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Ethics through Design: Medical data systems, chronically ill data subjects, and all the invisible things in between.

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Ethics of medical data practices and technologies are becoming the focus of growing research that intersect several fields, including Design. In this paper we posit that Ethics through Design offers a pragmatic approach to creatively address ethical impact assessment challenges in the medical domain. Through a case study of an EU-funded research project (SODA) that explores multiparty computing in medical contexts, such as dementia, we explore the idea of contextual and participatory ethics, as a way of *doing* ethics together with vulnerable data subjects and system end-users. We present the project research methodology and findings that drove us to more deeply understand data subjects' perceptions of own data practices and how they influence their wellbeing, in contrast with values and interests of system end-users' practices. Those groups are not usually studied in connection, however we are proposing that their intersection opens a spectrum of possibilities for future design research practice in the area of trustee systems that contributes to ethics of technology.

Keywords: Ethics, Technology, Multiparty Computing; Dementia; Data, Ethics through Design.

1 Introduction and Project Context

Digital technologies are becoming central to health and care practices. They mediate complex socio-technological systems and people whose data is being collected and used, known as data subjects. On a social level, data mediations can support development of structures of health services and public policy; while at the individual level, they are affecting care experience and ultimately, identities and narratives of health and illness. Interests in collecting, sharing, analysing and comparing medical data vary, and are shared by data subjects and professionals to improve medical knowledge, public health, clinical care, health devices, products and services.

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Multiagency data interoperation renders individual invisible transactions and intimate negotiations– data subjects and informal caregivers who often unintentionally work at generating, interpreting, and at times misusing measurements — with clinical situated practices and pre-programmed algorithms. Data transactions, far from neutral, are subjected to gender, class, nationality, personal history and contextual politics. Data subjects may or may not understand when and how they are providing data, what data sharing implies or even what data is or means for them. At the same time, data subjects have conceptions, ideas and rights on their data. As these intersect, a range of frictions arise.

Clinical and medical data collected through digital devices (e.g. insulin pumps) may usefully converge to form Biomedical Big Data (BBD). The 'datafication' (Van Dijck, 2014) of medical systems may yield new insights through machine learning and algorithmic categorisation, data might be repurposed to great effect to inform medical research more widely. However, currently, this processing is highly obstructed by incompatible data sets and systems that cannot interoperate across countries, neither agencies, eg. hospitals, private companies, general practitioners and care organisation. National and local data regulations place responsibility on data controllers and system end-users that spend significant time (weeks, months, even years) before information can be shared and become beneficial. Challenges also arise, because the "benefits" of data sharing may not directly impact data subjects, the promise is of a better healthcare future that does not belong to them.

Medical datafication may even imply a "trade off" of values, rights and freedoms. In the European Union fundamental rights regarding the protection of personal data, non-discrimination and the presumption of innocence are supported by values of dignity, freedom, democracy, equality and the respect of human rights (Büscher et al., 2018). The challenges of technological responsible innovation in alignment with human rights are formidable; in part because they are complex, in part because they are distributed across organisations, cultures and countries, but also because they conceal data practices and intimate negotiations. In the medical domain ethical tensions arise in particularly significant ways, the "trade off" in caring systems entails disparate power relations, vulnerable data subjects and fragile spaces and temporalities.

1.1 Multiparty Computing System in the Medical Domain

The overall aim of SODA project is to explore secure uses of Multiparty Computation (MPC) in the medical domain, focusing on chronic illnesses. MPC has the potential to offer data usage and multiagency interoperability without *actually* sharing data. Instead, processing is done on encrypted data, making it an efficient privacy preserving technique in which different parties never have to handle each other's data. This paper describes one of SODA studies; SODA-Lancaster lead by ImaginationLancaster in collaboration with Centre for Mobilities research Cemore (Lancaster, UK) and Alexandra Institute of Technology (Aarhus, Denmark) and particularly engages with the case of dementia data practices.

We used Collaborative Design processes to explore spaces and knowledges that emerge from the engagement with data subjects living with dementia and their caregivers as well as system end-users; clinicians, data scientists and BBD systems controllers. The aim was *not* to co-design artefacts, services nor products, but to inform an idea of collaborative contextual ethics. The aim was to *do* Ethics through Design (EtD). This paper discusses MPC ethical challenges and opportunities in the dementia domain emerging from EtD research approach.

1.2 The Challenge: Let's talk about data

For certain chronic diseases such as diabetes and renal disorders, data practices are very important part of controlling, coping and making sense of data subjects' own illnesses. In such cases, data interface with one's own body, social aspects of the disease and even, community making. In SODA studies with diabetics[1], stories about "managing front and backstage of data" emerged; for example, it was common to volunteer data in forums and communities where they can be helpful ("to myself or others"), but also hiding it in contexts in where data about illnes could be stigmatizing. We are calling these sort of decisions, intimate negotiations, and they are affected by and affecting trust.

