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Electronic Palliative Care Coordination Systems (EPaCCS): how widely are systems being implemented and what are they trying to achieve

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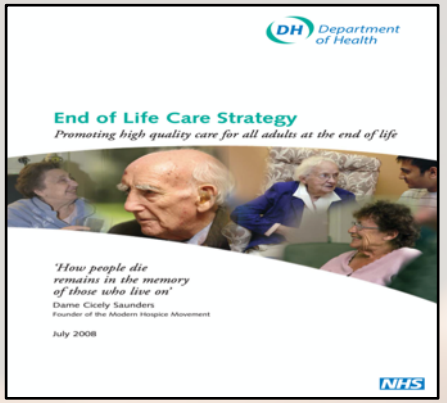
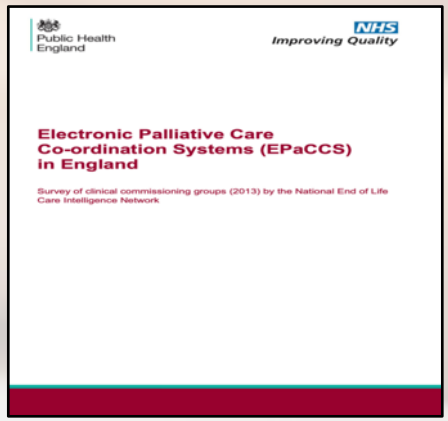
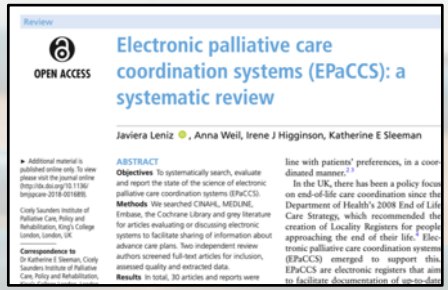
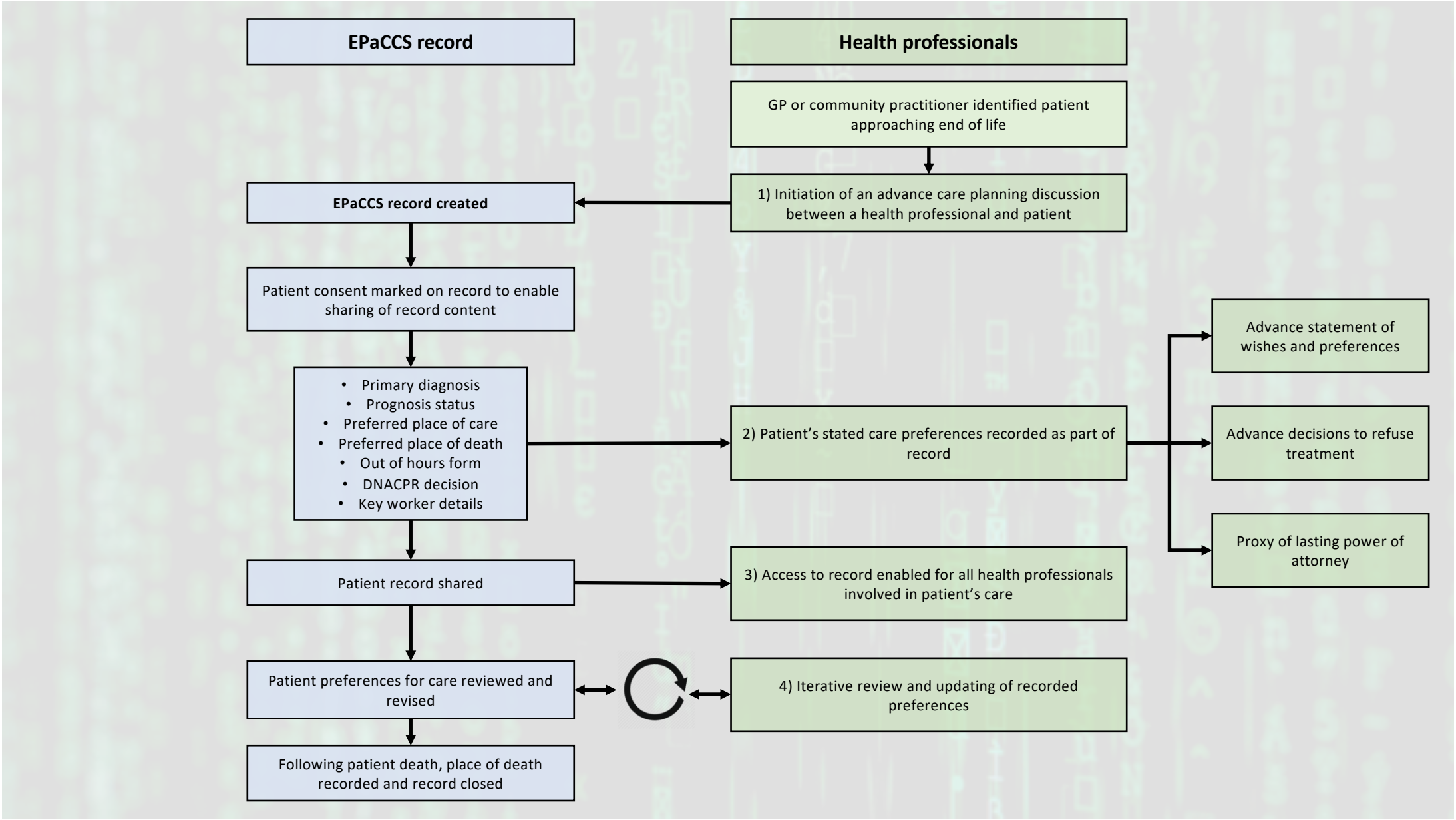
- **2008:** The End of Life Care Strategy - a mechanism for enabling coordination of care
- **2012:** Information standard for EPaCCS (SCCI1580: Palliative Care Co-ordination: Core Content)
- **2013:** Public Health England survey - 30% had operational EPaCCS, 53% planning for implementation, 5% no EPaCCS
- **2020:** Leniz et al review of evidence base underpinning EPaCCS in BMJ Supportive and Palliative Care








