7	5 or 6
8	4 and 7
9	(("end of life" or palliative or terminal) adj5 (decision making or talk* or conversation? or communicat*)).ti,ab,kw.
10	(difficult adj3 (conversation? or communication?)).ti,ab,kw.
11	1 or 2 or 3 or 8 or 9 or 10
12	exp telemedicine/
13	(telemedicine or tele-medicine or telehealth or tele-health or teleconsult* or tele-consult* or virtual consult* or remote consult*).ti,ab,kw.
14	(mobile health or mhealth or m-health or electronic health or ehealth or e-health).ti,ab,kw.
15	(virtual or portal or electronic or online or internet* or web* or digital).ti.
16	exp mobile phone/
17	personal digital assistant/ or tablet computer/
18	(cell phone? or cellphone? or mobile phone? or smartphone? or iphone? or tablet or handheld computer? or hand-held computer? or ipad? or mobile technolog* or app or apps).ti,ab,kw.
19	(internet-based or web-based).ti,ab,kw.
20	12 or 13 or 14 or 15 or 16 or 17 or 18 or 19

21	11 and 20
22	limit 21 to (english language and yr="2010 -Current")
23	conference*.pt.
24	22 not 23
ACP/End of life communication and PPE	
# ▲	**Searches**
1	living will/
2	(advance* adj2 (directive? or care plan* or decision*)).ti,ab,kw.
3	(treatment escalation plan* or living will?).ti,ab,kw.
4	terminal care/ or palliative therapy/ or conservative treatment/
5	exp professional-patient relationship/
6	family decision making/ or patient decision making/ or shared decision making/
7	5 or 6
8	4 and 7
9	(("end of life" or palliative or terminal) adj5 (decision making or talk* or conversation? or communicat*)).ti,ab,kw.
10	(difficult adj3 (conversation? or communication?)).ti,ab,kw.
11	1 or 2 or 3 or 8 or 9 or 10
12	protective equipment/ or exp eye protective device/ or exp protective clothing/ or surgical hood/ or surgical mask/
13	(personal protective equipment or ppe or facemask* or face mask* or face shield*).ti,ab,kw.
14	12 or 13
15	11 and 14
16	limit 15 to english language
17	conference*.pt.
18	16 not 17

APPENDIX 2: Summary data

Title	Journal	Aim	Enables/facilitators of ACP in community	Barriers to ACP in community	Lessons re. how health profs should support ACP
Barriers, enablers and initiatives for uptake of advance care planning in general practice: a systematic review and critical interpretive synthesis (Risk et al 2019)	BMJ Open	To answer the research questions: 1. What are the barriers and enablers to uptake of ACP? 2. What initiatives have been used to increase uptake? (General practice setting, Australia)	Enablers discussed by level (personal, interpersonal, provider, system). Enablers outlined in in table 4. Most successful interventions 1. influenced multiple levels, and 2. involved direct, person to person interaction, over multiple visits. Least successful were direct mailshots without reinforcement.	Barriers summarised in table 3. Much information about barriers, considered by level of influence (patient, relationships, provider, system). Detailed information about barriers tabulated over 3 pages, and outlined by level in 4 paragraphs. Common barriers across studies: lack of patient and provider knowledge; lack of provider skills and experience; patient, family and provider attitudes, and system issues related to time pressure, documentation challenges and mechanisms of information sharing	By stratifying barriers, enablers and interventions into levels of influence, the important relationship between activities operating across levels became evident. Within this complexity, it was understood that some interventions were more effective than others, and combinations of interventions were more effective again. There appeared to be a shift away from considering ACP as 'a singular action' to be achieved or documented, instead to view ACP as a set of discreet steps in a complex process. Interventions targeting multiple levels of influence were said to reinforce each other, and consequently were expected to yield greater and more sustainable effects than interventions targeting only one level of influence.

Cultural Factors Influencing Advance Care Planning in Progressive, Incurable Disease: A Systematic Review With Narrative Synthesis ([McDermott & Selman 2018])	JPSM	Review questions: How, if at all, does patients' and families' cultural background influence the acceptability of ACP for seriously ill patients? How might ACP need to be adapted to make it more cross-culturally appropriate? What cultural factors do clinicians need to be aware of in approaching communication and planning with patients and families about EOL issues?	Communication-focused, informal ACP interventions, e.g. question prompt lists and peer-mentoring schemes, may be more cross-culturally appropriate than a process focused on documentation.	Mistrust between patients and clinicians. Formal ACP may be less acceptable to non-white groups. Cultural variation in willingness to discuss death.	Avoid cultural stereotyping. Adoption of a more informal, discussion-based approach for certain cultural groups. "Cultural competence" training required by clinicians.
Examining Interventions Designed to Support Shared Decision Making and Subsequent Patient Outcomes in Palliative Care: A Systematic Review of the Literature ([Baik et al. 2019])	Am J Hosp Palliat Care	To detail and compare interventions supporting shared decision making in palliative care context	Interventions facilitating SDM categorised into the following groups: technology enabled models (eg. video, web-based programmes)(n=7), print materials (n=4), palliative care consultation (n=3), and structured meetings (n=3). Materials were designed to inform patients about possible medical interventions / level of care. Palliative care interventions tended to be delivered by an MDT, often involving home visits and tended to be a high intensity intervention. Structured meeting usually involved patients' families and were conducted according to a pre-	Delivering sufficient duration and frequency of SDM intervention required may be difficult to achieve. Unclear how well the material was actually delivered to patients.	Light-touch interventions e.g. video, DVD and web-based tools can help provide a platform for ACP discussions. The impact of these in terms of measures such as quality of life were not certain but there was no harm reported either. In the context of COVID, interventions delivered at distance might be highly relevant.

