Anticipatory Care Planning in Scotland

Supporting people to plan ahead and discuss their wishes for future care

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Summary

This paper reflects on practices and systems that support anticipatory care planning (ACP) in Scotland at the current time. The scope of the paper includes a high-level summary of the literature and activity in Scotland associated with ACP. Learning from this review will be used to explore what can be done further to support an ACP approach in Scotland. The paper highlights how the Key Information Summary (KIS) is currently being used to support ACP. It does not consider developments to support ACP in the future, such as work being done by NES Digital Service to develop digital ACP.

Anticipatory Care Planning (ACP) is a person-centred, proactive “thinking ahead” approach whereby health and social care professionals support and encourage individuals, their families and carers to plan ahead of any changes in their health or care needs. It is about having the right conversations and exploring preferences. ACP can benefit a variety of individuals, from those who are dealing with the early onset of a long-term condition, to those who have chronic and complex illnesses, or those who are approaching the end of their life.

There are data available in Scotland demonstrating an ongoing increase in the recording of important ACP information on the KIS, and an increase in the access to KIS from providers of unscheduled care. This is a proxy measure that indicates ACP information is available to a wider team of health and care professionals involved in the provision of care, and is accessed by services such as Scottish Ambulance Service, NHS 24 and Out of Hours services. These data suggest that the uptake of an ACP approach in Scotland has increased, albeit a wide variation in uptake and access to the information across health and social care partnerships exists.

A review of the published and grey literature summarising evidence around effectiveness, cost effectiveness and implementation of ACP is also included. The review found that ACP improves patients’ and family knowledge, shared decision-making and satisfaction with end of life care. Individuals with a KIS are also more likely to die outside of hospital and in their preferred place of death. The key messages from this review are presented alongside examples of work and learning from Scotland.

This paper concludes that health and social care partnerships could further increase capacity and capability of staff to adopt an ACP approach.
Introduction

Anticipatory Care Planning (ACP) is a person-centred, proactive, "thinking ahead" approach to care planning. It requires services and health and care professionals to work with individuals, their families and carers to have the right conversations about what matters to them. It promotes a shared decision making approach to care and helps individuals, their families and carers, to set personal goals so that ‘the right thing is done at the right time, by the right person with the right outcome’.

‘The conversation that is recorded in the Anticipatory Care Plan is a voluntary process and not legally binding. The plan should be updated to reflect changes in an individual’s thinking or circumstances as and when they occur.

The Key Information Summary (KIS) is an electronic clinical tool, which can be used to share components of an Anticipatory Care Plan. The KIS is linked to the electronic clinical systems used within General Practice in Scotland. It can therefore only be created and updated by professionals working within General Practice, and can be viewed by providers of unscheduled care, including NHS 24, GP out of hours services, Scottish Ambulance Service and Emergency Departments throughout Scotland.

Healthcare Improvement Scotland supports the implementation of ACP across Scotland via the Living Well in Communities portfolio. This document aims to present the evidence behind ACP, how the approach is being implemented in Scotland and key learning from Scottish initiatives.
Anticipatory Care Planning

What is Anticipatory Care Planning?

Anticipatory Care Planning (ACP) is a guided conversation between patients, their families, carers and professionals. This conversation gives people the chance to consider their options and ‘plan for the future’. It encompasses shared decision-making and allows people to communicate their wishes for their future care. Figure 1, below, encapsulates the key steps of an ACP conversation:

**Figure 1: key aspects of ACP**

The Living Well in Communities portfolio has created a range of support materials for individuals and professionals to support the implementation of anticipatory care planning. These can be found at [https://ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/](https://ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/)
Adopting ACP in Scotland

In Scotland, ACP has been considered important and beneficial when an individual’s needs become more complex. Different tools and resources are available across Scotland to support shared decision-making and the capture of anticipatory care planning conversations. A summary of anticipatory care planning discussions between an individual and the professionals and carers involved in their care should be shared via the Key Information Summary (KIS), providing appropriate informed consent is obtained.

Steps in the creation and sharing of the Key Information Summary:

The ACP conversation
People, who will benefit from ACP can be identified by health and social care professionals using a variety of tools, for example the palliative and end of life care identification tools comparator and frailty screening and assessment tools. An ACP conversation can be then initiated, to identify personal wishes regarding current and future care plan and a record of the conversation should be kept. The ihub created a document called ‘My ACP’ to capture ACP information. This document can be downloaded from the ihub Anticipatory Care Planning Toolkit web page.

Details of the conversation are added to the Key Information Summary (KIS) by the GP team
With consent from the person, details from the anticipatory care plan can be added to an individual’s General Practitioner (GP) clinical record via the KIS. This essential step enable unscheduled care services to access the person’s preferences at potentially critical points in their care.
Figure 2 shows that the number of people with a KIS in Scotland is increasing\(^1\). This will increase the opportunity to share a person’s preferences with unscheduled care services. From start to end of the data period (June 2017 to October 2019) number of KIS increased by 29%. With a 9% percentage increase in the last 12 months (November 2018 – October 2019).

![Number of KIS Nationally](image)

**Figure 2 - Number of patients in Scotland with a KIS. June 2017 to October 2019**

Figure 3 highlights that on average about 4.2% of the population of Scotland has a KIS. Aberdeen City HSCP has significantly higher numbers of people with a KIS (14.2% of the population). In Scotland, there is still a need to understand what the acceptable normal range is for this data.

