Contextuality and Intersectionality of E-Consent: A Human-centric Reflection on Digital Consenting in the Emerging Genetic Data Markets

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Abstract—Consent plays an essential role in different digital regulations, such as the European General Data Protection Regulation (GDPR). As a result, obtaining consent from data subjects (e.g. end-users or end-customers) are widely practised by many data controllers (e.g. service providers, companies, or organisations). Considering the importance and the widespread practice of consent-obtaining in different domains, critical and interdisciplinary studies of the current consent-obtaining mechanisms are highly needed. In this paper, we first shortly discuss an interdisciplinary human-centric perspective to consenting and propose that, among others, the contextuality of consent, as well as the potential intersectionality of consent, should be carefully considered in the development of consent-obtaining mechanisms. Then we elaborate on the distinction between "consent to personal data processing for commercial purposes" and "consent to personal data donations intended for research" in the field of *direct-to-consumer genetic testing* (DTC-GT). We show that based on our human-centric perspective, the contextuality and intersectionality of consent are sometimes overlooked in the current DTC-GT services, which are of considerable significance in the emerging genetic data markets. We hope that this paper can contribute towards the development of human-centric, accountable, lawful, and ethical (HALE) socio-technical information systems dealing with consent and privacy management as fundamental building blocks of a sustainable digital economy.

Index Terms—Digital Consenting, E-consent, Contextuality, Intersectionality, Data Protection, Privacy, Human-centricity, Accountability, Lawfulness, Sustainability

I. INTRODUCTION

Personal data is one of the drivers of the digital economy. With the advancement of digital technologies, more personal data are produced, collected, and used. This can potentially cause deep concerns regarding the invasion of *right to privacy*. As a result, data protection regulations such as the European General Data Protection Regulation (GDPR) aim to provide frameworks to protect individuals' personal data and privacy. According to various data protection frameworks, end-users'

consent is one of the bases for a lawful practice of personal data processing. However, obtaining human-centric, accountable, lawful, and ethical (HALE) [1] consents is not always easy. Moreover, many companies might not be willing to implement such HALE mechanisms due to their conflict of interest or business model.

Arguably, one of the businesses that need such HALE systems is direct-to-consumer genetic testing (DTC-GT), which involves collecting and processing very sensitive personal data, i.e. genetic data. In recent years, the commercial market for DTC-GT has been rapidly growing. In the past decade, mainly American companies such as 23andme, Ancestry, MyHeritage or FamilyTreeDNA have collected vast amounts of genetic data in proprietary databases. These companies specialize in providing a combination of health reports about potential genetic risks, carrier status, and traits, as well as genealogical family studies [2]. As a result of the strikingly cheap offers, an estimate of 17 million people have had their DNA sequenced worldwide by the end of 2018 [3]. Using this *big data*, companies can already refer to novel findings of genetic associations and traits [4].

Despite their potential benefits, the business models of some DTC-GT companies have caused considerable concerns regarding their end-customers' privacy. It seems that their business models do not rely on profit from the services they provide for their individual end-customers but on monetizing the collected genetic data through reselling them to other companies. Accordingly, the reuse of the collected sensitive data for commercial research is at the heart of an interdisciplinary controversy: considering that about 80 percent of the end-customers consent to reuse of their data for *[scientific] research* [5], there is a significant disagreement if the given/obtained consent is also valid for *commercial* research purposes [2]. Developing an interdisciplinary understanding of

consent and consenting (i.e. the action of consent-giving) is an essential step towards resolving such disagreements. Therefore, the aim of this paper is to reflect on the contextuality and intersectionality of consent and consenting from a human-centric perspective. We investigate the emergence of genetic data markets as an example of socio-technical information systems that collect, process and reuse sensitive personal data. We argue that to make these systems more human-centric, accountable, lawful, and ethical, the contextuality and intersectionality of digital consenting should be considered.

II. PERSONAL DATA PROCESSING UNDER THE GDPR: A SHORT BACKGROUND

According to the European General Data Protection Regulation (GDPR), "the protection of natural persons in relation to the processing of personal data is a fundamental right" (GDPR 2016, Recital 1) and "everyone has the right to the protection of personal data concerning him or her" (GDPR 2016, Recital 1). In order to achieve this objective, consent is considered by the European GDPR as one of the bases of lawful processing of personal data, among others [6], [7]. Although the GDPR aims to protect everyone's right to privacy and restricts the processing of personal data, the GDPR allows processing of personal data, among others, for "scientific or historical research purposes" (GDPR 2016, Article 9). This research exemption allows data controllers (including companies) to store sensitive personal data indefinitely and exempts them from the obligation to inform individuals when processing their personal data (such as their genetic data) [7].

