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GENETIC COUNSELING AND PREVENTIVE MEDICINE IN BOSNIA AND HERZEGOVINA

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INTRODUCTION

In September of 2015, fourteen governments, which make up Bosnia and Herzegovina (BiH),[1] devised a set of proposals for reform in several fields of national development, including healthcare.[2] The fourteen governments included the Council of Ministers of Bosnia and Herzegovina, the Government of the Federation of Bosnia and

1. The abbreviation is Bosnian for Bosnia i Hercegovina. The author prefers this acronym over alternative expressions like "B&H," given the seeming awkwardness of the ampersand in that coinage, as well as over "BH" which elides the "and." BiH is alternated in this Article with Bosnian. This is a term of adjectival/adverbial convenience that, rather than designate only Bosnians (one of the major ethnic groups in BiH), instead encompasses all citizens, including Croats and Serbs, the two other major ethnic groups of the country. In other words, although technically inaccurate, in the sense it is used in this Article, the designation is informal, and there is no suggestion that it is the exact equivalent or substitute for the full name.

2. *See generally* Reform Agenda for Bosnia and Herzegovina 2015-2018 (Working Translation), http://europa.ba/wp-content/uploads/2015/09/Reform-Agenda-BiH.pdf, *archived at* https://perma.cc/X385-JW5K [hereinafter Reform Agenda for BiH] (listing the proposals, which include measures of fiscal consolidation and six structural areas of importance, namely: public finance, taxation and fiscal sustainability; business climate and competitiveness; the labor market; social welfare and pension reform; rule of law and good governance; and public administration reform).

Herzegovina (FBiH),[3] the Government of Republika Srpska (RS), the Government of Brčko District, and the governments of the ten Cantons in FBiH—Una-Sana, Posavina, Tuzla, Zenica-Doboj, Bosnia-Podrinje, Central Bosnia, Herzegovina-Neretva, West Herzegovina, Sarajevo, and Canton 10 (West Bosnia Canton) (collectively "the parties").[4] All, except the Council of Ministers of Bosnia and Herzegovina, constitute the BiH healthcare system, which is organized around two entities, plus a self-governing unit—FBiH and its ten Cantons, RS, and Brčko District[5]—as elaborated upon later in this Article.

Broadly, the parties "recognize[d] an urgent need to initiate a process of rehabilitating and modernizing the economy . . . to foster[] sustainable, efficient, socially[-]just and steady economic growth, [and] creat[e] new jobs," among other goals.[6] Referencing healthcare specifically, the parties pledged to curtail "the burden on labor needs . . . by reducing contributions for health insurance, coupled at the same time with the need to ensure additional revenues for extra-budgetary funds to cover the losses generated as a result of the reduced contribution rate."[7] Additionally, the parties pledged to "seek financial and technical assistance [from] the World Bank to implement" several aspects of healthcare reform, such as "a solution for outstanding debts . . . and the definition of new models and sources of funding, with a more precise regulation of the network of health care institutions."[8] Finally, BiH authorities committed to "support an increase in excise duties on tobacco and alcohol which will be the direct income of the health insurance fund of the RS and health insurance funds in the FBiH,

3. The abbreviation of this unit includes an "i" in place of "and" for the same reason indicated in *supra* note 1 with respect to the state-level government.

4. Reform Agenda for BiH, *supra* note 2, ¶ 1.

5. The fact that both technically and substantively the state-level government is not part of the BiH healthcare system is an odd feature that this author returns to later in this Article. *See* text to *infra* note 225 and Part V.C.

6. Reform Agenda for BiH, *supra* note 2, ¶ 1. The document disclosed that "[c]oncrete actions aimed at fiscal and financial sustainability and socio-economic reform will be augmented by targeted measures: to strengthen the rule of law and the fight against corruption; and to strengthen administrative capabilities and increase efficiency in public institutions at all [fourteen] levels of government." *Id*.

7. *Id*. ¶ 8.

8. *Id*.

Cantons[,] and Brčko District by the end of 2015."[9] In an important study published in 2001, the Office of the United Nations High Commissioner for Refugees (UNHCR), based in Sarajevo, found "an increased demand from many sectors for improved and comprehensive information on the workings and quality of the health care system in Bosnia and Herzegovina."[10] These heightened demands for a more transparent healthcare system culminated in BiH authorities' pledging the above-mentioned healthcare reforms.

Bosnia and Herzegovina is a state of two entities, plus a self-governing unit, akin to a federation, dominated by three constituent ethnicities.[11] Geographically speaking, the country is located in south-eastern Europe in the Western part of the Balkan Peninsula.[12] With a

9. *Id*.

10. Werner Blatter (Chief of UNHCR Mission in Bosnia and Herzegovina), *Foreword and Acknowledgments* to UNITED NATIONS HIGH COMM'R FOR REFUGEES, HEALTH CARE IN BOSNIA AND HERZEGOVINA IN THE CONTEXT OF THE RETURN OF REFUGEES AND DISPLACED PERSONS (July 2001) [hereinafter HEALTH CARE IN BIH].

11. The following are the two entities and their dominant ethnic groups: (1) FBiH, controlled by Bosniaks and Croats, and (2) RS, controlled by Serbs. FBiH makes up 51% of the landmass of BiH, while RS constitutes 49% of the territory. SAŠA GAVRIĆ ET AL., THE POLITICAL SYSTEM OF BOSNIA AND HERZEGOVINA: INSTITUTIONS, ACTORS, PROCESSES 16 (Saša Gavrić ed., Sarajevo Open Centre 2013). The self-governing unit, belonging to both entities, rather than controlled by any of them, is Brčko District, established in 2000, in the aftermath of the war. *Id*. at 23. "The dominant ethnic groups . . . define themselves through religion: Bosniaks through Islam, Croats through Catholicism and Serbs through Eastern Orthodoxy." *Id*. at 17. For an overview of the BiH political system, see *id*.; and Michaela Führer, *Bosnia-Herzegovina's Political System*, DW (Oct. 25, 2011), https://www.dw.com/en/bosnia-herzegovinas-political-system/a-15486583, *archived at* https://perma.cc/GT9X-ZMT. For an insightful discussion on the roots of federalism in BiH, including the studied choice of the framers of the 1995 Constitution to minimize portrayal of the country as a federal system, see SOEREN KEIL, FEDERALISM AS A TOOL OF CONFLICT-RESOLUTION: THE CASE OF BOSNIA AND HERZEGOVINA, 1(363) L'EUROPE EN FORMATION [EUROPE IN FORMATION] 205 (2012), https://www.cairn.info/revue-l-europe-en-formation-2012-1-page-205.htm.

12. Depending on who is doing the counting and analysis, the Balkan Peninsula and region comprises ten or eleven states or political communities: Albania, Bulgaria, Croatia, Greece, Kosovo, Macedonia, Montenegro, Romania, Serbia, Slovenia, and, for some, Turkey. Along with BiH, some of these territories—Croatia, Kosovo, Macedonia, Serbia, and Slovenia—were part of the former Yugoslavia. John B. Allcock et al., *Balkans*, ENCYCLOPEDIA BRITANNICA, https://www.britannica.com/place/Balkans, *archived at* https://perma.cc/NG3U-JPAZ.

landmass of 51,129 square kilometers, BiH is comparable in size to the State of West Virginia in the United States (62,755 square kilometers), Croatia (56,594 square kilometers), and Slovakia (49,037 square kilometers).[13] With a total boundary length of 1,389 kilometers, BiH is bordered and surrounded by Croatia to the north, Serbia and Montenegro to the east, and the Adriatic Sea to the south.[14] Based on the pre-war census, in 1991, BiH had a population of 4.5 million people.[15] However, according to the latest 2013 census, BiH has a population of 3.5 million people,[16] the majority of whom are Bosniaks.[17] Therefore, the BiH population has declined significantly over the course of two decades.[18] BiH is a post-socialist state with a service-based economy.[19] BiH is one of six components of former

13. *Bosnia and Herzegovina: Location, Size, and Extent*, NATIONS ENCYCLOPEDIA, http://www.nationsencyclopedia.com/Europe/Bosnia-and-Herzegovina-LOCATION-SIZE-AND-EXTENT.html, *archived at* https://perma.cc/V5CH-FWXW; *West Virginia Population 2020 (Demographics, Maps, Graphs)*, WORLD POPULATION REVIEW, https://worldpopulationreview.com/states/west-virginia-population/, *archived at* https://perma.cc/SM7M-28PW; *Croatia Population 2020*, WORLD POPULATION REVIEW, https://worldpopulationreview.com/countries/croatia-population/, *archived at* https://perma.cc/9LXA-F8RJ; *Slovakia Population 2020*, WORLD POPULATION REVIEW, https://worldpopulationreview.com/countries/slovakia-population/, *archived at* https://perma.cc/D4GB-77TA.

14. *Bosnia and Herzegovina: Location, Size, and Extent*, *supra* note 13.

15. JENNIFER CAIN ET AL., HEALTH CARE SYSTEMS IN TRANSITION: BOSNIA AND HERZEGOVINA 3 (Jennifer Cain & Elke Jakubowski eds., European Observatory on Health Care Systems 2002).

16. *Bosnia and Herzegovina Population*, WORLDOMETER, http://www.worldometers.info/world-population/bosnia-and-herzegovina-population/, *archived at* https://perma.cc/CJH7-3C7.

17. Rodolfo Toè, *Census Reveals Bosnia's Changed Demography*, BALKANINSIGHT (June 30, 2016), https://balkaninsight.com/2016/06/30/new-demographic-picture-of-bosnia-finally-revealed-06-30-2016/, *archived at* https://perma.cc/35DB-T2YZ. According to the results, Bosniaks made up 50.11%, Serbs 30.78%, and Croats 15.43%. *Id*.

18. *Compare id*. (stating a population of 4.5 million in 1991), *with* JENNIFER CAIN ET AL., *supra* note 15, at 3 (stating a population of 3.5 million in 2013, thus demonstrating a population decline of one million since 1991). In 1991, 43.7% of the population identified themselves as Bosniaks, 31.3% as Serbs, and 17.3% as Croats. JENNIFER CAIN ET AL., *supra* note 15, at 3.

19. In 2017, based on GDP share, the economy of the country consisted of the following sectors: services (64.3%), industry (28.9%), and agriculture (6.8%).

Socialist Federal Republic of Yugoslavia (SFRY).[20] SFRY existed from 1945 to 1992; however, its roots go back to the Kingdom of Serbs, Croats, and Slovens, which was formed in December of 1918.[21] Although it was not until 1943 that its present boundaries were determined as part of a boundary making exercise for the whole of Yugoslavia, Bosnian awareness of their statehood or autonomy "date[s] back to between the tenth and twelfth century."[22]

This Article explores methods for promoting increased access to healthcare in Bosnia and Herzegovina through the preventive healthcare that genetic counseling offers.[23] More specifically, using the preventive technique of genetic counseling, within the context of bioethics,[24] this Article focuses on feasible measures to improve access to quality healthcare in BiH, from a political and public funding standpoint.[25] BiH maintains an abiding commitment to socioeconomic human rights, including healthcare, that dates back to its socialist incarnation in Yugoslavia.[26] However, BiH citizens *enjoy* these rights at a superficial level.[27] This is due to multiple forces that individually and collectively impacted these guarantees, which developed primarily because of the destruction of health and related critical infrastructure

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Europe: Bosnia and Herzegovina, CENT. INTELLIGENCE AGENCY: THE WORLD FACTBOOK, https://www.cia.gov/library/publications/the-world-factbook/geos/bk.html, *archived at* https://perma.cc/3HMA-XXXX.

20. The others, alphabetically, were Croatia, North Macedonia, Montenegro, Serbia, and Slovenia, plus two autonomous provinces, Voljvodina and Kosovo, subsumed under Serbia. John R. Lampe & John B. Allcock, *Yugoslavia: Former Federated Nation [1929-2003]*, ENCYCLOPEDIA BRITANNICA, https://www.britannica.com/place/Yugoslavia-former-federated-nation-1929-2003, *archived at* https://perma.cc/Q2FB-8TL4.

21. *Id.*; *Kingdom of Serbs, Croats, and Slovenes: Historical Kingdom, Balkans [1918–1929]*, ENCYCLOPEDIA BRITANNICA, https://www.britannica.com/place/Kingdom-of-Serbs-Croats-and-Slovenes, *archived at* https://perma.cc/BCL2-8HV6.

22. JENNIFER CAIN ET AL., *supra* note 15, at 3.

23. The term genetic counseling is defined in *infra* Part I.

24. *See infra* note 103 and accompanying text.

25. For the logic behind this approach, see *infra* Part III.C. on the four hallmarks of a good healthcare system and their use as a guide for reforming healthcare in BiH.

26. *See infra* Part II (tracing the historical background of healthcare in BiH).

27. *See infra* Part III (analyzing the features of the healthcare system in BiH).

during the Bosnian War from 1992 to 1995,[28] and its aftermath, with negative ramifications for healthcare and preventive medicine.

In the light of the dismal scenario, it is arguable that, in both quantity and quality, the healthcare goods BiH governments provide today fall below the level in Western Europe and within the country itself before the War.[29] First, the level of healthcare services provided to insured persons falls below the level guaranteed by law.[30] Second, despite the promise of an inalienable right to healthcare, a large number of the populace lack access to healthcare services because they do not have insurance or they experience difficulty accessing healthcare despite having insurance.[31] Third, BiH's healthcare financing system is characterized by unabated deficits across the two entities of the country; these deficits threaten the integrity and sustainability of the healthcare systems,[32] at a time of increased public demand for healthcare services, coupled with rising expectations for these services.[33] A range of factors lead to this increased demand for healthcare services: an increase in the number of chronic diseases;[34]

28. *See* Stephen J. Kunitz, *The Making and Breaking of Yugoslavia and Its Impact on Health*, 94(11) AM. J. PUB. HEALTH 1894 (Nov. 2004) ("[T]he impact of the disintegration of [Yugoslavia] . . . on health care and public health systems has been profound. Improving and converging measures of mortality before the collapse gave way to increasing disparities afterward."); JENNIFER CAIN ET AL., *supra* note 15, at 17 ("[A]bout 30% of health facilities were destroyed or heavily damaged during the war. Of the 80 emergency clinics [in the country] before 1992, . . . only 46 [survived] the war."); M Carballo et al., *Development of an Essential Drugs List for Bosnia and Herzegovina*, 90 J. ROYAL SOC'Y OF MED. 331, 331-33 (June 1997), http://europepmc.org/backend/ptpmcrender.fcgi?accid=PMC1296311&blobtype=pdf (discussing the negative impacts of the war on the healthcare system, including healthcare infrastructure). For scholarly histories of the Bosnian war, see Steven L. Burg & Paul S. Shoup, THE WAR IN BOSNIA-HERZEGOVINA: ETHNIC CONFLICT AND INTERNATIONAL INTERVENTION (M.E. Sharpe, 2d ed. 1999); and Carole Rogel, THE BREAKUP OF YUGOSLAVIA AND THE WAR IN BOSNIA (Greenwood Publishing Group 1998).

29. HEALTH CARE IN BIH, *supra* note 10, at i, 25.

30. *Id*. at 23.

31. *Id*. *See also infra* notes 178-79.

32. MARKO MARTIĆ & OGNJEN ĐUKIĆ, FRIEDRICH EBERT STIFTUNG SARAJEVO, HEALTH CARE SYSTEMS IN BIH: FINANCING CHALLENGES AND REFORM OPTIONS? 20 (Oct. 2017), https://library.fes.de/pdf-files/bueros/sarajevo/14124.pdf.

33. *Id*. at 11, 13.

34. *Id*. at 24.

increased information availability and awareness; "new needs for health services" attributable to "the continuing development of medical technology";[35] and "the habit of irrational use of health care services [among the populace], without taking into account the financial capabilities of the previous and the current systems of public health care in BiH" that some analysts attribute to one of the legacies of socialist rule.[36]

"A stitch in time saves nine" is an adage at the crux of this Article.[37] One way Bosnian leaders can help optimize *enjoyment* of healthcare services in this country is through relatively inexpensive means, like genetic counseling, that are intrinsic to healthcare. Nowadays, the emphasis in many healthcare systems, developed and developing alike, is primary healthcare, analogized as medical attention short of complex examination and treatment, that does not sacrifice quality.[38] Primary

35. *Id*. at 13.

36. *Id*. As Martić and Đukić elaborated, "unlimited access to all services provided in the area of primary health care, a large number of specialist consultancy diagnostic services, hospital treatment in the country and abroad, spa facilities, hospitalization and a number of other health services, were available to the population at the time of [former Yugoslavia]." *Id*. *Contra* Muhamed Saric & Victor G. Rodwin, *The Once and Future Health System in the Former Yugoslavia: Myths and Realities*, 14(2) J. PUB. HEALTH 220 (1993), https://www.nyu.edu/projects/rodwin/future.html (contesting three images that the authors argue "[m]ost of the existing literature on the organization and financing of Yugoslavia's health system perpetuated"). The reference to "irrational use of health care services" in the text and claim of "unlimited access to all services" in primary healthcare in the first line of this footnote calls to mind the complicated doctrine of moral hazard in behavioral economics said to occur when a person or group of persons "take[s] risks without having to suffer [the] consequences" of their risky behavior. *See* Will Kenton & Brian Abbott, *Moral Hazard*, INVESTOPEDIA, https://www.investopedia.com/terms/m/moralhazard.asp, *archived at* https://perma.cc/Z9XK-NAKJ.

37. James Baquet, *A Stitch in Time Saves Nine*, SHENZHEN DAILY (Nov. 11, 2010, 8:53 AM), http://www.szdaily.com/content/2010-11/11/content_5073819.htm, *archived at* https://perma.cc/Z9WZ-C5J6. Or, as the American founding father Benjamin Franklin (1706-1790) equally memorably put it, "[a]n ounce of prevention is better than a pound of cure." Quoted in Tara Craig, *Healthcare Marketing Compliance in the UK—Prevention Beats Cure*, PMLIVE (July 1, 2014), http://www.pmlive.com/pharma_intelligence/healthcare_marketing_compliance_in_the_uk_-_prevention_beats_cure_581532, *archived at* https://perma.cc/BPW7-EZ33.

38. *See, e.g.*, HEALTH CARE IN BIH, *supra* note 10, at 12. The concept of preventive medicine here calls to mind the children's animal song about five little monkeys who jumped on the bed. Each of the five bumped its head, and on each

healthcare is what the World Health Organization (WHO)[39] defines as "the first level of contact of individuals, the family and community with the national health system . . . and . . . the first element of a continuing health care process."[40] Preventive medicine pursued through means like genetic counseling arguably falls into that first element of a continuing healthcare process. It also meets the European Social Charter's mandate that state parties "remove as far as possible the causes of ill health."[41] Moreover, the fear that individuals at risk of

occasion, Mama monkey dutifully called the doctor who in each instance administered a preventive medicine: no more monkeys jumping on the bed. Intriguingly, each of the five ignored the advice, whereupon, with the fifth also—predictably—bumping its head, the doctor advised that all five monkeys be put to bed. Preventive medicine seems so basic yet for some reason it is easily overlooked.

39. The WHO is a, if not, *the* global healthcare czar. Founded on April 7, 1948, the day set aside as World Health Day, the WHO "direct[s] and coordinate[s] international health within the United Nations system." *About WHO*, WORLD HEALTH ORG., http://www.who.int/about/en/, *archived at* https://perma.cc/9RSG-VFQ4. BiH became a member of this body following its admission into the United Nations on May 22, 1992. *Bosnia and Herzegovina & UN*, BHMISSIONUN, https://bhmissionun.org/bosnia-and-herzegovina-un-3/, *archived at* https://perma.cc/4TD4-4PX3; *Countries*, WORLD HEALTH ORG., https://www.who.int/countries/en/#B, *archived at* https://perma.cc/7C8L-QZ3T (listing BiH as a member).

