Development of an ethical roadmap

CRAIG, Claire <http://orcid.org/0000-0002-3475-3292>, WALLACE, Jayne, MONTAGUE, Kyle, KOULIDOU, Nantia, FISHER, Helen, CARVALHO, Luis, GROOT, Linnea, TRUEMAN, Julie, LAWSON, Shaun, MORRISSEY, Kellie, DUNCAN, Trevor and SOUTH, Joshua

This document is the Accepted Version [AM]

Citation:

CRAIG, Claire, WALLACE, Jayne, MONTAGUE, Kyle, KOULIDOU, Nantia, FISHER, Helen, CARVALHO, Luis, GROOT, Linnea, TRUEMAN, Julie, LAWSON, Shaun, MORRISSEY, Kellie, DUNCAN, Trevor and SOUTH, Joshua (2021). Development of an ethical roadmap. Design for Health, 5 (1), 140-160. [Article]

Development of an Ethical Roadmap

Prof. Claire Craig, Lab4Living, Sheffield Hallam University, UK (c.craig@shu.ac.uk)
corresponding author
Prof. Jayne Wallace, Northumbria University, UK
Dr. Kyle Montague, Northumbria University, UK
Dr. Nantia Koulidou, Sheffield Hallam University, UK
Helen Fisher, Lab4Living, Sheffield Hallam University, UK
Luis Carvalho, Newcastle University, UK
Linnea Groot, Newcastle University UK
Dr. Julie Trueman, Northumbria University, UK
Prof. Shaun Lawson, Northumbria University, UK
Dr. Kellie Morrissey, University of Limerick, Ireland
Trevor Duncan, Northumbria University, UK
Joshua South, Northumbria University, UK

ABSTRACT

Ethics are a system of moral principles and branch of knowledge enquiry defining what is good for individuals and society. Academic disciplines operate within publicly defined ethical parameters created to support researchers through complex dilemmas. However, paradigms in interdisciplinary research, a growing focus on emancipatory and participatory methods and questions relating to an ethic of technology call for a rethinking of existing frameworks which are largely predicated on bioethics. This paper describes an enquiry that used a design-lens through which to explore existing ethical frameworks operating in health. Drawing was used as a method to build understanding and to make visible facets of the frameworks. These drawings provided a focus for a series of workshops to build understanding of the challenges faced by a range of different stakeholders engaging in research.

An Ethical Roadmap resource was created in response to the issues and questions raised during the enquiry. We suggest that the Roadmap creates the space for discourse, discussion and a level of rehearsal as potential ethical dilemmas are encountered and responses are worked through. The process potentially enables a reflective and reflexive process that may build self-awareness of how researcher values may manifest themselves in particular contexts and from the different disciplinary backgrounds of members within a team. We describe the Ethical Roadmap as ‘becoming’ rather than ‘finite’ and as a solid starting point from which researchers can develop the resource offering further, through use, introducing the open source version of the Roadmap.

Author keywords

Ethics, complexity, dementia, bereavement, design, HCI, interdisciplinary

INTRODUCTION

Researchers have a responsibility to conduct research in an ethical manner. Formal processes and codes of conduct are in existence to define parameters in which investigators should operate and build in safeguards that minimize potential harms to individuals participating in studies. Within academic contexts before undertaking research of any kind, it is usual practice for a research team to apply to an administrative body, e.g. a Research Ethics Committee, for ethical approval for the study. These committees comprising of academic and lay members are responsible for scrutinizing applications and making decisions as to whether the research should proceed. Decisions are based on the aims of the enquiry and how potential risks to participants are weighed against benefits that may arise from undertaking the research. The exact processes and the procedures are determined by the nature of the research and where it is undertaken. For instance, in the UK broader governance for research with patients within hospital or social care settings falls within the remit of NHS ethics approval systems. One caveat here is that ethical governance and processes varies across countries and that outside of academia, in industry for example, researchers are bound by ethical governance proceedures within their own company, which in some cases can be minimal. Further, in recent years there has been an increased call for institutions and organizations to adopt and develop their own ethical practices as evidenced by whitepapers and calls from research councils, governing bodies and industrial boards globally, for example Ethics in Artificial Intelligence’ (Open Ethics Initiative 2020).

Design researchers, within academia, are not and never have been exempt from this process. However, the last five years has seen a growing interest in ethics from within design and the HCI research community as evidenced by a plethora of papers and growing number of conference workshops about ethics (Van Wynsberghe 2013; Munteanu et al. 2015; Waycott et al. 2016; Tutenel et al. 2019; Sharkey 2014; Novitzky et al. 2015).

In part, this is because the skills of design researchers are being increasingly called on to address broader societal issues and questions (Chamberlain and Craig 2017). Within the UK, the Design Against Crime initiative (Gamman et al. 2004) and the Living Well with Dementia design challenge (Design Council 2012) are select examples from a broader raft of national social design initiatives. Rather than pursuing commercial or consumer related objectives, designers are harnessing and applying their skills for collective and social ends (Armstrong et al. 2014).

This has occurred in parallel to government funded research agendas which have positioned digital health-technologies as a potential solution to alleviate pressures placed on existing care services, reducing overall costs and carer burden (Petersson et al. 2012) . Inevitably the design and HCI communities have been at the forefront of this work and this has led to researchers undertaking studies in sensitive areas and with individuals living with complex and life changing conditions.

When working in such contexts designers and design researchers inevitably encounter so called sensitive areas of research, for instance, working with people with dementia, research in care homes and in end of life care. Whilst there is an acknowledgement of the value of design and HCI research in these settings, concerns are also emanating from the design community to question whether design researchers are well enough equipped to work in such ethically complex areas (Munteanu et al. 2015).