Data practices for people living with dementia are radically different. Neither data subjects, nor their caregivers, are in direct control of dementia data practices. The clinical monitoring is not mediated by personal or clinical devices, there are not any numbers to follow. The sporadic monitoring is purely qualitative, caregivers and clinicians follow aspects that indicate ability to keep up with everyday activities; managing bank accounts, visiting pharmacy, ability to drive, to make a meal.

In addition, the profile of a SODA participant living with dementia, is of a person who has grown older with very little contact and familiarity with personal digital devices, neither health devices nor personal computers or social media platforms.

In the specific case of the UK, the National Health System (NHS) owns patient's medical data. A culture of keeping one's own personal records - exam results, analysis, diagnostics, medical histories - has not been cultivated. Within the NHS system, personal medical data operates only at a local level. Data subjects rarely have access to their own records and in many places, medical data is still collected and stored physically. The NHS system is rapidly changing with current projects on a national scale of digital data repositories.

In contrast, BBD scientists and users of medical systems such as NHS, embrace a data epistemology that sets apart data subjects. It relies on knowledge produced by the analysis of patterns (Kitchin, 2014), in which the individual (its personal context, needs, data practices) is discarded in favour of data volume, significant enough to become a pattern. This has two consequences, the de-individuation of data subjects and the presumption of data as objective, anonymous and interoperable. The latter manifested in ideas such as, the more data is collected the nearer to reality data brings us, or, data sets can be added together, cross-analysed and used with different purposes. Such dataism (Van Dijck, 2014) can 'introduce machinic forms of reasoning into human affairs in ways that are difficult to align with human rights and values' (Büscher et al., 2018, p. 257).

The combination of individual data practices and system data practices opens up a relation rarely explored. In our investigation, the combination of digital divide and NHS data culture, means that ideas such as, personal medical data sharing, and the mere idea of data, are very unfamiliar, even abstract for data subjects. This lack of touch with one's own data accentuates digital inequalities of the system. Before exploring forms of given consent, perceived fears or benefits of data sharing and trustful systems, our study had to step back and start with questions of data; what is data? when or how do people living with dementia, often treated as *patients*, become *active* data subjects? what is the matter of data systems and how do data matter for subjects? The task was to design a methodology that explored

[1] Still work in progress, publication follow later this year.

that relation and bring together(apart) two perspectives within the system that data mediates; data subject's intimacy and the system's top-down vision.

2 Our Approach

The project premise is that co-design processes have the potential to create spaces for knowledge exchange in which the development of participants' own voice and agency are nurtured and supported. The aim of co-designing contextual ethics was to open up a relation that is usually flattened down or hidden - within datafied infrastructures of data pattern and data volume - by including the perspectives of; 1) data subjects and 2) system end-users.

In the case of people living with dementia, co-design also has the potential to directly benefit participants, as creative activities with peers and professionals constitute a much-needed opportunity to socialize, boost well-being and quality of life (Luján Escalante et al. 2017, Rodgers, 2018). Dementia involves neurophysiological symptoms such as loss of memory, mental agility, balance, mobility, and although there is no cure for it, cognitive and behavioural interventions can be most beneficial at improving life quality and slowing down the decline (Forbes at al., 2013).

The research methodology followed a design-led, cross-disciplinary, approach (participatory action research) (Büscher et al., 2004; Chevalier et al., 2013) inspired by the field of social futures research (Urry, 2016). It used creative methods including, play (Luján Escalante et al. 2017, Tsekleves et al. 2018), persona and scenarios (Wärnestål et al., 2014, Nielsen 2011), music, props and participatory storytelling (Kankainen et al., 2012; Morrissey, 2016)

In the case of end-users, we experimented with methods such as value scenarios (Nathan et al. 2007), controversy mapping and public experimentation (Marres, 2009) were part of co-design workshops used for 'infrastructuring' debate of diverse interests (Dantec and DiSalvo 2013).

2.1 Ethics through Design

In both cases, co-design methods were used to collect, assess, validate and contrast rich descriptions of participants' ideas, practices and perceptions. We posit this as Ethics through Design (EtD).

In Sanders and Stappers' (2008) seminal definition, co-design refers to 'the creativity of designers and people not trained in design working together in the design development process' (p. 6). EtD is not concerned with what is designed, but strictly with the value that emerges in co-design processes, conceived as a *milieu*, as a site that catalyses affections, knowledge and creative, generative, encounters. Co-design as *site of emergence* is then, temporary, fragile, heterogeneous and in conflict. (Luján Escalante, 2019).

EtD is a pragmatic approach to creatively address ethical challenges. It draws on Value Sensitive Design (Friedman, 1996), disclosive ethics (Introna, 2007), ethical impact assessment (Petersen et al., 2016, CEN CWA SATORI project 2016), responsible research innovation (von Schomberg 2013, Liegl et al., 2016) and principles and values to design IT systems in radically careful and carefully radical ways (Büscher et al. 2014). The EtD approach aims to be transformative as participants become responsible for innovation, having a much higher stake in its design, making and understanding (Hartswood et al., 2002; Couvreur & de Goossens, 2011) socio-technological knowledge that is always political, as it

is concerned with the power of hiding or offering visibility, inclusion and respect to the individual.

