Impact case study (REF3)

Institution: Lancaster University	
Unit of Assessment: UoA, 26 Modern Languages and Linguistics	
Title of case study: Improving healthcare communication through computer-aided discourse analysis	
Period when the underpinning research was undertaken: 2012 to 2019	

Details of staff conducting the underpinning research from the submitting unit:

Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
John Paul Baker	Professor	July 1996 to present
Gavin Brookes	Senior Research Associate	March 2016 to Oct 2016; July 2018 to present
Zsófia Demjén	Senior Research Associate	Mar 2013 to June 2014; May 2016 to Jul 2019
Jane Demmen	Senior Research Associate	Mar 2013 to June 2014; May 2016 to Jul 2019
Andrew Hardie	Reader	April 2002 to Aug 2003; Oct 2004 to present
Veronika Koller	Professor	September 2004 to present
Tony McEnery	Distinguished Professor	January 1990 to present
Sheila Payne	Professor	October 2006 to present
Paul Rayson	Professor	August 1990 to present
Elena Semino	Professor	October 1991 to present

Period when the claimed impact occurred: May 2014 to December 2020
Is this case study continued from a case study submitted in 2014? N

1. Summary of the impact

Communication through language plays a central part in the experience of illness and the provision of healthcare. By applying computer-aided discourse analysis to the study of language use in healthcare communication, Lancaster researchers have achieved significant improvements in the following areas:

- Diagnosis and support for chronic pain sufferers – by training over 1,000 pain clinicians to make better use of a language-based diagnostic questionnaire, and preventing cessation of support for approximately 1,000 patients through an evidential argument to maintain the online forum of the Trigeminal Neuralgia Association UK (TNA).

- Communication about cancer – supporting health practitioners in the UK, Mexico, South Africa and Denmark to better communicate with cancer patients by creating a 'Metaphor Menu for People Living with Cancer' (available through Cancer Research UK's website) and in applying it in cancer care settings.

- Use of patients' online feedback on NHS services – by upskilling the patient feedback team at NHS England through research-informed training, with benefits for all NHS users in England.

- More generally, the research has increased awareness of how to achieve sensitive and effective communication about illness, particularly cancer, by reaching over 10 million people via print, broadcast and online media outlets, in the UK and internationally (e.g., Spain, USA and Canada).

2. Underpinning research

Large-scale analyses of communication for, by and about different stakeholders in healthcare (patients, family carers, healthcare professionals) were conducted through 3 UKRI-funded projects in the ESRC Centre for Corpus Approaches to Social Science (CASS) at Lancaster University [G1, G2, G3]. CASS is internationally known for cutting-edge research in Corpus Linguistics (the computer-aided study of large collections of texts known as 'corpora') and its practical applications. In 2015, CASS was awarded a Queen's Anniversary Prize for Further and Higher Education. CASS members are regularly commissioned by individuals and organisations in the healthcare sector to investigate communication-related questions or problems, and this facilitates the impact of the Centre's research. The 3 research foci described below concern urgent and challenging areas of healthcare communication around chronic pain, cancer and patient feedback on NHS services. The research was carried out through collaborations involving Lancaster University linguists (Baker, Brookes, Demjén, Demmen, Hardie, Koller, McEnery, Semino), a computer scientist (Rayson), a healthcare researcher (Payne), together with an NHS healthcare practitioner (Zakrzewska) and stakeholder organisations (notably, the TNA, Cancer Research UK, and NHS England).

Communication about chronic pain in clinical and non-clinical settings

Between 2012 and 2019, Hardie and Semino employed corpus linguistic methods to investigate the use of language in pain diagnosis, and amongst interactions on the Trigeminal Neuralgia Association's (TNA) online patient forum. Following a request from a consultant in facial pain at Eastman Dental Hospital, London, a general English study was carried out on the usage of the 78 linguistic pain descriptors included in the McGill Pain Questionnaire (MPQ) – a widely used language-based diagnostic tool for pain (translated into 26 languages). The results of the linguistic analysis were then correlated with 800 patients' responses to the MPQ. Following a request from the TNA, the language used on the Association's online patient forum was analysed systematically. Key findings were as follows:

- The MPQ does not provide reliable evidence for one of the two aspects of pain it aims to measure, namely, pain intensity [R1].
- The TNA online forum provides an important source of emotional and social support for its members [R2].

