

FORCED DISPLACEMENT
IN CONFLICT SCENARIOS

ETHICS AND HUMAN RIGHTS PERSPECTIVES

Andrea Hellemeyer
& *Eduardo Díaz-Amado*

(EDITORS)

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Forced Displacement in Conflict Scenarios

Andrea Hellemeyer & Eduardo Díaz Amado, editors

Ethics and Human Rights Perspectives



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European eHealth Responses to Crisis Migration: A Critical Appraisal

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Introduction

In this chapter¹, we evaluate an emerging European approach in eHealth, developed in response to the post-2011 crisis of forced migration from conflict areas in North Africa and the Middle East. While a crucial part of healthcare is the existence of accurate and accessible health records, this is largely, if not entirely, lost in forced migration. Re-establishing the migrant's medical records is an urgent task, both for addressing pre-existing health issues and addressing the multiple health

¹ This chapter is based on a recent International Chair in Bioethics (formerly UNESCO Chair in Bioethics, Haifa) European Division publication. Feeney, O., Werner-Felmayer, G., Siipi, H., Frischhut, M., Zullo, S., Barteczko, U., Øystein Ursin, L., Linn, S., Felzmann, H., Krajinović, D., Saunders, J., & Rakić, V. (2020). European Electronic Personal Health Records initiatives and vulnerable migrants: a need for greater ethical, legal and social safeguards. *Developing World Bioethics*, 20(1), 27-37. <https://doi.org/10.1111/dewb.12240>. Previous versions of this work have benefitted from many comments. We wish to express our sincere thanks to Lisa A. Eckenwiler (George Mason University) for her extensive comments on our previous publication. We wish to thank the organisers and participants of the Virtual Conference on Refugee & Migrant Health, Mobility, Human Rights & Responsibilities, hosted online on October 9-11, 2017, with particular thanks to Lisa A. Eckenwiler, Sean Philpott & Samia Hurst for their generous input. We also wish to thank the organisers and participants at the 2017 UNESCO Bioethics Ireland Workshop on emerging research in Ireland, hosted by NUI Galway, Ireland on May 25, 2017; and at the 2017 UNESCO Chair in Bioethics 12th World Conference on March 21-23, 2017). Many thanks also to the co-editors of this volume - to Eduardo Diaz Amado and, with particular thanks to Andrea Hellemeyer (Chair of International Chair in Bioethics International Research Group 'Bioethics and human rights').

issues likely arising from the migration experience itself. Importantly, the system must be flexible, compatible and easily updated to be suitable for a mobile population within and across borders and moving throughout different languages, legal jurisdictions, health systems and sometimes differing cultural expectations. While highlighting the importance and benefits of this migrant-centred electronic Personal Health Record (m-ePHR) development, we recently identified several potential ethical, legal and social issues (ELSI) that need to be addressed in any application of such a system (Feeney *et al.*, 2020). We highlighted two European projects that have been established to respond to the diverse health challenges facing migrants, and where both include variants of m-ePHRs. However, in both cases, we noted that the aforementioned initiatives had not addressed important ethical, legal, and social issues, and we highlighted the subsequent risks for the migrants currently involved. In this chapter, we summarise our recent discussions on this topic. As highlighted by a recent publication by Chiesa *et al.* (2019), the potential of migrant-centred ePHRs, as well as scholarly assessments of such initiatives, are an emerging trend that is yet to be fully investigated. The lack of an adequate ELSI assessment and corresponding duty to develop one is vital in ensuring this potential is properly guided from its early stages.

eHealth in Europe, Migrant Crisis and Case for Extending eHealth Records

With developments in data sharing capabilities in ICT (eHealth), electronic personal health records (ePHRs) are increasingly poised to replace less transportable paper records. Despite the fragmented legal, regulatory, and socio-political contexts between different European jurisdictions, developing a common infrastructure for the sharing of sensitive data, such as health information in the context of cross-border eHealth services, is a key focus for the improvement of harmonised health services for Europe's citizens. The epSOS project was a €36.5 Million European Initiative (2008 to 2014) aimed to design, build and evaluate a service infrastructure that successfully demonstrated the potential of cross-border interoperability between electronic health record systems in Europe. The pilot project developed a limited number of locations across a number of European countries with different jurisdictions in order to highlight how the quality and safety of healthcare for European citizens when travelling to other European countries could be improved through the development of an ICT infrastructure enabling the sharing and transmission of health data between different European healthcare systems. Within different European countries, similar initiatives are in progress. The Directive 2011/24/EU (European Parliament & The Council of the European Union, 2011a) on patients' rights in cross-border healthcare and its establishment of the eHealth Network further develop the infrastructure to this end (Kierkegaard, 2011).² Recently, the commitment to creating a sustainable European environment for effective data sharing has been strengthened with the advent of the new EU General Data Protection Regulation on data harmonisation and data portability (Council of the European Union, 2017; European Parliament & The Council of the European

² Although general in its approach, this document could also play a role in this context.

