Section A

Institution: Durham University

Unit of Assessment: 26: Modern Languages and Linguistics

Title of case study: Performing Arab Cancer

Period when the underpinning research was undertaken: Between 2012 and 2020

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

Name(s): Abir	Role(s) (e.g. job title):	Period(s)employed by submitting HEI:
Hamdar	Professor	2012-Present

Period when the claimed impact occurred: Between 2017 and 2020

Is this case study continued from a case study submitted in 2014? ${\sf N}$

Section B

1. Summary of the impact: In Arab culture, the history of cancer is often the history of a silence - of shame, taboo, prohibition and repression – and this silence particularly affects women. This case study outlines the impact arising from staging Arab women's testimonies of their cancer experience both to the general public and to the medical community in Lebanon. The impact of this project includes: breaking the social taboo of cancer and minimising fear of it, influencing how doctors evaluate patient narratives of cancer, facilitating a support network for female cancer patients, creating a dialogue between the dramatic arts and the medical community in Lebanon and facilitating the implementation of an arts-in-health strategy at the Naef K. Basile Cancer Institute of the American University of Beirut Medical Centre.

2. Underpinning research: This case study emerges out of Abir Hamdar's research expertise in Arab medical humanities and, in particular, her research on female illness, disability and cancer in Arab culture. Her monograph *The Female Suffering Body: Illness and Disability in Modern Arabic Literature* (Syracuse University Press, 2014) is the first major study of the representation of female illness/disability in Arabic literature and culture. The book highlights the culture of silence that surrounds female illness in the region and connects literary representations with wider cultural discourses on illness and disability. This book and two other research outputs make an original contribution to furthering research in the medical humanities in relation to Arab women's illness narratives [R1, R2, R3].

Building on her earlier work, Hamdar's second research project on the Arab cultural history of cancer is funded by the Arts and Humanities Research Council's Open World Research Initiative. This is the first study to address the complex social, gendered and political discourses on cancer in the region and explores literary, filmic, theatrical and media representations of cancer. As part of her research on theatrical representations, Hamdar conducted ethnographic research (in the form of personal interviews) with female cancer patients from the Arab world (Lebanon, Syria, Jordan, Saudi Arabia, Egypt and Palestine) in April 2016. In 2017, these testimonies formed the basis of Hamdar's original play/ethnodrama Wasafuli al-Sabr [I Am Waiting For You], which draws on verbatim quotations from the interviews, recurring tropes that emerged amongst the interviewees as well as their emotional state to highlight women's subjective experiences of the disease. This arts-based research output dramatised the cultural taboo of cancer in the region, the implications of this (self-)enforced silence on Arab female patients and the impact of the disease on women's relationship with others – doctors, husbands, lovers, children, fellow sufferers [R4] with the intention of raising awareness of these issues to medical stakeholders and to relevant communities and institutions. Hamdar also wrote the script for a short film, which was based on the qualitative research. The film (also entitled Wasafuli al-Sabr) was used as a video installation at the start of the play. In addition, Hamdar's journal article on the Palestinian artist Rim Banna offers a cultural anatomy of the artist's post-illness body from her cancer diagnosis to her death [R5] while her article on staging silence offers a critical reflection on

the fieldwork, methodology and creative strategies that informed the writing and staging of *I Am Waiting For You* [R6].

3. References to the research:

R1. The Female Suffering Body: Illness and Disability in Modern Arabic Literature of the Levant and Egypt (1950-2005). (Syracuse University Press, 2014). ISSN/ISBN: 9780815633655, 9780815652908. This is the first major study of female illness and disability in Arabic literature and culture. The book has been described as: "A rich and provocative work that makes a much-needed intervention in the fields of Arabic literature and disability studies and fills an epistemological gap" (International Journal of Middle East Studies – 12.1(2016): 96-98); a "compelling contribution to the body of literary criticism of Arabic Literature" (al-Jadid, 19.69(2015) - an Arab equivalent to the Times Literary Supplement); and "an original, rich, and fruitful contribution" (Journal of the Society for Contemporary Thought and the Islamicate World 12 Nov. 2015). In 2014, Hamdar was interviewed by one of the Arab world's most popular intellectual cultural websites Jadaliyya about the book.

R2. "Aesthetic Visibility: Female Illness/Disability in Hasan Dawud's *Makhyaj Khafif*." *Al-Abhath: Journal of the Centre of Arab and Middle Eastern Studies*, American University of Beirut 58/59 (2011): 113-117.

