General Article

Collaborations in art and medicine: institutional critique, patient participation, and emerging entanglements.

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Abstract:

Collaborations between artists and clinicians or biomedical researchers have become increasingly common in recent decades, and now constitute a distinctive category of art-science collaboration. This article reflects on the intellectual and material conditions of such collaborations, exploring two genealogies for these practices – "sciart" and arts and health – and paying attention to two key areas: 1) the need for stakeholders to recognise fine art practice as research and knowledge-production (rather than merely illustrative, educational or therapeutic); 2) the challenges and opportunities presented by patient-participant involvement. Finally, it explores critical medical humanities as an emergent framework currently shaping these kinds of collaborations.

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Collaborations between artists and clinicians or biomedical researchers have become increasingly common in recent decades, and now constitute a distinctive category of art-science collaboration. This article considers projects in the field of health and medicine, where artists work with a range of other stakeholders – including clinicians, patient groups and interdisciplinary teams of academic researchers – to investigate medical technologies, patient experiences, and other health-related phenomena. Such projects often exceed a simple two-way collaborative model (implicit in the binary phrase 'art and medicine') of an artist working in partnership with a clinician or bio-scientist; more typically, a project will involve assembling and managing complex networks of relationships between multiple collaborators, each with different disciplinary norms and values, varying degrees of commitment to the project, and differing expectations regarding aims and outputs. This article reflects upon the intellectual and material conditions of such collaborations, exploring the practical forms that such partnerships take and the relations of power (both economic and epistemological) that are entangled within them.

It begins by addressing two frameworks that have shaped collaborative practices in art and medicine – "sciart", as defined through the Wellcome Trust's Sciart funding scheme (which ran from 1996-2006), and the arts and health movement (which has a much longer history [1]). The next section of the paper addresses two key themes. Firstly, it argues that many art and medicine collaborations exceed the illustrative, educational or therapeutic paradigms that they are typically discursively framed by, and proposes that rather than merely disseminating specialised medical knowledge to a non-expert public, such collaborations function as

"institutional critique", raising difficult ethical and philosophical questions about aspects of clinical knowledge and practice. Secondly, it explores the challenges and opportunities presented by patient involvement, which is often a distinctive feature of this kind of collaboration, paying attention to the ethics and labour of care involved in working with vulnerable health communities. Finally, I show how the critical medical humanities currently offer an emerging economic, practical and intellectual framework for art and science collaborations.

My findings are drawn from a series of interviews with fourteen artists and academics who had undertaken one or more collaborative projects in art and medicine since 2015. All projects were UK based, and interviewees were selected to ensure a range in terms of size, funding, and geographic location: the diversity of practices revealed by this process indicates the multiple forms that collaborations in art and medicine might take and cautions against over-generalisations about this field. I published the initial findings of my interviews as a practical tool kit for would-be collaborators, focusing on issues such as how collaborations are initiated, the processes that are involved, the outputs that might be expected, and how contracts, artists' fees, and copyright might be negotiated [2]. In this present article I use interview data to address specific themes raised in relation to the structures of collaborative work on art and medicine projects, focussing on bodies of work by four artists - Liz Orton, Beverley Hood, Sofie Layton and Jayne Wilton - in order to highlight particular issues. Unless otherwise stated, artists' quotes are taken from these interviews.

"Sciart" and arts in health: two genealogies for art and medicine collaborations

Art and medicine collaborations can be situated historically and methodologically in relation to two significant frameworks: sciart and arts in health. The Wellcome Trust's Sciart funding scheme (1996-2006), which supported "visual arts projects which involved an artist and a scientist in collaboration to research, develop and produce work which explored contemporary biological and medical science", has been credited with developing sciart as a distinctive category of collaborative practice [3]. A formal evaluation of the scheme, published in 2009, found that the programme had shaped a community of practitioners specializing in art and science collaborations, and had nurtured the growth of a new form of interdisciplinary work with clear links to other emergent models of art practice, including socially engaged art and a growing emphasis on academic research culture within the visual arts [4]. The scheme was found to have generated "considerable educational value", with artists' communicative abilities having "helped to demystify and make more intelligent aspects of contemporary science" for a lay audience [5]. The report also noted that "a significant minority" of respondents, particularly from the arts sector, had expressed worries about the instrumentalization of the arts in the service of (biomedical) science [6]. This anxiety around instrumentalization was echoed in comments made by the artists that I interviewed, with many recognising, for example, the "risk of appropriation, where you feel that you are making their [i.e. the scientist's] work sexy for them".

