

Anticipatory Care Planning Improvement Programme

Learning Report

Phase 3: 2018-2019

Long Term Conditions Programme

Edinburgh Health and Social Care Partnership

Let's Think Ahead!

An Anticipatory Care Plan (ACP) is about you, your health and how you want to be treated if you become unwell

Your GP can share your ACP with professionals involved in your care through a Key Information Summary

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Executive Summary

"Definitely thinking back to those days where people were not thinking about these kinds of things. We were not always doing the right things for the residents, the appropriate things." Care home staff member.

Background

There is now extensive evidence that Anticipatory Care Planning (ACP) can improve the quality of care of those with complex care needs.¹ Care home residents have had increasing levels of frailty over the last decade² and are a cohort for whom ACP has generated much interest. Reductions in inappropriate admissions to hospital from care homes have been achieved through creating high quality ACPs for residents.³ However, the benefits of ACPs go far beyond reducing admissions to hospital. Supporting residents and their family to have open and honest discussions about their health and wellbeing and wishes for the future, helps put the resident at the centre of decisions about their health. ACPs are a fundamental tool for ensuring shared decision making and managing medical risk proactively and effectively. ACPs are therefore entirely aligned with a Realistic Medicine ethos of care. The benefits of ACPs are equally true for people with chronic and complex care needs living at home.

The challenge was to develop a process that is not dependent on additional workload for already stretched primary care resources and one that is sustainable beyond the life of this programme.

The ACP Improvement Programme

For the last three years Edinburgh Health and Social Care Partnership's (EHSCP) <u>ACP team</u> has been working with care homes and GP practices to embed an ACP process in their routine care. We were keen to see whether training the care home staff in how to discuss ACPs with their residents and how to use the completed ACPs in an emergency would reduce the number of avoidable admissions to hospital. The tools used were developed from original work in a local GP practice with later support from Marie Curie. We started small with just four homes in 2016 and have steadily refined our tools and the training support offered so that last year we were able to work with 20 homes across Edinburgh.

¹ Holman, D., Sawkins, N. and Hockey, J. (2011). Experience of use of Advance Care Planning in care homes. In Thomas and Lobo (Eds). Advance Care Planning in End of Life Care. pp. 132-147. Oxford, Oxford University Press.

² <u>Care Home Census for Adults In Scotland</u>, ISD Scotland

³ Realistic Medicine: <u>Chief Medical Officer's Annual Report 2014-15</u>

Together these tools comprise the '7 Steps to ACP for Care Homes' (Appendix 1). Anticipatory Care Questions are completed with residents and families and passed to the GP practice, the ACPs are entered as special notes in the resident's Key Information Summary (KIS), that form is printed and returned to the care home. Our ACP facilitator worked with staff to train them in the process but also, crucially, to support them in having the sometimes challenging and complex conversations with residents and/or relatives on their wishes for future treatment.

The other key component of the training for staff was how to use the ACP-KIS to guide the management of a medical emergency by them, out-of-hours doctors and the ambulance service. These situations can create a lot of anxiety for care home staff and at times their initial instinct was to call for an ambulance.

"I find that staff are initially shocked that someone might not want to go into hospital for treatment and might want to be kept comfortable in the care home. It's been really important in providing us with confidence to speak about what people's wishes are if they become really unwell." Care home ACP champion

We helped care home staff complete reflective logs of each of the acute events and then met with them, and, initially, the GP to discuss all the episodes every 6-7 weeks in a series of learning cycles. Care home ACP champions in each home helped lead this learning process.

Findings and outcomes

An aim of the project was to reduce avoidable hospital admissions for residents in the participating homes by 10%. Exceeding all expectations the number of avoidable admissions has reduced by 56%. This is a testament to the energy and enthusiasm of the care home and GP practice teams in embracing not only the '7 Steps to ACP' process but the ideas and values of Realistic Medicine on which it is based.

Care home staff immediately understood the benefits of this approach. They all want to provide high quality person centred care and they hated to see residents ending up in hospital when it is unlikely to help them. When this did happen many staff felt as if they had somehow failed their residents. What is more, many of them were already having conversations about the future, but they found them difficult at times and didn't know how to use this information in the best way. The GPs were also delighted to get some help with gathering the information they needed to create a high quality ACP. They all wanted to do their best but had been overwhelmed with the time needed to do it properly.

The staff were really positive about the tools that comprise the '7 Steps to ACP for Care Homes'. The forms were seen as simple and easy to use. The training provided helped the care home staff, both nurses and social care workers, become confident in managing conversations on future health wishes for residents and relatives. The reflective logs and learning cycles helped embed that learning in the care homes and

GP practices, by resolving any process issues and highlighting clear examples of positive clinical outcomes.

183 new ACP-KISs have been created and 276 ACP-KISs reviewed and updated during this third phase of the programme, with substantial improvements in the quality of those ACPs demonstrated. The programme was successful in embedding an ACP process in 20 care homes across Edinburgh.

Future ACP improvements

The ACP team has already started using some of the learning from improving ACP with care homes to raise awareness of the benefits of ACP with unpaid carers. Working with Voices of Carers Across Lothian (VOCAL), we are testing ways of creating ACP-KISs both for carers and the people they care for. We are working with colleagues across Edinburgh's integrated health and social care system, supporting teams to take a structured approach to improving ACP for all those with complex health and support needs wherever they live in our community.

We need to continue to work collaboratively to:

- develop a care home ACP improvement and support package to both sustain improvements made and to test a scalable care home ACP improvement model
- carry out an evaluation of ACP with participating homes to help understand the cost saving of dramatically reducing avoidable admissions, and how the allocation of ACP resources could achieve the greatest benefit
- work in partnership with health and social care and voluntary teams to improve ACP for people living with long term conditions at home, work towards individuals having current copies of their ACP-KIS at home to inform shared decisions about their care and treatment
- engage with citizens to understand the level of ACP awareness and utilisation among the general public, co-producing resources to empower people to make the best use of ACPs when making informed choices about their care and support.

This programme has demonstrated that care home staff and GP practices will embrace ACP with enthusiasm and commitment when given support to do so, and that this results in significant improvements in the appropriateness of medical care for their residents. There are exciting possibilities for how this learning can be spread to other care homes and to all those living at home with complex care needs.

Dr Andrew Mackay, ACP GP Advisor, Long Term Conditions Programme, Edinburgh Health and Social Care Partnership, May 2019.

Introduction and Context

Anticipatory Care Planning (ACP) is a person-centred, proactive, 'thinking ahead' approach, with health and care professionals working with individuals, carers and their families to make informed choices about their care and support. It requires a supportive whole-system approach which puts individuals at the centre of decisions that affect them.

Whilst ACP responds to the challenge of providing care for an ageing population with increasing prevalence of long term conditions and multiple morbidities, ACP is relevant for all ages. ACP enables individuals with chronic and complex conditions to understand their current health and wellbeing, whilst anticipating and proactively managing their health and care needs. Optimal outcomes and improving quality of life through ACP are helped by early intervention when people have complex needs or changing circumstances.

For ACP to work we need to build on existing good practice, supporting innovation to spread learning and scale improvements. There is increasing evidence that appropriate access to community services and good anticipatory care, supported by the development of a Key Information Summary (KIS) that contains the right information, can reduce the risk of hospital admission by 30–50%⁴. Since 2016, the number of Key Information Summaries in place in Edinburgh has increased by 56%.

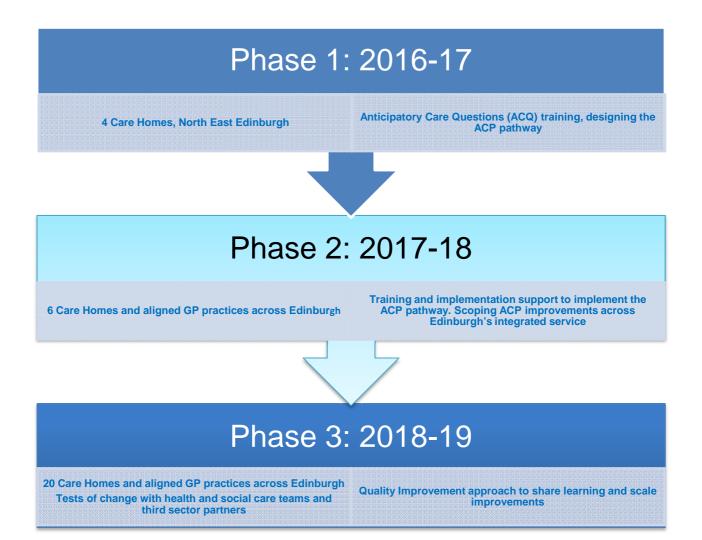
Edinburgh Health and Social Care Partnership's Long Term Conditions Programme recognised the value in supporting people to improve clinical and personal outcomes by planning ahead for their health and care. During January-June 2017 the Long Term Conditions Programme provided dedicated project and improvement support to test improving Anticipatory Care Planning with 4 North East Edinburgh care homes and aligned GP practices (phase 1). The shared aim was to support residents to think ahead about what matters to them, ensuring they have greater control and choice should their condition deteriorate. The Phase 1 evaluation report, written in June 2017, is included in Appendix 2.

Following the success of phase 1, funding was secured to share learning and test improvements with a further 6 care homes and aligned GP practices across Edinburgh during September 2017-April 2018 (phase 2). The Long Term Conditions programme ACP team engaged with teams across Edinburgh's integrated service sharing learning and scoping a collaborative approach to improving ACP. The phase 2 learning report, written in May 2018, is included in Appendix 3.

As phase 2 completed the ACP team successfully applied for funding from Health Care Improvement Scotland's ihub improvement fund.⁵ The funding secured the

 ⁴ <u>Best Practice Statement for Key Information Summary (KIS) from the Scottish Government</u>
 ⁵ Healthcare Improvement Scotland: <u>ihub improvement fund</u>

ACP team resource (Appendix 4) for a third phase during April 2018–March 2019, enabling ACP improvements to be scaled to an additional 20 care homes and to begin testing ACP improvements with health and social care teams and carer support organisations.



The ACP team has worked with partners to design an innovative care home ACP model, tailored to care home residents' health and care needs. Through testing improvements with care homes residents, care home and GP practice teams, a toolkit '7 steps to ACP for care homes' has been designed (Appendix 1). The toolkit enables residents to discuss their current and future health, and their care and treatment preferences should they become very unwell. This unique and innovative approach supports residents to explore the three most common deterioration scenarios for which residents are most often unnecessarily admitted to hospital. Care home teams found this leads to a shared understanding with residents and families and the health teams involved in their care, reduces stress in times of crisis, and gives the care home team the confidence to clearly communicate and act on individuals' wishes to improve their clinical and personal outcomes.

Phase 3 was taken forward in partnership with Voices of Carers across Lothian (VOCAL). Building on learning and testing ACP approaches with a view to improve personal and clinical outcomes for unpaid carers and people living at home with long term conditions or complex care needs.

This report shares findings and learning from phase 3 of the ACP improvement programme. Each section highlights points for shared learning to improve ACP. A summary of recommendations and learning points are provided in Appendix 5.

Aims and Objectives

Learning from phase 1 and phase 2 of the ACP improvement programme enabled the ACP team to design a structured improvement approach to working in partnership with 20 care homes and aligned GP practices across Edinburgh.

Improvement Aims

- Embed Anticipatory Care Planning and design reliable processes in 18 care homes in Edinburgh by March 2019.
- Reduce the number of avoidable hospital admissions by 10% within 18 care homes in Edinburgh by March 2019.

Objectives:

- 1. Develop and further improve the ACP toolkit for care homes.
- 2. Develop and further improve the ACP pathway with care homes, GP practices, out of hours, and acute services.
- 3. Provide guidance, teaching and support for care home staff in discussing and documenting care planning discussions with residents and families.
- 4. Build confidence and skills to enable care home staff to access and act on the agreed escalation of care, wishes and preferences as documented in ACP Key Information Summary (KIS).
- 5. Facilitate reflective learning sessions and structure improvements through learning cycles, sharing learning and improvements at an end of project learning event.
- 6. Establish a network of care home ACP champions to lead local improvements and provide peer support.
- 7. Develop an ACP training plan to provide ACP training to health and social care teams and third sector partners.
- 8. Scope and take forward ACP tests of change with health, health and social care teams, and third sector partners.

- 9. Establish an ACP Stakeholder Group to provide guidance, share learning and improvements.
- 10. Run road shows to raise ACP awareness with the general public and health and social care staff.

Project Approach and Methodology

An information event was held in April 2018 for Edinburgh care homes, GP practices and key stakeholders to share learning to date and set out the proposed approach to working with partners to improve ACP during 2018-9. Attendees heard from care homes that had participated in the programme and were able to discuss the challenges and successes experienced. Participants were asked to share what they learnt at the event and any ACP changes they would make.

Care home manager: "Things that have been discussed in the event and what/how this programme makes the whole process easy and compatible for the staff and the family, providing care for the patients in accordance with their wishes. It was important to hear from care homes and staff involved in the initial stage of the project, as well as those involved in developing it."

GP practice manager: "Update our Medical Practice GP registration form for new residents to include functional ability. Start using ACP questionnaire. Give out 'Let's Think Ahead' leaflet. We would like to have support from the Long Term Conditions team."

Care home team lead: "Importance of ACP conversations and information and how to use ACP appropriately. When to have ACP chats too, easier when well rather than unwell."

Care home manager: "We will review our current system following this event. Contact our lead GP to share our thoughts and agree action going forward. It is important to include all staff. The information from speakers was very helpful, and it would work for us."

Care homes and GP practices were invited to submit notes of interest following the event. Selection for participation in the programme was based on care homes size and location, A&E attendance and unplanned admission rates, and current use of ACP-KIS. When invited to participate in the programme a meeting was first arranged between the care home, GP practice and ACP team to discuss the agreed improvement approach and commitment required. Each participating care home and aligned GP practice signed up to the following.

Care home:

- Support and provide leadership in the exploration of current ACP practice within the care home setting.
- Identify care home ACP champion(s) within 2 weeks of training session.
- Support care home ACP champion peer support & reflective learning sessions.
- Complete 1-page ACP learning summaries (Appendix 7), collate to inform reflective learning sessions (with dedicated support from ACP team).
- Complete process measure forms (Appendix 8) to inform reflective learning sessions (with dedicated support from ACP team).
- Embed systematic approach as defined in the care home ACP flowchart (Appendix 1) and care home ACP champion working agreement.

GP:

- Create ACP-KIS and update when appropriate for each care home resident.
- Provide up to date hard copies of ACP-KIS to care home in a timely manner.
- Encourage and support ACP education and training needs of care home staff.
- Provide leadership in embedding the care home ACP flowchart (Appendix 1) in their practice.
- Provide guidance in encouraging the adoption of the ACP flow chart (Appendix 1) in the care home.
- Contribute to evaluating care home ACP improvements and sharing learning:
 - review learning collated from 1-page learning summary forms in each learning cycle (4-5 cycles, each cycle covers 7 weeks)
 - provide feedback to inform each reflective learning session (7 weekly, up to 5 learning sessions in total)
 - attend first reflective learning session, input to subsequent learning sessions and final learning event.

The ACP team committed to:

- Offer specific learning support and training to care home teams.
- Offer support to the care home and GP practice on the implementation of ACP pathway, embedding the use of ACP-KIS.
- Facilitate ACP process with the care home and aligned GP.
- Continuously refine and improve the ACP toolkit for care homes.
- Evaluate and share learning on the improvement of ACP in care homes:
 - o 3-4 learning cycles (each cycle covers a period of 7 weeks)
 - o facilitate reflective learning sessions
 - support collation and reporting of improvement data and learning summaries
 - host a care home ACP virtual network and provide a final learning event to share learning and improvement.

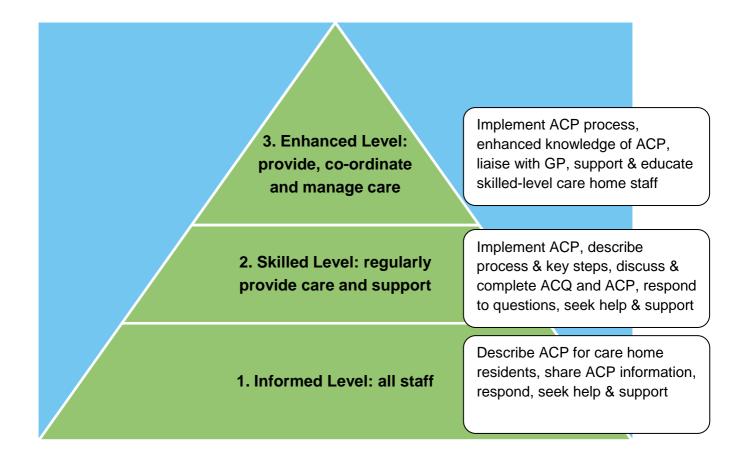
Learning point 1 Facilitating a discussion between partners about the ACP improvement approach, roles, responsibilities, specific commitments and support available is essential to the subsequent success of participating in the programme. A clearly defined agreement signed by all parties is required before participation in the care home ACP improvement programme can commence.

ACP training for care homes

The ACP facilitator provided ACP training to each participating care home. Building on learning from phase 2 a flexible approach was taken to ensure that training was delivered before the care home started making ACP improvements through implementing the ACP pathway.



The ACP facilitator further developed the phase 2 training content, structuring the session to meet the learning objectives of the multidisciplinary care home team different skill levels:



ACP training was designed to be delivered over 2 hours, however when needed this was contracted to a 1-hour session to ensure all relevant staff could attend. Whilst initial training was essential before care home teams could start to make ACP improvements, follow-up training was offered to accommodate staff turnover or ongoing training needs. Wherever possible, care homes' requests for additional ACP training were met, with care homes receiving between 1 and 5 sessions over the course of phase 3. In total, 193 care home staff attended ACP training, including: regional leads, managers, deputy managers, team leads, senior care workers and care workers, staff nurses, care assistants, students, supervisors and housekeepers, clinical leads and in-house trainers.

ACP training evaluation

On completion of each training session participants were invited to complete a post training evaluation. 99% of participants felt that the training met the ACP learning outcomes and objectives. 99% of participants felt that following training they were able to describe the purpose and benefits of ACP. 95% of participants felt more confident about having a conversation with residents about their wishes and future plans, and 96% felt more confident and able to have ACP conversations with residents' families, carers or close friends.

Three themes emerged from the feedback given by attendees:

The ACP process

- Training was concise and easy to understand the system, more clear now how to follow the process.
- Learning about the KIS part of the process.
- Further knowledge and understanding gained about KIS.
- Gives a better informed understanding of the anticipatory care plan.
- Very helpful and gained a lot more understanding about ACP.
- Very interactive with useful ACP scenarios and the team sharing their experiences from supporting our residents.

Person-centred approach and the people involved

- It was good to look at and think about what each person would want to happen in certain circumstances.
- Learnt about how to discuss ACP-KIS with residents and their family.
- Listening to colleagues' different points of view helped my understanding.
- Care home team had a lack of ACP knowledge, as did residents and family training will raise awareness with everyone involved.
- Important that the whole team was involved in the training, from housekeepers to managers, and we are all able to think about our role in ACP.

Team benefits

- All good interaction, team seemed to enjoy the training.
- Well explained, will simplify our job and save our time once all updated.
- Staff valued being able to speak up about what was going well in the home, what wasn't, and understanding how implementing the '7 steps to ACP' will enable ACP discussions with residents and their families.

Learning point 2 Defining the learning objects for different skill levels and tailoring the training accordingly enables each team member to understand their ACP role and encourages a focus on how non-trained staff can facilitate ACP discussions.

Learning point 3 Contracting the 2-hour training session to 1 hour is challenging from a training perspective and not the optimum approach, however in some cases this may be necessary to ensure all relevant staff are able to benefit from ACP training.



Care home ACP champions

During phase 2 the ACP team tested recruiting care home ACP champions to provide local leadership, advice and peer support, with the aim of supporting continuous improvement. Whilst it was acknowledged that embedding reliable ACP processes within an integrated system was critical to the success of sustaining ACP improvements, especially in a care environment with a high staff turnover, the emerging ACP champion network became a valued improvement mechanism for participating care home teams. The ACP team also found that having clearly defined local leadership in place through ACP champions was a key enabler for successful communication with each care home.⁶

Given the learning gained about the importance of having ACP champions in place, each phase 3 participating care home was asked to identify at least one ACP champion before starting to implement the ACP process ('7 steps to ACP'). Each care home ACP champion signed a working agreement with the ACP facilitator which set out the following roles and responsibilities.

ACP facilitator:

- Initial meeting with care home ACP champion to identify learning needs and support in implementing ACP with care home residents.
- ACP facilitator to offer specific learning support to the care home ACP champion.
- ACP facilitator set up regular meetings with care home ACP champion to discuss implementation of ACP.

Care home ACP champion:

- Identify specific learning needs for the care home.
- Support exploration of current anticipatory care planning practice within care home setting.
- Promote and implement the use of ACP-KIS on admission and reviews.
- Embed ACP pathway ensuring ACP-KIS is assessed as the first point of health deterioration and that the resident's wishes are known and shared.

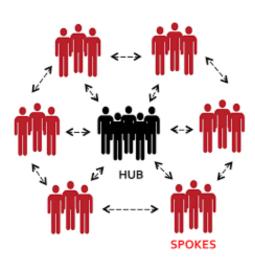
⁶ See phase 2 learning report, Appendix 3

- Promote and implement the use of ACP-KIS at the point of change in their health needs.
- Embed the use of ACP-KIS when contacting out of hours service, Scottish Ambulance Service, acute and primary health services.
- Share learning and good practice with the wider team in the care home.

84 care home ACP champions were recruited from 20 care homes participating in phase 3, joining the 11 care home ACP champions recruited during phase 2. All 95 care home ACP champions were invited to join a care home ACP champion network, facilitated virtually with the support of St Columba's Hospice through its involvement in project ECHO: Extension of Community Healthcare Outcomes. ECHO provides an education model for connecting communities of practice through teleconferencing and web-based technology.

Project ECHO Extension for Community Health Outcomes

- Widens access to palliative care knowledge and skills.
- Supports people delivering end of life care in settings other than the hospice.
- Methodology based on collaboration, inclusion and participation creating non-judgmental relationships.
- Creates a safe environment for sharing learning and good practice.
- Creates <u>communities of practice</u> where meaningful and sustainable learning and support occurs.
- Learning needs are identified by the communities.
- This is achieved using video conferencing technology, alongside proven facilitation and support systems.



Using a hub and spoke model, St Columba's Hospice provided the ECHO hub and the ACP champions' care homes were set up as spokes, enabling participation in facilitated practice based learning without having to make arrangements to be absent from the care home.

The ECHO network has provided care home champions with a safe space to reflect on success and challenges of taking forward ACP improvements, learning from one another and invited speakers.

Network meeting topics

- 1. What if families change their mind?
- 2. What is my role in ACP?

- 3. Feelings of failure when a resident dies in hospital
- 4. Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR)⁷ & Emergencies

Learning point 4 Local and lateral leadership through care home champions was a critical success factor of the ACP improvement programme. Providing a virtual care home ACP champion network in partnership with St Columba's Hospice and Project ECHO enabled shared learning, reflective practice and peer support which would otherwise not have been possible given the demands on care home staff time.

GP practice IT support for updating/creating ACP-KIS

One of the limitations of ACP-KIS is that it sits on GP practice digital clinical systems, either EMIS or Vision. Whilst ACP-KIS can be shared across the interface with other services, GP practice teams remain the authors - only those with access to the GP clinical system can create or update the electronic ACP-KIS. Throughout the duration of the ACP improvement programme GP practices have faced the challenge of an increase in the number of KIS requests, either to create new ACP-KISs or update the Special Notes section with key ACP information. Requests are made by care home teams and increasingly received from a range of health and social care teams.

To reduce the burden on the GP practice team, Portobello Surgery created a macro⁸ (which runs on Vision) to populate ACP-KIS information which would otherwise be inputted manually. Portobello Medical Practice hosted three peer support sessions for GP Practices (using Vision) aligned with the care homes participating in phase 3 of the improvement programme. The sessions included an overview of the ACP pathway and documentation in place between Portobello Surgery and the care homes it's aligned with; and a demonstration of using the macro to update ACP-KIS. The training enabled practices in which the sole responsibility for the creating ACP-KISs was with the doctor team to move to a shared process, through which data entry could be done by the admin team first before the clinical team reviews and authorises the ACP-KIS.

The three x 2.5 hour sessions were delivered at Portobello Medical Practice by the reception manager and IT manager. Seven GP practices attended the sessions, with twelve participants including: receptionists, GP, business manager, data manager

 ⁷ <u>NHSScotland DNACPR Integrated Adult Policy</u>
 ⁸ A macro is a single instruction given to a computer that produces a set of instructions for the computer to perform a particular piece of work.

and practice manager. Participants were offered a download of the macro report to enable it to run on their GP practice system.

Feedback from practice staff receiving support:

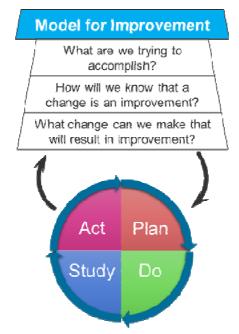
"We have found that the layout of the current ECS/KIS/ PCS software within Vision had been putting some GPs off using it, and the idea of a familiar template KIS data entry point was very attractive."

"I have since been able to import the macro and we have found it very useful."

Learning cycles

Designing an approach to testing and scaling improvements was a significant challenge at the outset of phase 3. Whilst ihub funding secured the ACP facilitator and project support manager posts for a further 12-month period, the project team resource allocation remained the same as during phase 2 (1 whole time equivalent (WTE) ACP facilitator and 0.5 WTE project support manager). An improvement approach was required which made efficient use of resources to improve ACP in partnership with 3 times as many care homes and aligned GP practices.