			specified interview framework. There was heterogeneity in outcome measures and inconsistent results as to whether there were improvements in patient /carer knowledge and satisfaction scores, quality of discussions or quality of life measures.		
Video decision aids to assist with advance care planning: a systematic review and meta-analysis (Jain et al. 2015)	BMJ Open	Systematic review to evaluate the impact of video decision aids on patients' preferences regarding life-sustaining treatments (primary outcome) Multiple secondary outcomes (e.g. patient knowledge of ACP)	Video decision aids result in greater knowledge related to ACP (but were not part of clinical care); most participants in most studies suggested they were at least somewhat comfortable watching the video(s); low-quality evidence suggesting that videos led to preferences for less aggressive care at end of life	It remains unknown from these studies whether these tools can increase congruence of end of life care with patient wishes.	Video decision aids may improve some ACP-related outcomes but need to be evaluated in conjunction with clinical care/as part of shared decision-making and conversations with clinicians
A systematic review of effectiveness of decision aids to assist older patients at the end of life (Cardona-Morrell et al. 2017)	Patient Educ Couns	Systematic review to describe the range of decision aids available to enable informed choice for older patients at the end of life Assess their effectiveness or acceptability	DAs at the end of life are generally acceptable to users, and appear to increase knowledge and reduce decisional conflict (but based on low-quality evidence) Family presence in medical consultation is associated with clinicians' enhanced willingness to provide additional biomedical information Making DAs an integral part of routine care would ideally incorporate administration of DAs earlier in the dying process	A multitude of DAs exist for screening and disease treatment but there is a scarcity of comprehensive decision aids for either generic EOL issues or specific EOL management approaches Many DAs are multi-format but require additional human or technical resources to be administered, which makes them comforting to patients but less suitable for routine care in busy clinical environments	Given the sensitivities of end-of-life, self-administered DAs are inappropriate in this context and genuine informed decision-making cannot happen while gaps in the instruments remain (e.g. lack of focus on patient values) DAs administered with clinicians' input have the benefit of additional resource available to patients for clarifications

			and should as far as possible not require any specialised skill except for initial instruction or support if required by the user	Duration of administration of the DA may limit information given and ability to deal with conflict and anxiety while the health professional is delivering routine care under pressure Hypothetical scenarios may not be as helpful or effective as decisions based on scenarios directly relevant to the patient's state of health	Use of DAs should not be seen as a single episode but their repeat use as disease progresses should be encouraged if feasible in routine practice – low regret and sustained satisfaction with decisions made over time; opportunities to change decisions as the disease progresses should be available and revisited; DAs should be flexible to adapt to temporal changes as illness progresses
The evidence supporting educational videos for patients and caregivers receiving hospice and palliative care: A systematic review (Cruz-Oliver et al. 2020)	Patient Educ Couns	Systematic review to explore evidence around and outcomes of education videos for patients and family caregivers in hospice and palliative care (68% were delivered in person)	Video education/interventions positively affect preferences of care and advance care planning, provide emotional support, and serve as decision and information aids ACP completion rate was not significantly different to other forms of educational information (e.g. written), but was higher when compared with narrative interventions Video DAs increased concordance between clinician's goals of care and proxy and patient preferences Participants generally expressed high levels of	Poor communication between patients and providers may limit patients' knowledge Meaningful options are often offered too late and preferences are rarely documented in medical records (Concern that sometimes video aids for cancer patients can have negative effects was not borne out by this review) Given the limited resources that hospice and palliative programmes might face, investment in video technology may also be limited Need more work to establish when face-to-face video delivery versus remote delivery will achieve comparable results	Videos are a promising tool for patient and family education in hospice and palliative care

| | | | satisfaction, helpfulness, and comfort; found videos an acceptable way to get support

Evidence reviewed here suggests that decision aids help patients and caregivers communicate more effectively and participate in shared decision-making with HCPs

Including more stories of caregivers' perspectives and experience in the ACP process increases participant identification with video content

Videos can be multi-media and often clarifies messages better than verbal communication – may be especially suitable for non-native English speakers and those with low literacy levels

This review of the evidence found that videos achieved improvement in choice of treatment, goals-of-care discussion, decision-making and change in caregiver attitudes and mood. | | |
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| **Advance Care Planning in Palliative Care for** | JPSM | To gain insight into what is known about the use and effects of ACP in | ACP for people with ID is not a uniform process but will take different forms depending on | Obstructing factors were difficulties in recognizing palliative care needs, and | Some elements of ACP have been studied, but more research is needed to |

