European Electronic Personal Health Records initiatives and vulnerable migrants: a need for greater ethical, legal and social safeguards

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Abstract: *The effective collection and management of personal data of rapidly migrating populations is important for ensuring adequate healthcare and monitoring of a displaced peoples' health status. With developments in ICT data sharing capabilities, electronic personal health records (ePHRs) are increasingly replacing less transportable paper records. ePHRs offer further advantages of improving accuracy and completeness of information and seem tailored for rapidly displaced and mobile populations. Various emerging initiatives in Europe are seeking to develop migrant-centric ePHR responses. This paper highlights their importance and benefits, but also identifies a number of significant ethical, legal and social issues (ELSI) and challenges to their design and implementation, regarding (1) the kind of information that should be stored, (2) who should have access to information, and (3) potential misuse of information. These challenges need to be urgently addressed to make possible the beneficial use of ePHRs for vulnerable migrants in Europe.*

Key words: ethical, legal and social issues (ELSI), migration, electronic personal health records, medical records, bioethics, values, vulnerabilities.

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Introduction

Collecting and maintaining health data of a rapidly migrating population in times of crisis is, amongst other things, important for ensuring adequate healthcare and accurate monitoring of a displaced and vulnerable peoples' health status. With developments in data sharing capabilities in ICT (eHealth), electronic personal health records (ePHRs) are increasingly replacing less transportable paper records. In addition to the usual advantages of improving accuracy and completeness of information, the flexibility of ePHRs provide evident advantages for rapidly displaced populations.[13]

Due to ongoing conflicts as well as evolving issues related to climate change, the prospect of using electronic-based cross-border eHealth responses for displaced peoples will continue to be a revisited theme into the future.[14] Such a focus dovetails with prominent European goals of cross-border eHealth (such as outlined in the provisions of the eHealth Action Plan 2012-2020) and highlights the importance of extending to, or replicating, the emerging eHealth initiatives for European citizens to incoming migrant groups.[15] A crucial element of this extension will be a necessarily tailored focus on the particular context and needs of migrating peoples – in other words, a focus that is centred upon migrants, or 'migrant-centric'. For such reasons, various emerging initiatives – such as Common Approach for REfugees and other migrants' health and Re-Health/ Re-Health2 – are seeking to develop migrant-centric ePHR responses in the European context.[16]

This paper highlights the various benefits of ePHRs for migrants and consequently the importance of such initiatives. We need, however, to address a number of significant ethical, legal and social issues (ELSI) and challenges of migrant-centric ePHRs. This paper outlines such challenges, and offers constructive suggestions for addressing them.

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[13] While in this paper we refer to health records and health-related information, we do note that these are complex definitions with equally complex and varied manifestations in reality. In general, the aim of ePHRs is to give patients access to their personal health information which can be shared across different settings and systems. There are still numerous obstacles to this ideal. For a recent review, see Ose, D., Kunz, A., Pohlmann, S., Hofmann, H., Qreini, M., Krisam, J., Uhlmann, L., Jacke, C., Winkler, E. C., Salize, H-J. and Szecsenyi, J (2017) 'A Personal Electronic Health Record: Study Protocol of a Feasibility Study on Implementation in a Real-World Health Care Setting', *JMIR Research Protocols*, 6(3) March: e33. Published online doi: 10.2196/resprot.6314 [date accessed: 14/2/19]

[14] With a particular applied focus, this paper contributes to a growing body of literature that was also recently expanded by this journal's recent special issue. See: Klinger, C., Odukoya, D. & Kuehlmeyer, K. (2018) 'Migration, health & ethics: Integrating discourses on the ethics of healthcare for migrants'. Bioethics, 32(6) July.

[15] When we use the terms 'migrants', 'migrating persons' or 'vulnerable migrants', throughout this paper, we use it as a shorthand for three different groups – asylum seekers, refugees and undocumented migrants. Each sub-category gives rise to different ELSI-related challenges and our overall research expands upon this. For the current paper, we are primarily focussed on the overall category of migrants (including all three sub-categories) but, on occasion, we utilise one or more sub-category where relevant.

[16] As will be discussed below, there has been significant developments in this area. See: E.C. (2017) 'Migration and health: REHEALTH 2 project to test extended use of Personal Health Records' *e-news*, 04/09/2017: http://ec.europa.eu/newsroom/sante/newsletter-specific-archive-issue.cfm?newsletter_service_id=327&newsletter_issue_id=4929&page=1&fullDate=Sun%2009%20Apr%202017&lang=def ault [date accessed: 14/02/19]

Two (overlapping) European developments

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, continues to be a key focus for the improvement of harmonised health services for Europe's citizens. The Directive 2011/24/EU[17] on patients' rights in cross-border healthcare and its establishment of the eHealth Network, reinforces this commitment.[18] Although not tailored for migrants, the broad wording used in this Directive could serve as a starting point for a more migrant focused approach. More recently, the new EU General Data Protection Regulation on data harmonization and data portability continues progress on creating a sustainable European environment for effective data sharing.[19] While there are still a number of crucial barriers inhibiting its full implementation, such as lack of public/healthcare professional confidence in the system, inadequate and fragmented legal frameworks, interoperability issues and regional differences in access to ICT, much progress has been noted over the last decade.[20] In the field of data sharing, important work is ongoing on tackling such outstanding challenges in the European context.[21]

The needs of newly arrived migrants from ongoing conflict situations also require a comprehensive response that dovetails with the aforementioned goals of cross-border eHealth.[22] Due to ongoing conflicts as well as issues related to climate change, the prospect of displaced peoples is likely to be a constant or regularly revisited theme into the future.[23] WHO Regional Director for Europe Zsuzsanna

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[17] Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare, Official Journal of the EU (OJ) 2011 L 88/45, as amended by OJ 2013 L 353/8. Available at: http://eur-lex.europa.eu/eli/dir/2011/24/oj.

