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UHC Charter Expert Papers

TOPIC OF FOCUS

Universal is universal: the commitment to Universal Health Care must be unequivocal. Effective universality must be ensured. There can be no room for nuances that could allow for any form of social exclusion or discrimination.

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Draft September 17, 2018

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Introduction

A primary focus of global health policy is how to best achieve universal health coverage (UHC) in low- and middle-income countries (WHO 2010). WHO defines universal health coverage as the provision of effective and medically necessary services to all people. These services include preventative, promotional, curative, rehabilitative and palliative care. UHC should enable everyone to access these services while providing them protection from punishing costs, which can be catastrophic and impoverishing, to the person or family in need. (WHO, 2010 and Clark 2014). Health is now widely recognized as a human right incorporating the determinants of health (Ooms et al. 2014; Sen 2008). The concept of health and its determinants as a human rights principle and the role of health protection in safeguarding the dignity of vulnerable populations create a moral imperative for implementing UHC (Meyer 2007), which is the practical expression of the right to health in the social environment (Ooms et al 2014; WHO 2012). Fidelity to the universality principle of the right to health means exclusion of any persons, in any form – explicit- or implicit- -- is unacceptable and must be guarded against to achieve health equity.

In low-, middle-, and high-income countries alike, however, there is consistent evidence that the lower an individual's socio-economic position, the higher their risk of poor health, disability, and death. There is a mutually reinforcing cycle between poverty and disability that is sensitive to access to health care, education and employment (Banks et al. 2017). Vulnerable population groups may be explicitly excluded from the advantages of UHC because of policy choices or political pressures and the trade-offs countries face. There is evidence of other forms of implicit exclusion from UHC based on cultural practices or failure to include access to services most needed by vulnerable populations, particularly those living with disabilities. Individuals excluded from coverage are not only more likely to face risk of impoverishment in the event of an illness, they are also more likely to experience a sense of social exclusion, vulnerability, and distrust of public institutions (IOM 2003).

The implementation of UHC should be understood in light of the best available care that is aligned with all appropriate resources, however, and not unlimited (Ooms et al. 2014). Countries face the challenge of balancing the moral imperative of universality inherent in UHC with the macroeconomic and fiscal realities that limit resources available to fully realize this aspiration. They also face political

challenges in societies where solidarity is weak or eroding. Even more challenging are deep-rooted cultural barriers, discriminatory practices, and societal prejudices that may keep the most vulnerable in society from benefitting from the full health and social protections that are the promise of UHC. In this paper, we examine the concept of universality and how it can be violated both explicitly and implicitly in country UHC policies and their implementation. We then examine options countries have explored to pursue truly universal coverage in the face of limited resources, especially public resources, and other social and cultural barriers to universality.

What do we mean by “universal is universal”?

Universal health coverage is universal when equal access to quality essential health care services and social and financial protections are afforded to all persons – young and old; healthy and sick; functional and functionally impaired or disabled; male and female; rich and poor; educated and illiterate; powerful and marginalized; formally, informally, or unemployed; of all sexual orientations, races, religions, languages, ethnicities and nationalities – unequivocally and simultaneously. Apportioning health care otherwise risks reinforcing segmentation of the health care system, as well reinforcing preexisting public perceptions of unequal access to, or unequal quality of care (Cotlear et al. 2015). It also risks undermining social cohesion, which has potential health consequences of its own and prevents UHC from reaching its full potential to contribute to the common good (Green et al. 2017).

Historical context of health and social determinants as human rights

When WHO recognized health as a complete state of physical, mental and social well-being, not merely the absence of disease (WHO, 1946), it acknowledged health as a fundamental human right and as a socially imbedded phenomenon. Two years later, with these words: “All human beings are born free and equal in dignity and rights” the 1948 United Nations’ Universal Declaration of Human Rights enshrined human rights and recognized the inherent dignity of all peoples (because in fact, one does not have dignity if one does not have rights). (Siegert, 2009). The UN declaration expresses the modern idea that dignity is conferred upon all humans equally because their humanness alone entitles them to “be treated with... decency and respect.” (Jacobsen, Siegert 2009)

The “right to health” principle acknowledges the essential role of health in a happy and productive human life. Over time it has generated an accumulation of “laws, institutions, policies, and practices” that collectively contribute to an “enabling environment that can best secure good health.” (Nygren-Krug 2013). A health-enabling environment in combination with universal access to good quality health care, protects individuals from illness, stimulates economic growth, fights poverty, (Rio + Zo) and fosters social cohesion (Green et al. 2017).

