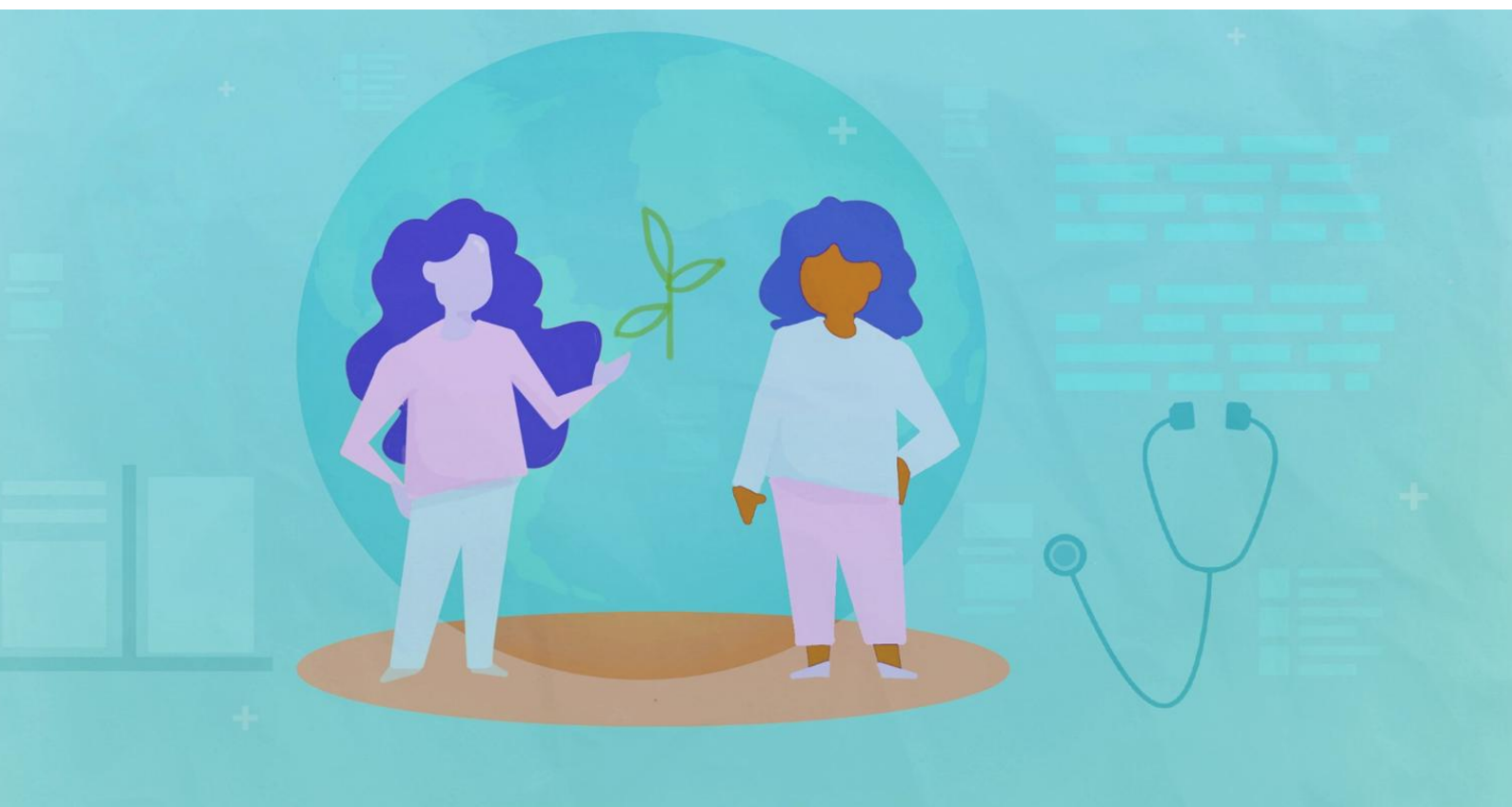


Health and science communication: Inequalities, inclusion and innovation

Book of Abstracts

March 2025



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Programme: Friday 21st March 2025

(GMT time)

Hybrid day: Attendance is possible:

- In person (at Lancaster University, UK, lunch and refreshments provided)
- Online (via Microsoft Teams).

Sign up here: <https://forms.office.com/e/Ks0VihGXpc>.

