Research

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Electronic care coordination systems for people with advanced progressive illness:

a mixed-methods evaluation in Scottish primary care

Abstract

Background
Electronic care coordination systems, known as the Key Information Summary (KIS) in Scotland, enable the creation of shared electronic records available across healthcare settings. A KIS provides clinicians with essential information to guide decision making for people likely to need emergency or out-of-hours care.

Aim
To estimate the proportion of people with an advanced progressive illness with a KIS by the time of death, to examine when planning information is documented, and suggest improvements for electronic care coordination systems.

Design and setting
This was a mixed-methods study involving 18 diverse general practices in Scotland.

Method
Retrospective review of medical records of patients who died in 2017, and semi-structured interviews with healthcare professionals were conducted.

Results
Data on 1304 decedents were collected. Of those with an advanced progressive illness (79%, $n = 1034$), 69% ($n = 712$) had a KIS. These were started a median of 45 weeks before death. People with cancer were most likely to have a KIS (80%, $n = 288$), and those with organ failure least likely (47%, $n = 125$). Overall, 68% ($n = 482$) of KIS included resuscitation status and 55% ($n = 390$) preferred place of care. People with a KIS were more likely to die in the community compared to those without one (61% versus 30%). Most KIS were considered useful/highly useful. Up-to-date free-text information within the KIS was valued highly.

Conclusion
In Scotland, most people with an advanced progressive illness have an electronic care coordination record by the time of death. This is an achievement. To improve further, better informal carer information, regular updating, and a focus on generating a KIS for people with organ failure is warranted.

Keywords
after-hours care; digital health; electronic palliative care coordination systems; general practice; palliative care; primary health care.

INTRODUCTION

Identifying people who would benefit from a palliative care approach, and ensuring that their needs and preferences are documented and shared across settings, is essential to providing well-coordinated care.[1,2] Electronic Palliative Care Co-ordination Systems (EPaCCS) are being developed to enable sharing of patient information, preferences across care settings, and inform emergency and out-of-hours care.[3]

Across the UK, regional systems include Coordinate My Care (London); the South-West EPaCCS; and the Leeds EPaCCS.[3,4] In Scotland, the Key Information Summary (KIS) was introduced in 2013 as an electronic care coordination system for anyone who might have urgent care needs, not just those identified for palliative care.[5] A KIS is created in primary care by GPs (in contrast to Coordinate My Care and other EPaCCS that allow users in a variety of settings to create and update a patient record). A KIS allows selected parts of the GP electronic patient record to be shared with emergency services (111 and 999), GP out-of-hours services, accident and emergency departments, ambulance services, hospitals, community nursing teams, and some specialist palliative care services.

A KIS record facilitates 'anticipatory care', a person-centred care planning process requiring healthcare professionals to work with individuals, carers, and their families, to discuss and document their goals and priorities for care.[6,7] For people with an advanced progressive illness, this includes information on cardiopulmonary resuscitation (CPR) status, preferences for place of care or death, treatment escalation plans, carer details, and anticipatory medicines (see Supplementary Boxes 1 and 2). An evaluation conducted in 2014, examined 605 patient records from nine general practices in one NHS board area and found that 60% of those who died with an advanced progressive illness had a KIS by the time of death.[8] Overall, KIS's were started 18 weeks before death, and those with a KIS were more likely to die in a community setting.

Despite the potential importance of EPaCCS, a recent systematic review found that evidence on EPaCCS is mostly expert opinion, and few rigorous evaluations have been conducted.[9] There is some evidence

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How this fits in

Electronic care coordination systems are being developed in many regions and countries to coordinate care for people with advanced progressive illnesses across settings. These can be generated across a national primary care system and automatically shared daily across emergency and out-of-hours care settings. In Scotland, an electronic care coordination patient summary is often started early in an advanced progressive illness with the patient's consent, helping to coordinate chronic disease management and early palliative care. Having an electronic care coordination summary was associated with a greater likelihood of dying in a community setting (home, care home, or hospice).

that people with an EPaCCS record are more likely to die in their preferred place compared with the general population.[4,10–12] Given the drive to roll out EPaCCS across the UK by 2021, including the KIS across Scotland,[13,14] ongoing evaluation is needed.[9]

This study aimed to describe the evidence on the roll-out of a national electronic care coordination system, with specific reference to palliative care. The authors sought to: estimate the proportion of people with an advanced progressive illness who had a KIS by the time of death and to determine when the KIS was started; examine which elements of anticipatory care planning were most frequently recorded in the KIS; and to explore general practice staff perceptions of the KIS to inform future innovations in electronic care coordination systems.

METHODS

Design

This was a mixed-methods study consisting of a retrospective review of the records of all patients who died in 18 Scottish general practices in four NHS board areas in 2017, and semi-structured interviews with at least one healthcare professional in each practice.

