Edinburgh Health and Social Care Partnership

# Future Care Planning Quality Improvement Journey Case Study

| | | | |
|---|---|---|---|
| Date Completed | 29 November 2023 | | |
| Locality / Reach | Edinburgh City Wide | Service / Department | Alzheimer Scotland - Post Diagnostic Dementia Service |
| Test Period | 10 January 2022 to 01 January 2023 | | |

## Aim (overall goal for this project)

Improve outcomes for people being supported by Alzheimer Scotland's Dementia Post Diagnostic Service (PDS) Link Workers through Anticipatory Care Planning (Future Care Planning) – now known as Future Care Planning.

## Change ideas

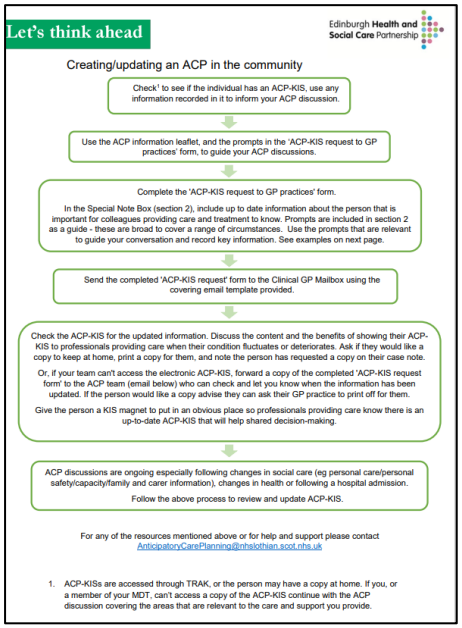
The Edinburgh-based Alzheimer Scotland Post Diagnostic Support (PDS) Link workers use the Generic Future Care Planning Community Bundle for social care teams to have Future Care Planning conversations with people following a diagnosis of dementia and their families/carers. With consent Future Care Planning information is shared with the individual's GP practice to update or create a Future Care Planning-Key Information Summary (KIS). The individual and/or family keep a copy of the completed KIS at home enabling the right information to be accessed at the right time to inform shared decision-making. Health and social care professionals (including Scottish Ambulance Service/NHS 24/Out of Hours Service) across the integrated system can access and act on the shared care and treatment preferences should the individual become unwell, improving health & wellbeing outcomes.

## Objectives

- Provide training on the Future Care Planning Community Bundle with the PDS team.
- Agree the Future Care Planning quality criteria tailored to care and support provided by PDS Link Workers.
- Adapt the Generic Future Care Planning Community Bundle for Social Care, tailored to care and support provided by PDS Link Workers.

LC= (PDSA) Learning Cycle

1. Social Care - Creating an ACP in the community Final V1.0.pdf
3. Anticipatory Care Planning in Community leaflet V5.0.pdf
4. Social Care ACP-KIS request to GP practices FINAL V 1.0.doc
5. Social Care Text for emailing GP practice Final V1.0.docx


Let's think ahead

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Creating/updating an ACP in the community

Check[1] to see if the individual has an ACP-KIS, use any information recorded in it to inform your ACP discussion.

Use the ACP information leaflet, and the prompts in the 'ACP-KIS request to GP practices' form, to guide your ACP discussions.

Complete the 'ACP-KIS request to GP practices' form.

In the Special Note Box (section 2), include up to date information about the person that is important for colleagues providing care and treatment to know. Prompts are included in section 2 as a guide - these are broad to cover a range of circumstances. Use the prompts that are relevant to guide your conversation and record key information. See examples on next page.

Send the completed 'ACP-KIS request' form to the Clinical GP Mailbox using the covering email template provided.

Check the ACP-KIS for the updated information. Discuss the content and the benefits of showing their ACP-KIS to professionals providing care when their condition fluctuates or deteriorates. Ask if they would like a copy to keep at home, print a copy for them, and note the person has requested a copy on their case note.

Or, if your team can't access the electronic ACP-KIS, forward a copy of the completed 'ACP-KIS request form' to the ACP team (email below) who can check and let you know when the information has been updated. If the person would like a copy advise they can ask their GP practice to print off for them.

Give the person a KIS magnet to put in an obvious place so professionals providing care know there is an up-to-date ACP-KIS that will help shared decision-making.

ACP discussions are ongoing especially following changes in social care (eg personal care/personal safety/capacity/family and carer information), changes in health or following a hospital admission.

Follow the above process to review and update ACP-KIS.

For any of the resources mentioned above or for help and support please contact AnticipatoryCarePlanning@nhslothian.scot.nhs.uk

1. ACP-KISs are accessed through TRAK, or the person may have a copy at home. If you, or a member of your MDT, can't access a copy of the ACP-KIS continue with the ACP discussion covering the areas that are relevant to the care and support you provide.


