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# Problematising Medical Data in Humanitarian Response

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## Abstract

This paper assesses the influence of the humanitarian innovation agenda on the aid sector, particularly medical humanitarian actors' increasing reliance on digital technologies. Pressure to innovate arises from the belief that technological advancements can save lives, leading to the exploration of new technologies in humanitarian contexts. However, the rapid, often uncritical, adoption of new technologies and data practices has raised ethical, political and institutional concerns. To this end, the paper surveys key debates and ethical challenges arising from the deployment of biometric and medical data technologies in humanitarian and disaster settings. To achieve this aim, it gathers issues into three major categories of enquiry: governance, power and control; justice and equity; and trust. These categories assist in conceptualising the moral and ethical tensions between technologies, data and actors in humanitarian spaces. The ongoing deployment of biometric and medical data technologies in humanitarian and disaster contexts raises significant ethical challenges that can only be addressed by practitioners and researchers together. The paper concludes with a call to jointly assess the broader implications of medical data innovations in humanitarianism, emphasising the need for further research and collaboration among different disciplines.

**Keywords:** medical data; humanitarian data; data studies; humanitarian biometrics

## Introduction

For over a decade, the aid sector has been in the thrall of the humanitarian innovation agenda (Currion, 2019). Burgeoning digital technologies – driven by twin forces of technological change and the marketplace – have created a sense of urgency and inevitability around the very idea of innovation (Jacobsen *et al.*, 2017; Sandvik, 2014; Scott-Smith, 2015). It is now axiomatic that 'every new emergency seems to trigger some new innovation' (PLoS, 2012: 1). The pressure to innovate emerges partly from operational necessity, for example, the need to accommodate for the obsolescence of old technologies and integrate new ones or the need to engage with host and donor communities in the same digital spaces they inhabit. But it is also a product of the widely promulgated (and largely untestable) assumption that technological innovation itself saves lives (Scott *et al.*, 2021; Redfield, 2012).

The assumption makes innovation itself a virtue. If innovation saves lives, it is almost a humanitarian duty to take advantage of everything and anything that is available – while simultaneously maintaining or improving standards of performance, safety and ethics. Thus,

there are those who argue that a clever, conscientious application of technology will ameliorate, if not eliminate, pervasive hierarchies of inequality in humanitarian action (Meier, 2015; Casey-Maslen, 2018). This pressure to innovate as a virtuous necessity has led to some humanitarian contexts becoming experimental laboratories for international organisations as they deploy data mapping, collation, or analysis software (Sandvik et al., 2017; Givoni, 2016).

Debates about contemporary digital transformation in the humanitarian sector have exposed potential ethical, political and institutional implications of uncritical, impatient adoption of technology and big data in humanitarian settings (e.g. Duffield, 2016). What is more apparent is that innovation by itself cannot save life. Innovation only makes a qualitative impact on well-being when attendant, routine structures and practices such as administration, maintenance, funding and oversight make new technologies safe, scalable and sustainable (Campo, 2021; Scott et al., 2021).

It is worth noting that innovation is not a new practice for humanitarians. The idea of humanitarian action itself was an innovation in moral conscience and social organisation (Fassin, 2012), while technological innovation in humanitarian action is just as storied. Mobile searchlights, for example, began as Red Cross 'electric locomobiles' intended to recover the wounded from late-nineteenth-century battlefields (Hutchinson, 1989: 338). If anything is new about the present, it is the scale, speed and rippling consequences of transformation – which often run far ahead of practitioners' abilities to structure, administer and consolidate developments, and to account for the attendant ethical issues that accompany these technologies.

Nowhere are these problematic dynamics so acute and potentially impactful as in the realm of medical data. Medical data are, by their nature, among the most intimate and sensitive of data. Subject to various layers of legal regimes globally, they can nevertheless be amorphous and hard to define. They may include personal information about patients, details about treatments or facilities, or unrelated data that could be linked to medical conditions. The simple fact of their existence can be controversial, while the very act of 'processing may create significant risks for a person's fundamental rights and freedoms' (Gazi, 2020). While widely practised, patient consent can take the form of a routinised ritual; the actual role and volition of patients in data gathering and processing has been under-analysed in humanitarian contexts. In this setting, the slogan – 'no innovation without representation' (Winner, 1992: 291) – becomes particularly relevant,

and suggests an alternative formulation: no data collection without representation. Thus, the intersection between medical data and their use in humanitarian response is especially important to analyse.