Although the Sciart scheme did not specifically focus on art and medicine collaborations, a significant proportion of funded projects engaged with biomedical research or clinical practice. A short section towards the end of the evaluation report refers to the role that artist-led projects might play in stimulating and enhancing communication between patient groups and healthcare professionals: the artist is described as a 'bridge' between these two

stakeholder groups and the art process framed as a practical tool for identifying and expressing aspects of patient experience [7].

The evaluation report further observes that the Sciart scheme inadvertently helped to grow the arts in health sector. Arts in health has an extensive history and there is a rich existent literature on the 'therapeutic' or 'healing' use of art within hospitals and other healthcare spaces [8]. In recent decades the arts have been embraced by UK policy makers as a cost-effective tool for public health interventions. In 2017, the All-Party Parliamentary Group on Arts, Health and Wellbeing published the second edition of *Creative Health: The Arts for Health and Wellbeing* [9]. Building on the WHO definition of health, as a 'state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' [10], and taking a broad definition of 'the arts', *Creative Health* is part of a flourishing literature extolling the beneficial effects of arts engagement for human wellbeing. However, critics have noted that this literature frequently exaggerates the transformative potential of the arts; is often highly selective in its evidence base; and fails to acknowledge that the benefits of creative interventions are not spread evenly through society [11].

Where *Creative Health* specifically addresses art projects that take place in healthcare environments, these are tacitly understood to be patient-centred and broadly therapeutic; scant attention is paid to the aesthetic or artistic qualities of such work, and there is little sense of the intellectual role that art practice might play in generating new knowledge about medicine and its institutions. Sheelagh Broderick has shown that art and health projects are often obliged to confirm to a clinical, evidence-based standard of evaluation in order to secure funding and be seen as legitimate; this approach, Broderick argues, is not congruent with contemporary arts practices [12]. Broderick concludes that there is a considerable level of ambiguity about what arts practices might mean for the artist, patient and healthcare professional, and suggests that further research on art and health as a field of practice is necessary to provide a nuanced conceptual frame as an alternative to the absolute authority of the clinic. This article contributes to that vital work.

Not just "illustrating" the science: art and medicine collaborations as institutional critique

Liz Orton's five-year project *Digital Insides* (2015-2020; Figs. 1-2) examined technologies of medical imaging, using the image as site of enquiry to explore different power relations that might operate and play out clinically, not just between doctor and patient, but also between the artist and the patient, or the artist and the participant [13]. Orton suggested that the project might be understood as an enquiry into the collaborative process itself, addressing "power, ownership, consent, ethics: [how] all of those things play out through the collaborative relationship." The project's outputs included an artist's book, *Every Body is an Archive* (2019), which combines different categories of medical image – software generated images, re-appropriated photographs from old medical textbooks, and contemporary restaged photographs made with collaborators – with enigmatic fragments of text extracted from longer dialogues with patients [14].

Digital Insides is an "artist-led" collaboration: Orton was responsible for conceiving the project, finding a clinician to work with, securing funding and managing the delivery of the project and its outputs. This can be contrasted with (for example) a collaborative model where an artist is engaged as part of a large multidisciplinary team researching a particular thematic (such as Jayne Wilton's work with *Life of Breath*, explored at the end of this

article): it is important to recognise that different structures of power and hierarchies of knowledge are implicated in different collaborative models.

Orton collaborated with Steve Halligan, professor of Radiology at University College London Hospital and Head of the Centre for Medical Imaging; this connection afforded Orton access to people and places that she could not have gained by herself, for example allowing her to observe patient clinics and attend multidisciplinary team meetings, learning about and reflecting on institutional values and processes from a non-patient position. By infiltrating the medical institution, Orton was able to pose questions about how medical imaging technologies actively shape understandings of what a body is. Rejecting a therapeutic, illustrative, or clinically evidence-based framework, she observed:

> I wasn't offering anything in terms of clinical understandings or outcomes or outputs – and some artists do [...] but I was trying to disturb assumptions [...] and trying to cast a different light on the relationship between images and care. It was really about an ethical or philosophical enquiry explored through imaginative as well as documentary approaches.