Recruitment of general practices

In Scotland, GPs are trained in generalist palliative care and provide palliative and end-of-life care to their patients, seeking advice and input from a specialist team as required. Average general practice list size in Scotland is approximately 6000 patients, though there is a large degree of variability.[15] This study sought to recruit practices ranging in size from just >1000 patients to >10 000 patients. Practices located in urban, suburban, and rural areas were purposively sampled. The authors identified

18 general practices varying in size and rurality across four NHS boards: Lothian, Fife, Ayrshire and Arran, and Tayside. Based on previous studies it was estimated that this would provide a sample of 1200 to 1300 patients.[8] Practices were informed of the study by the National Clinical Lead for Palliative Care member of the research team, or were contacted if they had been involved in previous studies with the research team.

Quantitative data collection and analysis; retrospective review of patient records

A GP, currently working in palliative medicine, collected data for all patients in each practice who died in 2017. Patients who died because of cancer, frailty, dementia, or organ failure (including liver, heart, renal, or pulmonary failure) were judged as having an advanced progressive illness. Data collected included dominant trajectory of decline, that is, cancer, organ failure, frailty and/or dementia; place of death; whether specific components of anticipatory care planning were documented in the KIS; and when information was first documented (see Supplementary Figure 1). One author rated each KIS as 'highly useful', 'useful', or of 'limited use', in guiding emergency or out-of-hours care at the end of life. These categories were developed by the multidisciplinary research team for the purpose of this evaluation and are described below:

- highly useful — clear plan regarding patient, and ideally family, wishes regarding current care and future planning;
- useful — some additional useful clinical information, but no clear wishes regarding current care or future planning; and
- limited use — a KIS present but no additional information added, no relevant boxes ticked, no free-text note.

Data were recorded in Excel and imported to IBM SPSS (version 24) for analysis. Strengthening the Reporting of Observational studies in Epidemiology (STROBE) guidelines were followed for reporting purposes.[16]

Qualitative data collection and analysis

Semi-structured telephone interviews were conducted by one of the authors, a general practice nurse trained in qualitative research methods. Most participants were GPs, as they create and update the KIS, and some worked in out-of-hours primary
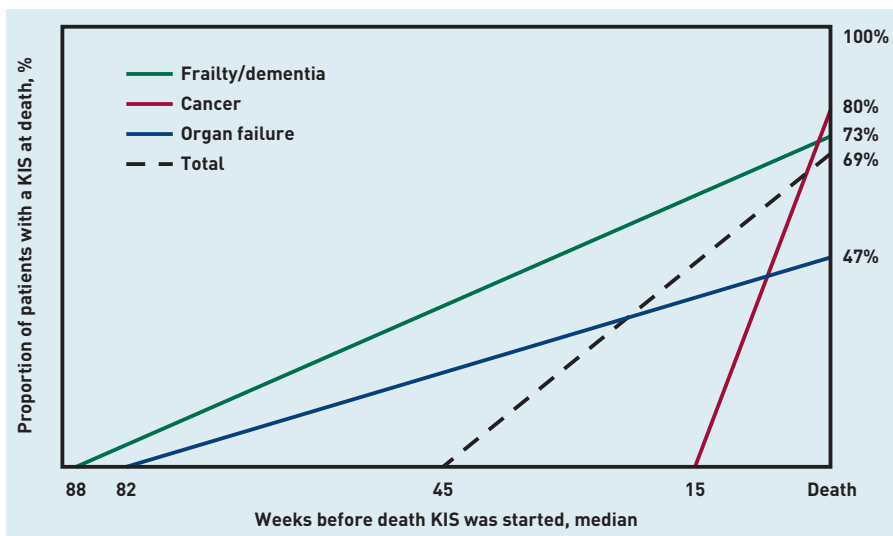
Figure 1. Proportion of patients with a Key Information Summary (KIS) in place before death, and if so, the median number of weeks before death KIS was started by trajectory. Percentages rounded to nearest whole.

care services. Data were anonymised, transcribed, and imported into NVivo (version 11) for analysis informed by a framework approach.[17] Standards for Reporting Qualitative Research (SRQR) guidelines were followed.[18]

Retrospective review of patient records

Sample characteristics. Data were collected from 1304 patient records. Of these, 79% of patients (*n* = 1034) died of an advanced progressive illness. Twenty-one per cent of patients died suddenly (*n* = 188, 14%), or of an unclear cause (*n* = 82, 6%), and were excluded from further analysis. The final sample consisted of 1034 patient records (51% female, 49% male). Median age was 79 years (range 25 to 103 years) and 408 (39%) were deemed to have frailty and/or dementia; 361 (35%) cancer; and 265 (26%) organ failure (Table 1). Nearly all had at least one comorbidity (*n* = 928, 89.7%) (data not shown).

