

Ethics by Design. Exploring Experiences of Harmony and Dissonance in Ethical Practice.

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Abstract: The positioning of design research as a response to complex challenges across disciplines, underpinned by participatory approaches highlights both a growing awareness of the discipline, and the recognition that design can offer a new perspective for exploration and innovation. However, critical to successful adoption of design research methodologies is an understanding of ethical practices that are inherent within the discipline. This paper presents the findings of two participatory design workshops entitled 'Ethics by Design' which aimed to make visible the implicit ethical considerations underpinning the ethical practices within design research. Drawing on experiences of design researchers engaged in a health context, the workshops highlighted the challenges and underlying assumptions around ethics emerging from design research in complex contexts. This paper posits that the ability of the design researcher to identify and acknowledge their own position is critical to delivering rigorous and robust design research capable of enabling co-ownership and co-direction.

Keywords: Ethics, Participatory Design, Health and Care, Innovation, Transformative Change.

1. Introduction

Across disciplines, researchers are required to demonstrate that ethical considerations have been made, with appropriate steps taken to address any issues identified (Banks & Manners 2012; Farrimond, 2013; Hammersley & Traianou, 2012). This is also true of design research, where a commitment to constant and consistent maintenance of ethical design is positioned alongside the ethical principles of disciplinary practice. However, this merging of research ethics and design ethics is not always streamlined, emphasised by the use of implicit practices and reinforced by increased cross-disciplinary working. Additionally, decisions on which way to approach the design process have their own ethical considerations, for example in practices such as Participatory Design where a moral choice is made to engage with and attempt to empower stakeholders in the design process (Steen, 2015). However, having made the choice to engage with people there are a multitude of different kinds of ethical issues which designers will encounter and negotiate at every stage of their project.

The literature suggests that the design practice is a critical element of enabling ethical understanding. Stahl (2013) states that “ethical perceptions and positions are often discreetly embedded in practices, and this is particularly true within design research whereby the participatory nature of design engagement is enacted through practice”. The embedded nature of ethics in design is also discussed by Tonkinwise (2004) who recognises it as being “ingrained” through the act of making rather than “being pursued as an explicit intention”. While this implicit understanding of design as inherently ethical may be well understood within the discipline, as design research expands its reach across disciplines, there is a risk that the ethical positioning of design may be less well understood. In order for designers to engage in complex contexts such as health research, there is a need to make explicit the ‘ethicality’ of participatory design research so as to support both the role of the design researcher and build a shared ethical understanding among other cross-disciplinary partners.

The positioning of design research as an approach to responding to new complex challenges across disciplines, underpinned by participatory and co-design methodologies highlights both the growing awareness of the discipline and a wider recognition that design can offer a new perspective, potentially creating opportunities for exploration and innovation. In addressing these challenges in new and complex contexts, design researchers must facilitate the integration of disciplines, practices and perspectives in supporting a shared language to emerge across the stakeholders involved. As discussed by (Raman et al, 2017) design is able to “support the co-production of values among diverse stakeholders by making them articulate and visible, to resolve conflict and to support meaningful decision-making”. The designer can therefore be seen to evolve from traditional role of ‘*the do-er*’, presenting a final solution to a client; towards ‘*the enabler*’, facilitating engagement among stakeholders, capturing multiple perspectives and working collaboratively towards the co-creation of an informed response to a complex challenge.

Considering design as an integrative discipline, the engagement of multiple disciplines and stakeholders requires the design researcher to be mindful of disciplinary nuances, theoretical paradigms, and be capable of managing multiple and often contradictory perspectives, with a sensitivity to personal bias. In addition to these external demands, the design researcher must also adapt and reframe their own assumptions, their beliefs and indeed their own working practices to address the next context. With this in mind, the importance of understanding and acknowledging the ethical landscape becomes an important consideration.

This paper provides an overview of the current landscape of design ethics within a health and care context. We initially discuss the complex relationships emerging between the creative approach of design research and structured ethical processes of health and care. Finally, we present the findings of a reflective workshop with design researchers working in health and care innovation and propose a model of understanding explicit and implicit ethical considerations in participatory design practice.

