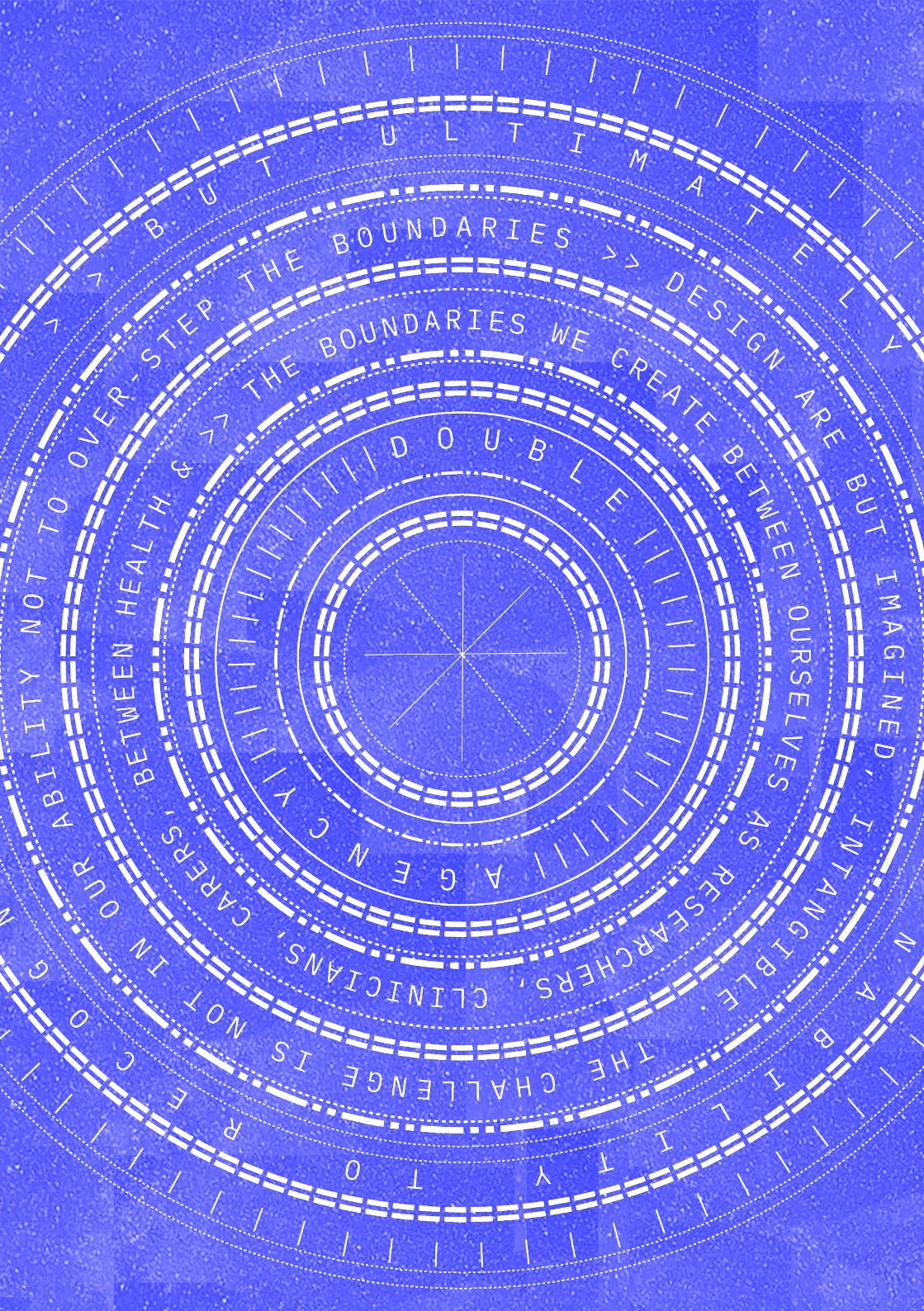
>> BUT ULTIMATELY
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RESEARCHERS, CLINICIANS, CARERS,
THE CHALLENGE IS NOT IN OUR ABILITY TO
>> DESIGN ARE BUT IMAGINED, INTANGIBLE.
NAVIGATE CONFLICTING


DOUBLE AGENCY

Thanks To All

Double Agency would like to dedicate this page to everyone who has made this publication and the Double Agency Intervention at *Design4Health2018* possible.

The concept of Double Agency arose out of the community of researchers who are part of the Cultural Communication and Computing Research Institute (C3Ri). **C3Ri** is Sheffield Hallam University's largest and highest rated community of researchers. The Institute includes two Research Centres, the Art and Design Research Centre and the Communication and Computing Research Centre.

Becky Shaw, in her role as Postgraduate Research Tutor, cultivates a vibrant and supportive research culture for doctoral candidates within C3Ri, and out of this we have debated and dialogued, critiqued and disrupted, created and played. This has helped develop much of what this publication is about. It should also be noted that the presence of **Lab4Living**, the trans-disciplinary research group of researchers in design, health-care and creative practices, has contributed to drawing this set of practitioners interested in this particular kind of cross-disciplinarity to itself.

Thank you to the researchers who gave their time and talent to write for this publication: **Frances Williams, Jonathan Michaels, Becky Shaw, Laçin Aksoy, Debbie Michaels** and **Claire Craig.** We thank you all for sharing your vulnerability, ideas, and experiences with us.

We would like to express our gratitude to **Claire Craig** and **Paul Chamberlain**, Co-Directors of the Lab4Living Research Centre at Sheffield Hallam University. Without their support and generosity, this printed publication wouldn't have been possible.

We feel incredibly lucky, that the Design4Health2018 planning team were willing to take a risk on us and make the space for the Double Agency Intervention at Design4Health Conference 2018. A special thank you to **Kirsty Christer, Heath Reed, Julie Roe** and of course **Paul** and **Claire**. You allowed us to push the boundaries of what is possible in conference settings. Thank you for being endlessly patient with us whilst we tried to tie down the detail of the project.

Thank you too to the wonderful **Neil Mayne**, who leant us his talents to build and realise the Double Agency Intervention booking system.

Finally we are also extremely grateful to Lab4Living and Design4Health for allowing us to host the launch of the **Critical Arts in Health Network (CAHN)** at Design4Health2018.

Thank you thank you thank you thank you thank you thank you.

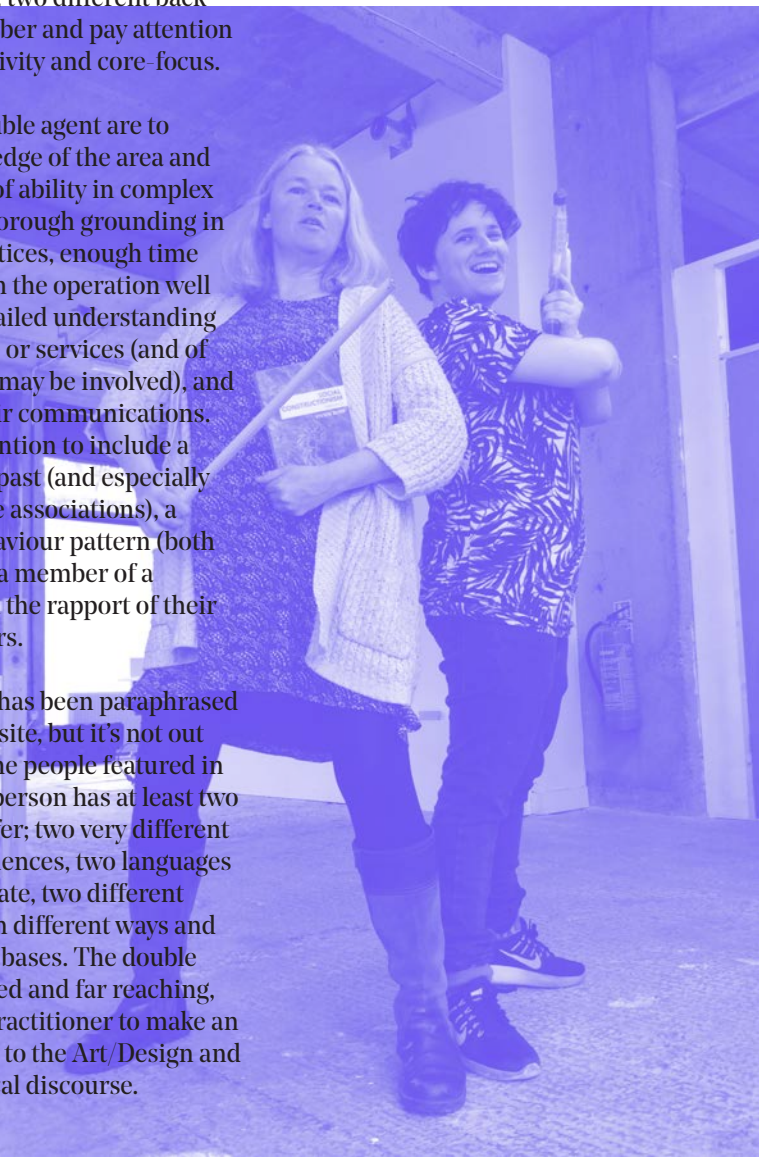
Double Agency - An Introduction

According to the Central Intelligence Agency (CIA) website, the double agent operation is one of the most demanding and complex counterintelligence activities in which a service can engage [1].

This makes sense. A person who sustains at least two different lives, two different back stories needs to remember and pay attention to each area with sensitivity and core-focus.

The requisites for a double agent are to have a thorough knowledge of the area and language, a high order of ability in complex analytic reasoning, a thorough grounding in local, and national practices, enough time from other duties to run the operation well and report it well, a detailed understanding of the adversary service or services (and of any liaison service that may be involved), and adequate control of their communications. Other things to pay attention to include a full knowledge of their past (and especially of any prior intelligence associations), a solid grasp of their behaviour pattern (both as an individual and as a member of a national grouping), and the rapport of their relationships with others.

This above description has been paraphrased from the same CIA website, but it's not out of place in describing the people featured in this publication. Each person has at least two kinds of expertise to offer; two very different perspectives and experiences, two languages to learn and communicate, two different practices that operate in different ways and through different value bases. The double agent's expertise is varied and far reaching, and this enables each practitioner to make an invaluable contribution to the Art/Design and Health/Wellbeing critical discourse.



The concept of Double Agency arose out of a dialogue within the community of researchers who are part of the Cultural Communication and Computing Research Institute (C3Ri) at Sheffield Hallam University.

Artist/Radiotherapist Sarah Smizz was the first of us to use the term Double Agent to frame her critical standpoint, and conversations within the doctoral school about patient experiences of health care led to a collaboration between Smizz and Designer/Occupational Therapist Julie Walters. Together, we speculated that art and design research tools and methods may be used to both foreground and resolve many pressing problems, one pathway at a time. The provocation Pathway Busters took examples from our own creative practices and applied them to individual encounters with health care interventions. It was presented at the Health Humanities and Arts in Health International Symposium, University of Derby in November 2017.

We are part of a growing number of art/design researchers who are interested in a critical discourse and honest and urgent re-framing of the role of the Arts in Health.

Boris Groys [2] locates the production of art in the realm of 'multiple authorship', where art is the product not only of the artist but also of choices made by curators, museum directors, museum board members, etc. Artists are encouraged, in order to survive, to take on multiple of positions: educator and artist, museum employee and curator, etc. The process of making work becomes inseparable from what is produced. Paul Carter, in his book "Material Thinking", calls this creation "acts of dismemberment"[3]. This flux enables elements that are seemingly opposite to be cut and united together, highlighting critical narratives and allows the invisible to become seen. It is particularly important in situations where power is distributed unevenly. Paying attention to these multiple perspectives, and how to utilize them, is just as important in healthcare decision-making, and in re-piecing together a history and a future for Art & Design in Healthcare.

Intra, Cross, Multi, Inter, Trans – all describe different disciplinarities. The imperative to make a success of interdisciplinary working is a constant theme in the academy and within health and social care services. However, there is a lack of crucial and close readings around this. Which pronoun fits Double Agency, where multiple perspectives and expertise sit within the same person? This is a question explored by many of the contributors to this publication.

Part of enabling agency means that we must distinguish (and show the interplay) between different dimensions of agency. We seek to go beyond one-sided points of view in Double Agency. Whilst routine, purpose, and judgment all constitute

important dimensions, nothing and no one can capture the full complexity alone. The dynamic interplay amongst our contributors brings a fresh look at the whole topic.

So in this publication, we present a series of practitioners working at the interface of Art/Design and Health/Wellbeing, collected around the idea of Double Agency.

It is hoped that this will be the first of a series of publications by the emerging Critical Arts in Health Network (CAHN).

To begin to reconceptualize agency as a temporally embedded process of social engagement, **Frances Williams** offers a critical reflection on the "Arts in Health" movement. She recalls how historically we have arrived here, what a critical model can offer, and what could happen if we're not open to one. Her piece comprises the background to the birth of the Critical Arts in Health Network. She draws on learning from a visit to Manchester's Maggie's cancer support centre and urges the Arts in Health field to address power imbalances within its own (internal) understanding and knowledge of itself in order to nourish and protect its commitment to social justice.

Julie Walters brings a critical dialogue about dominant paradigm values within healthcare, by playing with a combination of the digital and the handmade. Using her own image along with a series of props and metaphors she asks; what can be learned from paying scrupulous attention to the detail and process of a creative practice? Is it time for a new ethical framework for visual research? And do materialist epistemologies now deserve the same credibility within the academy as interpretivist and positivist ways of knowing?

Building upon this, **Jonathan Michaels**, reflects on his journey from medical doctor and vascular surgeon to artist and presents his thinking as a dry academic paper. No figures, no illustrations, just dense text. His piece considers the nature and limitations of evidence-based practice in healthcare and the potential for creative practitioners, either those with dual interests, or those embedded in a healthcare setting, to contribute added value to the process.

Becky Shaw digs deep into her artwork 'Hiding in Plain Sight', critically reflecting upon the material and spaces of healthcare, as a way to think about being a "double agent"; a researcher and a practitioner within healthcare and art. Through her work she grapples with issues of anxiety, especially to notions of belonging. Becky asks us as seekers, what are we trying to find? What marks on the spaces do we [want to] leave? And how can we be seen, or not?

Like Becky, **Laçin Aksoy** grapples with issues of anxiety. She brings her practice as an interior designer, and her expertise by experience of mental health issues, to virtual reality environments. Her work seeks to discover what comprises a therapeutic virtual environment for people living with anxiety. She works with the beauty and healing properties of biofilla, giving opportunities to those who may not have access to such environments in the physical world a Safe Space.

From here we have **Debbie Michaels** who draws on her background in art psychotherapy to anticipate the double agent encounters that will take place at Design4Health2018. She weaves this anticipation into critical reflections concerning her own encounters as she wanders in, out, and between different institutions, including those of health and social care, and academic art research. Her text invites the reader to become involved – to enter a speculative space – to wander and wonder – and to weave a speculative thread in response.