Proportion of sample dying with an electronic care coordination record (KIS). Overall, 69% (*n* = 712) of patients who died with an advanced progressive condition had a KIS. People with cancer were most likely to have a KIS (80%, *n* = 288), whereas those with organ failure were least likely (47%, *n* = 125) (Figure 1). Overall, a KIS was started a median of 45 weeks before death, but much earlier for people with frailty and/or dementia (88 weeks before death) and organ failure (82 weeks before death) than for people with cancer (15 weeks before death) (Figure 1 and Table 1).

The majority of KIS were judged by the clinical researcher as 'highly useful' (*n* = 367, 52%) or 'useful' (*n* = 308, 43%) to inform emergency or out-of-hours care decisions; only 5% (*n* = 35) were deemed of 'limited use'. Of the 712 patients with a KIS, 68% (*n* = 482) had their CPR status recorded within the KIS, and CPR discussions took place a median of 15 weeks before death (Table 1). For people with frailty and/or dementia, these discussions took place earlier with a median of 32 weeks before death, compared to 25 weeks for people with organ failure, and only 6 weeks for people with cancer. Over half of all patients with a KIS had their preferred place of care documented (55%, *n* = 390), and 43% (*n* = 307) their preferred place of death documented. Of those with a preferred place of death documented, 73% (*n* = 223) died there (data not shown). People with cancer had their preferred place of care and place of death documented much closer to death than those with frailty and/or dementia or organ failure. The name of a next of kin or carer was recorded in 60% (*n* = 424) of total KIS, but next of kin or carer contact details on less than half (44%, *n* = 312) of total KIS.

Variation. Practices varied in relation to KIS generation and completion. The proportion

Table 1. Descriptive overview of 1034 patient records

	Frailty/dementia	Cancer	Organ failure	Total
Total number of patient records assessed	408	361	265	1034
Patient records with a KIS, *n* (%)	299 (73)	288 (80)	125 (47)	712 (69)
Components of anticipatory care planning of total records with a KIS, *n* (%)[a]				
Resuscitation status recorded	222 (74)	188 (65)	72 (58)	482 (68)
Palliative care summary commenced	66 (22)	210 (73)	38 (30)	314 (44)
Preferred place of care recorded	180 (60)	152 (53)	58 (46)	390 (55)
Preferred place of final care/death recorded	153 (51)	118 (41)	36 (29)	307 (43)
Anticipatory medication started before death	71 (24)	108 (38)	27 (22)	206 (29)
Next of kin or carer recorded in KIS	196 (66)	156 (54)	72 (58)	424 (60)
Next of kin or carer contact details in KIS	127 (42)	129 (45)	56 (45)	312 (44)
Timing of anticipatory care planning, median weeks before death[b]				
KIS commenced before death	88	15	82	45
Resuscitation status discussed before death	32	6	25	15
Palliative care summary commenced before death	2	9	13	8
Preferred place of care documented before death	34	6	29	13
Preferred place of final care documented before death	14	6	8	8
Anticipatory medication prescribed before death	1	3	1	2
Place of death, *n* (%)				
Hospital[c]	168 (41)	149 (41)	158 (60)	475 (46)
Home	56 (14)	98 (27)	78 (29)	232 (22)
Care home	174 (43)	24 (7)	13 (5)	211 (20)
Hospice	3 (1)	78 (22)	3 (1)	84 (8)
Other	7 (2)	12 (3)	13 (5)	32 (3)

[a]Components of anticipatory care planning shows the number of patients with a KIS record containing the information listed. The % is the number of KIS's with each item of information recorded divided by the number of patients with a KIS by illness trajectory. [b]Median weeks based only on those patients with each component documented in the KIS. [c]'Hospital' includes both acute and community hospitals. KIS = Key Information Summary.
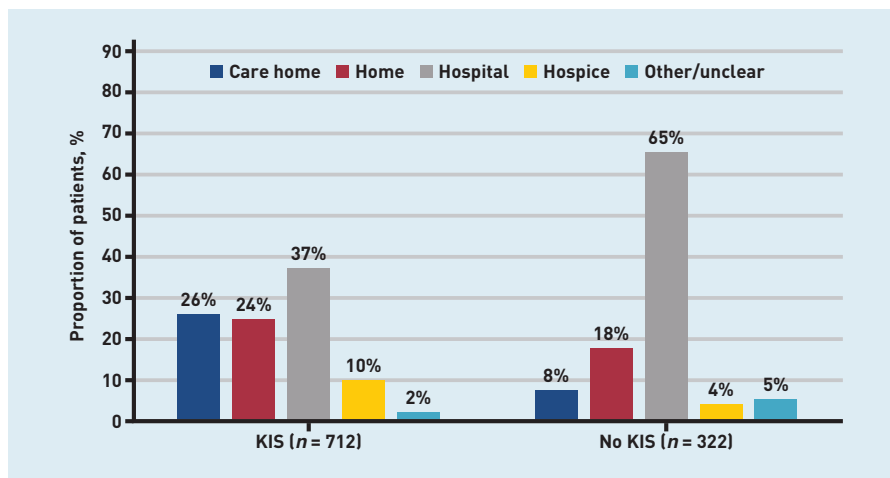
Figure 2. Place of death for patients with and without a KIS (n = 1034). Percentages rounded to nearest whole. KIS = Key Information Summary.

of patients with an advanced progressive illness who died with a KIS varied from 53% to 81% across practices. Documentation of resuscitation status within the KIS varied from 32% to 91%. Documentation of preferred place of death also varied, from 13% to 71% across practices (data not shown). Once a KIS was generated, it was updated iteratively, with information on resuscitation status, preferred place of care, preferred place of death, and anticipatory medicines added subsequently, though the order in which these components were added varied (data not shown).