Reflecting on learning gained working in partnership to improve ACP with 10 care homes during phase 1 and phase 2, the ACP team designed a structured quality improvement support package for care homes participating in phase 3. A framework for measuring and sharing ACP learning and accelerating improvements to an additional 20 care homes was designed using the Model for Improvement.⁹

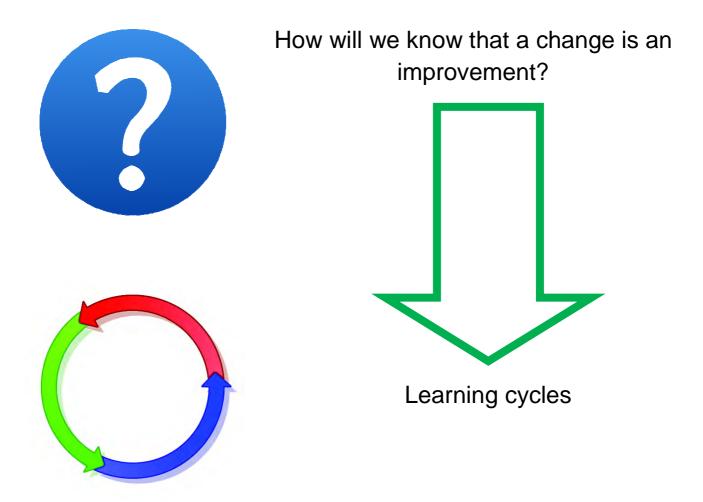


⁹ The Institute for Healthcare Improvement promotes the <u>Model for Improvement</u>, developed by Associates in Process Improvement, as a tool for accelerating improvement in healthcare organisations. The model has two parts: three fundamental questions, which can be addressed in any order; and the Plan-Do-Study-Act (PDSA) cycle to test changes in real work settings.

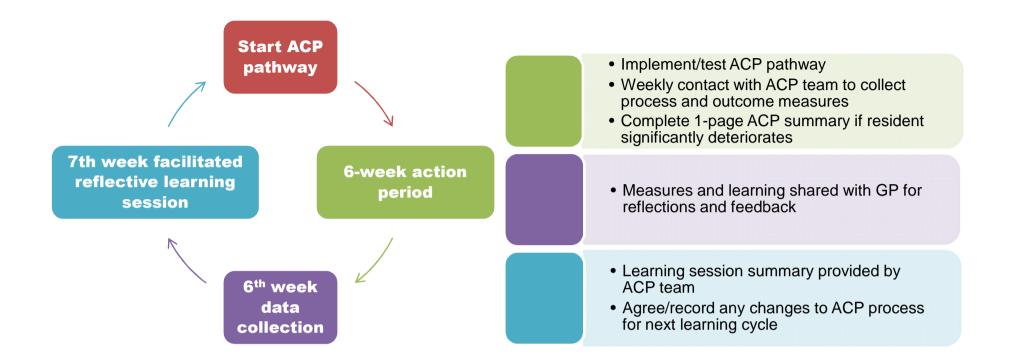


Care home ACP improvement approach: change process

- ✓ Partnership agreement
- ✓ '7 steps to ACP' training delivered
- ✓ ACP champions signed up
- ✓ Start using '7 steps to ACP'



Each participating care home and aligned GP practice worked through a series of learning cycles to test the '7 steps to ACP' implementation.



Each learning cycle consisted of a 6-week action period when learning was recorded through the collection of defined process and outcomes measures. During the 7th week of each learning cycle the care home team and GP reviewed a summary of learning gained to date and met to review progress. During these reflective learning sessions, care home teams and GPs reflected on their experience of improving ACP during the learning cycle, coming together to consider:

- What went well success?
- What did not go well challenges?
- What could you/will you do differently in the next learning cycle?

Any changes to the ACP improvement approach were agreed in the reflective learning session and tested during the next learning cycle.

To enable each care home to work through a series of learning cycles the ACP team provided the following improvement support.

- Weekly phonecalls with care home ACP champions to review progress and gather data through an appreciative enquiry approach. During the phonecall the ACP team completes the ACP process measure form (Appendix 8).
- Follow up on any process or communication issues between the care home, GP, out of hours and acute services, and residents' families.
- Baseline and improvement data collation on ACP-KIS quantity and quality for each partipating care home.
- Review a data report on a weekly basis to ascertain if any residents attended A&E or were admitted to hospital. Contact the care home ACP champion to ask if/how the ACP process was followed and encourage a reflective learning form to be completed (Appendix 7). Share learning with the GP and other services as appropriate.
- Summarise learning gathered during the action period for the care home team and GP to discuss during reflective learning sessions.
- Faciliate a reflective learing session during the 7th week of each learning cycle. Share a learning session summary and support any agreed changes to the ACP improvement approach during the next learning cycle.

Staggered start dates allowed the ACP team to schedule improvement support across the participating care homes. The majoirty of care homes completed 4 learning cycles, the care homes that started towards the end of the learning cycle schedule completed 3 cycles.

Evaluation

Reflective learning themes

Care home colleagues told us that reflective practice was a new approach for many of them and took a bit of getting used to. As the learning cycles progressed, care home teams found the reflective learning sessions to be a vital mechanism for both evaluating and continuing to make ACP improvements.

As part of the partnership agreement GPs committed to attending the first reflective learning session and subsequently attended as many sessions as they could. When not able to attend, GPs reviewed the learning cycle summary and provided written comments for discussion during the session. Discussions were commonly around: practicalities of implementing the ACP process/following the ACP pathway; having ACP discussions with residents and families; leadership and team working; improved care; and the impact on residents and families.

Extracts from reflective learning summaries – the following extracts are taken from reflective learning discussions and are themed by:



What could be improved?



What will we do differently?



Changes tested

ACP Pathway

Cycle 1

?

Delay with KIS printed off from GP Practices.

ACP facilitator liaised with GP Practice Manager to improve processing ACP-KIS.



ACP team organised training for GP admin staff.

GP practice new IT system developed for uploading information onto KIS. New ACP-KIS printed off for care homes.

Cycle 2

Some care homes have more than one GP practice looking after their residents. Care homes asked for KISs for all residents. The GP practices not signed up with the programme were unsure of the request.



ACP facilitator liaised with the GP practice managers at the relevant practices to raise awareness of ACP improvements and to print off ACP-KIS.

Practice admin staff and care home staff have established a system to print off ACP-KIS for care homes.

Cycle 3

Social work department holds power of attorney for residents but did not attend review meetings.

with care home staff emailing social worker about ACP and inviting social worker to comment.

Care home keeps an ACP communication log of contacts and discussions with social worker.



ACP Pathway



Care home to develop new resident assessment pack accessed on the iPad. The new system will allow staff to introduce/start to complete ACP at the initial visit.

Cycle 1

Care home staff are now aware of ACP-KIS and are familiar with using it. Care home follows the ACP flow chart and discusses ACP with residents and families at 6-month reviews.

Cycle 2

GP: "Whilst it is frustrating there appears to be no electronic way of sharing ACPs with the care home, there is now a robust system for updating the paper copy in the home every 6 months." Care home manager has developed a system to keep a record of the completed new patient registration forms and Anticipatory Care Questions, now all units have the same approach.

Cycle 3

There have been good reflections on requesting ACP medications. Now staff feel much more confident in initiating ACP medication discussions with GPs.

Cycle 4

GP: "Staff at the care home are diligent and enthusiastic about filling out ACPs. The current forms offer a simple structured approach to help address pertinent questions. This is hugely beneficial when it comes to making clinical decisions and in preventing unnecessary admissions."

ACP is now embedded into care home's care planning procedure. It is now part of the admission pack

ACP discussions with residents and families

Cycle 1

Difficult conversations: families asked to send residents to hospital when clinical indications are that it would not be in their best interest to do so.

All agreed that it should be respected if family preferred this option and also to help ensure their understanding of their loved one's clinical condition is realistic.



Both lead GP and ACP facilitator offered ongoing advice on discussing the treatment and outcomes for stroke.

Care home champions advanced their skills and confidence in ACP discussions.

Cycle 3

Family members have different views on preferences on acute deterioration which can make escalation of care difficult for the care home staff.

Discussions with families continue to be difficult when some family members want full intervention on escalation of care which might not be in the best interest of residents.

ACP champions and ACP facilitator shared their experiences and learning on ACP conversations.



ACP champions will continue to have ACP discussions with family members to gain a shared understanding on escalation of care.

ACP facilitator can support and facilitate ACP discussions with family members.



ACP discussions with residents and families

Cycle 1



Family members and staff all found '7 steps to ACP' easy to understand and complete.

Families and residents were more accepting of the discussions on death and dying and they were happy to complete the forms. It was a relief to the family members having an ACP in place.

ACP conversations helped residents and family members to think ahead and to plan for future care. The implementation went well, staff are much more confident having ACP conversations with residents, family members and next of kin.

Cycle 2

Residents are having appropriate care according to preferences discussed using the Anticipatory Care Questions. Some family members took a bit of time to complete the Anticipatory Care Questions. However, this reflects the complexity of making informed choices on escalation of care and care home staff have ensured they are always available for discussions and support.

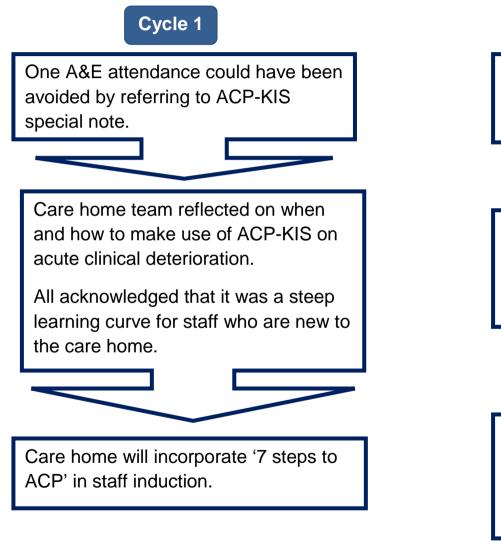
Cycle 3

Care home staff are all committed to implementing ACP. It has been a positive experience for everyone working with the residents and their families.

Success of ACP relies on everyone working with the residents. Care home staff are now confident and capable to have ACP discussions with residents and their families. Staff refer to the ACP-KIS on escalation of care ensuring residents' preferences are followed.

Cycle 4

A&E and admissions to hospital



Cycle 3

Care home is unsure if an updated ACP-KIS will be forwarded to them automatically when a resident is discharged from hospital.

ACP team will help to monitor the process for uploading information from hospital discharge letter onto special note and the care home receiving the updated ACP-KIS.

A reliable system is in place.

Care home now reviews ACP-KIS special note with GP after a resident is discharged from hospital.

A&E and admissions to hospital

Cycle 1



Care home staff read ACP-KIS before making a clinical decision on escalation of care.

Care home now has full access to ACP-KIS which enables staff to discuss escalation of care with emergency services. Cycle 2

Introduced a new weekly staff reflective learning session on previous week's hospital admission (if any) to find out if escalation of care could be dealt with differently.

Care home staff took copies of the resident's KIS when attending A&E department, A&E staff found it very useful. Cycle 3

Implementation of '7 steps to ACP' has been an overwhelming success for the care home. In addition to the outstanding audit on KIS (100% of residents now have an up to date ACP-KIS), care home staff have adhered to the '7 steps to ACP' on escalation of acute deterioration, ensuring appropriate care in an appropriate setting as per the residents' preferences.

999 calls



A number of 999 and out of hours calls were made by night staff when residents' conditions deteriorated when ACP-KISs could have informed decisions on escalation of care.

Care home implemented a new 24 hrs handover sheet with specific information on management of symptoms during out of hours.



The use of 7 steps to ACP Document 6 – Care Home Acute Clinical Incident Flow Chart would be beneficial to all care home staff particularly for night staff.



The new handover sheet has reduced 999 calls for symptoms management significantly.



Staff are now aware of ACP-KIS and will use it for clinical decision on escalation of care.

ACP facilitator arranged ACP training for night staff.

Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR)



By completing ACP, it has triggered the discussion and completion of DNACPR for a resident. This has highlighted the need for DNACPR training for nursing staff.

Patient registration form (7 Steps to ACP Document 2) in the section where DNACPR is recorded could be misinterpreted. It needs to be reviewed and made clearer.

Care home team will liaise with the lead GP on residents that do not have DNACPR status recorded.



ACP facilitator will source DNACPR training for nursing staff.

ACP team will review and improve DNACPR section of patient registration forms.

Care home will highlight important information on ACP-KIS special notes such as

DNACPR status and clinical management plan preferences for easy access.



New mini-care plan has been developed highlighting ACPs and DNACPR. The plans are placed in residents' rooms so easily accessed and family members are invited to read over them.

Improved Care

Cycle 2

Cycle 1



No hospital death was recorded during the learning cycle; it illustrates the good work of the care home and lead GP in having ACP in place so that preferences on end of life care were respected.

By referring to ACP-KIS OOHs contacts have been minimised and best care provided for residents within the care home.

ACP improves quality of care to residents. Residents are kept comfortable and have treatment in the care home rather that attending A&E or having an unplanned admission. The implementation of ACP in the care home has made a positive impact on reducing avoidable admissions.

Data on 'death in hospital' in the past few months is 'zero'. Care home staff respect and manage residents' preferences on preferred place of care and death.

GP: "The care home have found the '7 steps to ACP' extremely helpful both to their administrative duties and enabling them to provide better quality and continuity of care for residents. From the Practice perspective it has encouraged and enabled us to update the KIS records for residents." Data on 'Death in hospital' continues to be zero demonstrating the importance and benefits of the implementation of ACP.

Cvcle 4

GP, "Implementation of the ACP programme has been successful as it has benefited both the staff and quality of care to patients."

ACP can help facilitate a 'good death' in a care home setting.

Residents were kept comfortable in the care home according to their ACP when their health deteriorated. Everyone felt the importance of upholding the residents' wishes and preferences.

Leadership and Integrated Team Working

Cycle 1

Leadership in the care home and support from the lead GP are paramount to the success of implementing '7 steps to ACP'.

The support from the GP and the Practice team is pivotal to the success of ACP implementation.

It has been a rewarding experience for all parties starting to implement ACP in the care home. We have all learnt new skills and most importantly the team implementing new skills into practice has resulted in a sustainable approach for ACP in the care home.

Care home staff and residents have known each other for a long time, so having changes could be difficult. However, ACP champions have demonstrated the success in working with residents/family members and the team on making these changes. The success of ACP in the care home relies on everyone working together in the care home with the ACP champions taking the lead. It has been a rewarding experience for staff, residents and families with their preferences on care respected and followed.

Cycle 2

Implementation of ACP in the care home has been a huge success. The ACP champions are enthusiastic and focus on the implementation. The GP Practice is fully supportive of the '7 steps to ACP' being implemented which is a huge advantage.

This is a celebration of success for the ACP champions and the care home as they are now more skilled and confident in supporting clinical decision making processes with residents, families and GPs.



Leadership and Integrated Team Working

Cycle 3

Cycle 4



GP: "Looks very positive, we have been delighted with the new ACP, staff at the care home have done a great job of implementing these."

The care home has been taking ownership on the implementation of ACP and has thrived on improving quantity and quality of ACP-KISs so that residents' preferences are all respected.

The care home is highly motivated and committed in the implementation of ACP. Champions have evolved from novice to expert since the beginning of the implementation. Lead GP: "Thank you for all your hard work with this. We are totally committed to working together for Realistic Conversations, shared decisions about care with patients, family and care home staff and sharing this with all those clinicians who might be involved to ensure high quality appropriate care in accordance with patient wishes."

Care home manager: "Care homes sometimes don't feel part of the multidisciplinary team (MDT), staff feel caught in-between the GP and other professionals. From taking part in the ACP improvement programme nurses became more like clinical leads, they felt very much a part of the MDT, and more confident to speak with doctors about their residents."

The implementation of ACP in the care home has brought everyone together; it has improved communications between the GP practice, care home, residents and family members.

Case studies

Throughout the learning cycles if a resident was taken to A&E or admitted to hospital for unscheduled care the ACP facilitator encouraged care home staff to reflect on how the ACP process was followed (completing a reflective learning form, Appendix 7). From these reflections 12 case studies have been developed, included in Appendix 9.

Improvement measures

Phase 3 measurement plan

During phase 2 it was challenging to use data to drive improvements given a lag in data being available. It was difficult to extract how many A&E attendances and unplanned admissions to hospital were unnecessary or unwanted, and to determine the contribution improving ACP made to reducing 'avoidable' admissions. As part of the phase 3 improvement approach the ACP team developed mechanisms for care homes and GP practices to record and learn from real-time data.

Using the Model for Improvement⁹, the ACP team developed a measurement plan to support care homes and GP practices to test if the changes made during learning cycles led to an improvement. Using real-time data enabled participants to reflect on the impact of ACP changes made, come up with useful ideas for continuing to improve, and to see if these improvements were maintained. The relationship between the improvement aims and changes to be tested were explored and made explicit through developing a driver diagram. This helped to determine what measures needed to be tracked to answer the Model for Improvement's second question "How will we know that a change is an improvement" (driver diagram included in Appendix 10, measurement plan included in Appendix 11). The ACP team supported care homes to collect and review data throughout the learning cycles and reflective learning sessions.

Phase 3 methodology

Accident and emergency (A&E) attendance and admissions data were sourced from TRAKcare, the secondary care software system for NHS Lothian. The baseline data examines the period of April 1st 2017 to March 31st 2018, prior to the care homes implementing ACP training.

The test data period, April 1st 2018 to March 31st 2019, was downloaded daily from TRAK to examine A&E attendances by the care home residents from the 20 Phase 3 care homes in the preceding 24 hours. Each episode was reviewed and categorised as an avoidable or unavoidable A&E attendance and/or admission.

Criteria Review

The ACP facilitator reviewed each episode by examining the residents' diagnoses and ACP-KIS. The episode was categorised as unavoidable if the A&E attendance

reason was due to a fall, injury, or a complaint requiring immediate hospital assessment, for example: GI bleed, malena, cellulitis, blocked catheter, distended abdomen, renal colic, cholecystitis, retention of urine, PEG tube fell out, necrotic wound, low blood sugar, haematosis, epilepsy, deep vein thrombosis. The reason of attendance was sourced by reviewing the episode's clinical notes in TRAKcare.

For residents who were not categorised as having an unavoidable attendance during the initial diagnosis scope, the ACP facilitator then examined if an ACP-KIS was established at the time of A&E attendance which included a plan for escalation of care. If the resident did not have an ACP-KIS with a clear plan for escalation of care, the episode was considered as potentially avoidable. If the resident had an ACP-KIS in line with the '7 steps to ACP' intervention this would specify the agreed care plan for:

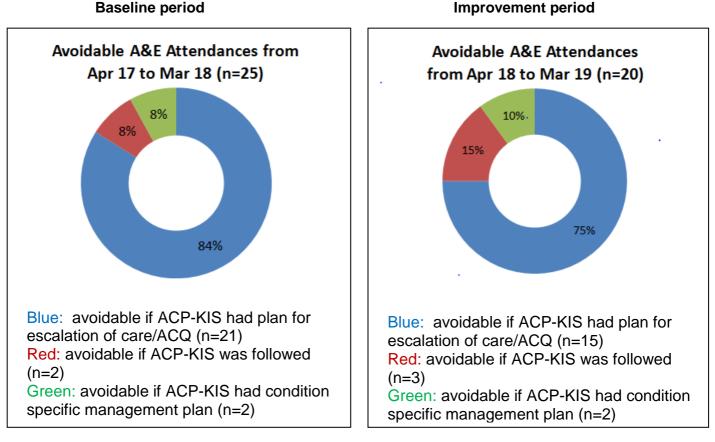
- a sudden collapse (such as from a stroke or heart condition)
- a serious infection that was not improving with antibiotic medication
- not eating or drinking because of being unwell.

If the ACP-KIS specified the resident wanted to go to A&E, this would be considered an unavoidable A&E attendance. If the resident specified a preference to be kept comfortable in the care home, or had a condition management plan in their ACP-KIS, but was taken to A&E, this was considered as an avoidable attendance. Also, if the resident was a site transfer from another hospital, this was categorised as unavoidable.

Phase 3 care home residents: A&E attendances

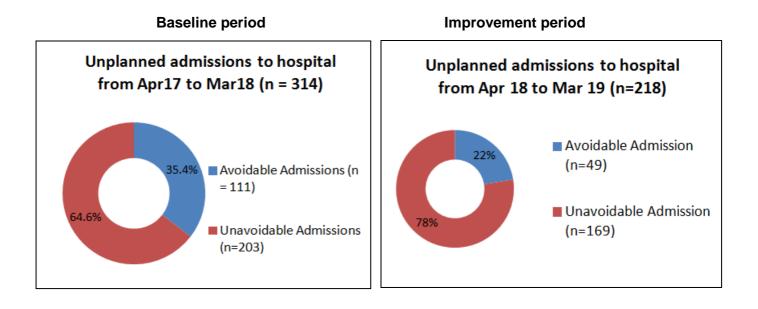
Avoidable A&E attendances decreased by 20% when comparing the baseline period (April 2017-March 2018) with the improvement period (April 2018-March 2019).

Avoidable A&E attendances, due to residents' not having an ACP-KIS with a clear plan for escalation of care, decreased by 29% when comparing the baseline and improvement periods.

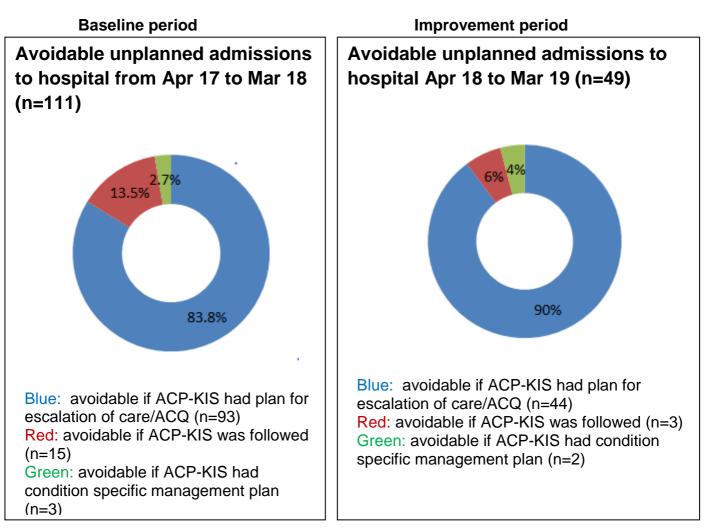


Phase 3 care home residents: hospital admissions

When comparing the baseline and improvement periods the total number of unplanned admissions to hospital decreased by 96 admissions, a 31% reduction.



Avoidable admissions decreased by 62 admissions, a 56% reduction. Avoidable admissions can be further broken down to:



Avoidable admissions to hospital due to the resident not having an ACP-KIS with a clear plan for escalation of care decreased by 49 admissions, a 53% reduction when comparing baseline and improvement periods.



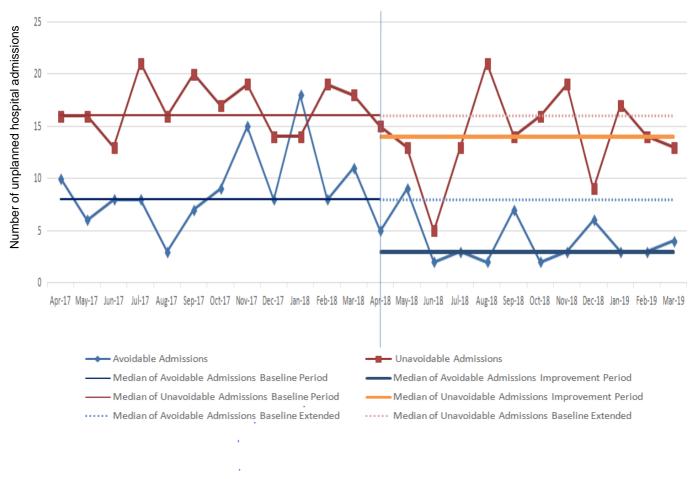


Figure 1: Unplanned hospital admissions from Phase 3 care homes

When examining the time series of all unplanned hospital admissions from the Phase 3 care home cohort, the median avoidable admissions dropped from 8 in the baseline period (April 2017 to March 2018) to 3 in the improvement period (April 2018 to March 2019). There is a statistically significant shift in avoidable admissions from June 2018 to March 2019 indicating that the reduction is likely to be attributable to the changes made to ACP through the improvement programme.

Phase 3 care home residents: place of death

Throughout the learning cycles care home teams reflected on enabling residents to have a good death and die in their preferred place of care. Data demonstrate that the majority of care home residents die in their care home.

	2015	2016	2017	2018
Care homes	261	242	158	261
Other settings	59	67	40	59
% died in care homes	81.6%	78.3%	79.8%	81.6%

Figure 2: Phase 3 comparison of places of death for care home residents in 20 care homes from January 2015 to December 2018

The majority of residents from phase 3 care homes were enabled to die in their care home. The median number of deaths in acute hospitals decreased from 4 during 2016 to 2 during 2018. Phase 3 completed in March 2019, the positive impact of ACPs on enabling a good death in the care home is not likely to be demonstrated in the data available (up to the end of 2018). Further analysis of place of death data will be carried out during 2019-2020.

Balancing measure: contact with out of hours

Contact with the Out of Hours service decreased by 6% for care homes participating in phase 3, when comparing April 2017-March 2018 with April-March 2019. The ACP team will continue to review contact with the Out of Hours service to evaluate if improving ACP processes within care homes contributes to any significant changes.

Learning point 5 A blended approach of facilitating reflective learning and informing improvement discussions with locally owned real-time data enabled care home teams and GPs to test and implement ACP improvements. Care home teams and GPs significantly improved personal and clinical outcomes for care homes residents through implementing and continuously improving the '7 steps to ACP' toolkit.