Like Debbie**, Sarah Smizz** is interested in the differences between being inside and outside of healthcare institutions. She challenges the 'dark matter' of institutionalization within healthcare and the aesthetics of it that allow a 'silencing' with regards to empowerment, agency and control. Smizz asks us to challenge the way we look and see, and how the things that we don't necessarily see, can have the biggest of consequences and make up within healthcare infrastructures, cultures and systems.

To place agency within such a temporal framework, and in order to move effectively beyond the division between instrumental and normative action, we must challenge dualisms that lie within healthcare's dominant paradigm. **Claire Craig** gives us a personal examination of the boundaries that we place around ourselves across research, academia, and in art & design and healthcare. These boundaries are imagined and intangible, however they dictate much of everything that gets created.

We have begun a critical dialogue and have started to show that by differentiating between the different dimensions of agency, we can help to account for variability and change in our capacities for imaginative and critical intervention within the fields of Arts in Health & Design For Health.

References:

[1]. CIA. Observations on the Double Agent. https://www.cia.gov/library/center-for-the-study-of-intelligence/kent-csi/vol6no1/html/v06i1a05p_0001.htm [Accessed August 12th 2018].

[2.] Boris Groys, 'Multiple Authorship', Art Power, Cambridge, MA: The MIT Press, 2008, pp.96—97.

[3]. Paul Carter. Material Thinking: the Theory and Practice of Creative Research, Melbourne Press, 2004.

The Whispering Gallery: creating space for criticality in Arts in Health

Frances Williams

Last year, I invited a group of friends and colleagues – academics, researchers, healthcare professionals and artists – to pilot the first gathering of the Critical Arts in Health Network (CAHN).

Hailing from different parts of the UK, we wanted to come together to address what we saw as the lack of critical attention surrounding art practice within this bourgeoning inter-disciplinary field. The discursive critical contexts, which enable art to be distinguishable as art, seemed to be thin on the ground here or, at the very least, interestingly repressed.

This rather odd situation has come about as a result of certain attitudes found on both sides of the Arts in Health bargain. This field is caught between others that are traditionally suspicious of one other but who nevertheless use each other for their own ends. Arts in Health presents and interesting case of 'double-agency' in its own right, one might say.

On the one hand, arts institutions increasingly embrace the 'health agenda', pursuing funding strands which link the transformational power of art with health and well-being aims. Yet literatures detailing the precise role of 'art practice' in recovery processes are rare. This is because art practice in health contexts is either seen as merely instrumental, or simply not distinctive enough, to warrant sustained attention on platforms within 'the art world'.

True, the organisation for Gallery Education, Engage, did devote one issue of its journal to this 'theme'. While one-off projects generate their own catalogues and reports (such as the Serpentine's Art + Care, A future). Other times, artists rather than curators, offer occasion to question the terms and conditions of Arts in Health practice. Becky Shaw's work, Transfer (2005) for example, marks an early exploration of context, one which saw her move the whole of Manchester Infirmary's art collection into Castelfield Gallery. But examples of what might be called 'critical arts in health practice' have never been explicitly brought together, let alone penetrated the pages of of dedicated Arts in Health journals.

On the other hand, academic research into art practice is curiously "downplayed in the Arts in Health tradition" (Newman et al, 2016: 6). Evidenced-based research, which seeks to prove beneficial clinical outcomes, is privileged over artist-led research

(McNaughton, 2012). In a neat turn of phrase, one commentator describes the field of Arts in Health as being bound by the "hegemony of the clinic" (Broderick, 2013).

Other commentators, have long characterised the 'art' in Arts in Health as suffering from an "eclipse" - a form of neglect which renders the affective qualities of art-making particularly vulnerable to becoming "lost in translation" (Putland, 2008). Posing the problem as a question, one convener asked: "Can the logic of numbers and of evidence based science be aligned with the kinds of embodied knowledges that animate art practice or the experiences that such practice can generate?"

The idea behind CAHN was to visit sites at which arts in health approaches could be both experienced and better contextualised. Aesthetics might form one part of discussions, but not exclusively so - with social, political and economic contexts also held in balance. As one friend both cautioned and encouraged at the outset,

"I feel sure you won't veer into 'art for art's sake' territory."

In seeking to articulate the claim of art to be understood as 'art' within the field of Arts in Health, we weren't seeking to reinforce this defensive posture or retain "the authenticity of art within parameters of social disengagement". We merely sought to make more explicit (assumed) thinking about art methods and art processes across

fields of practice - be they utilised in occupational therapy, community health development or forms of public health promotion.

We were keen to acknowledge, in fact, that Arts in Health is itself, a form of critique and challenge to biomedical knowledge, albeit one that falls uncomfortably within its clinical juristriction. One of the key tenants that drives the field of Arts in Health is a belief that the arts can humanise and improve (healthcare) through wholistic and integrated forms of creative practice. Issues of care - closely allied to the etymology of curation - lie at the heart of debates around what good healthcare constitutes (if not always 'good' art).

More broadly, we felt that assessments of particular projects were hidden away in the reports of evaluators (seen only by the funders) or else became part of a consultancy process. By contrast, we wanted to publicly share our direct experience and discussions and make space for critical reflection, engaging a wider community of interest. Those in the first CAHN group arrived from various disciplines - anthropology, sociology, psychology, art - and we hoped that these different backgrounds could inform the type of 'criticality' that could usefully converge and develop around our chosen foci.

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In pondering where to start, 'soft targets' initially came to mind. So many examples of Arts in Health located in hospital environments arrive from the recent past (in the 80s, 90s) and now appear strangely un-moored from their original intention. From folksy murals to corporate sculpture, everyday hospital art can often come across as tired - ripe for fresh attention or simply

in need of better curatorial care. This was something I had written about previously for an (internal) report commissioned by Guys and St Thomas Charity who had invited me to look into future possibilities for their art collection. (Though historic and rich, it lacked coherence, visibility, resource or imagination in terms of hang or strategy.)

Mindful of this example, I instead suggested we visit the brand new Maggie's Centre in Manchester. This example would be much harder to critique: the model was held-up as exemplary and had been designed and built with the bespoke purpose of aiding those in treatment and recovery from cancer. Unlike discreet works of art placed on any hospital wall, Maggies Manchester had been conceived as a total environment. Not only did it boast high-quality art works (borrowed from the Whitworth Gallery) but the building was itself designed by the world-renowned architect, Richard Rogers.

In addition to this impecccable pedigree, other factors played into my desire to breach the bounds of what was legitimate or possible to critique, allowing us to further self-reflect on the terms on which such a task might be performed.

Some of us in the CAHN group had 'insider knowledge' of either being given a diagnosis of cancer or else had experience of being closely-related to someone currently living with this disease.

This was how I had first come across the newly-built Maggie's Centre in Manchester. I was part of an audience who came to hear author Sophie Sabbage talk about her book The Cancer Whisperer. She offers a first-hand account of attempting to befriend the illness, countering dominant narratives which invite patients to 'battle' with it. The evening had felt very intimate and select. On her website forum, Sophie refers to her readers as 'cancer peeps' - a companionable term reflective of a shared sense of solidarity. This feeling was very palpable in the room that evening, if elusive to put into words.

My own PhD explores the collective solidarities which arise out of experiences of illness, setting them against the social, economic and political structures that enable them to coalesce into social movements. This is particularly the case regarding Breast Cancer, of course, where a totally new treatment paradigm was established out of the Women's Health Movement and feminist critiques of medical authority more broadly (Diedrich, 2016). Maggie Jenks, wife of architect Carl Jenks, was one such pioneer.

This was the basis, then, on which I approached Maggies as a 'user', asking if my little group of 'university-people' could also visit. I was very aware that we were not, on this occasion, the people for whom the Centre was primarily intended and at times on our visit we did feel like interlopers. I had certainly always felt the painful tension of being an intimate 'participant-observer', as you might say, in the process of my own partner's course of treatment and

recovery - being half-in and half-out of the existential implication any person faces when given a diagnosis. Epistemological questions naturally arise after such moments. After herself discovering she had breast cancer, the theorist, Eve Kosovky Sedgwick, became interested in Buddhist articulations of learning and consciousness. She acknowledges and explores experiential as well as conceptual forms of knowledge and observes (in herself) a gap which her cancer diagnosis underlines:

Perhaps nothing dramatizes the distance between knowledge and realization as efficiently at diagnosis with a fatal disease. As advertised, it does concentrate the mind wonderfully (even if by shattering it) and makes inescapably vivid the distance between knowing that one will die and realizing it."

Somehow this cry from the heart seemed to link to the current debates within the field of Arts in Health, where some forms of knowledge have been allowed to overshadow others, most especially in regard to the affective and embodied forms of knowledge which the arts best enable and employ.

Addressing this point directly, Amanda Ravetz, a proponent of artist-led research, proposed in a recent paper,

"an embrace of the potent edgeland" which Arts in Health represents. She calls for a more integrated division of labour between "implicit felt sense and logical reason" (Ravetz, 2017).

This would seem a more equitable way to deal with different frameworks of knowledge that are more often conceived of - and felt -as forms of 'battle':

profound internecine battles that have coursed within and across disciplinary subfields, as well as between disciplines thought to be relatively similar to one another (Callard & Fitzgerald, 2015)

Perhaps these public battles can also be seen more private as operating on the level of 'meeting points' established though forms of leaning-in and 'whispering"?

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Amanda, who is also my Director of Studies, joined us on the bus ride down Oxford Road to Christies' Hospital, where Maggie's sits at the end of a tree-lined avenue in residential Didsbury. Our group were well-primed and had read a number of possibly useful texts I had sourced and shared before hand which discuss the Maggie model. This included one paper by Joan Tronto - which more broadly explores the theoretical basis on which 'caring institutions' can and should be built (Tronto, 2010). Key to her account is a recognition of power relations and the problematisation of assumed values (in this case, the belief that the domestic family gives the best model for good care).

It felt useful to gather relevant reading materials around our visits / projects and let these also inform our experience. Our visit comprised a half hour tour by the Head of the Centre, Sinead Collins, before we sat down in a small room kindly allocated for the last hour. On the autumnal day we visited, the place exuded a calm and leafy atmosphere

punctuated by moments of carefully-managed activity. We first pondered the terms on which the entrance was constructed - an airy, glass foyer in which you could dump your baggage - before entering the long space. We enjoyed running our fingers through shag pile rugs and casting our eyes over the handsome array of soft furnishings.

The interior was an wooden frame which invited you to further explore its different spaces. As we did so, Sinead gave us an 'insider' view on how the place was run - highly unorthodox - explaining the choices, systems and values which underpinned the construction and use of the building. Her explanation, combined with the experience of walking around the space, was very provoking. It raised far many too points for our group to accommodate (and for this paper too, which can only touch on some of these).

Prime amongst these, was an exploration of the role of aesthetics in helping you manage your life (and your illness). A question that recurred was, 'is this what well-ness looks like?'

One member of the group (artist Becky Shaw) made reference to debates around social housing and the design of the tower block. She asked, to what extent can the design of buildings play into explanations of (anti) social behaviours? What other factors influence social behaviours, aside from architectural design, and how might one separate these?

Our group had a long discussion around to what extent Maggies' Centres sought to allow a shift in social relationships - whether this was mediated by class, gender or the debilitating effect of illness. We tip-toed past one woman undergoing treatment who lay sleeping in one of the chairs in the lounge. This was not something, we noted, that people are usually allowed to do in a public space. But this need to rest was here accepted and protected too.

A lively discussion also later ensued around the use of the kitchen which was set-up to allow visitors to make their own cups of tea. Artist Lawrence Bradby observed how he hadn't "lunged for the tap, but instead politely hovered". Such implicit protocols proved confusing to other male visitors, we heard anecdotally from Sinead, who expected her to make them a cup of tea. She humorously described how she spent hours "pretending to wipe the dishes" as a pretext for talking to the many visitors who felt better able to connect and reveal information about themselves on more equal terms in this informal way.

This surreptitious approach was one that informed the whole working of the place we soon discovered. It relied on the premise that Maggies' Centres were, as Jenks himself put it, "non-institution institutions" (Jenks, 2009). The effect of navigating hybrid, social spaces was confusing at times, throwing into question social roles, expectations and power relationships. No-one wore lanyards. Even the toilet doors were unmarked by the usual signage. Yet monitoring was being performed throughout the space all the time in very

unobtrusive ways. “We are assessing them all the time but covertly,” Sinead told us.

Her frank admission prompted discussion in our group around why the institution had to exercise these observational powers in this way.

Was it perhaps in deference to the lingering “burden of the clinic” as much as health and safety protocols? Or the differing monitoring demands present in public, rather than private, institutions?

Through its creation of hybrid forms of social space, Maggie’s was able to foster ambivalence and avoid being pinned-down: this gave the institution a certain reflexive quality that also served to hide some of its own mechanisms of observation and control.

No-where was this hidden agenda made more explicit than in our group being gifted with the private room for our subsequent discussion. After a final walk through the garden, we returned to the main building where Sinead took us up into the gallery where her workstation was positioned. She told us how she could ‘hear’ what was happening below, attendant to the habitual hubbub of operations, while also working on other things at her desk. She also showed us the two-way observation windows which gave her sight of all the private rooms along the corridor. We then took up position in one of these.

Was she perhaps, able to listen in, as well as see us? It felt a little transgressive for us to use the room within the Maggie's Centre to conduct this (critical) conversation between us. This informed our discussion of the very notion of criticality. As Amanda pointed out:

When we are being critical, what place and position are we able to do that from? Are we doing it from an assumed utopian space that we don't quite know we are occupying? Where do you stand when you are doing the critical thing? Aren't we also coming from the position of - it could be better, it should be different - which is also a kind of utopian position?

We vigorously discussed her point, returning to the idea of care advanced by Joan Tronto, who denies that her approach to caring institutions is in any way Utopian. Instead, she presents care as a mediated practice which always invites a degree of conflict. This is preferable, she argues, to accepting any consensus which hides the contested nature of care and its hierarchies of need. She concludes with her own proposition that "no caring institution in a democratic society (I include the family) can function well without an explicit locus for the needs-interpretation struggle, that is, without a rhetorical space".

The day of our visit, we brought our own rhetorical space, briefly occupying a side room at Maggies Manchester. This allowed us to discuss the institution, its values and how the implementation of these played out though the organisations operation (to which we were ourselves subject). Our observations were only made possible through participating in the experience of the institution, following on from our occupation of other institutions and roles, as 'patients', 'carers', 'clinicians' as well as 'doctors of philosophy'.

Perhaps our group was also a little covert about the nature of our likely conversation and our reason for attending. I had emphasised an "exploration of design" over critique per se. Going forward, we speculated that it would be necessary to gain trust over a longer period of time in order to fully share our observations with Sinead and others, like her, who assumed position of authority. In this way, our temporary (autonomous) critical space would be better-placed to offer a valuable addition to any internal dialogue, pre-existing within Maggie's.

