# Socially Engaged Art Practice for Mental Caring and Social Inclusion: The Case Study of the International Center for Wound Repair and Regeneration, Taiwan

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#### Abstract

This research offers analysis and findings from a series of socially engaged art practices implemented by The International Center for Wound Repair and Regeneration in Taiwan to enhance mental health and well-being and promote the social inclusion of patients of a rare hereditary disease: the 'Epidermolysis Bullosa (EB).' The EB patients often suffer from frequent formations of blisters on their body and skin. Such blisters form from low mechanical stress on the skin, and mucous membranes can trigger mental and health disorders, leading to the patients' lifelong needs for caring as well as social alienation. In 2020 the Center launched artist-in-residence schemes in the medical school and invited artist Hsu Jo-Chun (b. 1991) who is also an EB patient, to conduct an education program that brought the artist to visit different EB patients and co-create visual artworks that genuinely express each patient's aspiration and feelings. At the end of the program, the artist also curated an exhibition in the open space of a university hospital entitled' The Pain Will Fly Away,' which presented the works of herself and participants together, telling the stories of the community that experienced such a rare disease. In the following years, the artist and the Center continuously collaborated on socially engaged art projects in the public sphere. This action-research will discuss the process and findings of this long-term project, which aims to empower EB patients through artistic activities and increase the public's understanding of EB patients through workshops, exhibitions, and education to create a platform for the caring of collective individuals and advocacy of social inclusion.

Keywords: Social Inclusion, Socially Engaged Art Practice, Artistic Intervention in Transforming the Public Sphere

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#### Introduction

This paper provides discussions and observations from initiative research on a socially engaged interdisciplinary art project, a collaboration between artistic practice and medical service. The paper offers analyses and findings from a series of socially engaged art practices implemented by The International Center for Wound Repair and Regeneration in Taiwan to enhance the mental health and well-being and promote the social inclusion of patients of a rare hereditary disease, the 'Epidermolysis Bullosa (EB).' Inherited epidermolysis bullosa (EB) encompasses some disorders characterised by recurrent blister formation resulting from structural fragility within the skin and selected other tissues (Fine, 2010). EB patients often suffer from the frequent formation of blisters on their body and skin. Such blisters form from low mechanical stress on the skin and mucous membranes can bring mental and health disorders leading to the patients' lifelong needs for caring as well as social alienation.

In 2020 the Center launched artist-in-residence schemes in the medical school and invited artist Hsu Jo-Chun (b. 1991) who is also an EB patient, to conduct an education program that brought the artist to visit different EB patients and co-create visual artworks that genuinely express each patient's aspiration and feelings.

At the end of the program, the artist and researcher of the International Center for Wound Repair and Regeneration Lee Yi-Jun also co-curated an exhibition in the open space of Cheng-Kung University Hospital and its medical school, entitled' The Pain Will Fly Away,' which presented more than 40 pieces of works, including drawings and installation artworks from herself and participants (i.e., the EB patients and their family) telling the stories of the community that experienced such a rare disease. In the following years, the artist and the Center continuously collaborated on socially engaged art projects in the public sphere. Through artists' talks, participatory art workshops and exhibitions in a social venue (i.e., a public sphere of a medical system rather than a conventional art space), this socially engaged art project seeks to transform the usual routine of the medical service. This research will discuss the process and result of this long-term project, which aims to empower EB patients by creating artwork so that they can express and present themselves to the general public. In this way, their art collectively brings genuine emotions and messages from the inner world of rare disease patients that can have powerful impacts on the audience. In addition, through artistic activities and increasing public understanding of EB patients, the project intends to create a dialogical platform for the caring of collective individuals and advocacy of social inclusion.

The research includes discussions of the value of artistic creativity, challenges the conventional power structure of doctor-patient relationships, and open up questions about to what extent an established medical caring system could do for rare disease patients beyond treatment. This action-research also reflects on what could be the impacts and transformations from such a socially engaged art project to the medical caring system.

## **Project Description**

The International Center for Wound Repair and Regeneration was established in 2012 as one of the labs specialised in the research area of a rare hereditary disease, the 'Epidermolysis Bullosa (EB). EB is the name for a group of rare inherited skin disorders that cause the skin to become very fragile. Any trauma or friction to the skin can cause painful blisters. It is caused by a faulty gene (gene mutation) that makes skin more fragile. There is currently no

cure for EB, so treatments only aim at relieving symptoms and prevent complications such as infection. However, since it is an uncurable disease many EB patients and their close families can face life-long suffering and burden from caring for such a disease. EB patients often have difficulties in their social life, problems of social exclusion and discrimination (Chen, 2023).