\(^1\) The number of active KIS refers to the number of patients who currently hold a KIS, excluding patients who have changed GP Practice or died. Data provided by NSS digital security.
Figure 3. Patients with a KIS, as a percentage of partnership population based on average three months: data from July to October 2019.

The KIS can be accessed by unscheduled care services

Key Information Summary (KIS) can be viewed by emergency or out-of-hours services for example, secondary care, community teams, NHS24, the GP out-of-hours services, the Scottish Ambulance Service, hospital pharmacies and some hospices.

Data in figure 4 below shows that the number of times a KIS is accessed in Scotland is also increasing. Although this data is indicative only, it may suggest that the information in the KIS is being accessed by unscheduled care.

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2 The Ranked bar charts in figure 3 have been used to rank partnership data from low to high, and compare them to the mean (Scotland average). Simply because a partnership is the highest or lowest does not mean they are particularly different to the Scottish mean so colour is used to highlight statistically significant data. Data provided by NSS Digital Security.

3 Data provided by NSS Digital Security. It is important to note that we were not able to assess the quality and comprehensiveness of the information in the KIS and therefore its usefulness for health and social care staff. In addition, the number of times a KIS is accessed, may be influenced by administrative procedures in health boards.
Figure 4 - Monthly number of KIS accesses. Data for Scotland, June 2017 to October 2019

Interviews with key representatives from Aberdeen, Argyle and Bute, Angus and the city of Edinburgh, areas where there is a high percentage of population with active KIS, identified that these areas have:

- Invested in initiatives to promote awareness and skills development around ACP conversations.
- Raised awareness and understating of the importance of ACP amongst GP practice staff (this was considered a significant facilitator).
- Dedicated improvement support to improve processes around KIS updates in GP practices or funded projects that support the use of KIS.
- Established key stakeholder groups with a range of professionals across primary & secondary care including for example Scottish Ambulance Services and Out of Hours services. This promoted the development of a whole system approach to ACP.
- Focused on the development of cross professional working between primary and secondary care in the promotion of ACP.
- Some areas focused initially on the promotion of ACP in one area for example in care homes.
- In some rural areas there is a closer link between GP day services and Out of hours which promotes the use of KIS.
Anticipatory Care Plans – evidence review

A search of the secondary literature was conducted on the 7 November 2018 to identify reviewed articles published since 2016 on anticipatory care planning. The search was updated again in January 2020. Medline databases were searched. A full list of the search terms used is available on request. Grey literature (documents and other sources of materials such as reports) was also searched.

The literature was reviewed thematically and key messages extracted. The full literature review and the themes, can be seen in Appendix 1. Figure 5, below, sets out what the evidence says and key learning from Scotland.

Analysis of the published literature around ACP has also highlighted multiple expected benefits for patients with an ACP, these include:

- increasing patient autonomy and shared decision making through early conversations and planning ahead,
- reducing inappropriate interventions and repeated difficult conversations,
- reducing unscheduled hospital admissions,
- improving quality of care at the end of life, and
- enabling more people to die at their preferred place of death, leading to fewer deaths in hospital.

Appendix 3 contains a detailed analysis of the literature.
**Figure 5 – key messages from the literature and learning from ihub work in Scotland**

| Key messages from the evidence reviewed                                                                 | Examples of ihub work and learning from ACP work from across Scotland |
|-----------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------|
| **Recent studies suggest that individuals with an ACP are more likely to die outside of hospital and in their preferred place of death** | A number of ihub projects highlighted the benefits of anticipatory care planning and the experience of people involved. More information can be found [here](#). |
| There is consistent evidence for the benefits of advance care planning in terms of improving patient and family knowledge, shared decision making, documentation of care preferences, and patient and family satisfaction with end-of-life care provided. | A recent retrospective Scottish study reviewing 1304 medical records of peoples who died in 2017 from 18 practices across 4 Scottish health boards, concluded that people with KIS were more likely to die in the community (home, care home or hospice) compared to those without one (61% versus 30%).³⁵ |
| There is limited evidence of benefit in terms of improving patient outcomes including quality of life or reducing health service utilisation. | Similarly, an analysis of primary care data in NHS Lothian has shown that patients are more likely to die outside of hospital if they have a KIS, compared with those who do not (65% versus 27%) and if a preferred place of care and preferred place of final care is recorded.⁶ |
|                                                                                                           | The ihub created [guidance](#) for Health and Social Care Professionals to support effective anticipatory care planning maximising the opportunity to improve care coordination. |
| Key messages from the evidence reviewed | Examples of iHub work and learning from ACP work from across Scotland |
|----------------------------------------|---------------------------------------------------------------------|
| **Estimated cost savings associated with reduced health services utilisation have been reported for ACP** but there is currently limited published robust evidence to support firm conclusions. | Some small scale pilot studies in Scotland suggest that the use of ACP is associated with reduced health utilisation. For example, pilot work by the Edinburgh city HSCP supporting the adoption of ACP in care homes and their aligned GP practices, saw a 56% reduction in avoidable hospital admissions and 20% reduction in A&E admission from care homes. Further information is available [here](#). A similar pilot in Lanarkshire in 2009 reported a reduction in the number of Accident and Emergency attendances, number of patients with an emergency inpatient admission, and a reduced total length of hospital stay following the introduction of anticipatory care planning in 8 care homes.³ Another pilot study undertaken in one general practice in NHS Highland in 2010 showed a statistically significant reduction in rates of hospitalisation and occupied bed days following the introduction of anticipatory care plans for people considered to be at high risk of hospital admission.² People with an anticipatory care plan were also more likely to die at home compared with a matched control group who had access to similar inpatient facilities. |
| **Care providers express a need for training in how and when to initiate ACP conversations.** | Analysis of primary care data from NHS Lothian² suggests that since the introduction of KIS into GP practices, patients have a much greater chance of being formally identified for an anticipatory or palliative care approach. This study concluded that training is needed for GPs in how, as well as when, to have anticipatory care conversations.² Furthermore, a recent service evaluation in NHS Lothian identified that care home staff would welcome further guidance and support in having and documenting ACP discussions with residents |
### Key messages from the evidence reviewed