People With Intellectual Disabilities: A Systematic Review ([Voss et al. 2017](#))		palliative care for people with intellectual disabilities (IDs).	the degree and complexity of the disability and vulnerability of the person with ID. Professionals should use ACP as a flexible process depending on the needs and preferences of the individual and their relatives. Enablers include a good working relationships between professionals and relatives.	uncertainties among relatives and professionals about their roles and tasks in ACP. Physicians preferred to discuss end of life decisions in a stable and calm situation, when emotions were under control and enough time could be spent on a sensible discussion. However, this was often not possible because of a late diagnosis of illness. Professionals were not prepared to discuss end-of-life issues with the patient because they believed the patient would not understand and they did not know who had the authority to tell the patient directly. Therefore, if ACP occurred, it was often acute as a consequence of problems that had arisen, instead of anticipating possible problems that could appear in the future. Professionals did not always recognize non-verbal symptoms or saw symptoms as part of the disability.	investigate whether ACP should be used and what this process should look like within palliative care for people with ID. For example, it is still unclear when the process of ACP should be initiated, who should be involved, what the roles and tasks of the people involved should be, and what should be discussed. Moreover, no study included in this review used people with ID as participants in the study. Not much is known about how people with ID in palliative care can be involved in ACP. The lack of reported evidence means that the second research question about the effectiveness of ACP regarding the quality of palliative care and quality of life of people with ID cannot be answered. Authors state this is striking because the effects of ACP are well studied in various other patient groups for several types of interventions and programs.

An integrative review of stakeholder views on Advance Care Directives (ACD): Barriers and facilitators to initiation, documentation, storage, and implementation ([Hemsley et al. 2019](#))	Patient Education and Counseling	To examine the views and experiences of patients and their health care providers on developing advance care planning (ACP) and advance care directives (ACD); and determine barriers and facilitators to ACD development, storage, and use, including implications for people with communication disability.	Multiple barriers identified by the review, broken down into: initiation of ACP, documentation and implementation. Barriers (initiation): negative emotions/attitudes, lack of clarity re. responsibility, lack of time, uncertainty re. scope and timing, weak interpersonal patient-provider relationships, lack of awareness of ACP and its purpose, lack of provider education and skills, limited access to ACP tools. Barriers (documentation): poor quality documents, disputes over content advance care directives, inadequate storage advance care directives Barriers (implementation): desire to provide all possible life-prolonging treatment, fear of legal liability, paternalism (healthcare professional or family)	Overall facilitators to ACP highlighted as increasing education & training, improving access to information. Plus: Facilitators (initiation of ACP): appropriately timed discussions, agreeing on scope/content of discussions, clarification of professional roles, sensitivity to emotions, strengthening patient-provider relationship Facilitators (documentation): high quality forms, personalised content, improving storage and access Facilitators (implementation): strengthening policy guidelines, promoting open communication about advance care directives	Healthcare policy development is now needed to support both the documentation and implementation of ACD. Such policies need to support healthcare providers in having the knowledge and confidence to raise ACP discussions regularly during routine clinical interactions. Policy development on the storage, retrieval, and implementation of ACD is also required to strengthen the procedures around the development and management of ACD in the wider healthcare system. Note: not focussed on community settings.
Implementing advance care planning with community-dwelling frail elders requires a system-wide approach: An integrative review	Palliat Med	To understand how ACP can be better implemented for community-dwelling frail elders and to develop a conceptual model to underpin intervention development. The review	This review uses the COM-B behaviour change model as a conceptual framework to support the identification of necessary ACP behaviours. COM-B argues that for a person to change and sustain a change in behaviour, three interlinking	Barriers: Uncertainty of prognostication, therefore recognising when to initiate ACP, misunderstandings around what ACP means, and frail elders and their families not wanting to discuss death and dying because the topic	Reframing advance care planning as something that promotes living well now as well as planning for the future would relate more readily to frail elders' daily lives

applying a behaviour change model (Combes et al. 2019)		underpins a larger study to develop an intervention to facilitate ACP in this population using the COM-B behaviour change model.	elements are required: capability, opportunity, motivation. The study goes into detail exploring how best to implement these elements in motivating ACP behaviour change. Briefly, early engagement, which provides frail elders the greatest chance of being able to engage physically and cognitively with ACP, is the key Capability. ACP as part of everyday practice and something that occurs over time, rather than a single event, is the key Opportunity. Relationality and living well now are the key Motivations. This review demonstrates that frail elders focus on maintaining current quality of life rather than on ACP, with future planning seen as irrelevant for some within the context of their uncertain health trajectory.	feels taboo or challenges the frail elders' coping strategies.	
Improved patient participation through advance care planning in nursing homes-A cluster randomized clinical trial (Sævareid et al. 2019)	Patient Educ Couns	Cluster RCT of providing support/guidance to nursing home staff for ACP.	Increased patient participation in ACP if regular NH staff are responsible for implementation. Important to involve pts with cognitive impairment. Being open to what patients wanted to discuss, including existential and psychosocial needs.	Concern that ACP might be used to persuade patient to accept less treatment, thus reducing costs.	Building a culture where knowledge of ACP is widespread within an organisation, such as a NH - stimulates curiosity and engagement about ACP. Involve next of kin in the ACP process, particularly