Regardless of the limits of medical science and service for rare diseases such as EB, the Center aims to fulfil 'medical humanity' and 'holistic health care' for the patients (Chen, ibid). Since 2018, the centre has launched a series of charity concerts and drama camps, inviting EB patients, their families, and the public to participate in the events. It was in 2020 that Dr Lee Yi-Jun proposed the idea of collaboration with artists and launched a series of socially engaged art projects with EB patients to promote public audiences' knowledge and understanding of EB, thus transforming the medical profession and empowering EB patients. The experiment of mental caring and social inclusion for EB patients from this socially engaged art project that combines artist-in-residence schemes, art education programs for EB patients, exhibitions, and workshops in the NCKU hospital and medical school, carry on to this day.

#### Art for Art's Sake or the Transformation of The Public Sphere? Method and Action

A conventional understanding of art often concerns artists' devotion to making their artworks, the aesthetics of the art genre, and the viewers' appreciation of art. In addition, art is often produced in artists' studios and exhibited in museums or art spaces. It was in the 1960s that German artist Joseph Beuys (1921-1985) coined the idea of 'social sculpture' that challenged the possibility of creativity and suggested that artists' efforts could change society (Birchall, 2015). It was in the same vein that the concepts of a 'new genre public art' (Lacy, 1994) emerged in the 1990s. This 'new genre' had very much to do with addressing social issues and expressing activists' desires to interact directly with new audiences and accomplish concrete goals. They achieved this through profuse open-mindedness and by recognising the artist as a facilitator of others' creativity. With a similar ethos, community art development in the UK intended throughout the 1970s to engage with particular communities and issues concerning their benefits or identities. This brought a 'social turn' to artists' practices. Since the 1990s there has been an increasing number of artists' practices and theoretical publications focusing on socially engaged art, such as the studies of Claire Bishop (2012), Grant Kester (2004), and Pablo Helguera (2011). Socially engaged practice, also called social practice or socially engaged art, can include any art forms involving people and communities in debate, collaboration, or social interaction. This can often be organised as the result of an outreach or education program, but many independent artists also include such practice within their own work. Socially engaged practice can be associated with activism because it often deals with political issues. Artists working within this field often spend much time integrating themselves into the community they wish to help, educate, or share with. As Bishop's view on socially engaged art suggests:

When viewers become participants in a work of art or co-producers, there is a transition in the aesthetic considerations. It could be said that socially engaged art is the neo-avant-garde; artists use social situations to produce de-materialised, anti-market, politically engaged projects that carry on the modest call to blur art and life. (Bishop, 2006)

It is in this light that researcher and facilitator Dr Lee Yi-Jun's viewed himself as an activist taking part in a socially engaged art practice project with the aim of transforming and

renewing the medical community and in particular the caring system. Lee mentioned the following in a book published by the Center:

The traditional imagination of medical treatment and illness is a structure of opposition and duality, but holistic care is a parallel and inclusive relationship, so I set two goals initially. The first is to bring people from different occupations and classes closer together... Especially when the help of modern medicine to EB patients is minimal, how to make the boundaries of medical professions are unclear. How to help the patient create his value as a person with the whole team, this is the work worth looking forward to the target. (Chen, 2023: 238)

Working with the health sector is now an essential part of many cultural ecologists, with artists, designers, and professionals in the creative industry contributing their expertise to the spaces and experiences of healthcare, for and with staff and patients (Penketh and Riding, 2023; Campagnaro, Prima and Ceraolo, 2021). The World Health Organization (WHO) maintains that 'Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (Fancourt & Finn, 2019). In recent reports such as 'Creative Health: The Arts for Health and Well-Being' (APPG Arts, Health and Well-being, 2017), researchers provide evidence that the role of art has been influential in advocating the importance of artistic activities for health and well-being. These reports demonstrate how arts programmes significantly impact on hospital environments by supporting and encouraging patients' voice throughout their own treatment, and by humanising provision with the development of compassionate care initiatives that reduce isolation and enhance community cohesion (APPG Arts, Health and Well-being, 2017, Penketh and Riding, 2023).