1.1 Ethics in Design Research

The integral role of ethics in design is widely recognised across the literature (Fry, 2004; Steen, 2015; Tonkinwise, 2004), however Chan (2016) highlights that this is still an underdeveloped area, suggesting that a deeper insight is required to more fully understand and apply design ethics as “the study of morals and morality in design practices, and which encapsulates knowledge that evaluates, justifies and guides design”. Similarly, there are often practical challenges experienced by design researchers within a participatory design context. The process of gaining ethical approval can be

understood as a barrier to design research activity rather than as a valuable part of the design process, particularly within the domain of health and care.

The acknowledgement of creativity as an emergent and often unpredictable phenomenon can be positioned in opposition to the traditional framework of clinical trials in health research. However, when developing innovative solutions to health and care challenges, creativity can be seen as a critical element. As innovation continues to be a key driver for transformation, ethical processes in turn need to adapt to provide flexibility in their format and design to enable researchers to articulate their process and consider any ethical issues that may arise.

The application of this creativity within a health research context requires a radical shift in perception, both in the understanding of design research and an openness to creativity within a traditionally structured and well-defined domain. Akin to other approaches in the participatory research family, such as Participatory Action Research, Participatory Research, Action Research (Reason and Bradbury, 2008), design research is often misunderstood and misrepresented by ethical review committees. The application of approaches that are cyclical, integrative, use both qualitative and quantitative methods, and focus on the engagement and empowerment of people (Khanlou & Peter, 2004) towards transformational change are often significantly different to those traditionally adopted across health and care. Similarly, the use of iterative and emergent methodological approaches frequently do not match the benchmarks with which research ethics committees are familiar (Stevenson et al. 2015). However, this is not limited to the health context alone, even across academic institutions processes for ethical review can differ significantly (Farrimond, 2013; Vadeboncoeur et al., 2016).

More broadly, a lack of awareness and understanding around design research as a discipline, and in particular participatory design (PD) research can be seen to reinforce a siloed approach to health research activity. This creates challenges when seeking ethical approval and indeed can be viewed as being in conflict with PD ideologies. PD is the practice of negotiating values realised through participation (Iversen et al., 2012) in order to instill co-ownership, essential to the innovation of complex systems. The fluid nature of design provides the parameters in which to trial imagined action and explore potential consequences. The solutions emerging are an amalgamation of agreements and conceptions to which no one has individual ownership but rather a collective responsibility develops (Lloyd, 2009). By engaging in the social process of design, a multi stakeholder team also engage explicitly and implicitly in ethical decision-making (Lloyd, 2009), yet this approach could be seen as risky to those unfamiliar with a design research methodology.

Design practice is inherently fluid and emergent in its process and in response to external demands, design researchers often adjust their approach in order to comply with the more rigid processes of other research disciplines and contexts. Although this can be considered as an attempt to legitimise design research alongside domains such as social science, there is a risk that defaulting to existing research practices from outside design may stunt creativity or indeed, de-value the potential of design research. The challenge for the design researcher is to maintain autonomy while adhering to recognisable ethical practices and principles. For the individual design researcher, acknowledging and understanding an awareness of the ethical framing of transdisciplinary stakeholders alongside the demonstration of a personal ethical underpinning can be challenging.

At present, there is no agreed ethical code of practice to support design researchers in their practice (Chan, 2016). As a result, the ethical principles which support collaboration within a participatory design research setting remain underdeveloped. By developing a better understanding of the

experiences of design researchers working within a health and care context, the explicit and implicit ethical values adopted by individuals can be explored. This can highlight the emerging considerations for ethics by design and could work to inform improved ethical practice across the wider design research community. As a result, barriers between disciplines can be overcome to support a better understanding among stakeholders involved and further encourage innovation through informed risk-taking.

1.2 Ethical Dissonance between Participatory Design and Health

Participatory design research approaches differ significantly to the traditional research approaches upon which the UK's National Health Service (NHS) ethical review processes are based. Research is defined by the Health Research Authority (2009) as the quest "to derive generalisable new knowledge", typically requiring clear research questions, a defined methodology, and usually requiring Research Ethics Committee (REC) approval. The ethical framework that provides governance for all studies involving NHS patients, staff, and/or taking place on NHS premises is largely designed to assess clinical or quantitative research and can seem inharmonious with qualitative approaches to research (Stevenson et al., 2015). Banks (2013) acknowledges the difficulties in adapting and aligning qualitative social research approaches with the processes and procedures of institutional ethical review. The NHS research framework is well established and the challenges described earlier relating to a lack of awareness and understanding of design research create further barriers when submitting applications for NHS ethics review.