9.30-10.30am	Registration (with refreshments)
10.30-11.30am	Plenary: Distinguished Professor Elena Semino - Metaphors and vaccines: Opportunities and challenges
11.30-11.45am	Quick break
11.45-12.45pm	Panel 1: Health and technology Digital dialogues of infertility: Gender, identity, and stigma resistance in Muslim women's blogs <i>Fatema Alhalwachi (Birkbeck, University of London)</i> Dementia: What goes viral in the vast expanse of Twitter? <i>Chris Sanderson (Lancaster University)</i> Harnessing AI for genomic medicine: Patient voices and critical perspectives <i>Dr Shone Surendran (Guy's and St Thomas' NHS Foundation Trust)</i>
12.45-1.45pm	Lunch
1.45-2.45pm	Panel 2: Pregnancy and loss 'Blossoming' bumps or basketball bellies: How pregnancy is depicted and quoted in the media by journalists and those with lived experience <i>Eloise Parr (University of Birmingham)</i> Translating metalinguistic attitudes into lexical reform in healthcare? The case of pregnancy loss terminology in British English <i>Beth Malory (University College London)</i> "Parange" or "parent": Attitudes of bereaved parents towards French lexical innovations to refer to themselves and their babies <i>Océane Foubert (University of Lille)</i>
2.45-3.15pm	Refreshment break
3.15-4.15pm	SIG Showcase (5-minute research presentations)
4.15-4.30pm	Event close

Abstracts: Friday 21st March 2025

Plenary: Metaphors and vaccines: Opportunities and challenges

Distinguished Professor Elena Semino (Lancaster University)

What do memories, raincoats and snakes have in common? They have all been used as metaphors for vaccines by people with different views and communicative goals.

This talk is concerned with how, why and with what potential consequences metaphors are used to communicate about vaccines by different people in different contexts, including popular science books, public health campaigns, parents writing online, and podcasts by celebrity anti-vaxxers. It shows how different metaphors are used to achieve different communicative goals, from explaining how rapidly developed vaccines are safe, to suggesting that vaccines are part of a large-scale conspiracy at the expense of ordinary people.

Both opportunities and challenges arise from a consideration of these patterns in metaphor use and an appraisal of the world in the mid-2020s (e.g. a vaccine hesitant government in the USA). First, metaphors can be one of the tools to be deployed to address the loss of confidence in vaccines caused by the pandemic-related experience of being repeatedly infected by a virus after one or several vaccinations. Second, pro-vaccination metaphors by scientists and public health agencies tend to be clear and accessible but do not usually match the high emotional valence of anti-vaccination metaphors, nor the way in which anti-vaccination metaphors fit into a broader terrifying narrative of which vaccines are a part. An awareness of this mismatch may be helpful in crafting metaphorical and non-metaphorical future public health messages about vaccinations.

Panel 1: Health and technology

Digital dialogues of infertility: Gender, identity, and stigma resistance in Muslim women's blogs

Fatema Alhalwachi (Birkbeck, University of London)

Abstract:

This study is the first to address the impact of gendered, cultural and religious discourses on an under-researched subaltern group of infertile Muslim women bloggers. Taking a small story and case study approach, the analysis focuses on interactivity and positioning (Bamberg & Georgakopoulou, 2008; Georgakopoulou, 2009) in one woman's stories as she works hard to address normative expectations and dominant discourses which abound in Muslim societies. The paper highlights the stigmatisation and isolation women face, not only in the physical world, but sometimes in the online world too. We argue that Weblogs provide a unique and unexplored space where discourses of gender, sexual, and other identities are resisted and challenged. Simultaneously Weblogs can serve as both supportive and exclusionary sites in which bloggers' rights and duties become regulated. The study opens a window into the world of infertile Muslim women and has important implications for relevant healthcare and policy making.

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Dementia: What goes viral in the vast expanse of Twitter?

Chris Sanderson (Lancaster University)

Abstract:

In the age of social media, some health communication experts have called for a reexamining of existing messaging strategies (Sylvia Chou & Gaysynsky, 2020), with some trialing a social media-based communication project (Albrecht et al., 2022). Concerns surrounding misinformation on social media for health communication are prevalent, but should we aim towards utilizing social media, or would this entail fighting fire with fire? Social media is far from a 'free market' of ideas, particularly with the algorithm choosing which posts will be shown to whom (Twitter, 2023). Some studies suggest the algorithm promotes a 'rich-get-richer' effect, and a preference for sensationalist content (Dujeancourt & Garz, 2023). This provokes the question of whether these platforms systematically perpetuate inequalities through giving voice to some, and not others.

This study investigates this conundrum by looking at the ‘viral’ tweets in a bespoke dataset of 18.9 million tweets from 2013-2022 which contain either *dementia* or *alzheimer’s*. I develop a novel approach to creating sub corpora dependent on engagement, drawing in part on an existing statistical method called ‘TOPSIS’ (Muñoz et al., 2022). Less than 0.1% of the tweets in this dataset are classified as ‘viral’ using this method, which suggests a stark contrast between what is SEEN on Twitter against what is ON Twitter as a whole. To investigate these viral tweets further, I look at the type of accounts and discourses which have gone viral in this time period, and critically discuss the implications for health communication. I argue that a consideration of engagement can offer valuable insights into the discursive environment of social media, and I highlight the perhaps counterintuitive variation in viral tweets. For example, one account garnered over 570,000 likes on a single tweet, despite only having 8403 followers.