EPaCCS record
Health professionals
GP or community practitioner identified patient approaching end of life
1) Initiation of an advance care planning discussion between a health professional and patient
EPaCCS record created
Patient consent marked on record to enable sharing of record content
• Primary diagnosis
• Prognosis status
• Preferred place of care
• Preferred place of death
• Out of hours form
• DNACPR decision
• Key worker details
2) Patient's stated care preferences recorded as part of record
Advance statement of wishes and preferences
Advance decisions to refuse treatment
Proxy of lasting power of attorney
Patient record shared
3) Access to record enabled for all health professionals involved in patient's care
Patient preferences for care reviewed and revised
4) Iterative review and updating of recorded preferences
Following patient death, place of death recorded and record closed

Building on sand: digital technologies for care coordination and advance care planning

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ABSTRACT

Approaches using digital technologies to support advance care planning (ACP) and care coordination are being used in palliative and end of life care. While providing opportunities to facilitate increases in the completeness, sharing and availability of care plans, the evidence base underpinning their use remains limited. We

admissions and a decreased likelihood of hospital death.[6] However, the efficacy of ACP in palliative and end of life care is contested and remains controversial. Multiple, high-quality studies indicate ACP has no effect on patient outcomes[7 8] and its documentation does not serve as a reliable and valid quality indicator of

multiple and varied versions being implemented across the UK. We draw on findings from the currently limited evidence base underpinning EPaCCS and consider future steps to enhance their implementation for palliative and end of life care. The questions raised have broad relevance to technology-mediated sharing of care plans and care coordination, regardless of the technology platform or country.