Whilst there is a significant body of literature recognising the imaginative and intellectual work undertaken by an artist as a form of research [15] this is not necessarily appreciated by clinical collaborators, who might hold different definitions of "research". Orton noted:

> I wouldn't go so far as to say that they [the clinical collaborators] don't consider art to be research, but the way that valid research is defined through their current criteria is strictly clinical. None of my outcomes were clinical ... It is a question of defining value. Often the artist has very limited power in these situations.

Conducting an artistic research enquiry, Orton suggests, can be awkward if there is an expectation that the art will be complementary to the science. "Often the artist is expected to prove their usefulness or value within the collaboration, but [...] if you're trying to ask difficult questions, then that can be a bit uncomfortable."

Beverley Hood has collaborated on a range of art and medicine projects, including *Eidolon* (2013-2018; Figs. 3-4) a partnership with the medical simulation centre team at Forth Valley Royal Hospital [16]. An interdisciplinary performance project involving actors and dancers as well as clinical staff, *Eidolon* developed into a series of site-specific live performances delivered to a general public within medical simulation centres, exploring the psychological potential of these spaces and the life-like training manikins found within them [17].

As part of the initial research process, Hood embedded herself in the simulation centre over an extended period, going in several times a week as "just another pair of hands [...] There would be doctors in training, and I would actually be in the simulations, so I basically spent a lot of time observing, becoming one of the team." Hood was clear that her process is not simply about illustrating the science; rather, she is interested in asking addressing issues provoked by the context:

> I don't just go in to critique the science, [...] I go in to critique the context. I try to do it in a respectful way, I know that I am privileged to go into these environments, but I am also going to have philosophical and critical

> conversations about the work that they are doing because to me these are the important questions for society to ask.

Collaborative projects like *Digital Insides* and *Eidolon* can be productively read as institutional critique. In the 1960s and 1970s, a first wave of institutional critique explored and challenged the conventions of art institutions; this approach was adapted and expanded by a second generation of artists in the 1980s and 1990s, who added questions regarding subjectivity and embodiment to those of politics and economics [18]. More recently, the philosopher Gerald Raunig had argued that a "third wave" of institutional critique has given rise to "transversal" and "instituent" practices that can no longer be categorised as exclusively artistic [19]. Read through Raunig, Orton's and Hood's projects can be understood as "instituent"; that is, they do not situate themselves in opposition to the medical institutions, but work within them, exploring – and challenging – their logic from inside the system.

Working with patient-participants: who carries the burden of care?

Sofie Layton led on the *Heart of the Matter* (2016- 2018) a long running public engagement project exploring the medicine and metaphors of congenital heart disease; *Heart of the Matter* developed out of *Under the Microscope* (2014-2016), Layton's Wellcome Trust funded artist's residency at Great Ormond Street Hospital [20]. Working with bioengineer Giovanni Biglino and supported by a team that includes a health psychologist and arts producer with specialist knowledge of the field [21], Layton has facilitated workshops with clinicians, heart patients and their families (Fig. 5), creating a body of work that bring together clinical and patient perspectives about the heart. For example, *Making the Invisible Visible* (2016) is a collection of delicate sculptural hearts contained under glass bell jars, each a 1:1 replica of the heart of a patient with congenital heart disease, made with information derived from MRI data sets, reconstructed in 3D and produced with a digital printer [22].

Echoing Orton and Hood's comments, Layton observed:

> It's not just about getting the public to look at the science, but it's about getting the science to look at the different relationships that are going on.

Layton describes her practice as 'triangular', bringing together the perspectives of artist, patient-participants and clinicians. Working with patient-participants, Layton found that "people think that you are a therapist or an occupational therapist; you are not seen [...] as another professional within that landscape." In this context, it becomes important for the artist to be able to clearly articulate their own position:

> I felt that it was really important that I spoke for myself: when you are up against the medical landscape, which has such authority, it's essential that the artist has the language to hold that space.

Layton has regularly worked with communities of vulnerable patient-participants; whilst rewarding, this can potentially be time-consuming in terms of the burden of care that the artist might be expected to carry.

> It's not just about doing the workshops, it's about looking after the participants afterwards. What is the duty of care to that group? If you are working with 100

> people, that's a lot of extra care [...] and I don't think that people [...] necessarily appreciate the time involved in that.