The speed of technological innovation and its potential to impact on every facet of life has also led to increased pressure on Research Councils to create governance frameworks that support ethical decision making in these contexts (Cath et al. 2018). Questions have been raised as to whether existing ethical frameworks are sufficiently robust in light of the evolving innovations including research utilizing increasing applications of Artificial Intelligence (AI) (Floridi 2019). The establishment of the Digital Ethics Lab at Oxford University and the codes such as the European Ethics Guidelines for trustworthy AI in Europe (2018) are just two examples of how digital innovation is leading to more centralized approaches to shape broader ethical practices.

These developments offer an opportunity to explore the contribution that the HCI and Design community can make in the rethinking and development of more inclusive ethical frameworks that are fit for purpose. Potentially this offers a way to challenge ethics predicated on positivist epistemologies and deductive ways of knowing which can so frequently disadvantage the more emergent, inductive and constructivist approaches to research adopted by HCI and design research. Key work highlighting this challenge has come from Frauenberger et al. (2017) and Spiel et al. (2018) who all draw from feminist ethics, amongst other perspectives, to emphasize a more complex landscape of microethics that exists in reality than is often acknowledged in processes of ethics governance – something argued eloquently by Tronto (1998) through the concept of the ethic of care.

Whilst technological innovation may be a key catalyst to promoting recent debate and discussion in relation to ethics, criticisms of overly bureaucratic systems of ethics and governance have been emanating for some time from the broader health and social care research communities (Fox and Swazey 2008; Dewing 2008; Brody 2009). A particular challenge is the requirement set down by existing health and social care ethical frameworks that exact and detailed research protocols are submitted in advance and further approvals are required if amendments are needed for any deviation from these. These requirements have been critiqued by authors such as Dewing (2008) who has highlighted how the requirement to submit ethical protocols so far ahead of the research can result in a mismatch between what was described and approved and the reality of the situation in which researchers found themselves. A dichotomy can as a consequence result in researchers working unethically in spite of receiving favourable ethical review and sign-off. Indeed, Munteanu (2015) cites instances within their own research where ethical consents were received but individuals with poor literacy skills did not know what they were signing.

Alternative approaches described as situated ethics (Dewing 2008), which encourage a responsiveness of researchers to situations, have been proposed as an alternative. However, whilst in principle such approaches have been praised, the challenge is a lack of guidance and detail in relation to how to enact the practice of navigating complex situations. Moreover, whilst Design and HCI researchers may struggle to find their way existing formal ethical systems, particularly those in health (Waycott et al. 2016; Moncur 2013) evidence that researchers in these disciplines express equal anxieties in relation to the practices of working in an ethical manner in these unfamiliar contexts.

Valuable steps have been made to create practical tools to enable designers to incorporate ethical practices into the design process (Gispen 2017) but to date these have been focused predominantly on exploring ethics in the context of developing products and services. The challenge remains to craft methods and mechanisms to enable researchers to systematically identify and rehearse potential ethical dilemmas that may be encountered before they occur during the course of live research projects. These must offer space to build sensitivity and understanding of the wider questions and potential avenues of direction that can be taken during the research, effectively an operationalization of the situated ethics described by Dewing (2008). Further it is important that they support teams to discuss aspects of their project from a range of interdisciplinary perspectives to reflect the increased subject diversity in contemporary research teams. They must also concurrently reflect and feed into the requirements of existing procedural ethical processes, standards and frameworks. The remainder of this paper describes an enquiry that explores the role of design in understanding and responding to these issues. The aim of the research was to use a design-research lens through which to examine existing ethical frameworks and to create a series of tangible responses to the broader themes identified.

SUPPORTING THE ENACTMENT OF ETHICAL PRACTICES

Current research project

The design-led research project Enabling Ongoingness (Wallace et al. 2020) has provided an opportunity for us to contribute to this broader ethics research agenda and create an Ethical Roadmap resource. The focus of the enquiry is to reconceive how our digital content can be re-appropriated through new forms of curation and also bespoke creation of physical digital objects to give agency to individuals experiencing significant life transitions, including individuals living with terminal illness, people living with dementia and individuals who are bereaved. The development of robust ethical processes is therefore fundamental.

Our Ethical Roadmap is a way for teams of researchers to discuss, operationalize and enact ethical practices. The Enabling Ongoingness team is comprised of design, HCI and health researchers and we hope that the resources we have made will serve teams from across these disciplines and beyond.

The Unmaking of ethics

The first phase of this research process focused on an exploratory period to build understanding of the elements of existing frameworks, their embodied principles, philosophies and construction. This was achieved through critiquing, deconstructing and exploring existing ethical frameworks supported by our project partner organizations.

A number of existing ethical frameworks and descriptions of their operationalization as embodied in codes of conduct were examined. These included the Code of Professional Conduct for Nursing and Midwifery (2000) the Medical Councils' guide to professional conduct and ethics (2009), the British Psychological Society Code of Ethics and Conduct (2018) and the World Health Organisation Code of Ethics and Professional Conduct (2017). Time was also spent exploring the principles of biomedical ethics (Beauchamp and Childress 2001) that underpin the current Heath Research Authority ethical framework.

One of the immediate observations of all these frameworks was their dense written style and intangibility. The first element of this exploratory phase was a process of making the intangible tangible and the hidden visible through a visualizing of different approaches to framework construction. What follows is a series of drawings and extracts from the first author's reflective diary that attempt to articulate intangible aspects of the reviewed frameworks: examples of which are shown in **Error! Reference source not found.**, **Error! Reference source not found.Error! Reference source not found.**.