Association between KIS and place of death. Overall, 46% of patients died in hospital (Table 1). An χ^2 test was performed to examine the likelihood of dying in a community setting for those with a KIS compared with those with no KIS. For this analysis, 'community' consisted of deaths at home, in care homes, or in a hospice (51%, $n = 527$). Sixty-one per cent of those with a KIS died in the community compared to 30% of those without (Figure 2). There was a statistically significant association between having a KIS and dying in a community setting, $\chi^2 = 86.2$, $P<0.001$. The odds of dying in the community were 3.7 times higher with a KIS than without one.

Qualitative findings
Participants. Telephone interviews were conducted with staff in each practice. In 17 practices a GP was interviewed, and in one practice a group interview with two nurses took place. GPs had an average of 19 years' experience (range 3 to 32 years). Ten of the GP participants also worked out-of-hours shifts.

For characteristics of interview participants see Table 2.

Triggers for creating a KIS. Triggers for creating a KIS included an advanced progressive illness, in particular dementia or cancer; frailty along with declining functional status; complex comorbidities; and complex mental health issues. Patients who frequently called an out-of-hours department or were admitted to hospital were also identified for a KIS. A request from the hospital could trigger a KIS. Some GPs started a KIS if they felt the patient would be unable to describe their medical history clearly:

'... so there's the ... nursing home patients, the dying patients, the people who [have] cancer going through a cancer journey if it's at all awkward or complicated ...' (Participant [P] 6, Male [M], GP)

'I would most likely do it when I feel like a patient would be at risk ... if they wouldn't be able to accurately tell their medical history to someone who's working.' (P8, M, GP)

People with cancer were more likely to have a KIS, but there was growing awareness that people with other advanced progressive conditions could benefit:

'I think if you've got cancer you're more likely to get a KIS ... but ... for the last couple of years ... we're all getting better at recognising palliative care needs and hence putting in KIS data on folk with other non-cancer related problems ... severe heart failure, severe respiratory disease, dementia ...' (P4, M, GP)

Some participants noted that it is still harder to remember to start a KIS for people with advanced progressive illnesses other than cancer, as there is often no clear trigger to start the conversation or process:

'I'd say ... it's harder to remember to do them [KIS] for people [with chronic conditions] ... we don't have a particular way of flagging up and reminding people it's a good idea for patients who've got ... more chronic conditions.' (P13, Female [F], GP)

All practices held palliative or anticipatory care planning meetings, though these varied in frequency from weekly to once every 3 months. Following the palliative care meetings, the KIS would be reviewed or updated if new information needed to be added:

'We discuss ... our palliative patients certainly in pretty much every meeting ... we aim to quickly run through the KIS and

Table 2. Characteristics of interview participants

Participant Number	Sex	Role	Experience in role, years	Computer system EMIS/Vision	Out-of-hours experience
1a	F	Nurse	47	EMIS	No
1b	F	Nurse	25	EMIS	No
2	M	GP	32	Vision	Yes
3	F	GP	20	EMIS	No
4	M	GP	15	EMIS	No
5	M	GP	3	EMIS	Yes
6	M	GP	28	EMIS	Yes
7	M	GP	18	EMIS	Yes
8	M	GP	4	EMIS	Yes
9	M	GP	24	EMIS	Yes
10	M	GP	8	EMIS	No
11	F	GP	23	Vision	No
12	F	GP	20	Vision	Yes
13	F	GP	28	Vision	No
14	M	GP	14	Vision	Yes
15	M	GP	28	Vision	No
16	F	GP	19	Vision	No
17	F	GP	25	Vision	Yes
18	M	GP	8	EMIS	Yes

F = female. M = male.

just see if there's anything … new or anything different happen.' (P16, F, GP)

Participants were aware of tools, such as the Supportive and Palliative Care Indicators Tool (SPICT)[19] and the Scottish Patients at Risk of Readmission and Admission (SPARRA) score,[20] to help identify patients for a palliative care approach and a KIS, but formal screening tools were rarely used:

' … we get a feel of the frequency of contact, the nature of their problems and we decide it on that sort of basis, so no formalised way of doing it.' (P6, M, GP)

