

Predicting Effective Adaptation to  
Breast Cancer to Help Women to

## BOUNCE Back

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## THE BOUNCE PROJECT AT A GLANCE: MEETING THE CHALLENGE OF A MULTINATIONAL PROSPECTIVE STUDY ON RESILIENCE

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Coping with breast cancer is a major challenge. Thus, it is necessary for health professionals to help patients increase their psychological resilience toward better and faster recovery.

The BOUNCE project will explore the factors that influence breast cancer patients' resilience and their ability to resume a normal everyday life through cost-efficient clinical tools for patient empowerment.

BOUNCE develops and deploys advanced computational tools to validate indices of patients' capacity to bounce back during the highly stressful treatment and recovery period following diagnosis of breast cancer. Elements of a dynamic, predictive model of patient outcomes are incorporated in building a decision-support system to be used in routine practice providing oncologists and other health professionals with concrete, personalized recommendations regarding optimal psychosocial support strategies.

## BOUNCE RESEARCH IN THE MIDST OF COVID-19 MANAGEMENT: VOICES FROM THE FIELD

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### Adapting the study to COVID-19 crisis

At the end of February 2020, the first cases of COVID-19 were announced in Israel. Managing this unknown virus required the research team to adapt rapidly to the new circumstances. At the intra-organizational level, it was decided to move completely to online meetings and frequent follow-up between staff members. Furthermore, contact with patients and delivery of questionnaires were adapted, as much as possible, to online questionnaires, phone calls, and the special deliveries of questionnaires, in order to limit physical contact. Special attention was given to Arabic speakers, by conducting an online survey in Arabic, and to English speakers through home deliveries of the questionnaires. On the emotional level, special sensitivity and understanding was required for the fear and stress shared by the patients, due to their higher risk for COVID-19 consequences.


### Collaboration in light of the COVID-19 pandemic

It is our impression that the level of engagement and collaboration of patients enrolled in the study has remained unchanged. There have been however exceptions: one patient did not want to take part for fear of virus contamination through the printed questionnaires. There have also been delays in returning the completed questionnaires by certain patients who were still willing to take part in the study.

### Dual dealing with cancer and the COVID-19

An often raised issue by patients relates to potential complications of dealing with cancer and the likelihood of COVID-19 infection. The dominant emotions that arose were fear, loneliness, uncertainty and general impact on their mood that may also affect the content of answers to research questions and active participation. Regarding to previous struggles as a result of cancer, we find that the virus augments these challenges. One





young woman shared with us her difficulty in getting back to “normal life” having completed cancer treatments. She had four kids at home with her throughout the lockdown (she postponed sending them back to school as a precaution); this situation posed a greater physical challenge by having less time to rest and get better, and she reported experiencing an even greater emotional burden following cancer treatments. Another patient shared that even though she was heading back to routine, in light of the corona she had to re-plan the way she can “bounce back”. Other women reported a heightened sense of social involvement and contribution and had more time to devote to the study due to the lockdown.

### Personal feelings as caregivers and researchers in the time of COVID-19

COVID-19 is challenging in many ways, especially for us as researchers and health professionals. There is a constant concern that we might infect our patients, as they already have deficient immune system. This concern is mutual; patients are also worried that the medical staff might transmit the virus to them. Sadly, one of the nurses at our Oncology Department was found positive to the virus, causing a large number of staff members to be quarantined for two weeks and many of the patients who were treated by that nurse had to be tested as well. On the other hand, our patients might be source of infection, thus we would be part of a vicious cycle, infecting family at home and other patients at risk. More so, we meet up with our patients in small rooms often without sufficient ventilation. Keeping our face masks on might cause an uncomfortable feeling. Also, we find ourselves in the awkward position to keep reminding patients to put on their face masks properly.

As researchers we are aware of the sensitive circumstances, while asking our patients to think of their illness in relation to the constantly changing course of the virus and normal life. Indeed, our patients are faced with multiple sources of worry and threat. As professional medical staff we normally encourage our patients to maintain a normal lifestyle despite their illness, however with the threat of the current pandemic, this mission has never been more difficult.

Many women mentioned the corona virus while filling out questionnaires, giving it a great importance. The threat of the virus has become dominant along with the threat of cancer and the inadvertent burden of the treatments received; the emotional impact of the perceived threat is maintained by frequent reminders and cautionary advice by friends and family.

