



F1000

Health Open Research Case Study:

**Open research, policy-making,
and patient impact at Marie Curie**

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Evidence-based end-of-life care campaigns

Research funded by [Marie Curie](#), (the UK's leading end-of-life charity and charitable funder of palliative care research and a member of the Association of Medical Research Charities) published on [Health Open Research](#) shows the links between open research, policy-making, and patient impact.

This case-study discusses two research projects' influence on policy, including England's Health and Care Act and their influence on academics and researchers, including the [World Congress of the European Association for Palliative Care](#). Bringing together both researcher and lived experience perspectives, the case study demonstrates how health research can deliver real-world impact – improving lives for patients, their families and care givers – and how open research practices (including [open access](#), [transparent peer review](#) and [FAIR data](#)) can support this by enabling research to be published quickly and to be accessible whilst open peer review is undertaken.



Open publishing and transparent campaigning

This case study tells the story of how research funded by one health care charity utilized F1000's open research publishing process to make their research open and readily available whilst peer review is undertaken.

The UK's [Association of Medical Research Charities](#) is a founding partner of Health Open Research. The importance of open research publishing that accelerates the positive impact of health research— from lab-bench to bedside, is described by Dr Catriona Manville, AMRC's Director of Research Policy:

Over the last few years, we've seen inspiring examples of how publishing openly can help to accelerate the real-world benefits of medical research, including this Marie Curie funded research. The expansion of Health Open Research is an exciting prospect, providing new possibilities.

Marie Curie: building open into end-of-life and palliative care research

Marie Curie's policy and campaigns are evidence-based and that evidence is drawn from Marie Curie funded research. Any research funded by Marie Curie has 'open' hardwired in, from grant application to publication, to ensure research findings are [freely and widely accessible](#) to those who can use it to make a difference for people affected by dying, death and bereavement, such as policymakers and practitioners.

This case study focuses on two Marie Curie research studies and data published on Health Open Research between 2021 and 2022. One study explored the impact of Covid on hospices and palliative care in England's West Midlands region. The other was a documentary analysis of end-of-life and palliative care in strategies for England's Integrated Care Systems (the joined-up planning and delivery of health and care services in England). Both studies fed into Marie Curie policy reports and parliamentary briefings, influencing political and policy thinking and contributing to critical changes to the UK's Health and Care Bill (now the Health and Care Act 2022).

Impact of Covid-19 on hospices and Marie Curie's Compromised Connections Campaign

Dr John MacArtney, Marie Curie Associate Professor at the Warwick Medical School's Unit of Academic Primary Care, University of Warwick led research that explored the impact of the Covid-19 pandemic on hospice care in England's West Midlands region from the perspective of patients, carers, hospice staff and senior managers. It was the first study in the UK to provide an in-depth exploration of the experiences of all four groups in hospice services during the pandemic.

In Dr MacArtney's own words, he describes why the team chose to publish the research on Health Open Research instead of a more traditional publishing venue:

This review was developed so that such policy and practice recommendations could be contextualized with the rapidly evolving policy landscape. We wanted the research to reach as wide an audience as possible, including non-academic clinicians and the public – as quickly as possible. As the publishing Platform is fully open, I knew AMRC Open Research [now Health Open Research] provided a good way to achieve that.

This potential for the research to influence policy and practice was underlined in the independent and transparent open peer review, which commented that the research provided “a useful and timely summary of changes to hospice policies during the first year of the pandemic.” The peer review also signalled the review's future relevance to practice and policy, “Emphasizing issues around funding and service provision in this period should be relevant to both service providers and policy makers going forward.”