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In thinking about double-agency in this publication then, this story about how we set-up CAHN and our first visit to Maggie's Manchester offers a portrait of the valuable complexity that any exploration of criticality at particular site is able to afford. The experience

underlined the necessity, for me at least, for institutions to make space for (self) critique, as an essential part of any assessment of their own needs, as much as those they aim to serve, as these are inextricably linked. This task requires negotiations which are best held in open, if not always public, contexts, enabled by flatter hierarchies. Failing that, perhaps our semi-sanctioned occupation - our whispering gallery - offers one way of cleaving open a partial space for dialogue at the outset.

Returning, at last, to the wider question of criticality within the field of Arts in Health, valuable lessons can also drawn from the example of Maggies' Manchester too I believe. In order to progress, the field of Arts in Health needs to address power imbalances within its own (internal) understanding and knowledges of itself and use these to nourish and protect its commitment to social justice. This requires that its institutions must, in Tronto's words:

> *build in adequate and well-conceived space within which to resolve such conflict, within the organization, among the institutional workers and their clients, and more broadly as the institution interacts in a complex world (Tronto, 2013)*

We hope our first CAHN group has taken its first humble step towards making realisable this task, starting conversations around what works and what doesn't, why, where and for whom.

Without making space for criticality and the serious consideration of questions such as these, the field of Arts in Health, like any other institutional formation, runs the risk of condemning itself to its own determined 'success' and securing a consensus that serves to mask silent, unspoken forms of oppression.

References:

Broderick, S. (2011) Arts practices in unreasonable doubt? Reflections on understandings of arts practices in healthcare contexts, Arts & Health, 3:2, 95-109.

Fitzgerald, D & Callard F. (2015) Rethinking Interdisciplinarity across the Social Sciences and Neurosciences. Palgrave Macmillan.

Jenks, C (2003) The Architecture of Hope, Maggie's Cancer Caring Centres. Francis Lincoln. London.

Kosofsky Sedgewick, E. (2013) Touching Feeling: Affect, Pedagogy, Performativity. Duke University Press. pp.

Parr, H. (2017) Health and Arts : Critical Perspectives. Arts, Health and Wellbeing, A Theoretical Inquiry for Pratice, Stickley & Clift (eds).

Putland, C. (2008) Lost in Translation,The Question of Evidence Linking Community-based Arts and Health Promotion. Journal of Health Psychology, Vol 13(2) 265–276.

Ravetz, A. (2017) The researcher-maker's rigour in arts and health: myths, guidance and summoning.

Raw, A. at al (2012) 'A hole in the heart : confronting the drive for evidence-based impact research in Arts in health.', Arts health., 4 (2). pp. 97-108.

Sabbage, S. (2017) The Cancer Whisperer: How to let cancer heal your life. London.

Tronto, C. (2010) Creating Caring Institutions: Politics, Plurality, and Purpose, Ethics and Social Welfare, 4:2, 158-171.

Windle G, Newman, A. et al (2016) Carrying out research across the arts and humanities and social sciences: developing the methodology for Dementia and Imagination, Cultural Trends. pp 6.

The Creep

Becky Shaw

“For me, Utopia was now concerned with the messy navigation of the realities of research. I now related to a ‘dirty’ Utopia, where idealistic intentions result in the pragmatic navigation of the research journey and that there is some form of impact to healthcare practice . “

In 2016 film-maker Rose Butler and I made a series of works with healthcare doctoral students in the simulation wards at Guys and St Thomas' hospital. The work involved playing hide and seek, using various different types of cameras and sound recorders as part of the 'play'. In the resulting video footage the hider is barely seen (not surprisingly) but 'seekers' are often caught in the stereotypical pose of 'the creeper'- hands outstretched, shoulders hunched, legs bent, on tip-toes, calf muscles tense. This movement isn't necessary to the seeking but somehow the tension of the game, produces this comic posture. Looking at 'the creep' footage, I can't help but act out the gesture, and this stirs some familiar physical sensation of working as an artist in organisations- spaces where you are unsure how to move but you move anyway, doing something to see what happens. Your stomach is knotted, treading carefully, not wanting to be too visible, needing to be trusted, but knowing you need to not belong as that is what makes what you have to offer useful. This awkwardness seems intrinsic to working as an artist in healthcare, but perhaps others might recognise 'the creep' too, as part of any double agency, when working or researching between spaces or roles.

'Hiding in Plain Sight' arose when I was commissioned by Frances Williams, to spend a couple of months working with PhD students from the Florence Nightingale Faculty of Nursing and Midwifery. We were invited to explore what utopia might mean for healthcare researchers, as part of the year-long London Utopia festival. There was a group of eight, but with five 'core' participants. These were Elizabeth Abraham, Matthew Alders, Rita Forde, Jennifer Jackson, and Mavis Machiori. Their studies were diverse, but were all either still healthcare practitioners using the PhD to better their discipline, or changing roles moving into research or academia.

Our first conversation centred on the relationship between utopia and the process of changing roles.

Matt Alder talked about being a nurse and also a researcher and how on a daily basis he felt like a climber edging (creeping?) up a crevasse with practice on one side and research on the other. He felt he would fall if either was not there. He likened this in-between position to the precise definition of utopia, not as an ideal but as 'no-place' that might be a nowhere, or a place not like other places.

The group identified doing a PhD as a way to move to another place, a situation where they could operate differently. Sometimes being inside practice was ineffective and lacked the power to make change. Being a practitioner means knowing what your role is and belonging- being 'one of us'.

One of the group described the anxiety of learning to be a researcher, what a researcher's performance is expected to look like, and the discomfort of no longer being an insider,

The pressure of being seen working in a shared office. When I started (the PhD) you have lots to do, but you sort of have nothing to do, and you look at everyone else and even though you know they were at different stages, they all look so busy, 'what are they all doing?' I stopped coming in as, 'I'm just sitting here.' In work you don't have this, you are too busy, you don't have to construct your own time. (Doing the PhD) you have this huge thing in front of you but on a daily basis you are thinking, 'what shall I do? I have so much to do, but what will I do?'

Matt mapped out the moves he made while nursing- moving ten steps up the ward to the beds, carrying five tasks to do on the way at different stations, then having six new requests added that sent you back steps. Working with film-maker Rose Butler and her expertise in technologies of observation, we spent some time photographing the simulation ward, looking under and over furniture, unpacking the emergency 'crash' kit- a routinely repeated, fundamental part of critical care training. We laughed about the well-worn ideal to move research from 'benchside' to 'bedside' as we literally moved furniture around. Those of us who didn't belong in hospital worried about being caught doing something we shouldn't, but those who worked in wards shoved it around as though they owned it.

We played hide and seek for a couple of hours. The seekers wore go-pro cameras and the hiders wore sound recorders. The seeker had to seek with a digital camera, their goal to catch an image of the hider. The two hours involved furniture sliding across the room, gasping bodies trying to hold breath, bodies falling out of cramped positions and the explosive laughter of discovery. A week after the game, we read Walther Benjamin's text, 'A Child Hiding' together to think about the experience and also the relationship to working lives[2].

Moving round the space, the visible relationship between skin, bodies and the material of the ward started to be much less distinct and all of it became animate. Benjamin describes this as being enclosed in matter or even becoming part of matter- 'behind door he is himself door'. Similarly one of the group said,

"For some reason when people hide they creep, they use these mannerisms, these little steps, its cartoonlike. You whisper, and you become like little creatures. You were in a bin, you were under a blanket, there was some hair... then the objects were moving by themselves. You were like critters... the creeping movement is irrelevant to the task but we all do the performance.[3]"

In this commentary, both 'the creep' and the hider seem to be seen as animal-like. 'critters', part of the space but also part of the living matter of the ward. A plastic patient dummy lying in bed heaved with laughter as a 'seeker' crept nearer the hider, hidden underneath the dummy. A hider wrapped themselves up in hospital cellular blankets and withdrew deeper into the ward curtains as the seeker tried to get a photo, the seeker's outstretched hand clutching at something that seemed part snail, and part hair, curtain and blanket. At one end of the room where we had dumped our bags a figure that was part bed sheet ghost and part Baroque statue blatantly posed, reminding me of the terrible entity that animates bedsheets in MR James' 'Whistle and I will come to you, my lad' story[4]. James narrates, *'there seemed to be absolutely nothing material about it save the bedclothes of which it had made itself a body'*. This hiding figure wasn't creeping, but it was frozen still in a kind of whirl of movement.

Benjamin writes about how being found can 'petrify' the hider, weaving him 'forever as a ghost in the curtain', banished for life 'into the heavy door'. The group reflected on this possibility- that hiding might mean there is no return to daily life or to their standard human form. They saw this possibility as not entirely negative, more like a desirable state of reverie or an escape from the pressure of performance:

What if no one ever finds me? Maybe you evaporate like a spirit form. Maybe you aren't there anymore. What if you disappear? When you are not being found it's a different hiding space, like looking out of the window on the train- a space of the imagination when you're mind can run. It can seem a very long time. It's a weird internal focus.[5]

The group also reflected on what was left after the hiding game. They read the part where Benjamin talks about the spaces left after children collect Easter eggs, and likened it to the impact of their own hiding, saying, '*It's like a body shape has been left in the place. By hiding in this space you have made a black hole, a new negative space.*'[6] This phrase was unexpected and peculiar, and made me think about the affect of temporary, speculative works (or maybe


DIRTY
WASHING
ONLY
THIS IS NOT A RUBBISH BIN

all works) after they have gone– how, like the restructuring of bed linen by James' ghost, they leave materials unchanged but leave an affect or charge that changes how the space feels afterwards. Immediately after this phrase one of the group noted,

'Maybe every now and again you can see the knowledge that you have'[7].

Rather than being a thing you can see as a coherent addition, perhaps accumulating understanding is like the hole left– it has a presence and an affect and it draws stuff to it like magnetism.

In a publication about the project three of the participants, Matt, Mavis and Jennifer wrote about taking part in 'Hiding'. Matt Alders talked about how the project illuminated his own research into Resilience Engineering and confirmed his commitment to the way nursing is practiced, not how it is *planned*, seeing staff adaptation to pressure being the most significant factor that affects safety. Jennifer saw 'Hiding' as making a space '*between being and doing*' and a '*revolutionary*' and '*emergent*' means to '*explore (literally and figuratively) environments in a new way*'[8]. The project also offered a way to '*reconcile realities and utopias*' through thinking about action, process and role.

Maybe the fictional space of the simulation ward and also the game that is both real and also a kind of fiction enabled a reflection on the space between ideals and reality:

Inevitably, there is a distance between utopian practice and real-life practice. In this project, we aimed to inhabit and explore that space, to understand the gap in a tangible way[9].

Matt also reflected on the project and its relationship to utopia– the insertion of a blueprint of how life (and practice) could be.

For me, Utopia was now concerned with the messy navigation of the realities of research. I now related to a 'dirty' Utopia, where idealistic intentions result in the pragmatic navigation of the research journey and that there is some form of impact to healthcare practice[10].

Mavis saw the project as connected to an historic, anthropological process of defamiliarisarion to '*make the familiar alien in order to understand systems, processes and structures around us*'[11]. She saw the project as a way of directly reflecting on the experience of moving from practitioner to researcher and the way this upends and dismantles familiar knowledge, practice and roles,

All of a sudden, we enter an environment so familiar to us we could almost perform the various roles with our eyes closed – almost. The one role we go as, in that moment of entering the field – the research student –stops us from

performing the roles we have so effortlessly conducted in the past[12].

In 'Hiding' the moving body becomes a way of finding out about a space and practices that are themselves fundamentally about the management of bodies. 'Hiding' compresses literal experiences of bodies moving in space, with thinking about transition between practices and roles. The 'creep' is just one of many movements used, but it seems a particularly interesting one because it is hesitant and tense, comic, and has an association with being 'creepy'– underhand, sneaky or insinuating.

Anxieties about being underhand, or suspicion of manipulation, affects social arts practice and also researchers, as Mavis notes, *'when you are talking to your subjects even, you are trying to hide.'* [13]

'Hiding' muddies boundaries between bodies, spaces, living and non-living, and roles and practices of education, art, research and healthcare, with the 'creeper' awkwardly moving in the mud. I think about 'the creep', as a kind of emblem for a way of working– a negotiation or 'touching' the 'skin' of a context rather than re-modelling it or re-representing it. This is a kind of relationship with space where you do stuff to find out how it responds, as well as responding to it. The 'creep' is both a 'still' and a movement, like art and healthcare, which are both outcomes and exploratory, questioning, living processes. While art in healthcare has changed a lot, there's still the expectation that we should know what is being made and what effect it will have.

Instead 'Hiding' doesn't seek to communicate something we known or think already, but to try and 'touch' an entire context– its value is to position art practice and research as exploratory, not explanatory.

'Hiding' is confusing. It refuses to say whether it is pedagogic reflection tool, a means to generate community, research about space and work, or artwork. Like the etymological roots of 'confusion' in 'confundere' which includes 'together with' and the verb fundere– 'spread out' or 'stretch out' it refuses to be narrated into clarity.

Like the hiders and seekers, it is a strange amorphous blob that balks against being pulled into constituent elements or having bits knocked off it so it fits one definition more easily. I'm reminded of Jerome Harrington's use of the phrase 'points of visibility'[14]– these are the visible mushrooms that pop up from the invisible mycellar network below. A work is all these things, the working through, the propositional, as well as the forms that make the 'light of day'. This is not a valorisation of the not knowing– we all want to know– and the seeker is, after all, trying to find something.

However there is something important to recognise about the significance of the muddy, uncertain and speculative in research, healthcare and art.

In their writing about philosopher Baumgarten, Liselott Mariett Olsson, Gunilla Dahlberg & Ebba Theorell reflect on the significance of confusion and its etymological roots. Here confusion is not a dithering, indecisive space but a type of 'extensive clarity', where many thoughts, desires and affects are experienced at the same time[15].

References

[1] Mavis Machiori, in Hiding in Plain Sight booklet, produced for launch, Are you Feeling Better? Utopia Festival, Somerset House, September 2016.

[2] Walter Benjamin and Amit Chaudhuri (2009) 'A Child Hiding' in One Way Street and Other Writings. Penguin Modern Classics. Accessed 21/8/2018 https://books.google.co.uk/books?id=n6_Dk8zfOGgC&pg=PT19&lpg=PT19&dq=Walter+benjamin+child+hiding&source=bl&ots=d-bKZ1Unpt&sig=1oNgofU_hgzYhWFMinizPa2nETI&hl=en&sa=X&ved=2ahUKEwj67svCjP_cAhVBK8AKHekbDeI4FBDoATADegQIBxAB#v=onepage&q=Walter%20benjamin%20child%20hiding&f=false

[3] Group response, in Hiding in Plain Sight booklet, produced for launch, Are you Feeling Better? Utopia Festival, Somerset House, September 2016.

[4] M. R. James (1904) Whistle, and I will come to you, my lad' accessed 21/8/2018 http://www.thin-ghost.org/items/show/150

[5] Group response, in Hiding in Plain Sight booklet, produced for launch, Are you Feeling Better? Utopia Lab, Somerset House, September 2016.

[6] ibid

[7] ibid

[8] Jackson, Jennifer, 'Between Being and Doing' in Are you Feeling Better? Book produced to conclude the Utopia projects, ed. Frances Williams. 2016.