The barriers, illustrated by the characteristic tensions (see Table 1) between creative and emergent practice with risk-averse, pre-defined research trajectories of clinical practice, are often apparent in review feedback. Given that design research aims to create the conditions for, and engage people in a creative process, it is challenging to adequately articulate ethical rigour alongside creative freedom, particularly when applications are geared towards assessing scientific, quantitative research with a defined metric on which to measure success.

Similarly, NHS ethics is framed around the protection of participants and the mitigation of risk. The Health Research Authority (HRA) that governs NHS ethics stems from historical cases of misconduct and clinical trials, (Stevenson et al, 2015) aiming to do no harm which in turn has cultivated a risk-averse working culture. Research that is bound by ethical governance and only explicit in word but not in action is in Tonkinwise' (2004) view unethical as it automates a human response resulting in "unconscious" behaviours, creating an unsustainable "way of being". Similarly, time and resource restrictions as well as excessive paperwork in the health service can mean staff repeat behaviours learnt by predecessors in practice and are not afforded the time to think differently. In contrast, design education encourages risk taking in a design process. Students are taught to experiment and communicate without fear of ridicule in order to create multiple ideas rather than a single solution (McAra-McWilliam, 2007). Indeed, creativity and risk are critical for transformative change and innovation, which is made difficult in a risk-averse culture.

RECs that are unfamiliar with qualitative design-led approaches may therefore feel underqualified to appropriately judge the proposed research activity, often resulting in numerous clarifications of the methodological approach before a decision can be made. The inclusive nature of PD pose little risk to participants and researchers, however the existing ethical approval structure places it alongside high-risk research activities such as randomised control trials testing new pharmaceutical drugs. The application process for NHS ethical review can also be lengthy, resulting in extended time required to plan and subsequently amend the research protocol to satisfy the requirements for ethical review

(Teal and French, 2016). NHS proportionate review states 14 days for a provisional opinion to be returned once a valid application has been received (NHS, 2015a), however this is not inclusive of the time taken to resolve queries of the committee.

Uncertainty around where a design-led study fits within the research context of the NHS creates significant confusion. While the NHS' understanding of research requires REC approval, service evaluation is considered as "a way to define or measure current practice within a service" and does not require REC approval. PD is often positioned in the grey area between these two definitions: with a clear research question and methodology but with a very different aim of participant empowerment through participation (Iversen et al., 2012) in order to instill co-ownership, essential to innovation of complex systems. This suggests a need to redefine the ethical frameworks of NHS research to account for emerging methodologies that have much to offer the health and care context.

Additionally, the NHS is traditionally slow to access and adopt innovations, creating frustrations for innovators, clinicians and patients alike (Department of Health, 2016). Collaborative and integrated working practices are not fully embedded within NHS model, where a "silo mentality" enforces disjointed working patterns on a daily basis (NHS Partner Network, 2012; McCartney, 2016). However, the Accelerated Access Report (Department of Health, 2016) recognises that collaboration is crucial to streamlining the approach to innovation. From a PD perspective, Goddard (2009) states the importance of collaboration to transformative innovations. Core to this is the ethical motivation to support collaboration and active engagement between multiple stakeholders to envision futures (Robertson and Wagner, 2013 in Raman et al, 2017). This suggests that ethical PD can have a significant role to play in embedding innovation within the NHS, translating research into practice and contributing to improved collaborative activity.

Ethics within a health context can therefore be concerned with the balancing of risk factors vs beneficial impact (Stevenson et al, 2015; NHS, 2015b) and the question then becomes 'what do we risk if we do not allow more space for innovation within our health service?'

Table 1. Characteristics of Research Approaches.