By the end of the Cold War the conceptualization of health as a human right was internationally recognized as inseparable from all other human rights and that it should be addressed as such. (Nygren-Krug 2013). Thus, health as a human right and economic development conceptually merged

as it became clear that improving health is both a component and determinant of sustainable development.

The social and economic context of the right to health principle, and its interrelationship with human dignity, happiness and productivity compel decisive action toward UHC. Yet, significant peril exists in the power to determine who gets what, when, and how, in the distribution of health care services. There is a paradox in assuming governmental authorities are able to represent the views of vulnerable and marginalized populations – if this were possible, would the groups be marginalized to begin with? The principle of participatory decision-making is intended to allow for representation of the views of vulnerable or marginalized groups in health care, but if they are not able to advocate for themselves how will their needs be recognized?

In practical terms, the “right to health” cannot be separated from a right to social well-being because social well-being sustains good health, and good health enables the social participation that creates well-being. Neither can the right to health and social well-being be practically separated from economic development, as the “virtuous circle” phenomenon driving the relationship between health and social well-being, applies equally well to the relationship between financial stability and health. (Nygren-Krug 2013).

Social protection and safeguarding the dignity of vulnerable populations

Emerging literature in psychology, philosophy, and the social sciences illustrate the significant relationship between the experience of shame and health status, the extent of which indicates shame itself may well be a direct cause of ill health. (Dolezal 2017). Shame is recognized as a powerful force in a clinical encounter but neglected in the context of health and medicine. Shame is a powerful enough force to be considered an affective determinant of health. (Dolezal 2017).

Shame may be associated with reproductive health, sexually transmitted diseases, sexual preference, gender identity, genetic conditions, debilitating conditions, mental health conditions including drug and alcohol addiction, obesity, cancers or chronic conditions attributed to health behaviors for which the individual may feel responsible including HIV, developmental delays and disabilities, disfiguring illnesses, and poorly understood conditions such as narcolepsy and chronic fatigue (which are popularly construed as ‘laziness’). The social determinants of poverty and illiteracy are additional causes of shame with health effects.

Chronic shame is associated with minority stigma and social status threat. The increased stress resulting from belonging to any stigmatized group is well documented and directly correlated with chronic shame. (Dolezal 2017). Shame is a common element of dynamic social processes -- particularly those between powerful and powerless persons – relating to the inclusion or exclusion of individuals, groups or populations. This suggests that extra care should be taken to prevent exacerbating existing social schisms at every level when implementing UHC. Significant consideration must be given to potential perverse incentives, unintended negative health consequences, and social impact.

UHC has the potential to increase human dignity through relieving suffering and preventing or treating health conditions that undermine dignity and social status. Dignity is a particular concern for vulnerable and marginalized populations of low social status experiencing discrimination. Dignity is a salve to the shame of poverty, illness, disability, illiteracy, addiction, sexual violation, victimization and minority status.

The moral imperative of UHC

Is there a moral imperative for UHC? Belief in health as a human right suggests there is – belief in health as a profitable commodity does not (McKee 2013). To make an effective moral appeal for UHC requires an understanding of morality beyond the economic model of self-interest, because morality is generally about protecting others, and wanting to protect others is not always consistent with self-interest.

Moral judgements start with an intuition of what is right (Haidt 2007). The moral principles of caring and fairness underlie the widely (and deeply) held belief in health as a human right. This belief rests on the intuition that a moral society is collectively obliged to care for its most vulnerable individual members. Who needs protection if not the sick, the poor and the vulnerable? Who can provide protection if not the healthy, the wealthy, and the powerful?

A moral society demonstrates both caring and fairness on the level of the collective. Caring is demonstrated by relieving suffering through actively increasing health and wellness. Fairness is demonstrated through a system of distributive justice that allocates resources to increase social and financial stability, improving the lives of all members of society. UHC fulfills both requirements.