EtD follows the idea that attention to the social and ethical is not a constraint on IT innovation, but, on the contrary, the key to creating high quality IT for human empowering. The initiative asks how more ethically, socially circumspect and flexible IT research and innovation can be achieved if design can support accessibility to better drawn an inclusive "bigger picture", with detailed attention to capacity of balancing benefits and losses (Büscher et all. 2018). EtD aims to put values and ethics into practice, to explore aspirations, visions and ideas about data practices.

3 Research Design

3.1 Data Subjects

Partnered with Neurodropin Center and their support group in Lancaster, UK, 3 sessions were designed and facilitated with 6 participants living with dementia, 2 caregivers, 2 researcher co-designers, one ethical facilitator, a cartoonist and one storyteller. Sessions lasted around 2 hours. Participants arrived and settled in the space over tea and biscuits, sessions started with a music game, as an ice breaker and ended with a community lunch.

3.1.1 Exploring issues of Consent creatively

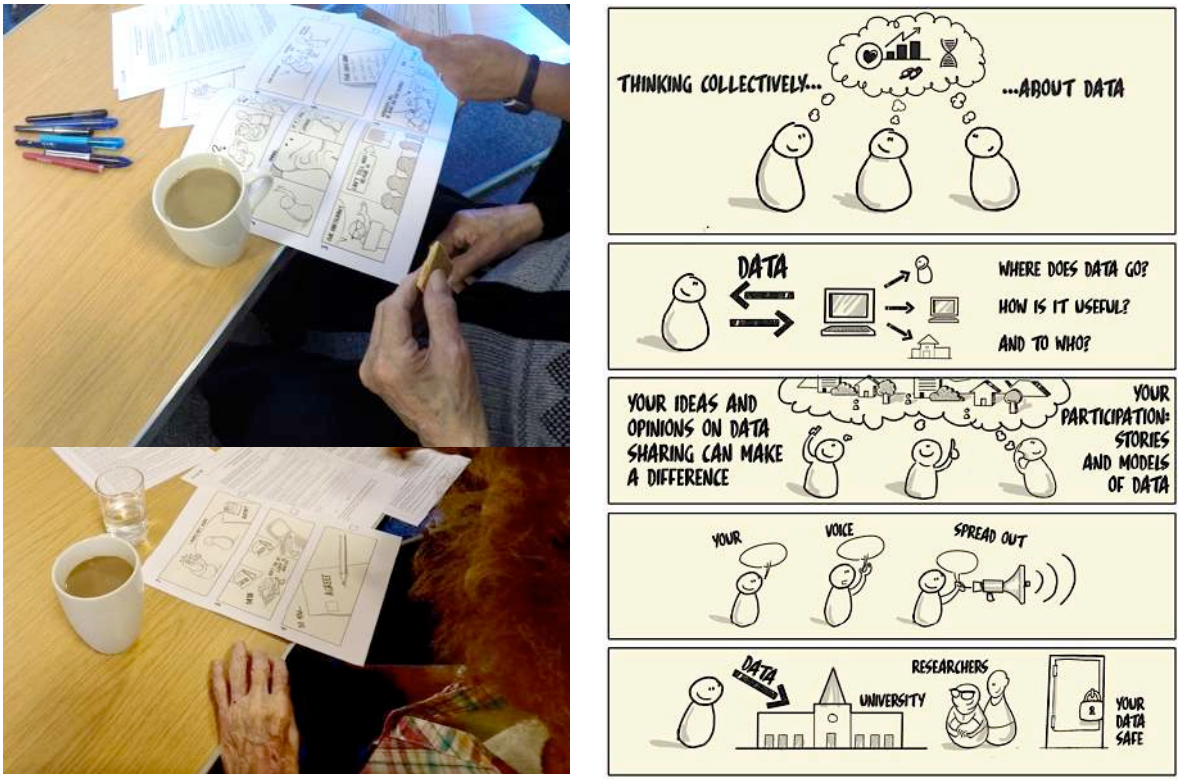

Figure 1: In the right, an extract of the Project Information Sheet. In the left, participants engaging with EtD consent tool, that included Participant Ethical Approval, Research Participation Consent and Project Information.

Experience from past co-design projects with people living with dementia (Luján Escalante et al. 2017, Tsekleves et al., 2018, Luján Escalante 2019), made evident that processes of

obtaining participant consent was not satisfactory, as caregivers and researchers had to read and explain point by point the documents, defeating the process of independent consent.