Union, 2016). The benefits are manifold, including, but not only, improving up-to-date information, accuracy, efficiency, sharing of important research, less duplication of work and ultimately better diagnoses and treatments for individuals and society. However, there are still several crucial barriers inhibiting its full implementation. These include issues of privacy and consent, data security, lack of public and healthcare professional confidence in the system, inadequate and fragmented legal frameworks, interoperability issues and regional differences in access to ICT (both within and between countries). Nevertheless, significant work is ongoing on tackling such outstanding challenges in the European context, and much progress has been noted over the last number of years (European Commission, 2012).³

Crucially, and the central focus of this chapter, such challenges are not the only ones facing Europe's healthcare structures in recent years. While migration—and forced migration—is not a new phenomenon, it became a particular focus in Europe since the 2011 political instability in the Middle East and North Africa. In 2015 alone, 1,015,078 sea arrivals of migrants and refugees were documented in Greece, Italy, Malta, and Spain (UNHCR, 2015). The needs of newly arrived migrants from ongoing conflict situations require a comprehensive response that dovetails with the goals mentioned above of cross-border eHealth and. Given the trauma of the migration experience itself, it could be considered more urgently needed than equivalent eHealth developments for European citizens.⁴ Due to ongoing conflicts around the world as well as forthcoming issues related to climate change, the reality of vast increases in the numbers of displaced peoples is likely to be a constant or regularly revisited theme into the future (Sifaki-Pistolla *et al.*, 2015; Jakab, 2015).⁵ The importance of the focus on data sharing for European citizens, including the focus of the above eHealth plans, relevant Directives and Regulations, is clear. However, there is also a clear need for an increased focus on the needs of migrating populations in terms of electronic data sharing or eHealth in both the EU and the wider European context. Accurately monitoring the health data of a rapidly migrating population both in times of crisis and in cases of continued migration trends is vital for ensuring adequate healthcare and monitoring a displaced and vulnerable peoples' health status. In addition to the usual advantages of improving the accuracy and completeness of information, the flexibility of ePHRs provides evident advantages for rapidly displaced populations. While we refer to health records and health-related information in this chapter, we note that these are complex definitions with equally complex and varied manifestations in reality. Chiesa *et al.* (2019) observe that the lack of clear definitions is a common issue that constitutes a barrier to

³ For more information, see www.epsos.eu. In addition, data sharing in the European context of health and genomics is a central focus of the COST Action IS1303 (www.chipme.eu).

⁴ It also dovetails with responses to intra-European interoperability taking account of the wider international perspective (Overview of the national laws on electronic health records in the EU Member States and their interaction with the provision of cross-border eHealth services. Final report and recommendations. (2014). Available at: https://ec.europa.eu/health/sites/health/files/ehealth/docs/laws_report_recommendations_en.pdf

⁵ As highlighted by Zsuzsanna Jakab (WHO Regional Director for Europe) when she noted that an “ageing population and migration are the two demographic factors that will shape the health challenges of the European Region in the 21st century” (Jakab, 2015, para. 3). Jakab also noted the current preparations for “a framework for long-term action on refugee and migrant health that could be discussed and agreed by the Regional Committee in September 2016” (para. 6).

the development of electronic patient records. For instance, with greater precision than we use here, they distinguish between electronic medical records (defined as “digital version of the paper records in health care institutions”), electronic health records (“information from all health workers involved in a patient’s care, with entries from multiple sites where care is provided”) and personal health records (“all personal information [...] entered and accessed electronically by healthcare workers over the person’s lifetime”) (Chiesa *et al.*, 2019, p. 889). For the purposes of this chapter, we do not distinguish to this same degree as we are looking at issues (benefits and concerns) in common to all variants of electronic health records for migrants.⁶ In general, the aim of m-ePHRs, broadly defined, is to give migrant patients access to their personal health information shared across different settings and systems. There are still numerous obstacles to this ideal (Ose, 2017).