ACP-KIS quality audit

The quality audit tool developed in phase 1 and 2 was used to measure the quality of KIS before and after phase 3 training. With reference to the 'Best Practice Statement for Key Information summary (KIS) from the Scottish Government'⁴, the quality audit tool comprised 7 key indicators to measure the quality of KIS for care home residents (figure 3).

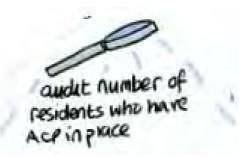


Figure 3: ACP-KIS quality audit phase 3, 20 care homes pre and post training

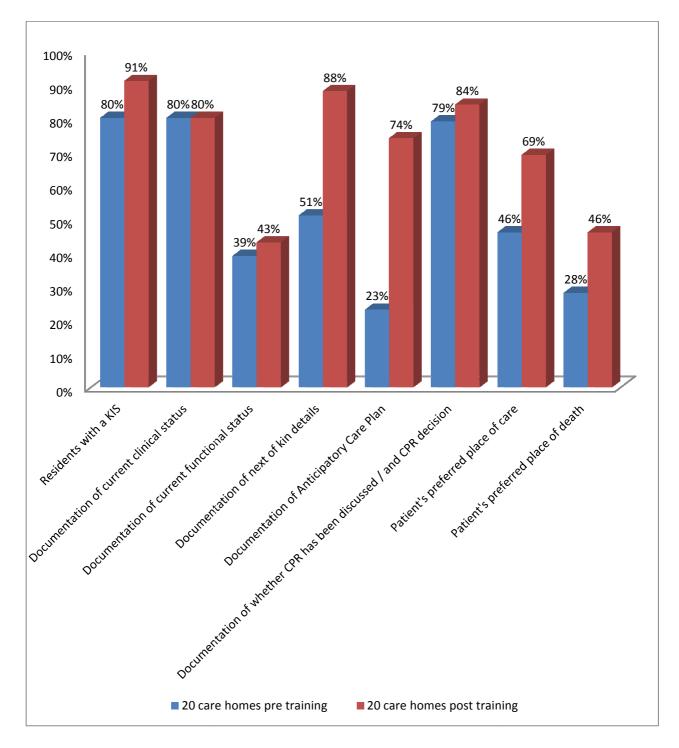
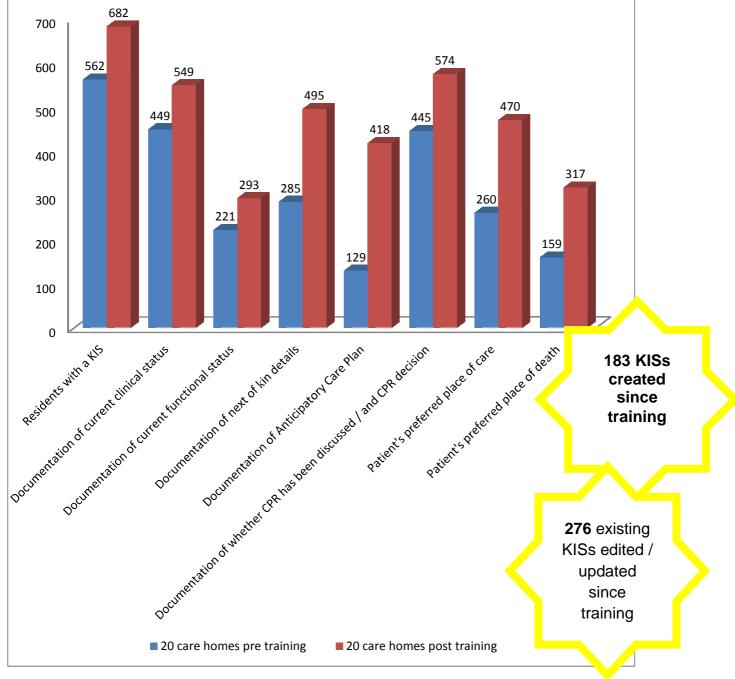


Figure 3 demonstrates an improvement across the majority of quality indicators in the 6-9 month period post training. Documentation of escalation of care in the event of an acute deterioration improved by 51% (described as 'documentation of ACP' in figure 3). Documentation of next of kin details improved by 37%, resident's preferred place of care improved by 23%, and preferred place of death improved by 18%.

Figure 4 shows the number of existing KISs updated and new KISs uploaded in the 6-9 month period post training. All care homes have engaged actively with their aligned GPs in implementing ACP either by editing or creating ACP-KISs. Since ACP training, 183 new KISs have been created and 276 ACP-KISs updated.





Evaluation and improvement of the care home ACP toolkit

Let's think ahead

7 Steps to Anticipatory Care Planning for Care Home Staff The 20 participating care homes and aligned GP practices implemented and tested the '7 steps to ACP' toolkit, improving its content to support the practical application of reliable ACP processes. Throughout the learning cycles reflections on using the toolkit led to improvements being suggested, carried out and reviewed.

Improvements include the following:

Document 2 – Care home patient registration form

- A new format was tested by care home teams who fed back the new format was improved and easy to complete.
- Information on falls is now included as a prompt to both care home staff and GPs.

Document 3 – Anticipatory care planning questions for care home residents

- Option (a) following the three ACP questions now reads, 'Keep you comfortable, **clinically assess you,** treat any pain or other symptoms, and care for you in your care home.'
- 'clinically assess you' is added so that it is clear to residents that they will be assessed by health care professionals should they become unwell.

Document 4 – Anticipatory care planning questions for relatives and close friends

- Option (a) following the three ACP questions now reads, 'Keep them comfortable, **clinically assess them**, treat any pain or other symptoms, and care for them in their care home.'
- 'clinically assess them' is added so that it is clear to relatives and close friends that the residents will be assessed by health care professionals should they become unwell.
- A new format with an improved layout was developed to record the details of the relatives/close friends that complete the form.

Document 5 – Care Home ACP flow chart

• The new flow chart is colour coded, red text denotes care home input, and green text denotes GP/GP Practice input.

• The new flow chart illustrates the importance of equal partnership between the care home and the GP Practice and ensures the review and update of ACP as per the care home review regime.

Document 6 - Care home acute clinical incident flow chart

- The Care Home Acute Clinical Incident Flow Chart is newly developed in response to staff requesting support on how to escalate care when an acute clinical incident occurs.
- The flow chart provides examples on when to phone for an ambulance and when to refer to ACP-KIS special notes on escalation of care.
- Agency staff and night staff particularly find this flow chart very useful in helping them make a clinical decision on escalation of care.

ACP Learning and Spread

ACP Stakeholder group

During phase 2 of the ACP improvement programme, the ACP team scoped partnership approaches to improving ACP with health and social care teams and voluntary organisations in Edinburgh. Moving into phase 3, an ACP Stakeholder group was formed, bringing together local teams from across Edinburgh's integrated service with representatives from national organisations, eg NHS 24, Scottish Ambulance Service and Scottish Care. The Stakeholder Group met 3 times between June 2018 and February 2019:

- providing input from a range of disciplines and sectors
- sharing and spreading ACP learning, and
- increasing the reach of collaborative approaches to ACP improvements.

Stakeholders contributed their expertise to developing a shared understanding of the barriers and enablers of effective ACP pathways, including improving the exchange of ACP information at the acute, primary, community and voluntary sector interface. Representatives from health and social care teams (Community Mental Health Teams, District Nurses, Multi-Agency Triage Teams, Community Pharmacists, Hub and Cluster Service Managers) translated shared learning into ACP improvements within their own settings. The ACP team began to work in partnership with a range of health, integrated health and social care, and voluntary teams to test ACP improvements.

Working in partnership to improve ACP in Edinburgh

Improving ACP with unpaid carers

The ACP team engaged with teams across Edinburgh's integrated service sharing learning and scoping a collaborative approach to improving ACP. In discussions

with Edinburgh Health and Social Care Partnership locality-based Multi Agency Triage Teams it was highlighted that unpaid carers would benefit from having an ACP-KIS. When an unpaid carer has an unplanned admission to hospital it is important to know who they care for and what alternative care arrangements can be put in place. Having these details included in the special notes of the ACP-KIS enables those providing care support (eg Out of Hours Service, Scottish Ambulance Service, Multi Agency Triage Teams) to identify the risk for the cared for person and make alternative arrangements in line with their wishes and preferences.

Voice of Carers Across Lothian (VOCAL) provides carers with a range of support: from emotional support and counselling, to advice on benefits, long-term care and power of attorney surgeries, advocacy, and information on planning for the future. In partnership with VOCAL the ACP team aimed to raise awareness of the benefits of ACP with unpaid carers and develop a structured approach for carers to create/update ACP-KISs (unpaid carer-GP ACP pathway). The ACP team delivered training to VOCAL staff, enabling VOCAL to hold ACP sessions as part of their established power of attorney surgeries. Outputs from testing approaches to ACP with carers include:

- ACP information leaflet (Appendix 12)
- ACP carer document, to facilitate ACP discussions between carers and their GPs leading to the creation of an ACP-KIS (Appendix 13)
- ACP-KIS fridge magnets and wallet cards, to prompt carers and those providing care and support at home to let emergency/out of hours services know there is an ACP-KIS in place and to access it at points of deterioration, and
- two filmed scenarios for training and raising awareness of the importance of ACP for carers:
 - o a carer and their GP discussing creating/updating the carer's ACP-KIS
 - a carer and the person they care for discussing updating/creating the cared for person's ACP-KIS.

VOCAL plans to recruit a dedicated volunteer to explain ACP and to book carers into the ACP sessions. VOCAL is integrating the approach to completing ACPs into existing workshops on future planning and emergency planning.

Learning from testing the ACP unpaid carer-GP pathway with VOCAL was shared with Edinburgh Health and Social Care Partnership's Edinburgh Carer Support <u>Team</u>. As part of its service the team carries out <u>adult carer support assessments</u> to provide carers with a plan to access council services and third sector organisations that can support their caring role (eg respite services, carer's emergency card, benefits advice, arranging a needs assessment for the cared for person, etc). The Edinburgh Carer Support Team immediately recognised the value in including ACP for carers and is testing the unpaid carer-GP ACP pathway. As part of the adult carer support assessment the team has an ACP conversation with the carer, completes

the Carer ACP Document (Appendix 16) providing the carer with a copy and forwarding a copy to the GP to update ACP-KIS. Working in partnership with the ACP team a Quality Improvement (QI) approach⁹ has been applied, testing the ACP change idea with 6 carers in the first learning cycle, with the aim of testing with an additional 25 carers during the second learning cycle by July 2019.

Improving ACP with Edinburgh health and social care teams

The ACP team is working in partnership with community pharmacists, dieticians, community mental health teams, district nurses, and home care teams to improve ACP.

Dieticians are initially testing an ACP change idea with care homes. Sharing nutritional support information on the residents' ACP-KIS special notes ensures this information is available to acute care teams in the event of an unplanned hospital admission. It also facilitates appropriate nutritional support and treatment during a hospital stay. **Pharmacists** are also testing a change idea with care homes, with the intention to include a polypharmacy review for new care home residents as part of the 6-week ACP review.



Community Mental Health Teams are identifying information from mental health care plans to share across the integrated system to support mental health patients when they present at A&E or contact out of hours/emergency services. An ACP pathway is being developed to test effective and efficient mechanisms for transferring agreed ACP criteria from mental health care plans to ACP-KISs. **Home care teams** and **district nurses** are also beginning to identify ACP information to share across the integrated system and test systematic approaches to transferring to ACP-KISs. The benefits of people living at home having a hard copy of their ACP-KIS is also being tested.

Learning point 6 People living with long term conditions or complex health needs at home may be in regular contact with multiple health and social care teams. Agreeing community care criteria to share in ACP-KISs provides immediate access to information that could improve care and treatment in the event of an acute deterioration. Taking forward tests of change will demonstrate if this approach to improving ACP can lead to improved personal and clinical outcomes and prevent unwanted or unnecessary hospital admissions.

Learning point 7 Health and social care teams' capacity to design, test and evaluate ACP improvements can be limited due to demands of delivering services. Providing a structured quality improvement approach and improvement support can help, as can having a shared understanding of how ACP enhances daily practice.

Improving ACP with acute care teams

The ACP team is working to improve ACP in partnership with Old Age Psychiatry teams at the Royal Edinburgh Hospital, Medicine of the Elderly and the Clinical Genetics Service at the Western General Hospital, and Medicine of the Elderly at the Royal Infirmary of Edinburgh.

Old Age Psychiatry at the Royal Edinburgh Hospital has designed and tested an inpatient ACP process, and is testing what ACP information to share with GPs when patients are discharged to upload to ACP-KISs. Similarly, Medicine of the Elderly at the Western General Hospital and Royal Infirmary continue to make ACP improvements for inpatients and are also testing what information to share with GPs when a patient is discharged. How the ACP information is included in the discharge letter, whether it is easily transferable to ACP-KIS, and if it is accessed to inform shared decision making, will be evaluated as part of this test of change.

The Clinical Genetics Service at the Western General Hospital identified key ACP information for Myotonic Dystrophy patients that is important to share with teams providing care and support in the event of an acute deterioration. In the first learning cycle 100% of Myotonic Dystrophy patients attending the clinic had the agreed ACP information/alert shared with their GP and uploaded to their ACP-KIS. The 2nd learning cycle will include providing a printed hard copy of ACP-KIS for patients to have at home, along with the ACP-KIS fridge magnet and wallet card. Spreading the ACP approach to include patients attending the clinic with different genetic conditions is being explored.

Learning point 8 Improvements to ACP pathways are successful when the ACP information shared is relevant, succinct and provided to GP practices in a format that is easily transferrable to GP digital clinical systems.

Learning point 9 Different teams and professions can make assumptions about the level of ACP information that has been shared or can be accessed across the integrated system. Having an agreed ACP pathway across the service interface provides access to important information in the absence of integrated/accessible digital systems.

Improving ACP with GP practice teams

The ACP team has worked in partnership with GP practice teams across Edinburgh to improve ACP pathways with 30 care homes during the 3 phases of the programme. Increasingly the ACP team is working with GP practices as key partners in the tests of changes being taken forward with health, health and social care teams, and carer support organisations. GP practices are taking forward innovative ACP approaches, for example Bangholm Medical Centre has adapted the VOCAL carer-ACP document (Appendix 13) to complete with patients when making home visits. The practice has completed 75 ACP-KISs for vulnerable patients living at home in the 5-month period since starting this initiative and is spreading the approach to other groups of patients who would benefit from having an ACP-KIS in place.

In addition to facilitating peer support IT sessions for GP practices as part of the care home improvement approach, the ACP team has produced guidance for creating and updating ACP-KISs in both GP digital clinical systems, EMIS and Vision (Appendix 14). These, together with the Frequently Asked Questions for Primary Care (Appendix 15), provide tips for avoiding or resolving some of the KIS system issues that GP practices have shared throughout the duration of the ACP improvement programme.

Whilst ACP-KIS can be shared across the interface with other services, GP practice teams remain the authors – only those with access to the GP clinical system can create or update the electronic ACP-KIS. A simple ACP-KIS system enabler is the ACP-KIS compatible Microsoft Office Word template first designed by Dr Carey Lunan in 2016 during her time as ACP clinical lead within the ACP team. Health and social care professionals who do not have access to GP practice digital systems can complete the template and email to the GP practice clinical inbox requesting the ACP-KIS is updated. The template provides guidance to identifying the key criteria for including in ACP-KIS, and is formatted so that when emailed to GP practices the information can be easily transferred to ACP-KIS. Many of the health and social care teams taking forward ACP tests of change are adapting the ACP-KIS compatible

Microsoft Office Word template to include prompts for their team's specific ACP-KIS criteria. Examples are included in Appendix 16.

Learning point 10 Without the support and commitment of GP practice teams ACP-KIS improvements would not be possible. The role of the ACP GP Advisor is critical to the success of GP engagement and buy-in, providing peer to peer support and guidance. GP practice managers and admin teams are the experts in creating and updating ACP-KISs and need to be at the centre of collaborative approaches to improving ACP.

Learning point 11 ACP-KIS system enablers (such as the ACP-KIS compatible Microsoft Office Word template) mitigate against disengagement from collective efforts to improve ACP. There are national developments in designing a shared digital platform with the potential to provide a system that is fit for purpose; in the meantime it is important to support local collaborations to design ACP pathways that are practical, efficient and effective.

ACP training plan

During phase 3, 63 ACP training sessions have been delivered to 404 staff members. ACP training was designed at three levels to meet the needs of participants, figure 5 shows the number of staff trained at each level.

Level	Description	Content	Number of staff trained
1	ACP awareness raising	Introduction to ACP and the improvement programme	
2	Tailored ACP improvement project training	7-steps to ACP for care home staff, Care Home- GP pathway	207
3	Tailored ACP improvement project training – NHS Lothian & EHSCP	Based on EC4H model, further developing practitioners' knowledge of ACP-KIS	42

Figure 5: ACP train	ning levels and	number of sta	ff trained durin	g phase 3
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ACP communication plan

In addition to the delivery of training and development of ACP improvement initiatives the ACP team has engaged with a range of partners from across Edinburgh, other health and social care partnerships, and national organisations. Raising awareness of the ACP improvement programme and aligning ACP improvement work with:

- The Care Inspectorate
- Scottish Care
- Care Home Providers
- Healthcare Improvement Scotland
- Scottish Health Council
- Scottish Government:
 - o Cabinet Secretary for Health and Sport
 - o Realistic Medicine Forum
- Royal College of General Practitioners

ACP public road shows

The ACP team hosted information stalls at four hospital sites across Edinburgh to raise awareness of the value of ACP with patients, visitors and staff. During phase 3 road shows were held at:

- the Royal Infirmary The Mall
- the Royal Edinburgh Royal Edinburgh Building Reception
- the Western General Anne Ferguson Building
- Astley Ainslie Hospital Smart Centre Reception

Resources were shared to guide discussions, explaining ACP with the public and staff, and establishing potential links with hospital services. The ACP team engaged in approximately 160 conversations and distributed 150 copies of <u>My Anticipatory</u> <u>Care Plan</u>¹⁰ and 200 copies of the ACP Information Leaflet (Appendix 12).

One visitor to the hospital shared:

"I wish that I had known about anticipatory care planning...it would have been helpful to have had this in place after my mother had a stroke. She didn't want to be resuscitated but she was, which was against her wishes...distressing for us all."

¹⁰ Guidance and template for creating ACPs. <u>ihub</u>, Healthcare Improvement Scotland.

Learning point 12: ACP is not a commonly known or understood term among the public and there are many practitioners working within health and social care who do not yet have a working knowledge of ACP. There is a need to continue to promote ACP at a both a local level and national level through engagement, partnership working and aligning with health and social care priorities.

Learning event

To celebrate progress and share approaches to improving ACP, a learning event was held at the end of phase 3, bringing together care home teams, multidisciplinary health and social care teams, third sector partners, and carers involved in improving ACP across Edinburgh's community. The event was held on Wednesday 6 March 2019 and attended by more than 140 delegates.

The aim of the event was to:

- share the Long Term Conditions Programme and partners' activities designed to improve ACP across Edinburgh City
- recognise the involvement and achievements of the Phase 3 care home teams and care home ACP champions
- share ACP improvements underway across community and acute services
- highlight why ACP matters from a national, out of hours, acute hospital, GP and health and social care locality perspective
- explore mechanisms that can support new and ongoing ACP improvements, and
- begin to scope a fourth phase of the Long Term Conditions ACP improvement programme.

An event report captures the content of the day, the presentations, discussions and suggestions for working together to improve ACP. Key themes include:

- roll out of ACP improvements across all care homes in Edinburgh
- continued support for the care homes that have participated in the ACP improvement programme to date
- spread ACP learning improvements to services supporting people living at home with long term conditions, and
- continuation of opportunities for reflective practice and for shared learning.

Please refer to 'Anticipatory care planning improvements: celebrating success and sharing learning in Edinburgh, Post Event Report, March 2019.'

Recommendations

- 1. Develop a care home ACP improvement and support package to support participating care homes to sustain improvements. With support from national partners (Healthcare Improvement Scotland, Care Inspectorate, Scottish Care) develop a scalable ACP improvement model which can be shared and tested across Scotland.
- 2. Undertake an economic evaluation of improving ACP with participating care homes to ascertain the cost saving of a 56% reduction in avoidable hospital admissions, and determine how the allocation of resources can achieve the greatest benefit.
- 3. Continue to work in partnership with health, health and social care, and voluntary teams to improve ACP for people living with long term conditions at home, improving the ACP community pathway. Work towards individuals having current copies of their ACP-KIS at home to inform shared decisions about their care and treatment.
- 4. Facilitate an ACP champions' network broadening out from care homes to include health and social care and voluntary teams involved in improving ACP.
- 5. Working with the Scottish Health Council review feedback from participating care homes' residents and families, and engage with citizens to understand the level of ACP awareness and utilisation among the general public. Co-produce resources to empower people to start ACP conversations early, enabling them to make informed choices about their care and support.



Acknowledgements

Grateful thanks go to the following for their participation, help, support and guidance.

- Participating care homes and GP practices
- Care home ACP champions
- Voices of Carers Across Lothian (VOCAL)
- Locality teams taking forward tests of change
- ACP Stakeholder Group members
- ACP Learning Event: speakers, panel members, facilitators and delegates
- Dr Kirsty Boyd, Consultant in Palliative Medicine NHS Lothian and Lead Tutor Effective Communication for Healthcare (EC4H)
- Hilary Gardner, Clinical Nurse Specialist, St Columba's Hospice and project ECHO: Extension of Community Healthcare Outcomes
- Ian Evans, IT Manager and Dori Gyulai, Reception Manager, Yvonne McBeth, Practice Manager, Portobello Medical Surgery
- Healthcare Improvement Scotland
- The Care Inspectorate
- Scottish Care

Appendices

Appendix 1: 7 Steps to ACP for Care Home Staff

Let's think ahead

7 Steps

to Anticipatory Care Planning for Care Home Staff

'Let's think ahead – 7 steps to ACP for Care Home Staff' was developed by the Long Term Conditions Programme within Edinburgh Health and Social Care Partnership. It provides a toolkit for Edinburgh care homes to embed an anticipatory care planning pathway. Dr Andrew Mackay (Lead GP, St Triduana's Medical Practice, Edinburgh) led a project in NHS Lothian, supported by a grant from Marie Curie, and developed the Anticipatory Care Questionnaires included in the toolkit as documents 3 & 4.

Anticipatory Care Planning I Long Term Conditions Programme I Edinburgh Health & Social Care Partnership I NHS Lothian I Canaan Park I Astley Ainslie Hospital I 133 Grange Loan I Edinburgh EH9 2HL

AnticipatoryCarePlanning@nhslothian.scot.nhs.uk Jan 2019 Working together for a caring, healthier, safer Edinburgh

NHS

Lothian



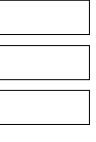
(Check Boxes please for actions 1 to 7)

- 1. GIVE 'Let's Think Ahead' leaflet to Resident/Family/Carers/ Close friend
- 2. READ Document 1
- 3. COMPLETE Document 2
- 4. COMPLETE Document 3 OR 4
- 5. MAKE AND FILE a copy of Document 3 OR 4 and Document 2 in your resident's care plan
- 6. GIVE THE ORIGINAL of Document 3 OR 4 to the GP with a completed Document 2
- 7. FILE DNACPR and the Key Information Summary report when returned from the GP

Please <u>ALWAYS</u>

- USE the KEY INFORMATION SUMMARY at points of deterioration
- BRING and USE the KEY INFORMATION SUMMARY at reviews
- RETURN ALL REVIEWS DATED AND SIGNED (SEE DOCUMENT 5 FOR GUIDANCE)

Initial & date





We want to know your preferences if you become very unwell. We will discuss with you.....

You may choose not to go to hospital to have further treatment. Would you prefer having treatment to make you comfortable in the care home?



Would you like staff to help you to look for treatment to prolong your life?

For further information please go to <u>http://www.whatmatterstoyou.soot/</u>
The leaflet maybe made available in a larger print, Braille or your community language, please email
<u>anticipatorycareplanning@nhslothian.soot.nhs.uk</u>
Readability & layout reviewed by NHSL Patient and Carer Information Group May 2018 – Review May
2021
V1.18



Let's think ahead

Talking about treatment and care in Edinburgh Care Homes

Information for residents, family members, carers and close friends about anticipatory care planning

Working together for a caring, healthier, safer Edinburgh

Lothian · CDINBVRGH·

Introduction

'Anticipatory' care planning means thinking and planning ahead and understanding what is happening with your health and care.

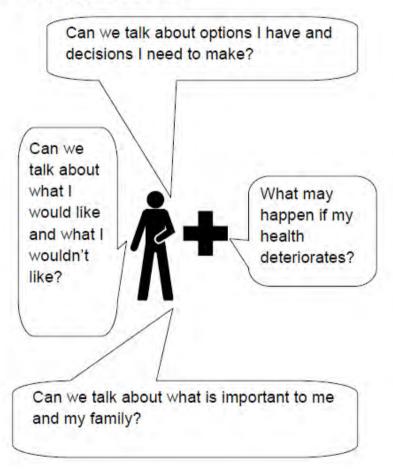
Care Home staff want to find out what matters to you and involve you in planning your care and treatment, as much as you are able and want to.

Care home staff will discuss your wishes with your family or a friend if you are unwell, unless you do not want this.

Some people may have already made a plan about their treatment and care. If you have one it would be very helpful to show this to the care home staff.

Please remember to tell Care Home staff if you have chosen someone to have a *Power* of *Attorney*.

Here are some things you might want to ask Care Home staff:





Document 1 Talking about Anticipatory Care Planning in a Care Home

This is a guide to help staff, residents, and their relatives or close friends talk together about making a Care Home Anticipatory Care Plan

Not all the questions apply to every resident. They are suggestions to help us think ahead, talk about what might happen, and plan each resident's care.

People who live in a care home often have long term health problems and become unwell at some point. No one knows when a resident's health may change so it is better to plan ahead.