(Insert Figure 1 here) Figure 1 Reflective Diary excerpt – rigidity of frameworks
(Insert Figure 2 here) Figure 2 Reflective Diary excerpt – potential process of reflection
(Insert Figure 3 here) Figure 3 Reflective Diary excerpt – collective wayfinding

Collective making and reimagining key themes

The visual metaphors shown in the sketches in **Error! Reference source not found.**, **Error! Reference source not found.Error! Reference source not found.** above formed the basis of two interactive workshops in 2018 with key project partners. The first included participants from Alzheimer's Society, the Dementia Action Alliance, the National Institute for Health Research's Collaborations for Leadership in Applied Health Research and Care (CLAHRC) and the Palliative Care Network. The second included a broader international audience comprising clinicians, researchers in healthcare and design as well as a small number of individuals who were experts by and through experience from United Kingdom, New Zealand and the Netherlands. The first and second author facilitated workshops and there was a total of 54 participants across both workshops.

Individuals were invited to reflect on their understanding of ethics and the strengths and limitations of frameworks they were aware of, and were then presented with sketches visualizing the different approaches as described above (Figures 1 – 3). Finally, participants engaged in an act of collective making of a framework of perceived core elements and values, which were woven together as in the warp and weft of fabric. Throughout this process individuals shared their reflections and we share here a number of the resulting key issues.

Both groups identified the paradoxes and dichotomies inherent in existing ethical procedures they needed to engage with as part of their research practice. These were often portrayed as opposing tensions. For instance, between bureaucracy and care, between the completion of procedures (form filling) and actual behaviours, and finally the tensions between the ‘letter of ethics’ as a type of law versus the ethos that sits behind them.

Inadequacies of ethical procedures and frameworks in the context of healthcare research were highlighted by participants, particularly in relation to the growing movement of co-production and co-creation in this field. One service user made the astute observation that:

‘I have been part of research processes where I have been able to engage in a rich act of co-creation, resulting in pieces I have been proud of [digital storytelling] and yet by anonymising my name you take away something of who I am as a person. You turn me into a subject rather than a co-researcher and participant’.

Design researchers participating in the workshops described the baffing array of ethical procedures and the current lack of training in art and design programs with regard to the most fundamental aspects of ethics. This was seen as problematic.

However one of the strongest themes that emerged from this element of the research was the challenge individuals faced in responding to unforeseen ethical issues as they arose. Participants from across design and health identified competing tensions between the need to create rigid boundaries that could and should not be breached whilist also embedding an element of flexibility to be responsive to particular situations:

Commented [CK1]: Between what and what? This is a bit unclear

'*The key word is uniqueness, and this should be valued: a framework should be established that could be individualized*.'

One metaphor that emerged was of a string shopping bag with sufficient structure to offer necessary support and containment but with sufficient flexibility to also be responsive and to change its shape to accommodate each situation.

This theme of responsiveness and inclusion was extended to discussions in relation to engagement and informed consent. Existing frameworks encountered by individuals were critiqued on the basis of their dependence on the written word which were seen as barriers to equal engagement and a sign of an imbalance in the power relationships that research can sometimes embody.

Reflections on workshops

The overall consensus from the workshops was the need to create something that was clear and easily understood, that had the flexibility to be used across a number of different contexts. Significantly there was recognition that fundamentally ethics is underpinned by a set of shared values that are enacted through relationships (relationship between researcher and participant/between members of a research team). Further, that this is an ongoing process, rather than ethics being a one-off action or event that sits within the research the ethical foundations pre-exist and enfold through the research process itself. These ethical principles act as touchpoints through which a project is constantly grounded and re-examined. Working through complex issues is then a natural part of the process and is not be shied away from. However, finding opportunities to explore potential issues that may arise offers the research team the opportunity to begin to understand how individual value systems manifest themselves in particular responses, and creates the opportunity for rich discussion within a relatively safe environment where people can reach a consensus of how to act or respond to particular situations. Given that ethics, then, is a journey on which the research team and participants travel over the duration of the study, it was felt that the term 'Ethical Roadmap' was more fitting than framework.

The final element of this phase of the research was to then develop a design response that embodied and reflected these insights. The roadmap was driven by our own team reflections at the start of the Enabling Ongoingness project, the challenges we anticipated in front of us during the project, our previous experience as researchers from health, design and technology backgrounds, our experience from previous multidisciplinary research projects, and the insights from the two workshops described earlier.

THE ETHICAL ROADMAP

In order to design and develop the roadmap the first and second authors set themselves four design challenges: (1) to create a range of resources that would assist a team pragmatically in making informed decisions and creating research resources, (2) to give people ways to see each others' viewpoints from different disciplinary (and personal) positionings, (3) to enable people to reflect on how to draw help into the project from other sources and (4) to help researchers build a collective vision *with participants* of the ways that a group will work together through a research programme and beyond.

Through an iterative and highly discursive design process, we arrived at a series of seven individual components that comprise the Ethical Roadmap, which we will now detail. For brevity we are describing the concluding components rather than the heavy detail of the iterations and their individual development. We do see the components as things that are still 'becoming' however and we are at a point in time where other researchers from a number of countries are using the Ethical Roadmap resources and feeding back to us with their reflections of using it and on how they are refining and developing the resources in relation to the specificity of their research contexts.