					for pts with cognitive impairment.
Effects of a nurse-led post-discharge advance care planning programme for community-dwelling patients nearing the end of life and their family members: A randomised controlled trial (Yue-Lai Chan et al. 2018)	Int J Nurs Stud	RCT: 3 nurse visits with patient and family member discussing 'my stories', 'my views' and 'my wishes', plus ACP leaflet vs 3 standard visits & ACP leaflet.	A structured, nurse-led ACP programme (3 weekly home visits) for patients nearing the end of life, leading to: Increased completion rates for advance directives, improved dyadic congruence between patients and nominated family members and a reduction in the patients' decisional conflict.	Poor health literacy in patients and their families, introducing ACP process too late in disease trajectory, heavy clinical workloads of medics who have to sign off ADs etc,	Need trained facilitator to facilitate discussion. Highly individualised and person-centred communication process. Time is needed to build consensus during the process of end-of-life care communication between patients and family members.
Advance Care Planning in Nursing Homes - Improving the Communication Among Patient, Family, and Staff: Results From a Cluster Randomized Controlled Trial (COSMOS) (Aasmul et al. 2018)	Front Psychol	To investigate the effect of an ACP intervention on communication among nursing home staff, patient, and family	ACP education programmed delivered to NH staff. The intervention included clearly defined tasks that should be performed by either staff or physician (COSMOS deliverables), which essentially involved monthly conversations between the primary nurse, patient and family. Conversations between family, patient, and the primary nurse increased in the intervention group as compared to controls. An intervention effect was found regarding increased satisfaction with communication on the part of both the nurses and the family and there was a reduction in nursing staff distress	This study suggests that the NH staff had difficulties continuing with ACP conversations when follow-up by researchers ended. The external facilitation is found to be key in improving outcomes in NHs and, because of this, the effect did not persist at follow-up assessment at month 9.	Important to include both the patient and family in the communication process. Staff support is necessary to maintain a good routine for ACP in NHs. Initiating ACP is demanding on staff members, who are advised to start the process of ACP early, aiming to build up relationships by carefully considering timing and receptiveness for all the involved.

Effect of the PREPARE Website vs an Easy-to-Read Advance Directive on Advance Care Planning Documentation and Engagement Among Veterans: A Randomized Clinical Trial ([Sudore et al. 2017](#))	JAMA Intern Med	RCT of PREPARE website vs easy to read advance directive form. PREPARE website included video stories, modeling of behaviours, and a 5-step process to motivate and prepare individuals to discuss their values and care preferences with family, friends and clinicians.	- Easy to read advance directive & PREPARE website. The PREPARE website is a literacy and culturally appropriate, HIPAA-compliant website. The authors re-conceptualized ACP as a process that evolves over time and includes many behaviors. Using video stories, modeling of behaviors, and a 5-step process, PREPARE was designed to motivate and prepare individuals to discuss their values and care preferences with their family, friends and clinicians. Through tailored algorithms, PREPARE asks individuals about their values and helps them make a commitment (ie, action plan) to do 1 ACP step. PREPARE then creates a unique, printed "Summary of My Wishes" and has the capacity to save individual's preferences. Reviewing PREPARE takes about an hour, or approximately 10 minutes per step. - In the absence of clinician- or systems-level interventions, the easy-to-read AD (AD-only) increased new ACP documentation to 25%. PREPARE plus AD increased ACP documentation to 35%. Both tools were rated highly in	- The paper identified that clinician barriers to ACP include a lack of training and system resources, especially in busy outpatient clinics. Patient barriers include difficulty understanding AD forms and feeling unprepared to make end-of-life medical decisions. - Prior studies have shown that passive ACP education with written materials is less effective than ongoing education by a trained health care professional. One reason may be the use of ADs and other materials written beyond a 12th grade/Year 13 reading level. The success of both PREPARE and the easy-to-read AD may be explained by their attention to both literacy and cultural considerations designed with and for diverse communities. - Limitations acknowledged were that the materials were viewed in study offices with computer access, and they note that study interviews and reminder calls may be activating. Other programs may need to include similar reminders in order to produce similar results.	- Easy to read AD/ACP workbook increased ACP documentation to ~50%. +PREPARE website, went up to 35%. +Facilitator, went up to 48%. - Some studies suggest some patients may always require a facilitator in order to engage with ACP. - Any patient-facing tool should be designed for population, with literacy and cultural considerations in mind. Outcome measured here is new ACP documentation on the electronic medical record 9 months post-intervention. - Both tools were rated highly in terms of ease-of-use, satisfaction, and helpfulness, suggesting that PREPARE and the easy-to-read AD could serve as scalable, easy-to-disseminate tools to improve the ACP process, especially in busy and resource-poor primary care clinics. - However, study-specific reminders may have triggered patients to

			terms of ease-of-use, satisfaction, and helpfulness, suggesting that PREPARE and the easy-to-read AD could serve as scalable, easy-to-disseminate tools to improve the ACP process, especially in busy and resource-poor primary care clinics. - Authors state studies show that some patients may always require a facilitator in order to begin engagement with ACP.	- Not stated, but assumed that the veteran population may be similar to civilian population?	engage with ACP, such as the study interviews and reminder calls – should the 'real-world' also include reminders for ACP? If so, who, when and how? Further considerations regarding this point may be required.
Engaging Diverse English- and Spanish-Speaking Older Adults in Advance Care Planning: The PREPARE Randomized Clinical Trial (Sudore et al. 2018)	JAMA Intern Med	RCT of PREPARE intervention (see above) but in diverse English/Spanish speaking older adults.	A well designed online website, created with and for diverse populations, together with easy-to-use AD, may aid in encouraging individuals to think about ACP.	Engagement in ACP remains especially low among minorities and patients with limited health literacy and limited English proficiency, and is less than 20% among Latinos. For health care systems and clinicians, barriers to ACP include time and resource constraints. For minorities, ACP is complicated by a lack of trust and prior experiences of racism, complex legal language in advance directives (ADs), and differing views on autonomy and decision making.	New ACP documentation (comprising of both legal forms and documented discussions) increased by 43% in this trial. The authors note that this is likely because the ACP intervention here, the PREPARE website, was co-created with and for diverse populations to mitigate literacy, cultural and language barriers. Easily accessible online tools that require little clinician input are valuable during the pandemic. Study-specific reminders may have triggered patients to engage with ACP, such as the study interviews and reminder calls – should the 'real-