Discussions about palliative care were started more readily following a significant event, such as a recent diagnosis of advanced progressive illness or hospital admission. It was more difficult for GPs to start discussions about palliative care where a person living at home was gradually becoming frailer. Though, often when they did, they found that the person had already accepted a shift of focus from prolonging life to quality of life:

' … if we're seeing patients just ourselves and they're maybe getting frail [and] elderly then we'd maybe talk to them about palliative care rather than active care — that is quite a difficult group to bring up that subject [with] though … but then actually often people do surprise us and they've got to that conclusion long before we have and are quite happy to have it acknowledged.' (P3, F, GP)

Components of anticipatory care planning within the KIS. All participants perceived the free-text section or 'special notes' as particularly useful:

'Some of us use the special note a lot … I use it every single time … instead of ticking boxes and adding diagnoses actually putting some real-life information in I think is important …' (P5, M, GP)

Clinical information on the level of intervention or treatment for the patient was often documented in the 'special notes' section and deemed very helpful for out-of-hours care. Specifics about the patient and family dynamics, preferred place of death, living situation, and accessibility regarding visiting the person at home, were also often recorded in the 'special notes' section and considered highly useful:

'Out-of-hours [it's] the special notes box that I go for, the most useful bit because of clinical information and ceiling of care … really useful information.' (P12, F, GP)

Perceived usefulness of the KIS for out-of-hours care. Almost all GPs and practice nurses recognised the value of the KIS for out-of-hours and emergency care, especially those who have experience of delivering out-of-hours care:

'I think the concept of having a shared summary with key information between all the different branches of … primary and secondary care is exceptionally helpful, exceptionally useful.' (P13, F, GP)

'I do out-of-hours work as well so I know how helpful it can be when the KIS is updated properly and I also know how unhelpful and frustrating it can be when there's no KIS.' (P9, M, GP)

Suggested improvements. Seven participants used the word 'clunky' to describe the KIS. Several related this to the incompatibility of the KIS with other clinical systems, such as those used by district nurses or social care. Participants also felt that KIS completion involved duplication of effort, as they had to re-enter some

information into the KIS that was already held within the patient's medical record. Many argued that this duplication could be reduced with more intelligent computer systems that could pull data between systems to auto-complete more aspects of the KIS:

'… at the moment there is this … feeling that you're duplicating what you're having to do so it's almost as if that information could be gathered from the notes that you're already putting into the system rather than having to put it in again.' (P17, F, GP)

'Um I think it's clunky … Because firstly to have five different tabs with multiple little boxes as a busy GP that's not likely to be easily filled in very quickly … I think that secondly as an out-of-hours doctor, [it is better] to have a paragraph which is very obvious which flashes up on your out-of-hours system. It gives you the current situation and any plans in one place as opposed to clicking on various screens and scrolling down.' (P7, M, GP)

The anticipatory care plan check box on its own had limited value, as much anticipatory care planning information was contained within the 'special notes' section of the KIS. However, if an additional anticipatory care plan was available, participants said that a link from the KIS to this care plan would be useful:

'I think maybe the anticipatory care planning bit could be expanded … I think it could be a tick box to say like COPD [chronic obstructive pulmonary disease] anticipatory care plans … with a link to print out what the anticipatory care plan was for … they could be added on to that to give to the patient an actual written document with bigger writing that they can see.' (P3, F, GP)

Participants recommended that staff external to primary care should be able to contribute to the KIS.

Some participants proposed that patients and carers should have more information about the KIS so they could request one. One participant suggested that the KIS should be developed in such a way that patients and carers could contribute to them:

'I think the other thing would be better patient and carer information because … they could and should come and ask … "I need a KIS", do people know [about the KIS and to ask]?' (P15, M, GP)

'… trying to develop a KIS that the carers could contribute [to].' (P2, M, GP)

Knowing when to review the KIS was sometimes problematic, a notification as a reminder to review a KIS would help ensure that a KIS is updated more regularly:

'I do some out-of-hours shifts as well … for me … the thing that is most helpful is the special notes but one of the challenges in ensuring that that's up to date. Very often as an out-of-hours GP you're reading special notes that are really out of date and not terribly helpful but you know if that bit's done properly that can be really really helpful.' (P17, F, GP)

A few participants suggested that clear guidance on the type of information to include in the special notes section would be useful:

[A] way to [improve the KIS] would be to encourage use of special note more somehow and perhaps guidance on how that function could be used better.' (P5, M, GP)

DISCUSSION
Summary
The evaluation found that 69% ($n = 712$) of people who died with an advanced progressive illness had a KIS. People with cancer were most likely to have a KIS (80%, $n = 288$), whereas those with organ failure were least likely (47%, $n = 125$). Most people who died with frailty and/or dementia had a KIS that was typically started >1 year before death (Table 1).

The existence of an electronic care coordination record indicates that anticipatory care planning, or perhaps even early palliative care, had commenced. Over two-thirds of people with a KIS had their resuscitation status documented (68%, $n = 482$), and just over half had place of care preferences documented (55%, $n = 390$). However, for many others this information was not recorded, and there was wide variation in levels of KIS completion across practices. Despite this, the vast majority of KIS's were judged to be useful, with the free-text section (special notes) providing the most useful information to guide emergency and out-of-hours care.