Potential Advantages of Migrant-Centric ePHRs

Successful implementation of pan-European migrant-centric ePHR (m-ePHRS) initiatives would better enable a number of key issues that face vulnerable migrants to be addressed. The migration between countries (from origin to transit to destination countries) creates difficulties in accurately maintaining and updating traditional methods of personal health records, especially given the cumulative health effects of the migratory experience itself (Chiesa *et al.*, 2019, p. 888). Forced migration is often associated with particularly acute health problems as the migratory experience can have significant negative impacts on a person’s health, as migrants often face particular health risks before, during and after they flee from their country of origin (Janssens *et al.*, 2006). In this context of cross-border movement, numerous issues can arise, including duplication of vaccinations, lack of awareness of current medications or previous adverse reactions to treatments. These issues can be compounded by culture and language barriers and other cultural barriers to accessing health care (Clark & Mytton, 2007; Hacker *et al.*, 2015; Langlois *et al.*, 2016). including differences regarding what is seen as appropriate health care. There is an increasing awareness of such barriers but ongoing difficulties in finding effective ways to address them, e.g., difficulties in ensuring accurate translation of technical, medical language. Migrant-centric eHealth initiatives would not only be of benefit to the migrants themselves but would also be of benefit to organisations, healthcare services and countries that receive migrants by saving resources and reducing duplication of workload (Clark & Mytton, 2007). Overall, such emerging cross-border eHealth initiatives can better monitor migrants’ health, passing from jurisdiction to jurisdiction, and thereby enabling a more efficient and cost-effective use of limited public health funds and personnel, especially in crises. Even if, as some point out, the burden of migrants on states and health services (and the corresponding savings in terms of avoiding duplication of examinations and treatments) may be overblown, savings of some lower-level would still seem prudent if possible without cost to the quality of healthcare

⁶ Comparing benefits and ELSI concerns between the different variants of electronic health/medical records would be an important task for another day.

itself.⁷ The possibility of ongoing revisions to medical information can also enable the complex and changing needs of vulnerable groups, including those acquired throughout migration: e.g., elderly persons, pregnant women, disabled people, persons who have undergone torture, rape or other severe forms of psychological, physical or sexual violence. With suitable safeguards in place, it can also apply to minors and those with diminished capacity, victims of abuse, neglect, exploitation, torture, cruel, inhuman and degrading treatment or who have suffered from armed conflict (European Parliament & The Council of the European Union, 2011b, art. 30). In general, there can be a better response to various unanticipated special needs of migrants⁸ resulting from forced migration (Janssens, *et al.* 2006). Forced migration can also highlight some special needs of women while flagging differences in health services provided in different European countries. For instance, migrating women can run a higher risk of unwanted pregnancy, induced abortion, sexually transmitted infection, HIV, experiences of sexual violence, both prior to and due to the migration process (Janssens, *et al.* 2006). These special needs in healthcare may often be difficult to integrate into more limited and static forms of paper-based medical records. The issue would be further complicated because European countries differ regarding legislation and practices on abortion, contraception, and other reproductive issues⁹. WHO (2020) reports, for example, that the use of contraception differs across Europe, where, in some countries, many women who need modern contraception are unable to access it. Apart from direct improvements to the healthcare services directed toward migrating peoples, there would be the potential for electronic health records to help build up a body of healthcare-related data — appropriately protected and only for improving healthcare outcomes — that can contribute to research and better evidence-based responses (Cheng *et al.*, 2018).

Potential Disadvantages of Migrant-Centric ePHRs

The very possibility of increasing the amount and individualised detail of the medical records held by migrants via the m-ePHRs, also opens up the possibility that this information can be used against their interests, either deliberately or accidentally. This issue was highlighted prominently in the UK, where a memorandum of understanding between the Home Office and NHS Digital allowed for the sharing of non-clinical data between the NHS (UK National Health Service) and immigration

⁷ I wish to thank Su-Ming Khoo from NUI Galway for the point of observing exaggerations in terms of migrant-related costs on states and healthcare services, even if duplications of healthcare exist.

⁸ According to Art. 30(1) Directive 2011/95/EU, “Member States shall ensure that beneficiaries of international protection have access to healthcare under the same [!] eligibility conditions as nationals of the Member State that has granted such protection”. According to Art. 19(1) Directive 2013/33/EU, “Member States shall ensure that applicants receive the necessary health care which shall include, at least [!], emergency care and essential treatment of illnesses and of serious mental disorders”.