Participatory Design	Health
Improvisation	Generalisation
Emergent	Risk averse
Iterative	Repetitive
Flexible	Rigid
Collaborative	Siloed
Embodied through practice	Regulatory
Implicit, ingrained	Explicit, conscious

This paper argues the importance of balancing risk with creativity in order to innovate in a healthcare context. There is a need to make visible the implicit ethical considerations which underpin and inform the ethical practice of participatory design research in order to broaden notions of ethical research in a health context. Through our discussion, we identify emerging challenges and assumptions in the relationship between research ethics and design ethics. Findings are discussed across three key themes emerging: Process - the preparation and formal procedure of gaining ethical approval and of applying thinking to practice and experience; Practice - the behaviour or in-the-

moment ethical practice employed within a participatory design approach; and Experience - conveying the reflection and experiential learning gained with the view of ethics as both a conscious and a subconscious act.

2. Ethics by Design

The following section presents a discussion of two reflective workshops entitled 'Ethics by Design' that embodied a process of collective reflection. The workshops involved a cross-disciplinary research team from The Glasgow School of Art responsible for the delivery of 'Experience Labs' for the Digital Health and Care Institute. The workshops aimed to develop a shared understanding of ethical practice towards distilling a set of shared ethical principles and values.

2.1 Method

Experience Labs are a design-led approach to co-creating sustainable health and social care innovations. The participatory design approach of Experience Labs brings together citizens, health and care professionals, academics and industry partners at an early stage of the design process to work collaboratively to share experiences of health and care, and dynamically prototype 'preferable' responses to current challenges. The approach has been employed across a wide range of health and social care areas to co-design services, care pathways, products, systems and future care experiences.

Participants were invited to attend each of the full-day workshops, delivered seven weeks apart. In addition to the internal staff attending, two academics with a special interest in ethics were also invited to participate. The first was a research developer from within the institution whose remit includes ethical review of creative research proposals; while the second was an academic from another institution whose area of ethical expertise is in health and care.

2.2 Participatory Workshops

The first workshop aimed to capture the lived experiences of ethics across the design research team, uncovering perceptions and perspectives in an open and exploratory way. Participants were asked to work in groups to reflect upon a recently completed Experience Lab, visualising their ethical experience using art, craft and other playful materials. Visual mapping (Figure 1) was considered an appropriate method to derive experiential learning from the experiences of participants and enable the capture of insights and key moments in the process.

Workshop two aimed to consider the implicit ethical practice of design research and shape the creation of a shared set of values and/or principles. Participants were invited to explore experiences of the practice of ethics, record insights, emerging ethical principles, values and/or practices onto a series of transparent discs labelled with each stage of the Experience Lab process (see Figure 2). The workshop concluded with a focus group discussion, highlighting key learning and examples of knowledge exchange and creation.



Figure 1. Workshop 1, Image credit Louise Mather, No Middle Name

2.3 Findings

The visualisations created in workshop one were initially analysed using ‘analysis on the wall’ (Sanders and Stappers, 2012) in order to quickly synthesise the key insights and cluster thematically. Both workshops were audio-recorded to capture the collective knowledge of the group and recordings were transcribed. The transcripts from each workshop were similarly analysed to synthesise and cluster emerging themes, and were also reviewed by an external researcher (Braun and Clarke, 2006) to identify any further themes and ensure a rigorous approach. The following section presents a discussion of the themes emerging.

Processes and procedures of ethics in health and care

This theme related to the preparation, process and procedures required to gain ethical approval for research across health and care. Each participant reflected upon this as a core component of Experience Lab projects, describing the challenges inherent in both internal institutional ethics review and the external NHS ethics process/protocol required for research within the health and care sector. The complexity of understanding and responding to particular ethical processes was acknowledged, with participants identifying ‘*knowledge of ethics paperwork*’ and ‘*navigation of external processes*’ as a necessary skill. Some also suggested this was confusing and time consuming, creating delays in projects. Participants also referred to the role of ethical committees and suggested that their misinterpretation of design research as an approach proved to be challenging.



Figure 2. Workshop 2, Image credit Louise Mather, No Middle Name

Enabling an ethical approach through contextual understanding

Experience Labs were described as an activity that enables a deep exploration of the lived experiences of stakeholders, creating the conditions required to design and respond to key challenges. It was recognised that in order to build sufficient understanding from which to design and prepare for a Lab, being immersed within the context was important. However, participants remarked that it can be challenging to gain access to people before ethics has been obtained, creating a barrier to developing baseline knowledge. This was reflected in decision-making, for example the choice of venue and location for the Lab. In one example shared, gaining an understanding of the prospective participants helped to define venue requirements, recognising that a physical space can appear to be accessible on paper but in reality it may not be suitable for the needs of participants. However, when gaining such contextual understanding was limited due to ethical frameworks, the resulting impact on the Lab design was significant.