EtD proposes ethical consent as a collaborative and creative process, moving beyond box ticking to explore consent as an opportunity for trust building via creative encounters and meaningful conversations. A tool was designed to collaboratively engage with an informed consent process. Ethical forms were 'translated' into visual media (See Figure 1), using comic strip format, and were used as tools to mediate our first encounter with participants and engaging them. The cartoons provided light relief from the written word, they illustrated and opened up debate about serious and sensitive topics. Furthermore, as a 'visual form they are simple but ideas rich' (Barlett, 2013), and worked as a boundary object (Star & Griesemer, 1989).

3.1.2 Participatory storytelling, Music and Props.

Figure 2: Props-as-probes: In the left, participatory storytelling character building. In the right, bottles and pharmacy paper bags, as props to facilitate conversations about medical data practices. Also, props to facilitate movement and participation.

Probes are commonly deployed in dementia projects (Wallace et al., 2013a and 2013b). With a shorter project duration, we used 'props-as-probes' (Morrisey et al., 2016) prioritizing quick and creative action in situated contexts. Props served as scaffold of design responses open but bounded; emphasizing the tangible and interlinked relation between creativity, communication and connection, constituting both the ends and the means of our iterative co-design process. The combination of props and music, allowed participants to be playful, to connect with the workshop activities, and to create social bonds. Props also were used to dress-up fictional characters in participatory story-telling, or to represent ideas such as personal medical data, data systems, money, time, medical treatments (See Figure 2).

By using participatory story-telling we drawn on 'performative experience design' (Kankainen et al., 2012) and story-telling in service design (Spence et al., 2013). The approach explored spontaneous performance and participation in narrative. It provided a platform from where different roles and rehearsals of self-expression, including verbal or non-verbal dialogue, sprung. Participants co-designers shifted from role to role, from one story node to other, creating a sense of freedom – from patient to doctor, from baby to elderly, from famous singer to young dancer, from story-teller to spectator. This method gave value to the creation

of active participative environments, and the possibilities for ways of being of people living with dementia can multiply beyond the *patient* identity.

3.1.3 Co-creating Personas & Scenarios

The first and second sessions were dedicated to co-creating (Tsekeleves et al. 2018) Persona and Scenarios (Wärnestål et al., 2014) respectively. Personas captured conversations about objects, stories, things and numbers that matter for individuals. Role shifting interplayed as well in the co-creation process, at times participants identified with Personas, at others, Personas represented a relative or a character in the story. Personas then, were mobilised into an interconnected 'datafied' medical context, the Scenario. Relating everyday activities with data generation, data sharing and data purpose. The Scenarios represented "a day in town" and were inspired by participatory story-telling.

Figure 3: Personas and Scenarios. In the top line, examples of Personas co-created by people living with dementia as co-designers. In the bottom, examples of Scenarios, inspired by a day of the Personas in town.

3.1.4 Visual Conversations and Constant Communication with Participant Co-designers

Sessions regarded participants as experts rather than patients. The last tool to facilitate co-design was used in a dynamic that emulated "an expert interview". Answers were recorded visually on the wall. Participants expressed pride and fulfilment at their voices being taken seriously.

Each session was followed by a postal correspondence with each participant. Postcards featured pictures of the workshop designs were sent with a personal note. Postcards worked as reminder for following sessions and as a souvenir or memento. Participants showed great enthusiasm receiving their postcards. At the end of the three sessions, a visual report was shared among participants, caregiver organisations and family members over a community lunch, however not many of the participants could attend as health conditions worsened.