Explicit and Implicit Exclusions of Population Groups from UHC

Exclusions from affordable access to all necessary health services of sufficient quality can be either explicit in UHC policies or implicit due to policy choices, cultural barriers, or other forms of social exclusion. Universal health coverage is universal when *explicit* exclusion of population groups from coverage-- such as exclusion based on income, nationality, migrant status, or disability -- does not exist. However, UHC policies may explicitly exclude some groups for fiscal or political reasons. For example, population groups are commonly excluded from coverage when countries initiate health insurance schemes for the formal sector workforce. This group is well-organized and easy to reach, but also already advantaged. A growing number of low- and middle-income countries that have embarked on this path to UHC also put in place subsidy mechanisms to include the poor, but this still explicitly excludes a large segment of the population that is employed in the informal labor force (Bonfert et al. 2014).ⁱ A number of countries that began Costa Rica is an example of a country that began with a model of social insurance that was tied to formal-sector employment and evolved to

ⁱ See Precept Four: UHC requires compulsory participation, comprehensive pool funding, subsidization and consolidation of the entire system.

include 'non-contributory' populations. It now seeks to cover the remaining populations through expanding the single public fund. New contribution requirements apply to self-employed workers and migrants (Clark).

Another group that is often explicitly excluded is migrant populations. UHC in a national context often translates into citizen entitlements, leaving migrant workers (documented and undocumented), refugees, and asylum seekers without adequate cover for access to health care. This has given rise to urgent labor and human rights concerns, with a particularly dramatic situation in Southeast Asia with its large number of both major labor-exporting countries--Indonesia, Philippines, Myanmar-- and labor-receiving countries--Malaysia, Singapore, Thailand (Khoon 2015).

Exclusion from UHC can also be *implicit*, such as when the coverage that is extended does not match need, or other physical or cultural barriers are allowed to persist that effectively limit access to necessary care. The U.K. is widely touted as having achieved UHC with one of the most equitable health systems in the world. Nonetheless, there is evidence that people with disabilities report worse access to services (including physical access into buildings) and worse satisfaction with provided services (Sakellariou and Rotarou 2017). They are more likely to report that their needs are not recognized, and that they generally face several barriers-- structural (e.g. lack of transportation), financial, and cultural (e.g. misconceptions about disability). Inequities and cultural practices related to gender are another source of implicit exclusion from the full benefits of UHC.

The underlying level of prejudice and discrimination in a society is often carried over into the degree of commitment to universality in UHC. The rights of girls and women are devalued by definition in patriarchal societies, for example, and his low status and access to power by women can extend to implicit and/or explicit exclusionary practices in the health care system. Inequities affecting women's health have been widely documented throughout the entire life course from the girl child to the older woman (WHO 2009). The most important risk factors for death and disability among women of reproductive age in low- and middle-income countries are lack of contraception and unsafe sex. These result in unwanted pregnancies, unsafe abortions, complications of pregnancy and childbirth, and sexually transmitted infections including HIV. A review of essential benefits packages, and element of UHC policies, however, found that only 20 of 152 countries included all of the following services in their packages: family planning, prenatal and delivery care, clean/safe delivery by trained attendants, post partum care and essential emergency obstetric care. So although women are not explicitly excluded from coverage in these countries, they are implicitly excluded from meeting many of their most pressing health needs (Ravindran TK 2012).

The HIV epidemic exposed the risk societal prejudice poses to the individual right to health and also the ability of a health system to respond to an epidemic concentrated among some of the most stigmatized members of society due to, among other things, their gender, sexual orientation, gender identity, drug use, or sex work. Often, people living with HIV avoid going to clinics for fear of having their status disclosed or of suffering further stigma and discrimination based on their HIV status. Across 19 countries with available data, one in five people living with HIV avoided going to a clinic or

hospital because they feared stigma or discrimination related to their HIV status. When people living with HIV wait until they are very ill before seeking help, they are less likely to respond well to antiretroviral therapy (UNAIDS 2017). In Russia where high-risk groups are not only stigmatized but also criminalized, the epidemic is expanding, in contrast to the global epidemic pattern (Beyrer et al. 2017).

It is well established in the research literature that social stigma, discrimination and marginalization due to minority status results in poorer health and lower life expectancy. While other material factors affecting marginalized groups certainly affect health outcomes, recent research supports the assertion that stigma, discrimination and marginalization are significant determinants of health in and of themselves (Dolezal).

Solidarity and the threat of populism

Committing to UHC and progressing through the subsequent phases of adoption and implementation to achieve and sustain it requires continual governance to balance competing interests and demands by making choices at every point of the process that potentially enhance or erode coverage, both explicit and implicit coverage (Maeda et al. 2014). Concern for fiscal sustainability may lead to compromises on inclusive coverage, generosity of benefits package, and level of cost sharing that erode multiple dimensions of coverage. Policies that support strategic payment systems, obtain more advantageous pricing on medicine, and target subsidies effectively, can enhance coverage providing better access to services and greater financial protection. The line between policies that enhance or erode coverage is not always clear (Maeda et al. 2014).