⁹ The area of technologically assisted reproduction will also be increasingly relevant in the longer term when such migrants become settled in a target country. See University of Cambridge Centre for Gender Studies (2015).. For a fuller analysis on issues raised on the EU front in the context of technologically assisted reproduction, see Frischhut, M. (2017)..

authorities (See O'Donnell *et al.*, 2019; Campbell, 2018). Depending on whether a person's status is an asylum seeker, refugee or undocumented migrant will have significant implications for the safety and security of their information held and sharable via electronic means. While it is helpful to identify the special health needs of individuals who are members of one of these groups, the status of being an asylum seeker, refugee or undocumented migrant is not health data or medical information itself (Clark & Mytton, 2007).¹⁰ Some migrants may also find the recording of their status to be potentially stigmatising and could fear that the information may be used against their overall interests instead of better addressing their health interests. As highlighted in the UK case, some European countries already use information about asylum seekers' physiological and medical states for purposes other than enhancing their health (European Parliament & The Council of the European Union, 2013, art. 25). For instance, applications for refugee status sometimes include medical reports written by medical doctors where the migrants' clinical signs and symptoms are assessed to be consistent, or not, with the alleged traumatic events on which the refugee claim is based. This potential misuse of migrant data (both health and non-health) combined with clinically inadvisable avoidance of related healthcare services by migrants may limit the potential benefits and effectiveness of m-ePHRs to such a degree that it is considered potentially dangerous for such data to be stored in the eHealth system at all. Age evaluations of asylum seekers can take the form of x-rays of teeth and bones or other medical information (e.g., results of gene tests) (Sauer *et al.*, 2016; Metsäniitty *et al.*, 2017). As under-age asylum seekers enjoy some benefits not available to adult asylum seekers, the perception by immigration officials will likely question whether a person who claims to be under-age is really the case. Whatever the appropriateness or not of such actions by immigration officials, the commandeering of healthcare data from independent healthcare services is problematic on several levels.¹¹ Apart from the risk of information collected by medical means being used for purposes other than enhancing the health of the migrant, there is the related issue regarding who should have authorised access to the information stored in the m-ePHR system. If immigrant authorities can legitimately have access to medical information relevant to the refugee application, there should be a way to distinguish and control the parts of eHealth records that can and cannot be given to immigrant authorities, especially to ensure that important health information that is not strictly required is not given.¹² While some aspects of such information might be helpful for policy formation, the medical privacy rights of the individual should be taken seriously. Protection of information from wrongful access is also important where the health information could be viewed as a valuable commodity to various groups and, as such, may entail a personal security risk for the migrants if effective access restrictions are not in place. The loss from one's bank details being taken can be problematic, but the bank details can be changed. A migrant's health details are not similarly replaceable or revisable in cases where stolen by others.

¹⁰ On special health needs see Hebebrand *et al.* (2016), and Langlois *et al.* (2016).

¹¹ Some EU member states are expected to carry out medical age-evaluations. The Asylum Procedures Directive (Directive 2013/32/EU) notes that European Union Member States "may use medical examinations to determine the age of unaccompanied minors within the framework of the examination of an application for international protection" (European Parliament & The Council of the European Union, 2013, art. 25).

¹² This "firewall argument" has been addressed by Carens (2015).

With the above challenges over what information is safe to store and who should or should not have access, it is not surprising that mistrust and suspicion are common among asylum seekers, refugees and undocumented immigrants (Janssens *et al.*, 2006). Ehealth monitoring may be a further source of mistrust, especially if a language barrier is still unaddressed in the system and the person is unfamiliar with digital records and cultural differences. Furthermore, there are questions regarding whether storage in databases deprives the migrant of any possibility to control it and to what degree this should be facilitated. The understanding of confidentiality and privacy differs between cultures (Eklöf *et al.*, 2015). In such cases, there may be a danger that a person omits to seek medical help because he/she does not want her health information to be stored. Designers of eHealth records need to be aware of potential fears and misuses in the design of the record and whether health-related information can be used in ways harmful or discriminatory to migrants (or to their dignity) by various groups. For example, refugees fleeing persecution may still fear for their lives in the European context. An electronic health record may be seen as a method of revealing their identity and movements that are to be avoided. Similarly, any record of where they may be similarly problematic for an undocumented immigrant and seen as something to be avoided, even if this adversely affects their healthcare.¹³ Even if their location is not directly recorded, the locations of the healthcare professionals storing the data may be identifiable, indirectly identifying the locations of the migrating patient.