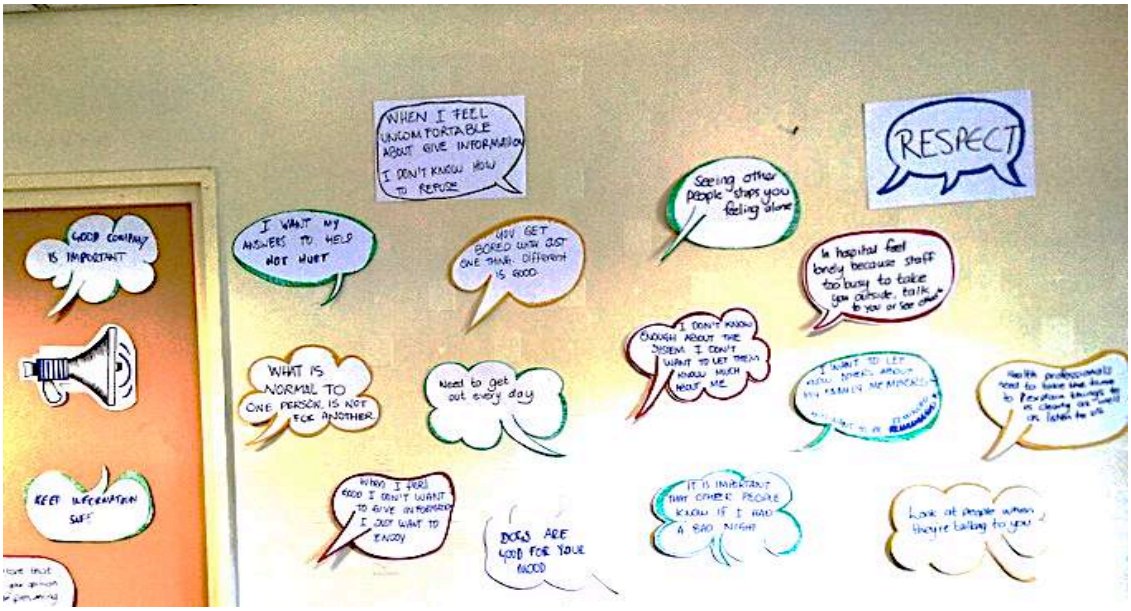

Figure 4: We called them 'visual conversations', because facilitators visually recorded conversations of people living with dementia playing the "data expert" role. Extracts of the interview filled the walls of the room and make it easier for participants to remember and for facilitator to go back to a certain aspect of the conversation.

3.2 End-Users

An EtD day-long session was designed and facilitated for NHS clinicians, academic and non-academic medical data scientists, NHS Business Intelligence, data regulatory body officers and Lancaster City Council policy officers from the Information Office.

3.2.1 Value Case Mapping

A method developed to collaboratively map data journeys and practices in Lancaster (UK), Building a complex picture from the data subjects out. The map made accessible the relation of data subjects and end-users. This exercise inspired by Nathan et al. (2007) aimed to expand and thicken a relation that is usually narrated along a thin line: I give consent to share my data, my data will be used for the benefit of others. This exercise wanted to visit, explore, inhabit the journeys of medical data, identify gate keepers, and understand practices of system end users, not just visualizing coincidences but also conflicts of opinions among participants.

The exercise allowed knowledge exchange supporting breaking silos of each participant's data disciplines by understanding responsibilities, values and interests. It offered participants to locate themselves and their own practices on the map, and to identify own practices challenges and opportunities. The exercise support reflection upon how to make systems

more beneficial, in terms of end-users and data subjects, and guidance were written in hexagons that cover the places in the maps showing ethical issues.

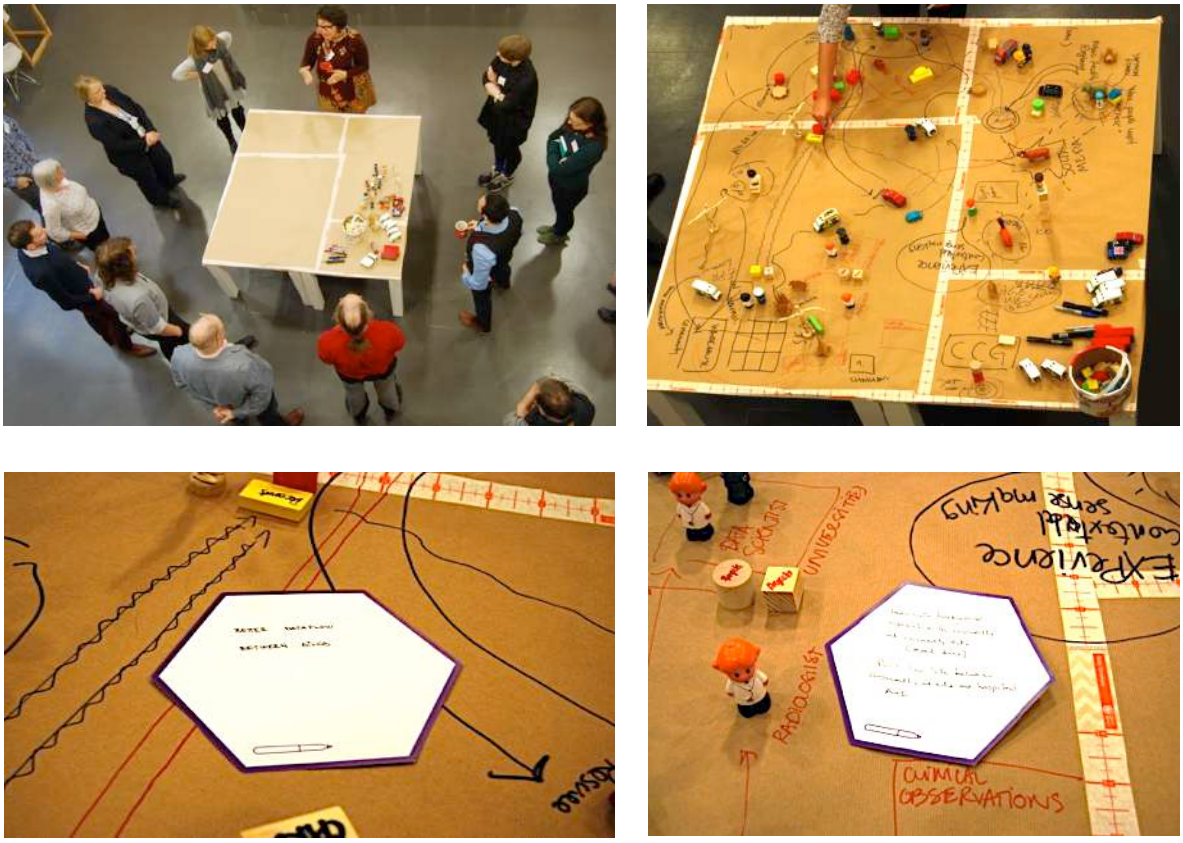

Figure 5: Value Case Mapping in the top and Practice-led Ethical Guidance in hexagons at the buttom.