CONTEXT OF EPACCS IN ENGLAND

EPaCCS have been implemented across a third of the 213 commissioning regions for healthcare in England when last surveyed in 2013.[13] An EPaCCS record is created by a health professional and is designed to be shared across all healthcare

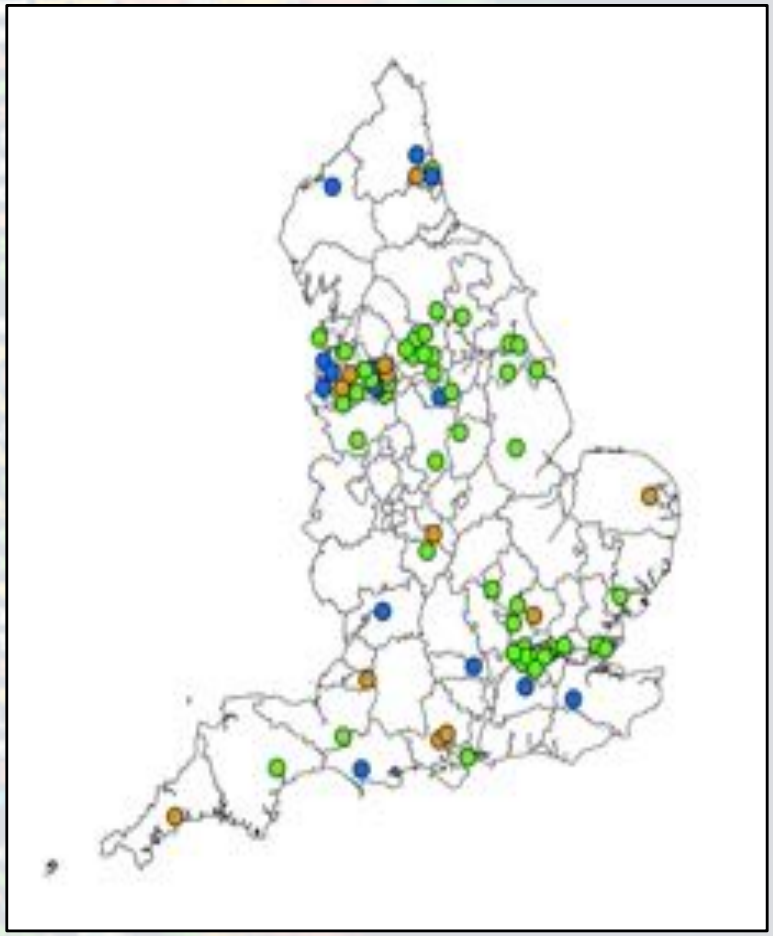
Methods

- National cross-sectional online survey of end-of-life care commissioning leads for Clinical Commissioning Groups (CCGs) in England