Metaphors in communication about cancer and the end of life

Between 2012 and 2018, a novel corpus-based approach was employed by Demjén, Demmen, Hardie, Koller, Payne, Rayson and Semino to evidence any potential harm associated with controversial 'violence' metaphors for cancer (e.g., 'my battle against cancer') and identify any benefits associated with 'journey' metaphors (e.g., 'my cancer journey'), the latter having been adopted by the NHS since 2007 [G2]. The team studied metaphors used to describe the experience of cancer and the end of life in a 1.5 million word corpus, consisting of interviews, online forum posts by patients with incurable cancer, unpaid family carers and healthcare professionals. Key findings were as follows:

- 'Violence' metaphors appeared most frequently in the data, and particularly in the language used by patients, with 'journey' metaphors being the second most frequently used type.
- 'Violence' metaphors can make patients feel anxious, guilty and inadequate, especially when the illness is incurable (as suggested by approximately 40% of occurrences), but they are empowering for some patients. 'Journey' metaphors do not appear to have potentially harmful effects (e.g., they do not generate feelings of guilt for not getting better), but can also be both empowering and disempowering, depending on who uses them and how (e.g., stage of disease and specific choice of linguistic expression).
- Other types of metaphors (e.g., involving fairground rides, sports, nature, music) can provide useful alternative perspectives on the experience of cancer [R3, R4].

Online patient feedback about NHS services

The NHS receives a large volume of free-text online feedback via its NHS choices website, which they found hard to analyse. In 2016, Baker was commissioned by NHS England to identify, with assistance from Brookes and McEnery, the key drivers for positive and negative feedback in a 29 million word corpus consisting of comments posted between 2013 and 2015. Key findings were:

- NHS services were evaluated positively approximately 3 times more often than negatively.
- Treatment exhibited the highest proportion of positive evaluative comments (87%), followed by communication (77%), interpersonal skills (44%) and system/organisation (41%).
- Staff members were much more likely to be evaluated both positively and negatively according to their interpersonal skills.
- Mismatches between patient expectations and actual staff roles were often an underlying driver of positive or negative feedback [R5, R6].

Overall, CASS research has revealed both problems to be addressed and opportunities to be exploited in how language is used to diagnose patients and to convey experiences of illness and healthcare. The findings are particularly relevant to improving patients' experiences of common and/or serious conditions such as chronic pain and cancer, and to drawing maximum benefit from the availability of unprecedentedly large amounts of patient feedback.

3. References to the research

[R1] Semino, E., Hardie, A. and Zakrzewska, J. (2019) Applying Corpus Linguistics to a diagnostic tool for pain. In Demjén, Z. (ed.) *Contemporary Applied Linguistics in Illness and Healthcare Contexts*. London: Bloomsbury, 99-128. Held at HEI. *[Arising from G1]*

[R2] Semino, E. (2019) Metaphorical descriptions of pain on a Trigeminal Neuralgia Forum. In Hart, C. (ed.) *Cognitive Linguistic Approaches to text and Discourse: From Poetics to Politics*. Edinburgh: Edinburgh University Press, 73-92. Held at HEI. *[Arising from G1]*

[R3] Semino, E., Demjén, Z., Demmen, J., Koller, V., Payne, S., Hardie, A. and Rayson, P. (2017) The online use of Violence and Journey metaphors by patients with cancer, as compared with health professionals: a mixed methods study, *BMJ Supportive and Palliative Care*, 7, 1, 60-66. https://doi.org/10.1136/bmjspcare-2014-000785 *Most downloaded article in the journal in the first 12 months after online publication. As of December 2020: 15,743 abstract and 18,113 full paper downloads. [Arising from G2]*

[R4] Semino, E., Demjén, Z., Hardie, A., Rayson, P. and Payne, S. (2018) *Metaphor, Cancer and the End of Life: A Corpus-based Study*. New York: Routledge. Held at HEI. *[Arising from G2]*

[R5] Brookes, G. and Baker, P. (2017) What does patient feedback reveal about the NHS? A mixed methods study of comments posted to the NHS Choices online service. *BMJ Open*, 7(4). https://doi.org/10.1136/bmjopen-2016-013821 *As of December 2020: 3,895 abstract and 8,066 full paper downloads. [Arising from G3]*

[R6] Baker, P., Brookes, G. and Evans, C. (2019) *The Language of Patient Feedback: A Corpus Linguistic Study of Online Health Communication*. London: Routledge. Held at HEI. *[Arising from G3]*

Peer-reviewed research grants:

[G1] Semino (PI), *CASS Transition Funding*, ESRC (2018-2023), GBP 864,105
[G2] Semino (PI), *Metaphor in End of Life Care*, ESRC (2012-2014), GBP 175,074
[G3] Baker (PI), *Beyond the Checkbox*, ESRC (2014), GBP 61,532

4. Details of the impact

CASS's corpus-based research on health communication has influenced professional practice and understanding, and improved the experience of patients as a result of close collaborations with healthcare professionals and stakeholder organisations. Regular coverage of the research in the national and international media has also ensured that the general public are now increasingly aware of how to sensitively handle communications around healthcare.