[9] ibid

[10] Alders, Matt, 'End Goal's in Are you Feeling Better? Book produced to conclude the Utopia projects, ed. Frances Williams, 2016.

[11] Machiori, Mavis, 'Not Knowing' in Are you Feeling Better? Book produced to conclude the Utopia projects, ed. Frances Williams

[12] ibid

[13] Mavis Machiori, in Hiding in Plain Sight booklet, produced for launch, Are you Feeling Better? Utopia Festival, Somerset House, September 2016.

Between Encounters: A Speculative Weaving

Debbie Michaels

"... feature of the problematic situation and, from their gradual discovery, designs an intervention..."

pinned to the wall?...can't move...is paralysed to some degree...waiting for my next intervention...

...of interplay with the material in which the intervention of the unconscious with its ambiguities to deal with the subject in traditional...

between encounters
a speculative weaving

Debbie Michaels

...feature of the problematic situation and, from their gradual discovery,

designs an intervention...

...practice. It is obedient to the intervention of unconscious promptings, risk-taking

This writing is an intervention. Image and text inter-vene – come

Plato – representation, distance between the viewer and reality...powerful...

between you, as reader and I, as writer. In reading you are

performing a part. Becoming weaver. Following a line and

...my going into the organisation is an 'intervention' – has a different quality to 'observation'...

weaving your own speculative thread in response – a thread that,

in all likelihood, I will know nothing about. However, in doing

...in retrospect, which can then be used to modify or focus the course of therapeutic interventions...

so, you are making an intervention – altering a course of events.

...of the self watches, as if from a distance, intervening as little as possible. When the picture...

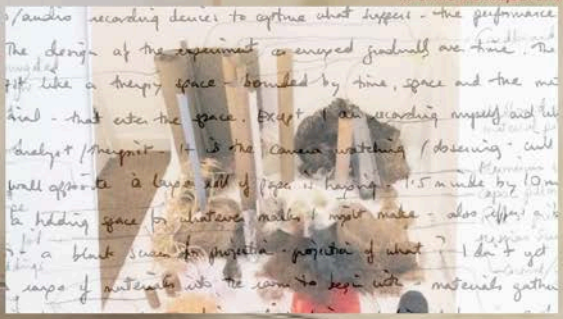
Involving yourself. Getting involved.

...interventionist works...

...any detail is 'An Intervention on the Transference.'...

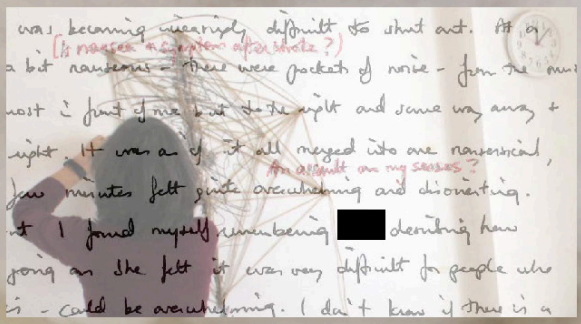
...intervening in something, trying something out and seeing what happens – very everyday...

As I begin to weave this narrative,
I imagine the space and our
encounter. It is a speculative
space. We may meet in person or
only in the spaces of this writing
and a reading between the lines –
in our imaginations. If we meet in
person – in the physical space – I
imagine that you will have made a
prior arrangement to attend this
session as part of a series of
encounters open to you. In that
sense it will not be an unexpected
encounter. It is planned. You will
have booked your appointment.
Signed up. Something will have
caught your attention or sparked
your interest. But exactly what
space we will meet in remains
uncertain. Our encounter may
take place in a private space away
from public view, or in a more
exposed arena – open to the
scrutiny of others. What *is*
known is that our encounter will
take place in an academic space.
In academia. A space designed
with a specific purpose in mind –
that of learning and the
production of knowledge.
However neither of us know, as
yet, what kind of encounter we
will have, what it will feel like or
what will happen within the
constraints of the allotted space
and time that we have. I can but
imagine, as may you. This
intervention is a staged encounter
– part performance, part art
installation, part research – where
you and I are actors in an
unfolding drama. Whether the
threads we weave will continue to
have life beyond this encounter
remains unknown. Perhaps they
will just end or be cut off
prematurely. A surprising sense
of nervous anticipation, as if I
am about to meet an art
psychotherapy client for the
first time. Except, of course,
this is not an art psychotherapy
intervention or psychoanalysis,
although I draw on both
disciplines. This encounter is
staged in an academic rather
than a psychotherapeutic arena.
The focus is subtly different,
although both – rightly – may

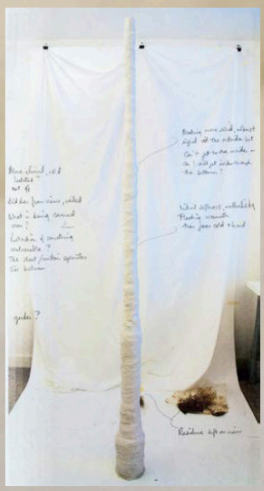


...affective moment when something is encountered
what is my subjective relation to what I see/encounter?
...the work is somewhere between the object and encounter...
...it focuses on spaces of production and of encounter...
...sought the poignancy of a direct personal encounter...
...For me the subject of the picture is...
... once an hour and kept notes recording each encounter...
...encounters with the institution (nature of, rules, conventions
etc., observation, booking)
...encounters with art and art-making...
encounters between them 'object personages'...
...confrontation of ourselves and our situations, and the problems we encounter when we do this...
...opportunity to catch ourselves in the act of encountering the world...
...and so to let us encounter ourselves in a way that we otherwise never...
...through my encounters with the organisation in the context of art-based research ...
...art as encounter which occasions thought...
...may not have been available prior to the encounter. A similar relationship is set up between...
...describe as an interactive 'in situ' encounter. This shifts our understanding of knowledge...
...material, professional, institutional encounter each other
and when methods of research are...
discourse around some of the difficulties encountered in crossing disciplinary boundaries and...

considered as places of research, reflexivity, and learning. In transferring the emphasis of my practice to a research setting I am shifting the focus of my intervention, and my attention, from the use of art *as* or *in* therapy to the use of my reflexive art-making process as an instrument for the investigation, exploration and critique of organisational culture. However,

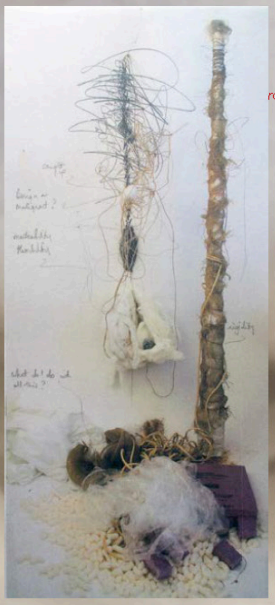


while set in an academic research context, this encounter is also personal – intimate. By entering the speculative space *between*, you are consenting to engage with a process – to enter into a dialogue, the outcome of which is uncertain – unpredictable. I imagine – speculate – that we sit facing each other, either side of a 'thing' which is arranged – situated – in a space between.[1] It 'intervenes' – comes between – interrupts. It is an invitation to engage with – and to reflect *in* and *on* – that engagement. To experience and follow its intertwining, intersecting, and overlapping lines, spaces and textures. To enquire into, wander, and wonder. To imagine. To speculate. To *not know*. As a process of 'speculative weaving' it is a performative gathering together or interweaving of materials in movement[2] – originally performed in response to twelve, weekly, observations in a community stroke rehabilitation day centre. Its presence here, for the purposes of this intervention, is part of a slow threading of strands through which I gather and weave old, new and re-purposed materials and processes – combining, reorganising, and redirecting their flow in anticipation of what might emerge. It is a gradual transformation – reconfiguring –



...issue being researched and 'direct, personal encounter' with the objects of our research. The...
...which moves closer to a fuller human encounter between two people and away from...
...encounters with art objects and live experiment with the creative process. If I had given...
...bear resemblance to the psychoanalytic encounte
in both, the ideal of evenly hovering...
...art work first and foremost involves the encounter between artist and materials at a particular...
encountering bodies
...their unanticipated (unconscious) thoughts and feelings pertaining to specific research encounters...
...my encounters with the institution/organisation/system is the core material I am working with...
...being prepared to lose ourselves in the encounter; risking not knowing as the condition of...
...when the first encounter with some object surprises us, and we judge it to be new or very...
providing we recognise that the object we encounter is not the same as what we already do know...
...between the vital materiality that we are and that which we encounter and with which we interact...
...through a form that responds to how art is encountered discussed and, perhaps most importantly...

of practice *in* and *through* practice – involving a careful weaving in, out, and between the personal, social, and institutional – the professional spaces of art, art psychotherapy, and academic research. In weaving I am attending to process – conscious and unconscious – rather than outcome. I trace and re-trace movements and gestures, returning to what's been woven time and time again – re-threading – and weaving anew.[3] As an act of durational weaving it requires introspection and observation of myself as weaver. It emphasises subjective experience, and my human capacity as researcher to be attuned, attentive and receptive to the implicit – unexpressed – in a social situation.[4] Attending to what I am weaving involves slowing down, stopping to reflect, and dwelling with uncertainty and not knowing – processes that often challenge, frustrate, and interrupt current institutional practices and demands – in both health and social care settings, and the arena of academic art research.



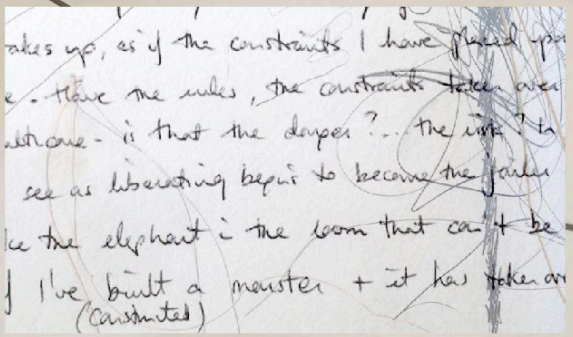
Notes:

[1] In *The Textility of Making* (2014) Tim Ingold describes a 'thing' as 'a place where several goings on become entwined' rather than an object that is complete in itself.

[2] Tim Ingold, 'The Textility of Making', *Cambridge Journal of Economics*, 34, 1, 2010, 91-102

[3] In referring to 'slow weaving' I appropriate the idea of 'slow reading' as described by Michelle Boulous Walker in *Slow Philosophy: Reading Against the Institution*, London: Bloomsbury, 2017.

[4] I draw here on a psychoanalytic method of observing organisations as described by R. D. Hinshelwood and Wilhelm Skogstad in *Observing Organisations: Anxiety, Defence and Culture in Healthcare*, London: Routledge, 2000.



Debbie is a PhD candidate in the Arts at Sheffield Hallam University. Her practice-based enquiry is concerned with the role of artist and art-making processes in interrogating and elucidating unspoken tensions between the individual and institution, and considers how the systematic use of the artistic process may be used as a primary way of examining experience.
She has a background as an art psychotherapy practitioner, clinical supervisor, and educator, with a Masters degree in the Psychoanalysis of Groups and Organisations, and has contributed to both psychoanalytic and art psychotherapy literature.

Stop. Breathe. Look. A Career in Four Parts

Claire Craig

“But what of the boundaries between past and present; between the site and me; my noticing isn’t objective, surely it is what I choose to notice. Isn’t what I see inexorably linked to who I am, how I view the world, who I am? How can I separate my history from the history that unfolds before my eyes, are we not intertwined?”

First a historian: Anglo Saxon archaeology my specialism. My heart still quickens as I recall the sense of discovery on a dig, peeling away the layers, feeling my way through cold soil, sifting centuries of earth, piecing together fragments of objects which had laid undiscovered for centuries– re-assembling fragile lives, hidden truths.

Arrive at the site. Stop. Breathe. Look. Breathe. Stay in the moment. Register the details. Notice. Connect with the earth. Trust your senses.

Archaeology is the science of noticing. Patience is a fundamental requirement. Looking for detail, those minute clues that tell the story of the tangible: how did people live, eat, work, survive and the intangible: values, dreams, hopes in this world and the next.

'Establish clear boundaries' my Oxford Professor told me. Contamination of the site is always a danger. Context is key. A good archaeologist will unearth deep truths but will tread lightly. 'And remember Craig, the context of where the artefact is found is just as important as the artefact itself.'

But what of the boundaries between past and present; between the site and me; my noticing isn't objective, surely it is what I choose to notice. Isn't what I see inexorably linked to who I am, how I view the world, who I am? How can I separate my history from the history that unfolds before my eyes, are we not intertwined?

Archaeology taught me much. It prepared me well for my career in occupational therapy.

My heart quickens when I recall each person I have worked alongside. Such a privilege: the sense of discovery, seeking out and piecing together fragments of meaning.

Arrive on the home visit. Stop. Breathe. Look. Breathe. Stay in the moment. Register the details. Notice. Connect with the environment. Connect with the person. Trust your senses. Listen to the unfolding narrative. Offer yourself.

Occupational therapy is a practice of noticing. Patience is a fundamental. The ability to listen, to build understanding, enable the person to reconnect with values, roles, meaningful engagements that lay at the heart of self, of being. Enabling the tangible: cooking, dressing, activities of daily living, supporting the intangible: those hidden values, dreams unrealised.

'Establish clear boundaries' our tutors told us. This is what it is to be a professional. The mark of a good professional is to draw near to someone, build intimate understanding but to maintain a distance so that you are untouched by human tragedy.

But what of me? Where do I sit within all of this? Which part of me do I leave behind? What of therapeutic use of self? What of my experience, my humanity? How is it possible to separate out the life of the individual I am working alongside and my own – are we not now part of each other's histories?

Occupational therapy taught me much. It prepared me well to be a family carer. My heart stops momentarily when I recall the moment of the phone-call that would change my life forever. Stumbling to find my way through the layers of confusion and chaos, piecing together fragments of lives, which had been shattered around me.

Arrive at the hospital. Stop. Breathe. Look. Breathe. Stay in the moment. Register the details. Notice. Connect with the environment. Recognise the glances, read the subtext, the unspoken. Prepare yourself. Smile, wait for the right moment, ask the questions.

Being a carer is a practice of noticing, of holding the self in the moment. Patience and trust are fundamental. The ability to ask the right questions, navigate the system. Contain emotion.

'Health-care professionals are the worst carers I was told' by the consultant. 'Too much knowledge is a dangerous thing. For this short time replace your books with magazines. Leave the uniform by the door. Relax. Trust. Respect boundaries. Leave the worry to us.'

But how can I unlearn what I know? How can I un-become who I am? How can I not be invested in this process when so much is at stake?

Being a carer taught me much. It prepared me well to be a design researcher. My heart quickens as I recall the continued sense of discovery, each enquiry, workshop, interview, uncovering new truths, piecing together evidence. Building understanding: unearthing new perspectives: treading different paths.

Arrive at the interview. Stop. Breathe. Look. Breathe. Stay in the moment. Register the details. Notice. Connect with the person. Trust your senses.