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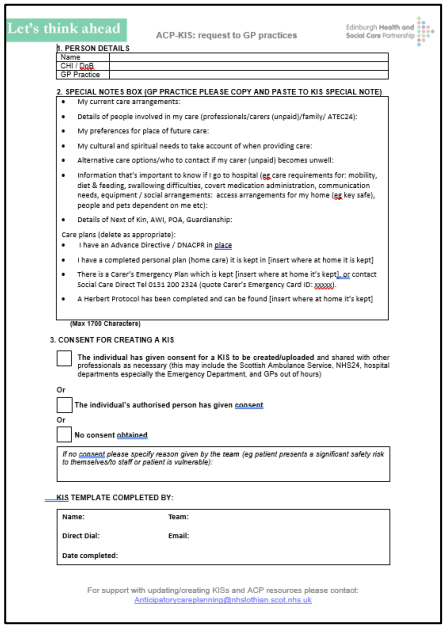
Let's think ahead

Anticipatory Care Planning

Information about treatment and care planning for people at home

what matters to you?

Anticipatory Care Planning: Community 1


Let's think ahead

ACP-KIS: request to GP practices

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1. PERSON DETAILS

| | |
|---|---|
| Name | |
| CHI / DoB | |
| GP Practice | |

2. SPECIAL NOTES BOX (GP PRACTICE PLEASE COPY AND PASTE TO KIS SPECIAL NOTE)

- My current care arrangements:
- Details of people involved in my care (professionals/carers (unpaid)/family/ ATEC24):
- My preferences for place of future care:
- My cultural and spiritual needs to take account of when providing care:
- Alternative care options/who to contact if my carer (unpaid) becomes unwell:
- Information that's important to know if I go to hospital (eg care requirements for: mobility, diet & feeding, swallowing difficulties, covert medication administration, communication needs, equipment / social arrangements: access arrangements for my home (eg key safe), people and pets dependent on me etc):
- Details of Next of Kin, AWI, POA, Guardianship:

Care plans (delete as appropriate):

- I have an Advance Directive / DNACPR in place
- I have a completed personal plan (home care) it is kept in [insert where at home it is kept]
- There is a Carer's Emergency Plan which is kept [insert where at home it's kept], or contact Social Care Direct Tel 0131 200 2324 (quote Carer's Emergency Card ID: xxxxx).
- A Herbert Protocol has been completed and can be found [insert where at home it's kept]

(Max 1700 Characters)

3. CONSENT FOR CREATING A KIS

☐ The individual has given consent for a KIS to be created/uploaded and shared with other professionals as necessary (this may include the Scottish Ambulance Service, NHS24, hospital departments especially the Emergency Department, and GPs out of hours)

Or

☐ The individual's authorised person has given consent

Or

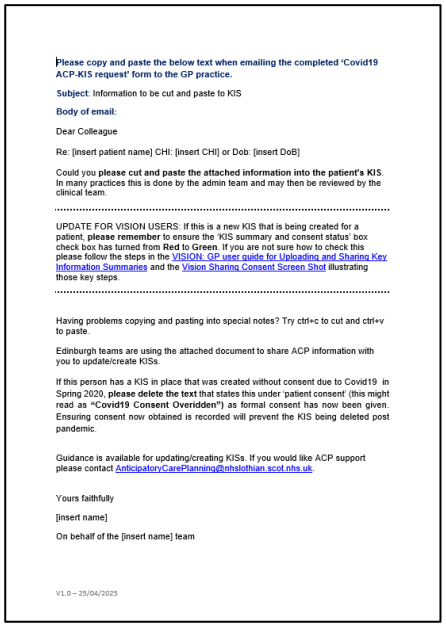
☐ No consent obtained

*If no consent please specify reason given by the team (eg patient presents a significant safety risk to themselves/to staff or patient is vulnerable):*

KIS TEMPLATE COMPLETED BY:

| | |
|---|---|
| Name: | Team: |
| Direct Dial: | Email: |
| Date completed: | |

For support with updating/creating KISs and ACP resources please contact: Anticipatorycareplanning@nhslothian.scot.nhs.uk


**Please copy and paste the below text when emailing the completed 'Covid19 ACP-KIS request' form to the GP practice.**

**Subject**: Information to be cut and paste to KIS

**Body of email**:

Dear Colleague

Re: [insert patient name] CHI: [insert CHI] or Dob: [insert DoB]

Could you **please cut and paste the attached information into the patient's KIS**. In many practices this is done by the admin team and may then be reviewed by the clinical team.

UPDATE FOR VISION USERS: If this is a new KIS that is being created for a patient, **please remember** to ensure the 'KIS summary and consent status' box check box has turned from **Red** to **Green**. If you are not sure how to check this please follow the steps in the VISION: GP user guide for Uploading and Sharing Key Information Summaries and the Vision Sharing Consent Screen Shot illustrating those key steps.

Having problems copying and pasting into special notes? Try ctrl+c to cut and ctrl+v to paste.

Edinburgh teams are using the attached document to share ACP information with you to update/create KISs.

If this person has a KIS in place that was created without consent due to Covid19 in Spring 2020, **please delete the text** that states this under 'patient consent' (this might read as **"Covid19 Consent Overidden"**) as formal consent has now been given. Ensuring consent now obtained is recorded will prevent the KIS being deleted post pandemic.

