

Global Interventions at the End of Life: Public engagement strategy

Catriona Forrest, Hamilton Inbadas, Shahaduz Zaman, David Clark

May 2015 (revised December 2015)

Objective

Our project is unusual in containing a high commitment to public engagement from the outset. The public engagement work began in March 2014, one year before project launch, and will continue through the four years of the study. Key to the early activity was the creation of the project blog and extended use of social media. Working closely with the University of Glasgow Communications Office enabled the project to attract a degree of media interest before commencement, which provided for heightened visibility in the launch month. Key to the launch was the commissioning of a 90 second animation, with three objectives: to convey information about the project; to stimulate interest and increase engagement; to resonate with and engage international audiences.

The global character of the project provides both challenges and opportunities for public engagement. We are seeking a global audience for our work, one that includes practitioners and policy makers in the field of end of life care, as well as wider groups of stakeholders, interest groups and interested publics. In addition, we seek to undertake specific public engagement activity within Scotland, and also within the project's 'home' region of Dumfries and Galloway. Closer to home provides the most opportunities for face to face engagement. Further afield, our activities will rely heavily on digital content of one sort or another.

Our developing strategy for Public Engagement seeks to lay out our key aims and objectives, recognising that to realise all of these will require additional resources beyond those already obtained within the project award. We plan to make a further funding application to the Wellcome Trust for project related Public Engagement, and will also seek resources from elsewhere.

Strategic objectives for public engagement

Within the specific framework of the project we seek:

- To increase public awareness of and engagement with our work
- To enable research activity and impact via collaboration and partnership working
- To create open, free and accessible online resources which will last beyond the term of the project
- To develop a model for innovative research in the medical humanities

Linked to this we see opportunities:

- To support public and policy debate in end of life issues in Scotland and to engage directly with end of life care interest groups in Dumfries and Galloway

- To promote the University of Glasgow as a world-class research institution and highlight the Dumfries Campus as an excellent place to work and study
- To acknowledge the Wellcome Trust as a funder of world class research on end of life issues

Key elements

Our public engagement strategy is based on four key areas: Communications, Digital content production, Open learning resources, Events.

1. Communications

Our project has placed a high value from the outset on the development of a clear communications approach, with particular attention being given to online media. Communication is central to our public engagement strategy. This part of the strategy will give guidelines on the timing and promotion of our work online and in the press. To this end we work closely with the University of Glasgow Communications Office and the Wellcome Trust Communications team to promote our work in the local, national and international press as well as online.

We have already (month two) had numerous articles in the local and national press and have had our work featured in online forums and Twitter chats. We have been interviewed on local radio and are planning question-and-answer events on Reddit.

Our existing communications channels are:

- Website www.gla.ac.uk/endoflifestudies
- Blog endoflifestudies.academicblogs.co.uk/
- Twitter @EndofLifeStudy
- Team members on Twitter @dumfriesshire @HInbadas @shahaduz_zaman @catrionaforrest
- University of Glasgow End of Life Studies on Facebook www.facebook.com/endoflifestudies/
- End of Life Studies on SoundCloud <https://soundcloud.com/endoflifestudies>
- UofG End of Life Studies on YouTube https://www.youtube.com/channel/UCFQcOmZr_3p8VahpSNkNhsQ
- LinkedIn

We work with the editors of these communication channels:

- University website
- University social media
- Dumfries campus website
- Dumfries campus social media
- Internal communications (University) – print and online
- Internal communications (Dumfries)
- College of Social Sciences research communications

- Wellcome Trust communications
- The Conversation
- Transformations

2. Digital content production

There are two dimensions to this area of work:

Topical content

We will produce content relating to current events and debates in subjects relevant to our work, and promote it according to our communications and digital content strategies. The aim here is to raise the profile of our research and establish our team as international experts in the field.

This will include full-length footage and short video excerpts from conference plenaries and presentations by our team members, as well as podcasts, presentation slides with audio where available, photographs, blog entries and filmed panel discussions. This content will use social media and digital strategies for distribution, as well as working with the press.

Case studies

This work focuses on case studies of specific interventions, drawn from our taxonomy and matrix – of interventions of differing character and location. In this context we are exploring questions about an intervention along the following lines: how was the intervention formulated; what does it contribute; how do/did key persons and stakeholders understand it; how was / is it being practised; what happens when it is translated to another culture?

Our intention is to produce short features to complement each case study, with the aim of increasing understanding of the subject and the research and widening public engagement. In some cases these will be text only or infographics, others will be commissioned as animations and others will be short factual films.