This leaflet aims to help care home residents, close family members, and care home staff to talk about making plans for treatment and care. Then everyone will know what things are important to the resident and what they would like to happen. It helps us make the right decisions when a resident gets unwell, particularly if that happens at night or at a weekend.

We always encourage our residents to take part in discussions about their care if they are able to do that. We involve the people who are close to them as well unless a resident chooses not to do that. A resident may have talked with their family or a close friend about this before. Some people will already have a Scottish Anticipatory Care Plan.

If a resident is not able to talk about anticipatory care planning, we ask those who know them well to tell us about what would matter to the person and what they might choose. If the resident has a welfare 'Power of Attorney' we involve them in care planning.

The plans we make for future treatment and care are put into an 'Anticipatory Care Plan'. These are not legally binding and are updated if the person's health or wishes change.

Here are some ways to have conversations about Anticipatory Care Planning. Most people can start a conversation. Sometimes a more experienced person needs to help with Step 2 and Step 3.

STEP 1: A GOOD PLACE FOR EVERYONE TO START

Talk about what the resident and their family/ close friend know already and what they think might happen in the future.

Some questions that might help:

- Do you know anything about anticipatory care planning? Have you made a plan before?
- How do you think you/ they have been doing recently?
- How did you/they find being in the hospital?
- Can we think about what has happened recently and why you/they are less well now than before?
- What do you think about your/ their health at the moment?
- What have doctors or nurses told you about your/their health?
- What are you expecting to happen with your/their health in the future?
- Is there anything that would worry you about your/their health or care in the future?
- Who is the person we should contact if you/they get unwell?
- It's good that you/they feel fine at the moment, but can we talk about what might happen if you/ she/he were to get more unwell again?

STEP 2: FIND OUT 'WHAT MATTERS MOST?'

It's really important for us to understand what is important to each of our residents as that helps us make good decisions about their treatment and care. This information and is included in their Care Home Anticipatory Care Plan.

Some questions that might help:

- What things are important to you/them that we should know about?
- When you think about the future, what would matter most to you/them?
- If your/their health did change gradually or more suddenly, is there anything you would like to happen or anything you would not want?
- Do you have any particular things you/they would like to be able to do? Is there anything we can do to help with that?
- People often have ideas about how much treatment they would want:
 - Some people feel that staying in their care home to be looked after and not going to hospital is the right thing for them.
 - Some people want to get better, if possible, but think that quality of life is important too.
 - These people might want to think about admission to hospital if there is a good chance of getting back to how they are normally. If hospital treatments may not help or could mean being in much poorer health, they would rather stay in their care home and be looked after by the care home staff and GP.
 - Some people are keen to get better even if that means going to hospital.
- What about you/ your relative?
- Have you discussed this together before?

STEP 3: TALK ABOUT 'WHAT HAPPENS IF?'

It is important that we talk about what treatments may help and those that will not help or are not what the resident would want.

These things can be hard to think about and you may want to talk to your GP and get more information – we can arrange that:

- It is hard to talk about getting less well but we are worried that if we don't do that we may not have good plans in place for your/ their care.
- When a resident's health deteriorates, they may become so ill that a decision will have to be made about whether or not we should send them to hospital. It is better for us to think about this in advance.
- We can look after people in the care home if they become less well or are dying and if they get symptoms like pain or breathlessness, or if they are feeling sick or being sick.
- Sometimes residents get an infection that can be treated in the care home with antibiotic syrup or tablets and we look out for that happening.
- Something we talk about with everyone is CPR or cardiopulmonary resuscitation; do you know anything about it? Has it been discussed with you before?
 - CPR is a treatment that can be used to restart the heart and breathing in some situations. Many care home residents have health problems that mean CPR would not work or leave them in very poor health.
 - We do not give CPR when a person is dying because we want them to die in a peaceful, comfortable and natural way.

Date:

Completed by:

Please complete all sections

Name		DOB
Admitted from:		
NOK/ family contac	t Name:	
(Please circle one of		Relationship:
above)	Address:	
	Tel no:	mobile:
Welfare guardian/	Name:	
Power of Attorney		
(Please circle one of above)	Address:	
above		
	Tel no:	mobile:
AWI in place? Yes	/ No	For Resuscitation? Yes / No / Needs assessed
		DNACDD ander in place? Vec / No
		DNACPR order in place? Yes / No
Consent for sharing	g information with Out of Hours	s doctor? Yes / No
Mobility	Independent Walking aids Nee	eds assistance Bed and chair bound Bedbound
·····,		
	(Please circle one only)	
Continence	Continent Urinary incontinence	e-wears pads/catheter in situ Faecal incontinence
	(Please circle one only)	
		on 1-2 words only No meaningful interaction
J		
	(Please circle one only)	
Communication	Speaks clearly Speech difficult	t to understand Unable to communicate verbally
	(Please circle one only)	
BP	Allergies	
	Never smoked Ex-Smoker	Current Smoker cigarettes /day
	(Please circle one only)	
Measurements	Weight Height	BMI
	-	
Flu vaccination give	en this season? Yes /No	
Falls	Previous Falls? Yes / No F	Falls Risk Factors Shared with GP? Yes / No
	Anticipatory care planning questi	ons given to patient? Yes/No
wishes	.	
	Anticipatory care planning questi	ons given to NOK/POA (please circle one)? Yes/No
Any other concerns	s?	

Anticipatory Care Planning; information for care home residents

What is Anticipatory Care Planning?

Thinking ahead and making a plan helps people who live in a care home, like you, make choices about their care. We call this Anticipatory Care Planning. It is important for us to talk with our residents, their family or a close friend about what might happen if a resident is unwell. If you have chosen someone to have Power of Attorney we will involve them too.

No one knows when a person's health may change so it is better to have a plan in place. Then everyone will know what things are important to you and what you would like to happen.

You might have talked with your family or a close friend about this before.

If a resident is not able to talk about anticipatory care planning, we ask those who know them well to tell us about what would matter to the person and what they might choose.

Some people feel that staying in their care home to be looked after in a familiar place and not going to hospital is the right thing for them. They may not want the upset of going to hospital for treatments that might not work. Being comfortable in the care home is more important.

Some people want to get better, if possible, but think that quality of life is important too. These people want us to think about admission to hospital if there is a good chance of getting back to how they are normally. If hospital treatments may not help or could mean being in much poorer health, they would rather stay in their care home and be looked after by the care home staff and their GP.

Some people are keen to try to get better even if that means admission to hospital. They want us to look for any treatments that could prolong their life.

How is a Care Home Anticipatory Care Plan made?

- Some people already have their own Anticipatory Care Plan. Other people have thought about planning ahead. You may have talked about this with your family before.
- We try to make the Care Home Anticipatory Care Plan soon after a resident moves into the care home so that we have the right information available if it is needed.
- Your Care Plan is looked at during the review meetings with the care home staff and if your health or wishes change. These plans are not legally binding.

Where is the Care Home Anticipatory Care Plan kept?

- The Anticipatory Care Plan is usually kept with your other records in the care home.
- A summary of your Care Plan is written by your GP and includes any information we have about your views and wishes. It is added to your record at the GP practice.
- If you agree, the Plan also is added to a secure electronic record (called a Key Information Summary) used by the GPs on duty for evenings and weekends (NHS24), local hospitals and ambulance staff.

What happens now?

• On the next page are some situations to think about. If you have any questions, please ask the staff or contact us at the surgery. We will be happy to discuss these with you.

Anticipatory care planning questions for care home residents

There are changes in health that do sometimes happen in frail older people.

Please tick the box that is closest to what you think you would like to happen. We will use this information to help us make a Care Home Anticipatory Care Plan for you

1. If you had a sudden collapse (such as from a stroke or a heart condition), what do you think you would like to happen?

Keep you comfortable, clinically assess you, treat any pain or other	
symptoms, and care for you in your care home.	
Contact a family member/ close friend, if possible, to help decide whether to	
send you to hospital, instead of dialling 999 for an ambulance.	
Send you to hospital for tests and treatments such as a drip, and other	
treatments for your condition.	
	symptoms, and care for you in your care home. Contact a family member/ close friend, if possible, to help decide whether to send you to hospital, instead of dialling 999 for an ambulance. Send you to hospital for tests and treatments such as a drip, and other

2. If you had a serious infection that was not improving with antibiotic tablets or syrup, what do you think you would like to happen?

a)	Keep you comfortable, clinically assess you, treat any pain or other	
	symptoms, and care for you in your care home.	
b)	Contact a family member/ close friend, if possible, to help decide whether to	
	send you to hospital, instead of dialling 999 for an ambulance.	
C)	Send you to hospital for tests and treatments such as a drip, and other	
	treatment given into a vein.	

3. If you were not eating or drinking because you were now very unwell, what do you think you would like to happen?

a)	Keep you comfortable, clinically assess you, treat any pain or other	
	symptoms, and care for you in your care home.	
b)	Contact a family member/close friend, if possible, to help decide whether to	
	send you to hospital, instead of dialling 999 for an ambulance.	
C)	Send you to hospital for tests and treatments such as a drip, or other	
	treatments.	

If we think that you have a serious fracture (such as a hip fracture) we would usually send you to hospital for treatment, as that would be the best way to care for you.

Is there anything else about your health and care that it is important for us to know? (Any specific illness or treatment that needs a plan such as epilepsy, diabetes or tube feeding)

If you DO NOT want this information shared with the emergencies services, tick here

Resident's name......Date......

Anticipatory Care Planning: information for relatives and close friends

What is Anticipatory Care Planning?

Thinking ahead and making a plan helps people who live in a care home make choices about their care. It is important for us to talk with our residents, their family or a close friend about what might happen if a resident is unwell. If your relative/friend has chosen someone to have Power of Attorney we will involve them too.

No one knows when a person's health may change so it is better to have a plan in place. Then everyone will know what things are important to them and what they would like to happen.

If a resident is not able to talk about anticipatory care planning, we ask those who know them well to tell us about what would matter to the person and what they might choose. Sometimes people have talked with their family or a close friend about this before.

Some people feel that staying in their care home to be looked after in a familiar place and not going to hospital is the right thing for them. They may not want the upset of going to hospital for treatments that might not work. Being comfortable in the care home is more important.

Some people want to get better, if possible, but think that quality of life is important too. These people want us to think about admission to hospital if there is a good chance of getting back to how they are normally. If hospital treatments may not help or could mean being in much poorer health, they would rather stay in their care home and be looked after by the care home staff and their GP.

Some people are keen to try to get better even if that means admission to hospital. They want us to look for any treatments that could prolong their life.

How is a Care Home Anticipatory Care Plan made?

- Your relative/friend may already have an Anticipatory Care Plan. Some people have thought about planning ahead. Your relative/friend may have talked about this with you before.
- We try to make a Care Home Anticipatory Care Plan soon after a resident moves into the care home so that we have the right information available if it is needed.
- The Care Plan is looked at during the review meetings with the care home staff and if the health or wishes of your relative/ friend change. These plans are not legally binding.

Where is the Care Home Anticipatory Care Plan kept?

- The Anticipatory Care Plan is usually in each resident's records in the care home.
- A summary of each resident's Plan is written by their GP and includes any information we have about their views and wishes. It is added to their record at the GP practice.
- If people agree, the Plan is also added to a secure electronic record (called a Key Information Summary) used by the GPs on duty for evenings and weekends (NHS24), local hospitals and ambulance staff.

What happens now?

• On the next page are some situations to think about. If you have any questions, please ask the staff or contact us at the surgery. We will be happy to discuss these with you.

Anticipatory care planning questions for relatives and close friends

There are changes in health that do sometimes happen in frail older people.

Please tick the box that is closest to what you think your relative/friend would choose. We will use this information to help us make a Care Home Anticipatory Care Plan for them.

1. If your relative/friend were to become unwell suddenly or had a sudden collapse (such as from a stroke or a heart condition), what do you think **your relative/friend** would like to happen?

a)	Clinically assess their condition, treat any pain or other symptoms, keep	
	them comfortable and care for you in your care home.	
b)		
	send them to hospital, instead of dialling 999 for an ambulance.	
c)	Send them to hospital for tests and treatments for their condition.	

2. If your relative/friend had a serious infection that was not improving with antibiotic tablets or syrup, what do you think **your relative/friend** would like to happen?

Clinically assess their condition, treat any pain or other symptoms, keep
them comfortable and care for you in your care home.

b) Contact a family member/ close friend, if possible, to help decide whether to send them to hospital, instead of dialling 999 for an ambulance.

c) Send them to hospital for tests and treatments for their condition.

3. If your relative/friend were not eating or drinking because they were now very unwell, what do you think **your relative/friend** would like to happen?

a)	Clinically assess their condition, treat any pain or other symptoms, keep	
	them comfortable and care for you in your care home.	
b)	Contact a family member/close friend, if possible, to help decide whether to	
	send them to hospital, instead of dialling 999 for an ambulance.	
C)	Send them to hospital for tests and treatments such as a drip, or other	
	treatments.	

If we think that a resident has had a serious fracture (such as a hip fracture) we would usually send them to hospital for treatment, as that would be the best way to care for them.

Is there anything else about this resident's health and care that it is important for us to know? (Any specific illness or treatment that needs a plan such as epilepsy, diabetes or tube feeding)

If you DO NOT want this information shared with the emergencies services, tick here \Box

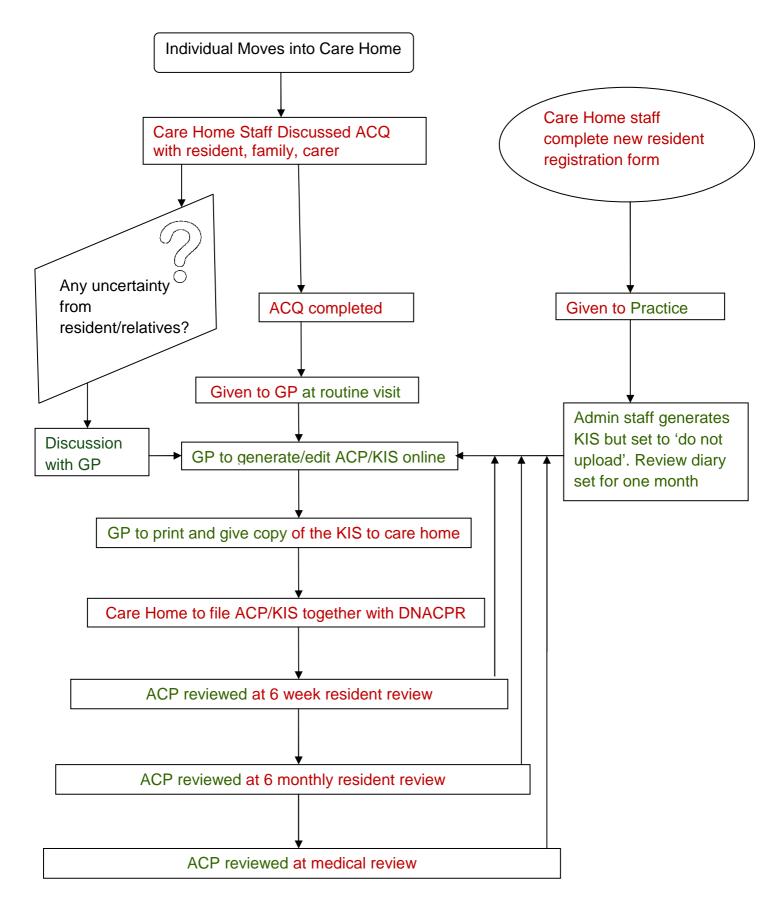
Resident's name..... Your name.....

Relationship...... Date...... Date......

I have / do not have Power of Attorney for the resident.

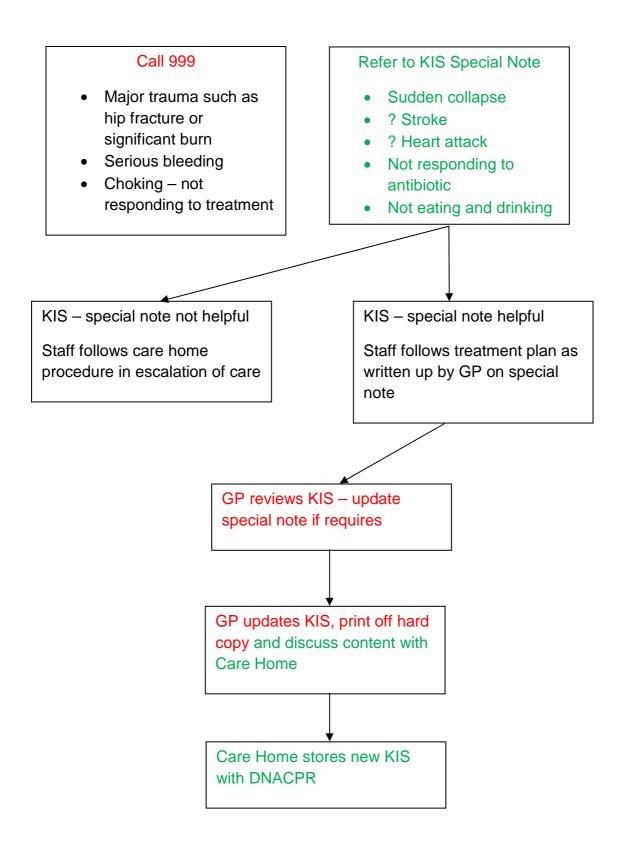
I have / do not have Welfare Guardianship for the resident.





Document 6

Care Home Acute Clinical Incident Flow Chart



Appendix 2: Phase 1 Anticipatory Care Planning in North East Edinburgh Care Homes

Phase 1: Anticipatory Care Planning in North East Edinburgh Care Homes

Project Team:

Gill Harker, ACP Facilitator John Raez, Project Support Officer Lisa Stewart, Project Manager Long Term Conditions Dr Andrew MacKay, Quality lead GP, North East Edinburgh Dr James Marple, Primary Care Practitioner Amanda Fox, Programme Manager Long Term Conditions Programme

Project Evaluation Report: June 2017

Introduction and Context

Anticipatory care planning is regarded as 'a philosophy which promotes discussion in which individuals, their care providers and those close to them, make decisions with respect to their future health or personal and practical aspects of care' (Scottish Government, 2011).

Completion of a well-structured, clear anticipatory care plan improves the likelihood that care home residents receive care that is appropriate to their needs and consistent with their goals and wishes (NHS Lanarkshire, 2015). For this to happen routinely, care home staff need to develop the knowledge, skills and confidence to engage in discussions about end-of-life care (Stone et al, 2013).

NHS Lanarkshire has taken a strategic approach to anticipatory care planning in their 87 care homes over a two-year period to widely establish (and firmly embed in practice) the anticipatory care planning process and related skills needed to achieve this. Between January 2014 to March 2015, 431 care home residents with an anticipatory care plan (ACP) remained in their preferred place of care following deterioration in their health. This was reported by staff as being beneficial for individuals and carers, with many examples of positive outcomes as a result of planning ahead and communicating their wishes through their ACP. Important learning can be taken from their approach and how they engaged with care home staff.

In North East Edinburgh, Dr Andrew Mackay led a project team to assess the use of an Anticipatory Care Questionnaire (ACQ) to support more effective communication between care home residents, families and health professionals when discussing goals of care and end-of-life care planning (Mackay et al, 2016). The evaluation highlighted that when there is no electronic ACP available (ACP-Key Information Summaries¹¹) or the ACP is vague about future care wishes:

"A call to NHS 24 may result in a protocol driven decision by a call handler which is neither in the best interests of the resident nor consistent with stated wishes about what they would want to happen. In summary, to make end of life care planning more effective and reliable in care home settings, we need robust systems, clearer documentation, better communication and better support for care home staff"

¹¹ Electronic ACPs are created and shared using software called the Key Information Summaries (KIS) which was introduced to all Scottish GP practices in 2014. These allow selected parts of the GP patient record to be securely shared with healthcare professionals across the wider NHS.

Aims and Objectives

Project Aim

The project to assess the use of ACQs concluded that effective anticipatory care planning should be available in all care homes from preadmission to the care home to bereavement for all residents and their families. To achieve this each care home and their aligned GP should have a systematic approach to agreeing, reviewing, recording and updating ACP-KISs and ensuring that these are easily accessible to all professionals who read them to guide decision-making. The aim of this project was to test and further develop ACQs in 4 care homes in the North East Edinburgh Cluster over a 6-month period from January-June 2017. Funding for the project was initially through the integrated care fund.

Two of the key findings and recommendations from the ACQ evaluation report formed the basis for this project:

- Improve systems for co-ordinating anticipatory care planning in care homes Care homes and the aligned GPs to develop a systematic approach to agreeing, reviewing, recording and updating ACP-KISs and ensuring these are easily accessible to all professionals who read them to guide decision making particularly during out of hours (OOHs) GP periods.
- Care home staff support for initiating care planning discussions
 Care home staff reported that they would welcome support and education in
 undertaking ACP conversations and the documentation of care planning
 discussions with residents and their families. For this to happen routinely, care
 home staff need to develop the knowledge, skills, and confidence to engage in
 discussions.

Objectives:

- To develop and test a structured approach to support 4 care homes in North East Edinburgh and their aligned GP Practices to adopt an agreed system to discussing, reviewing, recording and updating ACP-KISs.
- To provide guidance, teaching and support for care home staff in discussing and documenting care planning discussions with residents and families.
- To ensure the resident's responses will be documented in an ACP and made more widely available using the electronic ACP-KIS.
- To establish a process in each of these care homes to check for the presence and content of an ACP-KIS before contacting unscheduled care services.
- Enhance care home staffs' knowledge and understanding of NHS 24 / OOH services. Demonstrate through examples and discussion how the ACP-KIS can assist improved communication when contacting OOHs services with the aim of ensuring that the resident's wishes are respected.
- To develop and test training resources for the above that can be used as a model for future roll out to other care homes.

Project Approach and Methodology

GP and Care Home engagement

The NE Edinburgh locality was selected for this proposal. Dr Andrew Mackay, one of two GP Cluster Quality Leads (CQL) for the North East Edinburgh Cluster, provided consultancy to support the project. He engaged with the four GP practices covering the care homes and the care home managers and arranged initial meetings between the care home, the aligned GP and the ACP Lead Facilitator.

Meeting with: care home manager, aligned GP, lead quality GP & ACP lead

Positive engagement at this initial meeting was identified as the key to the success of this programme and also its sustainability in the longer term. Building positive and effective relationships with the care home team and the GP was central to the approach adopted.

The following was covered at these meetings:

- Having an experienced named nurse/senior carer with lead responsibility for anticipatory care planning in the care home can stream line the process and ensure each stage is completed and followed through. Likewise it is helpful to have a named GP from the GP Practice.
- The evaluation from the ACQ study found that when the ACP-KIS is not specific enough there is a greater risk of admission and of resident's wishes not being followed. Stating in the special notes section of the KIS: "if deteriorates please review on home visit and if possible should be managed in the care home" may not be specific enough to prevent an unnecessary A&E attendance or admission when an acute event occurs. NHS 24 has a protocols based approach which does not fit well with the needs of frail older people and may well result in an emergency admission against the wishes of the resident or their family. The Anticipatory Care Questionnaires were initially developed by St Triduana's medical practice try to address this issue by being more specific and clearer as to the wishes of the resident and their family.
- The ACQs are simple information leaflets detailing 3 common scenarios that may arise when a resident is frail and at risk of deteriorating and dying (Appendix 1):¹²
 - 1. In the event of sudden collapse, such as a stroke or a heart condition.
 - 2. Serious infection that is not improving with antibiotic tablets or syrup.

¹² The Anticipatory Care Questionnaire has been developed throughout the duration of the ACP Improvement programme, the most recent version is now included in the '7 steps to ACP for care homes' toolkit, see Appendix 1.

- 3. Not eating or drinking because the resident is now very unwell.
- The process and method is outlined for completing and reviewing ACPs in the care home using the Care Home ACP Flowchart (Appendix1).¹³ The means of communication are discussed and agreed, e.g. very often the designated GP makes a routine weekly visit on a set day. At these visits care home staff can hand over the newly completed ACQ and the GP can then create or update an existing ACP-KIS. A printed copy of this can then be given to the care home for their records. There currently is no option to electronically share the ACP-KIS between GP practice and care home.
- The ACQ programme involves a number of training sessions (depending on staff numbers, shift patterns and staff availability) and face to face meetings with the care home manager and the GP. The training sessions consist of small group work where participation and discussion is encouraged. ACP-KIS IT training can also be offered to the GP administrative staff who may be supporting the GP to create the resident's KIS.

Care Home Training and Support Activity

Development of training tools and support programme was tested and delivered to each of the 4 care homes. An initial meeting was held with the care home manager or designated ACP lead to scope the training needs of the staff, plan the training dates and the staff to attend (according to staff rotas). The training sessions consisted of small group work of 4-6 staff where participation and discussion was encouraged. Emphasis was upon the staff's own experience and relating that to how they might think a good ACP could improve the outcomes for their residents. Evaluation forms were handed out after each session and in light of the feedback changes were made to the training content and method of delivery. The training programme consisted of two 1 hour sessions:

Training session 1: Anticipatory care planning in the Care Home context

This session included:

- An ACP quiz
- Background to ACP in the context of frail elderly care home residents
- Guidance for the completion and reviewing ACPs using the ACQ leaflets and the importance of establishing a robust system and process between the care home and the GP.

¹³ The Care Home ACP Flowchart has been developed throughout the duration of the ACP Improvement programme, the most recent version is now included in the '7 steps to ACP for care homes' toolkit, see Appendix 1.

• The ACQ flow chart is used as a means to highlight each stage of the process. To assist the care homes a checklist (Appendix A) was developed to record and track the different stages in the process to ensure good communication and reliability.