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Harnessing AI for genomic medicine: Patient voices and critical perspectives

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Abstract:

Artificial Intelligence (AI) is a powerful tool with the potential to enhance clinical decision-making and patient care within the NHS. The Genomic AI Network of Excellence was established to support AI deployment and deliver exemplar programmes of AI for the benefit of patients, including improved and accelerated diagnosis and personalised medicine. This study investigates the role of AI in genomic medicine, focusing on cardiovascular health. In a study exploring public perspectives on AI in genomics, over 100 participants were recruited, revealing the central role of communication in enabling transparency and building trust with the public and patients in using AI within genomics. Building on these findings, the present work adopts a theoretically rigorous qualitative approach to examine patient perceptions, attitudes, and lived experiences of AI interventions in clinical contexts. As part of a larger mixed-methods project, this sub-study uses focus groups and semi-structured interviews with over 50 patients with lived experience of AI-assisted diagnostics in their cardiovascular care. While initial studies have highlighted concerns about data protection, transparency, and trust, they also revealed optimism regarding AI's potential to enhance care delivery, reduce errors, and mitigate biases. This in-depth study examines patients' perspectives to understand better how doctor-patient dialogue around AI-driven interventions may address or amplify their concerns. The analysis utilises a sociocultural framework situating clinical encounters within broader cultural contexts. This theoretical lens foregrounds the influence of cultural norms and beliefs in trust, acceptance, and resistance to innovations. Through a deeper understanding of patients' lived experiences that extend beyond the consultation room, the study underscores the significance of community backgrounds in shaping attitudes and perceptions. These insights aim to inform policies and practices prioritising patient-centred approaches, addressing diversity, inclusion, and ethical responsibility in AI-driven genomic applications. The study offers critical recommendations for equitable, culturally sensitive AI integration in healthcare.

Acknowledgements

This work was supported by the NHS England Genomics Programme through the Genomic Artificial Intelligence (GAIN) Network of Excellence.

Panel 2: Pregnancy and loss

'Blossoming' bumps or basketball bellies: How pregnancy is depicted and quoted in the media by journalists and those with lived experience

Eloise Parr (University of Birmingham)

Abstract:

Media depictions of pregnancy and childbirth are often seen by people long before they may experience pregnancy and can become the baseline to which a person compares their own experiences. This can be problematic as mainstream media tends not to be representative of the experiences of everyday people. The depictions of pregnancy most widely found in the media tend to be highly medicalised, remarkable and atypical. There is often a focus on celebrity pregnancies or high-risk pregnancies (Gow et al., 2012; Maclean, 2014, 2017) that have high shock value.

A corpus of 148 newspaper articles found through a keyword search of 'pregnancy' was created for this study to represent the narratives and discourses about pregnancy that are present in mainstream British media. The dataset was annotated for quotation and metaphor to examine the difference in the frequency and type of metaphor used in quotes by pregnant or recently pregnant individuals compared to those found in the body of journalistic reporting. This mixed methods metaphor analysis revealed that, although many of the metaphor sources were the same, journalists and quoted pregnant voices used metaphor to discuss pregnancy-related topics in ideologically different ways. The aim of this presentation is to examine these differences in metaphor use and the implications of these differences.

The results of this study suggest that the language and metaphors used to discuss pregnancy are influenced by the lived experience a person has. The frequent metaphorical mappings used by people with lived experience of pregnancy could be used to inform more empathetic communication about pregnancy that honours the experiences of those who have been pregnant. I argue that this could be achieved by mirroring the language used by people with lived experience, both on an individual and more general level.

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Translating metalinguistic attitudes into lexical reform in healthcare? The case of pregnancy loss terminology in British English

Beth Malory (University College London)

Abstract:

Despite longstanding, cross-domain recognition that reproductive health terminology can impact patient experience (Smith et al., 2020) and social attitudes (Austin et al., 2021; Malory, 2022), the diagnostic terminology of reproduction has, until recently, been largely overlooked by empirical research. Without empirical data, clinicians' 'consensus statements' (e.g. Johnson et al., 2020) and language guidance (RCOG, 2022), have drawn only on anecdotal evidence. Meanwhile, those affected have lacked a formal outlet for expressing dissatisfaction with linguistic resources available, which has instead arisen on social media. Here, many have contended that the lexicon of adverse pregnancy outcomes, such as *loss*, perpetuates outdated attitudes and problematic ideologies, making them unacceptable for use in clinical settings or elsewhere.