[18] Council of the European Union conclusions on Encouraging Member States-driven Voluntary Cooperation between Health Systems, OJ 2017 C 206/3. Although general in its approach, this document could also play a role in this context. Available at: http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:52017XG0630(01). See Kierkegaard, P., Electronic health record: Wiring Europe's healthcare, in *Computer Law & Security Review*, Volume 27, Issue 5, September 2011, 503-515.

[19] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation), OJ 2016 L 119/1, as corrected by OJ 2018 L 127/2. Available at: http://eur-lex.europa.eu/eli/reg/2016/679/oj.

[20] Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions (2012) 'eHealth Action Plan 2012-2020 - Innovative healthcare for the 21st century', pp. 3, 5. Available at: http://ec.europa.eu/health/ehealth/docs/com_2012_736_en.pdf

[21] It is important to note the fundamental groundwork done by the epSOS pilot project here (http://www.epsos.eu/). A key goal of epSOS was to demonstrate 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. In addition, data sharing in the European context of health and genomics is a central focus of the COST Action IS1303 (www.chipme.eu)

[22] 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: http://ec.europa.eu/health/ehealth/docs/laws_report_recommendations_en.pdf

[23] The interconnection between ehealth and refugees was also recently raised in a paper delivered at the eHealth Forum 2015 in Greece: http://www.ehealthforum.org/wp-content/uploads/2015/12/eHEALTH-Forum-programme_en.pdf

Jakab notes 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".[24] As migrants often face particular health risks before, during and after they flee from their country of origin, forced migration is often associated with particularly acute health problems[25]. These issues may be compounded by several barriers to accessing health care, including language barriers" and cultural differences regarding what is seen as constituting appropriate health care.[26,27,28] Even if there is awareness of such barriers and there is a willingness to address them, there may be difficulties in finding effective ways of overcoming these barriers (e.g. a lack of suitable interpreters and issues of trust) exacerbated by disruptions from crossing borders, even internal European or EU ones.

Notwithstanding the importance of the focus on data sharing for European citizens, including the focus of the above eHealth plans and Directive 2011/24/EU, there is 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. This is not an unrealistic demand. For instance, the legislative backdrop already seems conducive toward a more migrant-centric expansion where the concept of "medical records" in the above directive is a very broad one,[29] as it addresses "patients"[30] and is not restricted to "insured persons". In addition, when referring to the obligations of both the Member State of treatment[31] and the Member State of affiliation[32], the Directive also addresses electronic versions of

Conference paper on 'eHealth and GIS as tools for dealing with the issue of refugees in Europe' (2015) - Dimitra Sifakis-Pistolla, Medical School, University of Crete

[24] WHO conference on refugee and migrant health (Italy, November 2015): http://www.euro.who.int/en/media-centre/events/events/2015/11/high-level-meeting-on-refugee-and-migrant-health/news/news/2015/11/we-cannot-turn-away-our-eyes-highlights-from-day-1-of-the-high-level-conference-on-refugee-and-migrant-health; Dr 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". WHO conference on refugee and migrant health (Italy, November 2015): http://www.euro.who.int/en/media-centre/events/events/2015/11/high-level-meeting-on-refugee-and-migrant-health/news/news/2015/11/we-cannot-turn-away-our-eyes-highlights-from-day-1-of-the-high-level-conference-on-refugee-and-migrant-health

[25] Janssens, K., Bosmans, M., Leye, E. & Tammerman, M. 2006. "Sexual and Reproductive Health of Asylum Seeking and Refugee Women in Europe: Entitlements and Access to Health Services". *Journal of Global Ethics* 2(2), 183-196.

[26] Mytton, R.C.C. "Estimating infectious disease in UK asylum seekers and refugees: a systematic review of prevalence studies". *Journal of Public Health*, October 8, 2007, p. 1-9: 2.

[27] Hacker K, Anies M, Folb BL, Zallman L. Barriers to health care for undocumented immigrants: a literature review. *Risk Management and Healthcare Policy*. 2015;8:175-183. doi:10.2147/RMHP.S70173.

[28] Langlois EV, Haines A, Tomson G, Ghaffar A. Refugees: towards better access to health-care services. *Lancet*. 2016;387(10016):319-321. doi:10.1016/S0140-6736(16)00101-X.

[29] Art. 3 lit. m Directive 2011/24/EU: i.e. "all the documents containing data, assessments and information of any kind on a patient's situation and clinical development throughout the care process".

[30] Art. 3 lit. h Directive 2011/24/EU: i.e. "any natural person who seeks to receive or receives healthcare in a Member State".

[31] Art. 4(2) lit. f Directive 2011/24/EU: i.e. "patients who have received treatment are entitled to a written or electronic medical record of such treatment, and access to at least a copy of this record".

[32] Art. 5 lit. d Directive 2011/24/EU: i.e. "patients who seek to receive or do receive cross-border healthcare have remote access to or have at least a copy of their medical records".

medical records. Consequently, with regard to the wording of Directive 2011/24/EU, it could also play a role within this idea of ePHRs.[33]

The International Organization for Migration (IOM), the Council of Europe, and the Council of the European Union have recognised that better data collection and health information systems for migrants is needed in healthcare.[34] Initially reported in the 2015 WHO conference on refugee and migrant health, the European Commission developed a 'personal health record' template document in English and Arabic.[35] The template facilitates the reconstruction of a medical history for refugees without documentation, to help health workers provide appropriate care, and to enable refugees to carry at least an approximate record of their health history with them.[36] While this was an important initial step to meet refugees' health needs, other responses are interlockingwith the idea of an expansion of the potential of eHealth and ICT-based data sharing on a European level. The system might also be further developed and comprehensively apply to *all* vulnerable migrants: refugees, asylum seekers *and* undocumented migrants. The latter group seen to be the most vulnerable, as it currently tends to have access only to emergency health care.[37]

ePHR for migrants is addressed under two projects: (1) Common Approach for Refugees and Other Migrants' Health (CARE)[38] and (2) RE-Health[39], now completed and renewed under the title RE-Health2.[40] Both initiatives focus on collaboration with the main migration-gateway countries: Italy,