Several artists pointed out that the emotional impact of this labour should be acknowledged: when you are holding difficult conversations, one observed, it not only affects the participants, but also their interlocutor. For the *Heart of the Matter* Layton worked with a health psychologist who was able to provide support for both participants and artist, but Layton and others noted that this isn't necessarily the norm, especially for projects with limited budgets. Eleonora Belfiore has explored the unacknowledged costs borne by socially engaged artists working on participatory projects, noting that project-based funding rarely incorporates costs to ensure the fulfilment of care towards artists or participating communities; future research in this area might productively build on Belfiore's work to explore working practices by socially-engaged artists in the healthcare sector [23].

Several artists undertaking participatory projects in healthcare settings noted their surprise that such work did not generally require formal ethics clearance: effectively, because "art" was not conceptualised as "research" within this environment, normal ethical protocols did not apply. In such situations, artists were obliged to develop their own ethical processes.

Critical medical humanities as emerging framework for art and medicine collaborations

The Wellcome Trust is a major funder of the kind of work explored in this article. The Sciart scheme (1996-2006) was replaced by the Arts Awards (2007-2016), and the Public Engagement Fund (2017-2019). All three artists discussed thus far were recipients of Small Arts Awards from Wellcome in 2015: Orton for *Digital Insides*; Hood for producing *Eidolon*; and Layton for *Under the Microscope*. Since the Arts Awards scheme closed in 2016 there has been no funding stream aimed directly at artists. However, a number of artists are indirectly funded by Wellcome Trust as creative collaborators on Trust-funded interdisciplinary projects led by academics, managed through university departments, and operating under the label of medical humanities. If an initial wave of medical humanities typically instrumentalized fine art practices in the quest to "humanise" medicine, a second "critical" wave of medical humanities is currently making space for artists to "address difficult, more theoretically charged questions, and play a role much less benign than that of the supportive friend" [24].

Life of Breath (2015-2020) was a five-year Wellcome Trust funded research project co-managed by investigators at the Universities of Bristol and Durham [25]. Exploring the experience of breathlessness, the project team included twenty core staff and at least fourteen additional collaborators including a composer, a voice coach, an arts facilitator, and the artist Jayne Wilton. Prior to *Life of Breath*, Wilton had worked with breath and breathlessness for over a decade, collaborating with hospice patients and clinical researchers on devising techniques for bringing the usually-invisible breath to visibility [26].

Working with a large project team on *Life of Breath* afforded Wilton a new set of academic and experiential perspectives on breath. When asked what her most noteworthy output from the collaboration with *Life of Breath* was, Wilton responded "It's hard to know where it didn't touch my practice", giving as an example a series of 12 covers commissioned by *The Lancet Respiratory Medicine* in 2016. Whilst *The Lancet* was a separate commission to Wilton's work with *Life of Breath*, a quarter of the covers produced by Wilton took direct inspiration from her involvement in that project. For example, the cover of an issue on cystic

fibrosis had been inspired by a conversation with the anthropologist Andrew Russell, a collaborator on *Life of Breath*, who had told her about a qualitative study that assessed the differences in personal experiences and survival rates for young men and women with cystic fibrosis; this study gave Wilton the idea of using objects associated with gendered childhoods - marbles and beads - to recreate the chains of mucin's molecular structure [27; Fig. 6].

Wilton's experience with *Life of Breath* was a positive one: the project's lead academics were accustomed to working with artists, and the use of a creative facilitator in early meetings helped to ensure a level playing field between different types of knowledge and experience (artistic, academic, clinical, lived). If art and medicine collaborations continue to be initiated and shaped by interdisciplinary "medical humanities" projects such as *Life of Breath*, it is essential that academic partners acknowledge artists as fellow researchers and intellectual equals, and that universities and other funding bodies are prepared to properly remunerate artists for their work.

Conclusion

This article has identified two genealogies for art and medicine collaborations – sciart and arts in health – and has shown how contemporary collaborative projects by artists Liz Orton, Beverley Hood, Sofie Layton and Jayne Wilton exceed and challenge these two epistemological and practical paradigms. It has focussed in particular on the institutional framework for sciart established by Wellcome Trust's SciArt funding scheme: space constraints mean that it has been unable to engage at length with this organisation's relative power in the field or offer a comparative critique of a wider range of institutional support structures for art and biomedicine collaborations more broadly; these will be more fully addressed in a future publication. Nor has there been space in this article to assess the significance of gender, race and other identity categories in relation to disciplinary hierarchies of power: whilst prestigious sciart prizes like Ars Electronic have historically favoured the work of male artists [28], artists working in collaboration with biomedical researchers or clinical practitioners are predominantly female (including the four artists whose practices are explored here): this disparity might be productively explored by future qualitative and quantitative research [29].

