

# PREPARE: Evaluation of Electronic Palliative Care Coordination Systems to support advance care planning for people living with life-threatening conditions: A retrospective observational cohort study

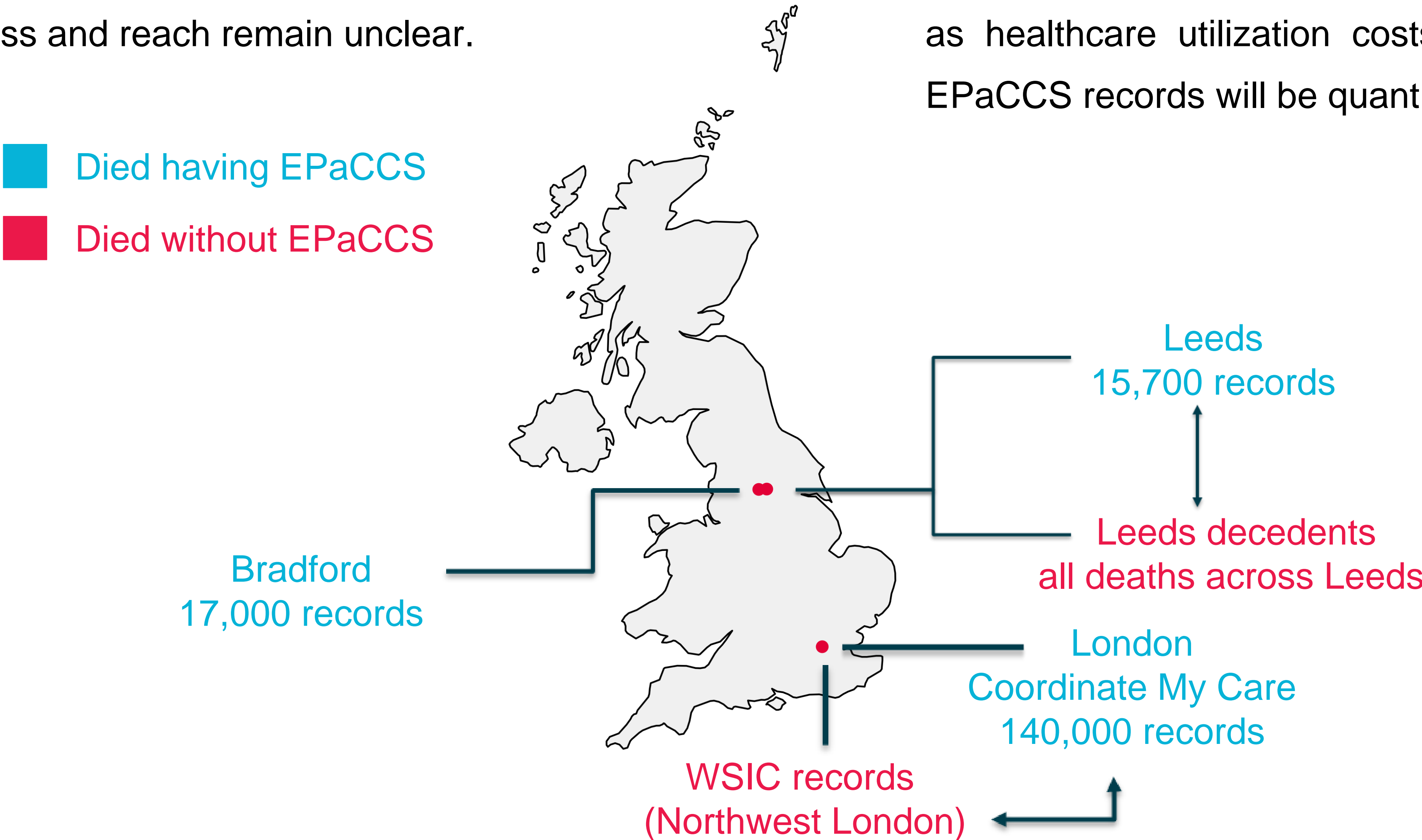


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## Introduction

End-of-life care in the UK often takes place in hospitals, contrary to many people's preference for home care. Hospital care at the end of life is associated with invasive, costly and sometimes futile interventions. Electronic Palliative Care Coordination Systems (EPaCCS) have been introduced to support advance care planning (ACP) and to digitally document and share patients' end-of-life preferences across health services. Despite their widespread implementation their effectiveness and reach remain unclear.



## Methods

We will describe the data fields within EPaCCS systems, describe their creation and content across three regions (London, Bradford, and Leeds). Social determinants of health (age, gender, ethnicity, and socioeconomic status) will be explored for their association with EPaCCS creation and the completion of ACP elements (ceiling of treatment, preferred place of care, and death and resuscitation status). Location of death and hospital utilization in the last 90 days of life as well as healthcare utilization costs for patients with and without EPaCCS records will be quantified.

## Objectives

1) Examine EPaCCS utilization patterns; 2) examine the association between social determinants of health and EPaCCS creation and end-of-life care decision-making; 3) compare EPaCCS outcomes and utilisation of health services for individuals with and without EPaCCS records.

## Design

A retrospective observational cohort study will be conducted to analyse EPaCCS data from three regions in the UK. EPaCCS data will be linked with longitudinal primary/secondary and community care data in a quasi-experimental analysis to examine end-of-life care outcomes of those with and without EPaCCS records.

## Results

The findings will provide novel public health insights into the characteristics of individuals with an EPaCCS record, their impact on end-of-life decision-making and health service use. The study will present a comprehensive analysis of healthcare outcomes and costs associated with EPaCCS use, offering valuable information and insights for policymakers, health professionals and the public.

## Conclusion

Whilst widely endorsed by the NHS, little evidence exists of EPaCCS benefits to patients, their families and society. This study will provide patients, clinicians, policymakers and health commissioners with valuable information into their continued use, where potential changes should be considered to enhance their delivery and implementation, and to what extent issues of inequity exist together with recommendations to 'level up' care.

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