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[33] Council of the European Union conclusions on Encouraging Member States-driven Voluntary Cooperation between Health Systems, OJ 2017 C 206/3. Although general in its approach, the "Council conclusions on Encouraging Member States-driven Voluntary Cooperation between Health Systems" could also play a role in this context. Available at: http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:52017XG0630(01). See Kierkegaard, P. (2011) Electronic health record: Wiring Europe's healthcare, in *Computer Law & Security Review*, 27 (5), September, 503-515

[34] From: "Within the EU, a consultation on "Migration Health – Better Health for All" in Lisbon in 2009 identified a number of areas for action, including the establishment of structures to support research and comparable data collection to better identify the health specificities of migrants (IOM 2009). The need for better health information systems on migrants has also been recognized in conclusions of the Council of the EU (Council of the EU 2010) and declarations and recommendations of the Council of Europe (Committee of Ministers 2006; Council of Europe 2007)". Rechel et al. in Rechel et al (Eds.) (2011) Migration and health in the European Union. eBook: available at: http://www.euro.who.int/__data/assets/pdf_file/0019/161560/e96458.pdf

[35] See: https://ec.europa.eu/health/sites/health/files/migrants/docs/personal_health_record_en.pdf [accessed 12 August 2018)

[36] It is worth noting the use of the term 'refugees' here: http://www.euro.who.int/en/media-centre/events/events/2015/11/high-level-meeting-on-refugee-and-migrant-health/news/news/2015/11/europe-is-europe-because-of-migration-highlights-from-day-2-of-the-high-level-conference-on-refugee-and-migrant-health.

[37] EPRS: European Parliamentary Research Service (2016). *The public health dimension of the European migrant crisis.*

[38] The project "CARE – Common Approach for REfugees and other migrants' health" aimed to promote a better understanding of refugees and migrants' health condition and in particular towards the health needs of fragile subgroups, such as minors, pregnant women and victims of violence, available at: http://careformigrants.eu/the-project/

[39] 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. Available at: http://re-health.eea.iom.int/re-health

[40] Project RE-Health2 –"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

Greece, Slovenia, and Croatia. Under CARE, Malta was also included. Funded by the European Union's Health Programme (2014-2020), the 'CARE' project aims to improve knowledge of, and to better respond to, migrant and refugee health needs, particularly in EU Member States experiencing strong migration pressure. The important objectives include putting into place appropriate health care responses, as well as improving control of infectious disease risk at the early stages of migrant's care, starting with medical assessment and treatment at reception centres at point of entry. This response would be further supported by better empowerment of health and non-health professionals (e.g. medical practitioners, social workers and cultural mediators) to tackle the specific needs of vulnerable migratory groups, especially women and children. More broadly, and which is an increasing consideration in the current political climate in Western nations, the project seeks to improve knowledge and awareness in general public with regard to true and false health narratives about migrants and refugees. Similarly, Re-Health/re-Health2, launched in 2016 by the Migration Health Division of the International Organization for Migration's (IOM) Regional Office in Brussels, seeks to support the capacity to provide healthcare to newly arrived migrants and refugees to the EU Member States under particular migratory pressure. In particular, this response seeks to rebuild the medical history of newly arrived migrants, facilitate transit to destination countries of this health data and to foster its integration in national health systems, supporting not just migrants, but also to ease pressures on health professionals and systems. As with the 'CARE' Project, key objectives include addressing the health-related issues of migrants arriving at key reception centres, as well as preventing and preventing possible communicable diseases.

Overall, 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 at reception centres are detected[41], 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. For both projects, a central component of their approaches is the development of a cross-border electronic personal health record (ePHR) system that is designed specifically for the healthcare needs of migrants.

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as also through supporting and fostering use of and capacity-building of health mediators**",** available at: http://re-health.eea.iom.int/

[41] For a legal analysis see Frischhut, M., & Greer, S. L. (2017). EU public health law and policy – communicable diseases. In T. K. Hervey, C. Young, & L. E. Bishop (Eds.), *Research Handbook on EU Health Law and Policy* (pp. 315–346, at pp. 339-340). Cheltenham: Edward Elgar Publishing.

CARE[42] developed an ePHR in the form of a USB stick that combined with software to enables trained health personnel to modify the data stored on the stick and in a data cloud. The USB sticks were distributed to a small number of migrants, and healthcare professionals were given a comprehensive manual on the usage of the corresponding software. The ongoing RE-Health2 initiative is also devoted to building an electronic database for migrants' health data, with a focus on data protection under different European guidelines. RE-Health brings together stakeholders in migrant health in order to establish a solid network for further collaboration. Additionally, RE-Health is aimed at training "health mediators": personnel with the intercultural skills needed to illustrate the benefits of health assessment to migrants, and to ensure that the basic human rights of patients are protected. Importantly, the expansion and use of ePHRs is 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.

Benefits of migrant-centric ePHRs initiatives

A successful implementation of such pan-European migrant-centric ePHR initiatives would allow healthcare practitioners (also incl. social workers, etc) across different European jurisdictions to address a number of issues that face vulnerable migrants. The migration between countries creates significant difficulties in maintaining accurate up-to-date personal health records when relying on traditional paper records. This may result in problems and inefficiencies both for the patients and for their healthcare practitioners, for instance through duplication of vaccinations or lack of awareness of current medications or previous adverse reactions to treatments. Thus, it seems clear that tailored 'migrant-centric' cross-border eHealth services would be beneficial. Cross-border eHealth initiatives might also serve the interests of countries receiving migrants by saving resources and avoiding duplication of the workload in health services already running on limited resources.[43] In summary, without the further development of such cross-border eHealth initiatives, there are a number of migrant-specific issues that may arise or be exacerbated [see table 1].