The bulk of the literature on UHC typically focuses on the technical aspects of UHC development, such as financing, capacity, benefits packages and the impact of policy on outcomes, avoiding examination of the complex political forces at work supporting or inhibiting the growth or reform of UHC (Fossati). This inattention fosters the circumstances that allow political threat to materialize unnoticed, potentially preventing effective and timely counteraction. UHC is fundamentally about social equity, and this can only be achieved through redistribution, which is only feasible if solidarity is a shared value in a society.

Evidence from a recent empirical study suggests populist movements pose a threat to solidarity and continued support for UHC in Europe (Pavolini 2018). Although European experiences cannot be assumed to be universally applicable, the populist movement is a global phenomenon threatening human rights worldwide (Roth 2017). In light of health as a human right interrelated with all other rights, it is prudent to assume the populist movement presents a serious threat to public support for UHC which may potentially have a corrosive effect on political will.

Both supporters and detractors of UHC lay claim to the moral high-ground: For those opposed to UHC (particularly in Western cultures), the intuitive moral judgement is that to give someone something of value which he or she cannot afford to pay for on his or her own (consistent with the perspective that health care is a commodity), is to do the person harm by diminishing their

autonomy and personal responsibility. Additionally, it penalizes (by forcing them to pay) those who can afford to pay, which is perceived to be unfair because it amounts to unequal treatment that is disadvantageous to those who ‘work hard to earn their pay’. (Haidt 2007, Pavolini 2018). This sense of unfairness is compounded when there is a perceived threat to freedom of choice (such as of healthcare providers) (Pavolini 2018).

Although morality is culturally determined, recurring populist themes relating to threats to the well-being of the authentic group members from cultural elites and outsiders resonate with many who struggle economically and resent the presence of immigrants and foreigners in the workplace (Pavolini 2018). Efforts to demonstrate the moral imperative of UHC in support of health as a human right must be sensitive to the various forms of morality in order to satisfy the moral intuitions of all stakeholders.

Overcoming Explicit and Implicit Exclusions to Achieve Universality

Progressive Realization of UHC

The ‘universal is universal’ principle of UHC is aspirational for many low- and middle-income countries and may not be immediately feasible within the macroeconomic and fiscal constraints.ⁱⁱ These countries need to prioritize their investments in UHC and make step-by-step progress over what may take many years. “Progressive realization” refers to the governmental commitment progressively move towards the full realization of UHC when there is a wide gap between the reality of limited access and the aspirations of universality (Pablos-Mendéz, Cavanaugh, and Ly 2015). Progressive realization makes the maximum use of all available resources as they evolve over time to implement universal coverage (Ooms 2014).

The concept of progressive realization of UHC is distinct from targeted implementation or targeted programs, although priority groups may be targeted for specific subsidies on the path to universality. Targeted implementation strategies opt to distribute access to selected groups within the total population. In Latin America, social segregation in health care is associated with health-system segmentation and a public perception of inequality in access to health-care services. Poor people are typically served by a poorly financed Ministry of Health, and formal sector workers are served by a relatively well-financed social security system. As the ideas of health and equality of opportunity as human rights have spread, the gap between these parallel systems has become increasingly unacceptable to the public (Cotlear 2015). Targeted health care coverage for the poor in the late 20th century contributed to significantly improved health outcomes population-wide, but the

ⁱⁱ Although fiscal constraint arguments are not entirely credible given the experience of countries such as Mexico, Thailand, and Rwanda achieved universal population coverage at relatively low levels of national income and per capita health expenditure. Thailand achieved universal population coverage in 2002 when gross national income was under US\$2,000 per person. When there is political will to prioritize UHC with political backing and fiscal resources, as well as commitment to effective resource management and strategic purchasing, UHC is not a luxury afforded only higher income countries.

segmentation of health care created a persistent perception of inequity and exclusion. The social segmentation that exists in Latin America grew from preexisting social inequality which gave rise to new forms of inequity over time and has become a barrier to positive change. (Cotlear 2015).