| Examples of ihub work and learning from ACP work from across Scotland |
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| and their families. Similarly an ihub project in an East Ayrshire care home highlighted the need to train a full range of care staff. Further information is available [here](#). |
| ihub learning suggests that promoting the understanding of ACP amongst a wide range of stakeholders is key to the success of ACP work in Scotland. |
| Completion of KIS, keeping it up to date and the sharing of information across services is a continued challenge. |
| ihub learning suggests that more work needs to be done around the transfer of information from anticipatory care plans to KIS and how to keep this information up to date. |
| A recent Scottish study from 2019 concluded that overall the information recorded in the KIS contained useful clinical information. This study also suggested that the update of KIS began earlier for people with frailty and or dementia and organ failure than for people with cancer. |
| An example of close working between primary and secondary care, targeting people most likely to benefit from ACP and ensuring that their plan is up to date is the work by the NHS Lothian. A post intensive care unit (ICU) pathway/toolkit risk assessment checklist was used to target people at risk of re-admission and an ACP was initiated and recorded. It was e-mailed to GPs in a format that mirrored KIS, making it easier for the information to be transcribed into the GP clinical system (through KIS) so that it could be shared with other services (for example out-of-hours services, NHS 24 and the Scottish Ambulance Service). |
| Preliminary results suggest that early unplanned admission of those ‘at risk’ was |
Key messages from the evidence reviewed | Examples of ihub work and learning from ACP work from across Scotland
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duced by 16%. Key learning was the importance of linking with community partners. Further information is available here.

Standardising documentation for recording ACP discussions may encourage uptake and thereby help integrate ACP into routine practice. | ihub learning is that there are several anticipatory care plan formats and templates in use within and across Health and Social Care Partnerships which was confusing to care providers and their service users. The ihub created a range of resources to support and facilitate implementation of anticipatory care planning. Further information is available here. An example, is the ihub support for the development of a children’s anticipatory care plan which was designed in partnership with the Children’s Hospice Association for Scotland (CHAS) and families receiving care, to facilitate a holistic and consistent approach to ACP. It aims to support care discussions, help the parents/carers of children who have a life limiting illness to plan ahead, and deliver meaningful outcomes.

More work is needed to support clinicians in secondary care and the wider MDT to become more actively involved with ACP and access KIS to ensure that this approach is maintained to a high quality, at all stages and in all settings when caring for individuals over the course of their illness. | ihub learning suggests that raising awareness that ACP conversations are part of staff roles is important and that a range of people and professionals are well-placed to have these conversations, including health professionals, social workers, and care home staff. A pilot study in South Lanarkshire illustrated the potential of independent advocacy workers to raise awareness and support people in care homes to complete anticipatory care plans. Local leadership support for anticipatory care planning at all levels and in all sectors is an important driver for the spread and use of this approach.
| Key messages from the evidence reviewed | Examples of ihub work and learning from ACP work from across Scotland |
|----------------------------------------|---------------------------------------------------------------------|
| Further research to improve patient identification for ACP could improve its utilisation. | The ihub describes a number of tools that can be used to identify people who are more likely to benefit from ACP, for example [palliative and end of life care identification tools](#) and [frailty screening and assessment tools](#). |
How can we further improve anticipatory care planning in Scotland?

From the evidence, anticipatory care planning can play an important role in meeting peoples’ preferences and care needs as part of a local model of care. To maximise the opportunities for anticipatory care planning, it is preferable if the following components are considered:

- **Identifying people before a crisis**
  Anticipatory care planning can be beneficial to individuals towards the end of their life or to those with long terms conditions such as frailty, dementia or organ failure. Identification tools such as the electronic frailty index (eFI) and other tools can be used to identify those more likely to benefit from ACP. Such tools serve to highlight individuals who have complex illness that is showing signs of advancing. They do not identify specific care needs of individuals, but rather highlight those who may benefit from a ‘thinking ahead approach’ and anticipatory care planning. A multidisciplinary team of health and care professionals can then Interpret and prioritise the outputs from identification tools.

- **Planning ahead**
  Anticipatory care planning is part of a process to help plan for the future. ACP conversations are therefore complex and require good listening and communication.
skills. Different members of the health and social care multidisciplinary team may have a role in discussing and agreeing plans. The plan is made accessible in the KIS for unscheduled care and can be accessed by multiple services. Improving the accessibility of the KIS to these services is therefore important.