The Ethical Roadmap is manifested in a series of seven components/activities that are held within the structure of a box (Figure 4). The components are: 'Value Cards', 'Moral Quality Cards', 'Critical Friends', 'Informedness of Consent', 'Team Member Roles', 'Provocations' and 'Warp and Weft'. These resources are supplemented by a general 'Introduction Sheet' and 'Glossary of Terms' and each resource has a series of worksheets to help direct each activity and help people define, prioritise and capture insights as they are used.

The Introduction Sheet describes each component of the roadmap to help a team navigate through the various activities. The suggestion is that participants start the journey with the *Value Cards* and *Moral Quality Cards* activities before they move on to discuss other components, as these resources are the building blocks and foundations of ethical concepts and thinking. The remaining resources can be explored in a non-specific order. We now describe each of the main resources in turn.

(Insert Figure 4 here) Figure 1 Ethical Roadmap box containing individual packs or resources/activities https://ethicalroadmap.org/.

Value Cards

All ethical frameworks are underpinned by sets of values and value systems. The most widely used and accepted values framework used in medical ethics is that espoused by Beauchamp and Childress (1979). Their principles of beneficence, respect for autonomy, justice and doing no harm (non-maleficence) have informed a range of frameworks used across health and social care research including the Ethical

Framework for the Counselling Professions (BACP 2018). The eight cards in our Value Cards pack ((Insert figure 5 here) Figure 2) are developed from Beauchamp and Childress (1979) and are inspired by the principles highlighted in the Ethical Framework of the Counselling Professions (BACP 2018). The cards represent eight personal values: *integrity, beneficence, respect, responsibility, justice, truth, honesty* and *non-judgmental* and activities focused on these words are intended to enable a team to explore and debate individual and collective values in specific contexts, to generate shared values.

(Insert figure 5 here) Figure 2 Contents of the value cards component of the Ethical Roadmap https://ethicalroadmap.org/

Disciplinary lenses cards (e.g. technology, psychology, health, design) add a further layer, promoting discourse between team members who may come from different academic disciplines. Through acts of sharing an opportunity arises for a team to identify points of convergence and divergence in the value systems inherent in these disciplines. Through a process of sharing and discussion the aim is to build understanding of how the team defines and prioritizes specific values in the research space in which they operate.

Moral Quality Cards

Whilst research teams may espouse to hold particular values the challenge is that these values can feel abstract and invisible. For research to be undertaken ethically values and value systems need to be manifested in particular behaviours. Activities associated with this element of the roadmap therefore seek to address the following questions: What are moral qualities? What do these look like in practice and how will I know these are being enacted? The descriptions of the moral quality cards were developed in partnership with a key stakeholder in our research.

There are ten cards in total in this pack: six moral quality cards and four enactment cards. The moral quality cards have two sides: one side describes a moral quality and the flip side offers a definition, that is open to discussion within the team. The moral quality cards are:

Courage to Listen: A commitment to listen to participants fears, challenges and feelings and be supportive and non-judgemental.

Loving Listening: A commitment to giving participants space/time to express their feelings.

Spotting Concerns: A commitment to a participant's safety - listening to their concerns and directing them to sources of help.

Tailoring our approach: A commitment to accepting a participant's values.

Bespoke Structuring: A commitment to developing an individualized structure and approach to conducting research in an effective and comfortable way for the participants.

Establishing Boundaries: A commitment to a two-way relationship within bespoke boundaries. Establishing boundaries when sharing an experience with participants.

Alongside these cards, we have added four enactment cards with questions: 'What will empathy be in action?', 'What will integrity be in action?' 'What will self-care be in action?' and 'What will participation be in action?'.

Moral Quality Cards demonstrate *how values can be put into practice*. We offer six drivers for actions that we think can be beneficial when used to motivate ethical development during research. Morals have strong influence on how we relate to each other (BACP 2018; Combes et al. 2016) and can help team members to think about their integrity and resilience within the research context and their relationship with participants.

The cards are invitations for team members to support each other through discussing how participant engagements could play out in practice and to build confidence and trust within the team through planning for a range of potential research dynamics that could develop during the project. The cards can be used as talking points to identify which qualities team members already possess and which the team would like to develop further.

Critical Friends

The Critical Friends resource comprises a Map, Role Cards and Timeline. All were developed to overcome two key ethical challenges identified in the broader literature. The first is the lack of opportunity to access and draw on the expertise of individuals who can directly share key insights and learning in relation to ethical issues encountered in similar research projects. At present few opportunities exist for researchers to learn from the experiences of others either undertaking or involved in the research process, potentially exposing individuals to the same issues on repeated occasions.

The second is the challenge of translating research knowledge into practice. At present in healthcare research, a 17-year gap exists between the time when new insights through research are generated and when these are applied in real-world clinical contexts. (Morris et al. 2011). This means that in effect individuals are denied the opportunity to experience the positive impact that this research could potentially have on their lives.

Commented [CK2]: do you have a reference for this?

This component of the roadmap provides the research team with the necessary tools to interrogate who may be important to include as critical friends over the lifecycle of the research. This includes identification of strategic partners who may play a vital role in the future implementation of the research and the mobilization of knowledge.