This review summarises key debates and ethical challenges that emerge from academic and practitioner scholarship on the deployment of biometric and medical data technologies into humanitarian and disaster contexts. Such a broad scope of issues can only be treated in summary; the paper does not aim to provide technical analysis or propose solutions to the dilemmas highlighted herein. Rather, it aims to articulate a series of questions to help inform future-focused research agendas. In some cases, it treats recent adaptations and discourses within the humanitarian field. In others, it highlights developments in related fields; these may yet have to reach humanitarian settings – but they are imminent. By zeroing on the criticisms and ethical complications of technological and medical data innovations in humanitarianism, this article illuminates the vibrant multidisciplinary interest in medical data studies and exposes shared conclusions (and potential collaborations) among these different approaches, disciplines and schools of thought.[1]

In assessing existing debates, we distilled key issues into three major categories of enquiry, related to governance, power and control; justice and equity; and trust. Each category highlights a key moral, ethical, practical or philosophical tension between technologies, the data they produce, and actors in humanitarian spaces. These divisions are admittedly arbitrary, yet they capture a range of thematic tensions. Issues often overlap – almost all debates around medical data innovations in humanitarian settings can fall into more than one of these categories. But to make issues amenable to analysis some form of compartmentalisation is needed. Thus, these three categories are conceptual aides that draw attention to overarching dynamics shared by otherwise disparate technical issues. In providing this framework, we signpost these issues for both practitioners and researchers, articulating overarching themes to assess how apparent minutiae of hardware, software, data processes and their human corollaries also function as forces at the historical and civilisational level.

## Governance, Power and Control

The first series of debates relates to issues of governance, power and control within the humanitarian sector. It highlights how questions about civil liberties, rights and personal security have become increasingly central in

discourses about the use of medical data in humanitarian settings.

## Deployment in Crisis Contexts

A current concern regarding the crisis narrative in humanitarian response is that it can justify uncritical deployment of biometric and medical data technologies. This can endanger data subjects, as well at the humanitarian organisations in possession of their data. The potential to prolong the power imbalances inherent in humanitarian action deserve attention, as do the potential ethical and authoritarian aspects of technology.

Gross discrepancies in power characterise humanitarian action, almost by definition. Such imbalances are ripe for abuse. Powerful actors have historically used humanitarian action for experiments in societal control and authoritarian practice (Barkawi, 2013). Deployment of experimental technology in humanitarian contexts enables these technologies to be piloted among presumably compliant populations – people struggling for basic life necessities are assumed less likely to insist on fundamental rights – and where the policy or regulatory frameworks may not be as developed. Consequently, proprietors learn how to streamline and market these innovations in their home societies (Sandvik et al., 2017; Jacobsen, 2015).

In such crisis environments, actors and technologies are perceived as 'cleansed' through their 'gift' to humanitarian actors and people in need (Mauss, 1990 [1925]). This process effectively legitimises the deployment of the technology. Emergency makes for a state of exception and justifies what would otherwise be problematic (Fassin, 2012).

This phenomenon is not unique to humanitarian settings, though humanitarian settings may represent a preeminent example of this practice. As Hosein and Nyst note,

> Emerging economies and developing nations across Africa, Asia and Latin America are seeing the rapid deployment of technologies that many more developed countries are hesitant to use, such as national identity registries using biometric technologies, and e-health systems with national registries of sensitive personal information, in the absence of legal safeguards and, indeed, critical analysis. (2013: 7)

Whether or not these technologies are deployed in a state of exception, they hold the high-modernist promise of enforcing legibility, in the classic sense, upon chaotic masses (Scott, 1999). In such cases, it is possible to argue that the promised social or administrative benefit of these technologies outweighs the risk, particularly if technology is portrayed as a 'silver bullet' for problems in the sector (Raftree and Nkie, 2011: 46).

Certainly, crisis rationales provided justification for the shift towards biometric identity technologies in the early 2000s. This shift was part of a broader global securitisation of the post-9/11 era and the evolution of an 'epoch of exceptionalism' whereby, for example, migrants from the Global South faced demands to provide biometric data in order to be granted an official (but othering) identity and access essential services like healthcare (Muller, 2004; Cheesman, 2020). Studies through a Foucauldian lens revealed the authoritarian relationships inherent in these technological innovations, in which certain groups of people, and certain bodies, became the target of attention (Jacobsen, 2015; Scott-Smith, 2015; Redfield, 2012).