**Accessing preventative models of care**

People can access preventative support in the community to help the plan become a reality. The plan itself is not enough; it requires support within the community. Without that community support to implement the plan, the patient’s wishes to live and die well may not be realised.

Doing the three together will have a greater impact on quality of life and ensure people’s personal choices and views are taken into account as part of their care planning. A wealth of tools and other resources to support ACP are available. We have included a selection of these resources in Appendix 2.

**Conclusions**

Published evidence and learning from work in Scotland supports the adoption of anticipatory care planning as a useful part of a local model of care. For patients, their families and carers there are benefits to having a conversation around their future care wishes and the creation of an anticipatory care plan. Health and social care professionals must be supported with training and time to facilitate these ACP conversations. There is also a variety of tools which can be used to support these discussions.

The KIS is currently the best way to share ACP information with providers of unscheduled care. There are over 200,000 people in Scotland with a KIS, and this number is increasing steadily. Studies have demonstrated the positive impact of having a KIS, with an increased likelihood that someone can be supported to die in their own home if they have an active KIS at the time of death.

Healthcare Improvement Scotland’s ihub will now work with a range of partners, including the NES Digital Service, Scottish Government and Third and Independent sectors to explore how best to further support the uptake and quality of anticipatory care planning in Scotland.
Acknowledgements

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We would like to thank local representatives from Aberdeen, Argyll and Bute, Angus, and the City of Edinburgh HSCPs for sharing learning from their local work with us.
Appendix 1: Evidence Summary

The following section summarises evidence from published and grey literature on:

- The benefits of ACP in relation to person-centred outcomes, service utilisation outcomes and cost effectiveness, and
- The challenges to effective ACP implementation with regard to:
  - awareness of the ACP process and identifying individuals for ACP,
  - confidence and skills to initiate the right conversations at the right time,
  - tools to capture ACP conversations and anticipated interventions,
  - recording and uploading up to date anticipatory care information onto systems, and
  - accessing and sharing anticipatory care plan information.

A search of the secondary literature was conducted on the 7 November 2018 to identify reviewed articles published since 2016 on anticipatory care planning. Medline databases were searched. A full list of the search terms used is available on request. Grey literature (documents and other sources of materials such as reports) was also searched. The literature was reviewed thematically and key messages extracted. The information is summarized under the following themes:

Outcomes

A pilot study undertaken in one general practice in NHS Highland in 2010 showed a statistically significant reduction in rates of hospitalisation and occupied bed days following the introduction of anticipatory care plans for people considered to be at high risk of hospital admission. People with an anticipatory care plan were also more likely to be able to die at home compared with a matched control group who had access to similar inpatient facilities. A more recent retrospective study reviewing medical records of peoples who died in 2017 from 18 practices across 4 Scottish health boards, concluded that people with KIS were more likely to die in the community (home, care home or hospice) compared to those without one (61% versus 30%). A pilot introduction of ACP in nine care homes in NHS Lanarkshire in 2009 reported a reduction in the number of Accident and Emergency attendances, number of patients with an emergency inpatient admission, and a reduced total length of hospital stay following the introduction of an anticipatory care plan. Since the introduction of KIS in Scotland in 2013, an analysis of primary care data in NHS Lothian has shown that patients are more likely to die outside of hospital if they have a KIS,
compared with those who do not (65% versus 27%) and if a preferred place of care and preferred place of final care is recorded. Similarly small pilots of targeted approaches to increase uptake of ACP (e.g. with a district nurses team in Ayrshire and Arran and community advanced physiotherapists working in care homes in Lothian) illustrate that an increase uptake of ACP resulted in more people dying in their preferred place of care. 

A review of ‘Coordinate My Care’ (CMC) records, an Electronic Palliative Care Coordination System in England (2012–2016) showed that 82.4% of deceased patients had died outside of hospital, 77.8% in their preferred place of death. However, there are as yet no trial data available to determine a definitive causal link between place of death and having an advance care plan. The latest NHS England national evaluation was unable to identify a statistically significant difference for death in usual place of residence or in hospital admissions or resource use between sites with and without ACP enabling initiatives (EPaCCS).

In the literature, a systematic review of randomised controlled trials (RCT) of the impact of advance care planning on outcomes in older adults (over 65 years) found evidence of increased documentation of end-of-life care preferences and use of advance care directives, and improved patient and family outcomes such as increased knowledge of ACP, understanding of end-of-life preferences and concordance with end-of-life wishes. The trials included in the review were conducted in community settings including nursing homes and there was considerable variation in the types of ACP interventions and who implemented them. The review found evidence from two trials of increased patient and family satisfaction with care and evidence from one trial that ACP decreased hospitalisation from nursing homes and health care services utilisation. None of the trials measured the effects of ACP on patient outcomes such as symptom management and the quality of end-of-life care or the death and dying experience. A systematic review that focused specifically on the effects of advance care planning interventions on nursing home residents concluded that ACP has beneficial effects in this population, including reducing hospitalisation, increasing the likelihood of residents dying in their preferred place of death, and care provided being consistent with resident’s wishes. The evidence supporting these findings was generally of low quality.