It may involve individuals who can share their experience and learning of similar projects and signpost the team to valuable literature that may have been overlooked. Through a series of carefully crafted activities the research team are enabled to establish a steering group. The Critical Friend Map, for instance, enables group members to identify the types of knowledge and expertise they might require specific to the research context. Participants are supported to capture their personal and professional networks. Within the map four categories of critical friends are described, each denoted by the type of experience they bring: a) *Future implementation experience* b) *Lived through experience* c) *Personal knowledge* d) *Knowledge of context.* Where gaps are identified, *Critical Friend Role Cards* are offered as invitations to individuals identified by the team. Space is included for the person to specify their preferred role and potential contribution to the project. The temporal nature of the research process is recognized, and *Timeline* allows the team to map particular contributions key members may play at anticipated points. An example is provided in the pack to illustrate how the Timeline can be used in practice.

Informedness of Consent

Informed consent is a key component of every ethical code from the Declaration of Helsinki to the Nuremberg Code and a core legal requirement of research. Ensuring that participation in the research study is undertaken on a voluntary basis requires that individuals are aware of the purpose of the research and what will be required of them including potential benefits and risks. The right to withdraw at any point as well as procedures for ensuring confidentiality must be made clear before inviting the person to formally agree to participate indicated by the completion of a signed consent form. The challenge of many existing consent processes is that information tends to be in written format, and this can disadvantage individuals with literacy needs and sensory and cognitive impairments. Obtaining written consent most frequently occurs before the research begins and frequently fails to recognize that a participant’s relationship with the research will shift and evolve over time.

(Insert figure 6 here)Figure 3 Contents of the Informedness of Consent section of the Ethical Roadmap https://ethicalroadmap.org/

This element of the roadmap recognizes that ethics is both situated and dynamic. The materials contained in this component are intended to support the design researcher in being responsive and ensuring that consent is not a single event but an ongoing responsive process that evolves as the research evolves. It invites research teams to think about the following: *How do we inform participants about the study? How often do we share the process we follow? Do we need informed consent every time we meet the participants? What is the format of the consent form? The language? The layout? Can we create something that can be iterative?* The resource cards offer talking points to explore ways to articulate methods used in research as well as ways to describe how the research may be disseminated. The *journey of consent* cards offer suggestions and examples of how a team might want to creatively explore informed consent.

Team Member Roles

Working ethically means recognizing and supporting the wellbeing of the research team as well as participants. Indeed, the emotional challenges facing researchers working in sensitive contexts are well documented in the literature (Watts 2008; Kinard 1996). Creating a positive environment where individuals are aware of their roles and where respective strengths are nurtured and celebrated is an integral part of this.

This component includes two activities: *Role Cards* and *Role Map* that aim to help researchers identify personal and collective strengths and competencies. There are ten team member roles in this pack, represented on ten cards. These built on the roles developed by Belbin (2010) and Kelley (2001). However, because Belbin's categorization derives from management thinking and Kelley's from design thinking, we created our team roles cards in a way we felt fits within the design research context. So doing, we added the detail of what each role encompasses in the three categories of Building, Organizing and Learning, as suggested by Kelley, but for each category, we suggested sub-categories associated with it. Each sub-category represents a role with a design research context. For example, the Learning category is divided into a) learning from theory *Theory/Practice Bridger* b) learning from people *Cross-Pollinator* and c) learning from context *Contextualiser*. On the back of each card, we present the contributions made to a project for each individual role. Empty cards are provided for the team to add more roles if they wish.

Team members might associate with more than one of the roles. The team role map allows participants to capture the primary roles that they most strongly associate with and also those that they identify with but to a lesser extent.

Provocations

Within this pack, there are approximately 40 cards that pose scenarios wherein ethical boundaries are crossed or are seen to be crossed. The scenarios are short provocations that describe a situation and offer a question (i.e. *You have permission to use somebody's data after his/her death. How long can you keep it?*) The cards aim to provoke discussions within the team and allow an opportunity for more experienced members to describe their experiences and how they have sought to mitigate against potential harm to participants, thereby creating a space for learning.

The cards are filtered in four broader categories: a) *Technology,* b) *Sense of self,* c)R*elationship between family members,* d) *Relationship between researchers and participants.* The selected provocation cards can be used at any point in the roadmap session to invite team members to think about the research context more broadly and/or align new members with the thinking and values of the existing team. More specifically, the provocations offer opportunities for team members to discuss frictions when considering different aspects of the research project. This was intended to help different teams to raise their concerns in areas that they felt more comfortable to discuss openly within the team. Unlike the other resources the Provocations cards are also useful within any of the other resources – they offer challenging questions that can facilitate group discussion related to any of the other topics in the roadmap pack.

Warp & Weft

Interactions with stakeholders on our project identified inadequacies of ethical procedures when considered in respect of the growing movement of co-production and co-creation in this field.

The invisibility of the ethical process and inherent power imbalance was also seen as problematic. The signing of a consent form, for example, was regarded by some of our stakeholders as reinforcing the positionality between the researcher and the researched. The underlying message was ‘you need to be protected’ with little room for discourse and negotiation in relation to what the research might actually entail and how complexities might be navigated. This is clearly out of step with the broader paradigm shift occurring within healthcare policy which calls for shared responsibility and autonomy in how services are delivered (Lorig and Holman 2004). The Warp and

Weft pack therefore includes empty strips of paper, an information sheet and a capture sheet.

The strips of paper invite people to write things that they would like and things that they would not like in relation to the project they were about to embark on together. Research participants, team members and critical friends are all encouraged to write their statements surrounding what they would and would not like to happen during the research process, thereby potentially offering a sense of agency within the process.

Digital Open Source Resource

The physical, paper-based resources are currently being piloted by a number of research teams through live projects in Australia, Switzerland and the UK. Each team is feeding back to us on their use of the resources and their critique of them. As we stated earlier in this paper, we see the Ethical Roadmap as a series of resources that are in a state of 'becoming' and always should be. We certainly see our Roadmap as a solid starting point, but not a finite resource.