The existence of a KIS was positively associated with dying in the community (home, care home, or hospice), and those with a KIS were more likely to die in a community setting (Figure 2).

Drawing on these findings, the authors outline several considerations for the development of electronic care coordination systems (Box 1).

Strengths and limitations
Overall, 1304 patient records were analysed from 18 diverse general practices across four NHS boards, resulting in a more generalisable sample than is possible in single-site studies. The majority of the 17 GPs interviewed did out-of-hours work, thus offering clear insights on electronic care coordination systems from the perspective of professionals working both in-hours and out-of-hours. Two practice nurses were also interviewed; however, a larger number of practice nurses may have provided more diverse responses. The study steering group was composed of stakeholders from academia, policy, ehealth, general practice, specialist palliative care, and community nursing, thus ensuring relevance to practice.

In terms of limitations, ratings of KIS usefulness had face validity, and were based on subjective judgement. The GP researcher needed to be located within each general practice when categorising each KIS (as patient identifiable information was not collected), and independent rating by a second rater was not practical. To guide the researcher, the usefulness categories were generated through consensus within the research team, and examples of each category were agreed in advance to guide judgements.

The records of deceased patients were examined, so data analysis was based on completed KIS. However, healthcare professionals visiting a patient earlier on in their illness may not have complete KIS information as the KIS is updated iteratively over time. Consequently, data on KIS completeness and usefulness reflect KIS content at the end of life only. Earlier on in a person's illness, the KIS may contain less information and may not be as useful.

It is possible that only practices that are proactive in the generation of KIS were identified for participation. However, the present study analyses show a wide variation in KIS utilisation across practices, showing that practices with relatively low levels of KIS generation were also recruited.

Comparison with existing literature
The proportion of people with a shared electronic care coordination record has increased from 60% to 69% when compared with the authors' 2014 evaluation.[8] This is also higher than reported in an evaluation of the Leeds EPaCCS, which found that 26.8% of patients dying with chronic advanced diseases between 2014 and 2015 had an EPaCCS.[4] The present findings also suggest that KIS are now created earlier than before; a median of 45 weeks before death, compared with 18 weeks in 2014.[8]

People with cancer were most likely to have a KIS (80%, $n = 288$), whereas those with organ failure were least likely (47%, $n = 125$). This reflects previous findings.[1,8,21–23] A diagnosis of advanced cancer often triggers anticipatory care planning discussions, but for people with organ failure, the triggers are less clear.[24] Different illness trajectories might affect the appropriate time of starting a KIS. Rapidly progressive cancer has a shorter final phase than frailty, so a KIS may be most relevant in the final weeks to months. In contrast, the slow decline experienced by people with frailty and/or dementia suggests that starting a KIS early would be appropriate.

Informal or family carers play a vital role in caring for the person with an advanced progressive illness and enabling them to remain in a home setting,[25] however carers were not always identified in the KIS. Challenges to identifying carers of people with a terminal illness have been documented.[26,27] General practices could be more proactive in identifying and documenting carer information within the KIS so that informal carers can be contacted quickly in the event of an unexpected or rapid change in the patient's health.

Significantly, the existence of an electronic care coordination record was found to be positively associated with dying in the community (home, care home, or hospice) (Figure 2). This supports findings

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Box 1. Considerations for the development of electronic care coordination systems

- Develop systems that can accommodate free-text information and provide guidance on what might be contained within free-text section(s). This might include clinical information, family dynamics, patient access information, and treatment preferences.
- Optimise interoperability so that relevant clinical information contained within the GP systems can be routinely extracted to populate fields.
- Enable write-access for all key professionals involved in the patient's care.
- Minimise duplication of tick boxes thus reducing inconsistencies.
- Improve documentation of timing information so it is clear when information was last updated, and when it will next be reviewed.
- Include a clear section on carer information, to specify, carer(s)' name(s), relationship to carer, and contact information.
- Brand and promote any new electronic care coordination system so it is viewed by the public as something that is helpful to have for any illness, and that they can request from their GP.

Ethical approval
The NHS South East Scotland Ethics Committee advised that NHS Research Ethics Committee approval was not required as the study constituted a service evaluation. The Public Benefit and Privacy Panel confirmed that approval was not required, as the authors were not collecting identifiable patient data. Written permission from each participating general practice was obtained to access the notes and Key Information Summaries of patients who died in 2017. Written consent from all interview participants was also obtained.

Provenance
Freely submitted; externally peer reviewed.

Competing interests
The authors have declared no competing interests.