A systematic review of the effectiveness of care planning discussions on outcomes for people at the end of life found evidence of association with increased completion of advance care plans and more optimal health care use. The review found evidence of increased concordance between patient and family wishes and improved patient and family satisfaction with end-of-life care, but insufficient evidence of benefit to patients’ quality of life. One RCT reported fewer episodes of hospital care, reduced length of hospital stay and greater use of hospice services. There was evidence from observational studies that associated earlier discussions with less hospital care and that care-planning discussions with a multidisciplinary team (MDT) reduced outpatient visits.
A recent systematic review of the effectiveness of advance care planning in improving end-of-life outcomes specifically for people with dementia and their carers included 18 studies, mostly based in care homes. Three of the included studies were RCTs, of which two were judged to be of low quality, and the others of a less robust study design. These studies assessed various types of interventions including written advance directives, end-of-life conversations and staff training. The majority of studies found that ACP was associated with some positive effects on end-of-life outcomes including place of death, hospitalisation, and patient or carer outcomes such as satisfaction with care, concordance, and physical or emotional distress. The review concluded that although the evidence base is limited, ACP is likely to be relevant and applicable to people with dementia and that it may, in some circumstances, be associated with a range of positive end-of-life outcomes. An earlier systematic review of controlled studies that focused on people with cognitive impairment or dementia found limited evidence of variable quality for the potential of ACP to reduce inappropriate hospital admissions.

A more recent systematic review and meta-analysis of 14 mainly US based studies, on the effect of advance care planning for people with heart failure, concluded that in the short term, ACP improved reported quality of life, patient satisfaction with end of life care and quality of end of life communication. It was unclear however whether this positive effect would mitigate over time. ACP interventions that included not only patients but also family members, offered follow-up appointments and considered ethnical preferences were more effective than ACP interventions that did not include these components. The authors suggested that in order to facilitate a better engagement with ACP in heart failure, ACP should be introduced at a significant milestone in the patient disease trajectory (e.g. deterioration in the person condition, move to a care home et) and should be part of an MDT approach to care.

A systematic review of mostly observational studies of many different types of advance care planning interventions in various settings broadly found that complex advance care planning interventions – as opposed to stand-alone written advance directives, do-not-resuscitate and do-not-hospitalise orders – appeared to increase compliance with patients’ end-of-life wishes, and may be more effective in meeting patients’ preferences than written documents alone.

A systematic review conducted to support National Institute for Clinical Care and Excellence (NICE) guidelines found evidence from three RCTs of moderate to very low quality suggesting that ACP may be beneficial in reducing emergency department visits and inpatient admissions compared with usual care for adults and young people with or at risk of an acute medical emergency; but made no difference to patient and/or carer satisfaction, family satisfaction or patient quality of life.
In summary, recent studies suggest that individuals with an ACP are more likely to die outside of hospital and in their preferred place of death but there is as yet insufficient evidence of a definitive causal link. There is consistent evidence from several systematic reviews for the benefits of advance care planning in terms of improving patient and family knowledge, shared decision making, documentation of care preferences, and patient and family satisfaction with end-of-life care provided. There is limited evidence of benefit in terms of improving patient outcomes including quality of life or reducing health service utilisation.

Cost effectiveness

The primary care pilot study of ACP undertaken in Scotland in 2010 reported cost savings associated with reduced unplanned hospitalisation. A local evaluation of the ACP project in NHS Lanarkshire (phase 2) estimated cost savings of £754,250 over approximately one year (2014–2015) based on 431 care home residents with an ACP who remained in their preferred place of care following a change in health (calculated on an average cost of £1,750 per patient for a five day stay in hospital). A recent pilot in NHS Lothian also illustrated that targeting ACP at high resource individuals might be cost effective, potentially reducing emergency admission by 35%.

The recent NHS Lothian primary care study report stated that GPs are writing more KIS than they are resourced for and that these resource issues need to be considered in order to ensure that patients can continue to be appropriately identified and offered ACP.

A cost analysis of CMC, an Electronic Palliative Care Coordination System in one Primary Care Trust in England in 2012 estimated a net reduction of £2,100 in the mean treatment costs for CMC patients compared with non-CMC patients, with higher costs for community services offset by lower costs for hospital, emergency and unplanned care.

An economic analysis of end-of-life care interventions concluded that additional data are needed to reach a firm conclusion about the cost effectiveness of patient care planning discussions. It recommended that future studies collect data on patterns of care, health-related quality of life, resource utilisation, and costs from a societal perspective including data relevant to the burden of dying for patients and their caregivers.

The NICE review of ACP for adults and young people with or at risk of an acute medical emergency found no relevant economic evaluations.

In summary, some studies report estimated potential healthcare cost saving that they attribute to ACP but robust cost estimates, underpinned by robust economic evaluations, are lacking, as well as evidence of any cash released to the healthcare system as a result of ACP interventions.
Implementation

**Identifying individuals for ACP**

Guidance on ACP for health and care professionals in Scotland states that individuals should be identified and offered interventions in a timely way to enable informed choice and ensure optimal outcomes.\(^4\) It advises that ACP can be prompted by a range of triggers based on the individual’s situation (for example frequent unscheduled contacts), condition (for example deterioration long-term conditions) and assessment (for example identified as vulnerable using risk predictive tools).