Training session 2: Communication skills for ACP discussions and using the KIS ACP in practice:

This session included:

- A review of positive communication skills, challenges for staff, and supportive communication approaches.
- The benefits of using the SBAR for Care Homes tool (Appendix B) which included prompts for assessment and communication with OOHs services and/or emergency services.
- Establishing a process in each of the care homes to check for the presence and content of an ACP-KIS before contacting unscheduled care services.
- Enhance care home staffs' knowledge and understanding of NHS 24 / OOH services.
- Increase the staff's confidence and communication skills when calling OOHs such as NHS 24 – how having an up to date copy of the ACP-KIS together with the DNACPR can assist them in ensuring that the resident's/family's wishes are respected.

Family and friend's information session

To raise awareness attendance at resident's family meetings was offered and taken up in 2 care homes. The Healthcare Improvement Scotland (HIS) ACP leaflets were used at these sessions in addition to a general discussion about the benefits of forward planning and sharing the plan with OOHs health professionals. Discussion and questions were encouraged. Unexpected questions arose, such as concerns about organ donation and the HIS leaflets proved very helpful as there was specific information and a website link for more information in relation to this topic.

The relative of one resident found her mother's time in hospital very distressing and was adamant that she should never go back into hospital. The session developed into an ACP conversation between the daughter, the care home manager and the ACP lead facilitator about her wishes for her mother's future care. The daughter was relieved at the opportunity the session had given her and she completed the ACQ at the end of the discussion.

Care Home ACP Resource Folders & Staff Training Certificates

All the resources and training presentations were compiled into an ACP Resource folder and given to the care homes at the end of the programme. As the project was only for 6 months the care home manager or care home ACP lead could use this for any new staff after the project had finished. Staff were also issued with training certificates for their personal development records.

Follow up meeting with the GP & the Care Home

On completion of the training a follow up meeting with the GP and the care home manager/ lead was arranged. At this meeting the GP and the care home discussed and clarified the process using the Care Home ACP flow chart. It was important at this stage that both the care home and GP were both clear as to how they would progress and who was responsible for each of the four steps:

- 1. Care Home conversation with the resident/family and recording their wishes using the ACQ.
- 2. Care Home to return the completed ACQ together with the new resident information sheet to the GP.
- 3. GP to create the resident's ACP-KIS and record the information from the ACQ along with other useful key information to create the ACP-KIS.
- 4. GP to print off the ACP-KIS and return to the care home.

Time was also given to establish that after the training all the staff were aware where the ACP-KISs were kept and to consult it at a time of change in the resident's condition and health or a change in their wishes. The ACP-KIS should also be consulted, reviewed and updated at a resident's 6-monthly review discussions.

It was also important to discuss and agree how they would begin to take forward this work with their residents and relatives. In one larger care home where both the GP and the care home staff felt they had a lot of work to do they agreed to start only with new residents until they gained confidence and the system became established. In another smaller care home where nearly all of the residents already had an ACP-KIS the GP and the staff agreed that they would undertake with all new residents but also start to have ACP conversations with existing residents and/ or their relatives.

Evaluation

Care Home Data Group

A Care Home Data Group was established to collate baseline information regarding unplanned activity in relation to A&E attendances, unscheduled hospital admissions, conversion from A&E attendance to an inpatient and the reason for A&E attendance or admission. The aim was then to re-examine this data at a time after the completion of the project to gauge if there had been a reduction in A&E attendances and hospital admissions. While data for the period April 15-September 16 became available prior to the project commencing, it was later acknowledged that it was unreliable and therefore it has not been included in this report.¹⁴

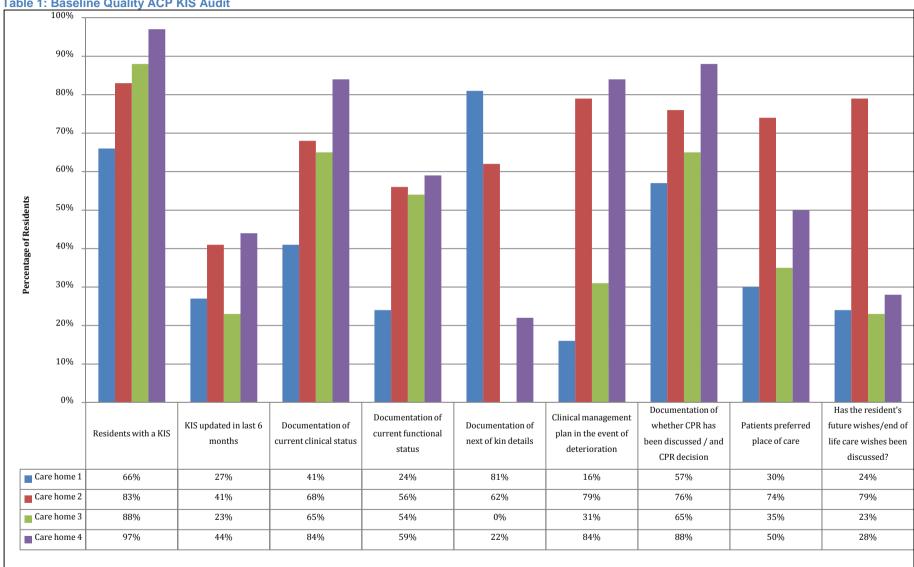
Reflection & Support

Follow up visits were arranged with 2 of the care homes to provide ongoing support. To assess whether the care home and GPs had established a system that was working and reliable, four residents (who had had an ACP conversation with the staff and recorded on an ACQ) were discussed and the reliability of the 4 steps of the process tested using the reliability tool (Appendix C) It was also an opportunity to discuss and reflect upon any occasions when the staff had contacted Out of Hours services. A reflective tool was developed to assist the staff to review their experience (Appendix D) and provided a guide and framework for their discussions. Had the staff checked to see if there was an ACP-KIS before phoning NHS 24 and was it helpful? Did the staff feel more confident when phoning OOHs services and discussing the situation? Did things go well? If not what would have helped or what would they do differently and any learning they could share with colleagues.

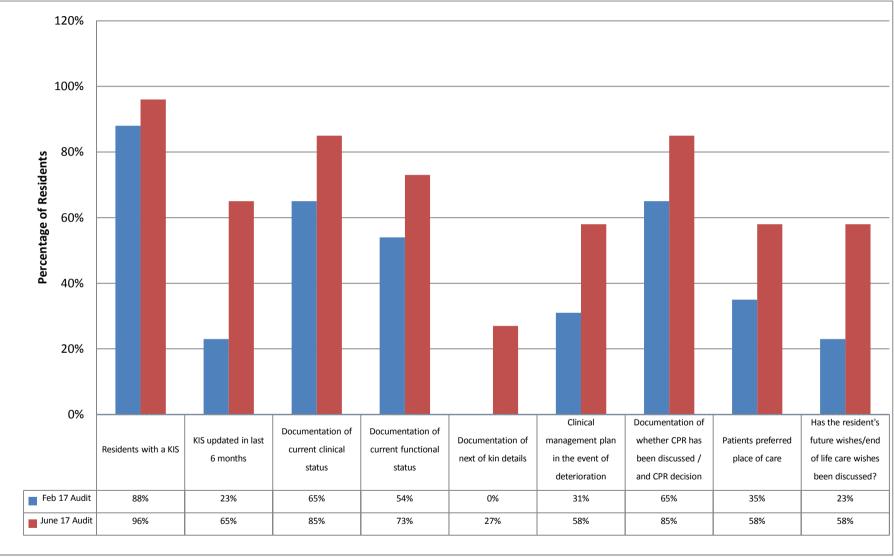
Baseline Quality Audit of ACP-KISs

A quality audit tool was developed (Appendix E) and a baseline quality audit was undertaken for each of the care home residents in the 4 care homes. The findings in table 1 show great variability among the 9 measures of the audit. For example, the number of residents with an existing KIS varied from 66% to 97%. The same audit carried out with care homes 3 and 4 following completion of the project shows improvements across these audit measures. As can be seen in tables 2 and 3, care home 3 went up from 23% to 65% against the audit measure 'KIS updated in the past 6 months'. Care home 4 went up from 28% to 93% for audit measure 'has the resident's future wishes/end of life care wishes been discussed?' As the second baseline audit was carried out only a few months after the first one, significant improvement is seen in both the quantity and quality of ACP-KISs within a relatively short space of time.

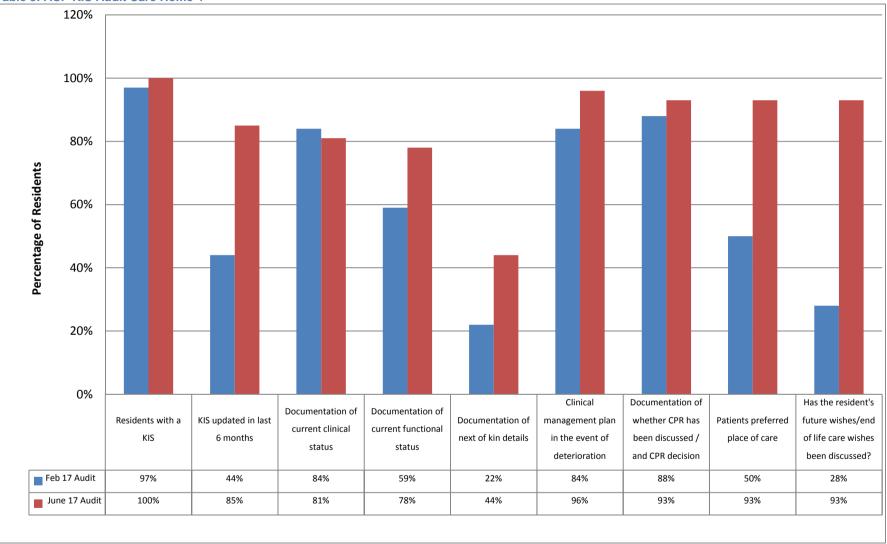
¹⁴ Data became available during phase 2 of the ACP improvement programme, and is included in Appendix 6.











Reliability

The use of the reliability tool tested whether the system established between the care home and the GP was robust and was also an opportunity to identify where things were not working well, prompting a discussion as to how any issues could be resolved.

A reliability audit was carried out at the end of the training. The small sample size (four residents in two care homes) limited the strength of any findings, but did suggest that the proposed ACP model could be quickly adopted by the care home staff and the aligned GP. For example tables 4 and 5 show that both care homes achieved 100% for completing the ACQ and sending it to their GP as well as the GP using this information to complete the ACP-KIS.

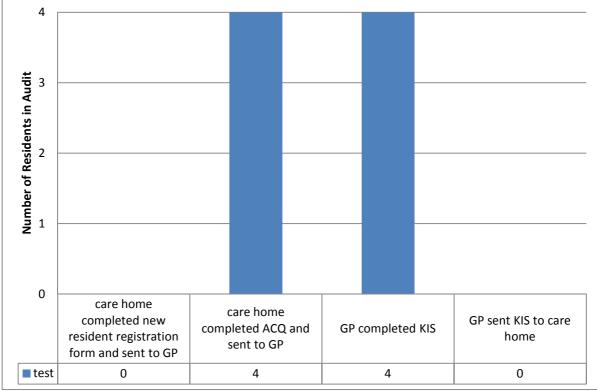


Table 4: Reliability Tool Audit June 2017 - Care Home 3

As can be seen in table 4, in care home 3 only 2 of the 4 objectives achieved 100%. The objectives with the best result were 'completion of ACQ and sent to GP' and 'GP completed KIS'. The first objective 'new resident registration form completed and sent to GP', (Appendix 1¹⁵) scored zero as the four residents were already resident in the care home. The last objective – 'GP sent ACP-KIS to care home' was also zero as there was no evidence that the printed ACP-KIS had been received by the care home. This was discussed with the care staff emphasising that this final step is

¹⁵ The New Resident Registration form has been developed throughout the duration of the ACP Improvement programme, the most recent version is now included in the '7 steps to ACP for care homes' toolkit, see Appendix 1.

crucial in order to ensure that a printed copy was readily available and easily accessible in the event of deterioration in the health of a resident.

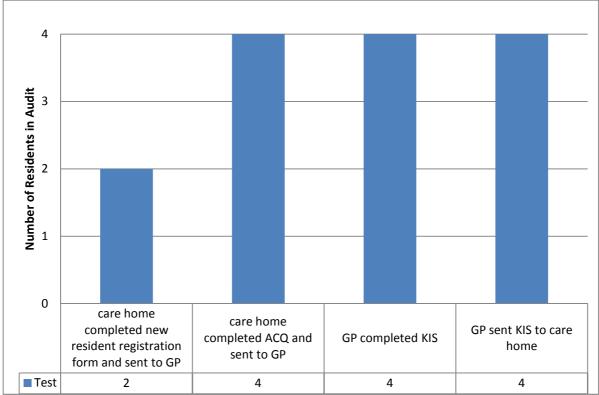


 Table 5: Reliability Tool Audit June 17 - Care Home 4

As can be seen in table 5, care home 4 met 3 of the objectives100%. The objective 'new resident registration form completed and sent to GP' achieved 50%, but as was found with care home 3, this is because 2 of the 4 residents were already resident in the care home and did not require a new resident registration form to be completed.

Training and Staff Evaluation

At the end of each training session evaluation sheets were completed. These were used throughout the development of the programme to change and tailor the training content and approach.

Table 6 shows findings from the questionnaires that were provided at the end of training session 1. This reports a positive trend showing participants mostly strongly agreed/ agreed that they had benefited from this session.

Table 7 shows finding from the questionnaires that were provided at the end of session 2. As for session 1, the participant's feedback highlights that learning outcomes for session two were met.

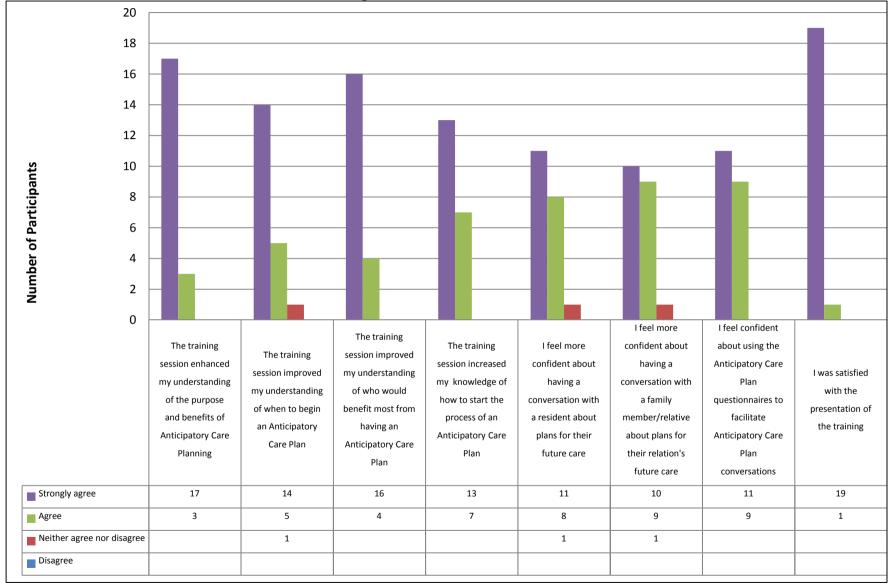


Table 6: Results of Evaluation Questionnaire from ACP Training Session 1 in 4 Care Homes

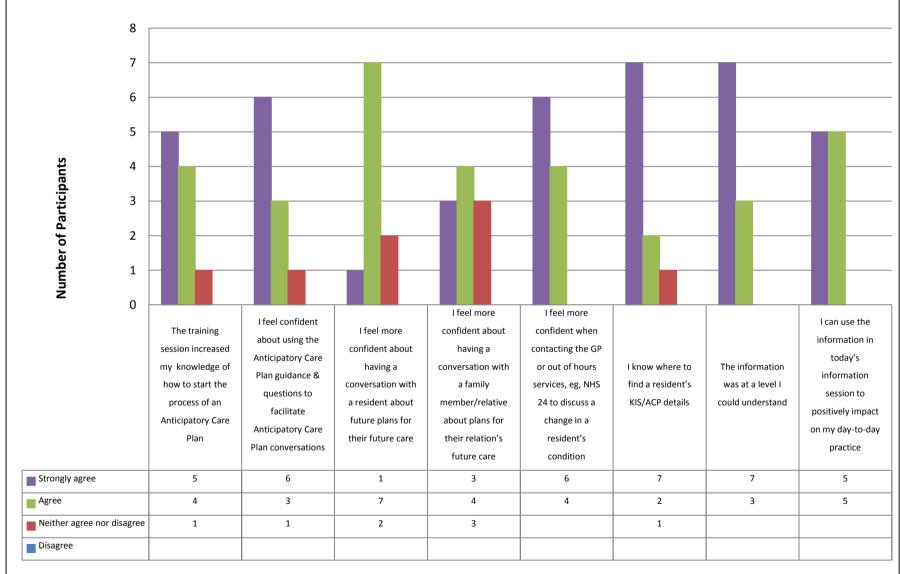


Table 7: Results of Evaluation Questionnaire from ACP training Session 2 in 4 Care Homes

Progress and Outcomes in each Care Home

The four care homes involved in the project volunteered to take part after the initial meeting with the Lead GP and Lead ACP Facilitator. Three of the homes employed nursing staff. They varied in size, offering 30-60 residential places and were owned by national care companies. The fourth home was privately family-owned; and employed no nursing staff.

During the initial training sessions staff related instances where events had not been managed well or they felt in the best interests of the resident. For example in one care home, staff recalled instances of scenarios where the absence of specific care instructions (e.g. an ACP or a DNACPR form) has resulted in inappropriate care for two residents. In one scenario, a lady was resuscitated when this should not have been attempted on the grounds of futility (but there was no DNACPR form in place). They recalled the experience of, *"watching someone being resuscitated, it's not like it is on Casualty - it was horrendous and the lady died"*. In the second scenario, a resident died en route to hospital in an ambulance when the admission should have been avoided, had there been an ACP in place. *"We all knew it was wrong - it was awful"*. During discussion with the team they felt that had the wishes of the resident /family been known by them all and had a plan been in place the outcome and experience would have been better, not just for the resident and family but also for the staff. It was very evident that these two events had a significant impact on all of the care team.

During training staff readily identified residents who they thought were a priority due to recent illness, recent hospital admission or concerns from family about future care. During a training session one carer instantly recognised the value of such an approach as she herself had suddenly been faced with making decisions when her mother's health suddenly deteriorated. She felt that it would have been far better for her and her mother had she been given the opportunity to think about things when her mother was gradually deteriorating rather than when her mother became acutely unwell.

Through the audit of the quality of the existing resident ACP-KISs it became apparent that there was enormous variation in the quality of the content of the free text written within the 'special notes' field within the ACP-KIS. Some had excellent detailed useful information but were lengthy and not concise or succinct. Others contained information as to future wishes but no other information such as current clinical and functional status. One or two were difficult to read and understand.

Care Home 1:

A care home owned by a national care organisation and is a purpose built with 6 units, with each unit having 10 rooms. The staff comprises of both trained nurses and carers.

At the initial meeting with the care home manager, the deputy, the GP and the GP administrative assistant (with a responsibility for the registration of new residents) all felt that they would very much welcome support and the adoption of a system and an organised process. The care home manager had recently taken over the management of the home and the GP felt that the workload was currently challenging and acknowledged that this was an area that was in need of improvement. This view by the GP was reflected in the baseline audit results in comparison to the other 3 care homes. To assist the GP good quality examples of ACP-KIS special notes were developed and shared with the GP to enable them to write concise, succinct and understandable special notes.

Care Home 2:

A purpose built nursing home with 47 rooms and is run by a family owned Scottish company. As well as frail elderly and residents with dementia it also caters for people with an acquired brain injury.

There was considerable delay in arranging suitable dates to deliver the training programme due to communication challenges with the care home manager, staff changes and staff availability. The ACQs were shared with the staff at the initial meeting by the GP & ACP Facilitator – staff started to use these resources before the accompanying training had been provided. The ACP facilitator became aware of this when the training did finally commence; it became apparent at the first session that the staff had been sending out the ACQs to relatives to complete with no supportive conversation taking place. At the first training session the ACP care home lead immediately recognised that their approach had not been best practice and that a good ACP conversation and that they understood the aims of why it was important that their wishes were known and shared. The learning from this is that the implementation of the ACQ resources requires training and ongoing support and that they cannot be adopted without this, otherwise there are risks for both the staff and the residents and their families.

Care Home 3:

A 30 bedded nursing home in a large converted Victorian house run by a Scottish based company.

There was very positive engagement from the care home manager and the aligned GP. At the initial meeting it was evident that the care home undertook anticipatory care at the palliative and end of life stages for residents but these plans were not shared with the GP. The GP felt that she had sole responsibility for the care home residents and that sometimes a KIS was completed but sometimes not, that she had no particular system and that she sometimes overlooked completing the ACP-KIS due to workload pressures. During the initial discussion with the GP and care home

manager it was evident that as a resident started to enter the end of life phase of care both the GP and the care home staff made plans and put things in place however they both realized that they did not plan together or share their plans with each other.

As part of the support offered, the ACP Lead Facilitator delivered KIS IT training to two of the GP Practice administration staff. They established a system within the GP Practice whereby the administration staff initiated the KIS from the details on the New Resident Information form¹⁶ (Appendix 1), they then passed it on to the GP to complete the clinical information and record the resident's wishes from the ACQ onto the KIS in the special notes section.

Care Home 4:

A family owned privately run care home in an adapted large house for female-only residents only.

There was very positive engagement from the care home officer in charge and her team of senior carers. The aligned GP already had created detailed KISs for almost all the residents bar one new resident. The existing KISs were detailed, well written, with good quality information but the care home staff were not aware of their existence and did not have a copy of them.

Case study

A Senior Carer reflected that when one very frail resident deteriorated, the staff had a conversation with the resident's family using the 'ACQ for relatives' (the resident was at this stage unable to participate in a discussion). The family did not wish their mother to be admitted to hospital but to be cared for and die in her home. The completed ACQ was given to the GP to then record on the KIS. The resident subsequently deteriorated guite guickly and the GP did not have time to record and return the printed copy of the ACP-KIS. A GP from the Lothian Unscheduled Care Service (LUCS) attended during out-of-hours and he initially wished to admit the resident to hospital. Although the family's wishes were not yet recorded on the KIS, the staff were able to confidently communicate the family's wishes to the GP. This had been facilitated by their recent conversation with the family and the confidence and skills that the training had given them. The learning and conclusions for the staff and the project team from this scenario was that they would keep a copy of the completed ACQ should it be required before the printed ACP-KIS is returned. The positive outcome on this occasion further enhanced the staffs' confidence in not only having thinking ahead conversations but that also in using the ACQ resources it had

¹⁶ The New Resident Registration form has been developed throughout the duration of the ACP Improvement programme, the most recent version is now included in the '7 steps to ACP for care homes' toolkit, see Appendix 1.

helped them to appreciate the benefits of recording and sharing residents' or their families wishes.

Ongoing development of the ACQ leaflets

Ongoing development and updating of the ACQ resources took place in collaboration with the Consultant in Palliative medicine who had been involved in further development of the ACQs. The updating reflected the concurrent work being undertaken by Healthcare Improvement Scotland on ACP resource documents, which were being developed at a national level.

Discussion and Recommendations

Overall, the facilitators' experiences of engaging with care home staff in delivering this project and its final evaluation suggest it has been well received by the four care homes and their aligned GPs. Evidence from the ACP-KIS audits, staff evaluation of the training sessions and the results of the reliability tests, point to improvements in staffs' skill set, knowledge, confidence and partnership working with GPs. There is evidence from the project that embedding a systematic approach to agreeing, recording and sharing anticipatory care plans ensures that residents and/or their relatives have been given the opportunity to discuss their future care wishes and that their wishes are recorded and shared. Importantly, conversations take place at a planned time rather than when a resident's health suddenly deteriorates.

Both the quantity and quality of the ACP-KISs improved in two of the four care homes. Time constraints of the project meant that in the second two care homes it was not possible to re-audit the quantity and quality of the residents' ACP-KISs following the completion of the training and establishment of the new ACP process within the care home.

The project has enabled the testing and development of a Care Home ACP Tool Kit for Trainers and also an ACP Resource Pack for Care Homes. The latter has been shared with all the four care homes involved and the Tool Kit for Trainers has been shared with a lead community nurse to use in a care home within an Integrated Health and Social Care Partnership in Lothian. It is recommended that ACP training becomes part of core induction for all new care home staff.

Evidence suggests (from experience in one care home) that the ACQ resources should not be implemented without support and training for the care home staff otherwise there is the risk that conversations will be poorly conducted or the leaflets simply handed out to residents or family and not used as part of a supportive and sensitive conversation taking place at the right time and in the right place. It should not be viewed as a tick box exercise; the forms exist to support quality conversations.

Although the project was designed and funded to run over a 12-month period, delay in recruiting to post meant that the project ran over a 9-month period (including a period of extension), to complete on 30th June 2017. Time limitations created challenges in arranging follow up visits, providing ongoing support to consolidate knowledge, practice and improve confidence in having conversations.

It is recommended that continued support and education is required to ensure sustainability of the established system between the care home and the GP. Staff changes both within the care home and the GP practice could potentially hinder the ACP processes being followed for each new resident, underlining the importance of ACP being included in any new staff induction. Both nursing staff and care home staff described some anxiety in initiating ACP conversations, thus ongoing mentoring and support around this is vital to sustain improvement. Non-nursing staff in nursing homes expressed the fact that they did not feel confident to take on this role as it would be out with their expertise and that the nurses and senior carers would undertake ACP conversations. Experience of delivering the training sessions to more inexperienced carers however demonstrated that they also had a vital part to play in building relationships and getting to know their residents preferences and wishes.

What cannot be underestimated is the importance of changing the culture within the care-home setting, that ACP is a vital part of high quality care, that everyone has a role to play in delivering high quality ACP, and that enabling this is the best way to ensure appropriate and patient-centred care for this vulnerable group of people in accordance with their wishes.

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Dr James Marple, Primary Care Practitioner, NHS Lothian.