### Some inspiring examples of resilience

Participating women gave us several encouraging insights of how they cope with the stress triggered by the current situation:

“Apparently the virus is not going away soon, therefore we have to learn how to live with it.”

“I’m taking care of myself ... I don’t go out without the face mask on and I don’t go to crowded places ... such as weddings.”

“Of course we are afraid and we think about it ... a lot; ... it is affecting all aspects of life; ... I’m trying to keep working and to maintain my routine; ... I am a physiotherapist working with intubated children ... it is very important for me to help them out and to be with them ... I am an active woman.”

## A PERSONAL EXPERIENCE OF A SOCIAL WORKER FROM A PSYCHO-ONCOLOGY UNIT DURING COVID-19 DAYS IN ISRAEL

By Shlomit Perry, PhD and Prof. Ruth Pat-Horenczyk, PhD  
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Thirty years ago, at the beginning of my professional career as a social worker at a cancer center, I met Tamar (an alias). She was then thirty-five, a single mother to a four-year-old son. She was diagnosed with stage II breast cancer and received chemotherapy. Her parents were deceased, and she had little support from her brothers. She worked in a high-tech company and was a very accomplished woman. Tamar wanted to understand as much as she could about her illness and she was very motivated to continue her daily life functioning, both at her workplace and home. I saw my role as a key supporter for accomplishing the goals she defined for herself. Throughout the

long psychotherapy process, we had many conversations about the chemotherapy and its effects. We explored together her fears that her son would grow up with no mother and discussed many other dilemmas about how and with whom to share her struggles and experiences as a cancer patient. She seemed to manage to reach her defined goals of remaining functional in her life both at the workplace and home.

Ten years later, Tamar knocked on my door again: This time it was colon cancer she was coping with. I supported her throughout the treatments. This time she also faced some rather challenging



questions from her 14-year-old son, including questions about the identity of his father and about the uncertainty of a future without a family. Tamar coped with the challenging situation in a remarkable way. She was able to combine introspection, exceptional interpersonal relationships, satisfying and supportive working relations and an ability to accept the harsh reality of her situation with flexibility and optimism. Tamar bounced back to life once again. I met her from time to time and was sure that she had managed to have a meaningful life; a wonderful relationship with her son and lots of good friends.

Tamar recently reappeared at our cancer center, about 15 years after the end of her second cancer, and this time with a metastatic disease of unknown primary. By now, her son was married and father of a baby and he accompanied her to the treatments. The COVID-19 crisis caught her at a time when it was clear that the chemotherapy wasn't working. She had to decide whether she would receive additional chemotherapy with a slim chance for survival. The reality of COVID-19 put additional burden on her decision for further treatment. Tamar was afraid of being at the hospital, fearing from the increased risk of the COVID-19 for cancer patients. Due to COVID-19, patients were allowed to come to the Day-care clinic alone, with no family, which was a problem for her. In a multidisciplinary family meeting, we all agreed on home palliative care. Her condition deteriorated rapidly. She stopped eating, had difficulty taking medication so a PICC line was installed. Tamar realized that her life expectancy was short and asked me to do a home visit as soon as possible. During our conversation, she stated that she understood that it was impossible to predict the end of her life and was not sure what an accurate prognosis (in terms of a number of days or months) would contribute to her. We had a long and meaningful meeting. She talked about her nearing death, and about her meaningful life. Together we redefined the goals of care and the specific difficulties at this point in time.

When I returned home, I found my husband with a high fever. Our GP believed that it was a UTI. She prescribed antibiotics and sent him for COVID-19 testing. Our family entered quarantine, awaiting the result of the test. But my main concern was about Tamar in her vulnerable state. It took several days until we received a negative test result for COVID-19 and I was able to breathe a sigh of relief. Throughout these days, my main concern was: what if I transmitted the virus to her? Will she die alone without family and friends who were so important

to her? How I, the one who accompanied her for 30 years and tried to do everything to help her, might eventually lead to her death in loneliness.