Justification of methodological approach

Design research activity within the health and care context was described as sensitive and bound by tension, requiring substantial justification of the research process in order to obtain approval from the NHS Research Ethics Committee. Participants noted creativity as ethically problematic due to its unpredictable nature, yet remarked on the opportunity it offers for innovation. The justification of creative activities was described as time consuming and there appeared to be challenges in defining and describing design research as a rigorous and robust methodology, hampered by the structured format of existing research ethics forms within the NHS.

Labs are designed to engage imaginations and support creativity among participants towards imagining preferable futures without cutting short the design process (McAra-McWilliam, 2007). Creativity was discussed as a vehicle to '*deconstruct preconceived ideas and construct new forms of meaning*' for participants. This deconstruction requires that participants have generated understanding of a context in order to engage with an ethical imagination (Lloyd, 2009) so as to critique concepts. In engaging participants in a creative process, there is also a need for the design researcher to work in a flexible way to adapt the Lab design 'in the moment' in response to the unexpected and emergent nature of design practice.

Despite being recognised as a significant challenge, some participants considered the process of completing an internal institutional ethics application as beneficial. Specifically, this was seen to support participants to define the scope of the research study and work towards shaping the proposed Lab plan, thereby explicitly engaging in the thought exercise of an ethics application. Some participants also discussed a conscious self-policing of ethical conduct over a longer duration to ensure formal ethical responsibilities were sustained, for example in relation to storage, security and dissemination of data.

The ethics of relationship dynamics and collaboration

Notions of trust emerged relating to managing relationship dynamics among participants in a Lab. This related to project partners relinquishing a degree of control over their ideas to the Lab team, acknowledging that the final ideas emerging may be significantly different to what they imagine (Teal and French, 2016). In building trust and supporting the creation of positive relationships, participants also discussed the need to balance the participant-researcher relationship throughout the process. Participants reflected upon the attempted dissolution of hierarchies, including recognition of the role of the design researcher within the context. Similarly, participants reflected on the need to recognise end-users as experts, valuing their lived experience and enabling the creation of a trusting environment within which people can share. However, participants also acknowledged that in creating a safe environment for participants to share experience, this may place the researcher in a position of vulnerability. For example, participants may be asked about their own personal experiences when taking part in introduction/ice breaker activities. The consideration of ethical boundaries between participants and researchers was a key ethical consideration and participants reflected upon developing strategies to mitigate this.

The definition of collaboration generated discussion among participants, highlight the associated ambiguity of the term. Some discussed participant validation as a form of output through collaboration, while other notes this as an opposite to collaboration. A common thread across the groups suggests that '*empowering*', '*giving voice*' and '*upskilling*' participants were core to creating collaboration and underpinned the structure of activities and tools used.

Addressing ethical sensitivities through asset-based design

Participants reflected that an asset based approach was seen to support an ethical imagination (Raman et al, 2017). Tools used within the Labs were described as '*generative*' and deployed as a way to support '*provocation for imagination*' and ensure a quality experience. These tools were highly context driven, created bespoke to each Lab to address specific project aims and support participation among stakeholders. The tools also supported equality among participants and the

development of relationships, e.g., storytelling through an object where researchers as well as participants shared an experience. However, it was noted that engaging stakeholders in this way raises issues related to emotional wellbeing, and participants acknowledged the importance of context sensitivity. The importance of choosing appropriate methods, those that were accessible and comfortable to Lab participants was also highlighted. Role-play and personas were frequently used as methods to understand issues and challenges within a particular context. However, participants highlighted the important ethical considerations required when using activities that offer a '*realistic*' way of exploring a '*real*' issue or challenge and the potential negative impact this may have.

Reflection and Communication for Ethical Design Research

Participants discussed the role of self-reflection within design research activity and suggested that supporting colleagues through the ethics application process contributed significantly to their deep learning (Fry, 2003). However, it was also noted that knowledge of the ethics process, in particular of the NHS ethics procedures was described as inherently personal to the individual project and as a result was not often shared across the team.