This paper draws on methodologically innovative empirical research on language attitudes and the experiential function of diagnostic lexis in contexts of pregnancy loss (Malory, 2025; Malory & Nuttall, 2024, 2025; Malory & Parr, 2025). Combining insights from qualitative and quantitative participatory research, the paper shows that diagnostic terminology such as *miscarriage*, *cervical incompetence*, and *termination* implies blame, increases self-reproach, and is associated with stigma, whilst clinical jargon, such as *empty sac* and *products of conception*, impedes comprehensibility and communicative clarity, acting as a barrier to health literacy and inclusion (Malory, 2025). Moreover, language perceived to hierarchize experiences of loss, such as *full-term stillbirth* prove divisive, and are embraced by some but rejected by others (Malory & Parr, 2025). These findings have facilitated evidence-based recommendations for individualised communication in clinical settings (Malory, 2024), and concrete, consensus-based recommendations for mass communication (Malory & Nuttall, 2024), as well as the development of a health communication training course for clinicians (Malory & Nuttall, 2025). This paper thus argues for the crucial role of evidence-based lexical reform in critical health communication scholarship aimed at combatting health inequalities and promoting social justice.

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“Parange” or “parent”: Attitudes of bereaved parents towards French lexical innovations to refer to themselves and their babies

Océane Foubert (University of Lille)

Abstract:

The suffering of parents experiencing perinatal bereavement is exacerbated by the subsequent silence surrounding the event (Lang et al., 2011). The lack of public recognition of perinatal death is reflected in the absence of a specific term to refer to bereaved parents and their babies. This is one of the manifestations of what Fricker refers to as *hermeneutical injustice*, defined as “the injustice of having some significant area of one’s social experience obscured from collective understanding” (2007: 156). To counter this absence, parents have coined lexical innovations to name themselves and their babies, particularly in online communities (Caliendo & Ruchon 2020). For example, there have been several petitions to include the neologisms *parange* (a blend of *parent* and *ange* – ‘angel’) and *enfance* (a blend of *enfant* – ‘child’ and *ange* – ‘ange’) in French dictionaries. The aim of this study is to systematically record the attitudes of bereaved parents towards self- and hetero-designations when referring to themselves and their babies. More specifically, a questionnaire was set up to gather bereaved parents’ opinions on 17 lexical units (13 naming

parents and 4 naming babies). Open-ended questions were also asked to allow parents to suggest other designations. To date, over 150 bereaved parents have responded to the questionnaire. The preliminary results show that there is no consensus on a lexical innovation for naming parents and babies, and some even reject the neologisms *parange* and *enfance* put forward in the petitions. Indeed, many reject the euphemistic nature of angel-based lexical innovations. In addition, the responses to the open-ended questions revealed that some parents argue that what they need is not a different terminology but a different understanding of what it means to be a parent. These findings will be used to promote more respectful linguistic practices surrounding perinatal death among healthcare practitioners.

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Programme: Tuesday 25th March 2025 (GMT time)

Online only day: Held on Microsoft Teams (GMT time). Sign up here:

<https://forms.office.com/e/Ks0VihGXpc>.

9.30-10.30am

Panel 1: Inequalities and medical terminology

"Seems like everyone has trauma these days": A Positive Discourse
Analysis of mental trauma

Joanne McCuaig (University of Birmingham)

How are LGBTQ+ people included within UK Health Policy? A critical
discourse analysis

Katherine Bristowe (King's College London)

South Asian languages in the United Kingdom and Eurocentric medical
terms: A discussion paper

*Alia Amir (SOAS, University of London) and Zahid Pranjol (University of
Sussex)*

11-12pm

Plenary: Professor Federico Marco Federici - Reflections on language as a social determinant of health

1-2pm

Panel 2: Communicating genital pain and menopause

Life with menopause – exploring diverse lived experiences through
digital audio diaries

Marleen Pauls (King's College London)

Putting gendered inequalities into words: Addressing women's chronic
genital pain in France and England

Dr Hannah Loret (University of Dundee)

Medical practices and health inequalities: The case of vulvar pain and
vulvodynia

Angela Zottola and Giorgia Riboni (University of Turin)

2.15-3.15pm

Panel 3: Communicating lived experience

Dialogues in transition: Building bridges in the communicative
relationship between trans people and healthcare professionals in
Spain

Emma Machado de Souza (University of Salamanca, USAL)

Illness narratives in an age of staged authenticity: A story-critical
approach to cancer influencers' sharing

*Korina Giaxoglou (The Open University) and Marion Nao (Kings College
London)*

"Listen, you don't wish you had Tourette's" – Multimodal Self- and
Other positioning in health awareness influencer discourse