In order to create a more accessible resource for the wider international research community and a means whereby the resources themselves can be developed further by users we have translated all of the packs into a digital, free, downloadable version and are hosting it on an open source platform (GitHub) https://ethicalroadmap.org/. Importantly, beyond each of the Ethical Roadmap resources now being online (in a format that can be either downloaded, printed and used as per the original paper based version, or interacted with online) GitHub enables teams to go beyond tailoring the resources to their specific projects and significantly to extend the resources conceptually. In brief, new extensions created by users of the individual resources can be seen by new users like a branch of a tree from the original Roadmap and we can absorb new thinking and changes to a specific aspect of one of the resources from users into the original version as a way to develop it in a transparent and community based way.

DISCUSSION

Ethics are the foundation of good research practice. Over the last 80 years, a number of frameworks have been established with the intention of creating parameters in which researchers can operate and which support the research community in navigating sensitive and complex scenarios. These challenge researchers to consider the potential impact that engaging in the research process might have for the individuals with whom they engage. However, this paper has highlighted that as interdisciplinary research, particularly design-led interdisciplinary research, grows these frameworks are becoming increasingly restrictive and potentially unfit for purpose.

The study has shown that a number of paradoxes with respect to existing ethical frameworks exist. Ethics cannot exist outside of a context yet to work ethically it is necessary to understand and to have agreed practices to ways of responding within such contexts. Developing procedural ethics whereby the exact processes and situations that the research will evoke has been a long-established approach. However, the static nature of this and the concrete fixed boundaries make such processes unable to be responsive to the situations as they arise. The danger then is that potentially the framework can itself constrain and inhibit an ethical responsiveness to each situation. The move to more situated ethics (Dewing et al. 2008) is welcome, but whilst this is gaining recognition there is a lack of support in how to enact and operationalize this.

Our research has taken a first step in responding to thes challenges. Using drawing as method we were able to begin to deconstruct, visualise and reflect on what is inherent in existing ethical frameworks. These drawings became the basis of conversations with participants who represented a range of stakeholders engaging in research. Through this process the importance of creating a space where questions relating to potential ethical questions and issues was recognised.

The intention of the Ethical Roadmap is to create this space and to enable the researcher to encounter fundamental questions and situations, which demand an ethical response within a safe space and to discuss these with other members of a team. Two processes occur here. Firstly, at one level, the roadmap may facilitate an understanding of how broader personal and team value systems might shape responses to potential ethical situations and dilemmas that may arise. There is the opportunity here for discourse, discussion and a level of rehearsal as potential ethical dilemmas are encountered and responses are worked through. Secondly, on a far deeper level the process may create a space for a reflective and reflexive process that builds self-awareness of how researcher values may manifest themselves in particular contexts. Through engaging in this process personal value systems are made visible and the researcher may for the first-time gain self-awareness and insight into their responses. Something akin to Ingold's (2013) description of 'knowing from the inside'. As a consequence it is postulated that a far deeper process of change is at work here.

The Ethical Roadmap hopefully offers a nuanced approach to ethics, but we recognize it is not a panacea. We acknowledge that it has limitations and serves as a first step as a resource. It is something that is ‘becoming’ and that others can add to and, through use, refine (and our commitment to the open source digital resource underpins this).

It constitutes a first step to addressing the inadequacies of existing frameworks but fundamentally a system change to current ethical frameworks and governance is required. Any system change must recognize that inter-disciplinarity is a growing feature of much research and that ethics boards must be more representative of and include input from a range of professions. Ethics boards must work more in partnership to support researchers working in hitherto unexplored territory where ethical questions/implications relating to broader digital contexts have yet to be fully understood.

Our research has highlighted that multiple approaches and ways of thinking about ethics exist. Design researchers need to be fully conversant with these. The power of the roadmap is that it makes this thinking transparent and offers a reflective space shared on equal terms with all participants.

CONCLUSION

As the skills of designers in addressing societal issues and questions becomes increasingly recognized, a growing number of design researchers will work in so called sensitive and complex areas of research; for instance, research with people with dementia, individuals who are bereaved and individuals living with life limiting conditions. It is vital that all researchers are well prepared to consider the broader ethical tensions and dilemmas they may encounter in such situations. In this paper we have highlighted how current ethical frameworks predicated on biomedical ethics do not reflect well design’s inductive approach and designerly ways of knowing. We have crafted an Ethical Roadmap, which is responsive to new paradigms in interdisciplinary research and questions relating to an ethic of technology. This roadmap embodies and most importantly operationalizes a situated, responsive ethics to ensure that designers and individuals participating in design research are indeed engaging in an ethic of care.

Acknowledgements

This work was supported by project partners: Cruse Bereavement Care, Hospice UK, Marie Curie, NCPC, Dementia Care, Dementia Positive, Dementia Action Alliance, BBC, NIHR CLAHRC YH, Alzheimer’s Society.

Funding

This work was enabled by EPSRC grant EP/P025609/1 add here]

Dr. Claire Craig is a Reader in Design and Creative Practice in Health and Co-Director of Lab4Living. Her research interests focus on the role of design in the promotion of health and wellbeing.

Jayne Wallace‘s research explores the potential of design, contemporary jewellery, digital technologies, and cocreative acts of making to support sense of self across a range of complex health and social care contexts.

Kyle Montague’s research explores the design and configuration of digital technologies to support participation and inclusion of marginalised communities.