Profiles

We aim to produce short biographical pieces about each academic staff member in the group. These will be aimed at an online audience and used to raise the individual's academic profile, encouraging student recruitment and furthering academic opportunities and connections. Such material currently exists online, in the form of text and photographs. Video biographies will be developed in due.

Biographical documentaries of key figures in hospice and palliative medicine

Here our aim is to educate, entertain and inform audiences interested in hospice and palliative medicine, and to increase this audience. These documentaries will build on existing text content which is on our blog, with audio and photographic resources, and in the longer term may be filmed as documentaries. They will be published online as an open educational resource to complement our existing content. They will be curated with external related content on our YouTube channel, and offered for screenings at special events relating to that individual (anniversaries, conferences, etc) and will feature at our own film festivals where our students and staff will run parallel workshops and Q&As.

3. Open learning resources

Our goal here, in line with the overall orientation of the Wellcome Trust, is to produce some public engagement materials that are free and open access and which will outrun the lifespan of the research project.

Open Educational Resources (OERs)

We are working with members of Open Educational Practices in Scotland (OEPS), an Open University project team which is developing a new platform upon which open educational resources (OERs) can be published and made freely available worldwide. OERs are high on institutional and government agendas with movements such as the [Scottish Open Education Declaration](#) leading the way for material to be openly available to access and use.

Following a series of workshops defining the potential reach and the audience requirements for free learning resources relating to palliative and end of life care, the project team is working on a production schedule with the aim of publishing the first module by the end of 2015.

Content from existing course material (specifically a level 3 undergraduate course built entirely around the goals of the project) is being modified and made appropriate for online publication with the help of experts from the Open University and the University of Glasgow College Learning Innovation Officer.

MOOC

Links to these OERs, we are also ambitious about the creation of project MOOC (Massive Open online Course) and have already begun seeking funding for development, with intended delivery in the academic year 2016/17. The MOOC will also be linked to the level 3 course (taught for the first time in 2014) which covers the same subject matter as the research project.

4. Events

We will use events to interact with the local communities and share knowledge within the University, the Campus, Dumfries and Galloway and across Scotland. Attending and organising events will help us to understand our audiences, inspire conversations, create networks, make the most of partnerships, engage with community partners and patient groups, connect with cultural organisations and artists, and will help us show evidence of impact. Examples will include:

- Seminars
- Consultations
- Conferences
- Lectures
- Film festivals
- Death Cafes
- Working with visiting academics, students and policy-makers

We will give particular attention to the phenomenon of Death Café movement as a cultural intervention. Our intention here is not only to organise our own events (the first of which took place in the village of Thornhill, Dumfries and Galloway in April 2015) , but also to study the movement more widely - forming an 'action case study'. We will be asking how they work, who is operating them and why, their benefits and effects, how they are changing as the interest increases, and whether it is possible to measure their impact. Following feedback after our first Death Cafe, we hope to work collaboratively to encourage more Death Cafés to be held on a regular basis. We are currently looking at a variety of types of venues with an eye to 'widening participation' to encourage different socio-economic groups to join in the discussion.

Operational objectives

- To develop a global online community based around our blog, increasing reach from 135 countries in 2014 to 192 in 2015 by using text, video and photo resources from our own team and by inviting guest bloggers
- To increase interaction with our online material (especially in countries outside the Global North) by inviting discussion and contributions, making use of existing contacts and building new ones with the support of the Communications Office
- To deliver a set of Online Educational Resources (OER), with the support of the Open University's Open Educational Practices Scotland (OEPS) and University of Glasgow colleagues in Learning Technology and Innovation
- To develop a series of six 15-30 minute documentary films, with additional funding and support from the University, the Wellcome Trust and other sources
- To develop and commission a series of six 1-2 minute animation films, with additional funding and support from the University, the Wellcome Trust and other sources
- To develop capacity for a series of death cafes in Dumfries and Galloway and the rest of Scotland, with support from the Scottish Partnership for Palliative Care and funding from the Wellcome Trust, the University and elsewhere
- To develop capacity and obtain resources to organise related events within Scotland including film festivals, seminars, workshops, and conferences.
- To foster opportunities to work with visiting academics, students, policy makers and activists in end of life issues in ways that further the strategic goals of the project as a whole, and Public Engagement in particular

Key success factors

- Correct identification of our audiences
- Correct analysis of what they need or want - what focus and level of resources are most useful?
- Correct analysis of where our audiences are located and how they will use our information and resources
- Understanding of the 'competition' - what other research and resources exist and what can we offer that is unique
- Building and maintaining key relationships with contributors and stakeholders
- Understanding of timeliness - key dates for interaction, publication and promotion