Finally, this article has claimed that critical medical humanities should be considered as a significant emergent financial, practical and intellectual framework. Whilst the university sector comes with its own institutional challenges, this represents an exciting opportunity for research organisations to establish a paradigm-shifting intellectual and creative agenda. To accomplish this, stakeholders must recognise fine art practice as a vital research methodology (that is, as more than merely illustrative, educational or therapeutic) and establish effective protocols for best practice in collaborative work.

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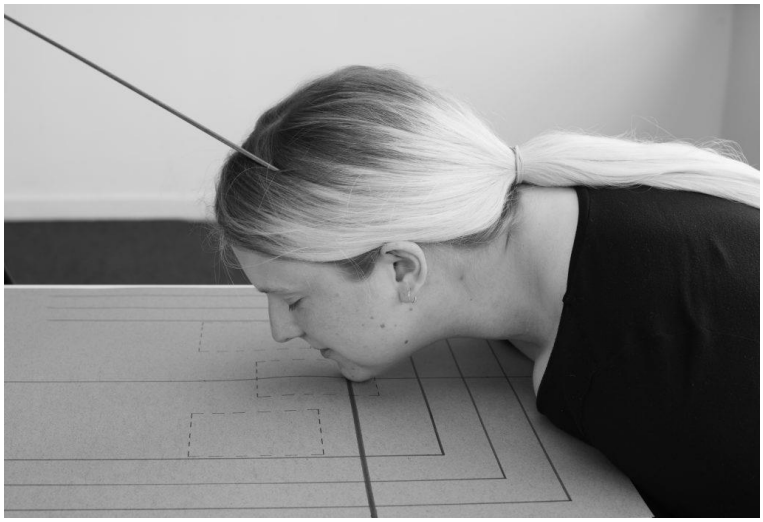
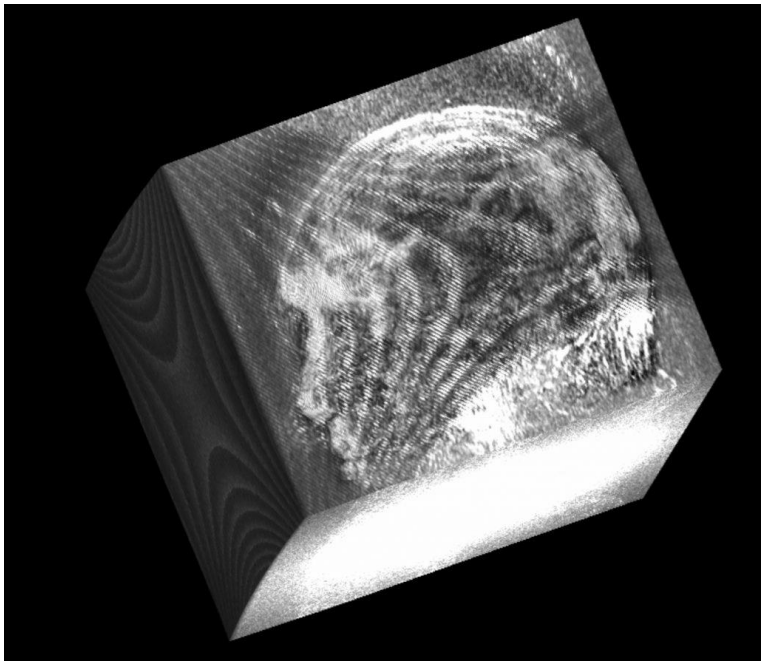
Author's biography

Fiona Johnstone is an art historian specialising in the intersections between contemporary art and medicine. She is currently a research fellow at Durham University's Institute for Medical Humanities.

Images





Figs. 1 and 2. Liz Orton, selected images from *Every Body is an Archive* (2019), an artist's book produced as part of the *Digital Insides* project. © Liz Orton.

