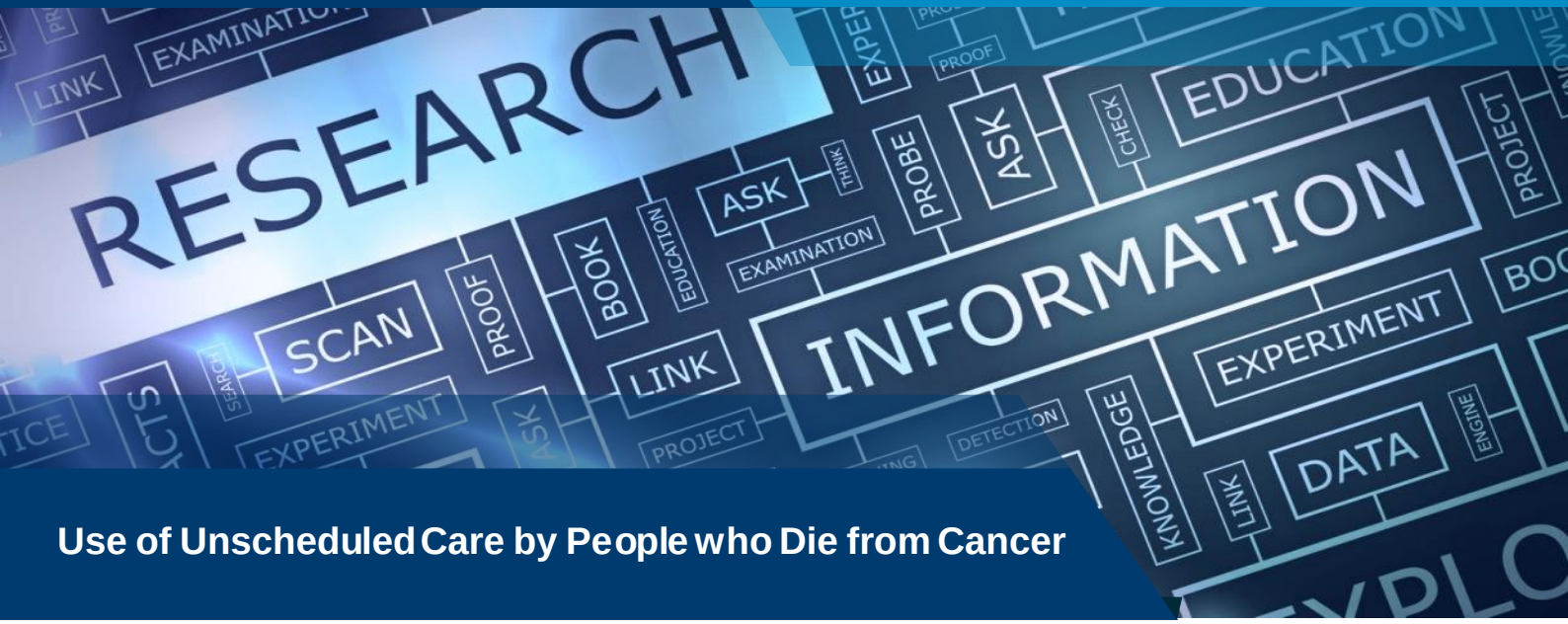
CHIEF SCIENTIST OFFICE

CODE: CAF/17/06

RESEARCH PROJECT BRIEFING




# Use of Unscheduled Care by People who Die from Cancer

## AIMS

To describe demographic, clinical, temporal and prescribing factors that are associated with unscheduled care use by cancer decedents in their last year of life.

## KEY FINDINGS

- Most people who die from cancer ('*cancer decedents*') (77.9%) attended unscheduled care in the year before death. Most cancer decedents attended GP Out-of-Hours only (GPOOH) (n*=1,070, 56.2%), others attending Accident & Emergency (A&E) only (n=204, 10.7%), or both GPOOH and A&E (n=630, 33.1%).
- Cancer decedents living in rural areas were less likely to attend unscheduled care.
- The commonest reason for attending GPOOH were: Palliative Care *(care given to improve symptoms without aiming to cure the disease*), pain, breathlessness, infection and gastrointestinal symptoms. In A&E, pain, 'unwell', falls, acute neurological conditions and breathlessness were the commonest presentations.
- Older cancer decedents and those with lung cancer were more likely to receive late diagnoses than younger ones and those with other malignancies.
- One in five cancer decedents were frequent users (≥5 attendances/year) of unscheduled care, and accounted for over half (57.7%) of unscheduled care attendances.
- Women, younger cancer decedents, and people with GI symptoms and infections were more likely to use GPOOH compared to A&E.
- Cancer decedents presenting with pain, breathlessness, acute neurological symptoms, or 'unwell' or 'palliative care' were more likely to use A&E compared to GPOOH.
- Cancer decedents who attended GPOOH, rather than A&E, had lower odds of being admitted to hospital following unscheduled care contact.
- Both GPOOH and A&E showed a substantial increase in attendances close to patient's time of death. Over half of all attendances occurred in the last 12 weeks of life.
- Three in four cancer decedents were prescribed strong opioids, two-thirds of whom were also prescribed laxatives and/or anti-emetics, one in ten were prescribed breakthrough medication.
- Cancer decedents who attended A&E, vs those who did not, had a higher number of prescriptions for most analgesia; those who attended GPOOH, vs those who did not, had a higher number of prescriptions for all drugs.
- Frequent or very frequent attenders received more than double the number of prescriptions per person that non-attenders.
- The term 'n' refers to the number of patients or attendances in a given group, followed by the percentage of the total that that number represents.