Research is a science of noticing. Patience is a fundamental requirement. Looking for detail, those minute clues that tell the story of the tangible: how do people live, eat, work, survive, how does design foster and contribute to wellbeing and the intangible: values, dreams, hopes in this world and the next. Just as an archaeologist I hone design research tools to sift through the layers, build understanding.

'Establish clear boundaries' the research textbooks tell me. Contamination of the data is always a danger. Objectivity is key. A good researcher will unearth deep truths but will retain a sense of separation from the research so that the research is dispassionate, pure.

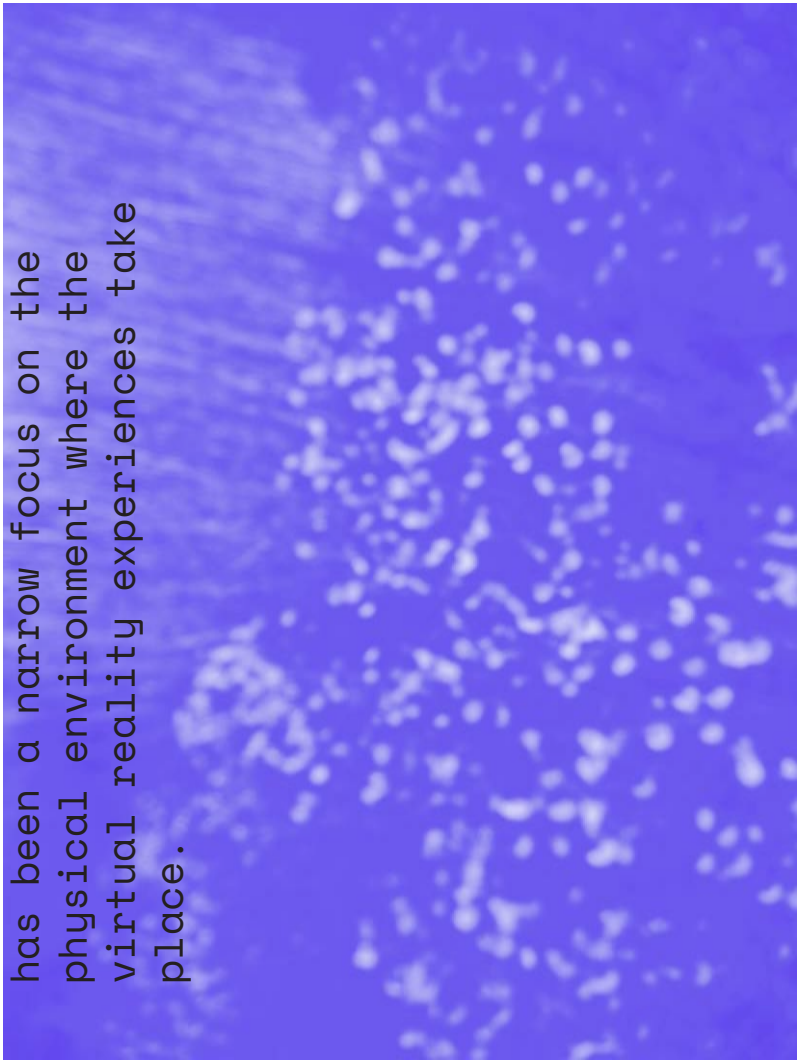
But what of me? Isn't what I choose to research, what I choose to notice, what I see inexorably linked to who I am, how I see the world, who I am? How can I separate my life from the insights that unfolds before my eyes, are we not intertwined?

During my PhD viva, a learned professor asked me 'but who are you? Are you an artist, a clinician, a researcher?' My answer was hesitant, 'I embody all these things.'

The boundaries we create between ourselves as researchers, clinicians, carers, between health and design are but imagined, intangible. The challenge is not in our ability not to over-step the boundaries but ultimately in our inability to recognise them.

Safe Space: Exploring the opportunities of virtual reality environments to influence wellbeing

Laçin Aksoy

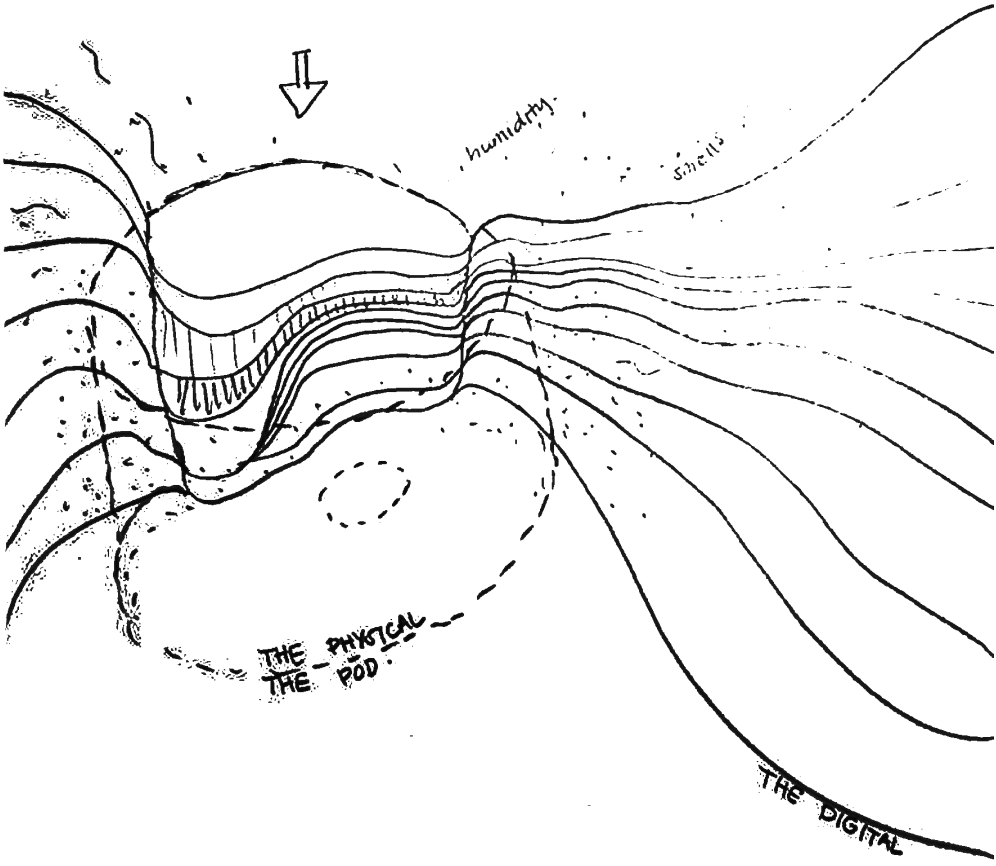


I define myself as a researcher and a cross-disciplinary designer with research focus on sensory experiences and technobiophilia within immersive environments.

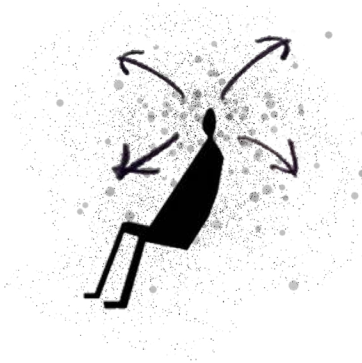
My journey of exploration on immersive environments started at the beginning of my final MA project. I was inspired by a seminar I attended on virtual reality environments and virtual reality experiences at Sheffield Hallam University. I have always been interested in sensory experiences but this seminar gave me the idea to explore the potential of VR.

This project has started with the intention of integrating VR and sensory design within interior spaces. Because I have experienced panic attacks and anxiety I wanted to explore the opportunities of VR to address these very common mental health issues. Maples-Keller, et al (2017) conducted a systematic literature review of studies implementing VR-based treatment for anxiety.

The review found that there is a 20 year history of research into VR used to treat anxiety disorders, the most promising studies have been on the treatment of phobias as part of exposure



based therapy. I also researched healing spaces, mindfulness and technobiophilia and positive distractions, wellbeing and sensory design and arrived at the research question:



'How can an increased level of immersion in virtual reality (VR) be utilised in therapeutic spaces for people who are coping with anxiety?'

Virtual reality has been increasingly used in health and wellbeing industry however, there has been a narrow focus on the physical environment where the virtual reality experiences take place. So my focus is exploring the further opportunities to improve wellbeing reconsidering this technology in relation to the physical environment. I aimed to create an immersive experience by including additional sensory input to the physical space, using principles of biophilic design by the incorporation of inspiration from the natural world. It is hoped this would enable the user to be fully immersed in the multi-sensory therapeutic experience and direct her/his attention from the anxiety to the moment and immersive experience itself.

One of the vital elements for mental health and wellbeing is a feeling of safety. Visualising an imaginary safe place can be relaxing for people who are anxious or stressed. Returning internally to the safe place is a way to relax and calm down when feeling triggered or overwhelmed. However not everyone has access nor can readily visualise or imagine such a space. My design aims to create beautiful and soothing experiences where the user can de-stress. My design allows for the experience to be tailored to the individual and negates the need for the user to visualise or imagine.

In order to have a better understanding of potential users' perception of aesthetics and therapeutic spaces I ran a workshop as a part of Sheffield Design Week. I asked the participants to create a composition using the multi-sensory elements to describe their ideal 'therapeutic space'. These compositions allowed the participants to communicate and share a memory or feeling of relaxation in a multisensory way. I gathered the different compositions of ideal therapeutic spaces and created five themes: mountain, beach, rain, tropical and field. Considering the time period of this project I decided to select one of these themes to continue the design process: field.

The key inspiration of 'field' was my visit to Trentham Gardens. I photographed the landscape design by naturalistic garden designer Piet Outdolf. The horizontal lines and

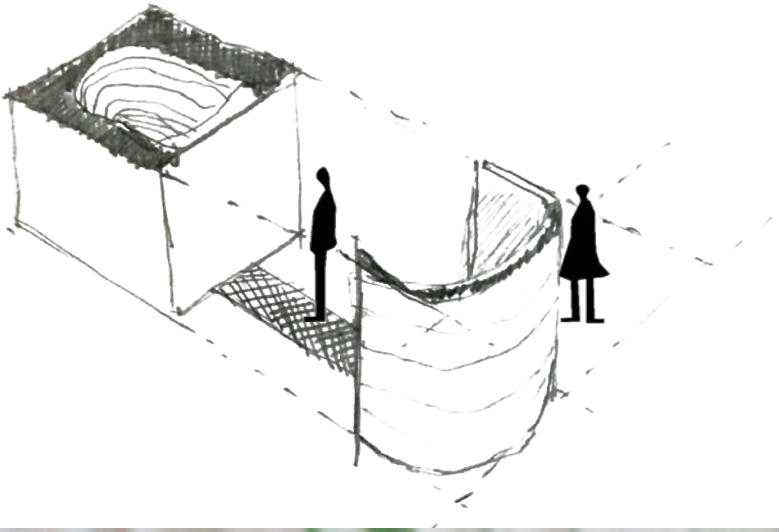
textures inspired me to create an organic and parametric form to create the physical space.
I wanted the user of this space to feel like the physical space was a small part of the virtual space, where I visually interpreted the sensory aspects such as scent and humidity.

I look forward to doing more research on immersive environments. The aim of taking this study further is to create an encounter/ installation/ experience in a physical space (for instance, work spaces, liminal or transition spaces that the public can be invited into) This interaction could raise awareness of issues such as mental health and quality of life as well as positively impacting on our daily lives.

During this project I have faced multiple challenges because of the cross disciplinary quality of this project.

My role as an interior designer was not clear in this project until I was reminded that I do not have to solve all the technical problems, by professionals who work with VR. Even though, I found it was a challenge it was a great opportunity to gain a new perspective of interior design, trying different methods to obtain knowledge and thinking thoroughly over a complex research question.

My next project will be to make a scale model of Safe Space in the physical world. I will then be ready to work towards a fully realised virtual environment based on the finding of my participatory user centered research.



Evidence-based practice and the role of the double agent

Jonathan Michaels

"Thus, an artist or other creative professional may either be cast in a role as a double agent, with a foot in both camps, or as a foreign spy, who has infiltrated behind enemy lines."

Introduction

I come from a scientific background. My father was a physicist and I was brought up in a home and schooling system in which scientific 'objectivity', knowledge and rationality were highly valued, whilst 'the arts', although valued, were seen purely as leisure or recreational activities. The month that I was born C. P. Snow published his original article entitled 'Two Cultures'[1], lamenting the divisions that had arisen between the sciences and humanities. He related this to the British educational system in which, as he described it, 'intense specialisation, like nothing else on earth, is dictated by the Oxford and Cambridge scholarship examinations.'[2]

I was a product of that system, directed by an examination at the age of eleven to a Grammar School where we were streamed from the start. Those with lower academic attainment were directed to art, technical drawing and practical subjects, whilst others were forced to give up such subjects in favour of a narrow science or humanities curriculum that fast-tracked them through 'O' and 'A' levels, allowing additional time to prepare for Oxbridge entrance exams. Thus, I gave up art and humanities subjects at an early age to focus on additional science, and studied medicine at University with the initial aim of becoming a research scientist.

My course changed when, as a first-year medical student, I was taught anatomy by a surgeon and experienced the operating theatre for the first time. For the next 30 years I built a career in academic vascular surgery, combining my clinical work with healthcare research.
Some years ago, I retired from my clinical practice and, alongside some continuing healthcare research, I developed my interest in art, studying it for the first time as an academic subject, first as a foundation course, then as an MA in Fine Art. This has been a challenging journey.

Whilst my personal experience of art has been that it is a source of insight and knowledge, helping me to explore and reframe my experience, I have found that the underlying theory and understanding of the research process often seems diametrically opposed to that in the scientific world. Such differences sometimes appear to stem from a fundamental divergence in world views and sometimes are simply the result of the different, and often exclusive, languages that have developed in different disciplines.

In the following reflections I consider the nature and limitations of evidence-based practice in healthcare and the potential for creative practitioners, either those with dual interests, or those embedded in a healthcare setting, to contribute added value to the process.

Research in healthcare and art

The rise of evidence-based practice

Evidence-based healthcare has brought enormous changes over my working

life. When I first qualified in medicine the term 'evidence-based' had not been invented and randomised controlled trials (RCTs) were relatively uncommon. A specialist clinician could expect to be aware of all the major studies in their field and guidance on practice came largely from peer groups of practitioners, or from review articles written by respected senior clinicians at the invitation of journal editors. The history of the rise of RCT's is more fully documented elsewhere[3] , but some idea of the scale of their adoption can be seen from the number of published papers indexed on PubMed that are identified by a filter for RCT's[4], which had exceeded 65,000 per year by 2016.

The huge expansion in published trials, with internet search engines providing access to a vast international literature of varying quality and relevance, mean that individual healthcare practitioners are no longer able to remain aware of all the potentially relevant literature in even a relative small specialist field, let alone to consider the relative merits and relevance of potentially conflicting results. This has led to the need for systems to filter and appraise literature and to identify and combine the results from many studies, which may differ in the exact questions addressed, the setting, study size and quality. It is this process of bringing together all the relevant information from a variety of sources that is at the heart of evidence-based practice.