Lee was inspired by the activists' approach and collaborated with artists of various disciplines, having hosted concerts and drama camps for EB patients' community since 2018. Since 2020 Lee has curated socially engaged art programmes and worked with artist and EB patient Hsu Jo-Chun. Although the 'effectiveness' of this project which is neither 'empirical research' nor 'art therapy' is at this stage not yet proven, Lee has sought to develop an action-research project that can transform the medical and caring system of a medical school at an university. I

# **Art Beyond Expression and Communication: Empowerment for the Community of EB Patients**

A 2017 report on creativity and well-being ends with a particularly pertinent quote from artist Grayson Perry:

Art helps us access and express parts of ourselves that are often unavailable to other forms of human interaction. It flies below the radar, delivering nourishment for our soul and returning with stories from the unconscious. A world without art is an inhuman world. Making and consuming art lifts our spirits and keeps us sane. Art, like science and religion, helps us make meaning from our lives, and to make meaning is to make us feel better. (APPG Arts, Health and Well-being, 2017)

It is important to recognise the importance of creative and cultural engagement in supporting the mental health and well-being of a generation of young people who have experienced very

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<sup>&</sup>lt;sup>1</sup> See the author's interview with Lee on August 2023.

particular challenges in recent years. Artist Hsu Jo-Chun was born and diagnosed with 'Epidermolysis Bullosa (EB).' When she was born and diagnosed with EB her mother, Mrs. Ku Bao-Ying, realised how much suffering and difficulties her daughter would have to overcome throughout her life. Mrs Ku recalled all the efforts her daughter and herself made for her to be able to cope with her illness and go to school to acquire an education at all costs. Since Jo-Chun's childhood, Mrs Ku has observed that her daughter is full of imagination and enjoys free-hand drawing so much that she can no longer pay attention to her pain and unbearable itchiness due to her physical condition. Unfortunately, the effects of the EB illness have made Jo-Chun's right eye almost blind, and her left eye could be significantly weakened because of a wound caused by a blister. Although the illness has made her eyes in a critical condition, this cannot stop Jo-Chun's dream of pursuing her career of being an artist. No matter how much such an illness tortured her body and mind, it could not hinder her enthusiasm for creation. In the world of art creation, she found a spiritual sustenance (Chen: 2023:66-76).

In 2020, Jo-Chun was awarded a curatorship for the group exhibition previously mentioned in the gallery of National Chiang Kai-Shek's Memorial Hall entitled 'The Pain Will Fly Away,' which presented more than 40 pieces of works from herself and the EB patients participants about the community that experienced the disease. While making this happen, Jo-Chun spent one year co-creating with some patients and visiting them at home to create artworks together. Some of the patients who could travel were invited to join Jo-Chun's studio for collaboration. The process of co-creating and the feeling of being supported by the art project greatly uplifted the patients, and some were encouraged to show their works to the public for the first time. It was through such an exhibition that the public had the opportunity to learn about this rare disease as well as the creativity of the community of EB patients. The exhibition helped the patients to display different kinds of works, and as suchthey became empowered by the public discovery of their unique creativities rather than attracting attention merely because of their disease.<sup>2</sup>

In the exhibition, Jo-Chun's work 'Looking for Protein' (Fig.1) was inspired by her series of genetic tests due to her particular skin condition. In the lab of The International Center for Wound Repair and Regeneration, when she observed the appearance of the cells under the microscope, she was amazed by the beautiful image, although she learnt from the doctor that the problem with the EB patients' skin arose from the shortage of a particular protein that should be contained in the skin of normal condition! In her ink painting, the micro image contains dots and lines that were transformed into a giant imaginary space, and the image also resembles the overlapping mountaintops in a brush painting. There is harmony within the movements in between the gaps. However, she still wishes the gap (i.e., the painted golden colour stripe that represents the missing parts of protein from the skin of EB patients), to be closed just because of her hope to be miraculously healed. (Chen, 2023:79-80).

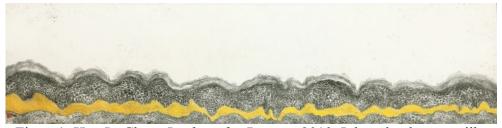


Figure 1: Hsu Jo-Chun, Looking for Protein, 2019. Ink and colour on silk

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<sup>&</sup>lt;sup>2</sup> See the author's interview with Hsu on August 2023.