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[42] 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

[43] Mytton, R.C.C. "Estimating infectious disease in UK asylum seekers and refugees: a systematic review of prevalence studies". Journal of Public Health, October 8, 2007, p. 1-9: 8.

Table 1: Some problems faceing migrants, especially without ePHRs[44]

- Inadequate monitoring of migrants' health, as they pass from jurisdiction to jurisdiction.
- Inefficient and cost-ineffective use of public health funds, especially in crisis situations where healthcare professionals, medication and other medical resources may be in short supply.
- Inadequately addressing of the complex and special needs of vulnerable groups (such as women, children and the elderly as well as disabled persons) at greater risk of suffering.[45]
- Inadequate response to special needs of migrants[46] where the fact of forced migration itself can have significant effects on people's health[47]
- Inadequate monitoring of special needs resulting from torture and other trauma

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Regarding the special needs of women, forced migrants run higher risk of unwanted pregnancy, induced abortion, sexually transmitted infection, HIV, experiences of sexual violence.[48] Moreover, such special needs are not limited to pregnant and lactating women. Thus, they have special needs in health care which may often be missed, or only partially met, if the medical practitioners had no access to health monitoring over time and locations. The issue is complicated by the fact that European countries differ with respect to legislation and practices on abortion, contraception and other reproductive issues[49]. WHO reports, for example, that:

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[44] While the focus here is most centrally on migrant needs themselves, such initiatives can improve the abilities of all relevant actors – from healthcare workers to governments to NGOs.

[45] E.g. elderly persons, persons with a long-term disease, persons suffering from rare diseases, pregnant women, disabled people, persons who have undergone torture, rape or other serious forms of psychological, physical or sexual violence, or minors who have been victims of any form of abuse, neglect, exploitation, torture, cruel, inhuman and degrading treatment or who have suffered from armed conflict. Cf. Directive 2011/95/EU of the European Parliament and of the Council of 13 December 2011 on standards for the qualification of third-country nationals or stateless persons as beneficiaries of international protection, for a uniform status for refugees or for persons eligible for subsidiary protection, and for the content of the protection granted, OJ 2011 L 337/9, available at: http://eur-lex.europa.eu/eli/dir/2011/95/oj, Art. 30(2). Vulnerable people are also addressed in Directive 2013/33/EU of the European Parliament and of the Council of 26 June 2013 laying down standards for the reception of applicants for international protection, OJ 2013 L 180/96, available at: http://eur-lex.europa.eu/eli/dir/2013/33/oj, Art. 25 (victims of torture and violence with regard to appropriate medical care etc.), as well as in Art.19(1) (healthcare for vulnerable persons). The application of the latter Directive has been extended to Ireland by OJ 2018 L 126/8.

[46] 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".

[47] Janssens, K., Bosmans, M., Leye, E. & Tammerman, M. 2006. "Sexual and Reproductive Health of Asylum Seeking and Refugee Women in Europe: Entitlements and Access to Health Services". *Journal of Global Ethics* 2(2), 183-196.

[48] Ibid.

[49] 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: https://www.cammigres.group.cam.ac.uk/researchfrontpage/copy_of_MigratingWomen_report_MSA_MA.pdf). For a fuller analysis on issues raised on the EU front in the context of technologically assisted reproduction, see Frischhut, M. (2017). Legal and Ethical Issues of Cross-Border Reproductive Care from an EU Perspective: Chapter 17. In M. K. Smith & L. Puczkó (Eds.), *The Routledge Handbook of Health Tourism* (pp. 203–218). London, New York: Taylor & Francis.

> Contraception use varies across the European Region. In some countries many women who need modern contraception do not get it. They may have to cope with poor quality of services, difficult access, high cost, custom and other cultural factors and many countries have a high unmet need for contraception and this has a greater impact on women's health and well-being across the life-course.[50]

The improved monitoring of and response to such healthcare needs would be complimented by the possibility that such eHealth solutions might also offer valuable data to create a more solid evidence base regarding migrant healthcare, and allow a more effective use of existing data, for example in order to formulate well-grounded policies or implement a permanent public health follow-up system. We believe that initiatives such as CARE and Re-Health/ Re-Health2 should be evaluated with regard to whether they allow capturing information on the above-mentioned factors, and whether they improve how these are addressed in practice.

Ethical, legal and social issues and challenges to migrant-centric ePHRs initiatives

Unfortunately, despite their merits, neither CARE nor Re-Health/Re-Health2 seem to place sufficient emphasis on ELSI considerations: their practical focus is mostly the practicalities of operationalizing the technology. Under a 'migrant-centric ePHR' or in a general eHealth system, it is important that proposed e-tools are ethically, socially and legally robust. Otherwise, these initiatives would not only fail adequately to address such problems facing vulnerable migrants, but would risk causing additional difficulties. For instance, in the case of CARE, the above-mentioned software manual for health professionals lacks information on safe handling of patient data or further ethical, legal and social issues. In the user manual, there is no mention of concepts that would seem important in this context, for example, 'ethics', 'social concerns', 'vulnerable' and so on.[51] 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 a number of legal documents on their website regarding data protection, but no other ethical issues (such as vulnerability, solidarity, fairness or justice) are mentioned.[52]

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[50] http://www.euro.who.int/en/health-topics/Life-stages/sexual-and-reproductive-health/activities/contraception

[51] See: http://careformigrants.eu/wp-content/uploads/2017/08/CARE-HTMS-User-manual.pdf

[52] See: http://re-health.eea.iom.int/e-phr; 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 (http://www.ethikrat.org/dateien/pdf/stellungnahme-big-data-und-gesundheit.pdf) 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 http://nuffieldbioethics.org/wp-content/uploads/DataEthics_ExecutiveSummary.pdf and