Similarly, during the 2015 European refugee crisis, the political invocation of 'crisis' and crisis narratives around migration both demanded and permitted radical measures (Jeandesboz and Pallister-Wilkins, 2016). This 'fueled demands for new ways of tracking, mapping and predicting human mobility' (Taylor and Meissner, 2020). Attention to the potential for authoritarian policing, tracking and surveillance – not just of migrant but also of domestic and foreign populations – and the attendant legal and human rights implications, is increasing (Kak, 2020; Lodinová, 2016; Deibert, 2013; Marino, 2021). In a crisis of a different sort, COVID-19 ignited debate over digital tracking in Europe and beyond. Notably, the UK's National Health Service (NHS) COVID-19 contract-tracing app and resulting parliamentary bills, ignited this debate in the UK (Clarke, 2020), whereas human rights groups highlighted privacy vulnerabilities in Bahrain, Kuwait and Norway contact tracing apps (Amnesty International, 2020).

The uncritical deployment of technologies is particularly concerning in contexts that lack legally enforceable safeguards, as is often the case in medical humanitarian contexts (Hosein and Nyst, 2013; Sandvik, 2020a, 2020b). The development of new technologies often outpaces the corresponding development of national and international legal and regulatory frameworks designed to protect users. This may exacerbate the vulnerabilities of those affected by crisis (Hayes, 2009; Coppi and Fast, 2019). This is especially true for biomedical research and data sharing across international borders or among international organisations (Kaye et al., 2018). This is also particularly relevant given the highly sensitive nature of medical data in humanitarian settings and other politically volatile contexts, where data can be instrumentalised. The choice of what data needs to be collected, with how to safeguard use, storage and sharing is simultaneously a complex ethical, technical and operational problem (OCHA, 2019; ICRC, 2020). It is further complicated by (at times overlapping) global legal

privacy regimes (for example, the European Union's General Data Protection Regulation [GDPR]) which come into play as information is collected, stored or transmitted across multiple national borders (Gazi, 2020).

## Data and Colonialism

Another area of discussion relates to data ownership. Technology interests often present a utopic vision of the future, thus obscuring the capitalist, asymmetric power dynamics at the centre of what Thatcher *et al.* have termed 'data colonialism' (2016). As they explain, it is a form of 'capitalist accumulation by dispossession' whereby personal aspects of our lives are collected, depersonalised and monetised. Thatcher *et al.* point to the example of End-User License Agreements as a means of privatising user data harvested through smartphone apps and other ubiquitous technologies. In the humanitarian space, these obscuring dynamics appear in discussions about, for example, refugee movements and 'good drones'; they raise questions of who owns (and who has the right to gather or use) personal and geospatial knowledge (Greenwood, 2021; Madianou, 2019; Sandvik *et al.*, 2015; Meier, 2016).

In a comparable manner, digital health devices can blur public and private interests (Collier *et al.*, 2017) – raising questions of workability and who exactly is helped by the invention of 'little development devices' and humanitarian gadgets. The use of identity biometrics, such as fingerprinting, iris scans and facial recognition, has already expanded within humanitarian contexts (Polk, 2020; Jacobsen, 2015). While biometrics are currently employed for identity verification at point-of-service locations, this humanitarian data harvesting has already expanded into the realm of humanitarian wearables (Sandvik, 2020a). Wearing a symbol of humanitarian aid – granting access to medical care, registration and food – could lead to a shift in how recipients are perceived by the humanitarian industry: from people to data producers, and data subjects. As Sandvik has noted, 'With the rise of wearables … we recognize the central premise of the global data economy: that beneficiary data is the product, not the tracking device, and that human bodies become data-producing units – aid beneficiaries become data subjects' (Sandvik, 2020b). Commercial firms such as PricewaterhouseCoopers (PwC) are increasingly involved in digital health innovations and in humanitarian crises, seeing opportunities for expansion and experimentation in the field (PwC, 2017). This simultaneously layers profitability into the already complex ethical calculus of humanitarian data technologies.