40. World Health Organization, Declaration of Alma Ata, International Conference on Primary Health Care, Alma-Ata, USSR, art. VI (Sept. 6-12, 1978), http://www.who.int/publications/almaata_declaration_en.pdf. Arguably, primary healthcare goes deeper than this. The International Conference on Primary Health Care in Alma-Atta identified eight essential elements of primary healthcare that in its thoroughgoingness range beyond basic healthcare:

> (1) education concerning prevailing health problems and methods for addressing them; (2) promotion of food supply and proper nutrition; (3) provision of an adequate supply of safe water and basic sanitation; (4) maternal and child healthcare, including family planning; (5) immunization against the major infectious diseases; (6) prevention and control of locally endemic diseases; (7) appropriate treatment of common diseases and injuries; [and] (8) provision of essential drugs.

WORLD HEALTH ORGANIZATION, THE WORLD HEALTH REPORT 1995: BRIDGING THE GAPS 88 (Box 18) (1995) [hereinafter WORLD HEALTH REPORT 1995].

41. European Social Charter (Revised), E. T. S. No. 163 (1996), rm.coe.int/168007cf93, art. 11(1). In 2008, BiH ratified the instrument, but BiH only accepted fifty-one out of the ninety-eight paragraphs of the agreement. The provisions BiH did not accept included the system of collective complaints contained in an Additional Protocol of 1995, which it did not ratify. This means only eligible non-government organizations, not individuals, can lodge complaints regarding

inheriting a genetic disorder may feel a lack of perceived control over an affected risk if they underwent susceptibility testing has been found to be overblown.[42] Recent epidemiological developments lend added credence and urgency to the theme of preventive medicine at the heart of this piece. One such outbreak currently raging through all four geographic corners of the globe is the COVID-19 pandemic, believed to be caused by the new Coronavirus.[43] The inadequate responses of many countries to the pandemic, more so by developing nations like Bosnia and Herzegovina,[44] underscore the need for stronger healthcare systems in these countries that are more responsive to health emergencies in an increasingly interconnected and interdependent international community.[45]

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governmental compliance with the Charter. *Bosnia and Herzegovina and the European Social Charter [Factsheet]*, COUNCIL OF EUR., rm.coe.int/pdf/1680492808, *archived at* https://perma.cc/YV7U-VEVL.

42. *See, e.g.*, Ruth E. Collins et al., *Impact of Communicating Personalized Genetic Risk Information on Perceived Control Over the Risk: A Systematic Review*, 13(4) GENETICS IN MED.: OFFICIAL J. AM. C. OF MED. GENETICS 273 (2011) (showing there is little evidence supporting the fear that feedback of personalized genetic risk information may lead to "fatalism," defined as "a lack of perceived control over the risk"). *See also* Lejla Mahmutovic et al., *Perceptions of Students in Health and Molecular Life Sciences Regarding Pharmacogenomics and Personalized Medicine*, 12 HUM. GENOMICS 50 (2018) (reporting the results from a survey of 559 students from biomedical fields, which indicated "a positive attitude of biomedical students in Bosnia and Herzegovina toward genetic testing").

43. *See Q&A on Coronaviruses (COVID-19)*, WORLD HEALTH ORG. (Apr. 17, 2020), who.int/news-room/q-a-detail/q-a-coronaviruses, *archived at* https://perma.cc/3UNS-L92T.

44. *See* Nidzara Ahmetasevic, *Bosnia and Herzegovina's COVID-19 Response Threatens Fragile Human Rights*, K2.0 (Feb. 4, 2020), https://kosovotwopointzero.com/en/bosnia-and-herzegovinas-covid-19-response-threatens-fragile-human-rights/, *archived at* https://perma.cc/Q8Z5-4UXG. *See also* Jakov Fabinger, *Ethiopian Airlines Flies Huge Boeing 777 to Tiny Bosnian Town*, SIMPLE FLYING (Apr. 24, 2020), https://simpleflying.com/ethiopian-airlines-bosnian-town/, *archived at* https://perma.cc/47BZ-YMB4 (commenting on the delivery of 200 ventilators to Banja Luka in Republika Srpska as part of an effort to improve the available medical equipment in the entity).

45. *See, e.g.*, *COVID-19: Looming Crisis in Developing Countries Threatens to Devastate Economies and Ramp Up Inequality*, UNITED NATIONS DEV. PROGRAM (Mar. 30, 2020), https://www.undp.org/content/undp/en/home/news-centre/news/2020/COVID19_Crisis_in_developing_countries_threatens_devastate_economies.html, *archived at* https://perma.cc/BJ9P-GYZJ.

Using the technique of preventive medicine embedded in genetic counseling, this Article contributes some answers about how to address the "demand . . . for improved and comprehensive information on the workings and quality of [BiH's] health care system."[46] In addition to this introduction and the conclusion, this Article has five parts. Part I provides a definition of genetic counseling that ties the term squarely to bioethics. Part II imparts historical background on the constitutional anchor of healthcare in BiH, paying tribute to the concept of healthcare as a human right in BiH that dates back to its socialist legacy from former Yugoslavia. Additionally, Part II lays the groundwork for the discussion later in Part III on the symbiotic relationship between healthcare and human rights. Part III outlines the features of BiH's healthcare system, including a gauge of the extent to which those features meet the hallmarks of a good healthcare system that, in addition to treating health as a human right, includes good laws, good funding, and good politics (i.e., politics friendly to healthcare). Part IV sets forth the status of genetic counseling in BiH as precursor to the main message in Part V. Part V highlights measures designed to achieve preventive medicine in BiH through genetic counseling. Together, Parts IV and V form the centerpiece of this Article and research. Finally, this Article concludes that as it struggles to recover from the still-felt effects of the gory conflict from 1992 to 1995 that damaged its economy and healthcare system, BiH should implement and promote preventive healthcare, achieved through genetic counseling, within the context of progress in public health issues like tobacco control. Despite using BiH as its context, this research is inherently comparative. This is most evident in Part III of the Article, which analyzes the features of the BiH healthcare system by drawing on examples from Europe and the United States and examines BiH through a set of benchmarks for assessing the viability of any healthcare system, whether developed or developing.

I. DEFINING GENETIC COUNSELING

Genetic counselors are workers who provide counseling related to genetic disorders. To define genetic counseling, it is necessary to first explain *genetic disorder*. A genetic disorder is a disease condition that

46. HEALTH CARE IN BIH, *supra* note 10, at i.

is caused by a mutation in an individual's DNA.[47] Genetic disorders may be classified into four major groups: (1) single-gene mutation (which could be dominant, recessive, or x-linked); (2) multiple-gene mutation; (3) chromosomal changes (i.e. entire areas of the chromosome can be missing or misplaced); and (4) mitochondrial mutations (which occur when the maternal genetic material in mitochondria mutate as well).[48] "There are over 6,000 genetic disorders, many of which are fatal or severely debilitating."[49] Every year, nearly 8 million infants worldwide, comprising 6% of all births, "are born with serious birth defects."[50] Of this number, an estimated 3.2 million, representing approximately 40%, become disabled for life.[51] Before 2003, the genes associated with many genetic disorders were unknown.[52] In 2003, the situation changed with the completion of the Human Genome Project.[53] Since then, scientists have developed genetic testing that can confirm a diagnosis or a carrier state of the

47. Liat Ben-Senior, *10 Most Common Genetic Diseases*, LABROOTS (May 22, 2018, 9:56 AM), labroots.com/trending/infographics/8833/10-common-genetic-diseases, *archived at* https://perma.cc/H985-VX4L. The acronym DNA is shorthand for deoxyribonucleic acid, "the hereditary material in humans and almost all other organisms." *What Is DNA?*, U.S. NAT'L LIBRARY OF MED.: GENETICS HOME REFERENCE, https://ghr.nlm.nih.gov/primer/basics/dna, *archived at* https://perma.cc/AA63-M7JP.

48. *See* Ben-Senior, *supra* note 47.

49. *Id*.

50. Ingrid Lobo & Kira Zhaurova, *Birth Defects: Causes and Statistics*, 1(1) NATURE EDUC. 18 (2008), https://www.nature.com/scitable/topicpage/birth-defects-causes-and-statistics-863/.

51. *Id*.

52. *See History of the Human Genome Project*, HUMAN GENOME PROJECT INFO. ARCHIVE 1990-2003, https://web.ornl.gov/sci/techresources/Human_Genome/project/hgp.shtml, *archived at* https://perma.cc/E5P8-EFEQ (referring to the international thirteen-year effort from 1990 to 2003 "to discover all the estimated 20,000-25,000 human genes and make them accessible for further biological study"); *see also Human Genome Project FAQ*, NAT'L HUMAN GENOME RESEARCH INST., https://www.genome.gov/human-genome-project/Completion-FAQ, *archived at* https://perma.cc/8BLR-VLDK.

53. *History of the Human Genome Project*, *supra* note 52. *See generally* VICTOR K. MCELHENY, DRAWING THE MAP OF LIFE: INSIDE THE HUMAN GENOME PROJECT (Basic Books 2010).

disease, or predict future illnesses and responses to therapy.[54] Now, over 2,000 genetic tests are available.[55] Table 1 contains a list of the ten most common genetic disorders.[56] Although only six out of the ten are ranked significant in prevalence in BiH, this is large enough to challenge a small, resource-poor country still reeling from the effects of an ethnic war that destroyed nearly one third of its healthcare infrastructure.[57]

TABLE 1: LIST OF THE TEN MOST COMMON GENETIC DISORDERS SUBJECT TO GENETIC TESTING AND THE EXTENT OF THEIR PREVALENCE IN BOSNIA AND HERZEGOVINA[58]

Item No.	Name of Disorder	Description and Characteristic Symptoms	Prevalence in BiH
1.	Cystic Fibrosis	An autosomal recessive chronic disorder that causes sufferers to produce thick and sticky mucus, inhibiting their respiratory, digestive, and reproductive systems.[59]	Significant, rather than negligible[60]

54. *See supra* notes 52-53; *see also* Symposium, *The Role of the Human Genome Project in Disease Prevention*, 23(5) PREVENTIVE MED. 591 (1994).

55. Ben-Senior, *supra* note 47; *see also* Kathryn A. Phillips. et al., *Genetic Test Availability and Spending: Where Are We Now? Where Are We Going?*, 37(5) HEALTH AFF. 710 (May 2018) ("As of August 1, 2017, there were approximately 75,000 genetic tests on the market, representing approximately 10,000 unique test types.").

56. Ben-Senior, *supra* note 47.

57. JENNIFER CAIN ET AL., *supra* note 15, at 17 (calculating the size of damage as 30%).

58. *See infra* notes 59-78 and accompanying text.

59. *See* ARUP LABORATORIES, CYSTIC FIBROSIS CARRIER TESTING: WHAT YOU NEED TO KNOW (July 2016), https://www.aruplab.com/files/resources/branding/Brochure_patient_cystic.pdf.

60. *See id*. A person's chance of being a carrier of this condition depends on that person's ethnicity. *Id*. The percentage of Caucasians living with this condition is 92%, topped only by Askenazi Jews at 96%. *Id*. Since Bosnians typically are classified as Caucasians, the prevalence of the condition in the country is not negligible. *See also* WORLD HEALTH ORG., THE MOLECULAR GENETIC EPIDEMIOLOGY OF CYSTIC FIBROSIS, ttps://www.who.int/genomics/publications/en/HGN_WB_04.02_fig2.pdf.

2.	Down Syndrome (also known as Trisomy 21)	A chromosomal disorder caused by the presence of all or part of a third copy of chromosome 21. Symptoms include delays in physical growth, characteristic facial features, and mild to moderate intellectual disability.[61]	Significant, rather than negligible[62]
3.	Fragile X Syndrome	A dominant disorder, linked to the X chromosome, that causes a range of developmental problems, including cognitive impairment and learning disabilities. Sufferers usually have delayed speech and language development by age two. Males are often more severely affected by this disorder.[63]	Probably significant[64]
4.	Hemophilia	A bleeding disorder, linked to the X chromosome, that affects	Probably insignificant[66]

61. *See* Amina Kurtovic-Kozaric et al., *Ten-Year Trends in Prevalence of Down Syndrome in a Developing Country: Impact of the Maternal Age and Prenatal Screening*, 206 EUR. J. OBSTETRICS & GYNECOLOGY AND REPROD. BIOLOGY 79 (2016), https://www.ejog.org/article/S0301-2115(16)30894-6/pdf.

62. *See id*. Down Syndrome is one of the most common birth defects that affect about 1 of every 750-1100 live births. *Id*. at 82. A study published in 2016 found that "[t]he calculated incidence for the live born T21 individuals in Bosnia [was] 1:999. The live-birth prevalence of T21 was 9.6 per 10,000 births and the total prevalence of T21 was 19.1." *Id*. at 79.

63. Jennifer A. Jewell, *Fragile X Syndrome*, MEDSCAPE, https://emedicine.medscape.com/article/943776-overview, *archived at* https://perma.cc/96AL-RZ78.

64. *See id*. Worldwide, Fragile X Syndrome is believed to be the most common cause of inherited mental retardation, intellectual disability, and autism, as well as the second most common cause of genetically associated mental deficiencies, second only to Down Syndrome. *Id*. "Fragile X Syndrome affects approximately 1 in 2,500-4,000 males and 1 in 7,000-8,000 females. The prevalence of female carrier status has been estimated to be [about] 1 in 130-250 [persons]; the prevalence of male carrier status is estimated to be [about] 1 in 250-800 [persons]." *Id*.

66. *See* WORLD FED'N OF HEMOPHILIA, REPORT ON THE ANNUAL GLOBAL SURVEY 12 (Dec. 2011), https://www1.wfh.org/publication/files/pdf-1427.pdf. With a population indicated as 4.6 million in 2010, BiH reported 140 people living with hemophilia. *Id*. Emphasis on "probably" is advised because the data BiH provided was for 2006 and given the tentativeness of the report, which cautioned that "[a]ll data

		the body's ability to produce blood clots. Symptoms include easy bruising, longer bleeding after an injury, and increased risk of bleeding inside joints or the brain.[65]	
5.	Huntington	An autosomal dominant disorder that causes certain nerve cells in the brain and the central nervous system to degenerate. It starts between the thirty- to fifty-year age range and leads to death fifteen to twenty years later.[67]	Probably significant[68]
6.	Duchenne Muscular Dystrophy (DMD)	A recessive genetic disorder, linked to the X chromosome, that is characterized by progressive muscle degeneration and weakness. It is caused by an absence of dystrophin, a protein that helps keep muscle cells intact, and usually leads to death in the early teen years.[69]	Probably insignificant[70]

are provisional." *Id*. (inside the front page of the document preceding the table of contents).

65. *What Is Hemophilia?*, CENTERS FOR DISEASE CONTROL AND PREVENTION, https://www.cdc.gov/ncbddd/hemophilia/facts.html, *archived at* https://perma.cc/XX7U-FYM5.

67. ŠEJMA BEGANOVIĆ ET AL., HUNTINGTON'S DISEASE-CASE REPORT 48 (2015), http://gyrus.hiim.hr/images/suplement2/neuro2015_Part24.pdf.

68. *See id*. (noting that as of 2015, 8-10 per 100,000 inhabitants in the world live with this condition, compared to 4.46 per 100,000 inhabitants in BiH).

69. *Rare Disease Database: Duchenne Muscular Dystrophy*, NAT'L ORG. FOR RARE DISORDERS, https://rarediseases.org/rare-diseases/duchenne-muscular-dystrophy/, *archived at* https://perma.cc/S38A-8U4W (the database is updated periodically with the last being in 2016).

70. DMD ranks as the most common childhood onset form of muscular dystrophy and mostly affects males, compared to girls. The worldwide numbers are about 1 in every 3,500 male births, compared to about 1 in 50 million girls. *Id*.; *Girls Living with Duchenne*, DUCHENNE UK (2019), https://www.duchenneuk.org/girls-living-with-duchenne, *archived at* https://perma.cc/929Z-EFYN. Given its status as "a rare genetic disease affecting only a small percentage of the population," the prevalence of DMD in BiH is assessed as probably insignificant. *Duchenne Muscular Dystrophy | Niche and Rare Pharmacor | G7 | 2015*, DRG (Dec. 2015), https://decisionresourcesgroup.com/report/141434-biopharma-duchenne-muscular-dystrophy-niche-and-rare/, *archived at* https://perma.cc/SJP6-N58E.

7.	Sickle Cell Anemia	An autosomal recessive disorder that is caused by abnormal hemoglobin, which results in distorted (sickled) red blood cells. Sickled red blood cells are fragile and prone to rupture, which leads to anemia, pain, delays in growth, and frequent infections.[71]	Probably significant[72]
8.	Thalassemia	An autosomal recessive disorder that is caused by abnormal hemoglobin and results in the destruction of red blood cells. Symptoms include anemia, fatigue, deformities of facial bones, delays in growth, and pale appearance.[73]	Probably insignificant[74]

71. *See Sickle Cell Anemia*, MAYO CLINIC, https://www.mayoclinic.org/diseases-conditions/sickle-cell-anemia/symptoms-causes/syc-20355876, *archived at* https://perma.cc/A3FJ-LHVE.

72. *See* WORLD HEALTH ORG., THE GLOBAL PREVALENCE OF ANAEMIA IN 2011 19 tbl.A3.1 (2015) (ranking BiH "moderate" in-between "severe" and "mild" in 2011 in a table for "Country estimates for children aged 6-59 months"). However, prevalence of the condition is assessed as probably significant for BiH because, although sickle cell trait affects African Americans disproportionately (about 8-10% of the estimated more than 100 million people worldwide with sickle cell trait), "[s]ickle cell trait can also affect Hispanics, South Asians, Caucasians from southern Europe, and people from Middle Eastern countries." *See Frequently Asked Questions Regarding Sickle Cell Trait*, AM. SOC'Y OF HEMATOLOGY, https://www.hematology.org/advocacy/policy-statements/2012/faq-regarding-sickle-cell-trait, *archived at* https://perma.cc/9BFX-HQ5U.

73. *Thalassemia*, MAYO CLINIC, https://www.mayoclinic.org/diseases-conditions/thalassemia/symptoms-causes/syc-20354995, *archived at* https://perma.cc/4S2A-QMC4.

74. *See* Tayebeh Noori et al., *International Comparison of Thalassemia Registries: Challenges and Opportunities*, 27(1) ACTA INFORMATICA MEDICA [J. OF ACAD. OF MED. SCIENCES OF BOSN. & HERZ.] 58 (Mar. 2019), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6511274/. The World Health Organization estimates the frequency of carriers of thalassemia and abnormal hemoglobin to be about "5.1% with nearly 226 million carriers worldwide." *Id*. at 58. Of this number, nearly 80% of thalassemia cases "are detected in the area extending from sub-Saharan Africa to the Mediterranean Basin, the Middle East, and South and Southeast Asia." *Id*.

9.	Tay-Sachs	An autosomal recessive disorder that affects both sexes equally and results in the destruction of nerve cells in the brain and spinal cord.[75]	Probably insignificant[76]
10.	Angelman Syndrome	A rare neurogenetic disorder that affects both sexes equally. Symptoms include delayed development, intellectual disability, severe speech impairment, and epilepsy. Persons with this condition require continuous care and are unable to live independently.[77]	Probably significant[78]

75. *Rare Disease Database: Tay Sachs Disease*, NAT'L ORG. FOR RARE DISORDERS, https://rarediseases.org/rare-diseases/tay-sachs-disease/, *archived at* https://perma.cc/6334-28JR (the database is updated periodically with the last being in 2017).