Another participant, Zhi-Jay (pseudonym), was a 20-year-old severe patient who thought he had no artistic talent and was unwilling to participate. However, Jo-Chun encouraged him to use a simple hole-punching machine to make holes in the paper roll. He recorded the various pains and how his body felt daily and, finally, Zhi-Jay completed a ten-meter-long visually stunning installation artwork, entitled "*Diary*". The installation is a diary-creation in a form that resembles bandages. (Fig. 2) It is like a diary in an abstract form but that concretely shows brief experiences on an everyday basis (Chen, 2023: 266).



Figure 2: Installation work *Diary*, in *The Pain Will Fly Away* exhibition, open space of medical school of Cheng-Kung University Hospital

Another work, a painting by Yu Ming (pseudonym) entitled "Tolerance of Every Difference", displays astronauts and aliens enjoying the beautiful scenery together in the vast and boundless universe, living in harmony and interacting happily. (Fig.3) Yu Ming believed this was the most beautiful scenery. Although he suffered from the disease the boundless universe meant this to him, he had unlimited space to pursue his dreams of experiencing such a beautiful scenery. The beautiful scenery and experience presented that he finally overcame the challenges of the disease and that he achieved self-realisation in his heart. Through his paintings, Yu Ming wanted to express that people can get along happily and should not be limited by diseases or other unwelcome conditions. Although Yu Ming is different from ordinary people, he also longs to get along in harmony with others and become good friends. He also hopes this painting can encourage other EB patients with the same disease as him to bravely fly towards their ideal (Chen, 2023:268-269).



Figure 3: Tolerance of Every Difference, by co-creation project particitant Yu Ming

Following the exhibition at the Gallery of National Chiang Kai-Shek's Memorial Hall, the show was displayed at the medical school of Chen-Kung University Hospital for three months. The corridors of the medical school, where the medical students and staff of the hospital passed through every day, were transformed into exhibition spaces and filled with artworks about the patients' feelings about life. Through the patients' artworks, the medical students and the wider audiences developed a better understanding of EB. The success of these two shows for the community of EB patients came as a broadcast of voices from an unknown outcast of society addressed to the public sphere in general and, in particular, the medical system. The expressive and narrative story-telling style created rich meanings and imaginations for the viewers to be able to understand the inner world of patients suffering from a rare disease.

In 2021, Hsu Jo-Chun was invited to artist-in-residence schemes in Taipei Artists Village, designed to promote cultural equality and diversity. At the end of the residency, she presented her works in an exhibition, 'The Pathway to Shadow - Cultural Diversity and Inclusivity Group Show'. Jo-Chun was inspired by what she saw from the microscope in the hospital lab while she had regular checkings and appointments due to her disease. The curator's statement of the show explained her work briefly:

From cell slice to gene sequence examined through the microscope, we realise that human beings are vessels of genes, and the mutation of genetic factors is critical to the proliferation of life. Using everyday paper as her creative medium, Hsu uses different paper fibres to create various spheres that refer to the collaboration between similar but different cells that exist and form the body. (Pan, 2022)

During this residency, Jo-Chun transformed her style and medium from Chinese ink painting into a three-dimensional work entitled *Co-Existance* (2022). (Fig.4) Again, she used her artworks and the public space to tackle significant issues of cultural equality, diversity, and social inclusion.



Figure 4: Co-Existance, 2022, Taipei Artist Village exhibition

After the exhibition, later in 2022, Jo-Chun was invited to the National Cheng-Kung University Medical School and Hospital for another artist-in-residence scheme launched by researcher Dr Lee Yi-Jun. The scheme, made up of the residency, education programs, workshops, talks, and a solo exhibition curated by Lee Yi-Jun and Tung Wei Hsiu (the author) and entitled "Making a Wish in the Boundless Universe", gave Hsu Jo-Chun the opportunity to connect directly with the audience. (Fig.5) The most notable feature of this

exhibition was her works created with hand-made pulp. Jo-Chun collected all kinds of waste papers such as daily diaries, rice paper for calligraphy practice, school examination papers, report cards and so on. She went to various departments to collect large stacks of medicine's lists and medicine boxes. She mixed all the materials of different papers together with water and put them into a blender to make all kinds of pulp. Then, she poured the different pulps into large washbasins and dried them in the shade to become pieces of drawing paper rich in texture and touch. These papers were transformed into an installation of balls of various sizes hanging in the space of the corridor of the medical school. This kind of 'recycling' is also associated with the meaning of 'cracks' (i.e., what was missing in the skin of EB patients). Jo-Chun said: "When I broke and dismantled something and then rebuilt it to create all kinds of wrinkles and seams on its surface, it is just like another stack of life" (Chen, 2023:81).



