

Call for Papers for a special issue of *Palliative Medicine*: “Big Data in Palliative and End-of-Life Care”

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We are delighted to announce a call for papers for a special issue of *Palliative Medicine* about big data in palliative and end-of-life care.

Big data is often defined by four Vs: it refers to any source of information of uncommonly large size (“volume”), composed of heterogeneous types of data (“variety”) created, updated and processed frequently (“velocity”) and of sufficient quality and accuracy (“veracity”) to generate valuable knowledge. These data are most often not collected for research purposes. They originate from different sources, for instance reimbursement claims, electronic medical records, administrative and census data, disease-specific registries, biobanks, wearable devices and sensors, or connected objects. Big data can sometimes be linked to other sources of information created specifically for research purposes (e.g. population-based surveys) or for monitoring patients in the clinical setting (e.g. connected medical devices).

Big data has powerful applications in healthcare research. It enables for generating scientific hypotheses, for comparing the effectiveness and the safety of various interventions in settings where randomized controlled trials may not be ethically or practically feasible, for evaluating the quality of care provided to patients in different countries, for monitoring patients in real-time without disrupting their daily life, or for making predictions based on seemingly imperceptible data patterns.

However, the specific role of big data in palliative and end-of-life care is not yet well established. There is still a substantial knowledge gap in how we could improve the life of people with advanced disease. Amid persistent inequalities and insufficiencies in the provision of high-quality palliative care, understanding what works and what doesn’t is essential to prioritize and foster the most adequate interventions. It is also important that we gain a better sense of what the patients, their family caregivers and the healthcare professionals around them need from the time of diagnosis until death. Routinely collected data could potentially address some of these challenges. The trove of real-world clinical information available to researchers enables them to reconstruct the healthcare utilisation of large groups of persons at a fraction of the cost of population-based surveys and without their widely acknowledged methodological caveats (e.g. selection bias, attrition due to major cognitive impairment, recall bias). Moreover, record-linkage with biological data stored in large biobanks will allow for investigating the complex interplay between genotype, phenotype, and end-of-life outcomes – for instance the progression of symptoms or the susceptibility to treatment-related adverse events.

Our aim is to publish rigorous original research, reviews and methodologies making use of big data in the context of palliative or end-of-life care. We seek high-quality contributions from across health and social sciences that have the potential to appeal to an international audience of clinicians, researchers, managers, educators and policy makers. Please note that a high priority will be given to original research questions of clinical, public health or societal relevance, relying on innovative methods. Strictly descriptive studies will be given low priority, unless they touch upon population, groups or outcomes that are currently understudied and for which the use of routinely collected is suitable.

Potential topics include, but are not limited to:

- Comparative effectiveness of pharmacological and non-pharmacological interventions for patients with advanced disease and/or their family caregivers;
- International and European comparisons in the patterns of care near the end of life;
- Social, economic or geographical inequalities in the provision of palliative care;
- Validation of predictions and prognostic tools based on routinely collected data for patients with palliative care needs;
- Text and image mining approaches for analyzing unstructured data in palliative care research;
- Evaluation of complex healthcare and social needs from diagnosis until the end of life,
- Methodological challenges in palliative care research relying on big data;
- Legal and ethical issues in big data palliative care research related to privacy, informed consent, and transparency;
- Patient and public involvement (PPI), bringing the perspective of patients in palliative care research based on big data;

Authors should submit an electronic copy of their complete manuscript through Manuscript Central: <http://mc.manuscriptcentral.com/palliative-medicine>.

Before submission authors should carefully read the journal’s Author Guidelines <http://www.uk.sagepub.com/journals/Journal201823?#tabview=manuscriptSubmission>, as papers that do not meet these requirements will not be processed through the system.

Deadline for submissions is Friday 17 April 2020.

For further information, please contact the Editorial Office: debbie.ashby@bristol.ac.uk