Guidance is available for updating/creating KISs. If you would like ACP support please contact AnticipatoryCarePlanning@nhslothian.scot.nhs.uk.

Yours faithfully

[insert name]

On behalf of the [insert name] team

V1.0 – 25/04/2025

- Test and adapt Future Care Planning Community bundle with all of Post Diagnostic Support (PDS) Link Worker team through a series of learning cycles.
    - PDS Link Workers have a Future Care Planning conversation with people referred to the service, talking through the Anticipatory Care Planning information leaflet for people at home.
    - PDS Link workers record information against the Future Care Planning quality criteria/discussion prompts, completing the *Social Care Future Care Plan-KIS Request to GP Practice* Form.
    - Using the template email PDS Link Workers share information (initially via the Future Care Planning Team for editing/quality review purposes) with GP practice teams to update the KIS.
    - PDS lead checks KIS on TRAK to review KIS has been updated including the shared information.
- The person diagnosed with dementia and/or their family keep a copy of their completed KIS at home along with copies of any Personal/Emergency/Care Plans to be accessed/inform shared decision making around care and support.
- Capture person/family member's feedback on their experiences of Future Care Planning conversations.

LC= (PDSA) Learning Cycle

- Capture GP feedback on the value of shared information in KIS.
- Using the supplied CHI numbers shared in the Future Care Plan-KIS Request to GP Practice Form, carry out a spot check audit on TRAK to review KIS quality, any A&E attendance/hospital admissions, and if/how KIS access has informed treatment and care decision-making.

## Prediction of what would happen when the test was carried out.

People and their families receiving post diagnostic support following a dementia diagnosis will be supported to think about and plan for future care and treatment preferences.

## What questions did we want to answer for this Future Care Planning Improvement and measures to determine if the prediction succeeds?

- Are link workers able to utilise the Future Care Planning bundle to facilitate Future Care Planning conversations and share key information across the integrated system?
- Would any adaptations need to be made to the Future Care Planning Community Bundle?

  - Number of people supported to have a Future Care Planning conversation.
  - Number of resources shared: leaflets, magnets, wallet cards.
  - Number of Future Care Plan-KIS forms sent to Future Care Planning team/GP practices.
  - Number of people with an existing KIS
  - Number of KISs updated with quality criteria.
  - Number of new KISs created with the quality criteria.

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| Tasks conducted to set up the tests of change (including key milestones to promote and encourage scale and spread across the Alzheimer Scotland Dementia Post Diagnostic Support Team) | |
|---|---|
| Activity | **Timeline** |
| Meeting: Connecting Power of Attorney and Anticipatory Care Planning Improvements - involving Partners in Advocacy; VoCAL; EHSCP Strategic Planning Officer for Older Adults and the Dementia Post Diagnostic Service Lead, Alzheimer Scotland. | January 2021 |
| Engagement with the Edinburgh Dementia Post Diagnostic Link Worker team - Presenting the Future Care Planning Community Bundle to the Link Workers to discuss a Test of Change Future Care Planning Improvement | 27 September 2021 |
| ➢ Investigate/confirm permissions to share Link Worker teams access to the NHS Lothian GP Clinical Mailbox email addresses | 20 January 2021 |
| ➢ Shared weblink to Future Care Planning Community bundle for Social Care Teams with the PDS Lead at Alzheimer Scotland. | 27 August 2021 |
| ➢ Share Edinburgh Carer Support Teams Future Care Planning GP Request form template prompts used for carers with Link Workers | |
| ➢ Meeting with Alzheimer Scotland | 31 August 2021 |
| ➢ Draft PDSA schedule for testing Future Care Planning with Alzheimer Scotland | 14 December 2021 |
| ➢ Agree Future Care Planning Quality Criteria (i.e. information sharing from care plans) | |
| Invited to Edinburgh Alzheimer Scotland Dementia Link Worker meeting to discuss getting them set up to start using the Future Care Planning Community Social Care Bundle and to introduce them to the Dementia Support Facilitator providing Dementia and Memory Support in General Practice in the East Edinburgh GP Cluster. | 15 November 2021<br>31 October 2022 |
| Future Care Planning Improvements | |
| ➢ Review, adapt and test the Future Care Planning Quality Criteria | 10 January 2022 to 01 October 2022 |
| ➢ Review, adapt and test the Future Care Planning Quality Criteria Pathway | 10 January 2022 to 01 October 2022 |
| ➢ PDS Link Workers start to have Future Care Planning conversations | 10 January 2022 to Present |
| ➢ Review, adapt and test the Future Care Plan-KIS GP request form | 10 January 2022 to 01 October 2022 |
| ➢ Long Term Conditions (LTC) Programme Team review completed Future Care Planning KIS Request form shared by PDS Link Workers | 10 January 2022 to 01 October 2022 |
| ➢ LTC Programme Team share completed Future Care Plan-KIS GP request form with GP Practice | 10 January 2022 to 01 October 2022 |