Figs. 3 and 4. Beverley Hood, selected images from *Eidolon*, 2013-2018. (Photo credits: Lindsay Perth, Alicia Bruce and Chris Speed)

Fig. 5. The *Heart of the Matter* workshop at RWA Bristol, 2017. (Photo credit: Stephen King)

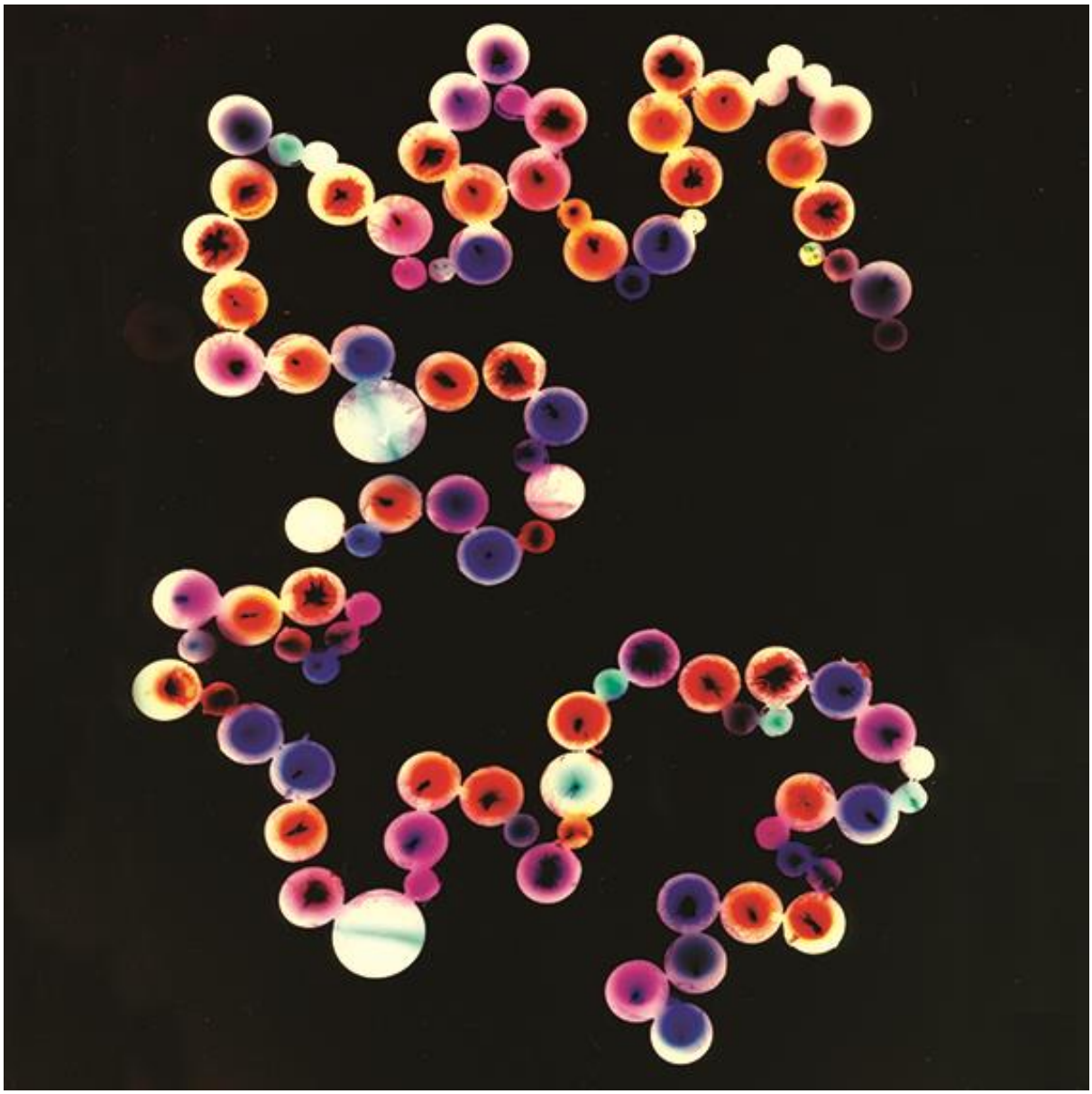


Fig. 6. Jayne Wilton, *Chain Reaction*, marbles and beads and light on photographic paper, 2015.