3.2.2 Creative ethical impact assessment.

After an MPC technical discussion and its potential for privacy preserving in the medical domain, participants in teams rapidly co-designed plausible data scenarios in which MPC is used in Lancaster. In this exercise we used a co-design tool, part of the Etikit, that supported participants to co-design, discuss, imagine and ethically assess (Büscher et al. 2018) each of the plausible data scenarios. The exercise is also supported by the *IsITethical?* Key Term Playing Cards

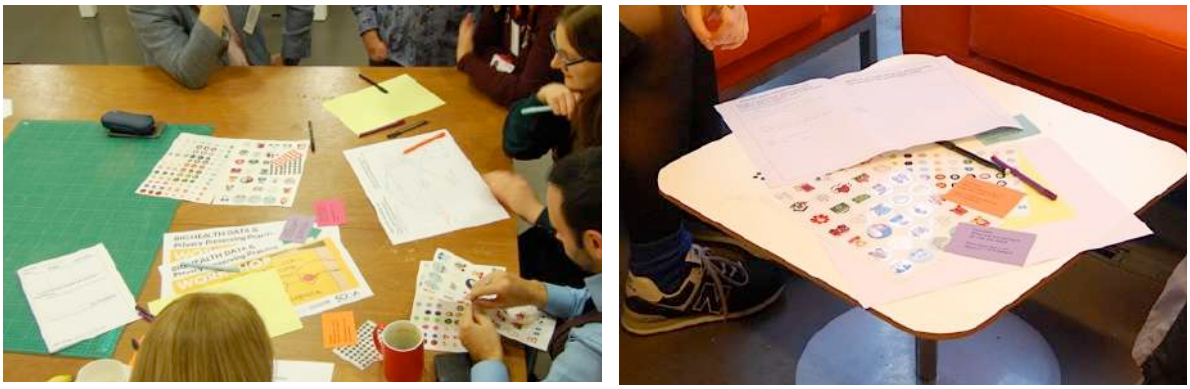

Figure 6: EtD co-design tool for rapid co-design speculative data scenarios and ethically asses them. They bring about ethical challenges and opportunities in a visual, contextual manner.

4 Findings and Discussion

4.1 Foreseen Benefits

4.1.1 On the principle of Responsible Research Innovation

- Case M. - Business Intelligence Manager from NHS.

At NHS local council level, our collaboration with academic data scientists has started to show patterns that allow us to propose hypotheses. For example, we noticed that stroke patients who are obese, if they are still alive after 30 days in hospital, they have a greater likelihood to survive than patients who have a normal weight. We speculated, this is because they have greater bodily resources to survive the hardships of hospitalisation. MPC could be useful to contrast and corroborate those patters at national level and even beyond.

4.1.2 On the principles of Accountability and Non-discrimination

- Case S. - Emergency Planner from Public Health England: herding cats in a crisis, or working with a list of lists.

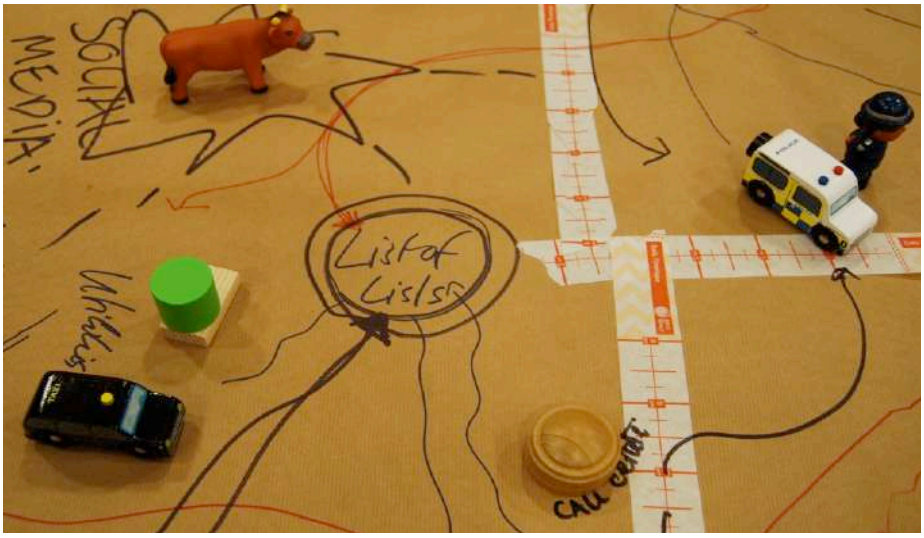

Figure 7: The 'list of lists' was thoroughly discussed at many moments of the day, it originally emerged during the value case collaborative mapping exercise, as the Lancaster Council Health planner was sharing some of the most pressing obstacle of her practice.