III. HUMAN-CENTRIC PERSPECTIVE ON CONSENTING

Based on an interdisciplinary literature and inspired by the enactivist [8] perspective to human cognition, Human and Cech [6] proposed a human-centric perspective on digital consenting. According to this view, consenting should be considered a socio-cognitive action in which cognitive, collective, and contextual aspects are in continuous interaction and co-construct the action of consenting (Figure 1). As it is discussed in [6], all three dimensions of consenting are widely ignored (or even misused) in the current data controller-centric practice of consent-obtaining.

Contextual aspects, i.e. the contextually of consenting and consent, is one of the fundamental aspects of this human-centric framework. The context can refer to different dimensions such as time, location, situation, intention, and purpose. In this paper, we reflect on this aspect based on the case of the emerging genetic data markets. We will later discuss that considering the contextually of consent (and consequently the intersectionality of consent) can contribute towards the development of more human-centric, accountable, lawful, and ethical (HALE) personal data and consent management frameworks and mechanisms.

IV. THE CASE OF DTC-GT AND GENETIC DATA MARKETS

In order to enable the control over one's personal data, the GDPR grants everyone the "right to erasure ('right to be forgotten')" (GDPR 2016, Article 17) on the basis of the posterior withdrawal of consent, e.g. "where there is no other legal ground for the processing" (GDPR 2016, Article 17). It is argued that the research exemption included in GDPR renders the right to be forgotten in the case of DTC-GT basically impractical [7]: after consenting to the reuse of the data for research purposes, [anonymized?] genetic data seems to be lost in large proprietary databases. This is especially problematic since DTC-GT companies cannot always fulfil their promise of anonymization in the context of genetic research [9], [10] but base the legitimacy of their research activities on the claim to anonymized data [4]. Besides the serious concerns regarding data subjects' lack of awareness about the actual consequences of personal data collection (and its processing or reuse) when consent is obtained [11], it can be argued that DTC-GT companies create markets for genetic data by ignoring the contextuality of consenting to donation for (medical) research and the diverging privacy expectations citizens have within that context [2]:

The rise of DTC-GT companies can be studied in a larger context of personal data monetization [2]. Zuboff [12] argues that Google was the first to realize how to treat behavioural user data collected from their website (and later across different websites and services) as a genuine resource or raw-material. Eventually, this led to the development of new marketplaces, where companies trade prediction products or, to put it bluntly, the privileged influence on user behaviour [12]. One of the assumed normative basis upon which these kinds of markets rest are the aggregated instances of consent to the processing of personal data per se.

That DTC-GT business models work analogously is not only obvious from the published statements of their employees [13] but can be inferred by the low prices as well as questionable distribution of free test kits in African countries [14]. Google perceives behavioural data as an economic commodity. Similarly, some DTC-GT companies perceive sensitive personal data (in this case, genetic data) as their commodity [7]. In this respect, it seems that it would be a mistake to argue that all consented individuals are willing to giving their data for commercial research purposes. Rather, it is more natural to interpret the consent to (medical) research as a form of data donation which resides outside the actual market interaction of buying the test kit and receiving the reports. In the first case, data subjects consent (and in fact pay) for the processing of the personal data to receive health or ancestry reports. In the second case, data subjects consent to using their sensitive
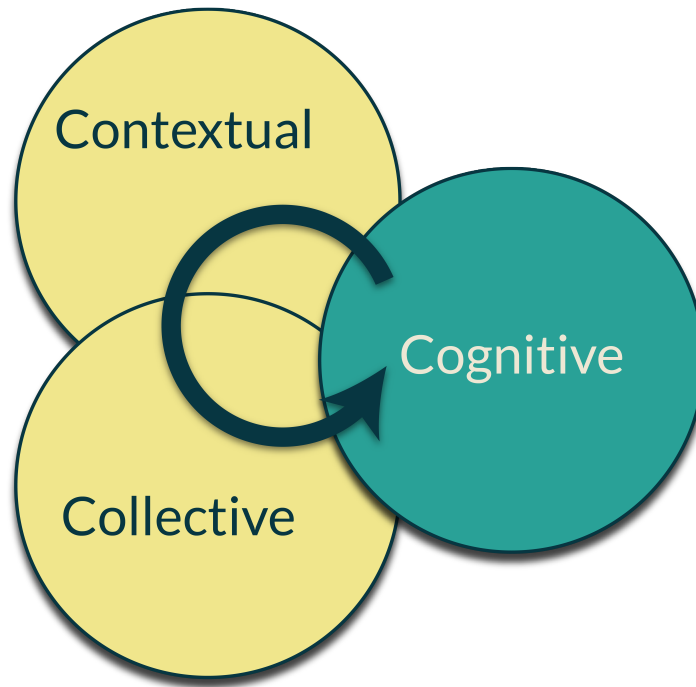
Fig. 1. Simple visualization of sociocognitive dimensions of *consenting* [6]; The social dimensions are coloured in *Khaki*.