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| | |
|---|---|
| ➢ Review, adapt and test GP Practice email template | |
| ➢ PDS Link Worker tests sending GP Request form directly to GP Practice | From 02 October 2022 |
| ➢ Distribute Future Care Plan Merchandise to Edinburgh PDS Link Worker – Lets Think Ahead Fridge Magnets; Lets Think Ahead leaflet, Wallet Cards etc | August 2021<br>January 2022<br>August 2023 |
| Future Care Plan Training delivery | 15 November 2021 |
| Future Care Plan Stakeholder Group attended by Alzheimer Scotland Link Worker Team | |
| 4 Learning cycles and follow up review meetings held to review implementation of the test of change and 1 check-in to review Future Care Plan Improvement work moving towards Alzheimer Scotland's Business as Usual model. | |
| ➢ Initial meeting to develop PDSA learning cycle | 10 January 2021 |
| ➢ Review meeting held to review Learning Cycle 1 running between 10 January - 21 February 2022 | 07 March 2022 |
| ➢ Review meeting held to review Learning Cycle 2 running between 21 February - 02 May 2022 | 02 May 2022 |
| ➢ Review meeting held to review Learning Cycle 3 running between 03 May - 11 July 2022 | 25 July 2022 |
| ➢ Review meeting held to review Learning Cycle 4 running between 12 July 2022 - 31 October 2022 | 31 October 2022 |
| Business As Usual Check-in meeting covering period: November 2022 - 08 January 2023 | 09 January 2023 |
| | |
| STUDY | |

## 1. Background

A meeting was held between the LTC programme Team, Partners in Advocacy, EHSCP Strategic Planning Officer for Older Adults, Alzheimer Scotland and VoCAL to discuss how we could collectively contribute to:

- improving practitioners' understanding of POA,
- improve uptake of POAs by individuals who would benefit from having one in place, and
- recording, sharing and accessing of key information which provides details of Power of Attorney in place.

As a result of these discussions Alzheimer Scotland's Edinburgh link worker team agreed to explore how they might be supported to use the Future Care Plan Community bundle to capture, record and share POA information, and to understand the current process/pathways in place. This also provided an opportunity to test the resources with another team across health and social care.

## 2. About Alzheimer Scotland Dementia Post Diagnostic Support Service

- The Alzheimer Scotland dementia post-diagnostic support Link Worker model involves supporting individuals to:

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- understand their illness and manage their symptoms,
- be supported to keep up their community connections and make new ones,
- have the chance to meet other people with dementia and their partners and families,
- plan for future decision-making, and,
- plan for their future support.

- **Size of team**: Post Diagnostic Support Services exist across Edinburgh, East and Mid Lothian. At the time of engagement, the Edinburgh Dementia PDS team comprised one PDS Lead and eight PDS Link Workers, funded by the City of Edinburgh Council.
- **Reach/scope of service:** Edinburgh.
- **Information captured by PDS service:** Future decision-making and planning for treatment, care and support. The link workers touch on POA/AWI conversations offering an opportunity for practitioners to record and share that information e.g., identification of those who would benefit from a POA; identify where a POA is in place but not yet recorded in KIS (e.g., delay in GP practice being notified or not being notified).
- **Length of support provided by service:** 1-Year post diagnosis support as described above. On discharge from the service information is shared with the person's GP.

## 3. Baseline Review

- A review of the Link Workers caseload at baseline identified that six KIS's showed varying levels of information in the 'KIS Special Notes' that met the KIS Quality Criteria, from having one line about a previous hospital procedure or some information regarding their last admission. Overall the level and quality of information in the KIS's was low, and last being updated 1 or 2 years previously. This offered some indications that the PDS Service caseload would benefit from an Future Care Planning conversation to update or create their KIS and would lead to overall improvement in the volume and quality if key information gathered.

## 4. Are link workers able to utilise the Future Care Plan bundle to facilitate Future Care Plan conversations and share key information across the integrated system?

- After an initial discussion with Alzheimer's Scotland Link Workers and a review of the Social Care Bundle the team was keen to start Future Care Plan improvements as soon as possible.

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So far the process has been good, most people spoken to are interested in the idea of completing the Future Care Plan and have sent one through to the Long Term Conditions Programme Team **Link Worker 2, LC1**

At a post diagnostic support group we go through 5 pillars and so gave out the Future Care Plan leaflets and this went down really well. **Link Worker 6, LC3**

- The PDS service provides support for people with a dementia diagnosis offers several opportunities over the course of a year to engage in conversations and gather information against the key quality criteria. Information would often be shared once all gaps were filled, however the information could be shared with the GP practice as and when new/additional information is captured.

haven't completed the form but talked to people about it and made notes am aware on radar and plan to complete. There's been a positive reaction from those we are speaking to. **Link Worker 6, LC2**

I've talked to people, made notes but not submitted one [Sic. Future Care Plan-KIS GP Request Form] yet – trying to get details of addresses for NOK family etc. which has led to the delays. **Link Worker 3, LC2**

- Following completion of the first learning cycle three of the eight Link Workers demonstrated that they were able to quickly pick up and use the bundle to facilitate conversations with people with a dementia diagnosis and family members. By the end of the four learning cycles all seven PDS Link Workers were using the Future Care Planning Bundle. The LTC Programme team provided support to quality review, edit and reshare feedback with the PDS Link Workers.