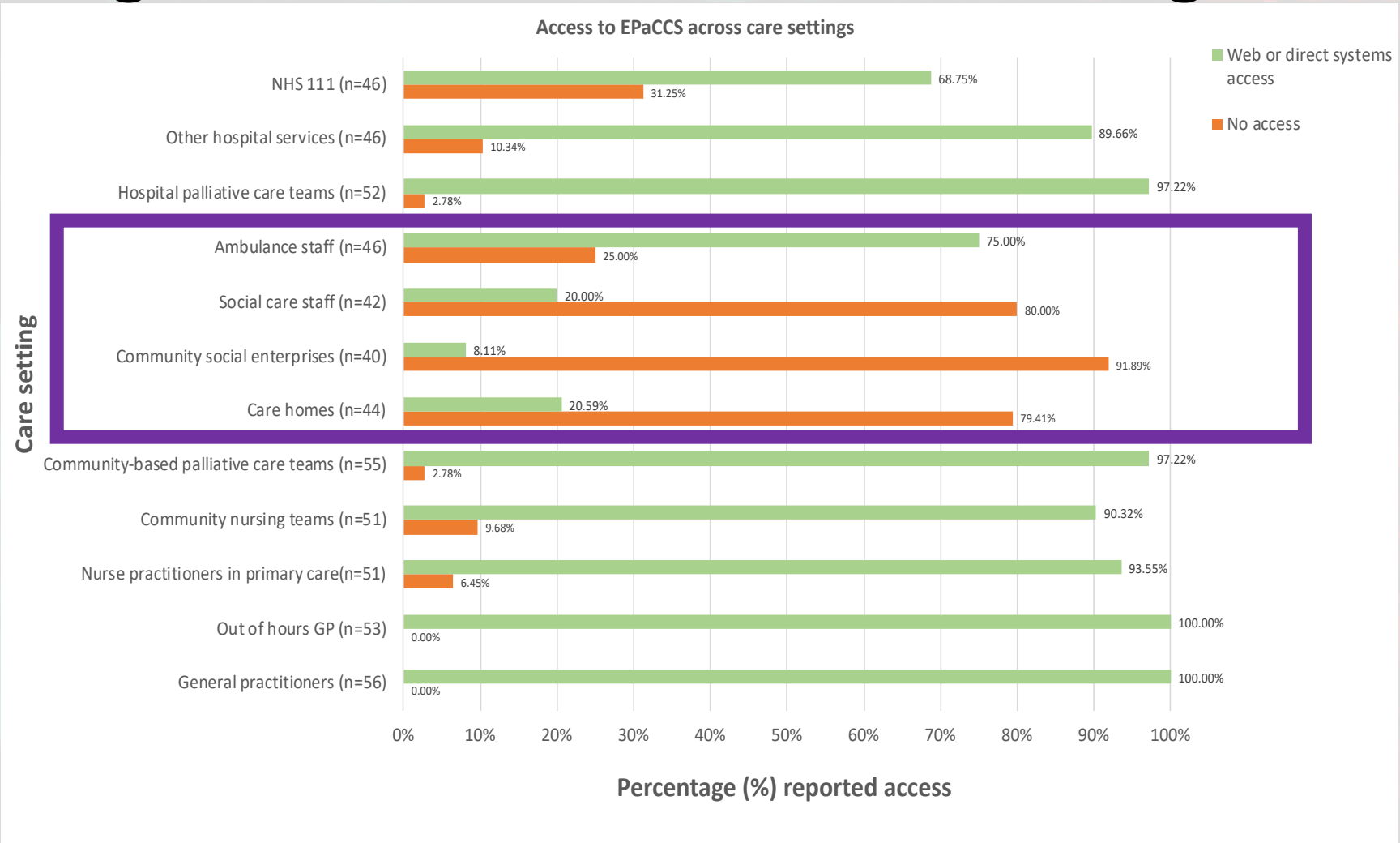
- We requested responses relating to:
  - Current implementation status of EPaCCS
  - Role of EPaCCS in information sharing
  - Intended impact of EPaCCS and its measurement
  - Routine patient-level data relating to EPaCCS

Findings – current implementation

- Out of 135 CCGs, 85 (63.0%) responded, with 57 (67.1%) having operational EPaCCS
    - 57 CCGs With EPaCCS
    - 13 CCGs In planning stage
    - 15 CCGs No EPaCCS