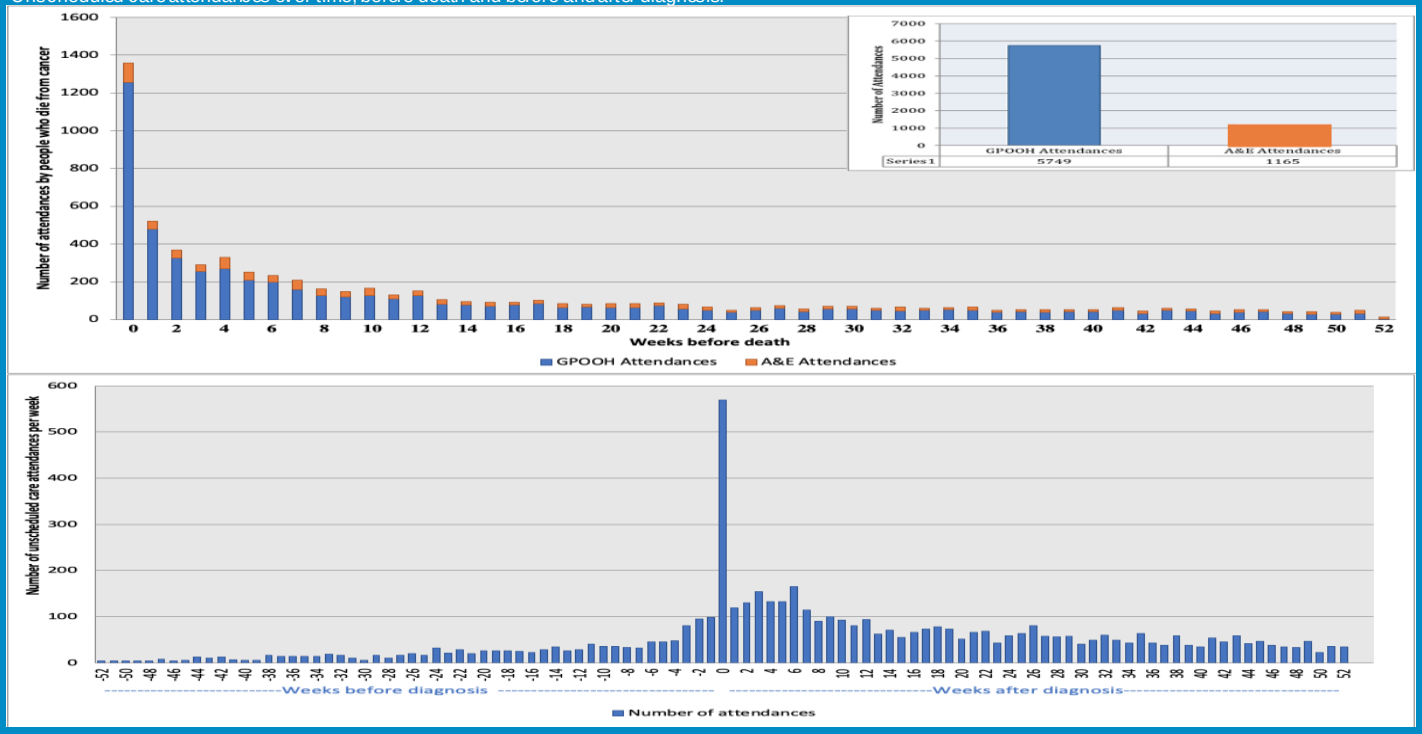
## WHAT DID THE STUDY INVOLVE?