All going well there are a few gaps to fill in the Future Care Plan-KIS documents [e.g., waiting for person to get back to confirm contact details for NoK]. Resources shared have been really helpful and people are keen to have the conversations. **Link Worker 1, LC1**

- The benefits of having the Future Care Planning conversations were shared during the PDSA review meetings, reflecting on their value for people with dementia and their families.

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There has been a flurry of activity and I usually complete the Future Care Planning form towards the end, when closing the support conversation. I also completed my first conversation with the carer (Discussed at the last learning cycle meeting). The Future Care Planning conversations have been really positive and people are always keen to get these in place.

**Link Worker 2, LC3**

I think it is especially helpful for people on their own so going to prioritise my conversations more for those who are on their own.

**Link Worker 3, LC3**

It gives people more reassurance, especially when they are on their own.

**Link Worker 4, LC3**

- The PDS support groups provided an ongoing platform for Alzheimer Scotland link workers to raise awareness for having 'thinking and planning ahead conversations' at their sessions. The link workers reflected on the lack of control people have over what information is recorded about them, so a process such as this helps show the importance/value of having a Future Care Plan-KIS in place as it puts control in people's hands.

Got feedback it makes sense to people – they are wanting to engage and are excited - feeling that they have that information stored somewhere and not just kept in their bedroom.

**Link Worker 5, LC3**

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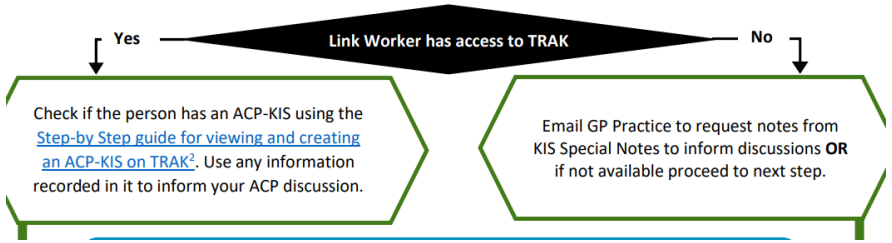
## 5. Would any adaptations need to be made to the Future Care Planning Community Bundle?

5.1 System enablers/blockers were identified early on when examining the *Pathway for Creating a Future Care Plan in the Community* requiring pathway adaptations to enable the test of change to move forward.

- The Link Workers in Edinburgh do not have access to TRAK. During the test of change the Future Care Planning Team accessed TRAK to review each person's KIS to inform the conversations initiated with link workers. Once the team moved t into a Future Care Planning business as usual model, a decision tree was included in the pathway presenting 2 options to proceed, depending on the link worker's access to TRAK.




PDS Lead "the Future Care Planning Improvement has been positively received because link workers build into the conversations discussions about the future so very relevant for the work link workers to do this piece of work, it makes sense."

PDS Lead, LC1

- Keeping a printed copy of the updated KIS with other personal plans at home is encouraged so individuals and their carers/family can share with practitioners to inform shared decision-making. The pathway was updated to include a step where the link workers gained the consent of the person to print a copy of their KIS.

**Link Worker** asks for consent for a KIS to be created/uploaded and shared with other professionals as necessary (this may include the Scottish Ambulance Service, NHS24, hospital departments especially the Emergency Department, and GPs out of hours). Ask for consent for the KIS to be printed and kept together with the personal plan, noting consent in their records.

5.2 The *Future Care Planning Community Information Leaflet* provides information for people, their family, or carers on to what they can expect from a Future Care Planning conversation with any practitioner. Following discussion, it was agreed the leaflet was generally enough to meet the needs of the PDS service when preparing conversations held by the Link Workers and no tailoring of this resource was needed.

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We are handing out leaflets, wallet cards as part of the discussions…
Link Worker 1, LC1

Up to the 23 January 2022 more than 600 Future Care Planning resources have been shared with the PDS Link Workers.

| **FUTURE CARE PLANNING Resources distributed to Team** | **Number** |
|---|---|
| leaflets | 220 |
| Wallet Cards | 220 |
| Fridge Magnets | 180 |
| Window Stickers | 73 |

**Table 1:** Running Total of Future Care Planning Resources distributed to the Future Care Planning Improvement team (4 learning cycles)

5.3 *Social Care Future Care Plan-KIS request to GP practices* form and associated KIS Key Quality Criteria (i.e., core, standard information which creates a quality KIS) provided link workers with the necessary tools for recording information gathered through their conversations with people they're supporting, their family and carers.

- Throughout the four learning cycles the link workers were able to complete the forms, requiring minor editing (e.g., removal of extra line spacing and duplicate information) to keep content within the character limit (1700 characters). Experience has shown that GP Practice Admin teams are unlikely to have time/capacity to edit text to meet the character limit set in the KIS Special Notes section. If the text is not within the character limit it's likely the KIS will not be updated with the quality criteria shared. Or it may be the case that only the text that is within the character limit is copied onto the KIS, potentially missing vital information that can inform shared decision-making. Editing out extra line/character spaces or repetitive text from the questions/prompts is therefore an important stage in the process.