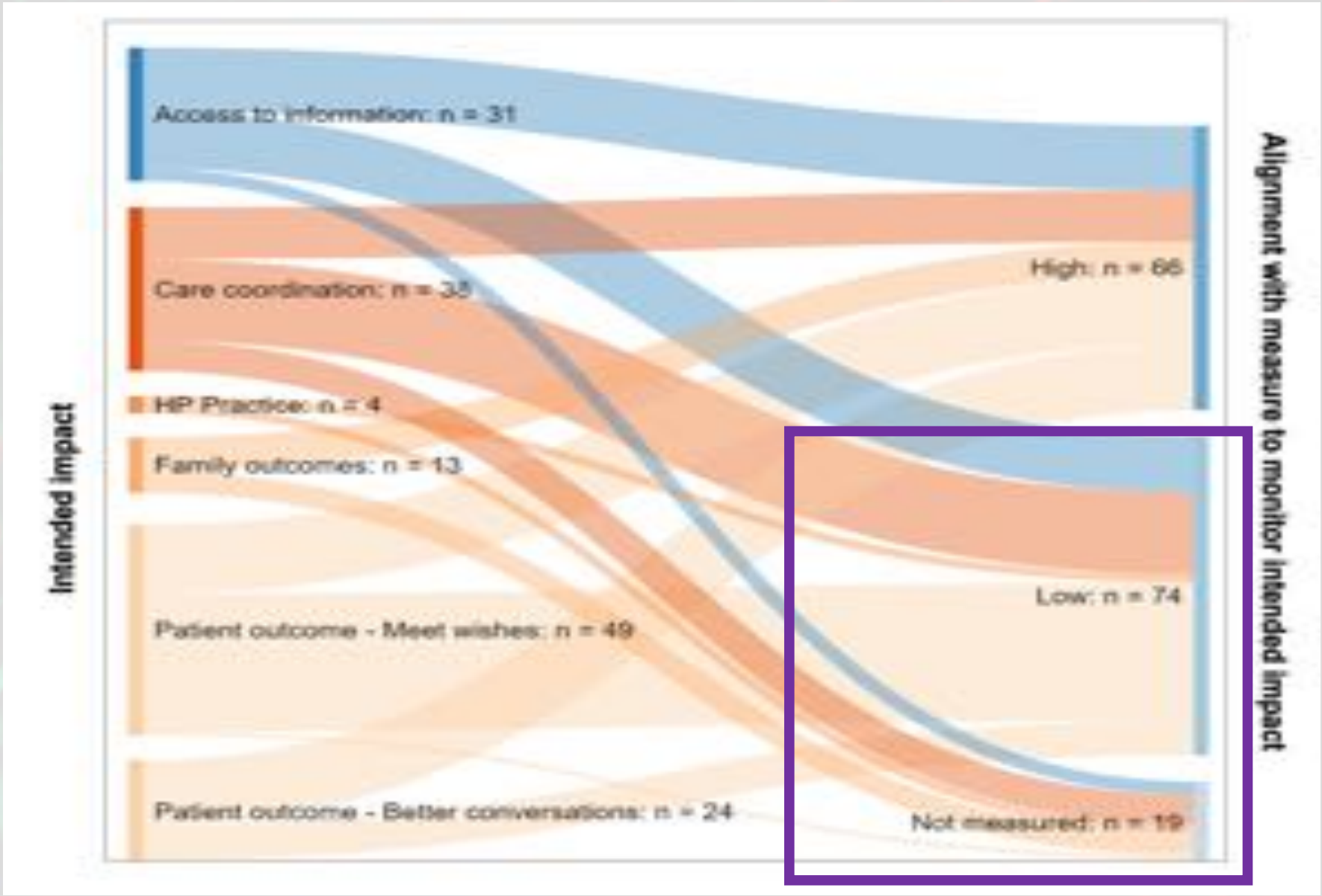
Findings – role in information sharing



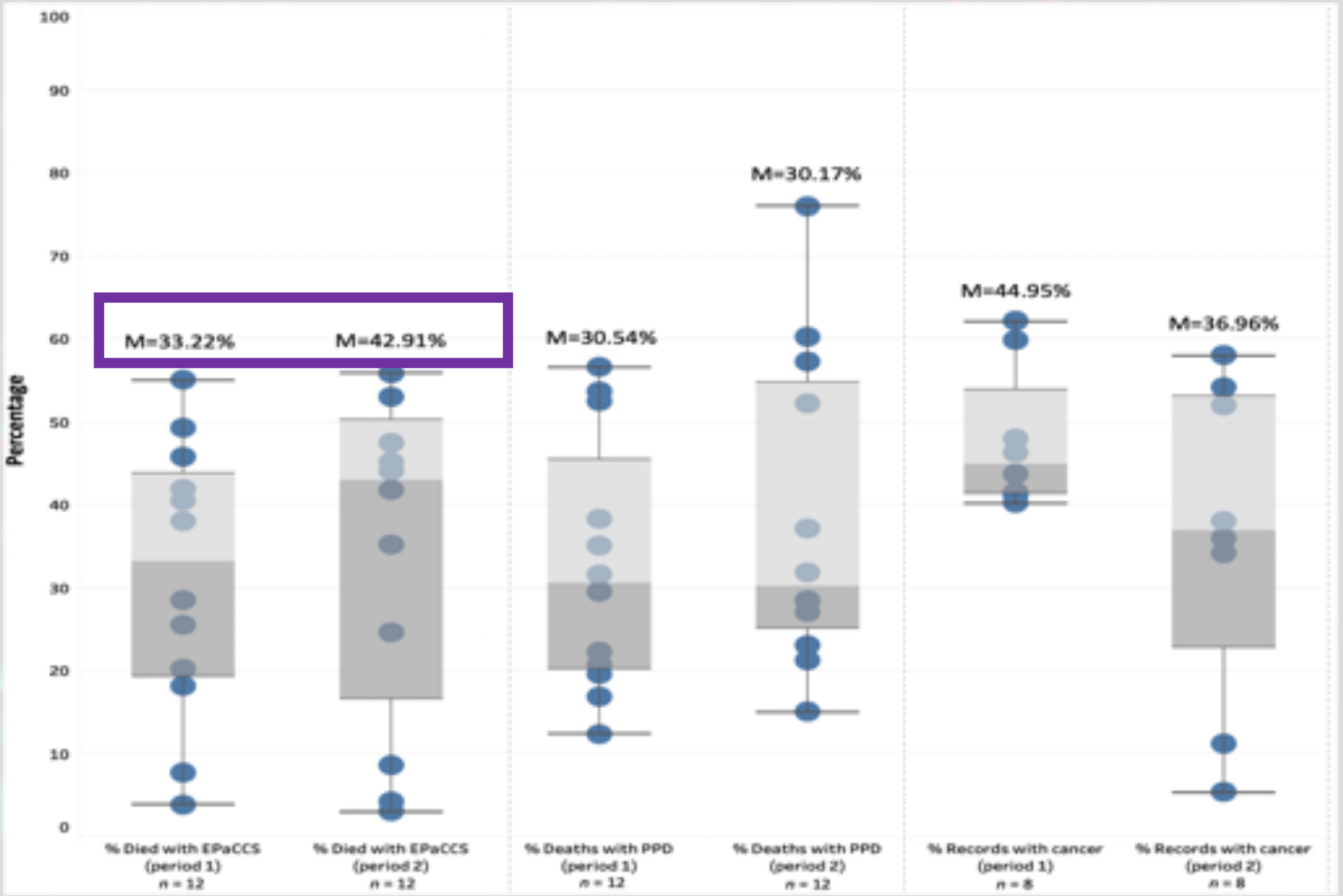
Findings – intended impact

Theme	Intended Impact	Number of responses		Total CCGs (*N= 69*) n (%)
		With EPaCCS (*N = 57*) n (%)	Planning* (*N= 12*) n (%)	
Access to information	Timely access to documented and shared care plans and patient preferences for care	28 (47)	3 (25)	31 (45)
Care coordination	Support coordination, continuity and delivery of patient-centred care between different health professionals and services.	29 (49)	9 (75)	38 (55)
Health professional practice	Improve identification of patients with palliative diagnosis and in last year of life	4 (7)	0	4 (6)
Family outcomes	Improve experience of end-of-life care for families	12 (20)	1 (8)	13 (19)
Patient outcomes	Increase likelihood of respecting patient wishes and priorities - *e.g. PPC/D, CPR*	40 (68)	9 (75)	49 (71)
	Better conversations – (*e.g. appropriate timing and content*)	22 (37)	2 (17)	24 (35)

Findings


Intended impact
Access to information: n = 31
Care coordination: n = 38
HP Practice: n = 4
Family outcomes: n = 13
Patient outcome - Meet wishes: n = 49
Patient outcome - Better conversations: n = 24
High: n = 66
Low: n = 74
Not measured: n = 19
Alignment with measure to monitor intended impact

Findings


Percentage
100
90
80
70
60
50
40
30
20
10
0
M=33.22%
M=42.91%
M=30.54%
M=30.17%
M=44.95%
M=36.96%
% Died with EPaCCS (period 1) n = 12
% Died with EPaCCS (period 2) n = 12
% Deaths with PPD (period 1) n = 12
% Deaths with PPD (period 2) n = 12
% Records with cancer (period 1) n = 8
% Records with cancer (period 2) n = 8

Conclusions

- There is considerable variation in how EPaCCS have been implemented across England
- Most EPaCCS do not allow sharing of information with care homes and social care staff, who often have central roles in end-of-life care
- There is limited alignment between the intended impact of EPaCCS and the current methods being used to monitor and assess whether impact is being realised
- Around one-third of people have an EPaCCS record at death and these are more commonly created for people with a diagnosis of cancer