76. The basis for the indicated assessment is because this disease is a rare condition more frequent among Jewish people of Ashkenazi descent, with approximately 1 in 30 carrying the altered gene for the disease, compared to about "[1] in 300 individuals of non-Ashkenazi Jewish heritage." The number translates into about 1 in 3,600 live births. *Id*.

77. *See Rare Disease Database: Angelman Syndrome*, NAT'L ORG. FOR RARE DISORDERS, https://rarediseases.org/rare-diseases/angelman-syndrome/, *archived at* https://perma.cc/RTB8-N7K3 (the database is updated periodically with the last being in 2018).

78. *Compare id*. (disclosing that the prevalence of this disease is about 1 in 12,000-20,000 people in the general population, although many cases go undiagnosed, which makes it difficult to determine the actual prevalence within the population), *with* Amina Kurtovic-Kozark et al., *Diagnostics of Common Microdeletion Syndromes Using Fluorescence* in situ *Hybridization: Single Center Experience in a Developing Country*, 16(2) BOSN. J. BASIC MED. SCI. 121 (2016), https://www.bjbms.org/ojs/index.php/bjbms/article/view/994/263 (finding for BiH a higher incidence than the rest of Europe from their analysis of a set of microdeletion syndromes, including Angelman Syndrome). Parallel to the National Organization for Rare Disorders (NORD), the study "emphasize[d] that the microdeletion syndromes are in general underdiagnosed," leading these investigators to caution that the results they unearthed "can serve as a preliminary basis for creating future guidelines for pediatric genetic diagnosis." *Id*. at 125. The study (and therefore its results) focused only on one entity, the Federation of Bosnia and Herzegovina, rather than all of BiH.

"Genetic counseling is a process designed to evaluate and understand a family's risk of an inherited medical condition,"[79] to help affected individuals make responsible and informed decisions about their own health or their child's.[80] During this process, a genetic counselor meets with individuals afflicted with a genetic disorder or at risk of passing on an inherited disorder, whether pregnant women, infants, or adults. The goal is to minimize the chances that sufferers or suspected sufferers will transmit the disorder to their offspring, but it is also to support individuals in the decisions they make.[81] Genetic counseling traditionally occurs in-person, but it may also occur via alternative methods like a telephone call or group counseling.[82] In this Article, the term genetic counseling refers to traditional in-person counseling.[83]

Consistent with the Convention on Human Rights and Biomedicine, genetic counseling is a "communication process,"[84] an antecedent to genetic testing.[85] Individuals respond differently to

79. *About Genetic Counselors: Genetic Counseling Prospective Student Frequently Asked Questions*, NAT'L SOC'Y OF GENETIC COUNSELORS, https://www.nsgc.org/page/frequently-asked-questions-students, *archived at* https://perma.cc/KN2E-32Q2 [hereinafter *About Genetic Counselors*].

80. Caroline Bowditch, *Genetic Counseling*, ENCYCLOPEDIA BRITANNICA, https://www.britannica.com/science/genetic-counselling, *archived at* https://perma.cc/HR8G-KTSJ.

81. *Id*.

82. Jeanna M. McCuaig et al., *Next Generation Service Delivery: A Scoping Review of Patient Outcomes Associated with Alternative Models of Genetic Counseling and Genetic Testing for Hereditary Cancer*, 10(11) CANCERS (BASEL) 435, 435 (2018).

83. *See generally id*. (noting that, compared to alternative methods, traditional in-person genetic counseling is linked with higher acceptance of genetic testing and patient satisfaction).

84. L. Kalokairinou et al., *Legislation of Direct-to-Consumer Genetic Testing in Europe: A Fragmented Regulatory Landscape*, 9(2) J. CMTY. GENETICS 117, 122 (2018) ("[G]enetic counselling is a communication process aiming to support patients in taking informed healthcare decisions, after understanding the benefits, limitations and implications of a genetic test for themselves and their family and being informed about available healthcare options.").

85. *See* Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, art. 12, E.T.S. No. 164 (Jan. 12, 1999) ("Tests which are predictive of genetic diseases or which serve either to identify the subject

genetic test results;[86] thus, to obtain individuals' informed consent, it is necessary to provide proper counseling by qualified genetic counselors who can help individuals understand the meaning and significance of their test results.[87] The Additional Protocol to the Convention on Human Rights and Biomedicine requires that genetic testing for health purposes be conducted under individualized medical supervision, accompanied by genetic counseling.[88] The treaty sets forth principles related to the quality of genetic services and genetic counseling. One such requirement is that tests predictive of genetic diseases should include appropriate counseling to minimize patients' misunderstanding of the test results and patients' potential anxiety and legitimate related concerns.[89] These concerns include embarrassment, discrimination, and stigmatization, if genetic information is improperly disclosed.[90]

The genetic counselor, "a healthcare professional with specialized training in medical genetics and counseling," is a central figure in genetic counseling.[91] As explained above, genetic counselors help

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as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and *subject to appropriate genetic counselling*.") (emphasis added); *see also* Kalokairinou et al., *supra* note 84 (discussing countries where genetic counseling is required or recognized as a necessity before conducting genetic tests, after, or both).

86. *See* Heidi Carment Howard & Pascal Borry, *Survey of European Clinical Geneticists on Awareness, Experiences and Attitudes toward Direct-to-Consumer Genetic Testing*, 5(5) GENOME MED. 45 (2013).

87. Kalokairinou et al., *supra* note 84, at 127 ("[I]t may be argued that, in the context of genetic testing, unless genetic counselling takes place, consent cannot really be informed.").

88. Additional Protocol to the Convention on Human Rights and Biomedicine, Concerning Biomedical Research, C.E.T.S. No. 195 (Jan. 9, 2007). *See also* Laurence Lwoff, *Council of Europe Adopts Protocol on Genetic Testing for Health Purposes*, 17(11) EUR. J. HUM. GENETICS 1374 (July 2009).

89. *See* sources cited *supra* note 88.

90. Kyle B. Brothers & Mark A. Rothstein, *Ethical, Legal and Social Implications of Incorporating Personalized Medicine into Healthcare*, 12(1) PERSONALIZED MED. 43, 44 (2015).

91. *About Genetic Counselors*, *supra* note 79 ("[In the United States], [b]ecoming a genetic counselor requires completion of a master's degree at an accredited genetic counseling program. These programs include rigorous didactic coursework, clinical training, and a research component. After completing this training, graduates must pass a board examination to become certified [as genetic

persons with genetic disorders and their families. They work in several areas of healthcare, including "hospitals, doctor's offices, genetic testing laboratories, research studies, public health, [and] insurance companies."[92] Genetic counselors practice in four main clinical settings: (1) prenatal, (2) pediatric, (3) adult, and (4) cancer care.[93]

In the prenatal setting, women or couples who are pregnant or planning to become pregnant may see a prenatal genetic counselor for various reasons, including personal or family history of a known or suspected condition; advanced maternal or paternal age, as the chances for chromosome abnormalities, such as Down Syndrome or single gene disorders, increase with parental age; and exposures during pregnancy that may cause birth defects.[94] In the pediatric setting, genetic counseling is appropriate for children with conditions, such as a family history of a genetic condition or suspected genetic condition, developmental delay, autism spectrum disorders, multiple health problems or birth defects, and abnormal physical features.[95] Establishing an underlying genetic cause for these problems can inform affected family members of "what to expect in the future, the prognosis, the chance of having additional children/family members affected with the condition, and [of available] support groups and services."[96]

In the adult setting, "individuals with a personal [or] family history or symptoms of an adult-onset genetic condition may benefit from genetic counseling to learn [the following]: [t]he risk that they or their children may be diagnosed with or develop an adult-onset condition [and the] genetic testing options available for diagnosis or predictive testing."[97] In the cancer setting, genetic counselors can help persons "determine whether . . . they have inherited an increased risk for cancer."[98] Under this clinical setting, "[persons] who see a genetic

counselors]. Some states require genetic counselors to have a professional license to practice in that state, and the number of states with this requirement is increasing.").

92. *Id*.
93. *Id*.
94. *Id*.
95. *Id*.
96. *Id*.
97. *Id*.
98. *Id*.

counselor include individuals with a personal or family history of cancer."[99]

A fine line arguably separates the phenomenon of genetic counseling from the broader species-enhancement techniques like eugenics[100] or gene editing.[101] Therefore, it is necessary to specify that in the limited sense it is used here, genetic counseling is the process by which patients and families at risk of an inherited disorder receive tailored advice (counseling) related to that disorder to minimize the chances of transmitting such disorder to future generations.[102] Genetic counseling is a preventive measure that is designed to catch a problem

99. *Id*. ("[This includes] cancer, such as breast or colon cancer, under the age of 50, two or more first-degree relatives on the same side of their family who have been diagnosed with cancer, more than one primary cancer in the same individual . . . , more than one type of cancer in the same individual, a rare type of cancer or tumor pathology, a known genetic mutation in a cancer susceptibility gene in their family, [and] an ethnicity associated with a higher frequency of hereditary cancer syndromes.").

100. Coined in 1883 by the British statistician and social scientist Sir Francis Galton (1822-1911), "eugenics" means "well-born," specifically science "relating to the production of good offspring." *See, e.g.*, Charles J. Epstein, *Is Modern Genetics the New Eugenics?*, 5(6) GENETICS IN MED. 469, 470, 472-73 (2003), https://www.nature.com/gim/journal/v5/n6/full/gim2003376a.html (quoting Galton). While bearing that fine line in mind, this Article limits itself to the narrower meaning of genetic counseling as used to minimize transmission of an inherited disorder to offspring.

101. Gene or genome editing involves "making specific changes to the DNA of a cell or organism" by adding, removing, or altering genetic material at particular locations in the genome, in an attempt to change the characteristics of the cell or organism in question. *What Is Genome Editing?*, YG, https://www.yourgenome.org/facts/what-is-genome-editing, *archived at* https://perma.cc/7JZ3-TUZV; *What Are Genome Editing and CRISPR-Cas9?*, U.S. NAT'L LIBRARY OF MED.: GENETICS HOME REFERENCE, https://ghr.nlm.nih.gov/primer/genomicresearch/genomeediting, *archived at* https://perma.cc/F4T8-L2VK. Changes to the DNA of a cell or organism may be made for the following reasons: for *research* (i.e., to understand the biology of the cell or organism and how it works); to *treat diseases*, such as leukemia and AIDS; and for *biotechnology* (i.e., "in agriculture to genetically modify crops to improve their yields and resistance to disease and drought"). *What Is Genome Editing?*, *supra*.

102. *See Genetic Counseling*, MERRIAM-WEBSTER, merriam-webster.com/dictionary/genetic%20counseling, *archived at* https://perma.cc/HJG6-8HQ2 (defining genetic counseling as "guidance relating to genetic disorders that is provided by a medical professional typically to individuals with an increased risk of having a child with such a disorder").

at an early stage before it festers and assumes complex dimensions, which may necessitate channeling scarce healthcare resources to resolve it. In this Article, genetic counseling does *not* include broader species-enhancement techniques, inconsistent with the tenets of bioethics.[103] As the Council of Europe advised, genetic testing must be a "non-directive" procedure, "adapted to the circumstances in which individuals and families receive genetic information," and "accompanied by appropriate counselling, both before and after the procedure."[104] Finally, this Article's focus is limited to genetic tests conducted in an approved clinical setting.[105] These tests meet the

103. *Bioethics* is the study of the ethical issues emerging from advances in biology and medicine. It is a multidisciplinary field (combining fragments of knowledge from medicine, law, philosophy, public health, public policy, and theology) concerned with the ethical questions that arise in the relationships among life sciences, biotechnology, medicine, politics, law, and philosophy. The field ranges beyond the codes of professional ethics to include attention to social changes caused by scientific and technological achievements. "To the already difficult question posed by the life sciences [as to] how far [we] can go, [bioethics adds pertinent] queries . . . concerning the relationship between ethics, science, and freedom." *Universal Declaration on Bioethics and Human Rights*, UNESCO, http://www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/bioethics-and-human-rights/, *archived at* https://perma.cc/F8RH-L82M. *See also* UNESCO SECTOR FOR SOCIAL AND HUMAN SCIENCES, BIOETHICS CORE CURRICULUM: SECTION 1: SYLLABUS ETHICS EDUCATION PROGRAM 14-18 (2016) (discussing "[t]he birth of bioethics" and explaining that bioethics seeks "to draw attention to the fact that the rapid advances in science has proceeded without due attention being paid to values").

104. Council of Europe, Committee of Ministers, Recommendation No. R(92) 3 on Genetic Testing and Screening for Health Care Purposes, principle 3, *reprinted in* 43 INT'L DIGEST OF HEALTH LEGIS. 284 (1992), http://hrlibrary.umn.edu/instree/coerecr92-3.html [hereinafter Recommendation No. R(92) 3 on Genetic Testing and Screening for Health Care Purposes]. Founded in 1949, the Council of Europe is an international organization currently made up of forty-seven member states that is committed to upholding human rights, democracy, and the rule of law in Europe. BiH joined the group in 2002 as the forty-fourth member and participates strongly in its affairs. *See, e.g.*, *Action Plan for Bosnia and Herzegovina 2018-2021*, COUNCIL OF EUR. (June 13, 2018), https://rm.coe.int/bih-action-plan-2018-2021-en/16808b7563. For an explanation of a "non-directive" procedure, see Kalokairinou et al., *supra* note 84, at 124; *see also infra* note 346 and accompanying text.

105. These tests break down into five distinct (sub)categories: diagnostic, predictive (or pre-symptomatic), carrier, prenatal, and preimplantation. ANGELA BALLANTYNE ET AL., WORD HEALTH ORG., MEDICAL GENETIC SERVICES IN

Council of Europe's rules relating to approval by a competent State authority and participation in an "external quality assurance."[106] This Article does not include tests that lack these clinical features—such as those undertaken by testing companies, which, because they ply their products directly to their customers, are known colloquially as direct-to-consumer (DTC) genetic testing companies.[107]

II. HISTORICAL BACKGROUND ON THE CONSTITUTIONAL LAW OF HEALTHCARE IN BOSNIA AND HERZEGOVINA

A. Provisions for Healthcare in Former Yugoslavia

After World War II, BiH became part of former Yugoslavia, where it enjoyed the status of a full-fledged republic, one of the six under that system.[108] Yugoslavia's 1974 Constitution, the most elaborate in the

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DEVELOPING COUNTRIES: THE ETHICAL, LEGAL AND SOCIAL IMPLICATIONS OF GENETIC TESTING AND SCREENING 15 (2006), https://apps.who.int/iris/bitstream/handle/10665/43288/924159344X_eng.pdf?sequence=1&isAllowed=y; *see also* Orsolya Varga & Jorge Sequeiros, *Definitions of Genetic Testing in European and Other Legal Documents*, EUROGENTEST, http://www.eurogentest.org/index.php?id=732, *archived at* https://perma.cc/S6RT-YYUU (appendix). *Diagnostic* testing, the most common of these tests, involves the diagnosis of a genetic disease, whether chromosomal or monogenic, in a patient with symptoms. BALLANTYNE ET AL., *supra*, at 15. *Predictive* testing estimates the risk to a person with no symptoms of developing a genetic disease in the future. *Id*. at 18. *Carrier* testing checks "whether a healthy individual is a carrier of a recessive mutation that may increase his [or] her risk of having affected offspring." *Id*. at 15. *Prenatal* testing, such as for Down Syndrome, identifies a "fetus[] at increased risk of congenital abnormality." *Id*. *Preimplantation* testing, conducted following an in vitro fertilization procedure, is performed "on one or two cells removed from the early embryo." Varga & Sequeiros, *supra*.

106. Recommendation No. R(92) 3 on Genetic Testing and Screening for Health Care Purposes, *supra* note 104, principle 2 (regarding quality of genetic services). The applicable guideline here specifies, "[i]t is desirable for centers where laboratory tests are performed to be approved by the State or by a competent authority in the State, and to participate in an external quality assurance." *Id*. principle 2(c).

107. Kalokairinou et al., *supra* note 84, at 118. DTC companies "stress[] the 'informational' and 'fun' aspects of their services" in a manner that some critics believe "underplay[] the health implications of their services." *Id*. at 127. They raise issues of effective regulation domestically and internationally, which is outside the scope of this Article. *See generally id*.

108. *See supra* note 20 and accompanying text.

country's history,[109] contains several fairly specific provisions relating to healthcare. They include Articles 186, 162, 163, 192, and 87, listed in order from most to least direct about a right to healthcare.[110]

For example, Article 186 stipulated "[e]veryone shall be entitled to *health care*," adding that "cases in which uninsured citizens are entitled to health care from social resources shall be spelled out by statute."[111] Article 162 stipulated "[w]orkers shall have the right to *health* and other kinds of care and personal security in work."[112] Article 163, which incorporated the right of workers to have social security through compulsory social insurance, provided that

> workers shall have, in conformity with statute, the right to *health care* and other benefits in the case of illness, childbirth benefits, benefits in the case of diminution or loss of working capacity, unemployment and old age, and other social security benefits, and for their dependents—the right to *health care*, survivors' pensions, and other social security benefits.[113]

Article 192 stipulated "[m]an shall have the right to a *healthy* environment. Conditions for realization of this right shall be ensured by the social community."[114] Titled "Conservation and Improvement of the Human Environment," Article 87 stipulated the following:

> Working people and citizens . . . shall have the right and duty to assure conditions for the conservation and improvement of the natural and man-made values of the human environment, and to prevent or eliminate harmful consequences of air, soil, water or noise

109. The document is 304 pages long and contains 406 articles. *See* Ustav Socijalisticke Federativne Republike Jugoslvije [Constitution of the Socialist Federal Republic of Yugoslavia] (1974), *translated in* Constitution of the Socialist Federal Republic of Yugoslavia, WORLD STATESMEN.ORG, http://www.worldstatesmen.org/Yugoslavia-Constitution1974.pdf (last visited Mar. 25, 2020).

110. *Id*.

111. *Id*. art. 186 (emphasis added).

112. *Id*. art. 162 (emphasis added).

113. *Id*. art. 163 (emphasis added).

114. *Id*. art. 192 (emphasis added).

> pollution and the like, which endanger these values and imperil the *health* and lives of people.[115]

Finally, Article 203 added that, although subject to certain limitations, such as "disrupt[ing] the foundations of the socialist self-management democratic order," and endangering the country's independence, these guarantees "shall enjoy judicial protection."[116] The main part of the ideological rivalry that marked the Cold War was a bifurcation of political-civil rights and socioeconomic rights: socialist countries privileged socioeconomic human rights over political-civil human rights, whereas capitalist countries did the opposite.[117] However, under Josip B. Tito from 1953 to 1980, commitment to socioeconomic human rights, healthcare included, was sincerely held, rather than opportunistic.[118] Testament to this assessment was that Yugoslavia ratified the International Covenant on Economic, Social and Cultural Rights (ICESCR) on June 2, 1971, nearly four years after signing it on August 8, 1967.[119] The ICESCR stipulates, in pertinent

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115. *Id*. art. 87 (emphasis added).

116. *Id*. art. 203.

117. *See* Philip C. Aka, *Fidel Castro and Socioeconomic Human Rights in Africa: A Multi-Level Analysis*, 43(1) FORDHAM INT'L L. J. 41, 75 (2019).

