

# The Methodological Challenges of Rapid Data Collection in a Pandemic

Lucy Hetherington<sup>1</sup>, Kirsty Tolmie<sup>2,3</sup>, Christopher McNally<sup>1</sup>, Sarah Bowers<sup>4</sup>, Isa Ouwehand<sup>1</sup>, Calum Hunter, Collette Harte<sup>4</sup>, Elizabeth Anderson<sup>5</sup>, Paul Keeley<sup>4,6</sup>

<sup>1</sup> Queen Elizabeth University Hospital, Glasgow, <sup>2</sup> Beatson West of Scotland Cancer Centre, Glasgow <sup>3</sup> Gartnavel Hospital, Glasgow; <sup>4</sup> Glasgow Royal Infirmary, Glasgow; <sup>5</sup> Inverclyde Royal Hospital, Greenock; <sup>6</sup> MVLS, University of Glasgow

**Abbreviated abstract:** Demographic data, patient symptoms and outcomes were captured, alongside drugs and doses used to control symptoms in COVID-19 positive patients referred to Hospital Palliative Care Team (HPCT) services in NHS Greater Glasgow and Clyde during a four-week period in March/April 2020. This resulted in the largest data set to date on the subject. We reflected on the challenges faced collecting data retrospectively at the peak of the pandemic.

## Related publication:

Hetherington L, et al. COVID-19 and Hospital Palliative Care—A service evaluation exploring the symptoms and outcomes of 186 patients and the impact of the pandemic on specialist Hospital Palliative Care. *Palliative Medicine*. 2020 Aug 14.

# Previous work, challenge, and approach

- The role of palliative care in a pandemic has not been clearly established.
- When it became evident that significant mortality and symptom burden accompanied the global pandemic in early 2020, the need for clinical information to inform clinical decisions became an urgent research priority.
- The COVID-19 pandemic presented clinicians with a unique set of challenges in both the understanding of the symptom complexes and in assimilating new information rapidly whilst also managing a high clinical workload.

# Techniques and Methods

## Methods

- We reflected on the challenges faced collecting data retrospectively on COVID-19 positive patients at the peak of the pandemic.
- These data were collected on patients referred to Hospital Palliative Care Team (HPCT) services in NHS Greater Glasgow and Clyde during a four-week period in March/April 2020.
- Demographic data, patient symptoms and outcomes were captured, alongside drugs and doses used to control symptoms.
- This resulted in the largest data set to date on the subject and was published in the journal, *Palliative Medicine*.

# Results and Conclusions

## **The process outlined a number of methodological challenges in collecting and analysing data:**

- The project could not capture data on patients with palliative care needs who were not referred to HPCTs.
- Changes in the way HPCTs practiced at the height of the pandemic may have resulted in loss of documented referrals, particularly when face-to-face reviews weren't required (e.g. telephone advice/ward visits).
- Data collection relied on retrospective analysis, multiple data collectors and extraction of data from clinical notes, some of which were incomplete.
- Strict inclusion criteria of PCR positive meant data on patients likely to have had COVID-19 (and treated clinically as such) was not captured.
- Symptom analysis relied on clinical notes rather than a validated symptom assessment tool.
- Drug doses collated and reported were prescribed on the advice of the HPCT. These may have differed from those prescribed for symptomatic patients with COVID-19 under the care of non-specialist teams. It is not possible to assess how differences in prescribing may have impacted on patient care, which could have been a focus of education.