Sheila Steel, Associate Improvement Advisor-ACP, Health Improvement Scotland.

Hilary Gardner, Clinical Nurse Specialist, Community Palliative Care Team, Marie Curie Hospice, Edinburgh

Gill Harker & John Raez

June 2017

Phase 1 Report Appendix A:

New Resident Anticipatory Care Plan Checklist

Name:

Date commenced:

	Action	Date completed	Signature
1	Complete New Patient Registration form & give to the GP at a routine visit		
2	Resident is competent: Discuss wishes & ACQ with resident OR Resident is not competent: Discuss wishes & ACQ with relative		
3	Any uncertainty from resident/relative \rightarrow discussion with the resident's GP		
4	ACQ completed by the Care Home statf (NB Keep a copy in the resident's file)		
5	Completed ACQ given to the GP at a routine visit (GP will record residents/relative wishes on the KIS)		
6	GP at routine visit will bring printed copy of the KIS		
7	ACP/KIS filed together with the DNA CPR (if completed)		
8	ACP reviewed at 6 week review with the resident/relative/social worker		
9	ACP reviewed at 6 monthly review with resident /relative/social worker OR If there is a change in the resident's condition/ hospital admission before the 6 month review		

Notes:

If there is any change in the resident's condition the anticipatory care plan should be reviewed.

Reassure the resident/relative that they are able to change their mind about their wishes for future care at any time ~ it is their plan.

Phase 1 Report Appendix B:

SBAR (Situation, Background, Assessment, Recommendations) for Care Homes Tool

DATE: TIME:	SIGNATURE: PRINT SIGNATURE:	DO YOU HAVE THE APROPRIATE DOCUMENTATION? - The KIS ANTICIPATORY CARE PLAN	
	SEEKING HELP AND ADA GP District nurse NHS 2	-TOP-TO TOP ASSESSMENT OF PALL	
S	I am from I am calling aboutbecause I am concerned that Has fallen <u>or</u> is not well <u>or</u> is not their normal self		
В	Has been ill <u>or</u> fell since/on Their Medical history is They can normally do They are complaining of They appear		
А	I have observed they are The KIS ACP says I have spoken to them and they have said I am concerned that I have carried out a top to toe assessment if a fall	WHO DID YOU SPEAK TO?	
R	I would like some advice about Is there anything else I should do? I would like someone to come and see I think they need medical attention How long will it take to arrive or if there is no improvement when do you want us to call again?	RESULT OF CALL?	

Phase 1 Report Appendix C: Care Home KIS ACP Process Reliability Tool

GP Practice:		Care home:		
Resident's name <u>:</u>		CHI:		
Audit Questions	Yes	Νο	Comments	
New resident registration form completed and sent to GP				
ACQ completed and returned to GP				
KIS ACP completed by GP				

KIS ACP printed and given to care home

Phase 1 Report Appendix D:

Care Home Resident clinical event reflective tool for care home staff using the ACP-KIS

Care home:_____

Date of completion:_____

Resident background and presentation: Resident new to care home? Medical condition? Did the resident have a KIS ACP?

Staff assessment and actions taken: Was the cause of deterioration expected? What assessment took place? Who was this discussed with?

Outcome: If during OOHs was NHS 24 contacted? If <u>not</u> during OOHs ~ was the resident's own GP contacted? Was the resident: able to stay in the care home? Taken to hospital? Admitted to hospital?

What went well:

What didn't go well:

Any take-away learning:

Things to consider when thinking about *what went well* or *what didn't go well*, for example,

- Was the resident's KIS ACP easily accessible?
- Was the information in the KIS ACP relevant and up to date? Was it useful in helping you manage the situation? For example, were the resident's wishes were clearly documented.
- If it was necessary to contact the resident's own GP, NHS 24, Ambulance Service ~ was the information in the KIS referred to in your conversation with any of these services?

Phase 1 Report Appendix E: Audit Tool for Care Homes ACP-KIS

Patient Name:	CHI:
-	

GP Practice: _____

Care Home:

YES NO Commen	YES	S NO	Comments
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DOES THIS PATIENT HAVE A KIS?

If yes – please proceed to complete the form

2. Has the KIS been updated in the last 6 months?

3. Is there documentation of current clinical status?

4. Is there documentation of current functional status?

5. Is there documentation of next of kin details?

6. Is there a clinical management plan in the event of deterioration?

7. Is there documentation whether of CPR has been discussed/ and CPR decision

8. Is the patients preferred place of care documented?

9. Has the resident's future wishes/end of life care wishes been discussed?

Appendix 3: Phase 2 Improving Anticipatory Care Planning with 6 Care Homes and Aligned GP Practices in Edinburgh

Phase 2: Improving Anticipatory Care Planning with 6 Care Homes and Aligned GP Practices in Edinburgh

ACP Project Team:

Carrie Ho, Anticipatory Care Planning Facilitator John Raez (until December 2017), Project Support Officer Dr Andrew Mackay, GP Advisor Anticipatory Care Planning Anna Wimberley, Project Team Manager Long Term Conditions Programme Amanda Fox, Programme Manager Long Term Conditions Programme

ACP Learning Report: May 2018

Introduction and Context

Building on the success of the North East Edinburgh Care Home Anticipatory Care Planning (ACP) project, funding was secured from Edinburgh Health and Social Care Partnership's Integrated Care fund to scale learning and improvements to a further six care homes and aligned GP practices in Edinburgh. Recruitment to the project team was required and determined the project timescales: September 2017-March 2018.

Aims and Objectives

Improvement Aim

To increase the quality, quantity and access to ACP-Key Information Summaries (ACP-KIS) in 6 Care Homes in Edinburgh by March 2018

Objectives:

- Develop and test a structured approach to using the Anticipatory Care Questionnaire (ACQ)/new patient registration form and implementing the ACP flow chart in 6 care homes¹⁷
- 2. Provide guidance, teaching and support for care home staff in discussing and documenting care planning discussions with residents and families
- 3. Ensure resident's responses documented in ACP and made more widely available using the ACP-KIS
- 4. Establish a process in each of the 6 care homes to check for the presence and content of an ACP-KIS before contacting unscheduled care services

Project Approach and Methodology

GP and Care Home engagement

To ensure spread and scale of learning and improvements from phase 1 which engaged with care homes from the North East locality, a considered approach was taken to engaging with care homes and aligned GP practices across all four localities to participate in phase 2.

Meeting with: care home manager/lead, aligned GP, ACP facilitator and GP ACP Advisor

Meetings were arranged between the Care Home, GP practice and ACP project team to discuss the structured ACP approach and improvement methodology. The aim was to explain and discuss the structured ACP approach, how this would fit with

¹⁷ These ACP resources have been developed throughout the duration of the ACP Improvement programme, the most recent versions are now included in the '7 steps to ACP for care homes' toolkit, see Appendix 1.

existing ACP processes, and agree improvements to be tested between the care home and GP practice with support from the ACP project team. Time constraints and limited availability necessitated that for some partners separate discussions with the ACP project team were arranged. Acknowledging the importance of having a shared understanding and setting clear expectations of partnership working, the project team developed a Tri-party Agreement setting out the project aim, the improvement approach and the roles and responsibilities of each partner (the care home, GP practice and ACP project team).

Learning point Agreeing the detail of partnership working before ACP improvement support commences (e.g. Care Home ACP training sessions and beginning to implement the ACP pathway) secures the commitment and leadership required from all partners to successfully test and implement reliable ACP processes.

Care Home Training and Support Activity

ACP training sessions were delivered to each participating care home. A flexible approach was taken to fit in with care home rotas/schedules, wherever possible a 2-hour training session was delivered, with a further training session arranged to accommodate further staff who were not able to attend.

ACP training outcomes:

- i. Provide information about ACP to all residents, their families and close friends
- ii. Include ACP in a Care Home admission
- iii. Use the ACQ in sensitive and effective discussions
- iv. Complete ACQ/ACPs accurately and efficiently
- v. Send completed ACP information promptly to GP
- vi. Make sure all residents have an up-to-date ACP-KIS
- vii. Use KIS report in each resident's reviews, and when contacting GP, Unscheduled care, Emergency service and other services
- viii. Reduce avoidable admissions to Hospital in line with a resident's wishes as documented in their ACQ

ACP training content included:

- Ice breaker: Just imagine . . .
 If you were not able to speak tomorrow, what are the 2 most important things that you would like to tell the people looking after you?
- What is Anticipatory Care Planning?
- Benefits of ACP
- Challenges to ACP
- Care Home Residents Complex Needs
- Effective communication skills: communication is more than just words
- Anticipatory Care Information leaflets for staff, residents, families and carers
- ACP conversations: how to open an ACP conversation with residents/families/close friends, timing of conversation, talking about 'what matters' and peoples' priorities, barriers to conversations, completing the conversation
- Key information summaries, importance of key ACP content
- How and why Key information Summaries are shared with GPs on call, NHS 24, Scottish Ambulance Service and hospital staff.
- ACP pathway and process documentation: what to complete and when, how to share and where to file, when to review and update.
- The role of Care Home ACP Champions.
- National resources and information
- Local resources and information, including Effective Communication for Health: <u>http://www.ec4h.org.uk/resources/acp-in-care-homes</u>
- ACP quiz what have we learnt?

How to explain what ACP/ACQ is to residents/families/close friends



Between November 2017-February 2018 the ACP project team delivered 14 training sessions to eight care homes. This included a refresher training session for a care home involved in phase 1 of the project. One care home interested in participating in phase 2 was not able to progress after training was delivered. In total, 81 care home staff attended ACP training including: regional leads, managers, deputy Managers, team leaders, senior care workers, staff nurses and care workers.

ACP training evaluation

On completion of each training session participants were invited to complete a post training evaluation. 95% of participants felt that the training met the ACP learning outcomes and objectives. 91% of participants felt that following training they were able to describe the purpose and benefits of ACP. 88% of participants felt more confident about having a conversation with residents about their wishes and future plans, and 87% felt more confident and able to have ACP conversations with residents' families, carers or close friends.

When asked 'What would you do differently after training?' four themes emerged from the replies:

Improved confidence level

- I feel more confident asking 'difficult' questions
- I can now approach residents family with more confidence
- I feel more confident on approaching residents
- I feel more confident about approaching conversation on end of live care/wishes
- I am more able and confident to discuss issues
- I feel more confident about speaking to families

Better ACP communication skills

- I'll listen to the resident and give my team lead information if needed
- I'll have more in-depth conversations regarding ACP with residents
- I'll have better discussions regarding ACP
- I can support new staff on how to begin conversations on ACP
- I can approach the subject much more positively

Better equipped to implement ACP-KIS

- I now have an understanding on ACP so will be able to put KIS into practice
- I'll use my knowledge to further support families and residents
- I now know better the concept of ACP and I can use this knowledge to support families and residents
- I am now more able to support new staff on how to begin ACP process

Completing and updating residents' ACPs

- I will understand better how to broach the subject with families as part of the 6-month reviews
- I will review my care plans and ensure I plan ahead
- I'll review KIS/care plans with a view to using the ACQ
- I'll be able to complete the ACP with my residents

Learning point Effective training for care home staff is essential to:

- raise awareness about why ACP is important
- develop the knowledge and skills required to have and record effective ACP conversations, and
- provide practical tools to implement a reliable ACP process to give staff the confidence to act on the information recorded in an ACP-KIS when a resident's condition deteriorates.

Learning point Scheduling 2-hour training sessions around care home rotas is challenging, however training is essential to support the development of knowledge and skills required to implement the ACP process. Beginning to implement/test the ACP process before training is delivered may not lead to improved outcomes.

Learning point Delayed training session dates resulted in participating care homes having reduced time periods to test the implementation of the ACP process before the project concluded in March 2018. ACP process implementation periods ranged from 2-5 months. Evaluating the benefits of implementing the ACP process within this short timeframe is challenging, requiring the ACP team to consider approaches to continued implementation support and evaluation.

Care Home ACP Champions

Each participating care home was asked to nominate at least one ACP champion to take the lead in implementing and testing the ACP process, with ongoing support from the ACP project team. Ten ACP Champions signed up from the six care homes participating in phase 2. Additionally, two ACP Champions were identified from two of the care homes that participated in phase 1.

Learning point Embedding reliable ACP processes in care homes existing care and support systems (including induction for new staff members) is essential to mitigate against ACP approaches being adversely affected by high-staff turnover or being over reliant on individual practices. Whilst acknowledging the importance of embedding reliable ACP systems, the ACP project team also recognise the value of individuals championing ACP approaches at the early stages of implementation and testing. Providing leadership, advice and peer support helps maintain continuous

improvement momentum enabling new and innovative ACP approaches to become part of standard, daily practice.

Evaluation

Phase 2 care homes: A&E admissions and hospital admissions

Phase 2 completed in March 2018, with the last ACP training session being delivered in February 2018 before implementing and testing the ACP process. At the time of reporting (May 2018) it is too early to determine if ACP improvements have had a positive impact on reducing A&E attendances and unplanned hospital admissions. The ACP project team and the Care Home Data and Quality Improvement Group will continue to review A&E attendances and hospital admissions of residents from the 6 participating care homes.¹⁸

ACP-KIS quality audit

We continued to use the same quality audit tool developed during phase 1 to measure the quality of ACP-KIS before and after the training.¹⁹ With reference to the Scottish Government's 'KIS Best Practice Statement' we have established 7 key indicators to measure the quality of ACP-KIS for Care Home residents:

- i. Documentation of current clinical status
- ii. Documentation of current functional status
- iii. Documentation of next of kin details
- iv. Clinical management plan in the event of deterioration
- v. Documentation of whether CPR has been discussed / and CPR decision
- vi. Patients preferred place of care
- vii. Has the resident's future wishes/end of life care wishes been discussed?

¹⁸ Data became available during phase 3 of the ACP improvement programme, and is included in Appendix 6.

¹⁹ See Phase 1 Report Appendix E

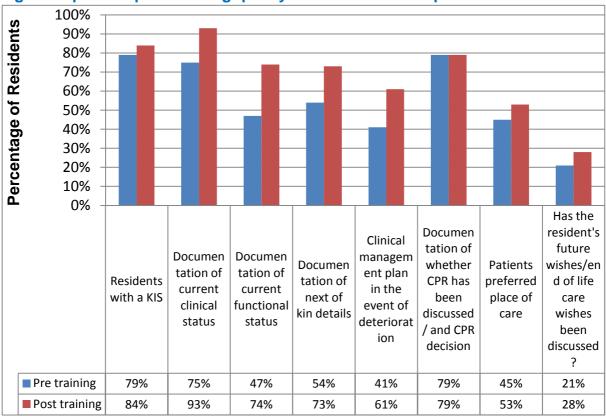


Figure 3: pre and post training quality audit of KIS for all phase 2 care homes

Figure 3 demonstrates an improvement across the quality indicators in 3-month period post training. Documentation of current functional status improved by 27% and there was a 20% increase in the number of clinical management plans in place in the event of deterioration.

Figure 4 shows the number of existing ACP-KISs updated and new ACP-KISs uploaded in the 3-month period post training. All care homes have engaged actively with their aligned GPs in implementing ACP either by editing or creating ACP-KISs.

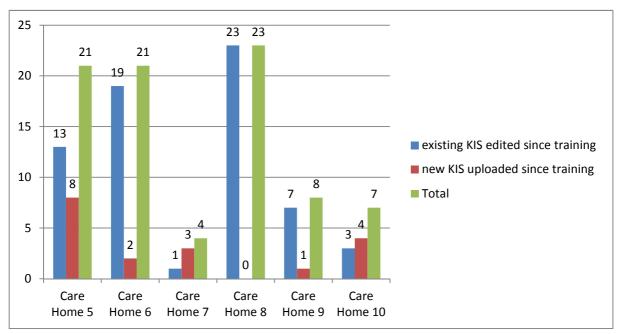


Figure 4: ACP-KISs edited and created/uploaded post training

Reflection & Support

Semi-structured interview

Semi-structure interviews were conducted in March 2018 with six Care Homes from phase 2 and two Care Homes from phase 1. The purpose of the interview was to measure:

- i. The impact on care home's practice
- ii. The implementation of the Anticipatory Care Questionnaire and the ACP pathway

Care Homes found the implementation of the ACP process and the use of Anticipatory Care Questionnaire useful and have seen a positive impact on their staff.

Team Leader: "I oversee staff in doing reviews, making sure they have read over the information that you have given us on ACP. I also did a development meeting... I have been really on board with things now, working well with the families. We don't have KIS reports for all the residents, I am in the process of looking through the files. Families now have a better understanding of ACP. It has always been an area that people shied away from in the past but now with the paper work and the guidance that we have, we are now able to approach it confidently...there is a process in place that's made a big difference." **Care Worker:** "We are looking to get a regular paper work day for myself and my colleague to sit down and go through everything [residents' care plans]... to keep it constantly updated... working with GP and get more anticipatory care planning into the care plans."

Care Home Manager: "The anticipatory care planning has always been a conversation that the Doctor had with the family...a lot of our staff felt wary about the conversation...having the knowledge of how to do it well and how to progress with an ACP has given staff more confidence. Information gathered at the first instance is a lot more detailed now."

Care Home Manager: "When we first started using the Anticipatory Care Questionnaire, it would be at six months review. And now we are completing the questionnaire sooner. So there's a change from 6 months review to as soon as possible after the admission, as soon as we can. Staff now make a point of reading the KIS."

Deputy Unit Manager: "The training has got people to think more. We have always been very person centred but there is a bit more now about what's important to people....we focus more on having a better quality of life and a better death. With the training I feel a lot better about my knowledge and I am now encouraging my staff to look at the KIS report...we have to do this together. The ACP flow chart is very helpful, it's like a step by step guide. It helps everybody, myself and the care staff. The ACP tool has a good lay out, it is simple to use."

Care Home Manager: "We went back to talk to the resident on Anticipatory Care Planning again, it was not easy...we talked about it again and the tool helped. It did help, it helps tremendously. I don't think we would get anywhere without using it."

Care Home staff also shared their experience of using the KIS to avoid unplanned admissions to hospital.

Care Worker: "I managed to get a Doctor to come out to see one of our residents because it states on the KIS report that she is not for hospital admission. I spoke to the Out of Hours service with the information documented on the KIS...Doctor came rather than take her to hospital by an ambulance and waiting for hours in A&E. It worked out the best for her....it was very beneficial for her, for us and her family. Her family was relieved that they didn't have to go to the hospital as well."

Care Home Manager: "KIS help preventing any unnecessary admissions to hospital...we are now able to say...the family and the resident wish to remain in the care home...that's what written on the KIS."

Deputy Manager: "The resident was discharged from the hospital and we updated her KIS. She was very keen that she does not want to be admitted to hospital again, she would like to be kept comfortable in the care home. A few weeks later, she

suffered from a chest infection. We kept her here and had antibiotics....and she recovered and is now more or less her usual self."

Team Leader: "The new resident has made it clear that he does not want to go to the hospital. When we went over the forms with him and his daughter, they were both delighted that this is documented. Other family members also commented that it is good that mum/dad is in a unit that people know them rather than going to a hospital where they don't know anybody."

Improving and developing the care home ACP toolkit²⁰

Let's think ahead

7 Steps to Anticipatory Care Planning for Care Home Staff 'Let's think ahead – 7 steps to Anticipatory Care Planning for Care Home Staff' is a care home ACP toolkit resource developed during phase 2. It is a step-by-step guide to support care home staff from introducing ACP to completing ACP and having a systematic approach to using ACP-KIS. All 10 care homes engaged in the improvement programme to date are using the toolkit which includes:

- i. Check list
- ii. Let's think ahead leaflet
- iii. Thinking about ACP in a Care Home for staff
- iv. Nursing/Care Home Patient Registration form
- v. ACP: information for care home residents
- vi. ACP: information for relatives and close friends
- vii. ACP flow chart

Care staff have provided positive feedback, commenting that the toolkit is simple to use and improves care planning and reviews. Care homes can now use the ACP

²⁰ The ACP toolkit has been developed throughout the duration of the ACP Improvement programme, the most recent version is the '7 steps to ACP for care homes' toolkit, see Appendix 1

toolkit as part of staff induction to introduce the importance of ACP and ensure all staff understands how to implement the ACP pathway.

A 'Let's think ahead' leaflet²¹ 'has been developed for Care Home residents/family/carers and close friends. Care staff have found this leaflet very helpful in setting the scene for ACP discussions, helping to facilitate conversations about thinking and planning ahead.

Learning point The 7 steps ACP toolkit is in its early stages of implementation and will be continuously improved by all practitioners using it, with support provided by the ACP team. It provides a tailored care home ACP process and accessible implementation tools to support care homes and GP practices deliver a structured ACP approach and meet the requirements set out by the Care Inspectorate, Scottish Care and Healthcare Improvement Scotland.

Recommendations

Working in partnership with an additional six care homes and aligned GP practices during phase 2 has enabled ACP improvements to be scaled across Edinburgh. Important learning and improvement has been shared across the 10 care homes that have engaged to date with positive outcomes for care home residents. It is recommended that additional care homes and GP practices are afforded the opportunity to benefit from ACP improvement support. The ACP team should consider learning gained to date to:

- design a structured project management and ACP quality improvement support package and secure funding to support an additional 18 care homes and aligned GP practices across Edinburgh
- further develop the training package for care home staff to develop ACP knowledge and skills
- support the development and implementation of reliable ACP processes through continuously improving the content and application of the '7 steps to ACP for care home staff'
- design approaches to measuring impact of the care home ACP improvement approach, facilitating reflective learning and data collection/analysis
- host a care home ACP champion network to sharing learning and provide peer support.

²¹ The 'Let's think ahead' leaflet has been developed throughout the duration of the ACP Improvement programme, the most recent version is included in the '7 steps to ACP for care homes' toolkit, see Appendix 1.

Appendix 4: Phase 3 - ACP project team

Carrie Ho, Anticipatory Care Planning Facilitator Amanda Fox, Programme Manager, Long Term Conditions Programme Dr Andrew Mackay, GP Advisor Anticipatory Care Planning Tracey Rogers, Project Support Manager Anna Wimberley, Project Team Manager, Long Term Conditions Programme

Appendix 5: Summary of recommendations and learning points

Recommendations

- Develop a care home ACP improvement and support package to support participating care homes to sustain improvements. With support from national partners (Healthcare Improvement Scotland, Care Inspectorate, Scottish Care) develop a scalable ACP improvement model which can be shared and tested across Scotland.
- 2. Undertake an economic evaluation of improving ACP with participating care homes to ascertain the cost saving of a 56% reduction in avoidable hospital admissions, and determine how the allocation of resources can achieve the greatest benefit.
- 3. Continue to work in partnership with health, health and social care, and voluntary teams to improve ACP for people living with long term conditions at home, improving the ACP community pathway. Work towards individuals having current copies of their ACP-KIS at home to inform shared decisions about their care and treatment.
- 4. Facilitate an ACP champions' network broadening out from care homes to include health and social care and voluntary teams involved in improving ACP.
- 5. Working with the Scottish Health Council review feedback from participating care homes' residents and families, and engage with citizens to understand the level of ACP awareness and utilisation among the general public. Co-produce resources to empower people to start ACP conversations early, enabling them to make informed choices about their care and support.

Summary of learning points

Each section of this report highlights points for shared learning to improve ACP.

Project approach and methodology

Learning point 1 Facilitating a discussion between partners about the ACP improvement approach, roles, responsibilities, specific commitments and support available is essential to the subsequent success of participating in the programme. A clearly defined agreement signed by all parties is required before participation in the care home ACP improvement programme can commence.

ACP training evaluation

Learning point 2 Defining the learning objects for different skill levels and tailoring the training accordingly enables each team member to understand their ACP role and encourages a focus on how non-trained staff can facilitate ACP discussions.

Learning point 3 Contracting the 2-hour training session to 1 hour is challenging from a training perspective and not the optimum approach, however in some cases this may be necessary to ensure all relevant staff are able to benefit from ACP training.

Care home ACP champions

Learning point 4 Local and lateral leadership through care home champions was a critical success factor of the ACP improvement programme. Providing a virtual care home ACP champion network in partnership with St Columba's Hospice and Project ECHO enabled shared learning, reflective practice and peer support which would otherwise not have been possible given the demands on care home staff time.

Improvement measures

Learning point 5 A blended approach of facilitating reflective learning and informing improvement discussions with locally owned real-time data enabled care home teams and GPs to test and implement ACP improvements. Care home teams and GPs significantly improved personal and clinical outcomes for care homes residents through implementing and continuously improving the '7 steps to ACP' toolkit.

Improving ACP with Edinburgh health and social care teams

Learning point 6 People living with long term conditions or complex health needs at home may be in regular contact with multiple health and social care teams. Agreeing community care criteria to share in ACP-KISs provides immediate access to information that could improve care and treatment in the event of an acute deterioration. Taking forward tests of change will demonstrate if this approach to improving ACP can lead to improved personal and clinical outcomes and prevent unwanted or unnecessary hospital admissions.

Learning point 7 Health and social care teams' capacity to design, test and evaluate ACP improvements can be limited due to demands of delivering services. Providing a structured quality improvement approach and improvement support can help, as can having a shared understanding of how ACP enhances daily practice.

Improving ACP with acute care teams

Learning point 8 Improvements to ACP pathways are successful when the ACP information shared is relevant, succinct and provided to GP practices in a format that is easily transferrable to GP digital clinical systems.

Learning point 9 Different teams and professions can make assumptions about the level of ACP information that has been shared or can be accessed across the integrated system. Having an agreed ACP pathway across the service interface provides access to important information in the absence of integrated/accessible digital systems.

Improving ACP with GP practice teams

Learning point 10 Without the support and commitment of GP practice teams ACP-KIS improvements would not be possible. The role of the ACP GP Advisor is critical to the success of GP engagement and buy-in, providing peer to peer support and guidance. GP practice managers and admin teams are the experts in creating and updating ACP-KISs and need to be at the centre of collaborative approaches to improving ACP.