More broadly, participants discussed the learning that takes place within a Lab and the way this informs future practice. Participants reflected that ethics was an explicit element of the planning and design of a Lab, including the completion of formal ethics applications. However, participants also acknowledged the implicit practice of ethics, the ethical nuances that occur within the Lab experience. This highlights the need to more explicitly share this tacit knowledge so as to create shared learning across design research.

Participants also acknowledged the particular importance of good communication with participants; the wider communities; and across the field of design to make ethical considerations more explicit. Strengths and opportunities for improvement were identified across examples of how the team communicates before, during and after a participatory workshop. However, there were noted challenges in recruitment, the inclusion of a media presence, and making time to reflect on the value of the research. This indicates the need to consider a strategic element to communication as part of preparation in future research. Reflecting upon the challenges posed, participants across all groups suggested that peer-to-peer mentoring could be offered to support the process of navigating and completing ethics paperwork.

Building ethical values through identity and shared narratives

The language used and terms involved to describe an Experience Lab was often seen as a challenge in how participants built an identity and shared narrative across the team. Terms such as co-design and participatory design were used interchangeably and it was acknowledged that these are increasingly used in traditionally non-design contexts, such as government publications, to involve the wider public in the design of many public services and creating a misunderstanding of these terms.

Participants also referred to the use of language when describing the interactions of stakeholders engaged in research activity, using words such as '*with*' and '*together*' rather than '*to*' or '*on*'. Words such as '*honest*', '*transparent*' and '*trust*' were also used, highlighting the implicit qualities of the research team and their approach to conducting design research. Participants also discussed the need to build an identity that makes visible the implicit individual values and mindset of the design research team. As the design research approach continues to evolve, participants acknowledged an opportunity to disseminate and share motivations to establish and explore compatibility of values

with other institutions, groups and individuals. In building an identity that communicates rigour of the approach, participants acknowledged the role and importance of the theoretical and philosophical grounding of Experience Labs.

3. Towards Achieving Ethical Harmony

The emerging themes described identify key ethical considerations for design research within a health and care context. The findings suggest that researchers are implementing mechanisms of self-support when completing formal ethical procedures, whilst also engaging subconsciously with ethics in practice. This can be understood as a critical part of the participatory design process and integral to ethically appropriate design research.

Through making visible the implications which underpin and inform the design process, three overarching themes of ethical reflection have been identified: Process (of applying for ethical approval, planning and preparation); Practice (of ethics employed during participatory design activity 'in the moment'); and Experience (through reflection and experiential learning of ethics in participatory design). Contributing to a model of ethical design research practice (Figure 3), these themes offer a unique insight to the consideration of ethics within a participatory design context, and create a guiding framework to ensure ethically informed design research across the health and care domain. The model (Figure 3), represents a valuable shift in recognising both the explicit and implicit consideration of ethics, and responds to Chan (2016) in fostering a deeper understanding of the application of design research ethics (in the context of health and care), broadening the notions of ethical participatory research.

3.1 An Ethical Process: applying for ethical approval, planning and preparation

Participants referred to the process of gaining ethical approval for design research activity, describing the challenges inherent across internal institutional ethics review and the external NHS ethics process/protocol required for research within the health and care sector. Process is an intricate balance between the formal demands or ethical procedure and the underlying principles of participatory design. It is concerned with the cognitive exercise of planning a course of action which best reflects the aims of the research, whilst also engendering a quality experience for participants within which they feel valued.

The ability to gain contextual understanding of the proposed stakeholder group, considering their needs and abilities is critical. This rich insight enables researchers to develop a rigorous and justified method of engagement, and supports the design of bespoke activities for collaboration, allowing multiple voices to be heard. In engaging participants in a creative process, there is also a need for the design researcher to work in a flexible way to adapt the Lab design 'in the moment' in response to the unexpected and emergent nature of design practice.



Figure 3. A Model of Ethical Design Research Practice. Visual Credit A Tulloch

3.2 An Ethical Practice: participatory ethics employed 'in the moment'

Ethical practice relates to the influence of formal ethical procedure on the iterative and responsive design research practice employed 'in the moment'. The insights reflected key elements of practice such as the skills and abilities of the design researcher, and the importance of sustaining positive relationships among stakeholders in order to develop co-ownership.