118. *E.g. id*. at 75 (discussing Cuba's prioritization of healthcare, among other things). As explained elsewhere with respect to Cuba under Fidel Castro, but equally true of many other socialist states, the bifurcation never made sense for the following reason:

> Socioeconomic human rights are guarantees of freedom [that, in addition to affordable healthcare, encompass] access to nutritious food, livable shelter, . . . affordable and skill-rich education, to enable individuals to provide these goods for themselves, without which non-socioeconomic rights (i.e. political civil rights), including even the right to life, ring hollow.

Id. at 49.

119. *Chapter IV - Human Rights: 3. International Covenant on Economic, Social and Cultural Rights*, UNITED NATIONS TREATY COLLECTION, https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-3&chapter=4&lang=en, *archived at* https://perma.cc/N22X-CNMY [hereinafter *Chapter IV - Human Rights*] (End-Note 3); *see also* International Covenant on Economic, Social and Cultural Rights, *opened for signature* Dec. 19, 1966, 993 U.N.T.S. 3 [hereinafter ICESCR]. The difference between signature and ratification is that, unlike ratification, signature does not establish consent to be bound, but it creates an obligation "to refrain from acts that would defeat [or undermine] the object[ive] [or] purpose of a treaty." Vienna Convention of the Law of Treaties art. 18, *opened for signature* May 23, 1969, 1115 U.N.T.S. 331.

part, that state-parties to the multilateral treaty "recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."[120]

B. Provisions for Healthcare in Bosnia and Herzegovina

In 1993, Bosnia and Herzegovina ratified the ICESCR in its own right as an independent state, free and clear of former Yugoslavia.[121] The multilateral treaty codified the provision in the Universal Declaration of Human Rights (UDHR) relating to socioeconomic human rights, including the right to healthcare. The UDHR stipulates, in pertinent part, "[e]veryone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care."[122] The Bosnian Constitution of 1995 cites the UDHR, the ICESCR, and several other human rights instruments as its sources of inspiration,[123] and incorporates the ICESCR into the Constitution by reference.[124]

Focus turns next to the two-plus entities that make up BiH, beginning with FBiH. The legal framework for healthcare in the entity comprises three main instruments: the Constitution, the Law on Health Care,[125] and the Law on Health Insurance.[126] FBiH's Constitution

120. ICESCR, *supra* note 119. The treaty goes so far as to lay out measures that these state-parties could use to realize fulfillment of this right for their citizens. Such measures include reducing the stillbirth-rate and infant mortality, and promoting healthy development of the child; improving all aspects of environmental and industrial hygiene; combatting all diseases, epidemic, endemic, and occupational; and creating conditions designed to guarantee medical service and attention to all of their citizens in the event of sickness. *Id*. art. 12(2)(a)-(d).

121. *Chapter IV - Human Rights*, *supra* note 119.

122. G.A. Res. 217 (III) A, Universal Declaration of Human Rights art. 25(1) (Dec. 10, 1948).

123. CONSTITUTION OF BOSNIA AND HERZEGOVINA, pmbl. (1995), *available at* http://www.ohr.int/ohr-dept/legal/laws-of-bih/pdf/001%20-%20Constitutions/BH/BH%20CONSTITUTION%20.pdf (unpublished version of the BiH constitution).

124. *Id*. Annex 1 (listing the ICESCR as No. 8 among "[a]dditional [h]uman [r]ights [a]greements [t]o [b]e [a]pplied [i]n Bosnia [a]nd Herzegovina").

125. The Law on Health Care (Official Gazette of the Federation of Bosnia and Herzegovina, No. 46/10, and 75/13).

126. The Law on Health Insurance (Official Gazette of the Federation of Bosnia and Herzegovina, No. 30/97, 7/02, 70/08, and 48/11).

stipulates "[a]ll persons within the territory of the Federation shall enjoy the right[] . . . [t]o health."[127] Together, the Law on Health Care, and the Law on Health Insurance specify the conditions under which persons become eligible for healthcare benefits.[128] They guarantee each FBiH resident a basic healthcare package, irrespective of income and resources.[129] Specifically, the Law on Health Care governs the principle, organization, and delivery of healthcare services in the Federation.[130] On the other hand, the Law on Health Insurance regulates health insurance as a part of social insurance, based on certain basic principles like universality, solidarity, and equity.[131] FBiH law guarantees every person the right of equal access to healthcare services, at all three levels of healthcare delivery (primary, secondary, and tertiary),[132] including receipt of medical attention during emergencies.[133] In FBiH, the Federation Government and the ten cantons share the responsibility of providing competent healthcare services.[134] The result is a decentralized arrangement whereby many responsibilities for healthcare reside with the cantons. There is one Federal Ministry of Health, and ten Cantonal Ministries of Health,

127. ANNEX 4 OF THE GENERAL FRAMEWORK AGREEMENT FOR PEACE IN BOSNIA AND HERZEGOVINA, art. 2(o) (Official Gazette of the Federation of Bosnia and Herzegovina, 1/94, 13/97) (1994), *available at* http://www.ohr.int/ohr-dept/legal/laws-of-bih/pdf/001%20-%20Constitutions/FBH/FBH%20CONSTITUTION%20FBH%201-94%20and%2013-97.pdf [hereinafter ANNEX 4 OF THE GENERAL FRAMEWORK AGREEMENT] (published version of the BiH constitution).

128. *See supra* notes 125-26.

129. *See id*.

130. MARTIĆ & ĐUKIĆ, *supra* note 32, at 6. *See* The Law on Health Care (Official Gazette of the Federation of Bosnia and Herzegovina, No. 46/10, and 75/13).

131. MARTIĆ & ĐUKIĆ, *supra* note 32, at 6. Universality is present when "no one is denied access to healthcare"; "solidarity is linked to . . . the need to ensure accessibility to all"; and "equity relates to equal access according to need, [without regard to] gender, age, social status or ability to pay." *Id*. at 5.

132. *See* HEALTH CARE IN BIH, *supra* note 10, at 2-4, 25-27. Elsewhere, this UNCHR source denominated them primary, specialist-consulting, and hospital. *Id*. at 16. This Article sticks with the less complex primary-secondary-tertiary classification, which is elucidated in *infra* Part III.B. on the features of the BiH healthcare system.

133. *See infra* notes 155-57 and accompanying texts.

134. ANNEX 4 OF THE GENERAL FRAMEWORK AGREEMENT, *supra* note 127, art. III(2)(b).

along with one Federal Health Insurance and Reinsurance Fund, and ten Cantonal Health Insurance Funds.[135] In FBiH, healthcare is predominantly financed from a compulsory stream of contributions.[136]

In important respects, healthcare provisions under Republika Srpska and FBiH laws are similar. First, in RS, as in FBiH, the applicable legal framework comprises the Constitution,[137] the Law on Health Care,[138] and the Law on Health Insurance.[139] Second, the RS Constitution likewise stipulates "[e]veryone [has the right] to health care . . . guaranteed in conformity with law."[140] Third, although more centralized,[141] RS, like FBiH, has comparable (but not identical) laws and organizational structures that perform similar functions. Finally, the Statute of the Brčko District, the legal instrument closest to a constitution for this self-governing unit, includes healthcare among the "[f]unctions and [p]owers of the . . . District."[142] Assisted by the

135. MARTIĆ & ĐUKIĆ, *supra* note 32, at 6, 6 chart 1, 7 (chart 1 displays the organizational structure of the healthcare system in FBiH).

136. MARTIĆ & ĐUKIĆ, *supra* note 32, at 7. For more information, see Part III.A (commenting on the characteristic features of the BiH healthcare system).

137. *See generally* CONSTITUTION OF REPUBLIKA SRPSKA (Official Gazette of the Republic of Srpska No. 21/92 – consolidated version, 28/94, 8/96, 13/96, 15/96, 16/96, 21/96, 21/02, 26/02, 30/02, 31/02, 69/02, 31/03, 98/03, 115/05, 117/05, 48/11), *available at* http://www.ohr.int/ohr-dept/legal/laws-of-bih/pdf/001%20-%20Constitutions/RS/RS%20CONSTITUTION%20OF%20REPUBLIKA%20SRPSKA.pdf [hereinafter CONSTITUTION OF REPUBLIKA SRPSKA] (Bosn. & Herz.).

138. The Law on Health Care (Official Gazette of Republika Srpska, No. 18/99).

139. The Law on Health Insurance (Official Gazette of Republika Srpska, No. 18/99).

140. CONSTITUTION OF REPUBLIKA SRPSKA, *supra* note 137, art. 37. More precisely, the RS Constitution provides that "[c]hildren, pregnant women and elderly persons shall be entitled to health care financed out of the public funds, while other persons shall enjoy such a care under the conditions spelled out in a law." *Id*.

141. SAŠA GAVRIĆ ET AL., *supra* note 11, at 22-23. The political entity has seven regions, but with nothing close to the autonomy of the cantons in FBiH: Banja Luka (putative capital), Doboj, Bijeljina, Vlasenica, Sarajevo-Romanija or Sokolac, Foča, and Trebinje.

142. Statute of the Brčko District of Bosnia and Herzegovina, art. 9(8) (Office of the High Representative, 1999), *available at* https://www.ilo.org/dyn/natlex/docs/ELECTRONIC/79577/85707/F241509038/BIH79577.htm.

Department of Health, the mayor plays an instrumental role in proposing and implementing healthcare policies.[143]

III. FEATURES OF THE BOSNIAN HEALTHCARE SYSTEM

This Part discusses three illustrative elements: (1) the two characteristic features of BiH's healthcare system, (2) the three levels of its healthcare system, and (3) the use of the four hallmarks of a good healthcare system as a guide for reforming healthcare in BiH.

A. Two Characteristic Features of the BiH Healthcare System

The BiH healthcare system is known for its fragmentation into numerous small units. Compared to the unified structure in the former Yugoslavia,[144] the BiH healthcare system is fragmented into thirteen units: FBiH, its ten Cantons, RS, and Brčko District.[145] This fragmentation complicates the provision of healthcare services, "increases management and coordination costs and adversely affects the rationality of management of healthcare institutions, primarily through the prism of untapped opportunities of economy of scope."[146] A second characteristic feature is the "Bismarck [m]odel" of a healthcare system, which provides access to healthcare services through mandatory health insurance, financed by payroll deductions, rather than government budgets.[147] Consistent with the model, each of the thirteen

143. *See id*. art. 50(1)-(2) (giving the mayor responsibility for implementing the laws of BiH as well as of the District and making the mayor responsible to the District Assembly for the "orderly management and administration of the District"); *see also id*. art. 51 (explaining how the heads of departments are to work with the mayor).

144. HEALTH CARE IN BIH, *supra* note 10, at i, 1.

145. MARTIĆ & ĐUKIĆ, *supra* note 32, at 6. Instructively, in their piece referenced repeatedly in this research, Martić and Đukić used the plural healthcare system*s*, rather than the singular.

146. *Id*.

147. *See generally* MARTIĆ & ĐUKIĆ, *supra* note 32. The Bismarck model harks back to German Chancellor Otto von Bismarck (1815-1898), whose "introduction of a statutory health insurance [in 1883] in Germany paved the way for a comprehensive social insurance system. Bismarck's goal was [twofold]: counter social unrest and socialism and also . . . weaken economically the voluntary social insurance of the trade unions and church-run labor federations." CESIFO DICE REPORT, BISMARCK VERSUS BEVERIDGE: A COMPARISON OF SOCIAL INSURANCE SYSTEMS IN EUROPE 69-70 (Apr. 2008), https://www.ifo.de/DocDL/dicereport408-db6.pdf.

units comprising the Bosnian healthcare system offers two types of health insurance: compulsory, which covers most citizens; and extended, which is a private, voluntary scheme for citizens who desire greater coverage than the one provided by the conventional method.[148] This Article focuses on the first compulsory category because this category covers most citizens. Under the compulsory scheme, the residents who receive employment income make contributions, which are deducted from their salaries and paid as follows: (a) for employed persons, by their employer; (b) for pensioners, by the relevant pension fund; (c) for persons dependent on social welfare, by the relevant welfare institution; and (d) for unemployed persons, by the employment agency that they are registered with.[149] These monies are then paid to the appropriate governmental entity or sub-entity (e.g., cantonal), which is then responsible for providing healthcare services to residents within its area of authority.[150]

Insured persons, individuals with health insurance who are obligated to make contributions to receive healthcare benefits, form a key element of the compulsory system. Based on the level of insurance coverage, these individuals may be divided into several categories: directly insured; insurance holders, such as family members, who are insured through the insured person, for whom no contribution is made; persons insured solely for "occupational diseases and work-related injuries; and foreign nationals insured [based] on . . . signed bilateral agreements."[151] Using Republika Srpska from 2014 to 2018 as a case in point, Table 2 depicts the structure of insured persons, together with their respective shares in the total revenue of the Health Insurance Fund. Table 2 highlights four notable facts. First, employees represent 31% of insured persons, but contribute almost 84% to the total revenue. Second, pensioners comprise more than 33% of insured persons but

148. HEALTH CARE IN BIH, *supra* note 10, at 2. *See generally* BOSNIA AND HERZEGOVINA, THIRD REPORT OF BIH ON IMPLEMENTATION OF THE EUROPEAN SOCIAL CHARTER [REVISED] (Nov. 2012), http://www.mhrr.gov.ba/PDF/LjudskaPrava/III%20IZVJESTAJ%20GRUPA%202%20eng.pdf ("[For example,] [t]he Law on Health Insurance [in Republika Srpska] governs the system of mandatory and extended health insurance, insurance rights, [and] the exercise of rights and principles of private health insurance.").

149. HEALTH CARE IN BIH, *supra* note 10, at 15 (relating to RS).

150. *Id*. at 2.

151. MARTIĆ & ĐUKIĆ, *supra* note 32, at 8.

contribute a miniscule 2.9% to the total revenue. To put things into perspective, in RS, pensioners' contribution is a marked departure from the figures of neighboring countries like Serbia (24%), Macedonia (21.8%), Montenegro (19.9%), and Slovenia (16.6%).[152] Together, employees and pensioners contribute nearly 87% to the total revenue of the Health Insurance Fund. Third, foreign workers who comprise just over 5% of the population, generate nearly an additional 5% of the total revenue. Finally, unemployed persons who represent nearly 25% of the population of insured persons (one out of every four insured persons) contribute only 7.3% of share to the total revenue of the Health Insurance Fund.

TABLE 2: STRUCTURE OF INSURED PERSONS AND THEIR SHARES IN THE TOTAL REVENUE OF THE RS HEALTH INSURANCE FUND[153]

Item No.	Insured category	Share in total number of the insured	Share in total revenue
1.	Employees	35.1%	83.9%
2.	Pensioners	33.4%	2.9%
3.	Farmers	0.4%	0.3%
4.	Unemployed persons	24.6%	7.3%
5.	Disabled persons from the War	0.8%	0.1%
6.	Refugees and displaced persons	0.1%	0.1%
7.	Foreign insured persons	5.3%	4.9%
8.	Social Work Center	0.4%	0.4%

Under the compulsory scheme, only insured persons are entitled to healthcare. Persons without insurance must make out-of-pocket payments to healthcare providers at the time of service, except during emergencies.[154] Under the BiH healthcare laws, medical assistance must be "provided to all persons in cases of emergency, regardless of

152. *Id*. at 20 (citing figures for 2011).

153. *Id*. at 19 tbl. 6 (citing the 2014-2018 Strategic Plan of the RS Health Insurance Fund and reproducing Table 6).

154. HEALTH CARE IN BIH, *supra* note 10, at 14.

ability to pay";[155] as such, physicians who fail to provide emergency aid may face criminal sanctions.[156] These emergency situations include "assistance with [childbirth] outside of hospitals, emergency transportation of sick and injured persons and women in labor to appropriate health institutions, medical treatment of sick and injured persons in health institutions or at home during weekends and holidays, [and] resuscitation during transportation."[157]

On the other hand, insured persons, in return for their contributions, receive a variety of services, including healthcare services, sick leave pay, re-imbursement for healthcare-related travel costs, and any other entitlements established by the applicable Health Insurance Fund of the unit in question.[158] Family members can also be reimbursed for healthcare-related travel expenses, even for treatment of work-related injuries and illnesses, treatment of drug addiction, and provision of blood bank services.[159] To access services in any BiH entity, insured persons must register and apply for a certified health insurance card.[160] For validation purposes, the branch office of the applicable Health Insurance Fund branch office generally certifies cards monthly; children's and farmers' cards, however, may be certified quarterly.[161] In all jurisdictions, those over fifteen years of age who are not in school can obtain personal health insurance by registering with the Employment Bureau.[162] Unemployed persons must also register with Employment Bureaus to gain access to health insurance and

155. *Id*. at 7 & n.45, citing The Law on Health Care, art. 39 (Official Gazette of Republika Srpska, No. 18/99) (mandating the organization of healthcare such that emergency medical assistance, including transportation, is available at any time).

156. *Id*. (citing FBiH Criminal Code, art. 246; and RS Criminal Code, art. 204).

157. *Id*. at 19.

158. *Id*. at 3-4, 3 n.19, citing The Law on Health Insurance, art. 31 (Official Gazette of the Federation of Bosnia and Herzegovina, No. 30/97, 7/02, 70/08, and 48/11) and The Law on Health Insurance, arts. 18-19 (Official Gazette of Republika Srpska, No. 18/99).

159. *Id*. at 18, 18 n.102, citing The Law on Health Insurance, art. 32 (Official Gazette of the Federation of Bosnia and Herzegovina, No. 30/97, 7/02, 70/08, and 48/11).

160. MARTIĆ & ĐUKIĆ, *supra* note 32, at 8.

161. *Id*.

162. *Id*.

healthcare.[163] To receive treatment, insured persons must pay a fixed copay, called "participat[ory] fee," that is determined by the applicable Health Insurance Fund.[164] However, in many jurisdictions, the following individuals may be exempted from these copays: pregnant women; those with a baby less than one year old; children under fifteen; senior citizens (i.e., persons sixty-five and above); handicapped persons; persons with certain contagious diseases; and persons with psychiatric and neuromuscular diseases.[165]

RS, unlike FBiH, has centralized healthcare services via the Ministry of Health and Social Welfare of Republika Srpska, the Health Insurance Fund of Republika Srpska, and the Public Health Institute of Republika Srpska.[166] The RS Ministry of Health and Social Welfare coordinates healthcare activities, "creates business policies and development strategies, [and] plans and coordinates the work of the health institutions network," among other responsibilities.[167] Along with other health institutions, the Health Insurance Fund of RS delivers primary, secondary, and tertiary healthcare services.[168] There are about 364 other health institutions listed in the Health Institution Register with the Ministry of Health and Social Welfare of RS.[169] Last but not least, the Public Health Institute of RS conducts research and education relating to public health and monitors RS residents' health.[170] Like in FBiH, the Health Insurance Fund of RS's main income sources include contributions for health insurance deducted from workers' salaries, contributions by pension beneficiaries, contributions from farmers, and

163. *Id*.

164. *See id*. at 7.

165. *Medicine in Bosnia-Herzegovina*, BEST COUNTRY (Aug. 27, 2019), http://www.best-country.com/europe/bosnia_herzegovina/medicine, *archived at* https://perma.cc/758U-J5DJ; The Law on Health Insurance, arts. 44-45 (Official Gazette of the Federation of Bosnia and Herzegovina, No. 30/97, 7/02, 70/08, and 48/11).

166. MARTIĆ & ĐUKIĆ, *supra* note 32, at 7.

167. *Id*.

168. *Id*. at 8. *See also* HEALTH CARE IN BIH, *supra* note 10, at 25-7 (covering RS alongside FBiH). For a description of these three levels, see *infr*a Part III.B.