Since the introduction of KIS into GP practices patients have a much greater chance of being formally identified for an anticipatory or palliative care approach based on the analysis of primary care data from NHS Lothian.\(^6\) Most practices made use of the ISD Scottish Patients at Risk of Readmission and Admission (SPARRA) data\(^19\) to identify patients for KIS while others were identified opportunistically or through regular MDT meetings. The SPARRA tool has widespread use in Scotland but has not been formally validated. Variation between practices in the number of patients with a KIS suggested that further research on training interventions to improve patient identification is needed to improve utilisation.\(^6,4\)

The Scottish palliative care Directly Enhanced Service (DES) has encouraged GPs to identify more patients with non-malignant disease for palliative care by supporting them to use the validated Supportive and Palliative Care Indicators Tool (SPICT).\(^6\) In a study of unplanned admissions in one acute hospital in Scotland, SPICT helped to identify patients with multiple unmet needs who would benefit from earlier, holistic needs assessment, a review of care goals and ACP.\(^20\)

The palliative care DES for 2019/20 has been revised and now encourages GP practices to consider a wider range to tools (such as the electronic frailty index) to help identify people who could benefit from an ACP.

In the secondary literature, a systematic review of advance care planning implementation studies identified prognostic uncertainty as an important factor affecting the clinical decision to initiate ACP such that patients whose future trajectory seems clear may be more likely to be offered the opportunity to consider ACP than those where the outcome of events is less predictable.\(^21\) This is supported by findings from a recent systematic review on ACP for patients with respiratory diseases that concluded that the chronic nature of respiratory diseases which are characterised by prolonged illness with interrupted

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\(^4\) Results of in-house analysis of ISD data on which organisations/ services are accessing the KIS are pending (R Davies, Data and Measurement Advisor, Healthcare Improvement Scotland, Personal Communication, 21 March 2018).
exacerbations, makes it difficult for healthcare professionals to identify trigger points for the initiation of ACP, especially for patients with chronic lung disease.\textsuperscript{37}

An earlier systematic review of qualitative studies that found that most frail and older people with no overriding medical condition would like the opportunity to discuss their end-of-life care also identified the onset of dementia as a prompt for early planning.\textsuperscript{22} A systematic review of studies that explored the perspectives of older people living in long-term care facilities and their family members about advance care planning discussions found some evidence that residents with dementia or cognitive impairment were able to consistently express their preferences when offered the opportunity to express their thoughts.\textsuperscript{23} Similarly, findings from a recent Scottish suggest that people with cancer were more likely to have information recorded in the Key Information Summary, an electronic clinical tool used to share components of ACP, than people with frailty, dementia and organ failure. However, frail people and people with dementia had information recorded in the Key information summary at an earlier stage before death than those with organ failure or cancer\textsuperscript{35}.

**Initiating ACP conversations**

Guidance on ACP for health and care professionals in Scotland states that initial discussion around ACP should involve exploring the individual’s understanding of their conditions and prognosis and gives suggestions on what to ask to help with that process.\textsuperscript{4}

It is recognised that some individuals may not wish to engage in discussions about future care as it involves them in thinking about a deterioration in their condition, and GPs might be unwilling to initiate ACP discussions as they may feel that discussing prognosis with patients will cause them undue distress and destroy hope.\textsuperscript{2} It is also known that the response from individuals and their relatives to the initiation of ACP conversations is unpredictable and emotionally complex and that such interactions between patients and staff can be demanding and stressful.\textsuperscript{21}

A systematic review of barriers and facilitators for GPs to engage in ACP found evidence to suggest that difficulties with defining the right moment, the attitude that it is the patient who should initiate ACP, and fear of depriving patients of hope were barriers; whereas skills to respond to a patient’s initiation of ACP, a longstanding GP–patient relationship and the home setting were facilitators.\textsuperscript{24} The review concluded that initiation of ACP in primary care may be improved by targeting GPs’ skills, attitudes and beliefs.

The study of GP’s views on KIS in NHS Lothian, wherein none of the GPs interviewed had received any formal training on discussing and delivering anticipatory care, concluded that training is needed for GPs in how, as well as when, to have anticipatory care conversations.\textsuperscript{6} Staff training and support needs have also been identified in other care settings, for
example in a study of ACP in early dementia where community mental health team staff in England identified training and supervision as key factors to increasing their confidence to initiate ACP conversations. A service evaluation in NHS Lothian identified that care home staff would welcome further guidance and support in having and documenting ACP discussions with residents and their families. A published study of care home staff experiences of initiating and completing ACP discussions in care homes in England similarly identified education as being important, and that role modelling ACP enabled staff to develop their skills and confidence in it.

In regard to timing, the NHS Lothian study concluded that earlier identification of individuals for ACP helps a series of conversations to take place over time between individuals and their GP rather than rushed discussions during the last days or weeks of life. When to initiate ACP conversations is a particular challenge in dementia with studies reporting general agreement among patients, carers and staff that the opportunity to discuss ACP should be offered to patients soon after diagnosis (but not at the point of diagnosis) when they are still able to make decisions about preferences for the future.

Two systematic reviews identified lack knowledge of treatment options, lack of time for ACP conversations and insufficient training particularly around legal responsibilities and communication were barriers for the implementation of ACP by healthcare professionals. A review of qualitative studies describing perceptions and experiences of health professionals with ACP in heart failure also suggested that lack of clarity as to who should initiate ACP conversations (whether a cardiologist or a GP) and fear that the conversation will destroy hope and relationships with patients, were identified as barriers to professionals initiating ACP conversations. Conversely, facilitators for professionals’ engagement with ACP in the context of heart failure were competency in managing complexity, robust knowledge of drug regimes, good understanding of legal frameworks, being able to identify level of patient need for information, clarifying values, knowing the patient and continuity of care.