					world' also include reminders for ACP? If so, who, when and how? Further considerations regarding this point may be required.
Improving the Adoption of Advance Directives in Primary Care Practices ([Wickersham et al. 2019](#))	J Am Board Fam Med	Pilot study comparing uptake of two advance directive forms: Oklahoma Advance Directive for Health Care (OKAD) and Five Wishes.	Clinicians were more positive about Five Wishes and its ability to represent the wishes of patients

Patients reported that Five Wishes captured their wishes 'quite well' or 'very well' – gave them flexibility to express their priorities

Although Five Wishes was longer than OKAD, no one found this a problem as it was easy to read

Clinicians felt that Five Wishes translated well into other languages and allowed cross-cultural differences to be discussed respectfully and sensitively

Conversations with clinicians increased acceptability of both forms even though interaction time was limited

Five Wishes included a free-text space where a number of personal and social issues could | Medical and legal jargon, and generally high reading level, meant that clinicians and patients felt less comfortable with OKAD – clinicians were worried that patients would not truly understand what they were signing, especially those with known literacy limitations

Patients often required assistance with OKAD

General challenges to implementation from clinicians' perspectives included no standardised implementation process, forgetting to offer the form, lack of sustainable reminders in place, novelty of AD process, time pressures, patients forgetting to complete/return forms, staff anxiety about conversation initiation, patient worry about something being wrong with them if ADs are mentioned

Difficult to capture the frequent wish for more than 1 | Five Wishes form was more readable, understandable, appealing, and seems to capture patient preferences for EOL care more effectively, and it more readily facilitated patient-clinician conversations

Identified 2 major rate-limiting factors for AD implementation (1) an understandable AD form that reliably captures patient wishes; (2) an effective process for offering AD forms in primary care settings; and (3) ensuring that AD forms are completed and documented in the chart in a timely manner |

				healthcare proxy in a prioritised manner, no provision for this in forms (but Five Wishes was better at this)	
How to achieve the desired outcomes of advance care planning in nursing homes: a theory of change (Gilissen et al. 2018)	BMC Geriatr	Theory development paper. Two stakeholder workshops, a contextual analysis and a systematic review to develop theory of how/why/when ACP works in nursing homes. Focused on outcomes of improving congruence between wishes and care received, & residents/family feeling involved/confident their care will be according to their wishes.	Based on the results of the systematic review and change workshops, 13 important preconditions identified that need to be fulfilled for the desired long-term outcomes to be achieved • identifies the availability of a sufficiently skilled trainer • who is available for all participating nursing homes, • the engagement of the nursing home management • is necessary to ensure full integration into routine nursing home care • provided by in-house staff, • trained nurses that are able to conduct ACP conversations • trained staff able to signal triggers for ACP and • knows how to pass on this information • informed care professionals • GPs and residents and their families [and care professionals that have the intention to take into account the wishes and preferences of nursing home residents and all to be willing to engage in ACP. • This is followed by the need for all involved care	Contextual conditions need to be in place for ACP to function successfully. A failure to provide these creates barriers that may hinder the achievement of the long-term outcomes. Based on the results of the systematic review - stakeholders' views and the contextual analysis, we identified the need for: sufficient resources (including funding, time and human capacity); a quiet private space where ACP conversations can be held; the commitment of everyone involved; a culture supportive of ACP in the nursing home so people feel free to reflect on and talk about death, dying and end-of-life issues; and an organisational culture that stimulates professionals to invest in ACP, despite the lack of financial incentives, staff shortages or staff turnover.	The approach used in this study has led us to the development of an ACP intervention programme that shares some key characteristics with those that have been developed before, such as an emphasis on in-service training for healthcare staff employed by the nursing home -providing standardised documentation, conducting structured conversations and promoting multidisciplinary awareness Additionally, important elements were added compared to existing ACP intervention programmes. Firstly, unlike other interventions such as Let Me Talk and the intervention by Morrison et al. this intervention programme has a substantial focus on the role of the facility itself.

			professionals to know these wishes [and the availability of a written record that is accessible To ensure quality of ACP is held high-standard, ongoing monitoring is necessary • If all the preconditions described achieved, nursing home residents who engaged in the ACP programme and their families should feel more involved in planning for the future		
Caring Decisions: The Development of a Written Resource for Parents Facing End-of-Life Decisions ([Xafis et al. 2015](#))	J Palliat Med	To develop resources for parents surrounding end of life decisions for their children through review + meta-synthesis + pilot intervention	Written resources for parents (pamphlets or books) to help them retain information. Deliver information in sensitive manner - 'simple, honest and delivered compassionately', benefits of peer-support from other parents	Lack of understanding of medical issues, not knowing what to ask, medical jargon (seen as confusing and overpowering), paucity of existing information, conflicting evidence or advice from healthcare professionals, lack of support or empathy from medical staff	Both parents and clinicians felt it was helpful for parents to be provided with written information. This should use simplified language - small printed handbooks + more extensive web-based resources, 'key terms' box with easy to understand information, inclusion of example questions for parents, give narratives from parents for insight, + provide support but acknowledge uncertainties
Feasibility of a video-based advance care planning website to facilitate group visits among diverse adults from a safety-net health	J Palliat Med	To assess the feasibility and impact of a video-based website to facilitate group visits to engage diverse adults in ACP (USA)	Group visits to view the PREPARE movie showed improved knowledge of ACP, increased discussion with others about decisions, increased surrogate designation, and trend towards AD completion (clinician	Primary care providers in safety-net settings (USA patients are uninsured or otherwise vulnerable) often do not have time to discuss ACP	Group visits with/and video decision aids show promise for promoting ACP amongst vulnerable populations