As a minimum, it would seem uncontroversial that migrant-centric ePHRs initiatives should adhere to and promote basic values and principles of the UN Declaration of Human Rights[53] and health care provision in liberal societies. This also includes taking into account the values enshrined in Article 2 Treaty on the European Union (TEU):

> The Union is founded on the values of respect for human dignity, freedom, democracy, equality, the rule of law and respect for human rights, including the rights of persons belonging to minorities. These values are common to the Member States in a society in which pluralism, non-discrimination, tolerance, justice, solidarity and equality between women and men prevail.[54]

There is an important relationship between specific health values of the EU (e.g. universality, access to good quality care, equity, and solidarity) and 'operating principles' (e.g. quality, safety, care that is based on evidence and ethics, patient involvement, redress, privacy and confidentiality). While we would view values as being more abstract than principles in this relationship, as the former lack specific limitations, in particular with regard to specific legal consequences and addressees, we note that principles and values are both necessarily interlinked.[55] The 2018 Report on digital ethics in the European context also applies the general values of the EU to digital ethics, thus addressing dignity, freedom, autonomy, solidarity, quality, democracy, justice and trust.[56] For the purposes of this paper, we hold the view that the different values at stake can be approached through the classical four basic principles of biomedical ethics: respecting autonomy, non-maleficence, beneficence and justice[57]. It is important to note that we recognise that principalism is not the only way to analyse the situation and we are aware of the problems of an exclusive focus on the four principles method. While we intend for the four principles to be understood very widely (e.g. the principle of justice can be seen to include solidarity), we do recognise that a wider focus on solidarity, feminist ethics and an ethic of care can also yield vital additional insight, with different concerns highlighted and different responses

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http://nuffieldbioethics.org/report/collection-linking-use-data-biomedical-research-health-care/population-research-data-initiatives).

[53] United Nations.Universal Declaration of Human Rights.UN website.http://www.un.org/en/universal-declaration-human-rights/ April 26, 2018. Accessed June 16, 2018.

[54] https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:12016M/TXT. Most of the provisions of the Charter of Fundamental Rights of the European Union (CFREU, OJ 2016 C 202/389) are not only addressed to EU citizens, but to all human beings, thus also migrants. E.g. Art. 1 (human dignity), Art. 3 (right to integrity, including free and informed consent), Art. 7 (respect for private and family life), Art. 8 (data protection), Art. 21 (non-discrimination), Art. 23 (equality between women and men), Art. 24 (rights of the child), Art. 25 (rights of the elderly), Art. 25 (integration of persons with disabilities), as well as, from a procedural lens, Art. 47 (effective remedy and fair trial). Both documents available at: https://eur-lex.europa.eu/collection/eu-law/treaties.html.

[55] Reimer, F. (2003). Wertegemeinschaft durch Wertenormierung?: Die Grundwerteklausel im europäischen Verfassungsvertrag. *Zeitschrift Für Gesetzgebung,* 208–217: p.209. (OJ 2006 C 146/1).

[56] Ethics Advisory Group. (2018). *Towards a digital ethics: Report by the Ethics Advisory Group established by the European Data Protection Supervisor, the EU's independent data protection authority.*

[57] Beauchamp, T.L. and Childress, J. Principles of Biomedical Ethics. Oxford University Press, 2013, 7th edition.

offered.[58] For the more extensive work of fully developing our ELSI recommendations, we would include an evaluation of a wider range of normative perspectives than we do here.[59]

However, our present purposes is the first step to importantly, and urgently, draw attention to the risks facing migrant-centred ePHR initiatives that are developed seemingly without ELSI considerations incorporated at all. To this end, we focus on raising this red flag by highlighting *some* problematic issues that are already evident with a focus on one sub-set of ethical principles. We anticipate that a more extensive analysis will highlight a wider number of challenges, using a wider normative framework, and, consequently, we expect that this will result in more robust recommendations to offer. While acknowledging their limitations, these four principles have been used widely in different contexts of biomedical/healthcare ethics and they can be taken to be quite inclusive regarding different ethically relevant issues – at least as a point of departure for highlighting ELSI considerations. Expanding upon the 'wide understanding' point above, the principles of beneficience and non-maleficence, for example, concern not just health related harms and benefits but also social, psychological and economic ones. Human dignity, basic human rights (such as right to life and freedom of thought) as well as privacy issues are also covered by these four principles. Violation of human dignity, restricting freedom of speech or violation of a patient's autonomy by insufficently clarifying subsequent medical procedures can all be seen as maleficient actions harming the person in question.The four principles are not based on any single general theory of ethics. Rather, a strength is that they are easy to accept from almost any theoretical point of view. Thus, they offer a relatively commonly shared basis for approaching health related ethical questions throughout different cultures and countries. Even though interpreting the principles into practical action recommendations may be challenging, they offer a good starting point for approaching the ELSI of the migrant-centric *ePHRs.* From the framework of the four principles, the beneficence of *ePHRs* solutions for migrants, health-care workers and governments can be realised, without maleficent consequences – especially for the most vulnerable part, the migrants. Transparency of content, access and use is crucial to respect the

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[58] For this wider focus, we would note the importance of such approaches evident in the literature such as Barbara Prainsack & Alena Buyx (2017) *Solidarity in Biomedicine and Beyond*. Cambridge University Press [doi.org/10.1017/9781139696593]; Carol Gilligan (2014) 'Moral Injury and the Ethic of Care: Reframing the Conversation about Differences' *Journal of Social Philosophy* 45(1) Spring, pp. 89-106 [doi.org/10.1111/josp.12050]; Ben Hayes (2017) 'Migration and data protection: Doing no harm in an age of mass displacement, mass surveillance and "big data"'. *International Review of the Red Cross,* 99(904), 179-209. [doi:10.1017/S1816383117000637]; Lourdes Peroni & Alexandra Timmer (2013) 'Vulnerable groups: The promise of an emerging concept in European Human Rights Convention law' *International Journal of Constitutional Law* 11(4), October, pp. 1056–1085 [doi.org/10.1093/icon/mot042]

[59] Indeed, we have recently formed a European network to develop this direction, which will be evaluating a wide range of normative approaches in conjunction with a collaboration with a multidisciplinary range of stakeholders, in order to develop robust ELSI recommendations to be adopted by the initiatives under examination in this paper, as well as forming the framework for new initiatives.

autonomy and human dignity[60] of migrants, and to be trustworthy and trusted. Complete clarity of the aims and purpose of including all the specific kinds of information in the ePHR system should be offered.