As Sandvik notes, while there is a literature on humanitarian goods and reciprocity in humanitarian settings, the 'gift' of data in humanitarian settings has not permeated these analyses (Sandvik, 2020b). Those who are provided the 'gift' of medicine or service provision via a corporate humanitarian gadget complete the cycle of reciprocity by providing their own data in return. Similarly, while there is an established literature on patient perceptions of medical data management in the global healthcare sector (Shen *et al.*, 2019), this literature emerges predominantly from high-income, high-technology settings. Our survey did not reveal a literature on patient privacy perspectives in humanitarian settings, an absence that calls out for empirical enquiry.

## Cyberattacks

Emerging paradigms of electronic warfare and criminality are another manifestation of power with significant implications for humanitarian actors. Hardware and software are vulnerable to leaks and cyberattacks (Parker, 2020), while personal security is linked to privacy concerns, since humanitarian data can be valuable to state agencies (Rahman, 2021; Eckenwiler and Hunt, 2014).

Humanitarian agencies are every bit as vulnerable as other actors (and conceivably more vulnerable in certain settings) to data security breaches. Denial of service attacks, cyberattacks on infrastructure and ransomware demands are increasingly common factors in conflict settings, while criminal actors are active globally. For example, malware targeted vulnerabilities in national hospital databases of the NHS in 2017 (National Audit Office, 2018).

International humanitarian law affords humanitarians and civilians only limited protections against these attacks (Buchanan and Tsagourias 2022; Rodenhäuser, 2020). As the International Committee of the Red Cross (ICRC) noted in 2015, 'the obligation to respect and protect medical facilities must be understood as extending to medical data belonging to those facilities'. However, swathes of personal data fall into a grey area that may 'not benefit from such specific protection, such as social security data, tax records, bank accounts, companies' client files or election lists' (ICRC, 2015: 43). Similarly, the UN Office for the Coordination of Humanitarian Affairs (OCHA) has noted that, 'while personal data can categorically be considered sensitive, more nuanced issues arise for non-personal data. For example, locations of medical facilities in conflict settings can expose patients and staff to risk, even if this data is not personal' (OCHA, 2019: 7).

Overall, debates related to governance, power and control raise key questions: to what extent does the use of biometric and medical data technologies in humanitarian settings support a global tilt towards

authoritarianism? Can these technologies become 'late-modern mechanisms of social exclusion' and control (Aas, 2006)? How can the ethics of innovation relate to humanitarian principles and 'do no harm' medical doctrine? These questions hold implications for communities outside of the immediate sphere of humanitarian intervention, both as recipients of a technology of questionable origins and through 'the commodification of good intentions' (Korf et al., 2009; Sandvik et al., 2017; Hosein and Nyst, 2013).

## Justice and Equity

Another area of debates relates to justice and equity. Technology is not neutral. All technologies, including data systems, are inherently political, rather than passive 'technical artefacts' (Winner, 1980; Heeks et al., 2019: 16). In some circumstances, technology and digitisation can serve to magnify asymmetries and undermine rather than improve accountability and transparency (Madianou et al., 2016; Martin and Taylor, 2020).

All technologies have a maker and a maintainer; humans – with all their attendant biases, cultural assumptions and unequal power dynamics – are ultimately the ones who extract and process data. Even (or especially) when data are mediated by algorithm, or so-called artificial intelligence, bias enters in through the programmer, the dataset, the user or some unanticipated interaction between them (Parada et al., 2023; Owens and Walker, 2020; Zou and Schiebinger, 2018).

Thus, technology and data can be influenced by, replicate and even reinforce existing human and health inequalities (Moran, 2021; Raza, 2022). Few, if any, legal safeguards exist on surveillance technologies within development and humanitarian contexts, posing serious risks to individual human rights and privacy (Hosein and Nyst, 2013; ICRC, 2020). Hierarchies of healthcare – mediated by geography, economic status, gender, race, class, sexual orientation and a multitude of other factors – have been well documented by doctors and academics alike (Iwai et al., 2020; Khan et al., 2022). A 'digital divide' exists in geographic and humanitarian contexts, contributing to further visible inequality along gender, racial, class or other lines (Bryant, 2019; Dodson et al., 2013; Bryant et al., 2020; Bryant, 2022). Power dynamics are exacerbated in settings where deep inequalities already pervade international aid and relief distribution, revealing multiple tensions between the humanitarian and the recipient, the Global North and Global South, doctor and patient, benefactor and beneficiary, agent and migrant as technology increasingly becomes a tool of control in humanitarian

settings (Jacobsen, 2015; Latonero and Kift, 2018). Religious or cultural objections to biometric data could exclude communities from access to identity cards and documentation, further compounding asymmetric power dynamics within the humanitarian/disaster context (Lodinová, 2016).