system (Zapata et al. 2018)			facilitators but did not help with AD completion itself)		
Health literacy: a study of internet-based information on advance directives (Stuart 2017)	Nurs Manag (Harrow)	To evaluate the quality and value of web-based information on ADs using validated health literacy tools	Credibility and accuracy is important User orientation – easy to use & written at the appropriate level Trustworthiness of the site is important – need for a quality indicator or a code of health information ethics for website based info (but potentially unrealistic?)	Many (up to 79%) of sites were considered unsuitable in terms of learning and informing; 30% of sites were classed as unreadable – if info is inaccurate or difficult to understand, patients risks making decisions about their care that may not be followed in practice Confusing, contradictory, and incomplete information – focus group participants unclear about what action to take	Health information (through evaluation with health literacy tools) is often not at a functional literacy level and does not inform or empower users to make independent and valid healthcare decisions Need to go beyond 'functional health literacy' to 'interactional health literacy' i.e. providing information that enables action (only 1 site out of 34 met this) Implications for those writing
Health System Advance Care Planning Culture Change for High-Risk Patients: The Promise and Challenges of Engaging Providers, Patients, and Families in Systematic Advance Care Planning (Reidy et al. 2017)	J Palliat Med	To describe early experiences in building a systematic, population-based ACP initiative focused on health system-wide deployment of an internet-based tool as an adjunct to a facilitator-based model	Tech-based tools improve patient education and offer a framework for family-centred discussions outside clinical settings	Tech-based tool only worked within a broader context of culture change and education about ACP – and tech barriers for older people so need a variety of tools (print and electronic) and forums to reach people Requires local adaptation to context and healthy system – sustainability?	Changing culture and systems to promote ACP requires a comprehensive vision with simultaneous interconnected strategies targeting patient education, clinician training, EMR documentation, and community awareness
Interventions for End of Life Decision Making for Patients	J Immigr Minor Health	To assess the literature around interventions addressing disparities in	Interventions (e.g. trained personnel, video images, web-based programmes and written	Cost may limit use – improving access to basic & free resources is needed	Few interventions exist to improve end of life care for patients with LEP (some for

with Limited English Proficiency (**Barwise et al. 2019**)		end of life decision-making and ACP for patients with limited English proficiency (LEP)	materials) were associated with increased AD completion and decreased preferences for some life-prolonging treatments – interventions seems generally feasible and acceptable However, these often require intensive human resource (e.g. home visits, counselling, specifically trained personnel) Video & modified AD forms also helped with low health literacy		Spanish, Italian, Greek, but not for other languages) Specific lack of decision aids in other languages LEP and poor health literacy may be concurrent and interventions that address both shortcomings simultaneously are vital.
Patient perspectives on advance care planning via a patient portal (**Jordan et al. 2019**)	American Journal of Hospice and Palliative Medicine	To describe patient perspectives on use of patient portal-based ACP tools	- Use of existing healthcare portal meant it was easy to navigate and convenient - Clinic-based conversations about current health issues/ future medical procedures often prompted patients to use ACP portal - Helpful that decisions were documented in medical records- mixed views on whether a follow up conversation with a HCP was needed - Liked the online option rather than paper (easier to complete and could be easily found in an emergency)	- Local legal requirements for witnesses to medical durable power of attorney forms would prevent this being implemented in some regions	Integrating online ACP with existing systems already in use by patients meant people were more likely to engage with ACP and made it easier/more convenient for them
A Website Supporting Sensitive Religious	JMIR Res Protoc	To utilize the context, input, process, and product framework to	Multiple stakeholders, including GPs, primary and palliative care nurses were	Suggestion made that medical practitioners would benefit from having the website	Religious/culturally-specific resources may help HCP to engage in advance care