Additionally, an extremely high standard of data security will be crucial for the migrants, whose further fate might also depend on who has access to their health data. As illustrated below, ePHR systems should be carefully set up to avoid discrimination, stigmatization or other forms of injustice, in terms of the kind of information included, access to this information, and use of this information. To reflect and implement these four principles (or equivalent) in migrant-centric ePHRs initiatives in a good way, questions like the following need to be addressed:

A. *What kind of information will be and should be stored in the eHealth system?*

This question pertains to all citizens, but creates special challenges with respect to vulnerable migrants. *Firstly*, should a person's status as asylum seeker, refugee or undocumented migrant be stored in the eHealth record? On the one hand and from the point of view of beneficence, it might be useful for spotting special health needs of individuals who are members of these groups.[61] On the other hand, being an asylum seeker, refugee or undocumented migrant is not health information or medical information, per se. People might find recording their status stigmatising and might fear that information could be used against their interests. Thus, also principles of non-maleficence as well as respecting autonomy are relevant to this question.

Secondly, should health information that can be used for non-health-care purposes in some jurisdictions be stored in the eHealth system at all? Some European states use information about asylum seekers' psychological and medical states for other purposes than enhancing his or her health.[62] This creates a challenge especially in the following two instances:

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[60] Human dignity is key, as it is the 'corner stone' of the EU's values; Frischhut, M. (2015). "EU": Short for "Ethical" Union?: The Role of Ethics in European Union Law. *Heidelberg Journal of International Law*, 75(3), 531–577, at 565-569; See also Frischhut, M. (2019, forthcoming). *The Ethical Spirit of EU Law*. Cham: Springer International Publishing.

[61] Mytton, R.C.C. "Estimating infectious disease in UK asylum seekers and refugees: a systematic review of prevalence studies". Journal of Public Health, October 8, 2007, p. 1-9: 6; On special health needs see e.g. Hebebrand, J., Anagnostopoulos, D., Eliez, S. et al. Eur Child Adolesc Psychiatry (2016) 25: 1. https://doi.org/10.1007/s00787-015-0807-0 and Langlois EV, Haines A, Tomson G, Ghaffar A. Refugees: towards better access to health-care services. *Lancet (London, England)*. 2016;387(10016):319-321. doi:10.1016/S0140-6736(16)00101-X.

[62] Directive 2013/32/EU of the European Parliament and of the Council of 26 June 2013 on common procedures for granting and withdrawing international protection, OJ 2013 L 180/60, available at: http://eur-lex.europa.eu/eli/dir/2013/32/oj, Art. 25(5).

1. In many European countries, asylum seekers go through screenings for infectious diseases upon arrival. Typically, asylum seekers are screened for HIV and tuberculosis, but can also be screened for parasites, hepatitis B, syphilis and malaria. Countries differ with respect to which health screenings (if any) are compulsory and which voluntary. Some screenings may be compulsory only for certain groups (e.g. pregnant women or individuals coming from high prevalence countries).[63]

The aim of these screenings is threefold: (a) to benefit the health status of the screened individual, (b) to prevent the spread of infectious diseases in the host country, and (c) to familiarise the asylum seeker with the health care system of the target country.[64] Sometimes the second aim may contradict with the interests of the vulnerable migrant and thus rises questions regarding autonomy, beneficence to the society and non-maleficence towards the individual migrants. The migrants may, for example, fear stigmatization and wish not to be tested for certain diseases. There has been evidence, for example, that asylum seekers are not willing to take HIV tests, as they fear the positive result might lead into deportation.[65]

If screenings are done mainly or solely to protect others from a disease an individual may carry, should its results be stored in the eHealth system? From the point of view of justice, it is notable that the kinds of screenings described are not usually compulsory for other people living and travelling in Europe. On the other hand, in many countries medical professionals have legal duties to report specific communicable diseases (e.g. hepatitis A, measles or ebola) that might be a risk to public health.

2. In some countries, immigrant authorities use or have used medical information to make a choice on whether a person is admitted with refugee status. Applications for refugee status sometimes include medical reports written by medical doctors. The immigrant authorities are interested in questions such as "Are the asylum seekers' clinical signs and symptoms consistent with the alleged traumatic events on which the refugee claim is founded?" and "Is the asylum seekers' ability to adequately present her or his case […] affected by her or his mental or physical health?"[66] It is hard to find out whether and to which extent medical information is currently used in this way in Europe. However from the point of view of non-maleficence, the mere possibility of this kind of usage of

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[63] Norredam, M., Mygind, A. and Krasnik, A. 2006. Access to health care for asylum seekers in the European Union – comparative study of country policies. European Journal for Public Health 16(3), 285-289: 286-287

[64] ibid, 288.

[65] Mytton 2007, 7. For a legal analysis see Frischhut, M., & Greer, S. L. (2017). EU public health law and policy – communicable diseases. In T. K. Hervey, C. Young, & L. E. Bishop (Eds.), *Research Handbook on EU Health Law and Policy* (pp. 315–346, at pp. 339-340). Cheltenham: Edward Elgar Publishing.