Practice-based research

Coming to art from a background in scientific research I came across a growing literature about practice-based research (PbR) as the dominant form of research in creative practice. However, I have struggled to identify the components that mark it out as a distinct entity. With the possible exceptions of philosophy or pure mathematics, I find it difficult to envisage research in any subject that is anything other than 'practice-based'. A randomised controlled trial in medicine must be based upon the practice that is the subject of such a study, and when a physicist experiments with The Large Hadron Collider she would seem to be undertaking a form of practice in particle physics.

Over thirty years ago I wrote a thesis on the subject of laser angioplasty. Medical lasers were a recent development and I was studying their use to unblock diseased arteries that cause circulatory problems in the legs. In one study, I would identify patients who required leg amputation due to such disease and obtain the necessary consent to use their amputated limb to experiment with different laser settings and devices. I might assist at the operation at the Whittington Hospital, following which I would put the amputated limb in dustbin bags and carry it back on the Northern Line to our laboratory at University College. I sometimes wondered if there are London Underground bylaws forbidding the carriage of human body parts, but it was best not to ask, as our research budget would not stretch to taxis. The subsequent experiments were carefully documented with photographs, photomicrographs and X-rays that formed substantial appendices to my thesis.

I find it difficult to see a clear conceptual

distinction between the role of the documented practice in that research, and in other scientific projects in which I have subsequently been involved, and the documented artworks that might be included in a thesis describing PbR in a creative discipline. Until recently I had not heard the term PbR used in medicine, but it has now started to appear in some healthcare fields, such as nursing[5], and the multi-disciplinary clinical audit that has taken place in healthcare for many years has similarities to the processes of reflective practice that are described in relation to PbR[6]. A potential difference between the role of practice in creative practice research, as opposed to other disciplines, is that the practice may not only provide the material or data that is the substrate for the reflections or analysis that leads to new knowledge but may also be an integral part of the process of knowledge production. This may help to explain the apparent difference in the status of practice as an aspect of research in various disciplines.

Hierarchies of evidence

In evaluating evidence in healthcare, studies are frequently classified into a hierarchy[7], with systematic reviews of RCT's as the pinnacle of a pyramid, considered the most robust methodology, and theoretical considerations or expert opinion as the least reliable[8]. The outcome of illnesses and of the associated healthcare interventions are fundamentally unpredictable. When a particular positive or adverse outcome occurs it may be impossible, in the individual case, to know whether this is attributable to the natural history of the illness or to the intervention. To know whether a treatment is effective it is necessary to look for generalisations through averaging results across many similar cases and comparing these between the different treatment options. To avoid the potential biases that might be caused if patients or clinicians were to select the treatment, random allocation is used, hence the RCT.

In designing a trial or identifying relevant evidence it is necessary to frame the question that the research is intended to address. A common format for this, that has been described in evidence-based practice, is referred to by the acronym PICO, for population, intervention, comparison and outcome[9]. Each of these is considered an important aspect in obtaining a robust answer to a specific question. The population must be as specific as possible, for example the same treatment may have different outcomes in different groups based upon demographic features such as age, gender or ethnicity. The intervention and comparisons need to be clearly specified and consistent, and the outcomes need to be specific, relevant and measurable.

Formal methods of research, such as the RCT, differ from the processes in which new understandings may arise through PbR, clinical audit or reflective practice. In experimental research a hypothesis or question is pre-specified, and a deliberate method undertaken to verify or falsify the proposition. In contrast, PbR and audit may lead to new understanding, sometimes in the shape of unexpected insights, through reflection on experience. Within evidence-based practice, such experiential methods for generating new knowledge are generally

seen as less robust, and thus of lower status, than experimental research.

Limitations of evidence-based practice

Reductionism and the fragmentation of knowledge

Whilst the past few decades have seen huge advances in healthcare and many new treatments, this has come at a cost, both in financial terms and in changes to the nature of healthcare delivery. A whole range of new academic specialities have emerged, dealing with different components of the research process, such as clinical trial methodology, systematic literature reviews, decision analysis, utility analysis and economic modelling. Knowledge has become fragmented into new specialist areas, raising some of the concerns expressed by Vandana Shiva thirty years ago[10] to describe the potential injustices that may be introduced due to the gulf between the scientific expert and non-expert;

> "... violence is inflicted on the subject socially through the sharp divide between the expert and the non-expert - a divide which converts the vast majority of non-experts into non-knowers even in those areas of life in which the responsibility of practice and action rests with them. But even the expert is not spared: fragmentation of knowledge converts the expert into a non-knower in fields of knowledge other than his or her specialization." [11]

The implications of this subspecialisation for the implementation of evidence-based practice is that sharp divides have developed between different specialties, and between academics and clinicians[12]. Thus, it is not unusual for complex processes of literature review, evidence synthesis and economic modelling to be carried out by academic experts who have no direct knowledge of the specific clinical conditions and treatments that are under consideration. Whilst they may seek input from clinicians with the relevant knowledge, the lack of shared understanding means that the capacity for the clinician to be fully engaged in the decision-making process is limited.

Evidence gaps

Major limitations to evidence-based practice arise from the disconnect that occurs between the issues that need to be addressed in clinical practice and the conversion of such issues into formalised questions that can be addressed through 'robust' research. Faced with a clinical problem; a specific patient with a set of symptoms, demographic features, comorbidities and preferences, it is impossible to identify research evidence for all potential treatment options in identical situations and covering all relevant outcomes. Thus, evidence-based guidance requires processes of simplification, generalisation, extrapolation, assumptions and value judgements. Some of these judgements may be explicitly considered with input from patients who have experience of

the condition or from those with clinical expertise in the field. However, it is often the case that many of the underlying assumptions and value judgements are never specifically addressed but are intrinsic to the methods and measures used in the generation or interpretation of evidence.

For example, in providing guidance about which treatment should be used for a potentially life-threatening condition, there may be a choice between a number of potential surgical or medical methods of treatment, all with specific profiles of potential risk factors, chances of mortality, complications or side-effects, and costs. RCT evidence will often be identified to inform the choices that need to be made, but studies will all have required a series of value judgements in their design; the choice and standardisation of treatment options, the population in whom the study was undertaken, the outcomes that are considered relevant. The decision-maker will need to bring together these sources of evidence and make further judgements about the quality and relevance of each study, the trade-offs between different outcomes, and the consideration of other potentially significant issues, such as resource availability, equity and cost effectiveness.

In many institutional settings, such as the national guidance produced by the National Institute for Health and Care Excellence (NICE) in the UK, it is common to roll up the potential risks and benefits into a model of cost effectiveness analysis that determines a cost per quality adjusted life year (QALY), upon which the decision can be made. Many of the assumptions required to carry out such an analysis require sources of information outside conventional research evidence. Examination of the copious documentation that supports such guidance shows that many aspects of the evidence rely upon value judgements or expert opinion from clinicians or the technical experts carrying out the evaluation. However, there may also be issues that are not explicitly considered, such as the presumptions that go into the calculation of QALYs or the way in which the trade-offs in the nature and timing of risks and benefits are conducted.

The role of the double agent

This paper questions the potential role of a creative practitioner, working with others in a healthcare environment, as a contributor to evidence-based practice. It is increasingly common to think in terms of multi-disciplinary teams, and in such circumstances the inclusion of artists or other creative professionals may be considered as a potential asset to such a team. Many healthcare professionals also have experience or interests in creative areas that may bring an additional dimension to their healthcare practice.

Thus, an artist or other creative professional may either be cast in a role as a double agent, with a foot in both camps, or as a foreign spy, who has infiltrated behind enemy lines.

In line with the previous discussion of the limitations of evidence-based practice I highlight two potential ways in

artist may make a contribution to this process. The first is as a 'non-expert' or outsider, who may recognise and challenge some of the preconceptions and underlying assumptions that go with the specialisation of academic disciplines. The second is as a potential contributor to the epistemic process, particularly in relation to the generation of knowledge that will fill those gaps that are not well addressed through 'scientific' evidence.

The non-expert

The artist is frequently an early adopter or vocal opponent of new ideas and technologies, whether in social, political or scientific realms. They may take on the role of challenging established thinking and testing the boundaries and limitations of new fields of activity.

Having come to new fields of study through an unconventional route, they will often approach the subject as an outsider or non-expert, without the baggage of the specialised terminology, assumed knowledge and underlying preconceptions that might go with a more conventional route into an academic discipline. As such, they may be well-placed to take a more holistic approach to a subject and to encourage specialists to articulate and justify, in lay terms, their underlying assumptions. Through such mechanisms they may encourage communication between specialists with differing expertise, who may otherwise remain embedded within their academic silos, divided from other experts by a specialist vocabulary and established disciplinary paradigms.

This is not a role that is unique to artists and, in a well-functioning multi-disciplinary team, experts in one field may be empowered to question and challenge the underlying assumptions of other disciplines. There may also be a place for involving those with a background in other fields, used to working under different paradigms, such as ethicists, sociologists, ethnologists, philosophers or lay representatives. However, the artist may bring something specific and different to this process, in that the methods and artefacts that are integral to artistic practice may provide an added dimension in facilitating a non-verbal form of communication.

Filling the gaps

Whilst the evidence hierarchy of conventional scientific research may help to identify the best estimates for the quantitative predictions required for the provision of evidence-based advice, there are many gaps in the evidence that are not easily addressed in this way. There are aspects of evidence that are relevant to the process but are less easily measurable and less amenable to such research methods. For example, most would agree that issues such as fairness, equity, dignity, compassion and autonomy are all relevant to evidence-based practice, and yet, even in the context of reductionist science, there are no simple quantitative methods for evaluating and incorporating these into

decision processes and they are rarely addressed in scientific research studies.

It is, perhaps, in these more subjective and qualitative dimensions that artistic processes may be of most relevance. Questions of value, aspects of the processes of care, preferences, and the trade-offs that may be required between competing healthcare objectives, are all concerns that may be amenable to the more deliberative and reflective processes that are commonly associated with artistic practice and practice-based research methods. Many artists and performers see their creative practice as a way of exploring the world through models and metaphors[13], potentially leading to new understandings. Keith Lehrer suggests that art can generate new understandings through a process that he terms 'exemplarization', suggesting that 'Art can provide us with a sensory experience that provokes us to reconfigure how we think about our world and ourselves'[14]. This is similar to Alva Noë's description of art as a 'strange tool' that is comparable to philosophy in providing a mechanism to generate new knowledge through promoting reflective processes[15].

Those issues identified as gaps in knowledge that are not easily addressed through quantitative scientific research may be most ideally suited to multi-disciplinary approaches that are not limited to the specific perspectives of the academic disciplines closely involved in the generation and interpretation of scientific research. Added value may be provided by a more inclusive approach to the development of evidence-based guidance that takes a wider view of the nature of relevant 'evidence' and includes creative practitioners in the process, along with other stakeholders.

Concluding thoughts

In these reflections I consider the possible role of creative practitioners in the implementation of evidence-based practice in healthcare, either as professionals with interests in both healthcare and creative practice, or as creative practitioners embedded in a healthcare environment. I have highlighted certain limitations to the process of developing evidence-based guidance, particularly the risk that such guidance is increasingly becoming the domain of subspecialist academic disciplines that bring with them particular value systems and paradigms of research. Such a danger is increased by the exclusive language and hierarchies that lead to decisions that may not be fully reflective of the views of the patients and clinicians for whom the advice is provided.

My personal experience has been that involvement in creative practice has helped me to re-evaluate some of my underlying preconceptions about evidence-based practices in healthcare.

I am, thus, suggesting that there may be a twofold role for the artist, firstly in challenging the implicit assumptions and unspoken value systems that may be inherent in such practices, and secondly in providing

an alternative paradigm of knowledge production that may be more suited to some of the preference-based evidence and value judgements that are required in the development of such guidance.

This is not to claim that these roles are the exclusive domain of creative practitioners, or that these provide an exhaustive list of the ways in which artists may contribute to evidence-based practice, but they are suggestions as to how a wider involvement of those with a broader view of the nature of research and research evidence may be beneficial in providing the necessary checks and balances to such processes.

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References:

[1] C. P. Snow, 'The Two Cultures', New Statesman and Nation, /6th October (1956), 413–4. These ideas were subsequently explored further in his 1959 Rede Lecture C. P. Snow, The Two Cultures and the Scientific Revolution: The Rede Lecture 1959 (14; Cambridge: Cambridge University Press, 1959) 62.

[2] Snow, The Two Cultures and the Scientific Revolution: The Rede Lecture 1959 at p20.

[3] Laura E. Bothwell et al., 'Assessing the Gold Standard — Lessons from the History of RCTs', The New England Journal of Medicine, 374/22 (2016), 2175–81.

[4] C Lefebvre, E Manheimer, and J Glanville, 'Chapter 6: Searching for Studies', in Jpt Higgins and S Green (eds.), Cochrane Handbook for Systematic Reviews of Interventions Version 5.1. 0 (2011). A direct link to the Pubmed filters is available at; http://work.cochrane.org/pubmed (accessed 28 Jul 2018)

[5] L. Anderko, C. Bartz, and S. Lundeen, 'Practice-Based Research Networks: Nursing Centers and Communities Working Collaboratively to Reduce Health Disparities', Nursing Clinics of North America, 40/4 (Dec 2005), 747–+.

[6] Graeme Sullivan, Art Practice as Research: Inquiry in Visual Arts (Los Angeles: SAGE, 2010). 110–111

[7] Patricia B. Burns, Rod J. Rohrich, and Kevin C. Chung, 'The Levels of Evidence and Their Role in Evidence-Based Medicine', Plastic and Reconstructive Surgery, 128/1 (2011), 305–10.

[8] Dartmouth Biomedical Libraries, 'Evidence-Based Medicine (EBM) Resources', http://www.dartmouth.edu/~biomed/resources.htmld/guides/ebm_resources.shtml, accessed 28 Jul 2018.

[9] W Scott Richardson et al., 'The Well-Built Clinical Question: A Key to Evidence-Based Decisions', ACP Journal Club, 123/3 (1995), A12–A12.

[10] Vandana Shiva, 'The Violence of Reductionist Science', Alternatives, 12/2 (1987), 243–61. ibid. pp. 243–4

[11] Jonathan A. Michaels, 'Bridging the Gap between Academics and Practitioners', The BMJ Opinion (London, UK: BMJ, 2016).

[12] Annette Arlander, 'Characteristics of Visual and Performing Arts', The Routledge Companion to Research in the Arts (Routledge, 2010), 315–32.

[13] Keith Lehrer, Art, Self and Knowledge (New York ; Oxford: Oxford University Press, 2012).

[14] In Alva Noë, Strange Tools : Art and Human Nature (First edition. edn.; New York: Hill and Wang, a division of Farrar, Straus and Giroux, 2015). Noe states; "Works of art are strange tools. Technology is not just something we use or apply to achieve a goal, although this is right to a first approximation; technologies organize our lives in ways that make it impossible to conceive of our lives in their absence; they make us what we are. Art, really, is an engagement with the ways in which our practices, techniques, and technologies, organize us and it is, finally, a way to understand that organization and,

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What Is It?