Trust is core in managing relationship dynamics with stakeholders, particularly in the dissolution of hierarchies. By creating a neutral environment where participants feel safe to share their experiences, consideration must also be given to the participant-researcher boundaries and strategies developed to mitigate risk. Giving voice and empowerment through participation underpin the activities and tools of PD (Khanlou & Peter, 2004) towards collaboration. In this way, ethical

motivation is realised in supporting collaboration and ensuring the active engagement of multiple stakeholders to envision futures (Robertson and Wagner, 2013).

Taking an asset-based approach supports an ethical imagination through the collective “sharing of assets and experiences” (Raman, 2017) and fosters trust among participants and the researcher. The practice of negotiating these complex landscapes, with the inherent power relations are crucial in order to facilitate an objective space with a balance of disruptive and constructive; having the intuition to be able to read participants; and flexibility to respond in the moment.

3.3 An Ethical Experience: ethical reflection and experiential learning

Upon reflection of collective experiences, the design researchers noted the value of the experiential learning and the view of ethics as both a conscious and a subconscious act. Engaging in self-reflection and supporting colleagues through the ethics application process contributed to a learning experience and generated knowledge of the NHS ethical process. In this way participants reflected that ethics was both explicit during planning and designing of a Lab, and in completion of formal ethics applications, but also an implicit practice during a participatory workshop.

Participants discussed the need to build an identity that makes visible the implicit individual values and mindset of the design research team. As the design research approach continues to evolve, participants acknowledged an opportunity to disseminate and share motivations to establish and explore compatibility of values with other institutions, groups and individuals through building an identity that communicates rigour of the approach and the importance of this when describing the position and theoretical grounding of PD.

3.4 A guiding model for ethical design research in health and care

Drawing on the lived experiences of design researchers active across the health and care context, the emerging themes of process, practice and experience begin to consider the implicit and informal ‘ethical imagination’ of design researchers. While it is acknowledged that the collective ethical considerations of a design research team comprised of the individual values and experience of each team member, this paper suggests that a wider shared understanding can contribute to a more informed, effective and ethically appropriate response.

In response, the model presented offers a framework to guide design researchers as they navigate the health and care context, recognising and indeed valuing the inherent complexities of working across disparate disciplines. The model is offered as a guide to support researchers as they prepare for, and address some of the emerging ethical challenges of design research in this context, encouraging reflection to support learning extended beyond individual projects and contributing to a better understanding and awareness of design research for health and care.

4. Conclusion

This paper draws on reflections on a range of ethical issues experienced in participatory design research in a health and care context. Drawing on the literature and practice we argue there is a need to make visible the implicit ethical considerations which underpin and inform the ethical practice of participatory research in order to develop deeper insight to more fully understand and

apply design ethics (Chan, 2016) and broaden notions of ethical research in a health context to include co-ownership and co-direction with participants.

Through our discussion of ethics, we have identified some of the marked challenges and assumptions in the relationship between ethics and design, specifically in relation to creativity and participation in design research. The relationship between the creative approach of design research and ethical processes is complex due to the nature of creativity as an emergent and often unpredictable phenomenon. Similarly, a “silo mentality” in the health sector enforces disjointed working patterns (NHS Partner Network, 2012; McCartney, 2016) making collaborative working highly politicised and complex. However, creativity and collaboration are critical for innovation, and as innovation continues to be a key driver in relation to transformation (Goddard, 2009), ethical processes need to provide flexibility in their format and design to enable researchers to articulate their process and consideration of ethical issues that may arise.

Given the collaborative nature of design research there is a need to develop ethical principles which support collaboration and communicate the ethical values to project partners and external ethics committees. As a result, we propose that further research is needed in the development of an explicit design research code of practice, not only to inform the process of gaining ethical approval, but to support the practice and experience of design researchers working in the health and care context, as well as how the model is perceived by NHS ethics committees. The model of ethical design research practice presented in this paper, offers a way to consider ethical practice and make visible the inherent ethical values held within the participatory design community which support collaboration and communicate these values to other territories.

By illustrating the challenges faced, assumptions and experiences of harmony and dissonance in the ethics of design research in complex contexts such as health and care, this paper posits that the ability of the design researcher to identify and acknowledge their own position is critical to delivering rigorous and robust design research which enables co-ownership and co-direction towards preferable solutions.

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