169. MARTIĆ & ĐUKIĆ, *supra* note 32, at 8.

170. *Id*. at 7-8.

contributions for the unemployed and other categories (made by the government).[171]

In Brčko District, however, responsibility for enforcing laws and regulations relating to healthcare falls on the mayor, who is assisted by the Department of Health.[172] This is true at all three applicable levels: primary, secondary, and (partially) tertiary.[173] But, like in the two entities, FBiH and RS, healthcare financing occurs through a Health Insurance Fund, primarily based on contributions from workers, farmers, and persons who are retired, self-employed, and unemployed, among other categories.[174] The Assembly of Brčko District, the closest entity to a legislature in this self-governing unit, decides the base and rate of contribution to the Health Insurance Fund.[175]

Contrary to the suggestion of inclusiveness that it connotes, the compulsory system still leaves many individuals and groups uncovered.[176] Some uncovered individuals include workers whose years of service have not been "linked," self-employed persons who have not paid their own health insurance contributions, and unemployed persons who have failed to extend registration with Employment Bureaus.[177] Overall, more than 15% of the BiH population is not covered.[178] Accordingly, from 2008 to 2015, FBiH covered about 85% of its population while RS covered about 70%.[179] Some speculate this disparity results because "a higher share of [the] population [is]

171. *Id*. at 8.

172. *Id*. This structure of responsibility is consistent with the Statute of the District (its constitutional document) and the Health Insurance Law of Brčko District. *Id*.

173. *Id*.

174. *Id*.

175. *See id*., citing Decision on the Base and Rate of Contribution for Health Insurance (Official Gazette of the Brčko District of BiH, 37/2009).

176. HEALTH CARE IN BIH, *supra* note 10, at 1 ("[W]hile the vast majority of the BiH population is nominally covered by a public compulsory health insurance scheme, in practi[c]e[,] many BiH residents experience difficulty in accessing health care."). *See also* MARTIĆ & ĐUKIĆ, *supra* note 32, at 8.

177. MARTIĆ & ĐUKIĆ, *supra* note 32, at 8 n.6.

178. *Id*. at 8.

179. *Id*. at 8, 9 tbl. 1 (including the methodological explanation under the table justifying the assessment of about 70% coverage for RS).

engaged in agriculture" in RS, a group that is often left out of the compulsory contribution framework.[180]

However, examined more closely, the higher coverage in FBiH is not as impressive as it looks at first sight because there are significant differences in coverage among the cantons in FBiH (see Table 3 below). Among FBiH cantons, large variations exist in employment rates and salary levels, which are two variables that are used to compute healthcare contributions.[181] Based on information presented in Table 3, from 2010 to 2015, Sarajevo Canton and Western-Herzegovina Canton registered an average of over 95% coverage, whereas Canton 10, for example, registered an average of below 64%.[182] The model of healthcare financing in the cantons, which are based mainly on employee contributions, engenders inequality among insured persons, "depending on the economic position of the canton and the place where the insured persons live."[183] In practical terms, this means cantons with fewer employees and lower salaries will have "lower health insurance coverage and lower allocations for public healthcare services per insured person."[184] However, citizens living in "poorer" cantons have no less need for health insurance than their counterparts in more affluent cantons.[185]

The gaps in coverage between FBiH and RS, and among the Cantons in FBiH, smack of discrimination, which is inconsistent with equity and equality in healthcare studies.[186] Those gaps imply that certain categories of the population, such as individuals who reside in rural areas, the poor, Romas, and uneducated persons, lack coverage, meaning they will seek to satisfy their healthcare needs in the commercial private sector, use quack doctors, or forego healthcare services altogether.[187] Attempts to address this issue in places like FBiH, where the government set up a Solidarity Fund, have not been

180. *Id*. at 8.
181. *Id*. at 27.
182. *See infra* note 189.
183. MARTIĆ & ĐUKIĆ, *supra* note 32, at 15.
184. *Id*.
185. *Id*.
186. *Id*. at 9.
187. *See id*.

successful, largely because those interventions fell short of redefining the structure of healthcare funding.[188]

TABLE 3: HEALTH INSURANCE COVERAGE IN FBIH BY CANTONS IN PERCENTAGES (2010-2015)[189]

Year	**2010**	**2011**	**2012**	**2013**	**2014**	**2015**
Una-Sana	72.98	73.25	73.78	73.96	73.35	72.16
Posavina	79.11	79.12	79.31	76.69	76.44	75.46
Tuzla	87.82	87.87	89.4	89.72	88.86	88.11
Zenica-Doboj	82.47	86.29	86.65	86.9	86.75	85.9
Bosnian-Podrinje	77.62	78.24	79.2	80.82	79.37	78.6
Central Bosnia	84.23	85.32	86.82	85.46	86.32	85.79
Herzegovina-Neretva	84.36	84.21	85.07	85.22	86.13	86.61
West Herzegovina	89.65	92	91.79	97.32	99.95	96.5
Sarajevo	93.94	94.49	95.74	95.08	94.92	95.64
Canton 10	66.84	66.7	67.07	63.84	63.94	63.7

B. Three Levels in the BiH Healthcare System

Three levels form the BiH healthcare system: primary, secondary, and tertiary. The thirteen units (organized around two entities) that make up this system emphasize these three levels to various degrees. Primary healthcare forms the bulk of the healthcare system. In BiH, primary healthcare is designed "to cover 70-80% of all medical

188. *Id*. at 15. *See also id*. at 25 (enumerating "[c]urrent initiatives for reform of health financing schemes" in the country). One of these suggestions for reform include the initiative by Jasmin Imamović, Mayor of Tuzla, who "advocate[d] rationalization of the healthcare system in FBiH by abolishing the system of healthcare management at the cantonal level and transferring competencies to the Entity and local levels." *Id*. However, the proposal triggered "different political reactions in FBiH and . . . there is still no unanimous political opinion on the matter nor the willingness to implement the solutions" the initiative signifies. *Id*. at 26.

189. *Id*. at 9 tbl. 2 (citing Federal Insurance and Reinsurance Fund).

cases."[190] Primary care is dispensed through four channels: Ambulanta (AMB),[191] Domovi zdravlja (DZ or "house of health"),[192] Hitna pomoci (HP or first aid and emergency medicine),[193] and Farmacia (PH or pharmacy).[194]

AMBs are basic ambulatory primary healthcare found in practically every village. In AMBs, usually a nurse does the daily work, with a general practitioner often visiting once or more a week, except in larger villages, where the general practitioner visits every day. In AMBs, both the services rendered and the equipment used to render those services are basic and minimal. AMB services include anamnesis,[195] clinical checks (e.g., non-invasive blood pressure, pulse rate, and temperature), prescription of a few drugs, and patient referrals to a DZ. AMB's equipment includes basic items like a Riva-Rocci,[196] stethoscope, and thermometer.

DZs are a second channel through which primary healthcare is dispensed in BiH. DZs are advanced ambulatory healthcare institutions located in the main villages of each municipality. DZs usually function in tandem with first aid or emergency medicine (HP) and sometimes connect to a pharmacy (PH). This pharmaceutical connection is significant, considering that in BiH, AMBs hardly refer patients directly to a hospital. Medical services at DZs include treatments over and above the level of the AMBs, and referrals. Equipment and staff deliver this higher level of service. Equipment at DZs include labs with facilities, such as ultrasound, endoscopy, and advanced X-ray machines. However, the use of such equipment, especially sophisticated ones, depends on availability of specialists and items like films, probes, and ultrasound gel. Staff who operate such equipment include general practitioners, epidemiologists, occupational therapists, gynecologists, obstetricians, and pediatricians. At DZs, an array of specialists from public hospitals or in private practice (on special

190. HEALTH CARE IN BIH, *supra* note 10, at 25-27 (noting only 10-20% of cases are actually dealt with at the primary level).

191. *Ambulanta* is Slovak for *infirmary*.

192. Dom zdravlje (DZ) equates to "House of Health" in Croatian language.

193. Hitna pomoc (HP) is Bosnian for *ambulance*.

194. Farmacia is Italian for *pharmacy*.

195. The term means a tale of medical history told by the patient, especially at the beginning of the doctor-patient relationship.

196. This term refers to a device used to measure blood pressure.

contracts with the government) visit DZs once or twice per week or month. These specialists include radiologists, experts in infectious disease, experts in internal medicine, ophthalmologists, experts in enterology, neuropsychiatrists, pneumo-physiologists, and orthopedic doctors, if available. Occasionally, these specialists include experts on family medicine and emergency medicine, but such specialists mostly work at the higher HP level. In BiH, access to specialist services, where these attentions are available, sometimes are based not on medical need but extra-medical factors, such as political connections.[197]

HPs are the third channel used to dispense primary healthcare in BiH. HPs are an amalgam of a first aid center, an emergency room, and a transport center. HPs are usually located in a DZ and operate twenty-four hours a day and seven days a week. In large cities, such as Sarajevo, HPs have their own independent building and infrastructure. Patients can access the services of an HP either directly or via phone call. In theory, "[n]ormally a car or ambulance is sent and[,] if available[,] a nurse, medical technician, and/or doctor will be sent as well."[198] In actual practice, ambulances are minimally equipped and sometimes, at best, are outfitted with oxygen (i.e., ventilators).[199] In other words, few HPs have well-equipped emergency cars or ambulances; HPs' work tools are often donated.[200] If and when a doctor accompanies these vehicles, the doctor usually carries basic medicinal materials.[201]

PHs are the fourth channel used to dispense primary healthcare in BiH. This channel comprises pharmacies that are run by the government, private pharmacies, and a scatter of humanitarian pharmacies stocked with drugs donated by international humanitarian organizations.[202] Although many state pharmacies are separate, some are attached to DZs where they support local healthcare facilities and provide basic drug materials to patients, such as bandages, syringes, and vials.[203] Pharmacies operated by international humanitarian

197. HEALTH CARE IN BIH, *supra* note 10, at 26.
198. *Id*.
199. *Id*.
200. *Id*.
201. *Id*.
202. *Id*.
203. *Id*. at 26-27.

organizations are also associated with DZs and sometimes with General Hospitals as well.

Secondary healthcare is provided mainly in general hospitals (Bolnica), which are usually located in the capitals of each canton (in the case of the FBiH).[204] Tertiary healthcare is provided mainly at Clinical Centers (CC or *Klinicki Centar* in Bosnian language).[205] Clinical Centers are often affiliated with tertiary institutions like universities and are generally located in capitals and other major cities, such as Sarajevo, Tuzla, Mostar in FBiH, and Banja Luka and Foca/Srbinje in RS.[206] Clinical Centers are the apex of the healthcare pecking order and are able to provide healthcare of the highest scope in every specialty, possessing the necessary equipment to render those services.[207] In principle, they are health institutions of last resort in referral "when GHs are not in a position to provide the necessary expertise, diagnosis, or treatment."[208]

C. The Four Hallmarks of a Good Healthcare System: A Guide for Reforming Healthcare in BiH

The following are the four hallmarks of a good healthcare system: good laws, good funding, healthcare as a human right rather than a privilege, and good politics. These factors are closely intertwined and thus may be separated only analytically rather than in a practical sense. Healthcare delivery is an onerous (but not an impossible) task because for a country to have a well-functioning healthcare system, all of these hallmarks must be present and converge.

The first hallmark of a good healthcare system is good laws. Many countries have a domestic legal system that includes its constitution (higher law) and the regional and international treaties relating to healthcare the country ratified, notably the ICESCR.

The second hallmark is good funding. Money is "the mother's milk of any healthcare system . . . and key to both access in healthcare and

204. *Id*. at 27.
205. *Id*. (emphasis added).
206. *Id*.
207. *Id*.
208. *Id*.

health outcomes."[209] Good funding, signified by the allocation of adequate revenue for healthcare services, is the lifeblood of a good healthcare system. The mark of the maturity of a state's healthcare system is the funding that, backed by the masses, the state's leaders are willing to devote to healthcare goods. However, it should be noted that a country can devote a sizable share of its GDP on healthcare, as the United States of America does,[210] but still get suboptimal healthcare delivery. This should not, however, downplay the fact that financing is an important starting point in the journey toward a good healthcare system. How much a nation is willing to devote financially to healthcare and the quantum of material sacrifices it is ready to make to get healthcare for the vast majority of its citizens speak to the nation's seriousness about improving healthcare. Few countries in the world have all the resources they need to meet their healthcare needs. Accordingly, achieving expanded healthcare requires the use of creative steps in funding, including efficient management of available resources and reducing waste.[211] Apart from promoting goals that include increasing the ability of a healthcare system to provide quality services, waste reduction also makes it easier for health ministries to mount a successful argument before their ministries of finance for additional healthcare funding.[212]

Adequate funding is important because financial barriers impede access to healthcare services. Governments are obligated to protect

209. Philip C. Aka et al., *Ghana's National Health Insurance Scheme (NHIS) and the Evolution of a Human Right to Healthcare in Africa*, 17(2) CHIC.-KENT J. INT'L & COMP. L. 1, 23 (2017).

210. Matej Mikulic, *Health Expenditure as a Percentage of Gross Domestic Product in Selected Countries in 2018*, STATISTA (Nov. 12, 2019), https://www.statista.com/statistics/268826/health-expenditure-as-gdp-percentage-in-oecd-countries/, *archived at* https://perma.cc/LXY7-AUFQ (noting that the U.S. expended about 17% of its GDP on healthcare in 2018). *See also* Lita Epstein, *6 Reasons Healthcare Is So Expensive in the U.S.*, INVESTOPEDIA, https://www.investopedia.com/articles/personal-finance/080615/6-reasons-healthcare-so-expensive-us.asp, *archived at* https://perma.cc/YD8V-6TPN ("If the $3 trillion U.S. healthcare sector were ranked as a country, it would be the world's fifth largest economy.").

211. WORLD HEALTH ORG., THE WORLD HEALTH REPORT: HEALTH SYSTEMS FINANCING: THE PATH TO UNIVERSAL COVERAGE, xi (2010) [hereinafter HEALTH SYSTEMS FINANCING].

212. *Id*.

individuals from impoverishment arising from illness, whether due to out-of-pocket payments or loss of income when a household member cannot work due to illness.[213] As then director-general of the WHO succinctly put it, "[n]o one in need of health care . . . should risk financial ruin as a result."[214] As people age, they become more susceptible to disease and disability; however, ill-health can afflict anyone at any age. Consequently, governments that are serious about making progress in reducing poverty must pay particular attention to providing quality access to good healthcare for most of their citizens. In a nutshell, good healthcare financing requires "rais[ing] sufficient funds" for healthcare, minimizing "reliance on direct payments to finance services, and improv[ing] efficiency and equity."[215]

The third hallmark is healthcare as a human right rather than a privilege that the government may withdraw if it chooses. Human rights are guarantees of freedom, such as life, liberty, security, and subsistence to which people as humans have rights.[216] Healthcare underpins many human rights, including the right to life,[217] thus, it may be viewed as the mother of socioeconomic human rights. However, just expanding healthcare does *not* automatically make it a human right; the state in question must expressly make healthcare a human right within the law.[218] Thus, a country might make great strides toward universal healthcare and yet fail to afford its citizens the human right to healthcare. The United States exemplifies this scenario. Expanded healthcare as a human right has several benefits, including an appeal to rights based solely on a person's humanity and a strategic push that can

213. *See What Is Health Financing for Universal Coverage?*, WORLD HEALTH ORG., http://www.who.int/health_financing/universal_coverage_definition/en/, *archived at* https://perma.cc/5ADD-24QK.

214. HEALTH SYSTEMS FINANCING, *supra* note 211, at vii.

215. *Id*. at xi.

216. *See generally* JACK DONNELLY, UNIVERSAL HUMAN RIGHTS IN THEORY AND PRACTICE 7-23 (Cornell University Press, 3d. ed. 2013) (analyzing the concept of human rights).

217. *See generally* The 8th Global Conference on Health Promotion, Helsinki, Finland, 10-14 June 2013, *The Helsinki Statement on Health in All Policies*.

218. *See generally* Aka et al., *supra* note 209; Philip C. Aka, *Analyzing U.S. Commitment to Socioeconomic Human Rights*, 39(2) AKRON L. REV. 417 (2006).

force governments to either hold the line on rights or increase those rights, rather than reduce them.[219]

Finally, the fourth hallmark of a good healthcare system is good politics. Healthcare is an "intrinsically political" phenomenon "built on principles of fairness and equity that require governments to allocate healthcare benefits according to need, and financial contributions according to ability to pay."[220] A transition to expanded healthcare is "primarily a political negotiation" between contending interest groups and stakeholders with divergent priorities, which may lead to "dysfunctional processes," if not handled well.[221] Accordingly, a government sends an important political message based on the healthcare funding it adopts.[222] "In many countries the health sector wields little political power or influence in decisions about the allocation of public funds[, . . . which promotes the view of healthcare spending] as a drain on scarce resources, rather than as an investment in the nation's future."[223] Moreover, it is partly because of the political influence over policy decisions that "[c]ountries with similar levels of health expenditure achieve strikingly different health outcomes from their investment."[224] Thus, politics play a key role among the hallmarks of a good healthcare system because all of the other hallmarks—good laws, good funding, and healthcare as a human right—are susceptible to political influence. Put differently, good politics is practically a function of the previous three hallmarks, i.e., politics shall be designed to achieve good laws and good financing to make healthcare a human right rather than a privilege that the government can withhold when compassion runs out. The following discussion examines BiH's position vis-à-vis the foregoing hallmarks.

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219. Aka et al., *supra* note 209, at 27-35.

220. David Heymann & Robert Yates, *Embracing the Politics of Universal Health Coverage*, CHATHAM HOUSE (June 25, 2014), https://www.chathamhouse.org/expert/comment/embracing-politics-universal-health-coverage, *archived at* https://perma.cc/65KF-K5LV.

221. *Id*.

222. MARTIĆ & ĐUKIĆ, *supra* note 32, at 22-23. *See also id*. at 27 (noting Croatia and Slovenia's approach "suggest[s] that the legacy of the former [Yugoslavia] has a strong influence on the current models").

223. WORLD HEALTH REPORT 1995, *supra* note 40, at 91.

224. HEALTH SYSTEMS FINANCING, *supra* note 211, at vii.

D. The Four Hallmarks: The Current Healthcare System in BiH and Means to Improve It

1. Effective Healthcare Laws

Part II of this Article noted an abiding yet abstract commitment to healthcare as a human right, evidenced in domestic and international laws, that goes back to the former Yugoslavia. For BiH, having good healthcare laws signifies an area of comparative advantage that needs to be built upon with respect to genetic counseling, as this Article elaborates later. This hallmark is not a one-time event in healthcare studies but rather an issue of constant improvement, which cannot be easily separated from healthcare as a human right and as good politics. On this hallmark, suffice it to say for now that BiH does not assign the state-level government a role in healthcare that complements the efforts at the entity and sub-entity levels; this is an anomaly that calls for urgent rectification.[225]

2. Adequate Healthcare Funding

BiH ranks even worse on good funding than on good laws. Numerous interlinked factors related to funding impede healthcare in Bosnia and Herzegovina, such as an inadequate share of the gross domestic product (GDP) devoted to healthcare; a low ratio of public spending on healthcare, relative to its neighbors, inconsistent with the concept of expanded healthcare; and the poor state of the BiH economy. A fourth set of factors, a number of them bureaucratic, completes this list of funding impediments. Due to these funding issues, "[a]t the current levels of treatment, the lives of persons in need of medical treatment for chronic diseases or conditions, even if these would not ordinarily be considered life threatening conditions outside BiH, may be jeopardized if they are forced to seek treatment in BiH."[226] The net effect is that, despite the promise of a compulsory health insurance program funded by the state, many residents live with nominal health coverage and forego expensive private medical services they are not able to pay for.[227]

225. *See supra* note 5 and accompanying text.