The above points outline only some of the potential ELSI concerns that can arise with any migrant-centric ePHR initiatives and highlight why such initiatives need to address such ELSI issues in the design and roll-out of their (otherwise admirable and much needed) measures. There are important benefits that migrant-centric ePHRs can offer, and these should be safeguarded with robust migrant-centric ELSI protections in place to prevent or mitigate potential unintended negative consequences, such as those noted above.

The Examples of CARE and Re-Health²

Currently, the ePHR responses for migrants are most explicitly addressed under two projects: (a) Common Approach for Refugees and Other Migrants' Health (CARE)¹⁴ and (b) RE-Health¹⁵,

¹³ Similar to Rechel *et al.* (2011).

¹⁴ The project CARE (Common Approach for REFugees and other migrants' health [2014-2020]) aimed to promote a better understanding of refugees and migrants' health condition and towards the health needs of fragile subgroups, such as minors, pregnant women, and victims of violence.

¹⁵ The RE-HEALTH action aimed to address PHR as an important health-related issue of migrants arriving at key reception areas, while preventing and addressing possible communicable diseases and cross-border health events. European Union & International Organization for Migration (IOM) (2016).

particularly by the follow-on RE-Health2 initiative¹⁶. Both projects focus on collaboration with the main migration-gateway countries: Italy, Greece, Slovenia, and Croatia. Under CARE, Malta was also included, and Re-Health2 has expanded to include Cyprus, Romania, and Serbia. CARE (European Union Health Programme, 2014-2020)¹⁷ developed an ePHR in the form of a USB stick that can be combined with software enabling trained health personnel to modify the data stored on the stick and in a data cloud. The memory sticks were distributed to a small number of migrants, and healthcare professionals were given a comprehensive manual on using the corresponding software. The ongoing Re-Health2 initiative is also devoted to building an electronic database for migrants' health data, focusing on data protection under different European guidelines. Re-Health brings together stakeholders in migrant health to establish a solid network for further collaboration. Additionally, RE-Health aims to train "health mediators", personnel with the intercultural skills needed to illustrate the benefits of health assessment to migrants and ensure that the basic human rights of patients are protected. These projects are designed to promote a better understanding of the health conditions of refugees and migrants. They are further designed to improve EU cooperation in monitoring activities and potential health risks. This means tailoring healthcare delivery to migrants' health needs, keeping the risk of infectious disease outbreaks under closer control at the early stages of migrant care, and overall taking better care of migrants' health across the European area. This, in turn, includes ensuring that any disease outbreaks and public health emergencies are detected at reception centres¹⁸, helping to prevent cross-border health threats and providing frontline healthcare workers with information about endemic diseases in the newly arrived migrants' countries of origin. In both projects, the expansion and use of ePHRs are considered crucial in supporting the EU Migration Agenda. The Action Plan on the Integration of Third Country Nationals and Promoting the e-PHR will also be in keeping with the broader goals of the EU Digital Agenda.

Unfortunately, as we recently highlighted (Feeney *et al.*, 2020), both projects have primarily focussed on overcoming technological barriers while placing far less (indeed, insufficient) emphasis on addressing ELSI issues in the design or roll-out of their respective ePHR systems. For the above issues to be adequately addressed by migrant-centric ePHRs, these proposed e-tools must be ethically, socially and legally robust (EDPS Ethics Advisory Group, 2018). Otherwise, it would fail to adequately address such problems facing vulnerable migrants while also risking the creation of additional difficulties. In CARE, for instance, the aforementioned manual for health professionals

¹⁶ Project RE-Health2 aims for the "Implementation of the Personal Health Record as a tool for integration of refugees in EU health systems" is a project focusing on "utilization of the PHR/e-PHR as universal EU tool for health assessments that aims at improving the continuity of care, making medical records available to health professionals within and from reception to destination countries, and facilitating data collection to better understand and meet migrants' and refugees' health needs as also through supporting and fostering use of and capacity-building of health mediators", European Union & International Organization for Migration (IOM) (2016).