and Cultural Advance Care Planning (ACPTalk): Formative and Summative Evaluation (Pereira-Salgado et al. 2018)		conduct a formative and summative evaluation of ACPTalk . ACPTalk is a website which was funded to support health professionals in conducting conversations within diverse religious and cultural populations. It aims to provide religion-specific ACP content and complement existing resources.	interviewed regarding the website design and content. Difficulties gaining consensus on religion-specific content were overcome by multi-organisational feedback. A total of 37 content reviewers included representatives of religious and cultural organizations, health care, and community organizations. The majority strongly agree or agree that the content used appropriate language and tone, would support health professionals, and was accurate. Findings indicated overall positivity in relation to accessibility, functionality, usefulness, design, and increased knowledge of advance care planning.	written in their own language. Extending comprehension could also be done through presenting more information visually. Additionally, individuals recommended an AD example, interpretations of complex legal-based ACP information, comparable websites for patients and families, and a related online chat service. Also suggested was further clarity on ACP terms through a larger glossary and acknowledging that different terms in different places can refer to the same thing.	planning with patients from these groups.
Patient experiences of nurse-facilitated advance care planning in a general practice setting: a qualitative study (Miller et al. 2019)	BMC Pall Care	To explore patients' perspectives of an ACP intervention designed to address common barriers to uptake in the general practice setting.	The GPs of participating patients completed a referral form. The GPNs then conducted ACP sessions with the patients. At the conclusion of the intervention, all patients that participated were approached for an interview. Nurse involvement in ACP can have significant benefits for patients, as they are able to	Common barriers for health professionals include a perceived lack of time and adequate training, experience, and confidence in conducting ACP. Patient-reported barriers include a lack of awareness of ACP or discomfort initiating or engaging in discussions about end-of-life. The extent to which patients	With adequate training and support, nurses working in general practice settings are able to initiate and facilitate ACP conversations with patients that result in positive patient outcomes.

| | | | clarify their preferences, make their wishes known, and reduce future burden for families.

The findings show that ACP conversation can be a two-stage process for many patients: a discussion between themselves and health professionals, followed by a conversation with their family. There is a need to provide additional support to patients in having these discussions with their family. ACP should be flexible, guided by patient preferences, and allow for shared-decision making if appropriate. | discussed their wishes with different members of their family varied. Consistent with previous research, these differences were related to factors including patient/family openness, acceptance of illness, family dynamics and physical distance of family members. | |
| **Development of a complex intervention to support the initiation of advance care planning by general practitioners in patients at risk of deteriorating or dying: a phase 0-1 study (Vleminck et al. 2016)** | BMC Pall Care | To develop an intervention to support the initiation of ACP in general practice. | Being aware of the potentially positive outcomes of ACP and having positive attitudes towards anticipating future, as well as positive experiences with ACP in the past.

Knowing that a patient is prepared to participate in ACP/patient initiating an ACP discussion themselves.

Knowing and caring for the patient for a long time, while a lack of time discourages GPs from initiating them during routine consultations. | A lack of confidence, skills and knowledge about ACP and how to initiate it.

The difficulty of defining the right time to initiate ACP.

Difficulties with judging a patient's mental capacity to participate in ACP and concerns about the legal implications of following their documented wishes.

A barrier that was often mentioned was the concern that initiating ACP discussions too early might deprive | The components of the intervention are: 1) a training program for GPs, 2) a register of patients eligible for ACP, 3) an educational booklet for patients about ACP, 4) a conversation guide to support GPs during discussions and 5) a structured documentation template to record the outcomes of the discussions. The components of the intervention were reviewed by two expert panels to refine and |

				patients of hope or create anxiety. The lack of a central system for recording the patient's wishes across different health care settings also contributed to the perceived irrelevance of ACP and was perceived as a challenge to initiating it. Many GPs expressed uncertainty about the usefulness of ACP or ADs as these are not always readily available in a patient's medical records or consistently recorded across the health care system.	improved the intervention. Highlights 4 components for successful interventions re ACP, all addressing some of the barriers and/or facilitators: 1. involvement of experienced and trained facilitators, 2. identification process for eligible patients for ACP discussion; 3. structured, patient-centred ACP discussion; 4. opportunity to complete ACP documents
Developing a web-based platform to foster end-of-life planning among LGBT older adults ([Beringer et al. 2017](#))	Gerontechnology	To describe the third phase of a three-phase national project, designed to foster end-of-life planning and to build a community among Canadian Lesbian, Gay, Bisexual and Transgender (LGBT) older adults.	LGBT older adults are described as being heavy users of social media sites in comparison to the rest of their age group. Smith et al. stated that LGBT-oriented legal advice, information about assisted living, and grief and loss counselling were among the greatest unmet health needs for LGBT older adults. The focus groups made it clear that being able to easily determine if a website is LGBT friendly is one less barrier. The website was designed with photos depicting same-sex couples, rainbow flags, and a logo incorporating these	While LGBT aging shares much in common with aging in general; a significant dimension of difference lies in the pervasive marginalization and discrimination that LGBT older persons have experienced over the course of their lives. LGBT older adults often rely upon friends in times of need and support, sometimes characterized as 'families of choice'. These limited (and non-familial) support networks however, may also exacerbate tendencies toward procrastination or avoidance of end-of-life conversations and planning in this community.	LGBT older adults are more likely to have no one to discuss end-of-life issues with – need for an advocate. Any 'LGBT-friendly' organization should talk to LGBT people and review the presentation of their materials, as they may not be as obvious in their inclusivity as they could be. Website is a good example of a product made with careful, considered, iterative dialogue with the community involved.