- Over the course of the 4 learning cycles the LTC Programme Team became aware that when the Future Care Planning-KIS GP Request forms were shared with the GP practice, information was either not copied into the KIS Special notes section or information was being copied that was not intended for the KIS. This led to further improvements being made to the GP Request form making it

LC= (PDSA) Learning Cycle

clearer to GP practices teams what they are being asked to copy and paste into the Special Notes section.

*5.4 Social Care Text for emailing GP Practice Template*

- To reflect amendments made to the Future Care Plan-KIS GP Request form directing practice teams on what information they should copy and paste (see Section 5.3 above) the template email was also updated.
- Link workers were supported to include additional instructions for practice teams where information in an existing KIS was out-of-date and could be removed as part of the update.

> Could you **please cut and paste the attached information (Within the Special Notes Section Only) into the patient's KIS**. In many practices this is done by the admin team and may then be reviewed by the clinical team.

- While consent is given to share information in a KIS, for KISs created for vulnerable adults during covid without consent, text was still visible in the updated KISs stating 'Covid19 Consent Overridden'. To ensure consent information isn't lost in KISs updated post pandemic, further guidance was shared with GP practices.

> If this person has a KIS in place that was created without consent due to Covid19 in Spring 2020, **please delete the text** that states this under 'patient consent' (this might read as **"Covid19 Consent Overidden")** as formal consent has now been given. Ensuring consent now obtained is recorded will prevent the KIS being deleted post pandemic.

- Link workers have a city of Edinburgh council email for the safe transfer of GP Request Forms but did not have direct access to the GP Clinical mailbox Email Addresses to do this. To facilitate the link workers move towards a Business as Usual model, permission was obtained from the Service Manager for Primary Care and Health Inequalities granting access to the list of emails.

5.6 Follow-up Social Care Text for emailing GP Practice Template. Once the Future Care Plan-KIS GP request form was shared with the GP Practice team approximately one week after, a review of the KISs on TRAK showed that occasionally there would be minor errors (e.g., duplication of shared information), or that information may not have been updated in the Future Care Plan-KIS.

- As a result a template email was developed to support any follow-up communications including prompts to check the consent box in the GP IT System (e.g., VISION) has been checked as covered in the initial template email described in section 5.4.

**Table 2:** Breakdown of Future Care Planning conversations that have led to KISs being updated or new KISs created by GP practices.

| | **Total since Future Care Planning Improvement started** |
|---|---|
| **Number of Future Care Planning Conversations** | 39 |
| Number of existing KISs updated | 27 |
| Number of New KIS created | 7 |
| Number of KIS Uploads outstanding[1] | - |
| Number of Future Care Plan -KIS not shared with practice | 0 |
| Number of Future Care Plan-KIS not updated by GP practice[2] | 1 |

Table 2 illustrates that many of the discussion taking place with the PDS Link Workers resulted in a significant proportion of existing KISs held in being updated with current, up-to-date information that could better inform shared decision- making. Please note above table does not include figures for KISs created for family members in their capacity as the person's carer.

Figure 1 below shows the outcome of the link workers' discussions with people with a dementia diagnosis and their family led to a marked improvement in the number of quality criteria included in the KIS special notes. As the KIS special notes is the only digital shared care plan that can be accessed by multiple services in Lothian, the inclusion of quality criteria is important to support shared decision making for family and key professionals involved in the person's care, support and treatment.

[1] Future Care Plan-KIS shared with GP Practice but KIS not updated or not possible to see update on TRAK

[2] Future Care Plan-KIS not updated due to cared for person dying or had been moved into a care home so carer information not updated