Similarly, in another review, the emotional nature of patient-professional interactions around ACP and the competing demands of other work have been identified as barriers to implementation, and a structured approach to interactions as an enabler. The unpredictable response from individuals and their relatives to the initiation of ACP conversations has been addressed by using conversational frameworks, preference elicitation and decision-making tools that direct interactions towards specific goals. Another systematic review of ACP interventions concluded that qualitative studies suggest that overall patient viewed participation in ACP conversations positively albeit emotionally difficult.

It is a common assumption in published studies that care providers should initiate ACP and studies with patients and carers have shown a belief that it is the care professionals’
responsibility to initiate ACP, suggesting a need for greater shared understanding in this area. 21, 24, 29

**Tools to capture ACP conversations**

The [ACP toolkit](#) developed for use across Scotland provides a document template ‘My Anticipatory Care Plan’, also available as a free electronic app, for individual’s to record what matters to them, details about their current health and care and their wishes if they become more unwell. 4 The guidance suggests that individuals may want to speak with family and friends, a care professional supporting them or an independent advocate to help shape and complete their plan. A pilot study in South Lanarkshire illustrated the potential of independent advocacy workers to raise awareness and support people in care homes to complete anticipatory care plans. 30

Advance care plan apps are also under development in England and a growing number of online consumer products are available for recording future care wishes and preferences. 3 Evidence comparing the utility of these tools with regard to ACP is lacking.

Tools to structure records of ACP discussions, such as the Advanced Care Planning in Early Dementia (ACP-ED) tool, have been shown to be useful for staff, providing structure to guide them in having and recording ACP discussions. 25 Standardising documentation for formal recording of ACP discussions is likely to encourage uptake by staff and thereby help integrate ACP into routine care. 28 Care is needed however to ensure that documentation does not limit the discussion, blocking opportunistic cues and encouraging a ‘tick box’ exercise. 27

A service evaluation in NHS Lothian (2015–2016) explored the acceptability of a primary care Anticipatory Care Questionnaire (ACQ) to the relatives of care home residents, care home staff and GPs. 26 The ACQ describes common scenarios that may arise when a resident is frail and at risk of deterioration and dying and the options for treatment and care. It is intended to enable discussion of the views of residents and their families about the goals of future care and for this to be reliably documented. The tool facilitated effective ACP by aiding the completion and updating of KIS anticipatory care plans for care home residents resulting in 64% of acute events being managed appropriately in accordance with their wishes. As a result of learning from the evaluation, work is continuing to further develop the ACQ and embed its use in the care home setting. 26
ReSPECT is a process that creates personalised recommendations for a person’s clinical care in a future emergency in which they are unable to make or express choices. It provides health and care professionals responding to that emergency with a summary of recommendations to help them to make immediate decisions about that person’s care and treatment. ReSPECT can be complementary to a wider process of advance/anticipatory care planning.

The plan is created through conversations between a person and their health professionals. The plan is recorded on a form and includes their personal priorities for care and agreed clinical recommendations about care and treatment that could help to achieve the outcome that they would want, that would not help, or that they would not want.

ReSPECT can be for anyone, but will have increasing relevance for people who have complex health needs, people who are likely to be nearing the end of their lives, and people who are at risk of sudden deterioration or cardiac arrest. Some people will want to record their care and treatment preferences for other reasons. The NES Digital Services is developing an electronic version of ReSPECT for use across Scotland.

Empirical evidence on the effectiveness of ACP tools or guides is limited. A recent systematic review of tools or ACP conversation guides suggested that most lacked theoretical underpinning. Empirical evidence on the effectiveness of the guides related to process measures such as knowledge about ACP, discussion rate, documentation rate, quality of communication, and decision conflict. Measurement of quality of life wellbeing, hospice use and concordance of preference and received care were used less often. The Review concluded which elements are essential to connect the persons value and preference with future care offered.

Recording and uploading anticipatory care information onto systems

In Scotland, anticipatory care plan information can be added to an individual’s electronic GP record via the KIS system introduced into all GP practices in 2013. The NHS Lothian study of GPs’ views on using KIS identified outstanding challenges with integration into GP clinical systems and ease of use as areas for improvement. This was further echoed by a more recent study that reported that many KIS were missing information regarding preferred place of care. The study concluded that more regular updating of KIS would improve completeness. However the time required to regularly review and update the 250 000 live KISs currently in existence in Scotland is considerable, and this needs to be considered alongside all the other clinical work undertaken within Primary Care.

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5 No further information was found to explore this in more detail.
The KIS template in the GP system has a ‘drop down’ box option for completing additional data fields that are not populated automatically from the GP record, and also the option to complete a free text box (the special note). There was a feeling among GPs interviewed in the NHS Lothian study that a well written free text summary within the KIS was the key to facilitating good anticipatory care, and was probably more important than ‘ticking all the boxes’.6 The GPs acknowledged difficulties with ensuring the KIS is well completed and kept up to date, and would welcome more dialogue between GPs and other MDT members with those colleagues being able to contribute more actively to ACP, KIS and what makes a good care plan.

**Accessing and sharing anticipatory care plan information**

In Scotland, the KIS allows anticipatory care plan information to be shared electronically from the primary care record across the wider NHS.