Supporting clinicians in pain diagnosis and preventing cessation of support for patients with trigeminal neuralgia

CASS research on pain-related data has (a) improved the processes by which clinicians diagnose pain [R1], and (b) prevented the cessation of support (via the TNA's online patient forum) for people living with trigeminal neuralgia [R2]. Since 2014, approximately 1,000 pain clinicians have been trained through research-informed workshops and CPD events (e.g., at the British and European Pain Societies and the Royal Society of Medicine) to modify, for the first time, their interpretation of patients' responses to the MPQ based on the research findings concerning its limited ability to assess pain intensity reliably – a previously unidentified problem. Further, amidst reports of the spread of misinformation, CASS's evidence and recommendations provided in [R2] galvanised the TNA into reversing its decision to close down its online patient forum in 2014. The forum has remained open for the benefit of approximately 1,000 current users, and remains open indefinitely to future patients. Evidence collected through analyses of approximately 2 million words from the forum include comments such as: "*You will find a wealth of support and advice on here, this has been my lifeline*"; "*This forum is brilliant for getting support from others who know what you are going through*"; "*talking here helps me so much*" [S1].

Improving communication about cancer and the end of life, for patients, healthcare professionals, charities

Prior to the research, claims and guidelines about useful or harmful metaphors for cancer and the end of life were not based on large-scale evidence from language use. The findings of CASS corpus-based research in this area have influenced communication practices in clinical settings and the media, and directly benefited people with cancer and those who support them [R3, R4,

S2-S9]. Since 2014, the research on (dis)empowering uses of metaphors has been disseminated to more than 1000 healthcare professionals in the NHS, hospices and staff at cancer and end-of-life charities through workshops, training events and many more through media engagement. As a result, feedback suggests the majority of professionals have reconsidered and refined their communicative practices and training provision. Feedback from a 2014 training session at St Joseph's Hospice, London for 30 people (specialists in cancer care and end-of-life care) showed how engagement with the research will influence practice: "*Will help with my area of care, will help me understand and think about what my patients and relatives are actually telling me. Will make me reflect and respond more appropriately*". Feedback from staff training sessions at St John's Hospice, Lancaster with 70 people (specialists in cancer care and end-of-life care) between 2017 and 2019 showed 100% of participants opted for 'strongly agree' or 'agree' in response to the statement: 'The session was relevant and useful to me' [S2]. After another user-engagement event, palliative care nurse and former Head of Research at Hospice UK, the national charity for hospice care in the UK, attested: "*your work has influenced my professional practice as a nurse, researcher, educator and human being*" [S3]. A palliative care physician and former Clinical Director at Hospice UK posted tweets that showed the influence of the research on her thinking and practices: "*heightened alertness to metaphor when talking to patients since today's session!*"; "*am listening in a new way!!*" (2014) and "*I have learnt from your work that different metaphors suit different people*" (2019) [S3; see also S4 for impact on end-of-life care practitioners]. The Senior Brand Manager at Macmillan Cancer Research has described Lancaster research as 'incredibly useful' [S5a]), and the Science Media Officer at Cancer Research UK wrote that "[the research] *is often referenced by the brand team*" [S5b].

A resource for patients - the 'Metaphor Menu for People Living with Cancer' - was launched in November 2019, based on a key finding that different people benefit from different metaphors for the cancer experience [R4]. The Metaphor Menu is an illustrated collection of 17 quotes providing alternative metaphors for living with cancer, and was created with input from cancer patients and staff from St. John's Hospice and Cancer Care in Lancaster. It is available online, as a leaflet and as a pack of cards. Launch events were attended by patients, healthcare professionals and charity volunteers in Lancaster and London. Feedback from the CEO of North West Cancer Research attending the event stated: *"Really useful. So many more different ways to talk about and understand a big and often frightening subject. We'll use this to re-consider how we talk about cancer"*; and another attendee "*As a previous cancer patient and the daughter of a cancer patient I feel so relieved that I needn't force myself to always fight with it. I can just live with it in balance. Cancer is a partner - sometimes we are together, sometimes we separate from each other.*" Shortly after the launch, the European Association for Palliative Care published the Metaphor Menu on their blog, reaching approximately 170 countries, and @Pallimed (a Twitter account representing US hospice and palliative care professionals with approximately 14,000 followers) tweeted a link to the Metaphor Menu with the comment: "*Love the #MetaphorMenu for cancer and it can be applied to any serious illness. Let's have more choices than 'battle' metaphors. Let people pick the one that resonates with them*". In early 2020, patient testimonies on the usefulness of the Metaphor Menu were included in an article published by the *Huffington Post UK* and in a *BBC Radio 4* broadcast. As of December 2020, the Metaphor Menu page had been visited approximately 3,700 times; an online evaluative questionnaire shows that, since November 2019, 25 people (healthcare professionals/cancer patients) have rated the Metaphor Menu at an average of 4.1 on a 5-point scale for usefulness. Cancer Research UK recommends the Metaphor Menu as a patient resource on their website [S6]. It has been included in a self-reflection toolkit for 20 women with breast cancer in the UK, developed by the Innovation Advisor at Imperial College Health Partners [S7a] and is being used in patient support sessions and by trainers of health professionals in Mexico, South Africa and Denmark [S7b].