Carolin Schneider (University of Duisburg-Essen)

Abstracts: Tuesday 25th March 2025

Panel 1: Inequalities and medical terminology

"Seems like everyone has trauma these days": A Positive Discourse Analysis of mental trauma

Joanne McCuaig
(University of Birmingham)

Abstract:

The nature of mental health is complex, as is the sharing about it. There is a combination of physical, behavioural, and social aspects, along with communication between people when talking about mental trauma. When individuals share experiences, the wording is not always going to align with expected medical or social outcomes but does reflect how the individual views the concept. This issue is worthwhile to investigate because differences in usage of the word *trauma* could lead to communication breakdowns. For example, a mismatch between expectation for access to mental health services between the public and clinicians because of what constitutes mental trauma.

In this session, Joanne McCuaig will share her PhD findings from analysing the word *trauma* using a five-layer framework she created. Joanne will discuss the ethical considerations and approaches to her data collection in her corpus assisted discourse analysis. She will then share initial recommendations for promoting mental health literacy in relation to traumatic experiences. This research is a work-in-progress.

How are LGBTQ+ people included within UK Health Policy? A critical discourse analysis

Katherine Bristowe
(King's College London)

Abstract:

Background: Health policymakers can leverage change to reduce inequities in care delivery and clinical outcomes. Despite legal progress lesbian, gay, bisexual, trans and queer (LGBTQ+) people have increased risk of some health conditions and poorer health outcomes linked to the discrimination they experience. In 2022, 42 regional integrated care systems were created across England to reduce health inequalities and improve wellbeing.

Aim: To examine the inclusion of UK Equality Act (2010) protected characteristics within the 42 publicly available integrated care system strategies, and to consider how LGBTQ+ communities are framed within these strategies.

Methods: Critical Discourse Analysis positioned within a social constructivist paradigm.

Results: Almost all strategies talked about the needs of their populations in terms of age (42/42), disability (42/42), gender (41/42), ethnicity (39/42) and maternity/pregnancy (39/32). 27/42 strategies mentioned religion. There were no references to marital status. 22/42 strategies referred to LGBTQ+ people, but only around 25% of references provided context about the specific needs of LGBTQ+ people, the health inequities they face, or services for LGBTQ+ people. Regarding gender minorities, there were eight mentions of trans people and no mentions of intersex people, despite some policies using the acronym LGBTQI. While there were two mentions of inequities in care delivery for trans people, the specific care needs of trans people were not described in any strategies, and there were a small number of examples where trans people were presented in a problematizing frame. Across all strategies there were only three references to systemic forces (e.g. homophobia, transphobia, discrimination) affecting LGBTQ+ people.

Conclusions: While the needs of some minoritized groups are well recognized within health policies, LGBTQ+ people remain marginalized. Further work is needed to educate policy makers to advocate for LGBTQ+ people and communities, and to ensure equitable and respectful inclusion of all minoritised groups.

South Asian languages in the United Kingdom and Eurocentric medical terms: A discussion paper

Alia Amir
(SOAS, University of London)

Zahid Pranjol
(University of Sussex)

Abstract:

The UK government's commitment to mental health and wellbeing is evident through its commitment of £2.3 billion. This presentation will, therefore, focus on the language of inequities in healthcare with a focus on how British South Asian communities are impacted by it.

According to Kachru (2008), South Asia is a proverbial tower of babel. In this tower of babel, many of the top twenty spoken languages of the world are used, which means that a quarter of the world in the region speak one or more of the South Asian languages (Ethnologue, 2024). Similarly, South Asian diaspora in the world and in the UK, specially, form a significant minority. However, the medical terms and names of the diseases in modern medicine, for example, are often not developed or created in South Asian languages, which has an impact on diagnosis as well as communication issues. As an example, the word *depression* in English does not have an equivalent medically accepted terminology. In the region, the UK and where diaspora exist, translations can vary for the medical terms. While standardisation of medical terms is one aspect of it, the medical terms in modern science often have Eurocentric leanings. This presentation calls for not only the need to develop standardised

terminologies in South Asian languages but also more information and training for mainstream medical NHS staff in understanding South Asian languages and cultures – as this will not help bridge the gap of efficient diagnosis but also help create language awareness among the patients about terminologies used for mental and physical health.

Plenary: Reflections on language as a social determinant of health

Professor Federico Marco Federici

(University College London)

Timely, effective, and accurate communication is at the heart of risk mitigation. It increases resilience and preparedness with health campaigns in support of at-risk communities in disaster lifecycles (preparedness, readiness, response, recovery, reconstruction) and mitigates the impact of crises. Effective communication reduces morbidity, mortality, and damage to property, and it does so best when it reaches all members of affected populations. For the World Health Organisation, effective communication also means 'understandable', that is, information must be available in a language and format that people understand (WHO, 2017). This perspective applies to preventative and responsive health campaigns (WHO, 2019), and matters for physical as much as mental health, where the idioms of distress have an impact on how symptoms of conditions and disorders manifest (Kirmayer et al., 2016; Patel & Hall, 2021).