The GP’s interviewed in NHS Lothian held positive views on the effectiveness of KIS for sharing anticipatory care information between themselves and GPs working out of hours but were less confident about KIS access in hospitals.6 **The study concluded that more work is needed to support clinicians in secondary care and the wider MDT to become more actively involved with anticipatory care to ensure that this approach is maintained at all stages, in all settings, when caring for patients over the course of their illness.**

A recent improvement project undertaken in one NHS Lothian hospital that sought to increase KIS access by clinicians within secondary care showed poor awareness of available KIS information among admitting clinicians at baseline.5 Interventions to improve KIS access and awareness of its importance among doctors in a Medical Admissions Unit were designed and refined over four Plan Do Study Act (PDSA) quality improvement cycles, which initially resulted in significantly improved KIS access (from 4% to 45%) but this was not sustained, dropping back to baseline levels after one year, despite ongoing staff education. The project showed that although access to KIS by doctors at the point of hospital admission can be significantly improved using a quality improvement approach sustainable, system-wide strategies are needed to maintain these changes in the longer term. The effect of changes made to the hospital’s electronic patient record system as a result of this study to improve ease of access to the KIS have yet to be ascertained. Lessons for future improvement projects included focusing iterative tests of change on discrete interventions because it is hard to conclude which interventions are potentially most effective when multiple interventions are tested simultaneously; and making sure that learners’ knowledge and knowledge retention over time is assessed after educational interventions in order to ascertain their effectiveness.5
As well as secondary care and the GP out-of-hours service, the KIS can also be viewed by community teams, NHS24, the Scottish Ambulance Service, hospital pharmacies and some hospices.\textsuperscript{5,6,6}

With regard to service users views on data sharing, 85\% of respondents to a YouGov survey (2014) agreed that any medical professionals directly responsible for treating patients should be able to access key elements of that patient’s GP medical records; 30\% were ‘shocked’, 40\% ‘annoyed’ and 61\% found it ‘worrying’ that this information was not available to accident and emergency departments with only 4\% thinking that was how it should be.\textsuperscript{31}

\textsuperscript{6 Results from in-house ISD data analysis on what organisations are accessing KIS are pending.}
Appendix 2: ACP resources

Here are some resources that can support anticipatory care planning:

Recording and sharing tools

My ACP
National ACP document developed by Healthcare Improvement Scotland to support anticipatory care planning.

Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)
The ReSPECT form is designed to summarise recommendations and patient’s wishes so that this can inform care and treatment decisions they receive, should they become unwell in an emergency and they are unable to make their wishes known at the time. The process is intended to encourage good conversations around anticipatory planning. It should help to create opportunities to discuss realistic treatment options and the aims of care that people would want more generally, and come to a shared understanding about care.

Anticipatory care planning in three questions
This questionnaire from St Triduana's Medical Practice in Edinburgh is given to relatives of new care home residents who lack the capacity to make decisions about their welfare. It asks how they think a resident would like to be treated in the event of the following:
- a sudden collapse,
- an infection not responding to antibiotics, or
- an inability to eat and drink due to illness.

Guides and training

Healthcare Improvement Scotland ACP toolkit
Resources produced by Healthcare Improvement Scotland to support Anticipatory Care Planning. Includes:
- My ACP
- My ACP for babies children and young people
- ACP – guidance for health and care professionals
- ACP – Things to think about
- ACP – What you need to know
- My ACP – Frequently Asked Questions
- ACP videos
Edinburgh Health and Social Care Partnership ACP resources
Reports, presentations and videos from Edinburgh HSCP’s Long Term Conditions Programme.

Talking about Care Planning: RED–MAP
A tool to guide discussions about ACP. It provides prompts under the following headings:

- Ready
- Expect
- Diagnosis
- Matters
- Actions
- Plan

Effective Communication for Healthcare resources
EC4H has a number of resources to support ACP, and has also compiled UK and international ACP resources.

NHS Education for Scotland Shared decision making training
NES has developed an e-learning module, Realistic Conversations – shared decision-making in practice, which is suitable for all health and care professionals. It provides a foundation in the skills, terminology and evidence base for shared decision-making, as well as practical hints and tips that professionals can use in practice.

Scottish Social Services Council Open badges
SSSC offers open badges in a range of topic areas, including communication and relationships in care settings and palliative and end of life care awareness.

Institute for Healthcare Improvement Conversation toolkit
How to Talk to Your Patients about End-of-Life Care: A Conversation Ready Toolkit for Clinicians aims to help professionals address some of the challenges of engaging with individuals and families in end-of-life care conversations over time. Each of the four case studies describes the progression of a person’s illness and outlines key considerations for professionals to engage individuals and their families in discussions about what matters most to them at the end of life.

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A Guide to Having Conversations about What Matters
Guide to having conversations with people about what matters to them from BC Patient Safety & Quality Council.

The House of Care
The House of Care is a model of care provision that is built around a care and support planning conversation. It aims to ensure that health and care systems are responsive to the needs of people with long term conditions.

Assessment tools

Frailty Screening and Assessment Tools Comparator
This Healthcare Improvement Scotland resource compares the features of different frailty screening and assessment tools at a glance, together with links to further information and research.

Palliative and End of Life Care Identification Tools Comparator
This Healthcare Improvement Scotland resource compares different palliative care identification tools, and includes links to further information and research.
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