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from previous evaluations.[8,12] In a South West England evaluation based on people who died between 2011 and 2012, Wye *et al* found that most people with an EPaCCS died in the community (range 87% to 93%), but noted selection bias given that so few patients expected to die within 1 year actually had an EPaCCS record (range 9% to 13%).[28] Wye *et al* suggested that the high proportion of community deaths may be due to the type of patients with an EPaCCS. In the present evaluation, as most people who died with an advanced progressive illness had a KIS, the likelihood of selection bias was much lower. Given that under optimal conditions most people would prefer to die in the community,[29] the present results add to growing evidence that the existence of an electronic care coordination record is associated with dying in the person's preferred place.[4,10–12]

Implications for research and practice
This evaluation study suggests that the drive to roll out a national electronic care coordination system in Scotland[14,30] is bearing fruit. More people have a KIS at the time of death than reported previously,[8] and KIS are being commenced earlier, suggesting more time for anticipatory care planning and early palliative care to promote health and wellbeing in the final years to months of life. The KIS was relatively new when the authors' earlier evaluation[8] was conducted. National policy prioritising identification and better care coordination for people with advanced progressive illness, alongside a Directed Enhanced Service (DES) for palliative care, is likely to have supported roll-out.[1,14,30] As primary care professionals have gained experience with KIS, they are more likely to create a KIS for patients who may need care out of hours. Local initiatives to commence KIS on admission to care homes have supported identification of those with frailty and/or dementia for a palliative approach. Roll out is set to continue with national incentives to ensure that everyone who would benefit from anticipatory care or a palliative care approach has a KIS.[31]

People with organ failure are still less likely than people with other conditions to have a KIS (Table 1). Similarly, it can be difficult to identify a trigger point to start a KIS for frail older people at home, as opposed to those in care homes. Approaches to identify these groups more systematically for anticipatory care are required. Healthcare Improvement Scotland has published resources and guidance to support identification of people for a palliative approach,[32] and tools such as SPICT are freely available.[19] Computerised searches to identify people in primary care based on who may benefit from a palliative approach could support identification, though need to be further evaluated and implemented.[33,34]

Completeness of KIS could be improved, and more up-to-date information on essential aspects of anticipatory care planning, including patient preferences regarding goals of care, place of care, and treatment escalation, would improve overall KIS quality. The KIS provides a structure to enable coordination, but greater openness to discuss future care needs of those with advanced progressive illness is warranted, alongside regular review and clear documentation of the person's changing needs and preferences.

Further research and evaluation is essential. Electronic care coordination systems are relatively new and rapidly evolving. Conventional research designs, assuming closed systems and experimental methods, are unsuited for such evaluations given the dynamic and constantly evolving contexts in which such systems are embedded. As argued by Greenhalgh and Papoutsi,[35] research designs and methods, such as mixed-method case studies, consider interconnectedness and can provide a rich understanding of how systems come together as a whole. Drawing together different data from multiple sources and future mixed-method evaluations, including case studies, is recommended to understand the contribution of having an electronic care coordination record for a person with an advanced progressive illness, their family, and the wider healthcare system, as well as unintended consequences that might occur when an electronic care coordination record is not in place.

REFERENCES

1. Mason B, Buckingham S, Finucane A, *et al.* Improving primary palliative care in Scotland: lessons from a mixed methods study. *BMC Fam Pract* 2015; **16:** 176.

2. Mason B, Epiphaniou E, Nanton V, *et al.* Coordination of care for individuals with advanced progressive conditions: a multi-site ethnographic and serial interview study. *Br J Gen Pract* 2013; DOI: https://doi.org/10.3399/bjgp13X670714.

3. Petrova M, Riley J, Abel J, Barclay S. Crash course in EPaCCS (Electronic Palliative Care Coordination Systems): 8 years of successes and failures in patient data sharing to learn from. *BMJ Support Palliat Care* 2018; **8(4):** 447–455.

4. Allsop MJ, Kite S, McDermott S, *et al.* Electronic palliative care coordination systems: devising and testing a methodology for evaluating documentation. *Palliat Med* 2017; **31(5):** 475–482.

5. Scottish Clinical Information Management in Practice. *Key information summary.* https://www.scimp.scot.nhs.uk/key-information-summary (accessed 25 Nov 2019).

6. Cumming S, Steel S, Barrie J. Anticipatory care planning in Scotland. *Int J Integr Care* 2017; **17(3):** A130.

7. NHS inform. *Make an anticipatory care plan.* 2019. https://www.nhsinform.scot/care-support-and-rights/palliative-care/planning-for-the-future/make-an-anticipatory-care-plan (accessed 25 Nov 2019).

8. Tapsfield J, Hall C, Lunan C, *et al.* Many people in Scotland now benefit from anticipatory care before they die: an after death analysis and interviews with general practitioners. *BMJ Support Palliat Care* 2016; **pii:** bmjspcare-2015-001014.

9. Leniz J, Weil A, Higginson IJ, Sleeman KE. Electronic palliative care coordination systems (EPaCCS): a systematic review. *BMJ Support Palliat Care* 2019; **pii:** bmjspcare-2018-001689.