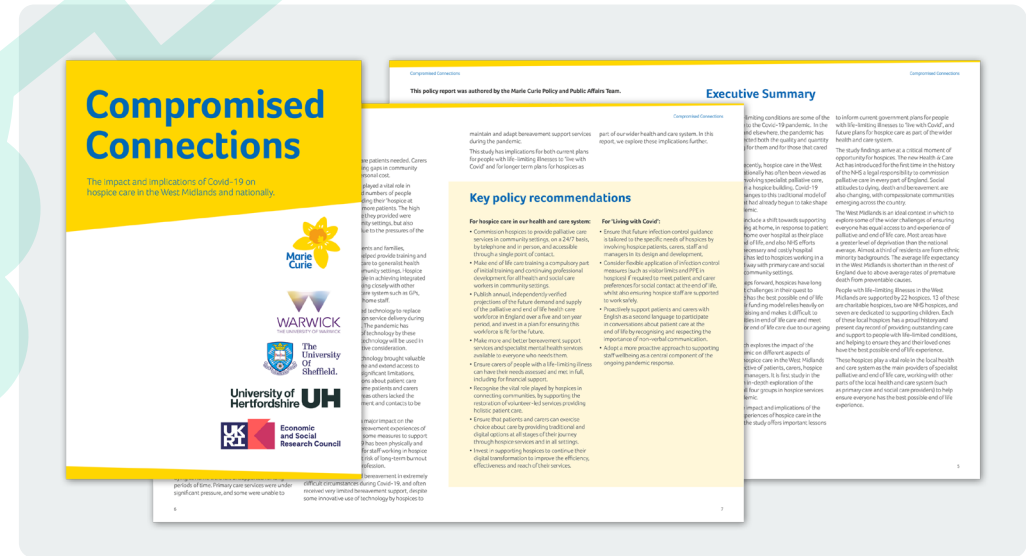


Marie Curie's Compromised Connections Report

The research fed into Marie Curie's [Compromised Connections report](#), with its focus on the lived experience and needs of end-of-life patients, their families, and their carers. Lynn Tatnell, key Patient and Public Involvement (PPI) contributor describes the impact of Covid-19 on hospice care:

I was very moved at the way Covid-19 affected the hospices [...]. Covid-19 meant big changes for hospice patients. The lockdowns meant that almost immediately hospices could no longer function in their usual manner. Life became dull and mundane with no visits of loved ones allowed. Death became a lonely affair without hands to hold nor comfort in the final minutes.

The review and Compromised Connections report influenced political and policy thinking on palliative care in the UK. The research featured in [Hospice UK's All Party Parliamentary Group](#) report on end-of-life care during the pandemic and the impact on hospices, with John MacCartney prominently quoted on the difficulties facing hospice staff, "We found it has also been challenging for staff to make clinical judgements regarding when a patient is in their last 24-48 hours of life, when communicating remotely or through PPE and screens." Members of parliament also hosted webinars focused on the research findings and [flagship nursing publications in the UK](#) continue to feature learnings from the review.



From the perspective of someone with lived experience, the importance of the research and its ongoing availability is reflected in Lynn Tatnell's comment, "Without this research by John, I doubt if any of the public would ever have imagined the detrimental affect Covid-19 had on a small community. I would never have given it a thought nor my colleagues, so by doing this research and publishing the findings as open research, John was able to disseminate the effects on the hospices all over the country."

Integrated Care Systems and England's Health and Care Act

England's Health and Care Bill, which came into law as the Health and Care Act in April 2022, was described on Marie Curie's campaigns webpages as "a once in a generation opportunity to make sure that all dying people in England get the care they want and need." To influence the drafting of the Bill, Marie Curie launched the evidence-based, public affairs-focused **Make End of Life Fair** campaign. The campaign built on research subsequently published on Health Open Research, with all findings and data available for scrutiny from, and use by, policy and public audiences.



A key objective of the campaign was to ensure that Integrated Care Systems' (ICS) duty to include palliative and end-of-life care was embedded in the new law. As part of the Better End of Life Program (a three-year collaborative project between Marie Curie, King's College London's Cicely Saunders Institute, Hull York Medical School at the University of Hull, and the University of Cambridge), the researchers analyzed the inclusion of palliative and end-of-life care in Integrated Care System strategies. This research was a critical piece of evidence for the Marie Curie campaign. Rachel Chambers, the Research and Projects Coordination Assistant at the Cicely Saunders Institute, King's College London on the Better End of Life program, described the importance of the research in influencing the Bill's passage, with the research being cited by peers as evidence to support the amendment. This amendment critically led to the eventual inclusion in law of the duty to provide palliative and end-of-life care:

The research was incredibly timely. It showed that palliative and end-of-life care was infrequently a priority within Integrated Care System strategies. Our research was published at a time when the Health and Care Bill was being debated in parliament and highlighted the gaps in prioritization of palliative and end-of-life care throughout England.

Health Open Research, an F1000 open research publishing venue

For the research teams and patient and policy-focused organizations (like Marie Curie), it is important to publish quickly and openly research findings (including all data) that can provide the evidence to influence policy. This open research publication helps maximize the impact of the research, keeps donors, patients, and their families fully informed, and provides the evidence-base for future policies and practices to build on. Rachel Chambers commented on the importance of publishing as open research:

Health Open Research allowed for rapid publication of our research paper and findings, while undergoing open peer review. This meant that we could share our findings promptly with the Marie Curie policy team and that they could be used to inform the Make End of Life Care Fair campaign immediately as well as parliamentary debates on the Health and Care Bill. We knew that subsequent open publication of the research would provide rigorous and open peer review and full transparency and availability of all data and findings. Importantly, this information can continue to be shared with policy makers who may be developing their own ICS strategies.





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and **impact** of open research
publishing at **F1000.com**



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