R3. "Female Physical Illness and Disability in Arab Women's Writing." *Feminist Theory.* 11.2 (2010): 189- 204. ISSN/ISBN: 1464-7001, 1741-2773 DOI: 10.1177/1464700110366816. **R4.** *Wasafuli al-Sabr* [I am Waiting for You] – Stage-Play/Ethnodrama. Recorded copy of the play available.

R5. "Voice of Resistance": Rim Banna, Cancer, and Palestine's Body Politic." *Medical Humanities.* 2019. DOI: 10.1136/medhum-2019-011649.

R6. "Staging Silence: Arab Women's Cancer Experience. *Studies in Theatre and Performance*. 2019. DOI: 10.1080/14682761.2019.1683348.

R4, R5, and **R6** resulted from a significant grant from the Arts and Humanities Research Council (AHRC) as part of their Open World Research Initiative: AH/N004647/1. The overall grant value is approximately GBP3,900,000 (approximately GBP500,000 to Durham University). Dates: 2016-2021. Hamdar is a Co-I on the "Cross-Language Dynamics: Reshaping Community," which is one of four main research programmes that AHRC is funding. All published outputs have been peer-reviewed in international journals. This research and related impact activities were recognised by shortlisting for an AHRC/Wellcome Medical Humanities Award, in the Best International Research Award category.

4. Details of the impact: The case study involved the staging of Arab women's real-life testimonies of their experience with cancer. It is based on extensive interviews with female cancer patients and their family members, whose testimonies were then adapted for the stage. The outcome is a stage play/ethnodrama written by Hamdar, *I Am Waiting for You*, which premiered in Beirut, Lebanon in July 2017 [R4]. Further performances have taken place to medical staff and cancer patients at three leading University hospitals in the country as well as to the general public.

The performances in Lebanon were highly significant because Lebanon is the center of medical tourism in the region, the site of the Arab world's most renowned medical school (American University of Beirut/ American University of Beirut Medical Centre [AUBMC]) and provides advanced cancer care to patients across the Arab world. Hospitals in Beirut are also regional centres of excellence for cancer treatment and influence cancer care across the Arab World.

The staging of the performance was undertaken in collaboration with the award-winning Lebanese theatre director Lina Abyad. A cast of Lebanese, Iraqi, Palestinian and Syrian actors participated in the play, some of whom were cancer survivors or had lost family members to cancer [R6]. Two leading oncologists from the American University of Beirut Medical Centre acted as consultants on the project and facilitated the Q&As with the general public. The performance marked the first instance in which cancer testimonials were embodied on the Arab stage and performed to both the general public and to healthcare practitioners and trainees in the region. A documentary about the play, directed by Paloma Yañez Serrano, from the Granada Centre for Visual Anthropology at Manchester University, was screened at three international film festivals in 2018: the

Estonia World Film Festival in Tartu (attracts approximately 3,000 attendees), the Pakistan International Film Festival (PIFF) (1,766 attendees), and the Film Festival of Zadar in Croatia (E10c).

In addition, Hamdar presented her research at a meeting organised by DIPEx International, an association of academic and non-profit groups working to enhance understanding of health and illness experiences globally for communities, healthcare professionals and policy makers. This meeting took place on 5 November 2019 at the University Medical Center in Groningen, Netherlands (approximately 150 participants) (E10c). A screening of the film followed the presentation. In 2020, the script of the play was also turned into a video installation directed by the Lebanese film-maker Dima Alansari and premiered at the Naef K. Basile Cancer Institute (NKBCI) of AUBMC to mark World Cancer Day. In total, approximately 1,200 cancer patients, medical staff and interns have watched the Hamdar-scripted play and the film. Overall, the research generated four key strands of impact:

1. Breaking Taboos and Lessening Fear of Cancer

The initial impact can be detected in the extensive media coverage of the play in national, regional and international newspapers, radio and TV (15 reviews + 10 interviews + documentary) (E10). The subject matter of the play and the Q&As that followed enabled it to play a key role in addressing a subject that historically, and even today, has the status of a cultural taboo. Some of the reviews described the play as follows: "taboo-breaking" (*al-Akhbar* newspaper); "De-demonises Arab women's cancer", "participates in a profound humanitarian mission: to clarify, to console and to calm" (*L'Orient Le Jour*); and "a sophisticated, distinguished and brave work" (*al-Mayadeen.net*) (E10a). Following the premiere of the play, an award-winning Lebanese novelist and critic said that one of the distinct features of this play is that "despite our fear of cancer, we come out of this fear" and "we [...] become more able to discuss cancer" (E7a).