¹⁷ CARE project provided the development of an integrated electronic system for tracking and monitoring the health status of migrants and refugees, available at: <http://careformigrants.eu/wp-content/uploads/2017/08/CARE-HTMS-User-manual.pdf>

¹⁸ For a legal analysis see Frischhut & Greer (2017).

on the usage of the corresponding software lacks information on the safe handling of patient data or further ELSI issues. There is no mention of ‘ethics’, ‘social concerns’ or ‘vulnerable’ in the user manual (CARE, 2017). There is some limited reference to legal aspects in the recommendations —i.e., the unclear legal status of various migrant groups— but not in relation to ePHRs. In the case of Re-Health/Re-Health2, there is mention of several legal documents on their website regarding data protection, but no other issues are mentioned (Re-HEALTH², n. d.).¹⁹

Providing adequate healthcare to rapidly migrating populations poses challenges in various fields. Up to date personal health records that are functional across European borders could prevent many unnecessary measures and complications. Electronic Personal health records, such as proposed and developed by the CARE and Re-health projects, could be a valuable tool if adjusted to face specific challenges, especially concerning the storage and access to personal data of the migrant. Although Directive 2011/24/EU on cross-border healthcare has been set up for EU citizens, it uses a neutral wording about “medical records”, which could also be utilised in our ELSI context. However, as we have shown, greater attention to ELSI issues is needed. In much of the literature, including in the two initiatives (CARE, Re-Health), there is a depiction of migrants mostly seen as “carriers of disease”, while far less focus is given to issues like benefits for migrants suffering from chronic disease as well as the many maternal health issues exacerbated by the migratory experience. This is particularly urgent in cases of pregnant women, unaccompanied minors, persons with disabilities, the elderly or strongly traumatised patients. Treating migrants as a single, cohesive group is very problematic, especially when there are significant individual and cultural differences among them (e.g., toward contraception or abortion, among others).

Overall, we conclude that there should be a much stronger focus on creating robust ELSI guidelines for the ongoing development and use of migrant-centric ePHRs to ensure that such records can effectively contribute to care in line with migrants’ own needs and preferences.

Concluding Remarks and the Next Steps

The EU Charter of Fundamental Rights (CFR) (European Union, 2016), legally binding since 2009, emphasises vulnerable groups such as children (Art. 24), the elderly (Art. 25) and people with disabilities (Art. 26). While clearly having an EU focus, most articles, including the aforementioned rights, are not only addressed to EU citizens but entitle all human beings, hence also migrants and refugees. The concept of vulnerable people comprises those “which are particularly prone to being

¹⁹ The German bioethics committee recently made a very detailed analysis regarding Big Data & Health (while not migrant-centric, it did focus on vulnerable groups in general) where they identified many more issues around the use of data than only security issues (https://www.ethikrat.org/publikationen/publikationsdetail/?tx_wwt3shop_detail%5Bproduct%5D=115&tx_wwt3shop_detail%5Baction%5D=index&tx_wwt3shop_detail%5Bcontroller%5D=Products&cHash=eaabo64e71492c426c4478bd6d69af66). In addition, the UK’s Nuffield Council made recommendations already in 2015 where they explicitly mention that following the law might not be enough to deal with data in health (See Nuffield Council on Bioethics, 2015; <https://www.nuffieldbioethics.org/publications/biological-and-health-data>).

harmed, exploited or discriminated include, among others, children, women, older people, people with disabilities, and members of ethnic or religious minority groups” (Andorno, 2016). This reference to discrimination opens up a broad range of vulnerable people, as the CFR prohibits discrimination on the grounds of “sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation” (Art. 21 para. 1). Therefore, most migrants and refugees might be seen as ‘multi-vulnerable’, as they potentially fulfil several of these criteria. As several EU directives in the field of migration and asylum emphasise the importance considering the specific situation of vulnerable persons, this idea of a European eHealth response to the migration crisis, which adequately takes into account an ELSI assessment, would be a good approach to filling these human rights with life.

In conclusion, we would make the following suggestions for any m-ePHR system, such as the two projects noted, for their systems to be ethically, legally and socially robust. We also make these suggestions with the knowledge that the systems above have been up and running on a trial basis and with real migrants involved, and apparently without any substantial ELSI work done to protect them or their health data. Firstly, we call for an immediate assessment and investigation of potential ELSI problems, both short-term and longer-term. This would require discussions between ELSI experts and key members from both CARE and Re-Health project, as well as migrant representatives and information technology people. One key outcome would be a list of key ELSI guidelines and information to be disseminated to staff working in CARE and Re-Health2, medical practitioners, IT support, migrant representative groups, as well as a short, clear, multi-lingual list of key do’s and don’ts for migrants using the m-ePHRs. Beyond the immediate action, there needs to be a longer, more comprehensive development of ELSI guidelines and recommendations, including updating and improving the emergency measures and moving broader (less immediately urgent, but important longer-term steps).

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