226. HEALTH CARE IN BIH, *supra* note 10, at i.

227. *Id*. at i, 1.

a. Current Impediments and Areas for Improvement

i. Small Size of the GDP Devoted to Healthcare

BiH spends less than the 10% of its GDP on healthcare, a threshold that many healthcare experts consider ideal.[228] WHO figures for 2014 (the most recent year for which information is available) show that BiH devoted only 9.6% of its GDP to healthcare.[229] Although seemingly respectable, the figure is below the numbers for European countries like Austria, Belgium, Denmark, France, Germany, the Netherlands, Sweden, and Switzerland, each of which allocates more than 10% of its GDP to healthcare.[230] With many lingering problems from the War that need to be addressed, BiH's single-digit allocations to healthcare are insufficient.

ii. Low Ratio of Public Spending on Healthcare

Indicative of the low outlay for healthcare in BiH is the low *public* healthcare spending per capita versus the relatively high *private* healthcare spending per capita. Based on WHO data, in 2014, BiH's public spending per capita on healthcare was $464 U.S. dollars (USD).[231] In 2015, 71% of total healthcare spending (amounting to 1.895 million Bosnian Convertible Mark (KM)[232] out of 2.669 billion

228. *See, e.g.*, William D. Savedoff, *What Should a Country Spend on Health Care?*, 26(4) HEALTH AFF. 962 (2007) (noting the WHO's suggestion of 5% but going beyond the recommendation to consider four approaches—peer, political economy, production function, and budget—after which Savedoff settles on the budget approach as the most feasible and readily quantifiable); *see also* WORLD HEALTH ORG., THE ABUJA DECLARATION: TEN YEARS ON 1-3 (2011) ("In April 2001, . . . African Union countries met and pledged to set a target of allocating at least 15% of their annual budget to improve the health sector. . . . However, [after ten years,] only [one], Tanzania, [had reached the] the target.").

229. *Bosnia and Herzegovina*, WORLD HEALTH ORG., who.int/countries/bih/en/, *archived at* https://perma.cc/WF8R-233D.

230. MARTIĆ & ĐUKIĆ, *supra* note 32, at 11. The precise numbers for France and Germany respectively are 11.5% and 11.3%. *Id*. The United States, used only as a nominal benchmark, not as a model for BiH, is at about 17% of GDP. Mikulic, *supra* note 210.

231. MARTIĆ & ĐUKIĆ, *supra* note 32, at 11 (citing WHO data for BiH in 2014).

232. *Id*. at 9. "The Bosnian Convertible Mark is the currency of Bosnia and Herzegovina. . . . [T]he most popular Bosnia and Herzegovina Convertible Mark

KM was public, while 29% (amounting to 774 million KM) was private.[233] This is probably due to the country's low GDP.[234] Regardless, the ratio of public spending to private spending is rather low, compared to European countries like Denmark, Germany, the Netherlands, and Norway, whose expenditures are about ten to twenty times higher per capita.[235] The increased private expenditure was particularly noticeable in areas like dentistry, diagnostics, over-the-counter drugs, as well as therapeutic and specialist services. The gap in expenditure in favor of the private sector results in investment in equipment, new technologies, and services, which often draws people to private or overseas healthcare institutions, instead of public ones.[236]

Note that public funding here does *not* mean budget funds. Instead, it comprises mostly compulsory health insurance funds from workers' contributions, analyzed in Part III.A, with budget funds covering about 9% of public expenditure and 6% of total expenditures.[237] These funds are mainly used for capital investments, public health, and

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exchange rate is the USD to BAM rate. The currency code for Convertible Marks is BAM, and the currency symbol is KM." *BAM - Bosnian Convertible Mark*, XE, https://www.xe.com/currency/bam-bosnian-convertible-mark, *archived at* https://perma.cc/8BLB-6N9Z.

233. MARTIĆ & ĐUKIĆ, *supra* note 32, at 9. Private sources include various forms of participation, such as direct payments to private practitioners for drugs and other therapeutic aids, as well as informal (i.e. unlawful) payments for medical services. *Id*. at 21. More than 50% of the private expenditure in healthcare in BiH goes into "medical treatment services, followed by medical supplies for outpatient-care services," financed predominantly from private resources, ancillary healthcare services, and so forth. *Id*. at 10 & tbl. 3. Medicines and therapeutic aids formed the greatest share of direct household spending (suggesting that the approved list of medications does not cover them). Of the amount "spent on out-of-hospital dental protections in BiH, 65% was funded from private sources, suggesting that [a] vast majority of the population uses the services of private dental practitioners." *Id*. at 21.

234. *Id*. at 11.

235. *Id*. at 10-11. Compared to its neighbors, in 2014, BiH's *private* healthcare spending was 2.76% of GDP—over and above 1.4% of GDP for Croatia, 2.6% of GDP for Slovenia, and the EU average of 2.2%. *Id*. at 11. Similarly, in 2014, the share of private expenditure in total health expenditure in BiH was 28%, double the EU average of 14%. *Id*. at 1.

236. *Id*. at 13.

237. *Id*. at 19. *See also id*. at 18 tbl. 5 (indicating a share of total expenditure of 0.02% for budget of BiH institutions, 3.5% for budget of entities, and 2.9% for budgets of cantons).

preventive initiatives.[238] Under the current system, employers and their employees bear the burden of financing health insurance. They are the only sections of the population contributing financially to the public healthcare system. Employers and employees, unlike other categories (such as the unemployed, pensioners, students, and farmers), pay more than their share in the population of insured persons.[239] Additionally, BiH has a highly informal economy, estimated at between 25% and 57% of the GDP, that generates no public revenues for the healthcare sector.[240] In short, under BiH's current system of healthcare financing, the surplus from employed persons' contributions covers the deficit of revenues generated by all other insured categories, even though the employed group makes up only slightly over one-third of the insured population.[241] For example, as shown with RS data in Table 2 above, from 2014 to 2018, employees comprised slightly over 35% of the total number of insured categories but contributed almost 84% of the total public revenue.

Juxtaposed with other countries', BiH's budget share for financing total healthcare expenditure ranks among the lowest.[242] For example, compared to twenty-nine other European countries, BiH ranked seventeenth.[243] Additionally, in a survey where the Netherlands placed first with 87% public funding and Albania last with 49.9%, BiH fell below the average of 76.2%.[244] Copays that insured persons must pay when they see a doctor, innocuously passed off as "participatory fees," threaten financial ruin for a broad section of the population.[245] "[O]ut-of-pocket payments for healthcare are those contributions [that] the poorest households and people usually cannot afford," which is often why these individuals delay or forego treatment.[246] In 2014, these payments accounted for 96.9% of private contributions for healthcare

238. *Id*. at 19.

239. *Id*. at 19 & tbl. 6.

240. *Id*. at 19. *See also infra* note 264 and accompanying text.

241. MARTIĆ & ĐUKIĆ, *supra* note 32, at 19.

242. *Id*.

243. *Id*. at 17.

244. *Id*.

245. *Id*. at 21-22 (discussing the negative impacts of out-of-pocket payments on the poor).

246. *Id*. at 21.

services.[247] The high number imposes a serious burden on families living near or below the poverty line.[248] It also means about half a million people delay purchasing medicines they need or seeking healthcare services, particularly preventive services.[249] This is a heavy burden for this group of people, which impedes their ability to escape poverty.[250]

iii. The Poor State of the BiH Economy as Impediment

BiH's dire economic condition complicates the inadequate public funding of healthcare in the country. In 2017, the Office of High Representative, which exercises oversight over the country to ensure it does not relapse into war, assessed "a[n] [economic] decline across several areas" in the country, compared to its neighbors.[251] That year, BiH had a GDP of $18.08 billion USD,[252] with a per capita income of $5,827 USD.[253] While on the surface these numbers seem modest for a small country still reeling from the effects of a bloody ethnic war, the figures conceal suboptimal scores on several key economic indicators,

247. *Id*. at 21 n.20. Items like voluntary health insurance completed the remainder of contributions. *See id*. at 21.

248. *Id*. at 22.

249. *Id*.

250. *Id*.

251. OFFICE OF THE HIGH REPRESENTATIVE, 51ST REPORT OF THE HIGH REPRESENTATIVE FOR IMPLEMENTATION OF THE PEACE AGREEMENT ON BOSNIA AND HERZEGOVINA TO THE SECRETARY-GENERAL OF THE UNITED NATIONS (May 17, 2017) [hereinafter 51ST REPORT ON BIH] (Part VIII. Economy), http://www.ohr.int/?p=97409. THE GENERAL FRAMEWORK AGREEMENT FOR PEACE IN BOSNIA AND HERZEGOVINA, Yugoslavia – Bosn. & Herz. – Croatia, Dec. 14, 1995 [hereinafter DAYTON PEACE AGREEMENT] (more popularly known as the Dayton Peace Agreement), which ended the Bosnian conflict of 1992 to 1995, gave the High Representative the power to implement the civilian side of that agreement. *See* DAYTON PEACE AGREEMENT, *supra*, art. VIII, Annex 10 (agreement on civilian implementation).

252. *Bosnia and Herzegovina GDP*, TRADING ECON., https://tradingeconomics.com/bosnia-and-herzegovina/gdp, *archived at* https://perma.cc/Y6DD-H3WQ.

253. *Bosnia and Herzegovina GDP Per Capita*, TRADING ECON., https://tradingeconomics.com/bosnia-and-herzegovina/gdp-per-capita, *archived at* https://perma.cc/Q8CF-PY45.

such as foreign direct investment (DFI),[254] the index of economic freedom,[255] ease of doing business,[256] human development,[257] global competitiveness,[258] and credit rating.[259] Additionally, BiH has an inefficient public sector,[260] a high unemployment rate,[261] high poverty

254. 51ST REPORT ON BIH, *supra* note 251 (Part VIII. Economy) (recounting that, in 2016, BiH ranked 4th in foreign direct investment inflows in Southeastern Europe on the U.N. Conference on Trade and Development's World Investment Report). *See also* COUNCIL OF EUR., PARLIAMENTARY ASSEMBLY, THE HONORING OF OBLIGATIONS AND COMMITMENTS BY BOSNIA AND HERZEGOVINA (Doc. No. 14465) 7 ¶ 10 (Jan. 8, 2018) [hereinafter HONORING OBLIGATIONS BY BIH] (stating that DFI decreased from 2.69% of GDP in 2014 to 1.67% in 2015).

255. *See* 51ST REPORT ON BIH, *supra* note 251 (Part VIII. Economy) (indicating that, in 2016, BiH ranked 109th out of 178 countries in the world, 39th out of 43 in Europe on the Heritage Foundation's Index of Economic Freedom, and 91st out of 159 economies on the Economic Freedom of the World Annual Report for 2016).

256. *Id*. (stating that BiH ranked 81st out of 190 countries on the World Bank's Doing Business Report in 2017, "the worst of all Balkan countries").

257. The country ranked 75th out of 189 countries in the 2018 UNDP's Human Development Report. *See* UNITED NATIONS DEV. PROGRAM, INEQUALITIES IN HUMAN DEVELOPMENT IN THE 21ST CENTURY: BOSNIA AND HERZEGOVINA 2, http://hdr.undp.org/sites/all/themes/hdr_theme/country-notes/BIH.pdf. This was a slight improvement from 2015, when it ranked 85th out of 188 countries. 51ST REPORT ON BIH, *supra* note 251 (Part VIII. Economy).

258. 51ST REPORT ON BIH, *supra* note 251 (Part VIII. Economy) (observing that on the World Economic Forum's Global Competitiveness Report for 2016-2017, BiH ranked 107th out of 138 economies, the lowest in the Balkan region).

259. *Id*. (observing that on the Standard & Poor's Rating Services for 2017, BiH ranked "B with stable outlook" based on factors like fiscal performance, robust indirect tax revenues, and debt burden).

260. HONORING OBLIGATIONS BY BIH, *supr*a note 254, at 7 ¶ 9. *See also* Ellen Goldstein et al., *Three Reasons Why the Economy of Bosnia and Herzegovina Is Off Balance*, BROOKINGS: FUTURE DEVELOPMENT (Nov. 5, 2015), https://www.brookings.edu/blog/future-development/2015/11/05/three-reasons-why-the-economy-of-bosnia-and-herzegovina-is-off-balance/ (counting a large public sector that constricts creation of private wealth among three major, mutually reinforcing imbalances that the country needs to correct).

261. *See* HONORING OBLIGATIONS BY BIH, *supr*a note 254, at 7 ¶ 9 (putting the number at 27.7% of the working population). This is especially problematic among the youth. *Id*. (indicating that about 60% or 6 out of every 10 youths are unemployed). Such a phenomenon has resulted in political corruption associated with job search. The Council of Europe's report cites a case in point involving the Secretary-General of the Party of Democratic Action (SDA), who was arrested in February 2017 for selling jobs in public companies. *Id*. at 7 ¶ 9 & n.5. According to the report, a job as

rate,[262] large-scale emigration from the country,[263] a large informal sector,[264] large-scale corruption,[265] and suffers from consumption of goods and services at a higher rate than it produces.[266] BiH also borrows extensively domestically and internationally, and it relies heavily on foreign aid.[267] The bottom line is that, although the World Bank ranks BiH as an "upper middle income" country, compared to many of its neighbors in Europe, in many respects, it is still a poor country, with negative ramifications for healthcare and preventive medicine.[268]

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an electrician for Elektoprivredra, the public electricity company, sold for €8,000. *Id*. at 7 n.5.

262. *See id*. at 7 ¶ 9 (noting 48% of the population lives below the poverty line). A fallout from this is that many BiH citizens depend on remittances from abroad as a significant source of income. *Id*. at 7 ¶ 10 (US $1,347.93 million in 2015). *See also* Goldstein et al., *supra* note 260 (noting about 20% of the country's GDP came from other financial inflows like foreign aid and remittances).

263. *See* HONORING OBLIGATIONS BY BIH, *supr*a note 254, at 7 ¶ 9 (noting one reason people are leaving is because of the scarcity of employment); *see also* 51ST REPORT ON BIH, *supra* note 251 (Part VIII. Economy) (stating that on the World Economic Forum's Global Competitiveness Report for 2016-2017, BiH ranked 134th out of 138 countries regarding the capacity to retain talent).

264. BiH's informal economy is estimated at 25-37% of the country's GDP. ANDREJA ŽIVKOVIĆ, BALKAN MONITORING PUB. FINANCES, ANALYSIS ON TAX JUSTICE: BOSNIA AND HERZEGOVINA 6 (Sept. 2017). This article defines "informal" broadly to include indicators such as when taxable income for social security is paid at the minimum wage level, although the actual salary was higher; taxable income for social security is reported as lower than the actual income paid; actual payment is higher than that written in the contract; no health insurance is provided on the main job; no social security payment is given on the main job; and when there is no written contract for the main job. *Id*. at 10.

265. 51ST REPORT ON BIH, *supra* note 251 (Part VIII. Economy) (observing that in Transparency International's Corruption Perceptions Index for 2015, BiH ranked 83rd out of 176 countries).

266. HONORING OBLIGATIONS BY BIH, *supra* note 254, at 7 ¶ 9 & n.4 (noting that, in 2014, imports represented 56.9% of BiH's GDP, while exports accounted for only 33.9%). "Exports are worth only 30 percent of GDP, one of the lowest in Europe. . . . If BiH exported as much as it did during Yugoslav times, its exports would be three times as high." Goldstein et al., *supra* note 260.

267. HONORING OBLIGATIONS BY BIH, *supr*a note 254, at 7 ¶ 10. According to this report, BiH maintains foreign currency reserves large enough to cover imports for six months. *Id.* at 7 ¶ 11.

268. Based on the World Bank's figure of $4,616 USD GDP per capita that the Council of Europe used, BiH has a 28% purchasing power per capita, which is lower

iv. Miscellaneous Impediments Somewhat Related to Inadequate Funding

The following are miscellaneous problems somewhat tied to inadequate funding that impede healthcare services in BiH: difficulties insured persons face when they try to take their coverage with them when they move to a residence outside of their registered area;[269] absence of any obligation by Cantonal Funds to transfer resources or data to FBiH Health Insurance Fund; failure of an affected contributing agency (i.e. company or institution) to pay its contribution(s) into an affected healthcare fund; absence of inter-entity or inter-cantonal cooperation;[270] and "undermin[ing] the effective operation of the principle of a common pool of resources and of commonly-shared risks" created by the existence of thirteen disparate healthcare systems' health funds (counting the two entities alone, without the Brčko administrative district).[271] Other impediments somewhat related to funding are as follows: "non-payment of contributions into the health funds"; lack of co-operation among the different healthcare jurisdictions on issues bearing on healthcare delivery;[272] a primary healthcare system designed to cover 70-80% of all medical cases that, in actuality, processed only 10-20% of the projected volume;[273] transportation problems due to a rugged topography;[274] and an emergency system that does not function well.[275]

Similarly, BiH "does not have sufficient pharmaceutical manufacturing to cover its entire needs," thus, it must depend on

than Albania's 30%, Serbia's 36%, Croatia's 58%, and Slovenia's 83%. HONORING OBLIGATIONS BY BIH, *supra* note 254, at 7 & n.3.

269. HEALTH CARE IN BIH, *supra* note 10, at 6-7, 23.

270. *Id*. at i, 7-9.

271. *Id*. at 23.

272. *Id*. at i, 1.

273. *Id*. at i, 1, 25 (referring to FBiH, one of the two entities that make up the country).

274. *Id*. at i. *See also id*. at 27-28 (commenting on the physical-environmental conditions impeding healthcare delivery in BiH).

275. *Id*. at 51 (pointing out that the country has "less than [one] vehicle per 100,000 inhabitants," with the result that in places where an ambulance is available, "it can take up to 3 hours for an emergency vehicle to arrive on-site following a call").

importing drugs to satisfy those unmet needs.[276] Neither the country's two entities nor the self-governing unit comes close to the ranges in drug quantity, 250-350, that the WHO recommends as ideal on the Essential Drug List (EDL).[277] Of the recommended range, FBiH maintained only a list of about 160 drugs and RS boasted a PL of 105, while Brčko District had neither an EDL nor PL.[278]

3. Healthcare as a Human Right

Healthcare as a human right is antithetical to the idea of healthcare as a privilege—a revocable gift from the government. As the discussion in Part II pointed out, Bosnia integrated former Yugoslavia's socialist approach of treating healthcare as a human right.[279] The only question is to what extent BiH citizens may enjoy that right. The European Union identifies several values in healthcare delivery—universality, access to high-quality healthcare, solidarity, and equity[280]—which are values that can serve as proxies in gauging healthcare as a human right.

4. Political Prioritization of Healthcare Reform

a. Methods for Diversifying the Current System

There is little indication that BiH's political leaders are treating healthcare as a high priority on their policy agenda. Over the years, political actors have pushed for healthcare financing reform.[281] This reform entails shifting away from excessive dependence on workers' contributions due to the following factors: a low share of employed

276. JENNIFER CAIN ET AL., *supra* note 15, at 76.

277. HEALTH CARE IN BIH, *supra* note 10, at 28. The EDL is the quantity of drugs that the WHO recommends "should be available free of charge in all countries as a basic standard of treatment." *Id*. From this standard, BiH has distilled a Positive List (PL), i.e., a list of drugs that state pharmacies or related healthcare outfits should have on hand and available to patients for free or subject to a small copay euphemistically known in BiH as a "participation [fee]." *Id*.