These dynamics raise questions around justice and equity that deserve reflection in advance of any deployment of data technologies in humanitarian settings. These might include: who is the service or software designed to satisfy? How can it be subverted, weaponised or otherwise used to cause harm? Who is ignored, missed or misrepresented by the data?

'Gifted' technology also raises questions of maintenance, obsolescence and sustainability. Proprietary software, hardware turnover and planned obsolescence are fundamental to the technology sector business model. This places the financial burden of updates, maintenance and specialist support on the consumer – in this case the humanitarian agency or their host population. Products no longer profitable may be discontinued, regardless of who might be reliant upon them. Similar issues are at play in the maintenance and upkeep of websites – as links become broken and information outdated – a phenomenon that Benton (2019) has termed 'digital litter'. In a related vein, Fast and Waugaman (2017) have examined practical issues related to online and offline functionality, leading to the redundant use of paper to supplement electronic systems, and the implications for data quality and usability. Humanitarian practice thus becomes beholden to the constancy of software, vulnerable to political or unintentional failures, bugs or flaws in updates, as well as the redundancy inherent in technological progress.

Medical data and biometric technologies raise additional issues of justice and equity, particularly in relation to the ethics of consent. Data sharing may fail to take adequate account of consent, creating breaches of trust, privacy and informed consent, and may be used for purposes outside of those originally identified (Hosein and Martin, 2010: 16). Those producing or providing data may not realise they are generating useful and valuable data/information (PLoS, 2012; Lawlor and Stone, 2001).

During humanitarian crises and environmental disasters, it is common for people to lose their personal documentation, paperwork and identity cards. The use of biometric data for identity cards or records has been promoted as a 'lifesaver' for migrants who require ID to access services and provisions by international organisations (Polk, 2020; Burt, 2019; Raftree and Steinacker, 2019). However, the extraction of biometric information

for identity processes, collected by NGOs, can also cause harm. Migrants in interviews have revealed how they have given access to identity data or personal technology (such as smartphones or laptops) in exchange for resources, without meaningful consent or understanding of how NGOs or agencies will use their data (Latonero *et al.*, 2019; Bellanova *et al.*, 2016). Recorded medical data then *becomes* the person's identity, placing a significant burden on the bureaucratic structures, data storage and personnel on the ground, with severe implications for human error on the refugee/migrant. Participation in assistance programmes may be contingent upon providing biometrics, without full awareness of what this means. These programmes are often implemented within the context of public–private partnerships (Latonero *et al.*, 2019; Jacobsen, 2015). Concerns about representations and images of aid recipients is not new to humanitarianism scholarship (de Laat and Gorin, 2016); however, discussions about medical data and technology have prompted further critiques about how these existing vulnerabilities might be amplified by consent and privacy concerns (Macias, 2019).

## Trust

Humanitarian organisations rely upon trust as core to their acceptance and security (Fast *et al.*, 2014). It is also the foundation of the medical act. Trust is likewise central to ensuring safe and secure data collection by actors in the field since this affects what and how much data people may be willing to share (HHI, 2011: 38).

Technological mediation of the humanitarian encounter is in step with other responses to the increasing insecurity of aid work, such as humanitarian subcontracting and the 'bunkerisation' of the aid compound (Duffield, 2010). This move from 'face-to-face interactions to face-to-screen' (Hunt *et al.*, 2016; Donini and Maxwell, 2013) represents a shift away from the humanitarian tenet of proximity – the person-to-person gesture that is meant to be at the heart of the humanitarian act (Healy *et al.*, 2019; Fast, 2017; Duffield, 2019). Those who live in humanitarian environments already make decisions, deviations and construct networks in response to their understanding of these dilemmas and implications of medical data on the ground. Such adaptations are rarely satisfactory. For instance, the World Food Programme ceased food deliveries in Yemen's capital city after Houthis refused to allow the registration of recipients' details for an anti-fraud database (Parker and Slemrod, 2019; Raftree and Steinacker, 2019).