Nantia Koulidou’s research focusses on digital jewellery in micro-transitions. Her methods are rooted in craft practices and participatory design.

Helen Fisher is a designer whose interests focus on the role of design in sensitive contexts including for people living with dementia and for people at end of life.

Luis Carvalho has a background in Computer Science and HCI. Recent research developed at LASIGE, University of Lisbon focussed on ‘Supporting Homeless People with IVR Systems’

Kellie Morrissey is a psychologist whose research interests lie at the intersection of health and politics in the design of digital objects and experiences in sensitive settings.

Linnea Groot ‘s interests are in exploring ways of creating designs that can be personalized by means of opportunities within the field of human-computer interaction.

Shaun Lawson’s research lies at the boundaries between computing, design and the social sciences, and exploring the use and significance of social media and other digital services in people’s lives.

Julie Trueman’s research interests seek to integrate her academic and tacit knowledge in design, with an additional focus on the pedagogy of learning.

Trevor Duncan’s expertise lies in designing with resistant materials. His research focuses on craft processes and digital technologies. Examples of his work are in the permanent collection in the Victoria & Albert Museum, London.

Address for correspondence

Dr. Claire Craig (corresponding author) Lab4Living, Sheffield Hallam University, Sheffield, UK.

Email: c.craig@shu.ac.uk

REFERENCES:

Armstrong, L. Bailey, J. Julier G, Kimbell, L (2014) *Social Design Futures.* Brighton. AHRC.

Beauchamp and Childress (2001) Principles Biomedical Ethics. Open University Press.

British Association for Counselling and Psychotherapy (2018) Ethical Framework for the Counselling Professions. London. British Association for Counselling and Psychotherapy.

British Psychological Society (2018) Code of Ethics and Conduct. Leicester. British Psychological Society.

Brody H (2009) The Future of Bio-ethics. New York, Oxford University Press.

Cath C. 2018 Governing artificial intelligence: ethical, legal and technical opportunities and challenges. *Phil. Trans. R. Soc. A* **376**: 20180080. http://dx.doi.org/10.1098/rsta.2018.0080

Combes B H; Peak P.W. Barrio B; Lindo, E; Hovey, K; Lim, O; Peterson-Ahmad; Dorel, T and Goran, L (2016) Revisiting Principles of Ethical Practice Using a Case Study Framework. Intervention in School and Clinic 2016, Vol. 52(2) 92–101

Chamberlain and Craig (2017). Design for Health: reflections from the editors. *Design for health*, **1** (1), 3-7.

Design Council (2012) Living well with Dementia Design Challenge. London. Design Council.

Dewing J. Participatory research: a method for process consent with persons who have dementia. Dementia 2007; 6: 11–25. doi:10.1177/1471301207075625.

Dewing, J (2008) Process Consent and Research with Older persons Living with Dementia. *Research Ethics Review. Vol 4, no. 2 pp59-64.*

Floridi (2019) Translating Principles into Practices of Digital Ethics. Five Risks of Being Unethical. *Philosophy and Technology.* 32 (2) pp.185-193.

Fox R C and Swazey J (2008) *Observing Bioethics.* New York. Oxford University Press.

Frauenberger, C., Rauhala, M., & Fitzpatrick, G. (2017). In-action ethics. *Interacting with Computers*, *29*(2), 220-236.

Gamman L and Pascoe T (2004) Design out Crime? Using Practice-based models of the design process in *Crime Prevention and Community Safety: an international journal*, *6 (4) pp.37-57.*

Gispen J (2017) https://www.ethicsfordesigners.com/tools

Holmwood, J. (2010). Research Ethics Committees (RECs) and the Creaking Piers of Peer Review. Sociological Research Online, 15(4), 1–4.

Ingold, T. (2013) Making: Anthropology, archaeology, art and architecture. London. Routledge.

Kelley, T. A. (2001). *The art of innovation: Lessons in creativity from IDEO, America's leading design firm* (Vol. 10). Broadway Business.

Komesaroff, P. A. (2008). From bioethics to microethics: The need to return ethical debate to the clinic. *Experiments in love and death: Medicine, postmodernism, microethics and the body*, 20.

Kramer, A. D., Guillory, J. E., & Hancock, J. T. (2014). Experimental evidence of massive-scale emotional contagion through social networks. Proceedings of the National Academy of Sciences, 111(24), 8788-8790.

Lorig and Holman (2004) Patient self management: a key to effectiveness and efficiency in care of chronic disease. *Public Health Report* May-Jun; 119 (3) pp239-43.

Markham, A., & Buchanan, E. (2012). Ethical decision-making and internet research: Version 2.0. recommendations from the AoIR ethics working committee. Available online: aoir. org/reports/ethics2. pdf.

Medical Council (2016) guide to professional conduct and ethics (8th edition). London, Medical Council.

Moncur W (2013) *The emotional wellbeing of researchers: considerations for practice. ICHI 2013: Changing Perspectives*

Morris, Z., Wooding, S. & Grant, J. (2011) The answer is 17 years, what is the question; understanding time lags in translational research. .*Journal of the Royal Society of Medicine.* Dec; 104 (12) pp.510-520.

Munteanu, C; Moncur, W; Molyneaux H and Romero, O'Donnell, S and Vines, J (2015) Situational ethics: rethinking approaches to formal ethical requirements for Human-Computer Interaction. Conference: CHI 2015, At Seoul, South Korea

Novitzky, P., Smeaton, A. F., Chen, C., Irving, K., Jacquemard, T., O'Brolcháin, F., ... & Gordijn, B. (2015). A review of contemporary work on the ethics of ambient assisted living technologies for people with dementia. *Science and engineering ethics*, *21*(3), 707-765.