Imagine you are faced with a rapid onset flood. My job is to identify vulnerable people with urgency. There are many places where vulnerabilities are captured, there are records at local authorities, utility companies, aid charities. Not all vulnerable people are on one list, because some people do not feel vulnerable or do not want to be categorised as such. Additionally, personal devices, such as fitbit or mobility aid scooter, may constitute commercial data sets that identify vulnerable people. MPC could be potentially useful, to create an integrated list of vulnerable people in the specific street in which the flood occurred, a 'list of lists' that identifies names and addresses.

4.1.3 On the principles of Dignity and Respect

- Case D. – Does he take sugar?

Since I have been diagnosed, I have disappeared. At clinics and care centres, doctors, nurses and caregivers no longer address me directly, all questions about me are not to me, they are to my wife. Those may be questions such as, did he have a good night? does he take sugar in his tea? How could MPC be useful to preserve my dignity? Can it share data that is important to me, and that is going to affect my wellbeing, so people have information and do not ask others like if I am not present.

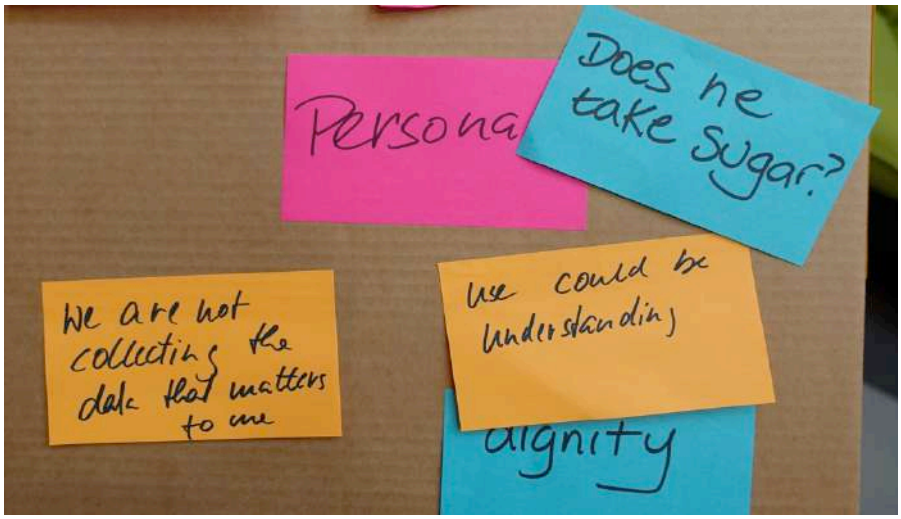

Figure 8: The 'does he take sugar?' story emerged in one of the exploratory workshops (Lancaster Nov 2018), it stayed with the project and informed many of the methods that were emerging.

4.1.4 On the principles of Proportionality and Humanity

- Case J. – Living with dementia in a care home, used to be a baker.

If during my everyday activities such as collecting my prescription at the pharmacy, visiting doctors and care centre, I am sharing information, such as my name and address with so many agencies and organisations, because my data is may be useful for them, how is it that MPC cannot be designed so my data is also useful to me? I usually forget my own address. How could this MPC work both ways? How could MPC be useful to me?

4.2 What would make MPC difficult: Challenges and Design Opportunities.

4.2.1 On the principles of Governability and Stewardship

- The issues of making MPC accessible and 'getting the questions right'

A premise of MPC is that all parties involved agreed on what the system can compute, which questions can be "asked". However, the process of deciding questions, how they should be asked, how data is collected and managed to support beneficial use of MPC techniques, present issues of governability and system stewardship.

Discussions with end-users speculated on the introduction of a certified trusted party such as NHS or Public Health England to act as arbiter and translator, policing and administrating the MPC. This raises all sorts of different questions: How often could questions change? What happens to old questions and answers? What if someone wants to leave or join the system? Will that affect guidelines for questions and data input? How trusted arbiter's transparency and accountability are guarantee? Who is allowed to ask what questions? What is allowed to do what with results?

Furthermore, end-user discussions evidenced a need for structuring a system that afford a widest range of questions, the system cannot be an “oracle”, as every question asked will leak information about the combined data sets, introducing then issues of privacy, purpose binding and data minimization.

Questions above show structuring an MPC system in the health domain presents interoperability challenges but also design opportunities. They also show a need for sufficient information about MPC and its limitations. The conversation about the introduction of trustee third party, partly would defeat one of the main purposes of MPC: to avoid human arbitrary. The EtD workshops show that participants may not trust nonhuman governability of sensible data.