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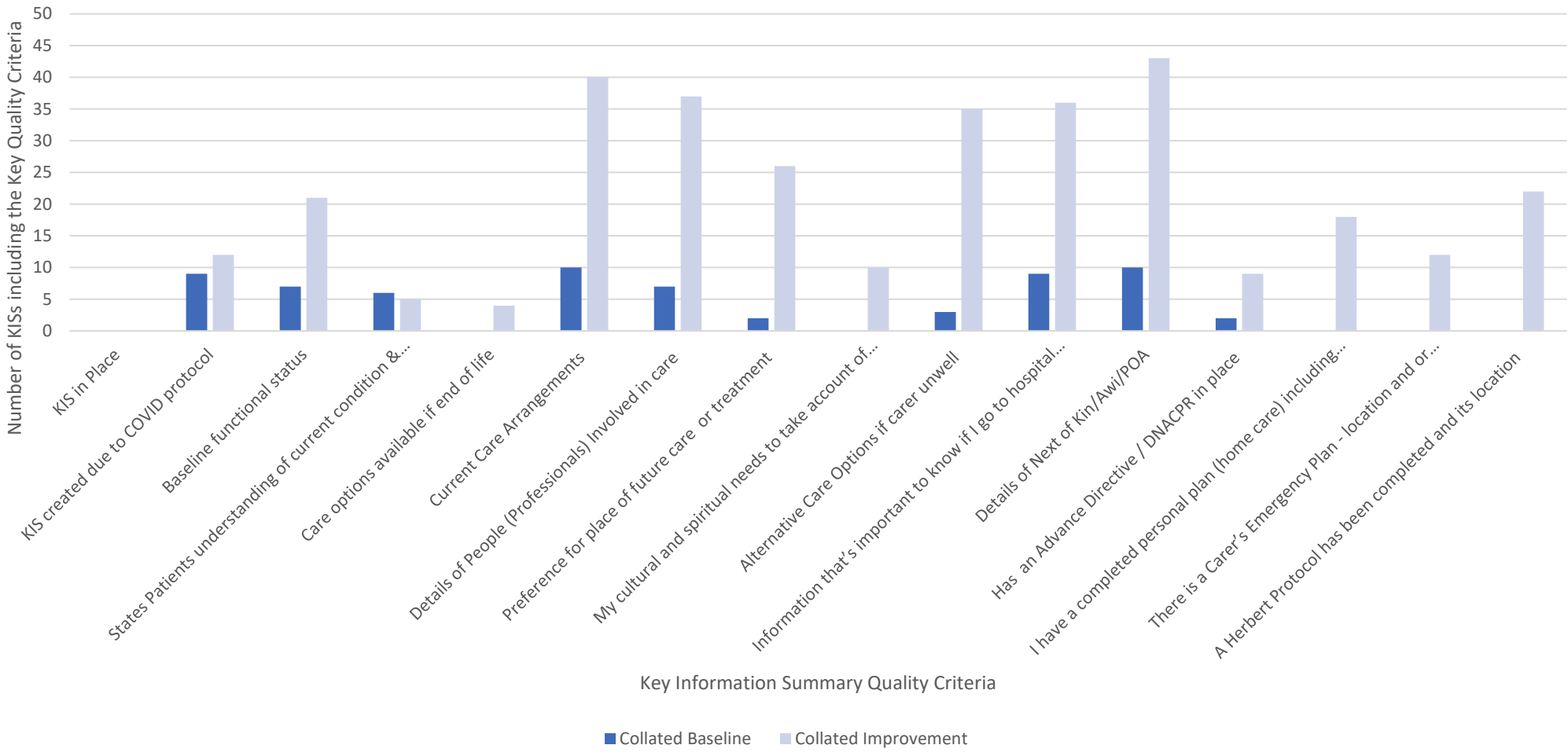
**Figure 1:** Alzheimer Scotland PDS Link Worker Test of Change; January 2021 to January 2022: comparing key quality criteria criteria included in KISs for people accessing the Dementia Post Diagnostic Support Service at baseline and again following 39 future




## 6. Unintended consequences of Future Care Planning conversations that make a difference

Family members involved in link worker discussions recognised the benefits of a Future Care Plan-KIS and indicated interest in having one put in place for themselves. The link workers were keen to offer support to family members, especially as they were already gathering information

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which could usefully inform a family member's Future Care Plan-KIS. Templates for the Carer GP Request forms, previously designed and tested with the Edinburgh Carer Support Team, were shared with the link workers to enable Future Care Planning improvements to happen with more carers in Edinburgh.

> Completed conversations with carers – will be others wanting to do that too so will share those documents.
>
> **Link Worker 1, LC2**

> Including carers came about as it made sense in the situation. The carer had health problems also so made sense to record this in case anything happened to them."
>
> **Link Worker 2, LC3**

> It's becoming routine part of the work, so I have got in the way of thinking that FUTURE CARE PLANNING is a standard piece now of our work. For people with complex health issues, it makes sense for them, so it's been good.
>
> **Link Worker 6, LC3**

## 7. Opportunities for future scale and spread

- Once the Alzheimer Scotland Team moved their Future Care Planning Improvements to a business as usual model, the adapted resources along with their feedback would go on to inform the development of a suite of Future Care Planning Social Care Bundles for social care teams, now available on the NHS Lothian public facing website https://services.nhslothian.scot/anticipatorycareplanning/community-health-and-social-care/ including: Link Workers (with a post diagnostic dementia support link worker focus); Carer Support Workers; and Homecare Teams. The test of change also led to the development and inclusion of additional resources: a step-by-step guide to Access-Generate a Future Care Plan-KIS on TRAK; Link Worker Future Care Planning Discussion Prompt Sheet and Link Worker Template text for Emailing Chase up on GP Request.