278. *Id*. (data as of 2000).

279. *See supra* Part II (background history on the constitutional law of healthcare in BiH).

280. *See supra* note 131 and accompanying text.

281. *See* MARTIĆ & ĐUKIĆ, *supra* note 32, at 25-26 (discussing current initiatives for reforming health financing schemes).

persons in an aging population, high unemployment rates, increased demand for healthcare services, a low average salary, and a deficit in healthcare funding caused by rising healthcare costs.[282] To elaborate on the deficit, in 2015, the Federation of Bosnia and Herzegovina and its ten cantons faced a problem of illiquidity that amounted to more than 120 million KM (about 60 million euros) in total unpaid claims of funds,[283] while its co-entity, Republika Srpska, had a loss of more than 20 million KM (about 10 million euros).[284] These factors leave the healthcare system vulnerable to economic recessions, which affect the availability of funds and create financial insecurity.[285] These factors also call for diversifying sources of healthcare funding by integrating non-contribution revenues into a system that relies on contributions based largely on wages.[286] According to Martić and Đukić, there are three ways to achieve diversification.[287] The remainder of this Part discusses each of the three ways alongside the role of good politics. In BiH, diversification is already underway, but the process has yet to yield tangible and observable results.[288]

b. Reallocating and Earmarking

The first way to achieve diversification is "ensuring alternative revenue sources [while] maintaining the same level of contribution rates."[289] The imagery this brings to mind is to mend, rather than end

282. *Id*. at 5, 26.

283. *Id*. at 17.

284. *Id*. at 15.

285. *Id*. at 19.

286. *Id*. at 23, 24, 28. Diversification serves the same purpose of inoculation against excessive exposure to risk as it does in investment. It is "a risk management strategy that mixes a wide variety of investments within a portfolio. The rationale behind this technique is that a portfolio constructed of different kinds of assets will, on average, yield higher long-term returns and lower the risk of any individual holding or security." Troy Segal, *Diversification*, INVESTOPEDIA, https://www.investopedia.com/terms/d/diversification.asp, *archived at* https://perma.cc/7XED-DSVY. "Diversification strives to smooth out unsystematic risk events in a portfolio, [such that] the positive performance of some investments neutralizes the negative performance of others." *Id*.

287. MARTIĆ & ĐUKIĆ, *supra* note 32, at 28-29.

288. *Id*. at 28.

289. *Id*.

the system as it is known now, modifying it. Alternative revenues may be provided by reallocating budget funds to increase the health insurance funds or by introducing additional earmarked revenue sources, such as "new excise duties on tobacco, alcohol, fuel, harmful soft drinks, and luxur[y] products."[290] As Martić and Đukić explain, taxes earmarked for harmful products help reduce their use and provide additional funds for financing treatment costs incurred because of consuming such products.[291] Good politics in this arena will serve the role of prioritizing funds for healthcare and efficiently utilizing available revenue. It is the lowest hanging fruit among the three options that has, however, yet to emerge.

c. Tax Restructuring

The second way is through tax restructuring, which ensures alternative sources of revenue by reducing the required health insurance contributions employees must currently pay from their salaries.[292] This option may include an increase in excise taxes on tobacco and alcohol.[293] It may also include additional alternative revenues, such as those generated by increasing indirect taxes, like the value-added tax (VAT) and property taxes.[294] Like the first way, this second model of achieving diversification is predicated on good politics that prioritizes healthcare funding, reduces wastefulness, and combats corruption. But, unlike the first option, it is a slightly more progressive diversification route that calls for more discipline, creative bipartisanship, and political will than Bosnian politicians, steeped in "ethnic security" twenty years after the war,[295] can muster.

290. *Id*.
291. *Id*.
292. *Id*.
293. *Id*.
294. *Id*.
295. *See, e.g.*, Vesna Bojicic-Dzelilovic, *The Politics, Practice[,] and Paradox of 'Ethnic Security' in Bosnia-Herzegovina*, 4(1) STABILITY: INT'L J. SECURITY & DEV., art. 11 (2015).

d. Complete Restructuring

The third possible means of diversifying healthcare funding on the list of proposals by Martić and Đukić is through a complete restructuring of the current healthcare financing model by transitioning to financing healthcare with budget revenues.[296] Under this approach, all citizens would be entitled to access state-sponsored healthcare without any prerequisites,[297] with two caveats: it would *not* preclude people from obtaining private insurance if they need extra coverage, and it would *not* preclude burdensome copays.[298] Even though this option does not increase individuals' health insurance contributions, it does not forbid increasing direct or indirect taxes.[299] In proposing ways of diversifying revenue sources, Martić and Đukić noted that their calculations did not explain how to collect funds and contract with service providers or what role the private sector should play;[300] the authors advised supporting reforms for each of these.[301] This observation calls for political involvement. If politicians succeed in accomplishing reforms, they will curtail "the burden on labor needs" that, among other pledges, they promised to implement in the Reform Agenda for Bosnia and Herzegovina 2015-2018.[302]

Compared to the first two approaches, this last category signifies a complete break from the past, ending the current system as we know it, rather than mending it. This approach assigns politics the highest role in healthcare decision making. Furthermore, of the three, this approach best promotes the principles of universality, equality, and solidarity in the distribution of healthcare goods and thus draws BiH closest to realizing healthcare as a human right.[303] However, this model demands

296. MARTIĆ & ĐUKIĆ, *supra* note 32, at 28.

297. *Id*.

298. *Id*. at 28-29.

299. *Id*. at 29.

300. *Id*.

301. *Id*.

302. *See supra* note 7 and accompanying text.

303. As Martić and Đukić elaborate, if consumption taxes, such as excise duties on luxury or VAT, covered a great part of health expenses, healthcare financing would be more progressive in the sense that the wealthier segment of the population who consumes more would pay more. The result is even better (in terms of bringing in

more political capital that currently does not exist in BiH and may not for some time, given the political divisiveness embedded in Bosnian politics twenty-five years after the war.[304]

IV. STATUS OF GENETIC COUNSELING IN THE BOSNIAN HEALTHCARE SYSTEM

The composition on genetic counseling in Bosnia and its significance for preventive medicine in BiH is incomplete without gauging the status of genetic counseling in the Bosnian healthcare system. This Part fills that gap. However, from an evidentiary standpoint, it is difficult to determine its status because there are still many moving parts related to genetic counseling in Bosnia and Herzegovina twenty-five years after the war. This difficulty is complicated by inadequate data. Accordingly, this Part examines BiH's ranking among European countries on a 2005-2006 survey and subsequent genetic counseling events, including three recent developments.

A. BiH's Rank in a Survey on Genetic Counseling in 2005-2006

Since the 1960s, European physicians and other medical personnel have provided genetic tests to their patients for health-related reasons within a clinical setting. These tests are usually preceded by a "medical referral, genetic counselling, and upon obtaining informed consent."[305] In contrast, genetic counseling in BiH is suboptimal. This suboptimal level mirrors the overall condition of the healthcare system, which includes genetic counseling. In 2005, EuroGentest, an agency of

more money) if the goods taxed are direct expenses, such as taxes on property and profit. MARTIĆ & ĐUKIĆ, *supra* note 32, at 29.

304. *See generally* Vesna Bojicic-Dzelilovic, *supra* note 295.

305. Kalokairinou et al., *supra* note 84, at 118. Within the context of genetic testing, medical supervision, genetic counseling, and informed consent are concepts connected to clinical practice, not aspects related to genetic tests as products, such as their clinical validity. These three often overlap in practice. For example, all three have fundamentally similar goals: "to guide users to make decisions about their health based on genetic tests that are appropriate for them, after understanding their benefits, limitations and possible implications." *Id*. at 126-27.

the European Commission,[306] sponsored a study published in 2006, which surveyed attitudes toward genetic counseling regulations and practices in thirty-eight European countries, including BiH. The survey revealed the following: of five questions, respondents from BiH answered yes to only one question[307]—whether it would be necessary or good to regulate practical work.[308] Notice that this is an affirmative answer that sounds very much like a negative because it mirrors the remaining answers: the respondents thought it would be a good idea to regulate practical work on genetic counseling because no such regulation at the time existed.

As to the remaining four questions, the same Bosnian respondents responded in the negative, i.e., that the following did not exist in BiH: legislation,[309] professional guidelines,[310] generally applied practices related to genetic counseling,[311] nor a "generally applied practice of informed consent."[312] The BiH respondents also reportedly answered that the country's genetic counseling could not be viewed as organized.[313] Regarding predictions of future development relating to genetic counseling, the respondents foresaw only "[d]evelopment through [the] private sector."[314] The relative lack of legislation concerning genetic counseling in BiH can be attributed to the newness of genetic testing and counseling. Whatever the reason, the paucity is

306. *What Is EuroGentest*, EUR. SOCIETY HUM. GENETICS (ESHG), http://www.eurogentest.org/index.php?id=160, *archived at* https://perma.cc/B9PM-KPWW. Funded by the European Commission, the executive arm of the European Union, this outfit works to harmonize genetic testing in Europe, with a view to ensuring that these tests "provid[e] accurate and reliable results for the benefit of the patients." *Id.*

307. ELINA RANTANEN ET AL., REGULATIONS AND PRACTICES RELATED TO GENETIC COUNSELLING IN 38 EUROPEAN COUNTRIES 11 annex 1 col. 4 (2006), www.eurogentest.org/fileadmin/templates/eugt/pdf/Results_of_survey_1_WP_3-1_Dec06.pdf.

308. *Id*. at 11 annex 1 col. 4.

309. *Id*. at 11 annex 1 col. 2.

310. *Id*. at 11 annex 1 col. 3.

311. *Id*. at 11 annex 1 col. 5.

312. *Id*. at 11 annex 1 col. 6.

313. *Id*. at 11 annex 1 col. 7.

314. *Id*. at 11 annex 1 col. 8.

paradoxical, given the nature of BiH, rooted in its socialist past, as a rule-bound and bureaucratic society.[315]

B. Genetic Counseling Events Since 2006

Since the 2005-2006 survey, considerable changes bordering on genetic testing and counseling have taken place in the BiH healthcare system. The first relates to laws. For example, all thirteen units that make up the Bosnian healthcare system now have their own healthcare and health insurance laws.[316] While these laws help protect patients' privacy, preserve their dignity, and keep their data confidential,[317] none of the legislation directly addresses genetic counseling. Instead, for example, as recently as 2012, growth in the field of genetic testing (a process inseparable from genetic counseling) remained at the infancy stage, with clinical testing limited to three purposes: "diagnostic[s], research, and basic human genetic research."[318] Inescapably, the limited progress includes the development of agency regulations to guide clinical practice.[319]

Another key development relates to the evolution of genetic testing centers across BiH, such as "the Clinical Center of the University of Sarajevo, the Institute for Genetic Engineering and Biotechnology at the University of Sarajevo, the University Clinical Center in Banja Luka, and the University Clinical Center in Tuzla."[320] Genetic tests are

315. *See, e.g.*, Mladen Lakic, *Bosnian Entrepreneurs Face Bureaucratic Obstacles to Success*, BALKANINSIGHT (Nov. 7, 2018, 7:06 AM), https://balkaninsight.com/2018/11/07/bosnian-entrepreneurs-struggling-with-administration-amid-creative-ideas-11-06-2018/, *archived at* https://perma.cc/4T8Y-KDXK; Dražen Huterer et al., *Bosnian Divisions Create Bureaucratic Headaches*, PRO.BA (2013), https://pro.ba/en/bosnia-divisions-create-bureaucratic-headaches/, *archived at* https://perma.cc/N2BH-MQ97.

316. *See* Sabina Semiz & Philip C. Aka, *Precision Medicine in the Era of CRISPR-Cas9: Evidence from Bosnia and Herzegovina*, 5 PALGRAVE COMMUNICATIONS 1, 3 (2019) (discussing the legal and constitutional provisions for healthcare in BiH).

317. *See supra* Part II.B. of this Article (discussing provisions for healthcare in BiH).

318. *See* Semiz & Aka, *supra* note 316.

319. *See id*. at 3-4 ("Genetic testing in Bosnia and Herzegovina" *and* "Genetic counseling in Bosnia and Herzegovina").

320. *Id*. at 3.

available to patients through physician referral and cover areas like prenatal DNA characterization, breast cancer risk, thrombophilia, and genotyping the spectrum of inherited disorders.[321] But because genetic counseling services are available for only a few rare diseases, current efforts in BiH laboratories have focused on advancing physicians' knowledge and professional skills in preventing and diagnosing rare diseases early on.[322] There has also been a focus on "increasing the number of highly specialized personnel" in clinical genetics.[323] Additionally, because BiH lacks certified genetic laboratories for complex diagnostic testing, the few that exist collaborate with certified laboratories outside BiH.[324]

A third recent development, reinforcing the second, is the emergence of several private labs offering direct-to-consumer (DTC) genetic tests as a way around the formal system.[325] Currently, the public healthcare system is increasingly asked to interpret and counsel on genetic information that has been generated privately or at the clinic.[326] The types of tests these private entities offer vary, including "tests that offer information regarding health enhancement (nutrigenomics, dermatogenetics); drug response (pharmacogenomics); and susceptibility for common complex disorders[, such as] cardiovascular diseases, depression, osteoporosis, [and] type 2 diabetes."[327] Although this commercial phenomenon is making genetic information increasingly available to the general public, it is provided without counseling and people are often unaware that their health risk

321. *Id*.

322. *Id*.

323. Vladmiri Guzvic et al., *Rare Diseases and Orphan Drugs Accessibility in Bosnia and Herzegovina*, 30(4) MATERIA SOCIO MEDICA [J. OF ACAD. OF MED. SCIENCES OF BOSN. & HERZ.] 297, 298 (Dec. 2018). The article defines "rare diseases" as illnesses, such as phenylketonuria and congenital hypothyroidism, that affect less than 1 in 2,000 people. *Id*. at 297, 299.

324. Semiz & Aka, *supra* note 316, at 3.

325. Pascal Borry et al., *Where Are You Going, Where Have You Been: A Recent History of the Direct-to-Consumer Genetic Testing Market*, 1(3) J. CMTY. GENETICS 101 (2010). *See also* Symposium, *Is There a Right Time to Know? The Right Not to Know and Genetic Testing in Children*, 42(1) J. L., MED., AND ETHICS 19, 20 (2014).

326. *See* Borry et al., *supra* note 325, at 103-04.

327. *Id*. at 102.

information is sold.[328] Many DTC genetic testing companies do not provide their consumers with appropriate pre- and post-genetic counseling; however, even when companies provide genetic counseling, concerns arise about the quality and mode of that service.[329] There is also a cost element. While it is important for persons to know their susceptibility risk, the expensive price tag of testing—sometimes more than the average salary of many workers in BiH—makes testing unavailable to many.[330] For this reason, countries should share approaches and draw on lessons learned in disparate locales rather than approach the issue alone.[331]

Finally, not all private companies or labs that offer genetic testing in BiH perform genetic counseling services inside the country. Instead, some of these companies or labs conduct genetic analysis in certified laboratories situated *outside* the country.[332] Subsequently, they share the test results with the patients and their physicians.[333] In some private companies or labs, certified genetic counselors from companies outside of BiH, assisted by a translator, advise via Skype.[334] Moreover, the relatively few centers and labs in the country that *have* developed technical and personnel infrastructure to implement more advanced genetic diagnostic services are "not financed from the mandatory health

328. *See id*. at 103.

329. *See* Howard & Borry, *supra* note 86, at 53-54.

330. Semiz & Aka, *supra* note 316, at 4 (citing Vladmiri Guzvic et al., *Health Technology Assessment in Central-Eastern and South Europe Countries: Bosnia and Herzegovina*, 33(3) INT'L J. TECH. ASSESSMENT IN HEALTH CARE 390, 390-95 (2017)).

331. Teri A. Manolio et al., *Global Implementation of Genomic Medicine: We Are Not Alone*, 7(290) SCI. TRANSNAT'L. MED. (2015) ("Abstract"). Transnational collaboration through the large research consortia and sharing information in the areas of health information technology, genomics, pharmacogenomics, education, professional development, and policy and regulatory issues appears to be imperative for the future efficient clinical implementation of personalized medicine at the global level. *Id*. ("Brief Landscape of International Genomic Medicine Projects" and "Opportunities for International Collaboration"). *See also* Paul Ndebele & Rosemary Musesengwa, *Will Developing Countries Benefit from Their Participation in Genetics Research?* 20(2) MALAWI MED. J. 67, 67 (2008) (arguing "for justice in the sharing of both burdens and benefits of genetic research").

332. Semiz & Aka, *supra* note 316, at 4.

333. *Id*.

334. *Id*.

insurance funds."[335] Consequently, the BiH population faces difficulties using these service centers.

V. IMPLEMENTING PREVENTIVE MEDICINE IN BOSNIA AND HERZEGOVINA THROUGH GENETIC COUNSELING

Bosnia and Herzegovina is ready to implement preventive medicine. The country's leaders can help establish preventive medicine in BiH through enacting genetic counseling laws, increasing public education, and implementing reforms that assign the state-level government increased role in healthcare design and implementation.

A. Creating Statutory Standards for Genetic Counseling Now Practically Lacking

Laws "form[] an important framework for practices and services related to genetic testing."[336] Laws serve an important function in "'standardiz[ing] practical work' . . . [and] 'guarantee[ing] the quality of treatment . . . patients and their families [receive] in all medical centers.'"[337] Furthermore, laws are particularly needed in countries like BiH, "where the development of genetic medicine may have been more recent and issues related to human genetics may be a newer area of consideration."[338] Accordingly, for knowledgeable observers, such as the respondents in the 2005-2006 survey on genetic counseling commented upon in the last Part, the absence of laws "has a negative impact on practical work in" in the field.[339] As indicated in Part IV.B. above on the review of recent developments relating to the status of genetic counseling in BiH, although the country has several laws that relate to healthcare, those are barely sufficient given their tenuous connection to genetic counseling.

Drawing on the 2005-2006 survey, as used here, law combines two concepts: legislation and professional guidelines.[340] *Legislation*

335. Guzvic et al., *supra* note 323, at 300.

336. RANTANEN ET AL., *supra* note 307, at 2.

337. *Id*. at 3 (quoting two respondents).

338. *Id*. at 4.

339. *See id*.

340. *See generally id*. at 2-3 (discussing legislation and guidelines related to genetic testing),

"refer[s] to official laws passed by the Parliament [legislative body] and additions that go through a Ministry."[341] Legislation addresses issues, such as whether a healthcare provider has the requisite training needed for a procedure or activity, like genetic counseling.[342] *Professional guidelines* as a term refers to "professional and other best practice papers" that are not binding authorities.[343] Professional guidelines may be viewed as rules that "affect counselling even though they do not specifically cover it."[344]

A good law in genetic counseling *should* cover clinical situations and topics regarding diagnostic testing, carrier testing, predictive testing, susceptibility testing for multifactorial diseases, prenatal diagnosis, pre-implantation diagnosis, testing of children and adolescents, and consent of the patient.[345] A good law should also address the following: who can perform genetic counseling; counseling persons from minority ethnic groups; counseling minors or persons with diminished capacity; providing psychological support during counseling; informing relatives of at-risk patients; issues relating to confidentiality, including circumstances when it is legally permissible to breach confidentiality; non-directiveness; and the duty to re-contact the patient.[346]

Although this is a comprehensive list of topics, the ones most often covered are prenatal diagnosis, informed consent, and

341. *Id*. at 2.

342. *Id*.

343. *Id*.

344. *See id*.

345. *See id*. at 14 annex 2 (charting "[d]ifferent clinical situations and topics related to genetic counselling in legislation, guidelines and practices of 38 European countries").