Recent data drawn from in-depth interviews on a cohort of older adults in England demonstrates that targeted policies have implications beyond the reach of the policy based on how the policies are understood by the general public and the targeted recipients. Narrowly framed needs-based, means tested or behavioral conditions attached to targeted entitlements introduce barriers to up-take, have psychosocial impact and erode public support. Targeted benefits introduced moral discourse on deservingness and legitimacy and invoked shame in association with need. Universal benefits were understood to be available to all and resulted in discourse that “fostered respect and solidarity” (Green). Although the evidence is thin, and the results of this study cannot be generalized, the suggestion that how policy ultimately impacts the psychosocial function of populations, the uptake of needed services, and social integration, should be considered a valid one. If the UHC policies serve to reinforce the social stigmatization of the targeted minority, the initiative itself has the potential to transmit some degree of negative health effect, through decreased service uptake, increased internalized shame and greater social division. In another context, Southeast Asian countries are vulnerable to potential leak of targeted benefits intended to help the poor, to the non-poor, through social favoritism (Tangcharoensathien) and mis-targeting (Maeda 2014).ⁱⁱⁱ

Progressive realization of UHC recognizes that fiscal capacity may be limited and prioritization and trade-offs are required, but it avoids the fragmentation and stigmatization of targeted programs. Instead, the UHC framework is stated explicitly as an over-arching goal for universal population coverage and a comprehensive minimum service package, with financial protection and further expansion of the package evolving over time as fiscal resource constraints ease. In the Kyrgyz Republic, for example, the journey toward UHC—which began with a comprehensive framework, a minimum “State Guaranteed Benefits Package,” and universal access to free primary health care—has been progressively unfolding for more than 20 years (Box 1).

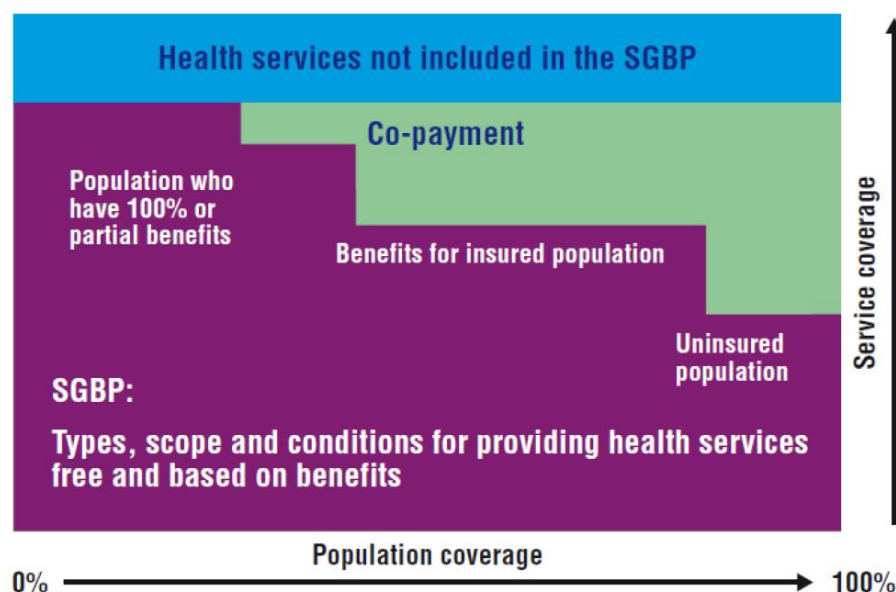
Box 1. Progressive realization of UHC in the Kyrgyz Republic

Now a lower-middle income country, the Kyrgyz Republic committed to progressive realization of UHC in 2001 as the country emerged from the post-soviet economic collapse and a health system that was severely eroded. At that time the country was categorized as a low-income country with a per capita gross national income below US\$300. The government introduced the *Manas Taalimi* national health reform program with the main objective of ensuring the financial sustainability of the health system and reduce the financial burden on patients. Without using the term “UHC,” the country set out on a path to incrementally provide access to essential services with increasing financial protection as the fiscal capacity of the government gradually increased (Giuffrida, Jakab and Dale 2013). The health reform framework included the definition of health benefits in the State

ⁱⁱⁱ See Precept Four: UHC requires compulsory participation, comprehensive pool funding, subsidization and consolidation of the entire system.

Guaranteed Benefit Package (SGBP), free primary care for all Kyrgyz citizens, official copayment for secondary care with extensive subsidies and exemptions from copayments, which allowed equal access to basic health services (Figure 1). This coincided with the introduction of a mandatory health insurance scheme financed through an earmarked payroll tax and general tax subsidies for the protected population. The Mandatory Health Insurance Fund acted as a single purchaser of services under the SGBP, which allowed for strategic payment systems and provider incentives to improve the financial sustainability and cost-effectiveness of the system.