[66] Cleveland, J. & Ruiz-Casares, M. (2013) "Clinical Assessment of Asylum Seekers: Balancing Human Rights Protection, Patient Well-being and Professional Integrity". *The American Journal of Bioethics* 13 (7), 13-15. See also Weinstein, H.M. &Stover, E. (2002) "Asylum Evaluations – The Physician's Dilemma". *Cambridge Quarterly of Health Care Ethics* 11, 303-318, and Asgary, M. & Smith, C.L. (2013) Ethical and professional Considerations Providing Medical Evaluation and Care to Refugee Asylum Seekers. *The American Journal of Bioethics* 13(7), 3-12.

medical data is enough to raise questions about which information should be stored. A further example are *age evaluations* of asylum seekers. Under-age asylum seekers enjoy some benefits not available to adult asylum seekers. Officials may not believe that a person who claims to be under-age really is so. In such cases EU member states are expected to carry out medical age-evaluations. The Asylum Procedures Directive reads as follows:

> 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 where, following general statements or other relevant indications, Member States have doubts concerning the applicant's age.[67]

The age of asylum seekers is determined by medical means such as x-rays of teeth and bones.[68] Other medical information (e.g. results of gene tests) may also be used in cases of uniting family members. If medical information is used for these purposes in some countries, and not for enhancing health of the individual in question, should it be stored in the eHealth system and shared with other countries? Against that background and the principle of respecting autonomy, should vulnerable migrants be able to control whether the types of medical information described are stored to the eHealth system? This leads us to a fundamental question: What counts as health information that should be included in a migrant's health record? A variety of considerations will determine whether inclusion of such information in an electronic health record will be appropriate.

B. Defining and controlling who will have access to the information.

Since the information collected by medical means (x-rays, gene tests, etc.) might be used for other purposes than enhancing the health of the individual in question, a further question is: who should have access to the information stored in the eHealth system? In particular, should immigrant authorities have access to information that may be relevant to the refugee application?

If medical information that may be used for other purposes than enhancing an individual's health *is* stored in the eHealth system, we suggest that for the reason of privacy there is a need to distinguish between those parts of eHealth records that can and cannot be given to immigrant authorities. On basis of all four principles (and we imagine related principles and values would concur), we would argue that certain kinds of information when used for non-healthcare purposes of adversely affecting

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[67] Art. 25(5) Directive 2013/32/EU.
[68] Sauer, P.J.J., Nicholson, A., Neubauer, D. et al. Age determination in asylum seekers. Eur J Pediatr (2016) 175: 299. https://doi.org/10.1007/s00431-015-2628-z and Metsäniitty, M., Varkkola, O., Waltimo-Sirén, J. et al. Forensic age assessment of asylum seekers in Finland.Int J Legal Med (2017) 131: 243. https://doi.org/10.1007/s00414-016-1498-x

refugee status,should not be given to authorities.[69] While some aspects of such information might be helpful for health policy formation, the medical privacy rights of the individual should be taken seriously. Protection of information from wrongful access is also important insofar as the health information may be a valuable commodity to various groups – from commercial entities with inadequate focus on meeting migrant needs[70] to emerging, technologically proficient far-right organisations and, as such, may entail a personal security risk for the migrants themselves if effective access restrictions are not in place.

C. *Avoiding misuse and misunderstandings regarding the eHealth system*

Mistrust and suspicion are common among asylum seekers, refugees and undocumented immigrants.[71] An ehealth recording may be a further source of mistrust, especially if there is a language barrier, unfamiliarity with digital records, and cultural differences. 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. Furthermore, there are questions regarding whether storage in a database deprives the migrant of any possibility to control the data, and to what degree this should be facilitated. The understanding of individual autonomy, confidentiality and privacy differs between cultures.[72] Designers of eHealth records need to be cognizant of potential fears and misuses in the design of the records, and need to be aware whether health-related information has potential to be used in ways harmful or discriminatory to migrants by various groups. For example, refugees who have been persecuted and still fear for their lives might perceive an eHealth record that records their location as highly problematic. Similarly, for an undocumented immigrant a mere record of where he/she has been may be problematic – at least if they do not have the right to be in the country in question.[73] This might be prevented if the location were not stored in the system. However, a

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[69] This use of health information for adversely affecting refugee assessments would, for instance, fail the principle of beneficience or the specific EU health value of solidarity. It should be noted that our argument here is to avoid the wrongful use by immigration authorities of health information that is collected for healthcare purposes and we are not addressing a seperate question of what information immigration authorities should collect themselves. This "firewall argument" has been addressed by Carens, J. H. (2015). *The ethics of immigration*. Oxford: Oxford University Press, pp. 137ff.

[70] This is not to say that all commercial entities are necessarily suspect, but only that some might be.

[71] Janssens, K., Bosmans, M., Leye, E. &Tammerman, M. 2006. "Sexual and Reproductive Health of Asylum Seeking and Refugee Women in Europe: Entitlements and Access to Health Services". Journal of Global Ethics 2(2), 183-196.

[72] Eklöf, N., Abdulkarim, H., Hupli, M, &Leino-Kilpi, H. (2016) Somali asylum seekers' perceptions of privacy in healthcare.*Nursing Ethics*.Aug;23(5):535-46. doi: 10.1177/0969733015574927.

[73] Similarly to Rechel et al. in Rechel et al (eds) (2011)*Migration and health in the European Union* "Indeed, migrants themselves may be reluctant to reveal information on their migration status or related variables. They may – not without justification (European Union Agency for Fundamental Rights 2010) – fear discrimination, stigmatization, exclusion or, in the case of undocumented migrants, even denunciation and deportation (Ingleby 2009; Gushulak 2010; WHO 2010)" (84). eBook: available at: http://www.euro.who.int/__data/assets/pdf_file/0019/161560/e96458.pdf

satisfactory solution requires further consideration/investigation, given that as long as the health care professionals storing the data are identified (which is usually seen important), the locations can be potentially detected.