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**LINK WORKER TEAMS ACP BUNDLE**

- 1.-Link-Worker-Team-ACP-Pathway_Creating-a-Quality-ACP-KIS-V1.0-1
- 2. Step-by-Step Guide to Access-Generate an ACP-KIS on TRAK(V1)
- 3. Anticipatory Care Planning in the Community Information Leaflet (V1)
- 4. Link_Worker_ACP Discussion Prompt Sheet V1.0
- 5. Link_Worker_ACP-KIS Request to GP Practices Form 2023
- 6. Link_Worker_Template Text for Emailing GP Practice V1.0
- 7. Link_Worker_Template-Text-for-Emailing-Chase-Up-on-GP-Request (V1)

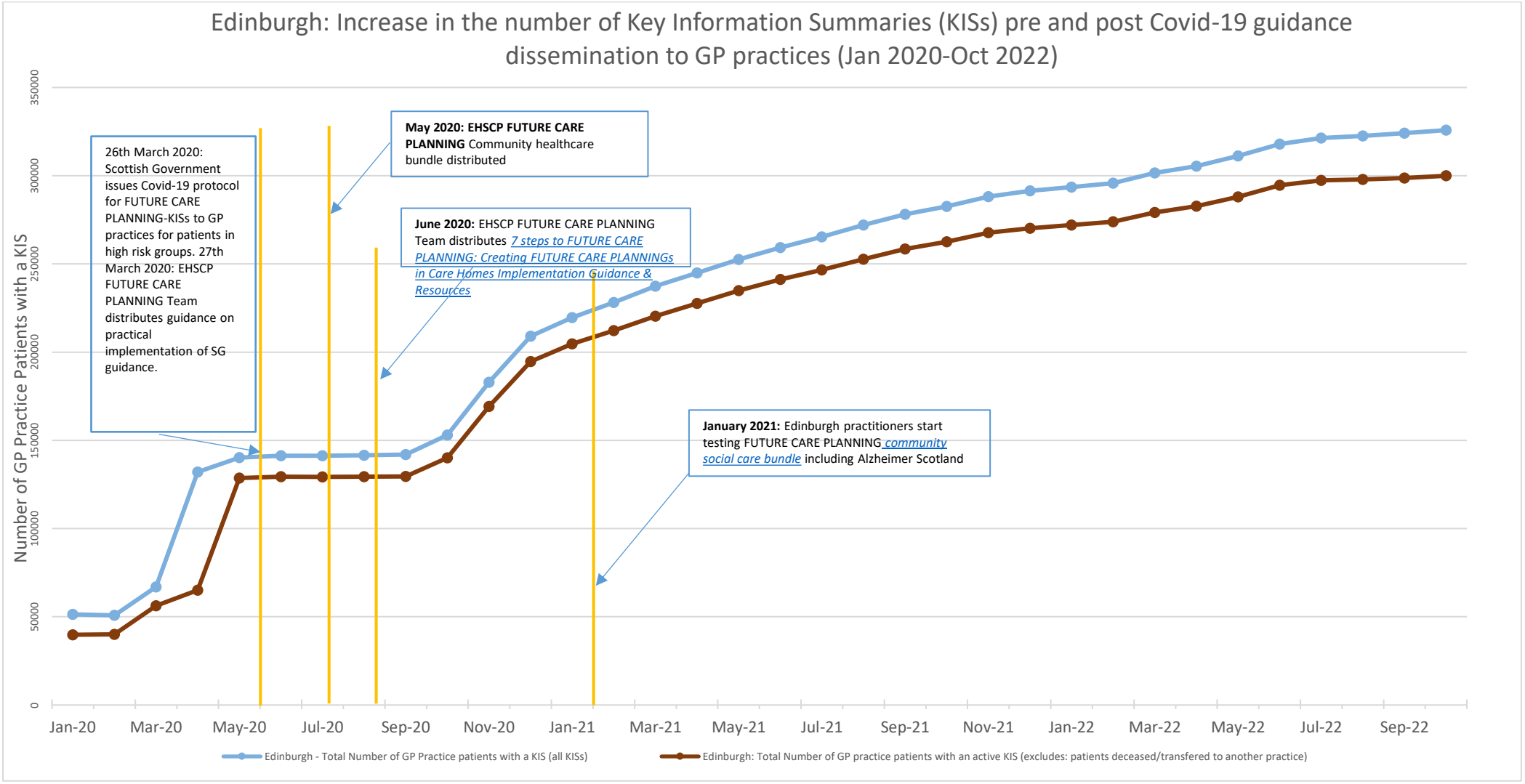
- PDS Link workers across East and Mid Lothian have TRAK access which offers scope to share Edinburgh's experiences and spread Future Care Planning improvements across the Lothians, testing transferability of the approach at a regional and national level.

> I cover the Future Care Planning improvement work as part of the link workers Support and Supervision so agree it does feel like it is becoming part of the normal process of what we [Alzheimer Scotland] do. I am keen to see it spread out to other areas and with other link workers. The plans we complete with people are rich with information and can be used.
>
> **PDS Lead, LC3**

- To support local efforts, further discussions are being explored to gain permission for granting link workers in Edinburgh access to TRAK, This would enable link workers to review KISs and plan for Future Care Planning discussions, and to subsequently check KISs for updated information.

LC= (PDSA) Learning Cycle

**Figure 2:** Edinburgh: Increase in the number of Key Information Summaries (KISs) pre and post Covid-19 guidance dissemination to GP practices (Jan 2020-Oct 2022)




LC= (PDSA) Learning Cycle