Although many would agree with the statements above, there are significant inequalities when it comes to accessing or asking for urgent, timely, and reliable information in languages other than the main societal language. The cascading impact of such inequalities on populations became apparent in hospitalisation rates, morbidity, mortality, and economic distress during the COVID-19 pandemic. Ethnic and linguistic minorities were disproportionately affected by the pandemic worldwide (Bouyzourn et al., 2023; Kaplan, 2020; Lawrence, 2020; O'Brien et al., 2021; PHE, 2020; Piller, 2020; Sachs et al., 2022; Zhang & Wu, 2020). The global differences in healthcare systems and their efficacy riddled with inequalities (Marmot, 2017), combined with communication strategies that often remained confined to a monolingual mindset (one region/one language), were predictable factors increasing risks (Petts et al., 2010). Culture, circumstances, and wealth have long been proven to impact individuals' health. Quantitatively providing the impact of language as a social determinant of health is more difficult and applied linguists had already called for additional research in this sector before the COVID-19 pandemic (Feuerherm et al., 2021; Showstack et al., 2019).

The impact of socioeconomic factors on access to information for crisis-affected communities in a language they understand has been described as disaster linguicism (Uekusa, 2019). Linguistic inequalities often affecting already vulnerable groups (women, people with visible and invisible disabilities, political minorities, etc.) preclude the attainment of linguistic justice (Piller, 2016; van Parijs, 2011) as if the naturally multilingual world remains constrained by the socio-political construct of monolingualism.

Social integration and language planning might increase access to information if (or when) multilingual communication solutions become part of emergency plans (O'Brien & Federici, 2020; Uekusa & Matthewman, 2023) and their implementation is monitored and evaluated (Cadwell et al., 2024). As communication in most large-scale events has progressively become multilingual (Federici, 2020), language is one such factor that determines people's

health and access to healthcare. This talk will argue that researchers can address systemic and endemic issues of social inequality by focusing on mechanisms that can enhance communication of health risks in multilingual settings. A refined understanding of the role of language as a social determinant of health would prompt us to think of ways of communicating risks in inclusive, life-changing, and life-saving ways that are of benefit to all in pursuit of equitable and more resilient societies.

Biographical note: Federico M. Federici is Professor of Intercultural Crisis Communication and Director of the Centre for Translation Studies, at University College London, UK. He holds a Laurea in Foreign Languages (Rome La Sapienza University), and a PhD in Translation (University of Leeds, UK). Previously, he designed the curriculum founded and directed the EMT MA in Translation Studies at Durham University, UK (2008-2014), where he also founded and directed the Centre for Intercultural Mediation.

He has published peer-reviewed articles in journals across different disciplines, from *The Italianist* and *Translation Spaces* to the *International Journal of Disaster Risk Reduction* and *Disaster Prevention and Management*. He edited *Language as a Social Determinant of Health* (2022), *Mediating Emergencies and Conflicts* (2016), and *Translating Dialects and Languages of Minorities* (2011). He edited *Translating Hazards*, a Special Issue of *The Translator* (2023). He co-edited volumes with Sharon O'Brien, *Translating Crises* (2023) and *Translation in Cascading Crises* (2019), with Christophe Declercq *Intercultural Crisis Communication* (2019), and with Callum Walker *Eye Tracking and Multidisciplinary Studies on Translation* (2018). Together with Kizito Tekwa, Ellen Harosh, and Angela Crack he is currently co-editing a special issue of *Linguistics Vanguard*.

He has co-authored reports on crisis communication policies (available [here](#)) and on multilingual communication in the humanitarian sector (available [here](#)). His research focuses on translation as an instrument to pursue social justice, multilingual healthcare communication, the study of translation in crises, news translation, and translators and interpreters as intercultural mediators. Federico was a member of the EU-funded INTERACT Crisis Translation Network (2017-2020) led by Sharon O'Brien (Dublin City University) and principal investigator of the project funded by the British Academy STRIVE Sustainable Translations to Reduce Inequalities and Vaccination hEsitancy (2021-2022).