Recommendations: the urgent need to address ELSI-related challenges

The above points A to C outline some ELSI-related concerns that can arise with any migrant-centric ePHR initiatives. While not exhaustive (and by no means attempting to be so), it should be already evident that such initiatives need to take ELSI-related challenges seriously, and that ELSI needs to be far more central than seems evident at present. There are immense benefits that migrant-centric ePHRs can bring and these should be safeguarded with robust migrant-centric ELSI protections in place, to prevent or mitigate potential unintended negative consequences arising from the use of ePHRs. This can be seen in, at least, the following four respects: Re-framing and fairly representing migrants in public discourse; improving participation and autonomy of the migrants in terms of their own healthcare; monitoring and evaluation; and awareness-raising and trust building.

In much of the literature, including in the two aforementioned initiatives (CARE, Re-Health/Re-Health2), there is a depiction portrayed of migrants mostly seen as "carriers of disease", while far less focus is given to issues like benefits for migrants suffering from chronic disease, dealing with trauma as well as the many maternal health issues highlighted above. This notion is also reflected by a EuroHealthNet policy paper on health needs of migrants.[74] This suggests that much emerging attention toward migrant health is viewed predominantly through the medical lens, without sufficient understanding of the important ethical, legal and social issues at stake. This is particularly urgent in cases of pregnant women, unaccompanied minors, persons with disabilities, the elderly or strongly traumatized patients. This is in compliance also with the Basic Ethical Principles in European Bioethics and Biolaw, relating to autonomy, dignity, integrity, vulnerability[75], and with the principle of respect for human vulnerability and personal integrity of the Report of the International Bioethics Committee of UNESCO.[76]

ELSI should also be carefully addressed where language, culture or funding barriers that might lead to difficulties in updating, understanding and use of any electronic medical devices. Treating migrants as

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[74] EuroHealthNet, Policy précis (2016) Making the link: migration, refugees and health needs, available at: https://eurohealthnet.eu/publications/policy-precis (accessed on 25 June 2018).

[75] P. Kemp, J. Dahl Rendtorff, The Barcelona Declaration Towards an Integrated Approach to Basic Ethical Principles, SYNTHESIS PHILOSOPHICA, 2/2008, pp. 239–251.

[76] IBC, 2013 http://unesdoc.unesco.org/images/0021/002194/219494E.pdf

a single, cohesive group is very problematic, especially when there are significant individual and cultural differences among them (e.g. toward contraception, abortion and so on). While there are significant benefits to the development of migrant-centric ePHRs, these tools could also be used against migrants' own interests. This is crucial when it comes to information concerning the physical or psychological condition of the migrant, which could influence the residency status of the person.

Additional safeguards are needed to ensure that health data are not used for other purposes than medical ones, but with a central and persistent focus on achieving the migrant's consent and understanding. In addition, given the frequently reduced level of control that migrants have over their lives, a robust ELSI-related focus could foster discussion toward further improvements in terms of migrants' control of their own healthcare. For instance, it may be possible to enable migrants to greater control over their own information or ask a health profession person (including physicians and hospital staff of all health professions) to update the migrant´s health record, on their behalf.[77]

Data collection methodologies must be firmly grounded in ethical principles and should not re-traumatize or otherwise harm migrants, ensuring that these technologies are never employed to facilitate discriminatory profiling of migrants, or to increase their vulnerability to surveillance. Personal data should be handled in a manner that protects confidentiality and the security of such data must be strongly protected to ensure the access of all migrants to their personal data, including data that are stored in automatic data files, and to enable migrants to request rectification or elimination of incorrect or wrongly assigned data.

These kinds of novel possibilities regarding control over one's data would likely contribute to the building of trust and thus enhance the usage of the ePHR.

Further issues that still need to be addressed concern acute or emergency situations where patients are non-conscious and thus unable to provide the permission (and the password) to the health care professionals, but where availability of information from the health record might contribute crucially to their treatment.

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[77] For instance, whenever a migrant uses the health system in any EU country, the form could be updated and recorded using the memory stick or uploading to a cloud–based site with the migrant themselves as sole or co-gatekeeper to the flow of the information. Doctors and health professionals who take care of the individual may get access to the cloud-based data with the permission (and password) of the individual. Importantly, access to the data should not be requirement for care. Thus, individuals would enjoy a high level of autonomy with respect to their health data. In this paper, we are only noting this as one possibility that should be subject to future analysis. On one hand, it is in keeping with building trust as well as dovetailing with increased patient participation in the wider medical and medical research contexts (for examples, see: Feeney, O. et al. (2018) 'Genuine participation in participant-centred research initiatives: the rhetoric and the potential reality' Journal of Community Genetics, Volume 9, Issue 2, pp 133–142; see also: http://www.bmj.com/content/346/bmj.f2614

Conclusion

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 they are adjusted to face specific ELSI–related challenges, especially concerning the storage and access to personal data of the migrant. Although Directive 2011/24/EU on cross-border healthcare has been setup for EU citizens, it uses a neutral wording with regard to "medical records", which could also be utilised in our ELSI-related context. However, as we have shown, a greater attention to ELSI is needed. Based on the urgent ELSI concerns identified in this paper, we conclude that there should be a much stronger focus on creating robust ELSI-related guidelines for the ongoing development and use of migrant-centric ePHRs to ensure that such records can make an effective contribution to care in line with migrants' own needs and preferences. Legal and ethical requirements can meet and complement each other, if the general and the health-specific values of the EU (as well as those in the field of digitalization) are respected and filled with life. Overall, the right to (digital) healthcare can be better implemented via a system that highlights the irrelevance of borders and the centrality of human solidarity.