data, not for commercial profit but socially beneficial practices. Changing the perspective and considering the *contextuality* of given consents make it apparent that some DTC-GT companies perceive end-customers themselves are the object of the trade from the outset: it seems that ancestry and health reports are just excuses for extracting the raw material at low or even zero cost as a form of dispossession for subsequent corporate profit [2].

V. THE IMPORTANCE OF CONTEXTUALITY FOR GENETIC PERSONAL DATA REUSE

To dismantle the problems of such a logic of sensitive data accumulation, we should pay close attention to the several steps within the above-described business practices. Firstly, it has to be noted that people do not sign up for medical research in the first place but are initially motivated to know more about their family history or future health prospects. Nevertheless, since most people take medical research to be socially beneficial, it is understandable why a large majority consents to the reuse of their personal data during the process (if we assume that the obtained consent is truly *informed* and not obtained using *dark patterns* [6] or other similar mechanisms). In this respect, it is crucial to realize that data donation is a non-market transaction on top of a commercial purchase. That, in turn, implies deviating data protection expectations based on the different contexts, one of commercial transactions and another of donation for medical research, in the case of DTC-GT. Arguably the latter relies on additional social values such

as confidentiality, benefaction and trustworthiness, which have to be taken into account [12]. Consequently, it is the mixing of a market and non-market medical *research* context which can be problematic and needs closer attention [2].