4.2.2 On the principles of Transparency, Fairness and Justice

- How can data work for me? Losing the data subject

The process of retrieving information (asking questions) to an MPC system is very opaque. How can data be designed to be accessible, palpable and to be just and inclusive. Can data systems help people living with dementia to remember, their addresses and personal information? How can data systems be designed to benefit data subjects in fair data transactions? How can the data subject’s interests, values and needs be preserved in the design of operability of data systems? Can MPC be useful to create a data culture that preserve ownership and self-determination, or is it always going to be about agencies and organisations?

4.2.3 On the principle of Trust

EtD conversations informed a variety of values; respect, dignity, interoperability, transparency, accountability, privacy. However, the discussion on trust, was one of the richest, not just among participants but also among researchers who constantly discussed trust exercised at various levels.

Institutional Trust emerges from the relationship between people and trusted institutions. We noticed how relations with partner organisations trust researchers because of the connection with a public university. We also noticed that care organisations - home, care centres and NGO’s - trust each other and trust is shared and transferred from one to another, i.e, both end-users and data subjects trusted NHS. The idea that there are institutions that can be trust with the most vulnerable was a constant during the project.

The study also experienced other aspects of trust, that even linked with institutional trust, relates to research and innovation, the idea that researchers mediate trust. People living with dementia and their caregivers, offered us unlimited trust and trusted the research and the co-design process with very few questions or doubts. They trust researchers for no reason with one’s own sensible data and creating trustee bonds in which sensible stories were shared.

Co-design processes open spaces of trust, and trust exercised in co-creative spaces put co-design researchers in debt, where *indebtedness* is not about a debt that follows from a transaction but, rather, a debt that is the condition of possibility (Barad, 1998, p. 7); the possibility to contribute to responsible research innovation. We thought about trust as ongoing practice beyond transactions or associations; it is to voluntarily open oneself up to

risk, vulnerability and to receive responsibility. It is supported by intellectual honesty and awareness of one's own limitations.

Trust in technology emerges when expectations are regularly met and grows as technologies become more dependable. Trust in information transactions is encouraged by doing what it says it does (and not less or more) and demonstrating repeatability, predictability, dependability, and, thus, reliability (Clarke et al., 2006; Büscher et al., 2009).

4.2.4 On the principle of Response-ability: Co-designing with vulnerable participants in fragile spaces.

Advancements in BBD techniques such as 'personalisation' and algorithmic profiling, make it easy for people to be treated 'not as persons but as mere temporary aggregates of data processed at an industrial scale' (EDPS, 2018). Hence, the need for revisiting and revitalising the principle of dignity is even more important. Looking for the lost vulnerable data subject in the complex obscure big data system, was a way to respond to the dignity call. The experience of co-designing ethics with people that are feeling unwell and whose health is deteriorating quickly, make of the space of affections that co-design opens, a very fragile one, that call for care, for care informing research practices and care informing relationships.

We are joining the sortilege of Haraways's neologism *response-ability* (1997, p.71). We propose a process of technology innovation fuelled by ethics, dependent upon trust that emerges and exercises within the fragility of creative encounters. It is simultaneously about staying responsible with the co-design process, loyal to its subjects and matters, and about taking care of one's abilities to respond to it.

5 Ethics through Design: A mode of conclusion

Technological Innovation methodologies, including medical and care technologies, move violently away from the perspective of the subject and towards relying on data analytics that tend to conceal the social to highlight patterns (Kitchin, 2014). They are assumed to yield new forms of knowledge embedded in data understood as synonymous with knowledge. However, data, more than patterns, are practices situated in organisational, political and fragile contexts.

EtD departs from the premise of co-design processes as a site of emergence (Luján Escalante, 2019), that build generative spaces, not just of designs or prototypes but of relations and values; ethical values. EtD builds on the idea of contextual and participatory ethics, more than theorising, it requires *doing* ethics together in the context of data practices. It moves away from the idea of ethics as a barrier to innovation, towards an understanding of ethics as highly contested, on-going processes that offer creative opportunities for responsible innovation. EtD reconceptualises ethical impact assessments, going beyond the legality or morality, (that are not necessarily ethical). It is building capacities for anticipating, noticing and addressing ethical tensions through co-creative methods to facilitate high quality IT research and innovation that that goes beyond box ticking. EtD does not just reconceptualise ethics but also design methods by asking questions like; what sort of things, tools, processes do we use to meaningfully collaborate with participants in ethical processes? How do these methods constrain, frame and generate certain ethical practices and not others?

EtD is engaging different stakeholders in the medical data interoperability systems, allowing SODA to explore the spaces and knowledges emerging from thinking together, realising and making real, medical data in the wider ecology of the social and material worlds of practicing wellbeing. SODA designed and re-purposed new and existing co-design tools and activities that facilitated the co-design process informed by the specificities of SODA contexts and participants, and allowed us to develop a deeper understanding of data subjects' perceptions of their own data sharing and how it influences their wellbeing.

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