Figure 1. Population coverage and subsidization under Kyrgyzstan’s State Guaranteed Benefits Package (SGBP)



Source: Kutzin et al. (2002).

Over time the country’s fiscal capacity has grown and the health system has continued to evolve to provide better access to necessary care with financial protection, and to take on new challenges. Per capita health spending has more than doubled since 2001, and out-of-pocket payments have been reduced as a total share, although still high at 43.3% of total health spending (Giuffrida, Lavado, Dale, and Temirov 2014).

Overcoming exclusions through civil society engagement and social activism

Belief in health as a human right is translated to belief in health as a social right through social activism which applies pressure on governments to fulfill the citizen’s right to health. In turn, this creates a pressing need to gain greater consensus to establish a framework for implementing right to health principles based on good practices (Nygren). Civil society, through social movements and unions, has played a fundamental role in the demand for UHC. Once commitments are made and UHC policies are in place, however, its maintenance and implementation are often delegated to laws

and agencies without much active participation by civil society (Borgonovi and Compagni 2013). The engagement of civil society social activists has been critical in overcoming inherent biases and exclusions in health systems in general, and is equally critical for the ongoing implementation of UHC.

In Bangladesh, for example, local activists forced greater inclusion in the health care system for the girls and women (the average age of victims is 11 years old) painfully and permanently disfigured by acid attacks, after the government failed to provide basic medical care to the survivors (Anwary 2003). More broadly, women's empowerment is a driver of maternal and child health (Ewerling 2017). Advocacy for those unable to advocate for themselves is imperative to meeting health needs and increasing equity. Mothers are passionate advocates for children. Driven by people living with HIV, grassroots activism created tremendous political and commercial pressure that led to an extraordinary reduction in the cost of drugs, which meant governments could afford to exponentially increase the number of people receiving treatment (UNAIDS 2017)

Attempts to include citizens and patients directly in priority setting exercises in several countries have met with mixed results (Litva et al. 2002; Wiseman et al. 2003; and Hogg et al. 2001). Borgonovi and Compagni (2013) summarize the benefits of such experiences as empowerment, sense of belonging, and accountability of citizens, but they note that problems remain. For instance, it is unclear how the few individuals involved in this kind of exercise can be representative of the diversity of preferences and interests of society. It is also possible for the most vocal activists to skew priorities and introduce other forms of bias in the system. The appropriate channels and modalities for the participation of civil society in health care systems are context-specific and not well understood, but it is clear that the barriers between UHC policy and citizen engagement need to be reduced, and transparent information flows in both directions and dialogue mechanisms need to be strengthened.

National Anti-Discriminatory Laws and Policies Beyond Health

There is increasing awareness that health inequity and exclusion across population groups is related to structural bias, and implicit exclusion from access to necessary health care cannot be solved within the health system alone. Activist groups are increasingly making the case to better leverage anti-discrimination and civil rights laws as a necessary, but not sufficient, step to ensure equity and inclusiveness in the health system (McGowan 2016).

Conclusions

Universal health coverage must truly be universal and not allow for implicit or explicit forms of exclusion from care and protection. Health and its determinants as human rights rely on health-enabling environments that are supported, protected and reformed by laws, institutions, policies, and practices at all levels of government, and society as a whole. The role of citizen engagement advocacy is critical to this process.

Nearly all countries struggle with truly universal and equitable population coverage, even when it is a stated aspiration and political commitment. Countries face the challenge of balancing these aspirations and commitments with the macroeconomic and fiscal realities they face. There are also political challenges in societies where solidarity is weak or eroding, which may worsen with the current rise of populism globally. Even more challenging are deep-rooted cultural barriers, discriminatory practices, and societal prejudices that may keep the most vulnerable in society from benefitting from the full health and social protections that are the promise of UHC. Some countries effectively manage and overcome the explicit exclusion of population groups from UHC that are driven largely by fiscal constraints with explicit policy choices, UHC frameworks, and long-term commitments that can be progressively attained as fiscal constraints ease. Implicit exclusions are more challenging by definition, however, and require much wider societal participation and engagement, and fundamental laws and policies against discrimination and social exclusion.

Constant learning and adapting is essential to the process of realizing the aspiration of UHC. Given the importance of understanding the personal experiences of vulnerable people in accessing needed care, the data driving policy decisions should include qualitative measures. Participatory models that involve representation for all citizens, particularly members of vulnerable populations, in policy development and decision-making processes at all levels to redistribute power and overcome the implicit exclusions that undermine the realization of health as a human right and UHC as a true expression of that right.

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