Learning point 11 ACP-KIS system enablers mitigate against disengagement from collective efforts to improve ACP. There are national developments in designing a shared digital platform with the potential to provide a system that is fit for purpose; in the meantime it is important to support local collaborations to design ACP pathways that are practical, efficient and effective.

ACP public road shows

Learning point 12 ACP is not a commonly known or understood term among the public and there are many practitioners working within health and social care who do not yet have a working knowledge of ACP. There is a need to continue to promote ACP at a both a local level and national level through engagement, partnership working and aligning with health and social care priorities.

Appendix 6: Phase 1 and Phase 2 care homes retrospective analysis

- A&E attendances
- unplanned admissions to hospital
- place of death

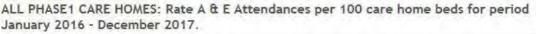
A Care Home Data and Quality Improvement Group was established during phase 1 to review care home quality improvement data. Data on admissions to hospital and A&E attendances by care home residents were available on completion of phase 1, however there were concerns about the quality of these data. Lothian Analytical Services carried out a two year survey of data quality and found considerable variation between the data sources. Having carried out further quality assurance checks the Care home Data and Quality Improvement Group is satisfied the Historic CHI data source provides reliable denominator data for rates of Care Home admissions to A&E and /or Hospital per 100 Care Home beds.

Phase 1 completed in June 2017, when completing the evaluation report it was too early to determine if ACP improvements had had a positive impact on reducing A&E attendances and unplanned hospital admissions for the 4 participating care homes. Lothian Analytical Services has supported the ACP team to review A&E attendance and unplanned admissions data during January 2016 – December 2017.

Phase 1 care home residents: A&E attendances

There was a reduction in A&E attendances from phase 1 care homes when comparing 2016 and 2017 data. Phase 1 completed in June 2017, figure 1 shows A&E attendances from all 4 care homes during 2016 and 2017.

Appendix 4: Figure 1



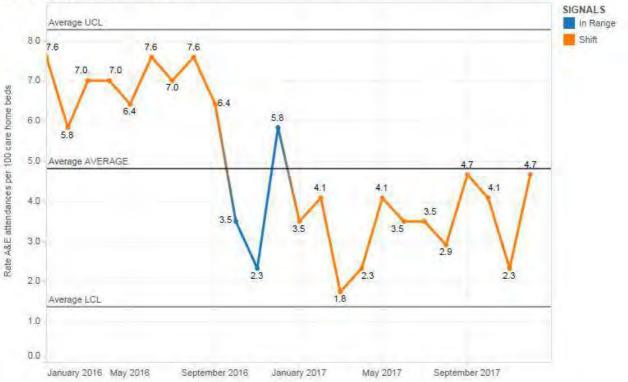


Figure 1 shows there is statistically significant reduction in the A&E attendance rate, with the median rate of A&E attendances per 100 care home beds reducing from 6.2 during 2016 to 3.5 during 2017.

Phase 1 care home residents: unplanned admissions to hospital

There was a reduction in unplanned admissions to hospital from phase 1 care homes when comparing 2016 and 2017 data. Phase 1 completed in June 2017, figure 2 shows unplanned admissions from all 4 care homes during 2016 and 2017.

Appendix 4: Figure 2

ALL PHASE1 CARE HOMES: Rate Unplanned IP admissions per 100 care home beds for period January 2016 - December 2017.

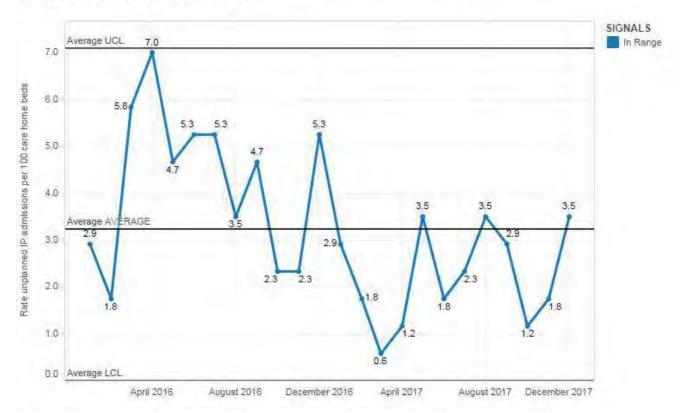


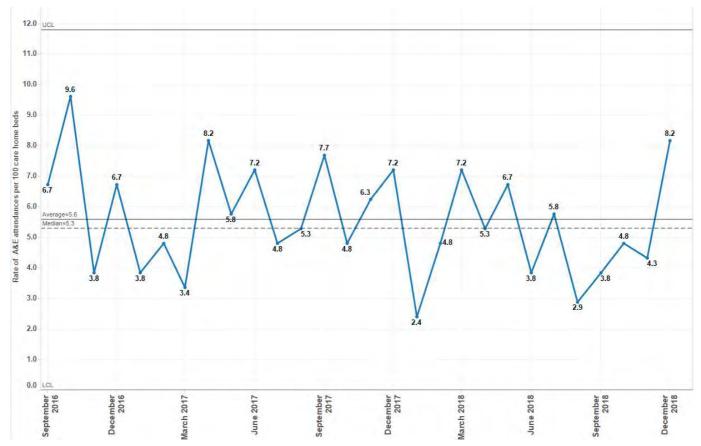
Figure 2 shows a reduction in the unplanned admission rate, with the median rate of unplanned admissions per 100 care home beds reducing from 4.7 during 2016 to 2 during 2017.

Phase 2 A&E attendances and unplanned admissions to hospital

Phase 2 completed in March 2018, with the last ACP training session being delivered in February 2018. When completing the phase 2 project report (May 2018) it was too early to determine if ACP improvements had had a positive impact on reducing A&E attendances and unplanned hospital admissions for the 6 participating care homes. Lothian Analytical Services has supported the ACP team to review A&E attendance and unplanned admissions data during September 16 – December 2018 (at the time of reporting, May 2019, data are not yet available post December 18).

Phase 2 care home residents: A&E attendances

Figure 3 shows A&E attendances from all 6 phase 2 care homes from September 16 – December 2018.

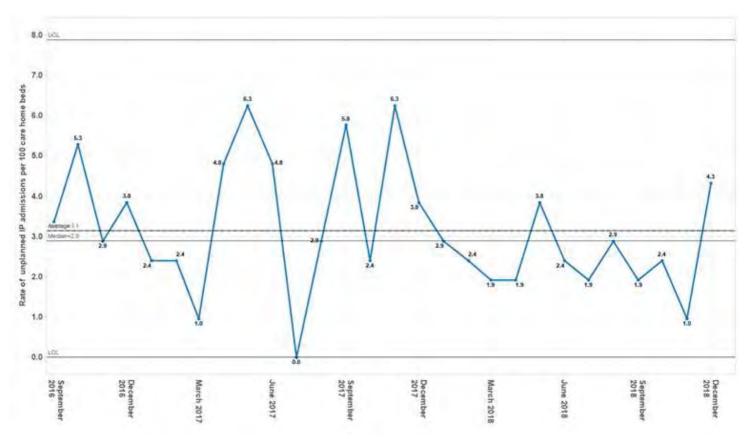


Appendix 4: Figure 3 A&E attendances per 100 care home beds phase 2 care homes, September 16 – December 19

With ACP training completing in February 2018, implementing the ACP process would be expected to begin to have a positive impact during April-December 2018. Comparing the improvement period, April-December 2018, with the same months in the previous year as a baseline, April-December 2017, the median rate of A&E attendances reduced from 6.3 to 4.8 per 100 care home beds.

Phase 2 care home residents: unplanned admissions to hospital

Figure 4 shows unplanned admissions to hospital from all 6 phase 2 care homes from September 16–December 2018.



Appendix 4: Figure 4 Unplanned admissions to hospital per 100 care home beds phase 2 care homes September 16 – December 18

Phase 1 care homes

Phase 1: comparison of places of death for care home residents in 4 care homes from January 2015 to December 2018

	2015	2016	2017	2018
Care home	33	58	46	55
Other setting	9	15	12	12
% Died in care homes	78.6%	79.5%	79.3%	82.1%

Phase 1 completed in June 2017. The majority of residents who died between 2015-2018 died in their care home, with a 3.5% increase of deaths in care homes over the period.

Phase 2 care homes

Phase 2: comparison of places of death for care home residents in 6 care homes from January 2015 to December 2018

	2015	2016	2017	2018
Care home	30	60	39	40
Other settings	11	27	15	13
% Died in care homes	73.2%	69.0%	72.2%	75.5%

Phase 2 completed in March 2018. The majority of residents who died between 2015-2018 died in their care home, with a 2.3% increase of deaths in care homes over the period. When comparing the baseline year, 2017, with the improvement year, 2018, there is a 3.3% increase in deaths within care homes.

Appendix 7: Anticipatory Care Planning Reflective Learning Summary

Anticipatory Care Planning (ACP) in Edinburgh Care Homes and GP Practices: Reflective Session Summary Report

Learning Cycle:

Care Home:

Date completed:

Attended by:

What went well - successes

What did not go well

What could you/will you do differently

Summary

Follow-up support/actions

E.g.

- Frequency of contact
- Timescale between each subsequent reflective session
- Method of communication email / face-to-face
- Ongoing support from ACP team offered.

Appendix 8: Anticipatory Care Planning Process Measure Form

Complete in the 6th week of each learning cycle, the ACP team will help you complete this form, please contact

anticipatorycareplanning@nhslothian.scot.nhs.uk

Care Home:	Care Home Manager:	ACP Champion:
GP practice:	Lead GP:	
Reporting period:	Reflective L	earning cycle number:
Completed by:	Date compl	eted:
To be completed by Care H	ome Manager	
a) Number of residents in	care home	
b) Number of new residen	ts	
c) Number of residents de	ceased	
d) Number of contacts with condition significantly d	n out of hours/999/GP when a re eteriorates	esident's
e) Number of A&E attenda	inces	
f) Number of hospital adm	issions	
To be completed by ACP C	hampion	
g) Number of New Patient	Registration forms completed a	and given to GP
h) Number of ACQs comp	leted and given to GP	
i) Number of ACP-KIS rep	ports and DNACPR forms filed t	ogether
	oorts used when contacting out ition significantly deteriorates	of hours/999/GP
 k) i. Number of resident cycle 	t reviews (see ACP pathway) du	iring learning
	S reports used at reviews	
I) Number of KIS reports	provided by GP	

GP comments and reflections:

Appendix 9: Anticipatory Care Planning Care Home Case Studies

Learning

- ACP training identified for care home staff.
- Care home staff should always refer to KIS before calling 999.
- Ambulance crew can ask for KIS hard copy upon arrival at care home.

Background

Care home resident collapsed in the care home. Care Home staff called 999 immediately without referring to KIS. Ambulance crew arrived and the resident was taken to hospital. Their KIS stated clearly 'do not admit resident to hospital, keep resident comfortable in care home. Treat symptoms, relieve pain and care for in the care home.'

How things progressed

Resident had a cardiac arrest on the way to the A&E department, resident had DNACPR in place. No CPR was performed. A&E doctor could not issue a death certificate because the resident died before arrival.

Learning

- Care home staff successfully made use of the KIS when contacting NHS 24.
- The resident was kept comfortable in the care home and a distressing situation was avoided.

Background

A care home resident had a fall with a significant bump to the head. Care home staff checked observations which were fine and responsive. The protocol for the head injury is to send the resident to A&E department for a check up. However, the KIS stated clearly that admission to hospital and attending the A&E department would be very distressing and so should be avoided.

How things progressed

- Care home staff contacted NHS 24, asking for a doctor to visit the care home, making reference to the resident's KIS. During the wait, the resident was made comfortable and reassured in the care home, while continuing observations on the resident.
- The out of hours doctor assessed the resident and it was agreed A&E attendance was not required.
- The family was informed of the incident and management of this event and were happy with the communications and rationale.

Learning

- ACP/KIS updated after hospital admission.
- Resident's preference was upheld.
- Resident stayed in the care home for treatment avoiding a distressing situation and reducing avoidable admission.

Background

- 80 yr old care home resident was admitted to hospital due to a chest infection.
- The resident was discharged quickly as they did not tolerate hospital admission.
- Care home staff therefore decided to review the resident's ACP with family members after admission. The family changed the preference from sending their loved one to hospital, to keeping the resident comfortable, treating any pain and symptoms in care home.

How things progressed

- A few weeks later, the resident had another chest infection, a very bad one.
- Care home staff and GP followed the ACP, antibiotics and ACP medications were prescribed. The resident recovered following the course of antibiotics.

Learning

- Care home staff referred to the special note and had a detailed discussion with ambulance crew on the management plan for acute deterioration.
- Despite the resident's preference unsure on hospital transfer for IV antibiotics, a clinical judgement to override the management plan on ACP was appropriate.
- Care home staff to discuss with the resident on ACP using the anticipatory care questions on review. The management plan for sudden deterioration, IV antibiotics and not eating and drinking in the anticipatory care questions are now a lot clearer to follow. This will help better inform all health professionals in making a clinical decision on escalation of care for acute deterioration.

Background

A Care home resident has a long term catheter in sit. The resident is able to communicate with others. Staff changed the resident's catheter and at the end of the procedure the resident became 'shaky'. Staff asked the resident if they were in pain the resident said they were not. Staff took observations, and found they were presenting with a raised temperature, blood pressure of 190/100 and a fast heart rate.

How things progressed

Staff read the KIS – special note before attempting NHS 24. The KIS stated 'Unsure about hospital transfer should IV antibiotics be required'. However, the line was busy and the resident became very agitated so staff called 999 instead. The Ambulance crew arrived, did an ECG, took observations again. The resident's temperature was 40°c and their blood pressure had dropped. Ambulance crew suspected the resident might have been suffering from a sepsis.

Staff and ambulance crew referred to the special note on acute deterioration management plan and they all felt the resident required hospital admission.

As a result the resident was admitted to hospital for IV antibiotics to treat urosepsis.

Learning

- ACP has empowered care home staff in engaging discussions with GP on arrangement of care
- Everyone was involved in the escalation of care, the decision was a shared decision based on realistic medicine and person-centred care.
- ACP can facilitate avoidable admission.

Background

Resident has lived in the care home since 2011. Resident has dementia and their functional status is mobile. Care home staff had discussions with the resident and family member on management of care, however no plan at the time was documented on KIS.

How things progressed

- The resident took ill so care home staff contacted the OOH GP for an assessment.
- Duty GP suggested sending the resident to the A&E dept for further assessment.
- Care home staff had good discussions with the resident and family member on their preferences on escalation of care. The care home staff had a real sense of what would be in the best interest of the resident with reference to person-centred care. The resident was very frail and would not cope with an ambulance transfer to hospital, waiting on a hospital trolley to be assessed in what can be busy, unsettling and distressing environment for the resident.
- Care home staff managed to discuss with the duty GP alternative arrangements with a realistic approach. The Lead GP made contact with the Hospital at Home service for further assessment.
- The Hospital at Home service assessed the resident and worked with the Care Home closely on the treatment providing huge support to the care home and resident.
- The resident fully recovered following this intervention.

Learning

• The Anticipatory Care Planning Questions will help residents/patient and their family to make an informed choice on how to escalate care should there be deterioration of health. For example:

Anticipatory Care Planning Question 2

If you had a serious infection that was not improving with antibiotic tablets or syrup, what do you think you would like to happen?

6	a)	Keep you comfortable, clinically assess you, treat any pain or other symptoms, and care for you in your care home.	
k)	Contact a family member/ close friend, if possible, to help decide whether to send you to hospital, instead of dialling 999 for an ambulance.	
C	c)	Send you to hospital for tests and treatments such as a drip, and other treatment given into a vein.	

ACPQ offers the possibility of transferring patient back to the care home for end of life care

- if patient has indicated preferred place of death and care is a care home
- with a discussion with care home and family
- The resident had stayed in the care home for 4 years and therefore ACP questions could have been discussed at reviews following any changes to health and care needs.

Background

- 71 yr old male care home resident living in care home for the last 4 years
- Learning difficulty, ex-smoker, previous alcohol dependence, schizophrenic
- Mobile and independent on daily activities
- Usually able to communicate clearly
- KIS with following information:
 - Special Note recorded on 04.05.2018 learning disability, anxiety, low mood
 - Resuscitation Status recorded on 30.08.2018 not for resuscitation
 - Anticipatory Care Plan agreed on 23.03.2016 schizophrenic patient, learning disability, no current behavioural issues, on depot

How things progressed

- The resident had a chest infection and was taking antibiotics for 5 days prior to hospital admission.
- The resident became very unwell with increased shortness of breath and was unable to communicate as usual.
- The GP assessed the patient and arranged a routine ambulance for admission.
- Resident was assessed by doctors in the hospital with an impression of Obstructive uropathy - ? cause for obstruction, Sepsis - ? source and Frail
- Investigations carried out, IV fluids and IV antibiotics were given as well as catheterisation to monitor urine output.
- The doctor explained to the family that the resident's kidneys were severely impaired causing urinary retention. The resident was very frail and would be reassessed the next day during the ward rounds.
- The resident's condition further deteriorated: refusal to eat; requiring personal care in bed; they became agitated; and was passing a very small amount of urine.
- The doctor discussed with patient's family that it would not be in the best interest of the patient to continue with active treatments, investigations or monitoring. An agreement was made to keep the patient comfortable with anticipatory care medications prescribed
- Nursing staff kept the patient comfortable with anticipatory medications and personal care, family members visited him regularly and were informed on his condition by phone
- Patient passed away in hospital after 4 days.

Learning

- The Care Home Manager will forward resident details to the ACP Facilitator to liaise with the GP and Practice on arranging KIS hard copies for the care home
- Refer to KIS/special note on clinical management plan on deterioration as per ACP in Care Home training
- Liaise with ACP Facilitator on residents that do not have KIS hard copies
- Follow '7 steps to Anticipatory Care Planning for Care Home Staff' on management of deterioration

Background

- After taking a residents' vital signs, the staff nurse decided to escalate care by calling 999
- No reference was made to KIS/special note on the clinical management plan when the resident's condition deteriorated
- It was felt the clinical decision making skill on escalation of care for this episode should not be influenced by the clinical management plan from KIS/special notes.
- The Care Home Staff Nurse had made contact with the resident's family/NOK on escalation of care, i.e. taken to hospital for further assessment, information on KIS/special note would not have been helpful on escalation of care because the son had changed the preference
- The Care Home Staff Nurse felt that pressure was put on her because the resident had passed away in hospital.

How things progressed

Resident was taken to the A&E department then admitted to the ward but passed away a day later.

Whilst the ACP/KIS stated that the patient was to remain in the care home and was not to have further hospital admissions the family/NOK had changed their mind and was keen for hospital management when the residents' health deteriorated. The GP agreed that an admission was unavoidable (though perhaps not in the resident's best interest, which is more apparent still with hindsight). It was felt that the nurse who was involved with this incident managed the patient appropriately given the family's wishes.

Learning

• It would be beneficial for care homes to understand how the NHS call handler triages sepsis cases so that care homes can communicate with the call handler effectively on a shared decision regarding escalation of care.

Background

- Care home resident with dementia has a recurrent chest infection and COPD
- Resident has also been on oral antibiotics for a UTI.

How things progressed

- Resident deteriorated over 5 days and was no longer communicating, nor accepting oral tablets / fluids / food. Temp was 38.4°C with a respiration rate of 25 in the morning
- The Care Home Staff Nurse called NHS 24 asking for an OOHs Doctor assessment, but was instead diverted to the ambulance service for questionable sepsis
- The Care Home Staff Nurse discussed with the NHS 24 call handler that the resident's conditions did not require an urgent ambulance call, and that an OOHs Doctor assessment would be more appropriate
- The resident was taken to the A&E dept, assessed by a Doctor and was discharged back to the care home for palliative care with anticipatory medicine prescribed
- The A&E Doctor spoke to the resident's family member on the management plan. The family member believed that the resident should not have been taken to hospital. The family member met with nursing home staff and they, as a team, had come to the agreement that:
 - the resident should not be for further hospital interventions, or IV treatment,
 - should be treated for comfort within the care home on further deterioration
- The A&E Doctor noted this conversation was echoed in the patient's last set of admission notes, "only for acute hospital admission if unavoidable (i.e. for fracture) but not for IV fluids or IV antibiotics."

Learning

• KIS/special note has specific management plan on chest infection so that everyone working with the resident has a clear guideline on escalation of care that could prevent avoidable admission due to a chest infection.

Background

- Care home resident with cognitive impairment, CVA with right sided weakness, type 2 diabetes, Ischemic Heart Disease.
- Recently admitted and discharged from hospital following a chest infection.
- Resident had a temp of 39.2°C, oxygen concentration on air 91%, complaint of right sided chest pain lasting for a few seconds on coughing. Reviewed by GP on the day before admission. The resident did not want to be admitted to hospital at the time. The GP recommended a course of antibiotics.

How things progressed

- Resident's condition deteriorated overnight with hypotension.
- Care home called 999 and the resident was taken to hospital.
- The resident was admitted to the ward for IV antibiotics and IV fluid.
- After two days of admission the resident was discharged for continued care back at the care home.
- The GP updated the KIS/special note with a specific management plan on future chest infections, "At risk of pneumonia, rapid onset and sepsis resulting in hospital admission. Therefore will keep stock of co-amox in NH for start immediately at onset of Sx of chest infection after assessment (phone or visit) by Dr."

Learning

- There is a good system in place to document and follow through escalation of care from Acute Service to Primary Care.
- Advice to GP on Immediate Discharge Letter is concise and precise.

Background

- COPD, dementia, Aortic Stenosis, Stroke.
- Progressively becoming short of breath and wheezing over last 5 days.
- Reviewed by GP for suspected exacerbation of COPD 2 days ago, Prednisolone and Antibiotic prescribed.

How things progressed

- The resident presented with severe shortness of breath and was wheezy. A Salbutamol inhaler was given back to back but without improvement. Care Home staff called 999 and the resident was taken to hospital.
- CXR showed signs of pulmonary oedema and right sided consolidation. In view of her history of severe aortic stenosis and mild MV impairment the resident was reviewed by cardiology who felt conservative management with furosemide was most appropriate. The resident improved clinically and was discharged back to the care home after 4 days of admission.
- Advice to the GP on the residents Immediate Discharge Letter:

"CHANGES TO DNACPR STATUS OR ANTICIPATORY CARE PLANNING: Consideration of escalation to Critical Care: No CPR Status: new DNACPR, discussed with daughter DNACPR form to accompany patient? Yes, discussed with daughter Preferred place of care: not discussed on this admission Additional information to consider for updating KIS? Please add new DNA CPR"

• GP updated KIS/special notes as per advice on discharge letter:

"Happy to stay in nursing home for all residents care. DNACPR done. NOK daughter - happy for all care to be done at nursing home. Not for escalation of care, not for resuscitation.

Preferred place of care and death – care home, have already documented on KIS prior to the admission."

Learning

While the clinical decision on taking the resident to the A&E department for further assessment and care reflected the appropriate level of care there were a number of improvements identified. Both the care home staff and ambulance crew felt it would be easier if the language on the KIS special notes gave clearer direction on what action should be taken to support staff in making a clinical decision on escalation of care. Whilst also accepting that not knowing what to do if hospital admission reflects the patient's own indecision.

Care home staff found the three specific questions from '7 steps to ACP' helpful in making a clinical decision on escalation of care. It would have been helpful for this patients (and other patients generally) to use the three ACP questions and have these uploaded onto KIS/Special Note. The care homes GP agreed that a vague KIS/Special note statement (see below) doesn't help in the decision making.

Hospital at home may be appropriate for this patient if a similar situation arises during their hours of work.

Background

NHS 24 phone line was busy and the Staff Nurse could not get through to a call handler. The resident became agitated so 999 was called instead whilst also referring to KIS/Special note on escalation of care.

How things progressed

On arrival to the care home the care home staff and Ambulance crew referred to KIS/Special note on escalation of care.

The language used on the KIS-special notes stated:

"Unsure about hospital transfer should IV antibiotics be required"

which they felt was too ambiguous. The resident was eventually taken to the A&E department for further assessment and care.

Learning

 Good communication from the acute service to care home and GP was important in the anticipatory care planning for this resident. The updated ACP enabled all involved in the residents care to have a clear understanding on the end of life care management.

Background

- Care home resident with cognitive impairment.
- Was seen to choke on some food around 14:00.
- Brief episode of cyanosis then improved.
- GP reviewed patient in care home advised observation.

How things progressed

- Increased shortness of breath in the evening with loud gurgling noises.
- Care home dialled 999. On attendance the paramedics recorded oxygen saturation on air 88%, improving to 98% on 15L of oxygen.
- The resident was taken to hospital.
- The resident received IV antibiotics and oxygen for Aspiration Pneumonia.
- Assessed by Speech and Language Therapist:

"Sadly, we are of the clinical opinion that patient is rather too frail (physical and cognitive) to consider other options for Clinically Assisted Nutrition - such as TPN via PICC or Central Venous Access Lines / RIG / PEG / etc."

• Patient was discharged back to the care home with advice to the residents GP on anticipatory care planning:

"Please consider updating the KIS with the following: Ideally for H@H treatment if becomes unwell again. DNACPR in situ. The daughter aware of risk of repeated aspiration and the fact that we are feeding at risk. If she deteriorates in the community, she might be suitable for involvement of community palliative care if required. ACP plan from this admission: not for RIG or PEGs, not for escalation if admitted to hospital."

- GP updated KIS/special notes according to the advice from the immediate discharge letter.
- The resident died peacefully at the care home four weeks after the discharge.