During the opening night of the performance, Iraqi actress and breast cancer survivor Namaa al-Ward shaved her hair on stage to challenge the taboo of hair loss that Arab female cancer patients often experience. Al-Ward also revealed her breast cancer scars on stage. Both acts were unprecedented in the history of modern Arab theatre and generated discussions on social media. A Lebanese journalist wrote: "I was so impressed by the courage to speak and especially to show ... the one who has shown her scars, the classic symbols of femininity, breasts and hair. What courage and strength from her part ... in a country that always wants to cover it up, deny it" (E7c). Commenting on the performance, the Clinical Professor of Medicine, Hematology and Oncology at AUBMC who is both the Director of the Breast Cancer Centre of Excellence at NKBCI and the Lebanese Breast Cancer Foundation, told the cast that the play "has achieved what takes us years to do", i.e. raise awareness and alleviate fear of cancer (E8).

Overall, the public performances and the Q&As that followed challenged the general perception that cancer is an end-of-life experience and gave public voice to female cancer patients. To this end, comments and feedback from the general public repeatedly pointed to the fact that the play's very subject matter was significant in breaking the taboo of cancer in Lebanon and the Arab world. Feedback also focused on the manner in which the subject was addressed with many stating that its approach had minimised their fear of cancer. Some of the comments included: "Thank you for making me realise that it's fine to be open about it"; "Very daring"; "Humanisation replace denial and taboo"; "Makes you think and change your perception"; "Thank you for turning negativity and fear into positivity and strength"; "your play was a closure to my relative's death from cancer"; "I am ready to face it now" (E4); "Thank you for making me feel like it is not the end of the world" (E9).

2. Giving A Voice to Cancer Patients and Facilitating Support Networks

Following each public performance, and inspired by the stories embodied on stage and by the Q&As, many cancer patients and survivors spoke for the first time about their experience with the disease. In some cases, patients and their family members were able to share experiences for the first time: a woman who had kept her five-year treatment a secret from her teenage children discussed her case openly, while a young man described the trauma he felt as a child at being kept away from his mother because he was not "supposed to know"

about her illness" (E4). In the words of the theatre director, "something very special is happening during these sessions. The theatre is transforming into a support group for cancer patients and their families" (E5). One actress also noted: "I feel transformed ... I feel I have more room for emotional empathy and caring" [E5, testimony 1].

In addition, cancer patients and survivors, medical experts, cancer NGOs and support groups were invited to participate in the public Q&As to facilitate dialogue, knowledge-exchange and networking. To this end, three leading oncologists from the American University of Beirut Medical Centre and seven NGOs and cancer support groups (including the Lebanese Breast Cancer Foundation, Spread Awareness Increase Detection (SAID) NGO and Balsam: The Lebanese Centre for Palliative Care) participated in the Q&As. SAID NGO also reserved one performance night to raise funds for Colorectal Cancer Awareness (E6a). Some cancer support groups noted that the number of patients who contacted them increased because of the performance. Overall, the performance and the Q&As created a new support platform which brought together health care professionals, patients and support groups in the same space for the first time as well as spreading awareness and synergies between existing groups.

Testimonials from cancer patients, physicians and cancer NGOs indicate that the performance and Q&As had a beneficial impact on cancer patients (E4, E6). In some cases, they helped cancer patients adopt a more positive approach to their treatment and in other cases they empowered female cancer patients by enabling them to confront some of the social challenges they were encountering. For example, a breast cancer patient who was being subjected to domestic violence because of her illness "went from being sorry for herself ...to standing up for herself" and even decided to seek help from a local organisation that targets family violence (KAFA-enough). As she told her physician, "watching the play gave me the strength to do this. I am feeling very empowered and I am going to change my approach" (E6d). Additionally, patients were able to seek direct support from cancer support groups, whose representatives were present at the performances (E6).

3. Forging New Relations and Enabling Dialogue with Medical Community Following the success of the public performances, the Lebanese American University Medical Centre-Rizk Hospital requested a special performance at the hospital for its medical staff, interns and students on 8 August 2017. A Q&A with the medical community also followed. The performance marked the first instance in which Arab adult theatre was performed at a hospital. By enabling the dramatic arts to enter into dialogue with the medical community, the performance was able to forge new relations in which the dramatic arts play a role in informing patient care as well as promote new themes, contexts and audiences for the performing arts more generally. In the words of a renowned Lebanese actor, with this play Arab "theatre has taken a different turn [...] It is no longer simply art designed to treat society [...] it has become treatment for doctors and patients" (E7b).