Julie Walters

"Crisps. I use these snacks as stimuli because they were in a shop I was passing while I was thinking. They are more than illustrations. They are thinking tools."

Julie Walters

Who am I?

When I think of myself as a double agent, I am struck by the number of different perspectives I bring to a design and health enquiry. I am an Art School, Design Trained Educator of Health Professionals, with dyslexic brain that thinks first in image and makes sense through metaphor, with a wealth of expertise by experience of mental distress and a survivor of the psychiatric system in the role of patient and carer. By this I specifically mean that; a) I have tried to care for people who have found themselves in the psychiatric system. b) At times I have become so distressed that admission to psychiatric ward occurred. b) I know being psychotic. d) I have a psychiatric diagnosis. e) I have experienced a number of medications and treatments, including Art Psychotherapy. That is the extent of my "service user credibility". As I recovered and found accommodation with all that, I became a mental health advocate, I became a Christian with a lay ministry as a Worship leader, a by-ear musician and singer. I also became a mother. I became an Occupational Therapist – that less understood health profession which is as much Art as Science, and who's practitioners doggedly hold on to the philosophy that '"Man", through the use of his hands as they are energised by mind and will, can influence the state of his own health' (Reilly, 1962, p2).

In 2007 I found Digital Storytelling, the facilitated, personal short film making practice of Joe Lambert and colleagues at StoryCenter (www.storycenter.org). I fell in love with the potential it affords to express and create, to be heard and seen and known. And so began my long journey of exploration with this practice and ultimately my submission to the pain and privilege that is interdisciplinary research.

Double agents like me bring a multi-faceted way of thinking to challenge the practices and culture of health care. We use art and design methods to critique, disrupt, reveal and explain. We can "pathway bust" because we are simultaneously insider and outsider. Both credible and vulnerable. And, because we know, only too well, what being a patient is, getting it right really matters. Its personal.

What IS it?

Title

Personal storytelling for wellbeing; using creative digital media to explore form, content and process

Title OF MY RESEARCH

Here is the focus

the forms are digital story And stopmotion animation

the process is a 2day workshop in a small Group

a different form

My Pot ~~contains~~ for me holds a memory of the process of my King, it. its a failed pot, and I would not have kept it. But the workshop facilitator Fired it and Gave it back to me - transformed. ~~but as yet unfinished.~~ I remember Her Kindness ~~and her care of me~~. She cared for my pot so she cared for me. I was off sick from work - pottery Burn out Recovery Haptic time creative time

#Valued

Attention to A Specific Workshop at a particular place and Time

unique

non-repeatable

non-generalisable

Review of Literature .....

1. when writers publish about digital storytelling the words are privileged above the multimedia elements - so Why make a Film and not a memoir or a poem?
2. How does the workshop leader or facilitator influence? Attention to Co-production and the impact of feedback
3. Arts on prescription..... which Art and Why? what are the Active ingredients of different media forms?
4. the occupational therapy core skill of ACTivity Analysis..... No one is writing about it as a Research tool.

Crisps. I use these snacks as stimuli because they were in a shop I was passing while I was thinking. They are more than illustrations. They are thinking tools.

The onion ring is the frame for seeing. Who is holding it? What is it framing? Questions of power, Epistemic injustice and Hermeneutical injustice (Fricker 2007). The screaming silences (Serrant-Green 2011)
The clinical gaze. (Foucault 1973)
Co-Creation, Co-Design, Co-Production – what do these terms really mean?

1

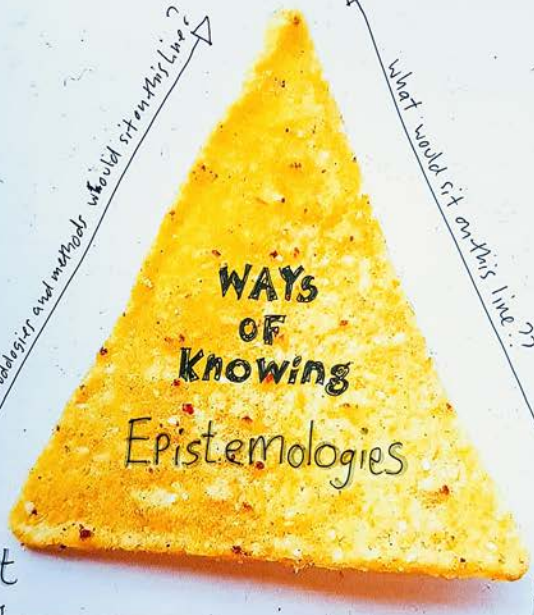
Visibility and invisibility. Research participants are protected by being made anonymous, but what about their right to be acknowledged as author of works that are made as part of research? By protecting, the researcher may be silencing and stealing. Can my research contribute to the development of a new ethical framework for visual research?

2

Materialist

what methodologies and methods would sit on this line?

what would sit on this line??



Interpretivist

Positivist

Research paradigms in health and social care are often conceptualised as a Line- a spectrum between these two ways of knowing e.g. (Allsop 2012)

But what if its not a line but a Triangle??

Julies references

Julies' References

Allsop, J (2012) Competing Paradigms and Health Research: Design and Process. Chapter 2 in Saks, M. Allsop, J. (eds) *Researching Health: Qualitative, Quantitative and Mixed methods*. Sage, London.

Foucault, M (1973) *The birth of the clinic: archaeology of medical perception*. London: Routledge.

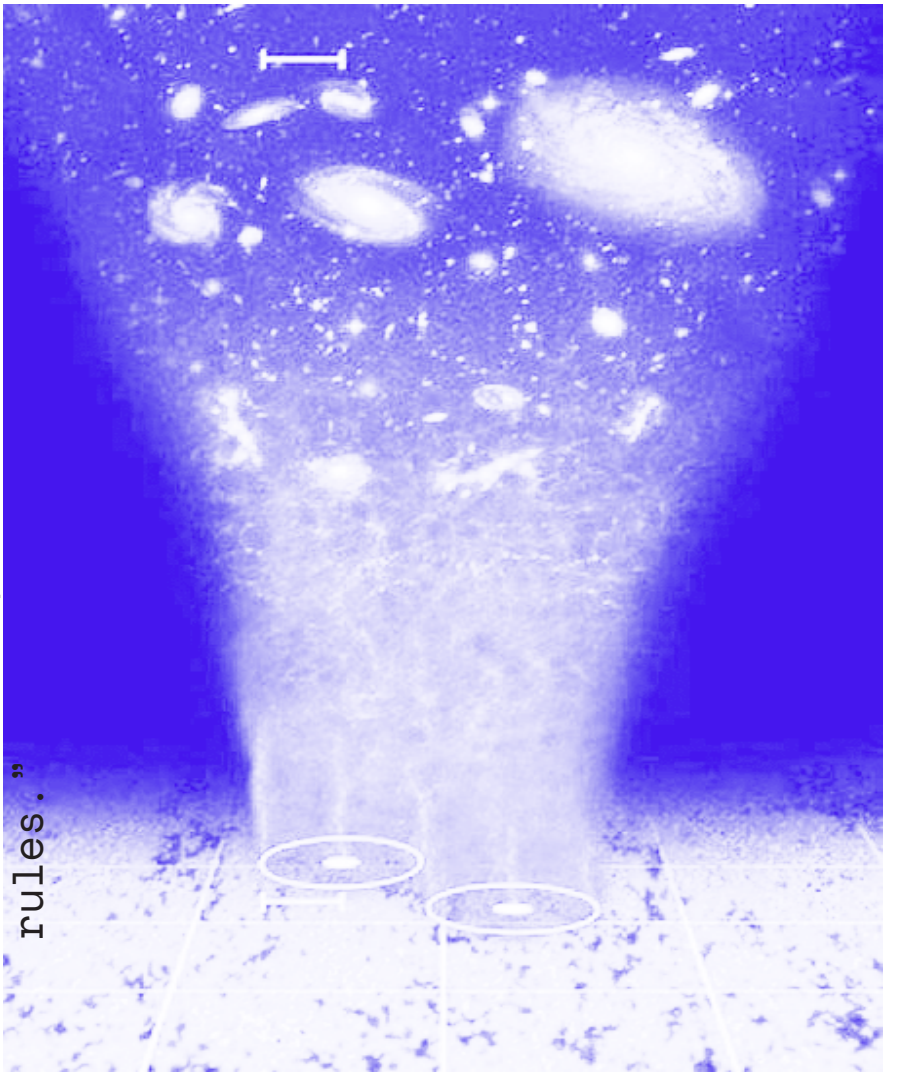
Fricker, M (2007) *Epistemic Injustice: Power & the Ethics of Knowing*. Oxford Press. Oxford.

Reilly, M (1962) Occupational therapy can be one of the great ideas of 20th century medicine. *American Journal of Occupational Therapy*, 26,1-9

Serrant-Green, L (2011) The Sound of 'Silence': A Framework for researching sensitive issues or marginalised perspectives in health. *Journal of Research in Nursing* (online 16 Nov 1020 at DOI: 10.1177/1744987110387741) Volume 16 Issue 4 July 2011 pp. 347 - 360.

The Hunt for Dark Matter Within Healthcare Pathway Experiences

Sarah Smizz



“Everywhere we look.
There are unspoken
rules.”

For years, a material in the universe called "dark matter" has confused astronomers and physicists alike.

The astrological hunt for Dark Matter in the universe is an exciting one. In the 19th-century, a French astronomer Urbain Le Verrier proposed the existence of a new planet, Vulcan, to explain strange wanderings in the orbit of Mercury. He was wrong, it transpired, because he was using an outdated theory — Newtonian gravity rather than Einstein's general theory of relativity. And no Planet Vulcan has ever been found since, but Mercury still has a strange orbit[1]. So here we are left with this question, what causes the visual distortion, the wanderings of an orbit?

Today, scientists are much more certain about what dark matter is ***not*** than they are of what ***it is.***

Firstly, what it is not: because it is "dark" this means that it can't be in the form of stars and planets that we can see. It is also not in the form of dark clouds of normal matter; which is matter made up of particles called baryons because we would be able to detect it by the absorption of radiation passing through baryonic clouds. Thirdly, dark matter is not antimatter, because we do not see the unique gamma rays that are produced when antimatter annihilates with matter.

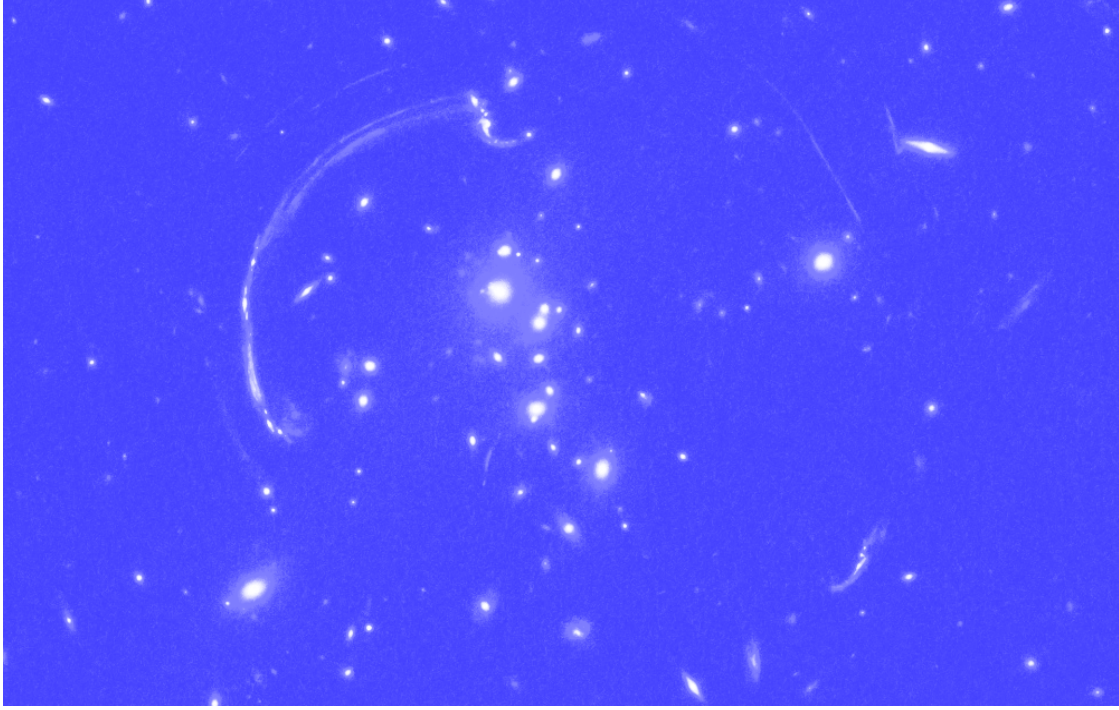
In fact, researchers have been able to infer the existence of dark matter only from the gravitational effect it seems to have on visible matter.

In the 1930's, astronomer Fritz Zwicky was able to begin to explain the discrepancy between predicted and observed rotation speeds of stars in the galaxy. He had observed a cluster of galaxies, the Coma cluster, which he calculated needed at least 400 times the mass to hold itself together. Then astronomer Vera Rubin, in the 1970's, confirmed this idea by observing the velocity of stars moving around the centre of the neighbouring Andromeda galaxy. She observed that the stars at the edge of the galaxy moved with greater velocity than expected, indicating that the disk of visible stars was surrounded by an even larger halo of matter that couldn't be seen[2].

This gravitational effect is what is called Gravitational lensing. Normal lenses such as the ones in a magnifying glass or in a pair of glasses work by bending light rays that pass through them in a process known as refraction, in order to focus the light somewhere (such as in your eye).

But Gravitational lensing works in an analogous way and is an effect of Einstein's theory of general relativity – which is simply put as: mass bends light. The gravitational field of a massive object will extend far into space, and cause light rays passing close to that object (and thus through its gravitational field) to be bent and refocused somewhere else. The more massive the object, the stronger its gravitational field and hence the greater the bending of light rays - just like using denser materials to make optical lenses results in a greater amount of refraction.

Dark matter is invisible, but it does have mass, making up around 85% of the mass of the Universe. This means that light



Galaxy cluster RCS2 032727–132623, a cluster about 5 billion light-years away, gravitationally lensing a galaxy that's even more distant at 10 billion light-years away. Credit: NASA, ESA, J. Rigby (NASA Goddard Space Flight Center), K. Sharon (Kavli Institute for Cosmological Physics, University of Chicago), and M. Gladders and E. Wuyts (University of Chicago)

rays coming towards us from distant galaxies will pass through the gravitational field of dark matter and hence will be bent by the lensing effect. This then makes objects visually displaced, or presenting visions of things that may not actually exist in that form.

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Reading Gregory Sholette's 'Dark Matter: Art and Politics in the Age of Enterprise Culture'[3], where he discusses that the marginalised artists (the 'dark matter' of the art world) are essential to the survival of the mainstream but are largely ignored, I began to realize that there is the equivalent of a "Dark Matter" within our healthcare pathways. I believe that this 'Dark Matter' is having a destabilizing impact on how experience is created, made, and presented. How this then inevitable effects the paradigms of healthcare, and patient information, and ultimately effects the idea of epistemic injustice for both patients and staff within the pathways.