10. Smith C, Hough L, Cheung CC, *et al.* Coordinate My Care: a clinical service that coordinates care, giving patients choice and improving quality of life. *BMJ Support Palliat Care* 2012; **2(4):** 301–307.

11. Broadhurst HL, Droney J, Callender T, *et al.* Advance care planning: the impact of Ceiling of Treatment plans in patients with Coordinate My Care. *BMJ Support Palliat Care* 2019; **9(3):** 267–270.

12. Callender T, Riley J, Broadhurst H, *et al.* The determinants of dying where we choose: an analysis of Coordinate My Care. *Ann Intern Med* 2017; **167(7):** 519–521.

13. Department of Health. *Our commitment to you for end of life care. The government response to the review of choice in end of life care.* 2016. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf (accessed 25 Nov 2019).

14. Scottish Government. *Health and social care delivery plan.* 2016. (accessed 25 Nov 2019).

15. NHS National Services Scotland, Information Services Division. *General practice — GP workforce and practice list sizes 2008–2018.* 2018. https://www.isdscotland.org/Health-Topics/General-Practice/Publications/2018-12-11/2018-12-11-GPWorkforce2018-Report.pdf? (accessed 25 Nov 2019).

16. von Elm E, Altman DG, Egger M, *et al.* The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *Prev Med* 2007; **45(4):** 247–251.

17. Gale NK, Heath G, Cameron E, *et al.* Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013; **13:** 117.

18. O'Brien BC, Harris IB, Beckman TJ, *et al.* Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med* 2014; **89(9):** 1245–1251.

19. Highet G, Crawford D, Murray SA, Boyd K. Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. *BMJ Support Palliat Care* 2014; **4(3):** 285–290.

20. Information Services Division Scotland. SPARRA. Health and Social Care. 2010. *What is SPARRA?* https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/SPARRA (accessed 25 Nov 2019).

21. Zheng L, Finucane A, Oxenham D, *et al.* How good is primary care at identifying patients who need palliative care? A mixed methods study. *Eur J Palliat Care* 2013; **20(5):** 216–222.

22. Harrison N, Cavers D, Campbell C, Murray SA. Are UK primary care teams formally identifying patients for palliative care before they die? *Br J Gen Pract* 2012; DOI: https://doi.org/10.3399/bjgp12X641465.

23. Evans N, Costantini M, Pasman HR, *et al.* End-of-life communication: a retrospective survey of representative general practitioner networks in four countries. *J Pain Symptom Manage* 2014; **47(3):** 604–619.

24. Kimbell B, Boyd K, Kendall M, *et al.* Managing uncertainty in advanced liver disease: a qualitative, multiperspective, serial interview study. *BMJ Open* 2015; **5(11):** e009241.

25. Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006; **332(7540):** 515–521.

26. Carduff E, Finucane A, Kendall M, *et al.* Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources. *BMC Fam Pract* 2014; **15:** 48.

27. Carduff E, Jarvis A, Highet G, *et al.* Piloting a new approach in primary care to identify, assess and support carers of people with terminal illnesses: a feasibility study. *BMC Fam Pract* 2016; **17:** 18.

28. Wye L, Lasseter G, Simmonds B, *et al.* Electronic palliative care coordinating systems (EPaCCS) may not facilitate home deaths: a mixed methods evaluation of end of life care in two English counties. *J Res Nurs* 2016; **21(2):** 96–107.

29. Gomes B, Calanzani N, Gysels M, *et al.* Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC palliat care* 2013; **12:** 7.

30. Scottish Government. *Strategic framework for action on palliative and end of life care.* 2015. https://www.gov.scot/publications/strategic-framework-action-palliative-end-life-care (accessed 25 Nov 2019).

31. Scottish Government. *The Primary medical services directed enhanced services (Scotland) 2019 palliative care scheme. NHS Circular: PCA(M)(2019)06.* 2019. https://www.sehd.scot.nhs.uk/pca/PCA2019(M)06.pdf (accessed 25 Nov 2019).

32. Healthcare Improvement Scotland. *Palliative and end of life care Identification Tools Comparator.* 2019. https://ihub.scot/improvement-programmes/living-well-in-communities/palliative-and-end-of-life-care/palliative-and-end-of-life-care-identification-tools-comparator (accessed 25 Nov 2019).

33. Mason B, Boyd K, Murray SA, *et al.* Developing a computerised search to help UK general practices identify more patients for palliative care planning: a feasibility study. *BMC Fam Pract* 2015; **16:** 99.

34. Mason B, Boyd K, Steyn J, *et al.* Computer screening for palliative care needs in primary care: a mixed-methods study. *Br J Gen Pract* 2018; DOI: https://doi.org/10.3399/bjgp18X695729.

35. Greenhalgh T, Papoutsi C. Studying complexity in health services research: desperately seeking an overdue paradigm shift. *BMC Med* 2018; **16(1):** 95.