The overall design was a retrospective cohort study of all 2,443 residents of the Tayside region of Scotland who died from cancer over a 30-month period from 2012 to 2015. The population was identified posthumously using General Register Office death registration data and included all those whose cause of death was cancer in position 1 of the death certificate. Routinely collected clinical data for all attendances in the last year of life was linked using the Community Health Index (CHI) number, which is used as a single patient identifier throughout NHS Scotland. CHI-linked data were obtained from the Cancer Registry (Scottish Morbidity Records), Scottish Executive Urban Rural Classification (SEURC classifies postcodes in terms of remoteness and rurality), Scottish Index of Multiple Deprivation (SIMD, categorises deprivation into quintiles from SIMD1 [most deprived] to SIMD5 [least deprived]). Data were cleaned, anonymised, stored and analysed in the SafeHaven platform in the Health Informatics Centre (HIC) at the University of Dundee. Coding of clinical attendances was done by clinicians at the time of attendance and recorded in the medical notes. Frequent users were defined as those with 5 or more attendances per year, very frequent users were defined as those with 10 or more attendances per year. All analyses were conducted using SPSS (Statistical Package for Social Sciences) version 25.

## WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

The majority of cancer decedents attended unscheduled care in the year before death. Most only attended GPOOH (n=1,070;56.2%), with the rest attending A&E only (n=204, 10.7%), or both (n=630, 33.1%). Age, gender, deprivation and cancer type were not significantly associated with unscheduled care attendance. People living rurally were less likely to attend unscheduled care (AOR=0.64(0.50 to 0.82)). Pain was the commonest clinical reason for presenting (GPOOH:10.5%, A&E:28.8%). 11.9% of people dying from cancer were frequent (≥5 attendances/year) users and accounted for over half (57.7%) of unscheduled care attendances. Many attendances occurred in the last week (19.7%), four weeks (36.7%) and twelve weeks (60.3%) of life. Prescribing of palliative care medications increased towards the end of life. Eight in ten cancer decedents were prescribed opioids; however, only two-thirds were co-prescribed laxatives or anti-emetics, and only one in ten were prescribed breakthrough medication. Cancer decedents who attended unscheduled care received more prescriptions per person in all drug categories, compared to those who did not attend unscheduled care. Frequent and very frequent attenders received more than double the number of prescriptions per person for every drug category compared to non-attenders. Multiple demographic factors, cancer type, and timing of diagnosis influenced whether or not cancer decedents were prescribed particular drugs or drug categories in their last year of life.

Unscheduled care attendances over time, before death and before and after diagnosis:



## WHAT IMPACT COULD THE FINDINGS HAVE?

- Improvements for patients, policy and practice could include:
- Recognition of the key role that unscheduled care, particularly GPOOH, plays in meeting community care needs for people dying from cancer.
- Providing education and training in managing patients with palliative care needs, as well as common presenting complaints in patients with advanced cancer, for all clinicians working in unscheduled care.
- Enhancing recognition of the key symptoms of pain, breathlessness, GI symptoms, and infection, that result in unscheduled care use.
- Using 'trigger' events or times, which increase likelihood of future unscheduled care use, to implement additional levels of care and support for patients.
- Enhanced education and support for patients and families to equip them to deal with the dying process and facilitate appropriate self-care.

## HOW WILL THE OUTCOMES BE DISSEMINATED?

These findings have been, and will continue to be, disseminated through publication in high-impact clinical journals, presentations at academic conferences, targeted dissemination of results to relevant third-sector organisations, including PATCH Scotland and workshops and seminars to lay and policy audiences including the Scottish Palliative Care Research Forum, the Scottish Partnership for Palliative Care, and NHS Boards. Current publications from this research include:

- *Mills, SEE, Geneen LJ, Buchanan D, et al. Factors associated with unscheduled care use by cancer decedents: a systematic review with narrative synthesis. BMJ Supportive & Palliative Care. Published Online First: 13 October 2020. doi: 10.1136/bmjspcare-2020-002410*
- *Mills SEE, Buchanan D, Guthrie B, Donnan P, Smith BH. Factors affecting use of unscheduled care for people with advanced cancer: a retrospective cohort study in Scotland. British Journal of General Practice. 2019;69:e860–8.doi:10.3399/bjgp19X706637*

Next steps in research include further qualitative analysis of the free text information collected in the GP Out-of-Hours dataset, and generation of a Clinical Prediction Risk tool to determine individual's personal risk of unscheduled care attendance.

## CONCLUSION

Unscheduled care attendance by cancer decedents was substantially higher than previously reported, increased dramatically towards the end of life, was largely independent of demographic factors and cancer type, and was commonly for pain and other palliative care symptoms. Most cancer decedents seen in unscheduled care were close to their date of death. Prescribing in the last year of life was associated with demographic, cancer type and temporal factors, and was associated with type and frequency of unscheduled care use.

## RESEARCH TEAM & CONTACT

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**Additional Information**

Proposed date for viva 16/2/2021