I did not worry about my children. I was confident that my husband would recover. I was certain of my own health. For five days and nights, Tamar was in my thoughts. For the first time, I paused the risk for my patient. This morning Tamar passed away surrounded by her loving son and friends. I was left with a painful awareness of the burden of my work on my personal life to which new and unprecedented dimension of COVID-19 was added.

## Concluding Comments

### Did Tamar show resilience?

As we conceptualize resilience being "a process of maintaining healthy, adaptive, or integrated positive functioning over the passage of time in the aftermath of adversity", Tamar certainly was resilient. She manifested resilience in her personal and professional life inspiring other patients and the treatment team.

### What were the protective factors which facilitate the resilience trajectory?

According to her social worker, her optimistic attitude, her strong social ties, having a very meaningful life, being open to her experience, her ability to manage her illness with self-awareness, curiosity and knowledge, and her ability to maintain personal and professional support – all contributed to the magic of resilience.

### How can we take care of our professionals and protect them from compassion fatigue?

The care for our caregivers should be an integral part of professional training and institutional policy. We need to increase awareness of medical doctors, nurses, psychologists, social workers and administrative workers to the impact of their work on their personal and professional life. The health system has the responsibility to provide guidance and services for self-care, peers' support and professional counselling to mitigate the potential risks for compassion fatigue, secondary traumatization and burnout. In addition, growth and compassion satisfaction can be facilitated and enhanced in this challenging context.

The COVID-19 reality confronts us with special and unprecedented challenges since caregivers can constitute also a risk for those highly vulnerable patients whom they care for.



## THE BOUNCE STUDY IN THE ERA OF THE COVID-19 PANDEMIC IN PORTUGAL

By Diana Frasilho, PhD, Berta Sousa, MD, MSc  
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The COVID-19 pandemic, besides affecting people's health and wellbeing across the globe, is taking a toll on research and is forcing most projects to quickly adapt to physical distancing measures. Projects using digital solutions were more capable of giving an immediate outbreak response. This was the case of the BOUNCE study which relies mostly on patient self-reported information registered through a digital platform designed by Noona Healthcare.

### How many patients are using the digital platform at the Champalimaud Clinical Centre in Portugal?

Since March 2020, when Portugal started experiencing the effects of the COVID-19 pandemic, we saw an increase in the number of participants preferring to use the digital platform. At the Champalimaud Clinical Centre around 77% of the patients enrolled in the BOUNCE study are now currently using the Noona digital platform to report information on key factors involved in building and maintaining resilience.

### What were the main challenges faced so far?

The current Pandemic situation challenges data collection. We had to increase efforts related to asking people to continue to focus on responding to the questionnaires on time and asking patients that usually prefer paper-pen questionnaires to enroll in Noona instead. Overall, the pandemic situation strengthened participants' use of the

Noona digital solution to comply better with the social distancing measures.

### The importance of tracking resilience factors during high-stress situations?

Based on patient verbal reports, we find that the prospective design of the BOUNCE study on resilience, is enabling patients to track their own wellbeing during the COVID-19 pandemic, enabling deeper self-understanding and empowering patients. This information is important as patients can verbalize better their concerns to the clinicians.

### Lessons Learned and Next Steps

The COVID-19 pandemic is challenging health systems globally. In Portugal, there are reports of increased mortality during the early stages of the pandemic that was 3 to 5-fold higher than what can be explained by the official COVID-19 deaths. This is calling for an urgent increase resource capacity across all health services. At Champalimaud Foundation, the implementation of remote consultations to cope with the pandemic is showing that digital technology is in fact rapidly reshaping the health system. This new reality highlights the emerging opportunity for BOUNCE study to incorporate a resilience decision-support system used in routine clinical oncology practice to provide physicians and other health professionals with concrete, personalized recommendations regarding optimal psychosocial support strategies.

## TESTING THE FIRST VERSION OF THE BOUNCE TOOL IN HUS

By Dr Paula Poikonen-Saksela, MD  
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HUS, coordinator of BOUNCE and one of the project's clinical partners, set out to utilize preliminary insights gained from the early phases of the project to improve patient care. This goal is realized as part of our long-term plan to elaborate the care path for breast cancer patients as part of the HUS Comprehensive Cancer Centre operational model. HUS aims at to enhance personalized breast cancer care and augment patient-focused interventions by improving visibility of patients with low resilience.