The research into communication about cancer, particularly with regard to avoiding disempowering metaphors, has also reached the public through worldwide media coverage: *The Independent*, *The Times*, *The Daily Mail*, *TIME*, *New York Times* blog, *The Vancouver Sun*, *New Scientist*, *VICE Canada*, *New York Magazine*, *Il Sole 24 Ore* blog and *El Pais*. The research is often referenced when media controversies over metaphors relating to the illness of a prominent

person arise. For example, Semino's work was cited on *NBC News* and in the *Washington Examiner* following the death of US Senator John McCain (2018), and referenced in a *YouTube video* by US clinician and communication consultant Bruce Lambert following US TV presenter's Alex Trebek's cancer announcement (2019) [S8]. Cumulatively, the insights provided by the research are likely to have touched the lives of millions of patients worldwide.

The reach of this research focus goes beyond communication about cancer. In spring 2020, the Lancaster approach to metaphors for cancer inspired an international initiative for effective metaphor use in communication about the Covid-19 pandemic, #ReframeCovid. As part of this initiative, the findings from CASS research on the most and least appropriate metaphors to be used in public communication about the pandemic have been reported in, amongst others, the *Daily Mail*, *Der Spiegel*, and the *Atlantic* magazine. The influence of the research goes even beyond healthcare; the Metaphor Menu has inspired the adoption of a similar approach by the President of the International Coaching Federation (Germany) and Director of Solutions Academy, who confirms *"The idea behind metaphor menus is very applicable in my field of coaching and coach training… By becoming aware of whether the metaphors we inadvertently use are serving us or whether an alternative metaphor or alternative metaphors might not be serving us better, coaches can help clients create more choices and different perspectives for themselves"* [S9].

Upskilling NHS staff, to maximise the use of patient feedback about NHS services
Prior to working with CASS, the patient feedback team at NHS England largely relied on quantitative numeric data to analyse and understand what patients thought about NHS services; they considered the techniques they had previously used to analyse free-text responses to be inadequate. The research commissioned to CASS remedied this situation. Following a report on the findings of the research, in 2015 NHS England commissioned an instructional video with accompanying written training materials, which were made available on the staff intranet to its 6,500 employees. These new resources have enabled the feedback team to use corpus linguistic software independently in the analysis of patient feedback, in perpetuity. As a consequence, the Care Quality Commission stipulated that any new software for textual feedback analysis is compatible with the tools developed in CASS, so that the training provided by the team continues to be relevant to their exploration of patients' feedback. The corpus-based approach was endorsed as *"The most sophisticated [they] had seen"*, while a Senior Research Manager at NHS England testified: "*This has been particularly useful and has helped develop our knowledge and understanding of textual analysis methods"* [S10]. A new study of feedback on NHS cancer services has recently been commissioned, and preliminary findings are being used by NHS England to set priorities for service improvements and to improve the design of future surveys [S11]. The NHS's ability to optimise usage of patient feedback has already benefited millions of patients, and will continue to do so for years to come.

5. Sources to corroborate the impact
[S1] Testimonial from consultant at Royal National ENT and Eastman Dental Hospitals (2020).
[S2] Testimonial from Learning & Development Coordinator at St. John's Hospice (2019).
[S3] Testimonial from Palliative Care specialists: Nurse and former Head of Research at Hospice UK; Physician and former Clinical Director at Hospice UK (2019).
[S4] Testimonial from Chaplain at Lancaster Royal Infirmary (2019).
[S5a] Testimonial from Senior Brand Manager at MacMillan Cancer Research (2015); and [S5b] Science Media Officer at Cancer Research, UK (2016).
[S6] Patient Web Information Team at Cancer Research UK (2021).
[S7a] Testimonial from creator of 'Breast cancer self-reflection toolkit' at Imperial College Health Partners (2021); [S7b] emails from trainers of healthcare professionals in Mexico, South Africa and Denmark (2019, 2020).
[S8] Selected media reports on research on metaphors and cancer, and on Metaphor Menu for People Living with cancer (2014 to 2020).
[S9] Testimonial from President of the International Coaching Federation (Germany) and Director of Solutions Academy (2021).
[S10] Testimonial from Senior Project Manager at NHS England (2019).
[S11] Testimonial from Senior Insight Account Manager at NHS England Insight and Feedback team (2021).