This dilemma – the move away from proximity and the familiarity and trust it is supposed to engender – happens alongside a burgeoning ecosystem of misinformation and disinformation as weapons of war and tools of diplomacy (van Solinge and Marelli, 2021).

There are negative implications for the principle of neutrality if data collection, processing or analysis is undertaken externally to the humanitarian organisation (ICRC, 2020). Yet humanitarian organisations – as part of the global information technology infrastructure – overwhelmingly rely upon major third-party service providers to house data, provide IT infrastructure and, increasingly, with the advent of workable AI, process and analyse that data. Humanitarian actors are thus intertwined with a capitalist industrial complex that is far from neutral in the eyes of many patients and host communities.

Unsafe data sharing, particularly in situations of armed conflict, can compromise the safety of 'data subjects' (ICRC, 2020) and poses new questions around access (Jacobsen and Fast, 2019; Fast, 2022). Should aid agencies transmit data to third parties with weak protection standards, differing motivations or imposed legal obligations, it could expose patients and other vulnerable categories of people to security risks both within the immediate humanitarian context and in their future life outside of crisis (Nonnecke, 2017; GPPi, 2021; Fast, 2022; Diepeveen and Bryant, 2022). Interoperability can also enable 'function creep' whereby information is used for purposes beyond the original intent (Soliman, 2016; Hosein and Nyst, 2013: 7; Taylor *et al.*, 2016).

In large-scale crises, the vast amounts of data generated – and the new technologies often imported or invented to deal with it – can cause confusion. As digital mapping and tracing increasingly become 'tools of the trade' for emergency response, reams of data are amassed by agencies during humanitarian crises (Altay and Labonte, 2014). Troves of data can 'paralyse' a humanitarian organisation as much as inform it, through volume and sheer complexity (Meier, 2015).

Interoperability of data is also a factor in large-scale interventions, since datasets gathered by different agencies on different platforms cannot always be made to cohere. New hardware or software may be intended to address these issues, but will often initially slow processes in the field, as implementation brings unforeseen issues 'such as insufficient battery charge, printer malfunction and basic unfamiliarity with the system' (Jafar, 2020: 47). New software can stymie workers, while uncertainty over the reliability of crowd-sourced data can slow response (Deibert and Scott-Railton, 2016: 327). Instead, adaptations of existing technology may be more

effective in crisis contexts (Fast and Waugaman, 2016; HHI, 2011: 30–3). As with all innovations in crisis, these data technologies may inadvertently shift risk onto more vulnerable communities (Kalkman, 2018: 3) or exclude them altogether (Davis, 2020).

## Conclusion

This has only been a partial summary of contemporary issues influencing medical data technologies in humanitarian settings. Attempting an overview of key issues and authors, we raised key issues that surface within the themes of governance, power and control; justice and equity; and trust. The humanitarian act – like the medical act – has always been predicated on trust: beneficence as the principal motive and outcome. Trust is the central constitutive component of the relationship. Naturally, motive and means have never been pure; questions of power and justice are always at play; the medical humanitarian act is fraught with moral complexity. But accelerating medical data technologies confound this relationship further. Patient data can travel unanticipated and sometimes untraceable pathways, further muddying the ethics of informed consent, choice and care. This can multiply existing power differentials and inequalities. These are overlapping, not exclusive, categories; most of the phenomena and dilemmas discussed here evoke more than one of these themes. Yet divisions are conceptually necessary to treat such a heterogeneous subject matter, and call attention to the preeminent implications for patient well-being and humanitarian operations as a whole.

Medical humanitarian settings might not make for qualitatively different data ethics, but they do make for quantitatively different consequences. In any setting, a medical data breach can do long-lasting harm; in authoritarian or conflict environments they can be deadly. Where existing vulnerabilities, inequities and power differentials are already acute, it matters how medical data is managed. This is the urgent relevance of medical humanitarian data studies as a branch of broader and established enquiries into humanitarian and data ethics. We hope this article will spark further dialogue and research around the topic of medical humanitarian data technologies, with the ultimate aim of improved safety and autonomy for those living in crisis and conflict.

## Note

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