As the next step towards the clinical use of the resilience predictor tool HUS plans to test the tool starting in the Fall of 2020 based on the early modelling results of BOUNCE. A cohort of consecutive breast cancer patients similar to those enrolled in the BOUNCE prospective study who receive some type of medical therapy for early breast cancer will be offered the option to participate in this feasibility study. Patients will be recruited at the start of their oncological treatments. During this pilot we will test the data



## Aggiungi un sintomo

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	Nausea o vomito	<input type="checkbox"/>
	Difficoltà a mangiare	<input type="checkbox"/>
	Problemi di stomaco o intestinali	<input type="checkbox"/>
	Febbre	<input type="checkbox"/>
CANCELLARE		SEGUENTE

collection workflow for measuring resilience. Patients will provide answers to a selected set of brief questionnaires in the Noona electronic platform. The data will be exported to the resilience predictor tool located at FORTH, Greece, where an individual resilience score will be estimated. Patients with estimated low levels of resilience will be offered targeted interventions. The type of intervention will be customized based on the most likely determinants of resilience for a given patient. Information about the clinical utility of resilience predictor tool will be collected. Resilience will be measured at baseline and at 3-month intervals over a period of 12 months. The main end-point of this study is patient compliance to the intervention.

The interventions available for the purposes of this preliminary study comprise psychosocial support, exercise and nutrition guidance to avoid weight gain during and after breast cancer treatments. Our original plan for this study was to use a digital platform for psychosocial support but during the current COVID-19 pandemic we decided to convert all the interventions to digital form in HUS Health Village My Path platform. This digital approach will improve the palette of supportive interventions as they are easily available to a large number of patients both in normal and pandemic conditions safely and cost effectively. All the interventions were designed for this study by professionals i.e. oncologists, psychologists, physiotherapists and nutrition therapists with extensive experience in treating women with breast cancer.



## THE EXPERIENCE OF IEO DURING BOUNCE PROJECT

By Greta Pettini and Ketti Mazzocco, PhD

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The use of electronic medical devices is rapidly growing and gaining acceptance in clinical practice. Among BOUNCE partners, Noona Healthcare developed a fully responsive web application accessible through a web browser and suitable device, designed for cancer patients. The Noona mobile service, within BOUNCE project, allows the collection of study-relevant information through self-report questionnaires and remote monitoring of patient responses. Such mobile solutions, enabling remote completion of questionnaires, has facilitated participation to the research study, especially among those who live far from the hospital and do not have regular physical access to the hospital premises. Electronic devices are certainly a practical tool for patients, because they allow them a certain level of autonomy in completing the questionnaires, allowing them to choose the best place and time to contribute to the

research. This is of particular importance for the European Institute of Oncology (IEO), for which the vast majority of patients reside all around Italy and remote monitoring guarantees continuity of care.

In spite of these important advantages of electronic devices, some drawbacks are present. Patients approach several questionnaires on their own, without a health professional specialist who could help them in real-time. Cancer diagnosis, together with medical and surgical interventions affects patients physically and emotionally. The various questionnaires used to measure the broad construct of resilience, sometimes place the patient in front of potentially anxiety-provoking scenarios which may drive some patients to withdraw from the study or simply skip the most sensitive questions.



In the IEO experience, the very first face-to-face encounter with the patient represents a critical moment in which to motivate the participant to adhere to the study in the long term. Devoting adequate time to explain the study goals, the complexity of the resilience construct and the consequent need for multiple questionnaires and repeated measurements has been shown to increase motivation to remain engaged in BOUNCE. Placing follow up calls to patients in order to check

the status of questionnaires and to provide support for their completion within the Noona platform increased the perception of care in our patients. Coherently with this last point, several patients expressed their gratitude for the attention IEO demonstrated to their psychological well-being.

The big challenge for healthcare workers involved in the BOUNCE project is perhaps to take into account the downside of technology that could enhance usability at the expense of patient-professional relationship. Therefore, a further objective is to try to reduce this distance, working on both professionals' and patients' prejudices regarding the use of technology in the health care and psychological support domains.