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Panel 2: Communicating genital pain and menopause

Life with menopause – exploring diverse lived experiences through digital audio diaries

Marleen Pauls
(King's College London)

Abstract:

Menopause is more than hot flushes and night sweats. Various factors such as socioeconomic status, workplace experiences and ethnicity are also at play in shaping lived experiences. The physical and mental aspects of menopause are thus situated in and interact with sociocultural contexts, so experience is unique (Lazar et al., 2019). Taking this complexity into account, one of the aims of my PhD study is to try to address a lack of diversity in menopause research by working with community group gatekeepers to reach participants from different ethnic backgrounds. Ethnicity has been shown to impact menopause, for instance in age of onset and presentation of symptoms (Santoro & Sutton-Tyrrell, 2011). It is thus essential to listen to underrepresented voices to gain insights into the complexities of menopause.

Currently in data collection, this study takes a qualitative approach and elicits audio diaries in which participants chronicle their day-to-day lives with the menopause. They capture a range of their experiences in their own words: physical and mental symptoms, interactions with family and friends, doctor's appointments as well as thoughts, attitudes and emotions. Over the course of two months, participants record a short entry a few times a week, so the diaries cover the complex, even contradictory nature of lived experiences (Williamson et al., 2015). The analysis of this longitudinal data will take a discourse-based approach centred around social cognitive linguistics. For instance, a focus on metaphor use would lend itself to an examination of how speakers conceptualise abstract notions like health, specifically menopause, by drawing on concrete experiences (Semino, 2008). The analysis will be guided by the dataset to examine how linguistic features provide evidence for mental conceptualisations of menopause in the participants' individual social contexts.

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Putting gendered inequalities into words: Addressing women's chronic genital pain in France and England

Dr Hannah Loret (University of Dundee)

Abstract:

Women's long-term genital sexual pain is a debilitating issue, compounded by challenges related to gender, stigma, and the social determinants of health. Access to care can be complex and often relies on local availability and funding of care, as well as healthcare professional inclination and knowledge. Qualitative research addressing this issue cross-nationally is limited. The present study therefore sought to explore conceptualisations of women's genital sexual pain in France and England, outlining the ways experiences of care can depend on the manner that this pain is described and communicated in complex private and semi-private national health systems.

This research adopted a qualitative approach, using semi-structured interviews and an analytical framework informed by concepts of power and reflexive thematic analysis. Self-identifying women and people experiencing vulvovaginal pain (n=20) and professionals with experience in this area (n=8) were interviewed in France and England to gain a deeper understanding of these issues. Previous research has revealed the multi-layered difficulties faced by women affected by this pain in multiple areas of their lives, but little has explored how a cross-national lens, considering two different healthcare systems, could create insights into areas of improved knowledge and inclusive practice.

This paper will explore the ways that stigma was described by the participants of this study, with a particular focus on the way that power dynamics were communicated and described, and how stigma relating to gender could interact with stigma related to other experiences of disadvantage. This paper will also explore the significance of findings around the appropriation of narratives and languages of pain by participants in the study, closing with a reflection on the potential power of challenging stigma through describing and communicating experiences of distress and discomfort.

Medical practices and health inequalities: the case of vulvar pain and vulvodynia

Angela Zottola and Giorgia Riboni (University of Turin)

Abstract:

Drawing on the assumption that discourse plays a central role in the collective construction of illnesses (Conrad and Schneider, 1980), this paper explores the linguistic resources utilized to describe persistent vulvar pain – a condition long ignored or minimized by health care professionals (Labusky, 2015) – within the scientific community. In recent years this issue has received more attention and is currently undergoing a process of pathologization, which entails a narrative shift from possibly being a psychological problem to being recognized as a disease. The term *vulvodynia* has been introduced to label and provide a pathological

status to this long-lasting pain, for which adequate categorization is still lacking (Bornstein et al., 2016).

Discourses around vulvodynia are thus something that not only reflects its reality but actively contributes to its identification as an illness. In particular, narratives constructed around the scholarly definitions of this condition may significantly affect the common perception of vulvar pain and vulvodynia, impact research as well as diagnostic and therapeutic procedures, and ultimately improve the wellbeing of women affected by it.

Starting from the premise that the systematic analysis of narratives can reveal implicit aspects of narratives themselves, those who create them and those they are aimed at (Toolan, 2013), this paper adopts a corpus-assisted approach to explore the shifting constructions of vulvar pain and vulvodynia within medical discourse. To this aim, an ad hoc data set including scientific articles published in English over the course of the last 25 years has been built and analyzed as the starting point to reconstruct the narrative that led to the contemporary understanding of this silenced disease.