Figure 5: Exhibition opening held in the passage connecting the medical school and Cheng-Kung University Hospital

During the residency and the exhibition, medical school students and medical care staff could take part in the workshops as well as exchange ideas with the artist and make their own pulp balls made from papers collected from their daily lives and turn them into sculptures. (Fig.6) The whole experience explored the spiritual meaning of the material that relates to the body and personal life through the art practice - just like the materials Beuys used were also recurring motifs in works suggesting that art, common materials, and one's "everyday life" were ultimately inseparable. In this respect, making art with the artist and using materials from one's own life becomes both educational and therapeutic (Simane, 2021). In this regard, artists have indeed the potential to bring change to the real world rather than make art exclusively for the artworld.



Figure 6: Participants and workshops during the exhibition

# Conclusion: The Impacts and Effectiveness of the Socially Engaged Art Project in a Medical System

After surgery, I always sewed up the wound of the patients and left. In the past, I thought I had done my job. Only now I realise the significance of caring for patients' pain. In the future, I will be even more sympathetic and pay more attention to the pain of my patients! (Chen, 2023: 270)

The above quotation was from the dean of the medical school of National Chen Kung University, Prof. Shan, Yan-Shen, after he became aware of and experienced Dr Lee's socially engaged art project. As already mentioned Dr Lee, who worked for the International Center for Wound Repair and Regeneration, has been since 2018 key to the series of artistic events aiming at improving the medical caring system and regenerating the public sphere to the benefit of both the patients and the medical staff. His approach is action-research, which he experiments with artists of different disciplines and the wider audience.

The overall research on socially engaged art practice is still going on and far from being complete. If the research does not aim at producing a result from some empirical method, it

certainly seeks to transform the public sphere as a form of 'soft activism' of which art and the artist are the catalysts. This has so far been achieved by taking Dr Lee's action-research as the core method.

'Is this going to work?' A question that Lee asked to himself after the first drama camp organised for EB patients and their families in 2018 (Chen, 2023:264). Lee is certainly also very concerned with aspects of effectiveness. Following feedbacks from the patients, their families, and the doctors of the medical schools and hospitals (Chen, ibid.), Dr Lee was from 2020 onward able to regard his entire endeavour as an instance of socially engaged art practice. This is when he began to ask artist such as Hsu Jo-Chun to become more involved with patients and engage with the medical caring system within the public sphere. Dr Lee has since seen his ideas being accepted with even further expectations for more artistic events in the future from the administration and staff of NCKU medical school and hospital.<sup>3</sup>

As for artist Hsu, she has gradually experimented other modes of expression through her art practice and changed from making mainly traditional ink paintings to using different mediums such as installation art as well as different approaches such as socially engaged art. Artist-in-residence schemes, exhibitions and workshops brought her art beyond the conventional notion of the studio practice and transformed it into a social experience of dialogical and collaborative nature. She engaged in art activism, changed the feelings of the other patients, and renewed the way doctor-patient relationships are thought in the health care system. In contemporary art history, legendary British artists John Latham (1921-2006) defined 'artist as incidential person' to bring changes to the social organisation or community (Rycorft, 2019). Beuys also had his well-known motto of 'artist as shaman' to express the ability to heal society. They both pioneered a form of intervention that inspired subsequent artists to enhance community life and address issues of individual and collective sense of identity.

As Penketh and Riding put it recently about the intersection of art and health care:

Whilst the intersections of arts and health often amplify the ongoing debates between the intrinsic and instrumental value of the arts, in recent years we have all experienced the arts in very personal and often profound ways. (Penketh and Riding, 2023:213)

Our overall research in socially engaged art pratice certainly takes into account perspectives from model artists and remains by nature interdisciplinary. However, given the arts' potential for contributing to health matters the research equally considers the kinds of practice that are experienced in the most personal and profound ways.

As far as the on-going experimental project at The International Center for Wound Repair and Regeneration is concerned, it has created a platform for dialogue. The project is making us aware of artistic expression's power to voice the feelings of a community with a rare disease. Freire views dialogue as an 'inter-subjective investigation', as a way of getting to know the 'others' and yourself. (1996). The dialogical practice is obviously also vital for artistic intervention in the medical caring system, for it fosters understanding of differences and transformations for sociocultural inclusion.

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<sup>&</sup>lt;sup>3</sup> See the author's interview with Lee on August 2023.

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