346. *See id*. Non-directiveness, one of the clinical situations and topics enumerated, is present when the geneticist or medical personnel provides genetic information in a balanced fashion, without undue pressure on or coercion of the patient. Typically, this would require providing information that "include[s] the pertinent medical facts, results of tests, [and] the consequences and choices." Additionally, the counselor would "explain the purpose and nature of the tests and point out possible risks." Significantly, these steps are not an exhaustive list of what may be needed to adequately ensure non-directiveness. Recommendation No. R(92) 3 on Genetic Testing and Screening for Health Care Purposes, *supra* note 104, principle 3.

confidentiality.[347] Professional guidelines mostly address "counselling in the context of prenatal diagnosis, testing of children and adolescents, non-directiveness of counselling[,] and who can perform genetic counseling."[348] Nonetheless, BiH needs a statute that broadly spells out certain guidelines regarding quality control of genetic counseling, one which the health ministry could then flesh out with specific regulations to facilitate implementation. The idea is to create statutory standards for genetic counseling that are currently practically nonexistent.

New legislation would signify that an issue in question has made its way successfully to the public policy agenda and is acquiring some level of legitimation.[349] Creating statutory standards for genetic counseling would also provide indispensable guidelines for administrative agencies, beginning with the Ministry of Health. New legislation does not have to cover all of the topics enumerated in the comprehensive list set forth in the previous paragraphs, but, at a minimum, it needs to address the following: parameters of genetic testing, non-discrimination for individuals with genetic problems, privacy, and confidentiality.[350] Adopting this proposal to create statutory standards for genetic counseling will benefit impoverished people, who, unlike their more materially-fortunate compatriots, cannot afford access to good healthcare abroad, such as in the United States, the United Kingdom, Canada, and even neighboring countries in this region with better healthcare systems and access to healthcare services than the ones BiH affords.[351]

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347. RANTANEN ET AL., *supra* note 307, at 3 (based on information from opinion surveys).

348. *Id*.

349. *An Introduction to the Public Policy-Making Cycle*, POINT PARK UNIV. ONLINE (June 14, 2017), https://online.pointpark.edu/public-administration/policy-making-cycle/, *available at* https://perma.cc/ZF4E-G9LP (focusing on the United States and particularly on Phase 3 on "Policy Legitimation," which is reached when the public views the government's action on the policy matter in question "to be legal and authoritative").

350. *See generally* INST. OF MED., DIV. OF HEALTH SCI. POLICY, COMM. ON ASSESSING GENETIC RISKS, ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY (Lori B. Andrews et al. eds., National Academies Press 1994) (discussing concerns regarding confidentiality, discrimination, and genetic testing in general).

351. This is a practice some critics derisively call "medical tourism." *See, e.g.*, Michael D. Horowitz et al., *Medical Tourism: Globalization of the Healthcare*

B. Increased Public Education Bearing on Genetic Counseling

The Council of Europe's directive relating to genetic testing and screening for healthcare sets forth some rules for good practices in genetic testing and screening.[352] These rules include Principle 1 on informing the public.[353] Principle 1 prescribes that "[p]lans [to] introduc[e] . . . genetic testing and screening should be brought to the notice of individuals, families[,] and the public."[354] It further provides that "[t]he public should be informed about . . . the[] availability, purpose, and implications [of genetic testing and screening, in particular,]" and where they can go to access those services.[355] Principle 1 adds that "[s]uch information should start with the school system and be continued by the media."[356] These definitions make the point clear. While by no means amorphous or a residual variable, increased public education must be broadly defined to create the desired greater public awareness about genetic counseling, including its connection to preventive medicine.

That expansively defined, public engagement is *not* limited to informing and consulting individuals; instead, it also encompasses initiatives designed to educate the public on and foster research of emerging technologies. To ensure ethically-reliable and socially-acceptable application of new genetic technologies, it is important to recognize the attitudes and concerns of the general public as they relate

Marketplace, 9(4) MEDSCAPE GEN. MED. 33 (2007). However, the overall lethargic response of many advanced healthcare systems, including the United States', to the COVID-19 pandemic puts a big question mark on the perceived benefits of medical tourism. *See, e.g.*, Jacquelyn Corley, *U.S. Government Response to COVID-19 Was Slow. But How Does It Compare to Other Countries?*, FORBES (Apr. 10, 2020, 8:12 PM), https://www.forbes.com/sites/jacquelyncorley/2020/04/10/us-government-response-to-covid-19-was-slow-but-how-does-it-compare-to-other-countries/, *archived at* https://perma.cc/EBH9-BTAW.

352. *See generally* Recommendation No. R(92) 3 on Genetic Testing and Screening for Health Care Purposes, *supra* note 104.

353. *Id*. principle 1.

354. *Id*. principle 1(a).

355. *Id*. principle 1(b).

356. *Id*.

to these technologies.[357] In a nutshell, increased public education is fundamental for disseminating bioethical principles related to genetic testing and counseling to the BiH public and for promoting widespread application of these new techniques.[358] Beyond individuals and the public, other stakeholders within society have important complementary roles to play. Patient organizations can advocate for patients at all levels of the government.[359] Here, the associations of health professions should exercise a more active role in organizing continued professional education in BiH health centers and clinics on genetic testing and counseling. Universities, including sections of these higher education organizations versed on issues related to genetic counseling and preventive medicine can do the same. If nothing, such shared role could go a long way in integrating the healthcare system in BiH and improving professional communication across the various health institutions.[360]

Studies show that BiH physicians generally lack knowledge related to genetic tests and might not feel competent to interpret their results.[361] To minimize errors in assessing health risks and to promote disease prevention and treatment options, it is imperative to improve the education of physicians and other health professionals who deal with matters related to genetic counseling. Especially, these professionals should learn about appropriate ways to utilize genetic tests. In addition

357. Davit Chokoshvili et al., *Public Views on Genetics and Genetic Testing: A Survey of the General Public in Belgium*, 21(3) GENETIC TESTING AND MOLECULAR BIOMARKERS 195, 195 (2017) (focusing on Belgium).

358. Mahmutovic et al., *supra* note 42 (conclusions).

359. Guzvic et al., *supra* note 323. *See also* Lynn G. Dressler et al., *Genomics Education for the Public: Perspectives of Genomic Researchers and ELSI Advisors*, 18(3) GENETIC TESTING AND MOLECULAR BIOMARKERS 131, 138 (2014) (suggesting that roundtable discussions, expert discussions, workshops, and symposia are needed to bring together key interdisciplinary stakeholders in academia, government, profit, and nonprofit organizations to create programs in genetic education for the general public).

360. *See* Ahmed Novo et al., *Measures to Improve Integration of Healthcare in Federation of Bosnia and Herzegovina*, 31(1) MATERIA SOCIO MEDICA [J. OF ACAD. OF MED. SCIENCES OF BOSN. & HERZ.] 71 (2019) (focusing on FBiH rather than the whole country).

361. *See* Diane Hauser et al., *Views of Primary Care Providers on Testing Patients for Genetic Risks for Common Chronic Diseases*, 37(5) HEALTH AFF. 793, 794 (2018).

to point-of-care learning and clinical decision support systems developed to provide physicians with information regarding pharmacogenetic tests and personalized medicine,[362] there are also opportunities to learn more about genetic testing and counseling through online modules and participatory learning strategies.[363] Furthermore, future BiH health professionals should be educated on pharmacoeconomics because it will allow them to actively participate in establishing the process for assessing health technology.[364]

One final factor, for this author, bearing on increased public education relates to the lack of university-level education in genetic counseling in BiH. The education and professional training required for genetic counselors in Europe are marked by disparities shrouded in varied standards of registration, substance, and duration of instructions and clinical training, down to the existence in some countries of programs in genetic counseling that other countries lacked.[365] The European Board of Medical Genetics has recommended that genetic counselors receive a master's degree to meet appropriate academic and professional standards.[366] In considering whether or not to adopt this recommendation, Bosnian authorities may also want to keep in mind that the advice is in harmony with existing practice in the United States.[367]

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362. *See, e.g.*, Peter H. O'Donnell et al., *Pharmacogenomics-Based Point-of-Care Clinical Decision Support Significantly Alters Drug Prescribing*, 102(5) CLINICAL PHARMACOLOGY & THERAPEUTICS 859 (2017).

363. Susanne B. Haga et al., *Primary Care Physicians' Knowledge, Attitudes, and Experience with Personal Genetic Testing*, 9(2) J. OF PERS. MED. 29, 37-38 (2019).

364. *See* Tarik Catic & Selma Skrbo, *Pharmacoeconomic Education for Pharmacy Students in Bosnia and Herzegovina*, 25(4) MATERIA SOCIO MEDICA [J. OF ACAD. OF MED. SCIENCES OF BOSN. & HERZ.] 282, 282-83 (2013).

365. *See generally* Milena Paneque et al., *Development of a Registration System for Genetic Counsellors and Nurses in Health-care Services in Europe*, 24 EUR. J. HUM. GENETICS 312 (2016) (discussing the start of the genetic counseling profession and the attempt by the European Board of Medical Genetics to build a registration system for professionals, with a brief overview of that system's progress).

366. *Id*. at 312.

367. *About Genetic Counselors*, *supra* note 79 (noting that in the United States, genetic counselors are required to complete a master's degree at an accredited genetic counseling program).

C. Last Word on Reform

The state-level government in Bosnia and Herzegovina should exercise a greater role in healthcare. This is an important component of reform, elaborated in the discussion on good laws as healthcare reform in Part IV.C.1, that has been overlooked. The state-level government should make financial contributions to avoid conflict with the entity-level governments. Under the Constitution of 1995, as well as under the ICESCR of which BiH is a state party, the state-level government has healthcare obligations that it fails to shoulder when it takes the type of lackadaisical, lead-from-behind, role it has assumed in healthcare funding. In addition to not comporting with the strictures of reforming healthcare through good *laws*, as elaborated in this Article,[368] this laggardness equally fails the test of reforming healthcare with good *politics*.[369]

CONCLUSION

Appropriately, this Article ends as it began, with the Reform Agenda for Bosnia and Herzegovina 2015-2018. Since 2015, encouraged by the international community, BiH has contemplated reforms, including healthcare reforms, designed to facilitate its integration into the European Union.[370] BiH is a state trying to rebuild its economy after the destruction of a war that damaged its healthcare system; preventative healthcare achieved through genetic counseling is the best way to repair the damaged system. Because today, diseases morph from infectious to chronic categories,[371] prevention has assumed

368. *See supra* Part III.D.1.

369. *See supra* Part III.D.4.

370. *See, e.g.*, Reform Agenda for BiH, *supra* note 2, ¶ 3 ("The priorities for reform were previously discussed with International Financial Institutions (IFIs) and the EU."); *id.* ¶ 2 ("All levels of government are mindful that meaningful progress on the implementation of the agenda for reform will be necessary for a membership application to be considered by the EU.").

371. *See generally* Siobhán M. O'Connor et al., *Emerging Infectious Determinants of Chronic Diseases*, 12(7) EMERGING INFECTIOUS DISEASES 1051 (2006); INST. OF MED., THE INFECTIOUS ETIOLOGY OF CHRONIC DISEASES: DEFINING THE RELATIONSHIP, ENHANCING THE RESEARCH, AND MITIGATING THE EFFECTS – WORKSHOP SUMMARY (Stacey L. Knobler et al. eds., National Academies Press 2004).

increased importance in healthcare administration and delivery. Little wonder that in the United States, the Affordable Care Act (ACA) established under then President Barack Obama was predicated largely on preventive medicine.[372] This morphing of diseases into chronic categories also helps explain why, obviously from a preventive standpoint, newborns in the U.S. are screened for a panel of treatable genetic disorders.[373] Although its basic statistics, composited by and memorialized in life expectancy, rank above average,[374] BiH exhibits low numbers compared to many countries in Europe.[375] Preventive

372. Patient Protection and Affordable Care Act, H.R. 3590, 111th Cong. (2010) (amended by Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152, tit. IV, 124 Stat. 1029). *See also Preventive Services Covered Under the Affordable Care Act*, NAT'L CONFERENCE OF STATE LEGISLATURES (Feb. 2014), http://www.ncsl.org/research/health/american-health-benefit-exchanges-b.aspx, *archived at* https://perma.cc/B5GQ-TEFR; Vera Gruessner, *How the Affordable Care Act Changed the Face of Health Insurance*, HEALTHPAYER INTELLIGENCE (June 15, 2016), https://healthpayerintelligence.com/features/how-the-affordable-care-act-changed-the-face-of-health-insurance, *archived at* https://perma.cc/7GWF-NQK3 (discussing how the Act's "[p]reventive medicine provisions incentivize accountable care"); Nadia Chait & Sherry Glied, *Promoting Prevention Under the Affordable Care Act*, 39 ANN. REV. PUB. HEALTH 507 (2018) (addressing the Act's goals and specific provisions).

373. *See* GENETIC ALL., D.C. DEP'T OF HEALTH, UNDERSTANDING GENETICS: A DISTRICT OF COLUMBIA GUIDE FOR PATIENTS AND HEALTH PROFESSIONALS 20 (2010) ("Each year, more than 95% of all children born in the United States (at least 4 million babies) are tested for a panel of diseases that, when detected and treated early, can lead to significant reduction in disease severity and possibly even prevention of the disease."). As this document elaborated, "[w]ithin 48 hours of a child's birth," healthcare workers obtain samples, called a 'blood spot,' from newborns. Then, they submit the blood for testing at state-owned or state-approved laboratories, where it is "analyzed for up to 50 diseases, including phenylketonuria (PKU), sickle cell disease, and hypothyroidism." *Id*.

374. *See, e.g.*, H. Plecher, *Bosnia and Herzegovina - Statistics and Facts*, STATISTA (Feb. 8, 2019), https://www.statista.com/topics/4644/bosnia-and-herzegovina/, *archived at* https://perma.cc/NGS4-Z5FZ. For example, as this source points out, compared to other countries in Europe, life expectancy at birth in BiH is high. *Id*. In 2017, that number was 77.13 years. H. Plecher, *Life Expectancy at Birth in Bosnia & Herzegovina in 2017*, STATISTA (Dec. 11, 2019), https://www.statista.com/statistics/452587/life-expectancy-at-birth-in-bosnia-herzegovina/, *archived at* https://perma.cc/PZ5T-S86B.

375. *See, e.g.*, *Life Expectancy at Birth, Total (Years)*, WORLD BANK, https://data.worldbank.org/indicator/SP.DYN.LE00.IN, *archived at* https://perma.cc/9J9R-4SX8 (covering the period 1960-2017) (showing BiH has a life

medicine, especially genetic screening, can improve those numbers. And given increased awareness of the possible influence of environmental factors embedded in popular attitudes can have on genetics,[376] the emphasis on preventive medicine could be broadened to include pressing public health issues, such as tobacco control.

Smoking is an endemic problem in BiH.[377] About 50% of adults smoke, and "non-communicable diseases account for 45% of deaths."[378] "Tobacco consumption is a serious health, economic, social, and financial issue for BiH[, . . . which] increase[s] diseases, disabilities, and premature deaths, [and places a] financial burden on smokers and their families, health service providers, and employers."[379] In November of 2012, the World Bank organized an international conference on tobacco control held in Sarajevo.[380] The conference was held in partnership with Bosnian authorities (at both the central and entity levels) and the government of Switzerland.[381] The two-day conference promoted tobacco control in BiH. Various countries which participated in the conference shared their experiences regarding best-practices for tobacco control programs.[382] Participants included "key government officials and health specialists from Albania, [BiH], Brazil, Kosovo, Montenegro, Slovenia, Serbia, Turkey, and Ukraine, as well as experts from the World Health Organization, the World Bank, and civil society."[383] At the conference, Mr. Sredoje Nović, then Minister of Civil Affairs, declared, "'[t]he fight against tobacco is one of the key

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expectancy of 77, whereas it is 83 for Norway, France, and Italy, 81 for Germany and Slovenia, and 78 for Albania).

376. *See, e.g.*, Kendra Cherry, *The Age Old Debate of Nature vs. Nurture*, VERYWELLMIND, https://www.verywellmind.com/what-is-nature-versus-nurture-2795392, *archived at* https://perma.cc/KQ6G-JBNQ; Ingrid Lobo, *Environmental Influences on Gene Expression*, 1(1) NATURE EDUC. 39 (2008).

377. *Smoking: An Endemic Problem in Bosnia and Herzegovina*, WORLD BANK (Nov. 20, 2012), http://www.worldbank.org/en/news/feature/2012/11/20/smoking-an-endemic-problem-in-bosnia-and-herzegovina, *archived at* https://perma.cc/H4YJ-H9U6 [hereinafter *Smoking in BiH*] (feature story on the International Tobacco Control Conference held in Sarajevo on November 5 and 6, 2012).

378. *Id*.

379. *Id*.

380. *Id*.

381. *Id*.

382. *Id*.

383. *Id*.

battles that we in Bosnia and Herzegovina have to lead in the period ahead.'"[384]

Nonetheless, several years after the conference, smoking remains pervasive in BiH.[385] It is estimated that five million people die worldwide as a direct consequence of tobacco smoking and an additional half a million die from second-hand smoke. For a relatively small country, BiH contributes significantly to this death toll.[386] The ethnic conflict from 1992 to 1995 likely contributed to these public health dilemmas.[387] Instead of surrendering to it, BiH should build on its past by committing to socioeconomic human rights, including healthcare. BiH's shortcomings regarding genetic counseling demonstrate the progress that remains to be made. As it struggles to recover from the still-felt effects of the gory conflict that damaged its economy and healthcare system, BiH should implement and promote preventive healthcare, achieved through genetic counseling as well as through progress in public health issues like tobacco control.

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384. *Id*.

385. *See, e.g.*, WORLD HEALTH ORG., REGIONAL OFFICE FOR EUR., TOBACCO CONTROL FACT SHEET: BOSNIA AND HERZEGOVINA 1 (2016) [hereinafter TOBACCO CONTROL FACT SHEET] ("Based on the current level of adult smoking in Bosnia and Herzegovina . . . premature deaths attributable to smoking are projected to be as high as 600,000 of the more than 1.2 million smokers alive today . . . and may increase in the absence of stronger policies."). This fact sheet listed the following tobacco control policies, both for FBiH and RS (listed in Tables 2 and 3 respectively): smoke-free laws, services to help smokers quit, mass media anti-smoking campaigns, warnings on cigarette packages about the dangers of smoking, enforcing bans on tobacco advertising, promotion, and sponsorship; and raising taxes on tobacco products. *Id*. at 2-3. The report card on the war against tobacco in BiH, to the extent that such war exists, highlights the issue that indoor public places in BiH (such as healthcare facilities, educational facilities, government facilities, indoor offices and workplaces, restaurants, cafes, pubs and bars, and public transport) are not completely smoke-free. *Id*. at 3 & tbl. 4. Similarly, bans on direct and indirect advertising in both FBiH and RS are still incomplete. *See id*. at 4-5 tbls. 5-6.

386. *Compare Smoking in* BiH, *supra* note 377, *with* TOBACCO CONTROL FACT SHEET, *supra* note 385, at 1.

387. *See supra* note 28 and accompanying text. For a discussion on how wars negatively socialize individuals to pick up habits like smoking, which impact public health, see Associated Press, *Smoking in the Military: An Old Habit Dies Hard*, NBC NEWS, http://www.nbcnews.com/id/32608436/ns/us_news-military/t/smoking-military-old-habit-dies-hard/#.XXpHESgzZPY, *archived at* https://perma.cc/323V-FLVX (focusing on the USA).