Because I am not in any sense an impartial observer, I bring to my research my own issues connected to my inherited history. I use my own life a lot like text: the gaps in my own medical care, the stuff I had witnessed as a radiotherapist like patients not been given the 'right' [amount/type/form] of information, and the navigation of these multiple spaces have all sort of guided my intuition.

And as I have sat there in many hospital departments, as a radiotherapist, as a patient, and ultimately as a researcher, trying to get a grasp on what experience looks and feels like for others, all I can see are rules.

Yes, protocols, pathways, guidelines, targets. But also unspoken rules. A set of defined decisions. And also, a visual language and layout and culture. Everywhere we look. There are unspoken rules.

I think to graphic designer Matt Ward's, blog post on The Infrastructural Sublime[4] of his experiences looking after his father going through cancer treatment and how he started to think about the infrastructures of care and experience. How they are way too complex, yet he asks how do we pin-point these things, when they're not obvious, and they're not directly visible, in order to make things better?

I realized here that I've been drawn to this dark matter quality of the pathway all along within my research and practice; how the institution of healthcare, especially cancer care, constructs a vision, or visuality of itself through images, colours, materials, that then metaphorically and literally affect the experience, and even care, of that pathway. A Dark Matter that seems to dictate environment, visual design, ways in which we communicate, and a risk-adverse culture. Professionalism in-leui of humanism.

Every hospital I go to, the layouts, the languages are all the same – or very similar. Yet research (scientific, nor Evidenced Based Design), can't seem to provide us with *why* that visual language is chosen. What is the understanding of its affect, and why that, or why it should matter to people.

When it comes to the printed matter of clinical health experiences, another visual language is used. One that often matches its environmental surroundings (bleak, dull, plain, extremely clinical). But the NHS has specific printed matter guidelines. Two specific fonts, Pantone colours for specific areas. 'Ambulance Yellow' and 'Emergency Red' are my favourites. There is a 'style guide' on exactly how to layout your posters and leaflets. And it is very clear – you can't change these rules to suit different patient groups like children. The kids will just have to have boring, unengaging patient information leaflets too.

You could argue that the environment, imagery or how your leaflet is designed and presented doesn't really matter, especially in a life-threatening instance. And that would be true. But most of us will go through the healthcare system whilst we are harbouring chronic symptoms, or conditions, or on-going lengthy treatments of all kinds.

Here, our lives will often feel like they're out of our control. A life revolving around set and often unmoveable appointments, a language and a process which strips us of our identity and what matters to *us*. An unruly body, for whatever reasons, in a system that actively separates the body, mind and social, which leaves us grasping for control in some way.

Much research has proven that good patient information leads to better care and experience outcomes. Yet, collectively, we fail in testing the accessibility, and the engagement of our patient information. They go against the general conventions of modern-day design. And a lot of patient information is written to standards above the UK national average reading age of 9 years old, and this makes a lot of it inaccessible.

As an artist and designer I see instantly the problem, aesthetically, without even looking into the content. As a radiotherapist, I aspired to do better – being able to bridge across two worlds, with 2 different needs.

But there are rules. We get told this as researchers, but we get told this even more so as Healthcare Professionals.

These rules are to maintain 'brand integrity'. But what I am starting to learn is that it's also a structure that allows the culture of the NHS to not challenge *why* things are a specific way. Maybe we could not challenge this if all the material, and things produced, matched the NHS style guidelines. But quite a bit of it does not.

So then, we can question: it really isn't *'the rules'*?

It is this strange dark matter, this mass problem - the culture, a rigid set of paradigms – that is causing some gravitational lensing. It is obscuring the ideas of what is allowed, what can be done, and what is possible. It makes us believe that this vision is what is real and appropriate – despite presenting an experience that rarely exists or prepares us towards our healthcare experience.

But it's difficult because we can't see this dark-matter, and it takes a lot of courage to take the first step towards change.

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Perhaps the most significant sign of the existence of dark matter, however, is our very existence. Despite its invisibility, dark matter has been critical to the evolution of our universe and to the emergence of stars, planets and even life.

This is because dark matter carries five times the mass of ordinary matter and, furthermore, does not directly interact with light. Both these properties were critical to the creation of structures such as galaxies.

Dark Matter is mystifying because of our human perspective. Each of us has five senses, all of which originate in electromagnetic interactions. Vision, for example, is based on our sensitivity to light: electromagnetic waves that lie within a specific range of frequencies. We can see the matter with which we are familiar because the atoms that make it up emit or absorb light. The electric charges carried by the electrons and protons in atoms are the reason we can see.

Some people, on first hearing about dark matter, feel dismayed. How can something we do-not-see exist? Yet, each time people learn about it in a new context, many get confused or surprised.

There is no reason that the matter we see should be the only type of matter there is. The existence of dark matter might be expected and is compatible with everything we know.

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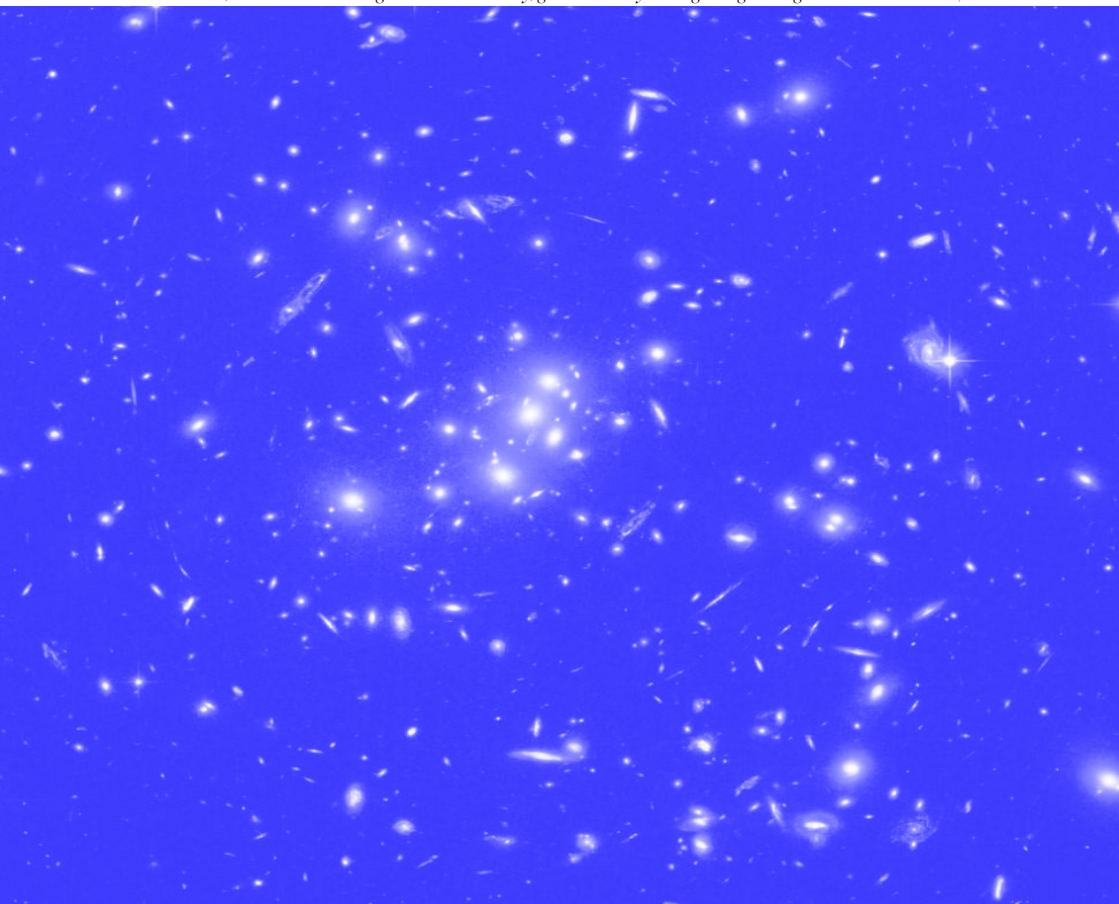
In Professor George Vaillant's research work titled, "*Triumphs of Experience*", he showed that there is a predictor of a flourishing of life that remains robust over time. In the people he studied, he showed that their capacity for intimate relationships has determined whether or not they have flourished in all areas of their lives. Emotions such as joy, forgiveness, hope, love and faith, which are largely absent within clinical environments (for staff & patients) are the factors that determine, irrespective of their starting point, the often significant challenges that life has thrown at them[5].

Cluster Abell 383, zoomed in on its Brightest Cluster Galaxy, gravitationally lensing background galaxies. Credit: NASA/STScI



"*You can't tickle yourself*", Vaillant says. To stimulate emotions that lead to and sustain change, you need others. This is why we need a creative and relational approach to look at this Dark Matter in healthcare. We need to find a way to keep these human factors in view whilst not reducing them to yet another meaningless exercise in box-ticking.

Why do we ignore the role of good relationships in our health systems and beyond? We don't even have the language for this type of activity in our public policy, which eschews the metaphors of growth and collaboration into war like vocabular of targets. I think we forget them, because they can be messy and they require time. But it is risky because not all relationships work out. ***But that is okay.***

It is time to try and find out what this dark-matter is, what stops us from digging deeper? How can we make use of it for something greater? How can we use this Dark Matter to help us rebalance power and experience in health care?

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Perhaps some confusion lies in the name. Dark matter should really be called transparent matter because, as with all transparent things, light just passes through it. Nevertheless, its nature is far from transparent. Just like physicists and astronomers, we would like to understand, at a more fundamental level, what exactly dark matter is.

Is it made up of a new type of fundamental particle, or does it consist of some invisible, compact object, such as a black hole? If it is a particle, does it have any (albeit very weak) interaction with familiar matter, aside from gravity? Does that particle have any interactions with itself that would be invisible to our senses? Is there more than one type of such a particle? Do any of these particles have interactions of any sort?

Often the way to capture it, is to see what "trace" is left.

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The quest to see the dark matter makes us ask, how can we learn to see the unseen? What instruments can be invented, or used, to see what can not be seen?

In the search for dark matter in healthcare, we can see that art and relationships - and the witnessing of these - can have the power to capture it too. The scientific quest for dark matter is a collective one, much like that of the double agent, and this in turn can provide us with a more critical forum to develop change and new opportunities that are real, and not illusionary.

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References

[1] Simon Warrel. *The Hunt for Vulcan, The Planet Wasn't There.* National Geographic, https://news.nationalgeographic.com/2015/11/151104-newton-einstein-gravity-vulcan-planets-mercury-astronomy-theory-of-relativity-ngbooktalk/

[2] Gianfranco Bertone. History of Dark Matter. University of Chicago, https://arxiv.org/pdf/1605.04909.pdf

[3] Gregory Sholette. Dark Matter
Art and Politics in the Age of Enterprise Culture, Pluto Press, 2010.

[4] Matt Ward. The Informational Sublime. SB129. https://sb129.com/2014/11/14/the-infrastructural-sublime/

[5] George Vallient. *Triumphs of Experience.* Harvard

The boundaries we create between ourselves as researchers, clinicians, carers, between health and design are but imagined, intangible. The challenge is not in our ability not to over-step the boundaries but ultimately in our inability to recognise them.

- Claire Craig

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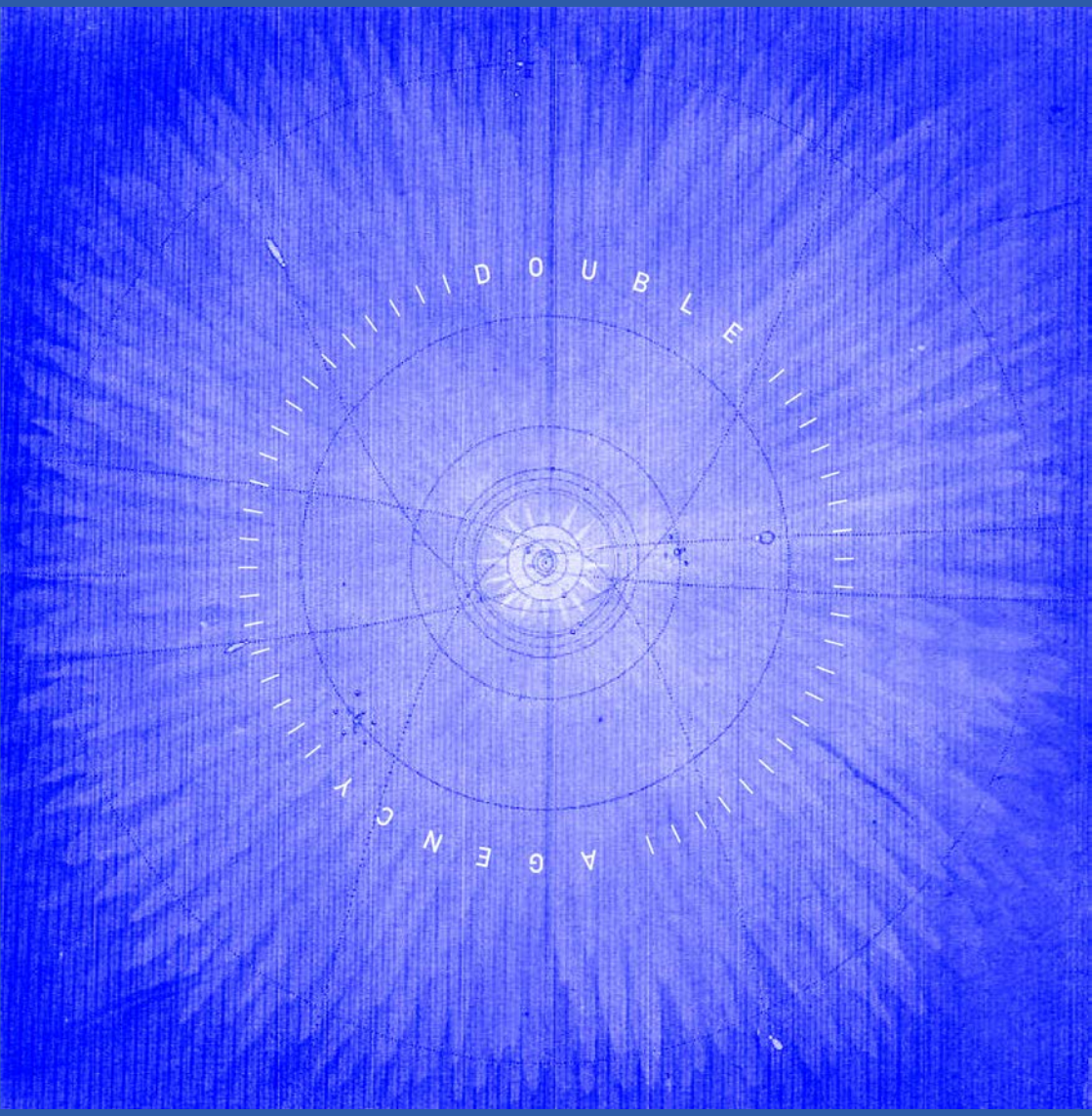
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