Another special performance took place in Beirut on 8 February 2018 to mark World Cancer Day (4 February annually). The performance was hosted by NKBCI of the AUBMC, which is one of the leading cancer institutes in the region that offers medical care to patients across the Arab world and shapes cancer education and practice. The event took place on the premises of the hospital. The play was also the opening event of BBCC-6: Annual Beirut Breast Cancer Conference which is organised by NKBCI. Over 200 national and international physicians, nurses, medical students and interns, as well as cancer patients and representatives of cancer NGOs, attended this performance and participated in the Q&As that followed. The significance of this event was multifold:

 It allowed the play to be performed both to leading physicians in the Arab world as well as to medical staff and patients at the centre. The additional performance also enabled the project to consolidate the relationship between the dramatic arts and the medical community established by its earlier hospital performance. In the words of the play's director: "This production has offered us all, theatre makers, audience, doctors and patients the opportunity to meet. To experience theatre as a tool in the process of knowledge-exchange is empowering [...]. This play proved [it is] a force of change and a tool for transformation" (E5).

- The performance prepared the ground for the implementation of an arts-in-health agenda that NKBCI has identified as part of its strategic aims. To quote the Director of NKBCI: "The play has paved the way for our new awareness strategy of combining arts and medicine. It has impacted the AUBMC family as well as our community. Such performances [...] should become the standard of communication within our societies for change to take place in people's attitude [...] towards cancer" (E1-Letter).
- Hamdar's work on this play led to her appointment as Creative Consultant at NKBCI where she will support the delivery of an Arts-in-Health programme over the next four years (E1-Memorandum).

In addition, the play was performed at the Nabih Berri Government University Hospital in the South of Lebanon on 1 December 2018, thus allowing engagement with hard-to-reach areas and with medical practitioners who deliver healthcare in rural parts of the country.

4. Informing How Doctors Evaluate Patient Narratives

The play's focus on patient testimonials had an impact on physicians' understanding and perception of patient narratives and subjectivity. While cancer treatment in Lebanon and other parts of the Arab world has a good reputation, little attention has been paid to patient narratives. By highlighting women's individual experiences with the disease as well as their affective response to oncologists and their clinical practice, the play provided new insights for understanding patients' experience of cancer. In the words of the Professor of Clinical Medicine and Chair of the Department of Internal Medicine at the Lebanese American University School of Medicine and LAUMC-Rizk Hospital, the play "led us to question ourselves and to reevaluate our approach to patient care and self-education. I believe that this play is a landmark in the area of reality theater and a must in medical education" (E2). An oncologist at LAUMC-Rizk Hospital also told the cast after one hospital performance: "I never realised this is how my patients felt when they came to see me" (E3). A general medical practitioner also felt that the performance and the post-play discussions allowed "us not just to empathise but to understand" the experiences of cancer patients (E3). A medical student at LAUMC-Rizk hospital also wrote: "This was meaningful art...it has been incredibly beneficial to me both as a med student and a human being more importantly" (E9). Finally, following the success of the play, the cast will continue to perform it independently of Hamdar's work.

5. Sources to corroborate the impact:

E1. NKBCI: Letter from Professor of Medicine, Hematology & Oncology and Director of NKBCI (AUBMC) + Memorandum of Agreement Letter on Creative Consultancy.
E2. Email/testimony from the Professor of Clinical Medicine and Chair of the Department of Internal Medicine at the LAU School of Medicine and LAUMC-Rizk Hospital (LAUMC-Rizk).
E3. Feedback from Oncologist at LAUMC-Rizk Hospital (oral comment) + Recorded feedback from General Medical Practitioner.

E4. Testimonies and feedback from cancer patients and survivors and their family members: available on sticky notes, and visual and audio recordings of patients sharing experiences for the first time (English, Arabic & French).

E5. Email/testimony from the theatre director and the cast of the play (English & Arabic). E6. Email/Testimony from Cancer NGOs and support groups: a) Director of SAID NGO; b) Director of *Barbara Nassar Cancer Association* (Arabic); c) Pink Steps testimony on social media; d) Voice recording from family medicine practitioner and director of *Balsam: The Lebanese Centre for Palliative Care.*

E7. Feedback from Cultural Critics & Theatre Practitioners: a) Visual recording of feedback from two Lebanese novelists and critics (Arabic); b) Feedback from Lebanese actor (Arabic); c) Comment on social media from Lebanese journalist.

E8. Feedback from Clinical Professor of Medicine, Hematology and Oncology at AUBMC, Director of the Breast Cancer Centre of Excellence at NKBCI and founder and Director of the Lebanese Breast Cancer Foundation.

E9. Feedback from medical staff and students for LAUMC-Rizk Hospital and NKBCI performances (English and Arabic).

E10. Media coverage: a) Reviews, interviews and segments about the play on national, regional and international media (15 reviews+10 Interviews: Arabic, English & French); b) Documentary about the performance; c) Figures for PIFF, Estonia Film Festival and DIPEx International conference.