			rainbow themed colours. They also included more LGBT-specific content, including videos covering topics such as 'The impact of HIV/AIDS on LGBT aging' and 'LGBT aging and going back into the closet'.	Substantial research notes that LGBT older adults are suspicious of health care institutions and consequently delay seeking formal care. By virtue of the demographics, LGBT persons infrequently turn to kin for support and are even less likely to have conversations about care.	The focus group research confirmed that a lack of information about the LGBT-friendliness of resources, and the context within which such resources are often presented, has the potential to impact and delay health care and end-of-life planning. Emphasises need for LGBT specific and friendly resources. This is especially true for the older cohort of LGBT seniors who came of age in an environment hostile to homosexuality.
Piloting Me and My Wishes—Videos of Nursing Home Residents' Preferences (Towsley et al. 2020)	Journal of Pain and Symptom Management	To evaluate the feasibility and acceptability of person-centred videos of residents discussing their preferences for daily and EOL care (Me & My Wishes)	Participants included those with moderate cognitive impairment and various mental health diagnoses Most participants were eager to share their videos, enjoyed the production process (thinking, filming, editing, distributing) as it gave them the opportunity to think and talk about their preferences Can be shared with different people – family and staff Questions easy to understand for residents & gave them a structure to think through their	People may not want to be filmed due to being self-conscious One participant was concerned that their wishes may be misinterpreted 14 out of 41 family members were not interested in viewing the videos, or were too busy, or had strained family relationships Some participants identified no benefit to their care home sharing the video (but might not have immediate impact)	Acceptable and feasible process, including for people with mild-moderate cognitive impairment and serious mental illness But there was lower family enrolment than expected (some who did participate said that it was irrelevant as they were not involved in daily care)

			preferences Able to return to the video to confirm preferences with participants in the future Family and staff rated messages positively as timely, accurate, adequate, complete, credible; relevant and useful for EOL care – particularly increased staff knowledge of preferences Offers a starting point for EOL conversations Equipment simple and easy to use with little experience but still provides a high quality video	Family and staff concerned about what to do if preferences change	
Proxies Viewing Decision Support Video in Nursing Home Report Higher Advance Care Planning Engagement (Loomer et al. 2019)	Journal of the American Medical Directors Association	To survey patients' (long term nursing home residents) and proxies' engagement with ACP after viewing a decision support video. Measured engagement with ACP by 3 self-reported responses: thinking differently about medical choices, discussing medical choices with a provider, and making changes to advance directives. 5 videos could be shown, according the patient's	1. Watching a decision support video (specifically the one giving general information about ACP for healthy adults). These patients were more likely to think differently about medical choices, have a conversation with health care provider about medical care choices, and make changes to their advance directives. 2. Being cared for by health care system 1 (rather than 2), and 3. Rating health as excellent, were also associated with prompting proxies to think differently	None described	Discussion notes that these results may suggest that the video intervention has more impact for those patients who previously enjoyed relatively good health and therefore hadn't been exposed to ACP discussions previously. So the video intervention (specifically the one giving general information about ACP for healthy adults) may have an enabling role in the early introduction of

		situation: (1) "Goals of Care for Any Patient," (2) "Goals of Care for Patients With Advanced Dementia," (3) "Decisions About Hospitalization," (4) "Decisions About Hospice," and (5) "General Information About Advance Care Planning for Healthy Adults.	about medical choices and to have a conversation about medical care choices. Discussion suggests use of the video may have an enabling role in the early introduction of the ACP concept in the illness trajectory.		the ACP concept in the illness trajectory.
Use of Video Decision Aids to Promote Advance Care Planning in Hilo, Hawai'I ([Volandes et al. 2016](#))	Journal of General Internal Medicine	Primary - to test the hypothesis that implementing an ACP video would increase local ACP documentation; Secondary - that the same hypothesis would increase hospice use and decrease hospital deaths and healthcare costs	Intervention arm saw increase in ACP documentation from 3.2% to 39.9%. Also a decrease in hospital deaths and increase in hospice use. Also resulted in decreased costs.	Introduction suggests scalability and cost of ACP interventions are two significant barriers. Inadequate training of healthcare professionals	ACP video decision aids promote more informed decision making and do so quickly and inexpensively. Videos felt to 'empower and activate' patients to hold ACP discussions and allow them to better align these discussions with their beliefs, Videos used to support (not in place of) ACP conversations. Available on video or mobile app. Payment incentive scheme was used, which may have accounted for some of positive findings
Overcoming educational barriers for advance care planning in Latinos with video images ([Volandes et al. 2008](#))	Journal of Palliative Medicine	To test the hypothesis that limited education might obscure the true relationship between Latino patients and their end-of-life care preferences.	Improving health literacy	Health literacy, rather than 'culture' necessarily, can act as a barrier. While attention to patients' culture is important, it is also important to avoid ascribing choices to culture that may actually reflect inadequate comprehension.	Educational level is an important variable to consider in research and in patient care when communicating about end-of-life care preferences. Attention to communication barriers

					with techniques like the video used in the current study may help ensure optimal end-of-life care for Latino patients irrespective of educational level.
An evaluation of 2 online advance directive programs (Klugman & Usatine 2013)	Am J Hosp Pall Care	To explore 2 attempts at creating a better advance directive in Nevada and Texas, where Web sites and mobile applications provide education, guided interviews, storage, and retrieval in multiple languages.	When asked why they chose to use this particular Web site for this task, in both Nevada and Texas the most popular answer was "ease of use" (NV 64.8%; TX 65.5%). This factor also meant they would recommend it to family and friends. For Nevada, the second most popular reasons for using the Web site were based on personal recommendations. In Texas, the second reason was the free cost followed by referral from another Web site, with personal recommendations falling to fifth place.	The only negative comments related to the fact that there was too much Texas-specific language in the document, written by people from other states.	Websites for ACP should be free of charge and easy to use, and should use locally appropriate language.