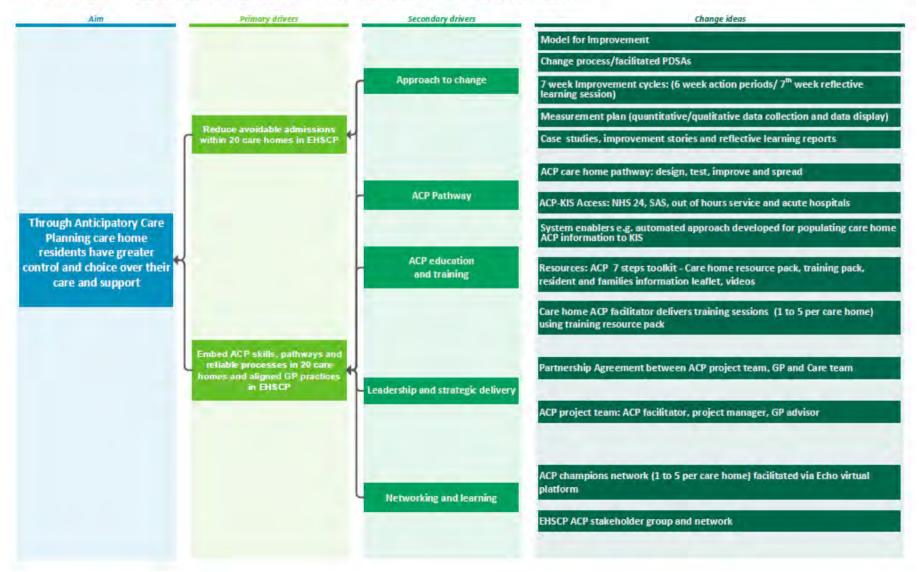
Appendix 10: Driver Diagram - Improving ACP with Care Homes and GP Practices



Improving ACP in Edinburgh Care Homes Driver Diagram

Last updated on 25 March 2019

High level change theory for Improving Anticipatory Care Planning in older peoples care homes in Edinburgh Health and Social Care Partnership (EHSCP)



Appendix 11: Measurement Plan - Improving Anticipatory Care Planning with Care Home and GP practices



Name ACP team

Date Phase 3

Area: Edinburgh Health and Social Care Partnership

Name of measure Also specify which type of measure (e.g. percentage / count / rate / variable (eg time, volume etc) / days or cases between) and what you are measuring. Indicate underneath whether it's an Outcome (O), Process (P) or Balancing (B) measure	Concept being measured and why it's important to look at this What is the purpose of this measure? i.e. what questions do you want answered in relation to your improvement efforts? What goals are you trying to achieve?	Operational definition Clear, precise definition of the measure and how it is calculated. Include numerator and denominator if it's a % or rate. What / who is included or excluded?	Data collection Who is collecting it? How often and when? Where is the data coming from? What's the sampling method and sample size (if used)?	How will the data be displayed and shared~?
Number of residents in care home	Bed occupancy	Resident list	Care Home Manager /champion shares with ACP team at	Secure file transfer

			start and end of project	
Number of new residents	New residents for ACP discussion and ACQ completion	Local count (each new resident registration/admission to care home)	Care home manager/champion on occurrence, shared with ACP team on weekly basis	ACP process measure forms
Number of residents deceased	Number of residents who have passed away for bed occupancy and place of death	Local count (on each occurrence)	Care home manager/champion on occurrence, shared with ACP team on weekly basis	ACP process measure forms
Number of New Patient Registration forms completed and given to GP	Number of re-designed New Patient Registration forms completed and given to GP to inform ACP	Local count (on occurrence of each registration form completed and given to GP)	Care home manager/champion on occurrence, shared with ACP team on weekly basis	ACP process measure forms
Number of ACQs completed and given to GP	Number of ACQs completed and given to GP to inform ACP-KIS	Local count (on occurrence of each ACQ completed and given to GP)	Care home manager/champion on occurrence, shared with ACP team on weekly basis	ACP process measure forms
Number of KIS hard copies provided by GP	Number of completed KISs printed by GP and shared with	Local count (on occurrence of each KIS hard copy given to care	Care home manager/champion on occurrence,	ACP process measure forms

	Care Homes to act on	home)	shared with ACP team on weekly basis	
Number of ACP-KIS reports and DNACPR forms filed together	Number of ACP-KIS reports and DNACPR forms filed together to be accessible to those responding to resident's deterioration	Local count (on occurrence of each DNACPR form filed with ACP-KIS)	Care home manager/champion on occurrence, shared with ACP team on weekly basis	ACP process measure forms
Quality of KIS Content	If KIS information could inform shared decision making about agreed escalation of care and residents preferences/wishes	Presence of each KIS quality indicator and ACQ information	KIS Audit pre and post training KIS review following A&E attendance/admission	Charts shared with care homes
			ACP Facilitator accesses KIS on TRAK	
Number of contacts with out-of- hours/999/GP when a resident's condition significantly deteriorates	Number of residents who become unwell referred for medical review (GP/NHS 24 clinical advisor) or 999 call made.	Local count (on occurrence of each resident deterioration when medical review is requested)	Care home manager/champion on occurrence, shared with ACP team on weekly basis	ACP process measure forms

		Business Objects daily report on A&E attendances and unplanned admissions	Lothian Analytical Service, daily BOXI report	Process measure spreadsheet
Number of ACP-KIS reports used when contacting out of hours/999/GP when a resident's condition significantly deteriorates	Number of ACP-KIS reports used when calling 999 or requesting medical review to inform shared decision making on escalation of care	Local count (following referral for medical review or calling 999 to see if KIS was accessed/used)	Care home manager/champion on occurrence, shared with ACP team on weekly basis	ACP process measure forms
Number of unplanned hospital admissions	Number of unplanned admissions to review if ACP was in place/followed and if admission was appropriate or potentially avoidable	Local count (on occurrence of each resident's unplanned admission to hospital)	Care home manager/champion on occurrence, shared with ACP team on weekly basis	ACP process measure forms
		Business Objects daily report on unplanned admissions	Lothian Analytical Service, daily BOXI report	Process measure spreadsheet
		Reflective learning on if admission was necessary or avoidable (on occurrence of each	Care home team/GP following each unplanned admission	ACP reflective learning form following acute deterioration

		unplanned admission) Reflective learning discussion on unplanned admissions during the 7 week learning cycle	Care home/GP/ACP team 7-weekly reflective learning sessions	ACP reflective learning summary report
Number of A&E attendances	Number of A&E attendances to review if ACP was in place/followed and if attendance was appropriate or potentially avoidable	Local count (on occurrence of each resident's attendance at A&E)	Care home manager/champion on occurrence	ACP process measure forms
		Business Objects daily report on A&E attendances	Lothian Analytical Service, daily BOXI report	Process measure spreadsheet
		Reflective learning discussion on A&E attendance during the 7 week learning cycle	Care home/GP/ACP team 7-weekly reflective learning sessions	ACP reflective learning summary report
Number of resident reviews (see ACP pathway) during learning cycle	Number of resident who had a review during learning cycle, to ascertain if ACP-KIS formed part of the review (to see if escalation of care is still appropriate/needs updated).	Local count (on occurrence of each resident's planned review)	Care home manager/champion on occurrence, shared with ACP team on weekly basis	ACP process measure forms

Appendix 12: ACP information leaflet

Some information that you might want to think about including in your ACP

- Your health and what might happen in the future
- Your home situation, who supports and cares for you and their contact numbers
- Contact numbers of the key professionals involved in your care



- Plans for what to do if your carer is unwell
- Name and contact details of your Next of Kin and anyone holding POA (if any)
- · Specific plans for your treatment and care

Your GP or nurse will be able to discuss what's important to you, your wishes and help make treatment plans if your health gets worse gradually or more suddenly.

With your consent, your GP can create a Key Information Summary (KIS) for you including your ACP. KIS can be read by NHS staff in the community and hospitals.

For further information please go to http://www.whatmatterstoyou.scot/ The leaflet maybe made available in a larger print, Braille or your community language. Please email <u>anticipatorycareplanning@nhslothian.scot.nhs.uk</u>

Layout & Readability Reviewed by NHSL Patient and Carer Information Team For Review: Feb2022 V 1.0 Feb 2019 what matters to you?

Let's think ahead

Information about anticipatory care planning

It's a good idea to plan and think ahead

VOCAL can provide support to create an ACP for you and/or the person you care for.

2 0131 622 6666

Working together for a caring, healthier, safer Edinburgh



Introduction

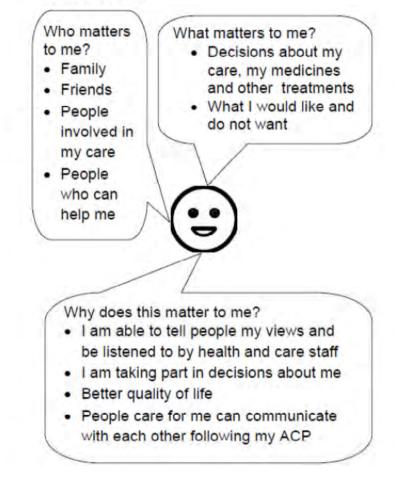
What is Anticipatory Care Planning?

'Anticipatory' care planning (ACP) means thinking and planning ahead and understanding what is happening with your health and care.

Why put a plan in place?

No one knows when their health and care needs may change. Planning ahead can help you have more control and choice over your care and support.

Please remember to tell the staff looking after you and your GP practice if you have chosen someone to have a *Power* of Attorney (POA) for you. If you are creating an ACP, you might want to think about:



Appendix 13: ACP Carer Document developed with VOCAL

Dear Dr

I have been thinking ahead about my health and health care needs. I would like the following information to be included in my Key Information Summary (KIS). I am aware that this information will be shared with the emergency care services such as NHS24, ambulance control, out of hours GP services and the hospitals, and I give my consent for this to happen.

Name:	D.O.B.:
Signature:	
Date given to GP:	
1a.Next of Kin	
Name:	Relationship:
Contact details:	
1b.Power of Attorney	Yes/No
Name: Contact details:	Relationship:
2. I need help with:	
Washing & dressing	Yes/No
Eating & drinking	Yes/No
Walking	Yes/No Please specify:
Communication	Yes/No Please specify:

3.	Μv	carer's	details
••			

Name:	Relationship:
Contact details:	

4.	l am	а	carer	for

Name:	Relationship:
Contact details:	

5. Key health and social care professionals involved in my care

Name:	Job title:
Contact details:	
Name:	Job title:

Contact of	details:
------------	----------

Name:

Job title:

6a. What is important to me should I become very unwell

6b. Anything that I would like or don't want for me should I become very unwell

6c. My preferred place of care should I become very unwell

6d. My view on hospital admission if my health deteriorates suddenly

6. I have Advance Directive or Statement Yes/No

If yes, who has a copy?

7. Any other Information?

Appendix 14: ACP-KIS guide for GP practices: EMIS & VISION users



KIS-ing with Confidence! A guide for EMIS users...

- Choose a patient that you feel would benefit clinically from having their medical info shared with emergency healthcare staff in the form of an anticipatory care plan. SPARRA/HHG/Frailty Index lists can help with this, but clinical judgement is most important.
- 2. Talk to the patient, and the carers/relatives if appropriate, get consent to share this info unless there are very clear indications not. Explore any specific wishes they may have in the event of deterioration.
- 3. Open up the patient record in consultation mode or medical records. Click KIS on the toolbar, or press 8 on the keyboard. This opens up the KIS screen. If you are in consultation mode all the information on the KIS will be added to an open consultation. This may be appropriate or it may clutter your consultation.
- 4. The screen opens up on the consent tab. Choose the appropriate patient consent (consent given or consent declined). If you chose one of the consent override options you must fill in the free text field on the right to provide some explanation.
- 5. At the bottom of the screen tick the box for review date and set the practice review date it is suggested this could be 1 year
- 6. You should work through each tab in turn to ensure you have added appropriate information.
- 7. You must explicitly add past medical history on the 'Current Situation' tab, the edit button on the right hand side lets you see currently active problems or you can remove this filter and see a "Full History" view, click on items that you feel are appropriate to share to add them to the KIS.
- 8. To ensure a consistent approach across health boards and to avoid confusion for clinicians reading the KIS at the other end, current advice is now to enter all free-text information in the special notes tab of the KIS screen rather than in the ACP box. The special notes box will default to "never expires" unless a specific date is set. Here clinicians can add the additional personalised patient info that isn't covered in the pre-populated data or the drop downs which you think would be useful to share with emergency users. Consider including info about
 - a. baseline functional status

- b. when and how to escalate treatment
- c. how far treatment should go
- d. any patient specific wishes.
- e. Who are the key individuals and services involved in their care and how to contact them.

Entering the date you have reviewed the KIS can be useful although on some hospital/ooh systems the date when the special notes were last edited is clear to users.

- 9. If the KIS being created is to be used as an ACP rather than for just basic special note-type information, also click on the Current Situation tab then select Has an Anticipatory Care plan from one of the dropdowns about half way down the screen (which this then adds Read code 8CMM.00 to the patient record). This also allows the practice to run specific searches for ACPs.
- 10. Once ready to go, go back to the consent tab click on "decision to send KIS" button, and then click Ok to save the KIS data to the system.
- 11. If there is red writing along the message bar at the top of the page then either the consent process has not been completed, the decision to send is not confirmed or the review date has expired.
- 12. Print off copy of ACP for all care home patients and consider for other patients too, such as those with regular carers. To print a KIS report. Access Medical Record (F11) screen, Click KIS or press 8; The Key Information Summary screen is displayed, click Report View or press R. You can elect to print without medication by clicking a bottom of the page. The KIS information is displayed in report format and then Click Print HTML Report.

For more detailed information, and patient information leaflets see http://www.ecs.scot.nhs.uk/kis



- Choose a patient that that you feel would benefit clinically from having their medical info shared with emergency healthcare staff in the form of an anticipatory care plan. SPARRA/HHG/Frailty Index lists can help with this, but clinical judgement most important.
- 2. Talk to the patient, and the carers/relatives if appropriate, get consent to share this info if at all possible. Explore any specific wishes they may have about future care in the event of deterioration.
- 3. Open up the patient record in consultation manager. Click on "list" tab and "ECS summary management" at top of list. This opens up the KIS screen
- 4. Go to "summary and consent status" (found just under patients address), click on "more" to expand up the screen; there are 3 separate sections for ECS (implied consent/opt out) and KIS and PCS (both explicit consent/opt in)
- Click on the "change" box next to "No KIS consent status recorded" and choose the appropriate option (consent given or consent declined if consent declined, choose the reason from the drop down menu and enter info in the free-text box: eg "vulnerable adult" from drop down "patient has severe dementia", unable to give consent in the free-text)
- 6. Suggest set the practice review date to 1 year (use shortcut of 1y) by clicking on the "+" to the right of "No Practice review set".
- 7. KIS will auto-populate with certain information from the Vision record eg anything with a "priority1" Read code
- 8. It is worth checking the past medical history box to ensure accuracy and also to check that any sensitive information is only shared if appropriate; do this by clicking on the "update" tab (priority 1 Read codes in the top box are all automatically included unless un-ticked; other Read coded items in the bottom box can be included if they are ticked)
- 9. To ensure a consistent approach across health boards and to avoid confusion for clinicians reading the KIS at the other end, current advice is to enter all free-text information in the special notes box at the bottom of the KIS form (which will default to "never expires" unless a specific date is set). Here clinicians can add the additional personalised patient info that isn't covered in the pre-populated data or the drop downs, that you think would be useful to share with emergency users. Consider Including info about

- baseline functional status
- when and how to escalate treatment
- how far treatment should go
- any patient specific wishes. Who are the key individuals and services involved in their care and how to contact them.
- 10. If the KIS being created is designed to be used as an ACP rather than for just basic special note-type information, also click on the "patient has ACP" box (which this then adds Read code 8CMM.00 to the patient record). This will also open up a free-text box suggest write "patient has ACP see special notes field" here. The other benefit of ensuring that this box is ticked is that practices can then run searches for ACPs specifically by Read code.
- 11. Once ready to go, click on "decision to send KIS" (found in the summary and consent status) and the KIS traffic light at the top of the form will change to green.
- 12. Print off copy of ACP for all care home patients and consider for other patients too, such as those cared for at home. Go to the top RHS of the screen where it says "report" (there is a small printer icon next to it) Click on the drop-down and select the OOH summary report this opens a screen showing which info is being sent. Click on the printer icon top LHS of the screen

For more detailed information, and patient information leaflets see http://www.ecs.scot.nhs.uk/kis

Appendix 15: ACP-KIS - frequently asked questions for primary care

What is a KIS and what is an ACP?

The Key Information Summary (KIS) is the document created in your GP software and shared with others. This might be quite simple information, such as what the key safe number is and little else. If a KIS contains information about a person's functional status, medical conditions, wishes for future treatment and contact details for relevant family and/or agencies involved in their care this will constitute an Anticipatory Care Plan (ACP). Generally, if the information contained in a KIS is likely to meaningfully influence a person's management it would qualify as an ACP.

Can our hospital colleagues see the KIS?

Yes they can! There are two routes for information from the KIS to be seen on TRAK. The full version can be seen but KIS information is often viewed in a brief form through the Emergency Care Summary. This also includes prescribing information so is very frequently accessed for hospital admissions. This includes the KIS 'Special Notes' box but not many of the others. This is one of the reasons why putting the patient information in the 'Special Notes' is generally encouraged.

Can the ambulance service see the KIS?

Yes, but it is not entirely straightforward to do so and viewing rates have generally been quite low. There are programmes ongoing to try to address this.

What will happen to the KIS when someone leaves the practice?

There is no current mechanism for KIS transfers between practices so when a person moves practice their KIS will go blank. This is a source of intense frustration to colleagues in secondary care as well as to us. We therefore encourage all in primary care to ensure that the KIS is copied to Docman prior to a patient leaving.

How will the hospital/out of hours know the KIS is up to date?

It is possible to see on TRAK and Adastra when a KIS has last been edited. However, it is not possible for them to see the 'Special Notes Review Date'. That is just visible on Vision/EMIS. Therefore if you review a KIS it is helpful for you to edit it in some way, even if that is just adding another full-stop.

Will things I code in Vision or EMIS appear on the KIS automatically?

Yes for major codes on Vision but not for EMIS. These need to be manually added.

Are there specific codes I should use when creating a KIS?

The Read code 'Not for Resuscitation' is visible on the KIS but not on ECS. Therefore it is helpful to code 'Not for Resuscitation Form in place' instead.

9W2 'Power of attorney held' is automatically imported into a KIS. 'Power of attorney' is not.

Appendix 16: ACP-KIS compatible Microsoft Office Word template & ACP Carer Document

INTRUCTIONS:

If you wish a patient to have information added to their existing Key Information Summary (KIS), or have a new KIS created, please use this template to share the information with the patient's GP. This template may also be formally incorporated into a discharge letter template.

The KIS can only be created within the GP surgery, so this form should be completed electronically by the clinician and then **emailed** to the GP practice clinical mailbox. Please **do not** post the forms as this does not allow information to be cut and paste into a KIS. **"Information to be cut and pasted to patient's KIS"** should be the subject of the email.

The full list of email addresses is located on the intranet (access healthcare A-Z, GP clinical email addresses, or use link below)

http://intranet.lothian.scot.nhs.uk/Directory/GPClinicalEmailAddresses

Please note that relevant **past medical history**, **medications**, and **allergies** will be automatically "pulled" from the GP record when this information is transferred to KIS therefore is <u>not required</u> to be separately recorded on this form.

There are five sections on this form that need to be completed:

- **1.** Your details
- 2. Patient details
- **3.** Special Note The freetext information box which constitutes the most useful section of the KIS
- 4. DNACPR section (if applicable)
- 5. Consent

1. YOUR DETAILS:

Name:

Role:

Date:

2. PATIENT DETAILS:

Name:

CHI:

Address:

3. SPECIAL NOTES BOX

This is the section where clinicians can add the bulk of the information which constitutes the KIS (such as an anticipatory care plan). Aim to be concise and specific about which information is included here, as it can be viewed by clinicians across NHS Scotland. KIS is designed mainly to aid clinical management of complex patients when they present to unscheduled care.

Consider Including information about baseline functional and clinical status; when and how to escalate treatment if acute deterioration; how far treatment should go; any patient specific wishes (place of care, death); patient awareness of condition and prognosis; any specific clinicians involved in their care who would wish to be contacted out of hours; any specific arrangements at home – package of care, NOK details, access arrangements (keysafe etc.); legal issues (such as power of attorney, treatment under AWIA 2000 etc.)

The following areas are useful when considering what to include, as appropriate:

1. Relevant baseline functioning in terms of clinical status and/or functional status (*For example, baseline O2 sats for patients with COPD, mobility, cognition*)

2. Key health and social care professionals involved (names, contact details)

3. Next of kin or Power of Attorney details? (*Names, telephone numbers and whether they would wish to be contacted in an emergency or prior to any major decision making is reported to be particularly useful*)

- 4. Contingency plan should the main carer fall sick
- 5. Clinical management plan in the event of deterioration
- 6. Documentation of the preferred place of care?
- 7. Other patient-specific wishes?

8. Documentation of which local community-based health and social care services could be considered to allow the person to remain at home? (*This will vary with local health, social care and third sector service provision across localities. eg ELSIE team, MERRIT teams, CRT and IMPACT teams, the IOPS service, and others*)

9. Documentation of whether end of life care has been discussed and specifically whether or not this includes CPR discussion, decision and documentation (see below)

Please enter information in box below.

(be aware that the Special Note allows for a maximum of 2048 characters)

INSTRUCTIONS FOR PRACTICE TEAM: PLEASE CUT AND PASTE THE BOX ABOVE INTO THE PATIENT'S KIS SPECIAL NOTES

4. DNACPR STATUS

Please X as appropriate.

Has DNACPR form (<i>this should accompany patient on discharge</i>)	Yes	No
If no DNACPR form, has DNACPAR been discussed with patient?	Yes	No
What is the patient's DNACPR status:	For resus	Not for resus
Has CYPADM form (Children and young people acute deterioration management form)	Yes	No

INSTRUCTIONS FOR THE PRACTICE TEAM. PLEASE CODE THE ABOVE INFORMATION

5. CONSENT

The patient has given consent for a KIS to be uploaded and shared with other healthcare professionals as necessary (this may include the Scottish Ambulance Service, NHS24, hospital departments especially the ED, and GPs out of hours)

Or, if a patient lacks capacity consent can be given by an authorised person, such as a Power of Attorney or parent of a young child.

The patient's authorised person has given consent for a KIS to be uploaded.

No consent for a KIS upload but this has been overruled

Lack of consent can be overruled if a patient presents a significant safety risk to themselves or to staff, or they are vulnerable.

If no consent please specify reason given by the **team** for not obtaining consent:

ACP-Carer document

1. PATIENT DETAILS:

PATIENT:	
Name	
DOB	
CHI	
Address	
GP PRACTICE:	
PRACTICE:	

2. SPECIAL NOTES BOX. PLEASE COPY AND PASTE TO KIS SPECIAL NOTE

(allows a maximum of 2048 characters)
XX is a carer for XX, Carer arrangements for XX, if XX becomes really unwell:
To help make arrangements for <mark>XX</mark> please call: XX next of Kin:
Care and treatment preferences: if XX becomes unwell,

3. CONSENT

Has the patient given consent for a KIS to be written and shared with other healthcare professionals as necessary (this may include the Scottish Ambulance Service, NHS24, hospital departments especially the ED, and GPs out of hours)?

Consent must be explicitly given to allow a KIS to be written. Only in specific circumstances consent is not legally required, such as:

- **Patient lacks capacity** (eg dementia, severe learning disability, young child)
- Safety Issues (eg patient presents a significant safety risk to themselves or to staff)

Please X as appropriate

YES consent given by XX

NO consent not obtained If no consent Please specify reason given by the **team** for not obtaining consent:

KIS Word template completed by:

XX Carer Support Hospital Discharge Worker , Edinburgh Carer Support Team,
 Direct Dial: XX
 Carer Support Team Helpline:
 Email: XX
 Date completed: XX

Phase 3: 2018-19		
Care Home Locality	Care Home	Aligned GP Practice
	Marian House Care Home	Grange Medical Group
	Ashley Court Nursing Home	Hermitage Medical Centre
	Glencairn Care Home	Boroughloch Medical Centre
SE	Braeside Care Home	Conan Doyle Medical Centre
	Gilmerton Care Home	Southern Medical Group
	Gilmerton Neurological Centre	Southern Medical Group
	Colinton Care Home	Craiglockhart Medical Group
	Queensbay Lodge Residential Care Home	Milton Surgery
NE	Ferrylee Care Home	Leithmount Practice
	Letham Park Care Home	Bangholm Medical Centre
	Strachan House Care Home	Murrayfield Medical Practice
	Drumbrae Care Home	Barclay Medical Practice
NW	Manor Grange Care Home	Barclay Medical Practice / Murrayfield Medical Centre
	Sir James Mackay House Care Home	Murrayfield Medical Practice
	Laverock House Residential Care Home	Long House Surgery
	Lennox House Care Home	Long House Surgery / Bangholm Medical Centre
	Northcare Manor Care Home	Slateford Medical Group
SW	North Merchiston Care Home	Polwarth Surgery
500	Fords Road Home	Slateford Medical Group
	Cairdean House Care Home	Craiglockhart Medical Group

Appendix 17: Participating care homes and GP practices phase 1-3

Phase 2: 2017-18		
Care Home Locality	Care Home	Aligned GP Practice
NW	Belgrave Lodge	Ladywell Medical Centre East
1400	Eagle Lodge	Murrayfield Medical Practice
	The Elms	Morningside Medical Practice
SE	Morlich House	Morningside Medical Practice
	Oaklands Care Home	Morningside Medical Practice
SW	Clovenstone Care Home	Whinpark Medical Practice
Phase 1: 2017		
Care Home Locality	Care Home	Aligned GP Practice
	Southpark Care Home	Durham Rd
NE	Milford House	Southfield Medical Practice
	Forthland Lodge	St Triduana's Medical Practice
	Castle Green Care Home	Milton Road Surgery