Existing resources / core competencies

- Established academic expertise and professional experience
- Established 'end of life' academic, professional and community networks, with global reach
- A website, built on the University's T4 system
- A blog, based on the WordPress blogs developed by the University Communications Office
- Social media - Twitter, Facebook, LinkedIn
- A You Tube channel
- Photography - we are developing a set of images which document the project
- Existing lecture material and other educational resources
- University campus and resources (Dumfries and Glasgow) as locations for events
- Support from the University Communications Office - press advice and contacts, distributing press releases, developing relationships with media partners, raising profile of our team members locally and globally
- Collection of 800 audio interviews and transcripts gathered by David Clark between 1995 and 2004. This oral history of palliative care includes activists, world figures and local people.
- Broadcast-quality camera equipment, suitable for observational documentary footage and interviews

Developing resources

- Developing academic capacity in outreach and engagement
- Delivering a communications strategy and guidelines, with support from the University and Wellcome Trust communications offices
- Delivering strategic digital content which develops in line with advances in best practice
- Developing in-depth documentary 'pitches'
- Developing understanding of audiences' online behaviour
- Creating a monthly journal which documents our project activity in detail
- Developing fluency in communications and social media for the whole team
- Increasing networks of press and PR contacts, informal and formal
- Developing a calendar of key global dates, events and milestones relevant to hospice, palliative and end of life care
- Curating external content on our YouTube channel
- Developing collaborative relationships and partnerships outwith the University
- Developing collaboration with the Wellcome Trust
- Gathering expertise in developing open access resources, with support from the Open Educational Practices team and the Open University

Conclusion

Our Public Engagement strategy is still developing. This document describes its second iteration. We will need to give careful attention to its content, ambition and deliverability. It will also be necessary to obtain further resources to realise the full scope of our ambition. We are developing our plans in close dialogue with our main funder, the Wellcome Trust.

Appendix

Our digital presence

<http://www.gla.ac.uk/endoflifestudies> our website

- <http://www.gla.ac.uk/research/az/endoflifestudies/projects/globalinterventions/> Project page with animation film on our website
- <http://www.gla.ac.uk/research/az/endoflifestudies/staff/> Staff profiles on our website

<http://endoflifestudies.academicblogs.co.uk/> our blog

<https://www.facebook.com/endoflifestudies> Facebook page

<https://twitter.com/EndofLifeStudy> Twitter

https://www.youtube.com/channel/UCFQcOmZr_3p8VahpSNkNhsQ YouTube channel in development

Our project in the press

<http://www.ehospice.com/ArticleView/tabid/10686/ArticleId/14272/language/en-GB/View.aspx>

<http://www.bbc.co.uk/news/uk-scotland-south-scotland-31769507>

<http://palliverse.com/2015/03/09/global-interventions-at-the-end-of-life/>

<http://endoflifestudies.academicblogs.co.uk/spinal-column-article-by-melanie-reid/> (reproduction with kind permission of The Times)

<http://www.dgunlimited.com/death-cafe/>

<http://www.dailyrecord.co.uk/news/local-news/death-cafes-designed-people-talk-5511605>

<http://glasgow.stv.tv/articles/317119-university-of-glasgow-dumfries-campus-hosts-first-ever-death-cafe/>

<http://www.ehospice.com/Default/tabid/10686/ArticleId/14785/>

<http://www.scotsman.com/news/beating-the-last-great-modern-taboo-1-3758620>

<http://www.designcouncil.org.uk/news-opinion/reinventing-death-twenty-first-century-0>

<http://www.gla.ac.uk/research/horizons/spring2015/howtodiewell/> **How to die well**, Horizons (University of Glasgow research publication, print and online)

http://www.gla.ac.uk/news/headline_305063_en.html **Report highlights global need for palliative care**

http://www.gla.ac.uk/research/news/headline_357665_en.html **Major research project to compare end of life treatment around the world**

http://www.gla.ac.uk/about/avenue/issue57january2015/news/headline_378718_en.html **Global perspectives on end-of-life interventions**, Avenue (University of Glasgow alumni publication)

http://www.gla.ac.uk/staff/news/headline_402995_en.html **UofG hosts its first Death Café**, Campus e-news (internal staff news)

http://www.gla.ac.uk/staff/news/archives/2015/march/headline_397461_en.html **International End of Life Studies team start work**, Campus e-news (internal staff news)

(to 13 May 2015)