## BOUNCE SEMANTIC MODEL

By Haridimos Kondylakis, PhD

Computational Bio-Medicine Laboratory, Institute of Computer Science, Foundation for Research and Technology – Hellas, FORTH, Greece

One of the key achievements of the BOUNCE project is the BOUNCE semantic model, able to conceptualize and describe both retrospective and prospective data available through the BOUNCE lifetime. The development of the BOUNCE semantic model is based on the following principles: a) Reuse: Avoid “reinventing the wheel”

and reuse already established high quality ontologies. b) granularity: Annotations or mappings cannot be extracted from a single ontological resource. So, multiple ontologies should be used; c) modularity: Create a framework where different ontologies would be able to integrate many modules through mappings



between ontologies. To this direction the BOUNCE semantic model reused and extended the iManageCancer Semantic Core ontology a modular ontology, with multiple modules, covering the entire cancer domain, using state-of-the-art subontologies and terminologies. One of the extensions was the BOUNCE Psychological Ontology (BPO), supporting a unified data annotation for the psychological data of the project in both the external, the retrospective data and the prospective data collected throughout the lifetime of the project. The ontology successfully captures constructs from a vast number of psychological questionnaires and also the interrelations between those constructs conceptualizing existing knowledge from domain experts.



Figure 1. Some of the questionnaires modeled using the BPO

## FUTURE EVENTS

By Ketti Mazzocco, PhD

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### 3rd Dissemination Virtual Event of the BOUNCE Project: From resilience predictive model to decision making

The third dissemination event of the BOUNCE project entitled "From resilience predictive models to decision making" will be organized virtually by the European Institute of Oncology, in order to give

the possibility to all interested people to participate in this post COVID-19 period.

The BOUNCE virtual event will drive attention to the relevance of assessing breast cancer patients' resilience at a very early stage of the care pathway. In the past three years the BOUNCE Consortium has developed a mathematical model to predict patients' resilience based on medical, biological,



psychological and social factors that characterize each patient. The predictive model will inform health professionals in adapting the decision making according to the patient's needs.

The event aims to increase the visibility of the BOUNCE predictive model framework and to generate interest on different stakeholders on its utility and future implementation within medical decision making processes.

The event will take place on the GoToWebinar platform on **September 23rd, 2020 from 10:00 to 17:00**. Free registration at the following link:

<https://attendee.gotowebinar.com/register/3089533524613077264>




### Ongoing activities by BOUNCE researchers in Israel

1. BOUNCE researchers are in the process of obtaining permission to create a dynamic end-user group of health professionals and breast cancer survivors from across the country. This highly motivated group will be invited to use the pilot version of the Decision Support tool to be built within BOUNCE in the context of both face to face workshops and on line Training Programs. This process will actively engage actual patients in the development of BOUNCE tool functionalities and interface elements.
2. Transcribed interviews with breast cancer survivors undergo qualitative analyses by social science experts toward a report on cultural elements of cancer survivors needs.
3. Training videos are known to have a great impact on both learning and motivation in health care. To address this need, BOUNCE experts in Israel are working with the Israeli National Cancer Society and other related NGO to develop teaching vignettes derived from videotaped presentations of health professionals involved in cancer care and cancer survivors.

## BOUNCE PARTNERS

	Helsinki University Hospital Comprehensive Cancer Center <b>HUS</b> <a href="http://www.hus.fi">www.hus.fi</a> Finland
	Foundation for Research and Technology – Hellas <b>FORTH</b> <a href="http://www.ics.forth.gr/cbml">www.ics.forth.gr/cbml</a> Greece
	European Institute of Oncology <b>IEO</b> <a href="http://www.ieo.it">www.ieo.it</a> Italy
	Institute of Communication and Computer Systems <b>ICCS</b> <a href="http://www.iccs.gr">www.iccs.gr</a> Greece
	NHG Consulting <b>NHG</b> <a href="http://www.nhg.fi">www.nhg.fi</a> Finland
	Hebrew University school of Social Work and Social Welfare <b>HUJ</b> <a href="http://www.sw.huji.ac.il/node/2472">www.sw.huji.ac.il/node/2472</a> Israel
	SINGULARLOGIC <b>SiLo</b> <a href="http://www.singularlogic.eu">www.singularlogic.eu</a> Greece
	Champalimaud Clinical Center <b>CF</b> <a href="http://www.fchampalimaud.org/en/clinic/">www.fchampalimaud.org/en/clinic/</a> Portugal
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