Nursing and Midwifery Council (2018) The Code: Professional standards of practice and behavior for nurses and midwives. London. Nursing and Midwifery Council.

Open Ethics Initiative https://openethics.ai/ (last accessed July 2020).

Petersson, I., Lilja, M., and Borell, L., 2012. To feel safe in everyday life at home–a study of older adults after home modifications. *Ageing & Society 32*, 5, 791-811.

Sharkey, A. (2014). Robots and human dignity: a consideration of the effects of robot care on the dignity of older people. *Ethics and Information Technology*, *16*(1), 63-75.

Spiel, K., Brulé, E., Frauenberger, C., Bailly, G., & Fitzpatrick, G. (2018, August). Micro-ethics for participatory design with marginalised children. In *Proceedings of the 15th Participatory Design Conference: Full Papers-Volume 1* (pp. 1-12).

Stanley, L, and Wise, S (2010) 'The ESRC's 2010 Framework for Research Ethics: Fit for research purpose?' Sociological Research Online, Volume 15, Issue 4.

Strech D, Mertz M, Knuppel H, Neitzke G, Schmidhuber M. The full spectrum of ethical issues in dementia care: systematic qualitative review. Br J Psychiatry 2013; 202: 400–6. doi:10.1192/bjp.bp.112.116335.

Tronto, J. C. (1998). An ethic of care. *Generations: Journal of the American Society on Aging*, *22*(3), 15-20.

Tutenel, P; Ramaekers, S and Heylighen, A (2019) Learning from video research with children in a cancer care ward. T*he design journal: Proceedings of the 13th EAD conference University of Dundee, 10-12 April 2019*, **22** (sup1).

Van Wynsberghe, A. (2013). Designing robots for care: Care centered value-sensitive design. *Science and engineering ethics*, *19*(2), 407-433.

Wallace J; Thomas, J; Anderson D and Olivier, P (2018) *Design Issues*, 34 Number 1. Winter.

Wallace, J., Duncan, T., Lawson, S., Trueman, J., Montague, K., Carvalho, L., Groot, L., Craig, C., Fisher, H. and Koulidou, N., 2020. Design research to support ongoingness. *Bereavement Care*, *39*(2), pp.88-92.

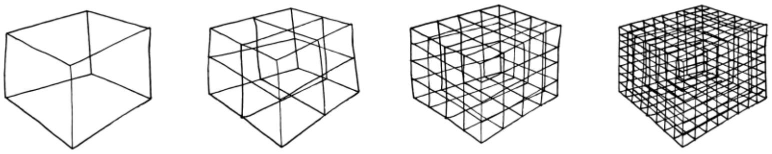
Wechsler M, Fogarty L. Decision making for participation in dementia research. Am J Geriatric Psychiatry 2013; 21: 355–63.

Ward, K. (2018). Social networks, the 2016 US presidential election, and Kantian ethics: applying the categorical imperative to Cambridge Analytica’s behavioral microtargeting. Journal of media ethics, 33(3), 133-148.

Waycott, J., Munteanu, C., Davis, H., Thieme, A., Moncur, W., Mcnaney, R., Vines, J., and Branham, S., 2016. Ethical Encounters in Human-Computer Interaction. In *Proceedings of the 2016 CHI Conference* (San Jose, California DOI= http://dx.doi.org/10.1145/2851581.2856498.

World Health Organisation (2017) Code of Ethics and Professional Conduct. Geneva. WHO.

FIGURES TO BE USED IN TEXT WHERE SPECIFIED EARLIER

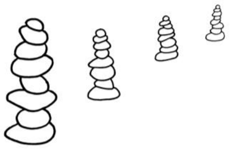


Diary reflection: "The frameworks are so wide-ranging in relation to the detail they offer. All seem to hold a series of clear principles (the outer struts), but there is a balance, the less structure the framework holds the more flexible but the less stable. As it becomes more dense it becomes the more rigid and the flexibility is lost."

Figure 1 Reflective Diary excerpt – rigidity of frameworks

Diary Reflection: "If an analogy of a roadmap is taken a stage further, perhaps we can think of this as a process of reflection or meditation. The important element is reflecting, recognizing that there are multiple ways to reach the final destination – something far more akin to situated ethics, to Dewing's work. There are dangers though. Without any guidance or value system this could simply reinforce and unhelpful or unethical way of being."

Figure 2 Reflective Diary excerpt – potential process of reflection



Diary Reflection: "One thing I am particularly struck by is whether it is possible to simply subscribe to a set of universal principles? What is the true purpose of an ethical framework and by its very nature are these principles not linked to culture, to time and to place? Is ethics a way of policing a way of working, of setting out parameters? If so, who creates these parameters? If we look to the principles of autonomy or justice – is there not an inherent power imbalance where the ethical framework is imposed, is created from the outside rather than being crafted with the community? Supposing ethics was a form of collective way-finding with insights and knowledge shared by those who have walked the past before? Rather than being a framework, supposing ethics was a roadmap based on casuistry, so that we learn and build rather than starting from the beginning. This then becomes a more distributed, shared process and one where we do not start each time from the very beginning but build on collective knowledge and understanding?"

Figure 3 Reflective Diary excerpt – collective wayfinding

Figure 4. Ethical Roadmap box containing individual packs of resources/activities.

Figure 5. Contents of the value cards component of the Ethical Roadmap

Figure 6 Contents of the Informedness of Consent section of the Ethical Roadmap