Keywords: medical discrimination, gender, narratives in professional settings, pathologization, silenced disease, vulvar pain, vulvodynia

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Panel 3: Communicating lived experience

Dialogues in transition: Building bridges in the communicative relationship between trans people and healthcare professionals in Spain

Emma Machado de Souza (University of Salamanca, USAL)

Abstract:

This study explores the communicative experiences of transgender individuals within the Spanish healthcare system, aiming to identify both bridges and barriers that shape their interactions with healthcare professionals. While effective clinical communication is widely recognized as essential for patient-centered care (Scholl et al., 2014), trans individuals frequently encounter obstacles related to inadequate knowledge, insensitive practices, and a lack of respect for social identities, such as the correct use of names and pronouns (Bos & Bos, 2023). Utilizing a thematic analysis approach (Braun & Clarke, 2006), in-depth interviews with ten trans participants highlight critical areas of improvement, notably in the knowledge deficits of practitioners regarding gender-specific needs. Participants report a pervasive sense of discomfort and avoidance, often fearing discrimination or misinterpretation that may deter them from seeking necessary care (Kcomt, 2019). Notably, the study identifies significant variability in healthcare experiences across regions in Spain, which underscores the need for standardized, inclusive policies (García Acosta, 2020).

Beyond highlighting barriers, the findings also reveal instances where empathetic communication has positively impacted care, demonstrating the potential for improving clinical interactions through sensitivity and respect (Redfern & Sinclair, 2014). This research offers unique insights into the Spanish context, contributing to the development of evidence-based recommendations that can enhance healthcare experiences for trans patients. The results advocate for a structured, inclusive approach in medical training and policymaking, prioritizing the dignity and autonomy of trans individuals in clinical settings.

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Illness narratives in an age of staged authenticity: A story-critical approach to cancer influencers' sharing

Korina Giaxoglou (The Open University) and Marion Nao (Kings College London)

Abstract:

Illness narratives in an age of staged authenticity: a story-critical approach to cancer influencers' sharing

Illness narratives have been gaining public visibility on many social media platforms e.g., Instagram and Tik Tok, garnering large online audiences and creating a new type of influencer: the 'cancer influencer'. This category refers to social media users with large audience followings of more than 10,000, who are undergoing – or have received – treatment for cancer and who use their platform profiles as sites for sharing their illness narrative as well as for awareness-raising. This 'cancer storytelling boom' attests to the broader contemporary mobilisation of storytelling for a range of purposes, including self-branding, which has prompted story-critical approaches (Mäkelä and Meretoja, 2022). Although recent research has brought to the fore key aspects of narrativity and affectivity that cancer influencers draw upon (e.g. Stage et al., 2020), little critical attention has been paid, so far, to the uptake of these narrative performances by cancer patients and survivors.

In this paper, we present the first stages of our Open Societal Challenges project, in which we set out to explore the implications of this cancer 'storytelling boom' on the mental health and wellbeing of cancer patients and survivors. Applying critical narrative and affective positioning concepts analysis in select examples of cancer influencers (Giaxoglou, 2021), we document and scrutinise the practices that characterise these modes of sharing and we then examine cancer patients' views and reactions to these. Our aims are to show (a) how illness, and specifically cancer, is mobilised as a resource for staging 'the real', conventionalising illness identity and affective positionings, and (b) to explore the extent to which the circulation of these narratives and positionings has a negative impact on the wellbeing of cancer patients and survivors. Our paper contributes to the critical study of illness narratives across online and offline practices of health-related communication.

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“Listen, you don’t wish you had Tourette’s” – Multimodal Self- and Other-positioning in health awareness influencer discourse

Carolyn Schneider
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Abstract:

In recent years, a growing number of content creators have used social media to raise awareness about health conditions while simultaneously sharing personal aspects of their everyday lives, including routines and leisure activities (e.g., Garcés-Conejos Blitvich and Georgakopoulou, 2024). Some creators focus entirely on advocating for their causes. This is also the case with Tourette’s Syndrome (TS), a neurological disorder characterized by involuntary repetitive movements and vocalizations (Fremer et al., 2024). This pilot study explores a video by Tourette’s Syndrome influencer Jack Francis, in which he discusses his lived experience with the condition, shedding light on both the challenges and realities of living with Tourette’s.

Using multimodal frameworks (Kress and Leeuwen, 2001; Norris, 2019) and positioning theory (Harré and van Langenhove, 1999), this study examines how Jack Francis employs a range of multimodal strategies, such as verbal language, involuntary tics, gestures, and facial expressions, to position himself and his audience. The analysis focuses on how these multimodal actions construct his identity as a relatable and credible representative, while also positioning the audience to foster empathy and awareness of TS.

This further investigates how these multimodal elements are metapragmatically managed (Caffi, 2016; Bublitz and Hübler, 2008) to establish rapport and align with the audience (Spencer-Oatey, 2008). Specifically, it looks at how disruptions in his speech caused by involuntary tics are not merely obstacles, but key components of the influencer’s communicative process. The findings suggest that these multimodal disruptions, while challenging, effectively support the communicator’s goals by raising awareness about TS and strengthening the relationship with the audience through authentic and transparent self-representation.

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