VI. INTERSECTIONALITY OF CONSENT AND HALE PERSONAL DATA PROTECTION AND CONSENT MANAGEMENT

We argued that *consenting* is a contextual action and *consent* is a contextual phenomenon. Since consent can be given or interpreted in relation to multiple contexts by different involved actors, as it is visualised in Figure 2 using the example of genetic data markets, the conflicting interpretations of consent on the intersection of different contexts (e.g. time, location, situation, intention, and purpose) can cause the serious concerns that were discussed in the previous sections. Considering this, inspired by the literature on the intersectionality of social phenomena [15], [16], we argue that the intersectionality of consent should be well considered in the development of human-centric, accountable, lawful, and ethical (HALE) data protection and consent obtaining mechanisms. However, a few challenges need further investigation in future. Among others: 1) considering that the context (e.g. the purpose of research projects) can change over time, how would consent be re-obtained? Development of *dynamic consent* [17], [18] frameworks can be one solution to this problem. 2) Foreseeing all use cases (e.g. contexts) is a difficult task; how would the potential conflicts between obtaining *broad consent* and
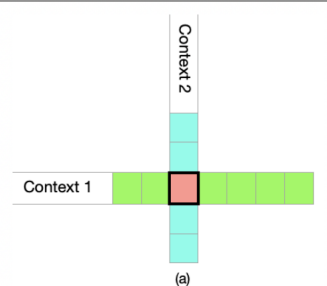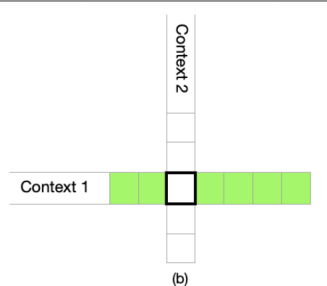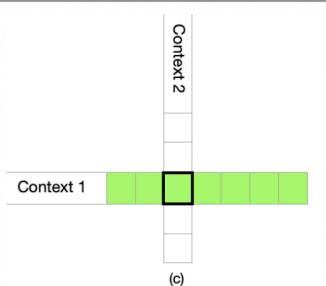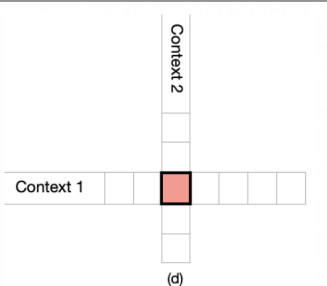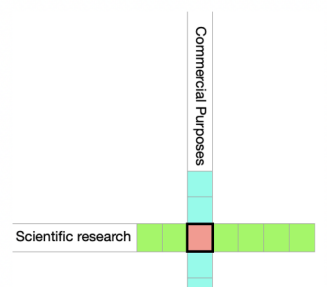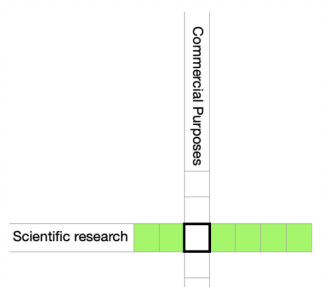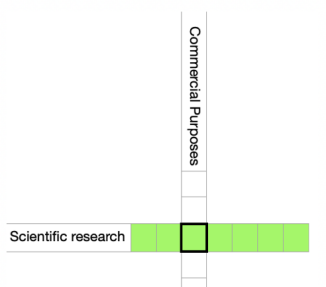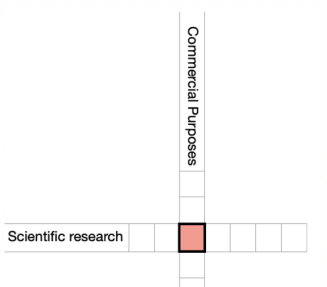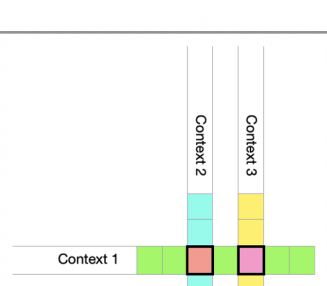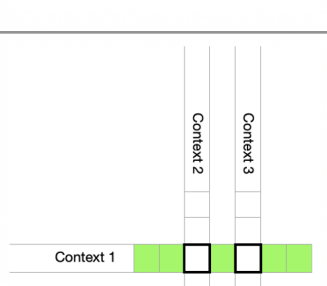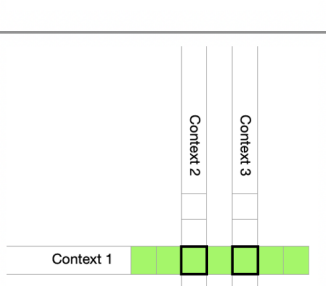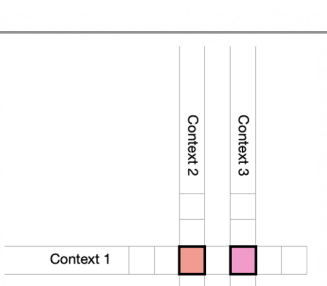
Fig. 2. Simplified visualization of the intersectionality of consent

specific consent be resolved? 3) How could the challenges of transparency and understandability of consent-obtaining mechanisms be tackled if multiple intersecting contexts are involved?

Here, based on our previous works, we provide a set of complementary suggestions for the realization of Human-centric, Accountable, Lawful and Ethical (HALE) [1] personal data protection and consent management frameworks:

- *End-user empowering socio-technical information systems* [19] that function based on human needs and values [20], [21] and consider human-centric [6], [22] aspects of personal data protection and *consenting* should be developed.
- The widely ignored (or even misused) aspects of personal data protection and *consenting*–i.e. *cognitive*, *collective*,

and *contextual* aspects [6]–should be considered in the development of personal data protection and consenting management frameworks.

- Development of Human-centric Personal Data Protection and Consenting Assistant Systems (PDPCAS) [23] can be considered an essential step towards empowering end-users to manage their personal data and consents.
- Novel mechanisms for the automated communications of data protection and consent related data between data subjects, data controllers, and data processors are needed. Specifications such as the Advanced Data Protection Control (ADPC) can fill this gap [24].

VII. CONCLUSION

In this paper, we critically engaged with the field of direct-to-consumer genetic testing (DTC-GT) in order to explain the

particular need for interdisciplinary understandings of consent and data protection management, including their contextuality and intersectionality, in particular in business sectors dealing with sensitive personal data processing. We pointed towards the emergence of genetic data markets and the prevailing breach of the contextuality of the obtained consent during data accumulation and reuse processes. We additionally approached the current research exemption under the European GDPR. This study reminds us that personal data protection is multidimensional: human-centric, accountable, lawful, and ethical (HALE) personal data protection and consent-obtaining frameworks and mechanisms should be co-created by considering different interdisciplinary cognitive, ethical, legal, technical, societal, and economic perspectives. This might seem complicated, but it is a requirement for the realization of a *sustainable digital economy*.

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