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Global health systems and policy development: implications for health literacy research, theory and practice

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Abstract. Accessible and responsive health systems are critical to population health and human development. While progress has been made toward global health and development targets, significant inequities remain within and between countries. Expanding health inequities suggest a widespread and systemic neglect of vulnerable citizens, and a failure to enshrine within policies a responsibility to tailor care to the variable capabilities of citizens. Implementation of health and social policies that drive the design of accessible health systems, services, products and infrastructure represents the next frontier for health reform. Within this chapter we argue the need to consider health and health literacy across policy domains, to operationalize the intent to address inequities in health in meaningful and pragmatic ways, and to actively monitor progress and impact within the context of the Sustainable Development Goals (SDGs). We contend that viewing and developing policies

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and systems within a health literacy framework will assist in placing citizens and equity considerations at the center of development efforts.

In this chapter, we explore the relationship between health literacy and equitable access to health care, and the role of health system and policy reform. We first explore international policies, health literacy, and the SDGs. We then explore national policies and the role that national and local services and systems play in building health literacy, and responding to the health literacy challenges of citizens. We discuss the World Health Organization’s (WHO) Framework for Integrated People-Centered Health Services and the way in which health services are being encouraged to understand and respond to citizen health literacy needs. Each section of the chapter ends with a summary and a review of health literacy research and practice. Throughout, we illustrate our points through ‘vignettes’ from around the world.

**Keywords.** Health literacy; policy; health and education systems; disparities; health reform; access to care; organisation and delivery of care

1. **Introduction**

Accessible and responsive health systems are critical to population health and human development. While progress has been made toward global health and development targets, significant inequities remain within and between countries. Emerging health challenges, such as the Zika virus, and ongoing complex, multi-faceted public health problems, such as diabetes, require strategic, coordinated and sustained responses. In this chapter, we explore the role of health literacy theory and practice in strengthening global and national policies and systems of importance to health, and in promoting and improving equity. Further, we identify opportunities to undertake research to promote ongoing systems development.

People make decisions about their health within personal, social and environmental constraints. The availability and accessibility of health and social services interact with the health literacy of individuals, families and communities to influence health decisions (see Figure 1). In another chapter, Levin-Zamir et. al. describe the influence of cultural context upon the health literacy of individuals, families, and communities [1]. In this chapter, we focus on the national and international policies and systems that influence health decisions and behaviors.
Figure 1. The interaction between health literacy and the health literacy responsiveness of services. Reproduced from: Dodson, Beauchamp, Batterham and Osborne, 2015 [2]

1.1 Why national and international policies are important to health literacy research, policy and practice

Health decisions and actions, at their core, emerge from an interaction between the capacities of individuals, and the contexts within which they ‘live, learn, work, play and love’ [3,4]. Since these contexts are shaped by policy, it can be argued that policy is a central influence upon the health literacy of a society. Expanding health inequities in many developing and developed countries suggest a widespread and systemic neglect of vulnerable citizens [5], and a failure to enshrine within policies a responsibility to tailor care to the variable health capabilities of citizens. Implementation of health and social policies that drive the development of systems, services, products and infrastructure that are accessible to all represents the next frontier for health reform. Viewing policies and systems with a health literacy lens will assist to place citizens and equity considerations at the center of development.

Policies can be international, national or local. International policies establish global or regional objectives and expectations. They enable collective action to be taken and inequities between countries to be addressed, and they facilitate sharing of knowledge in relation to system and human developments. National policies set out national priorities, goals, objectives, targets and resourcing, and drive national and local development. Local policies, not explored in this chapter, often sit within national or regional frameworks, and respond to the needs of their local populations and communities.
1.2 Structure of this chapter

In this chapter, we first explore international policies and health literacy, using the example of the Sustainable Development Goals (SDGs). We then explore national policies, using the example of the WHO Framework for Integrated People-Centered Health Services. We then examine services and systems, both those that develop health literacy (e.g. education systems through the life course) and those that respond to the health literacy needs of a population to promote health, prevent illness and support citizen management of diseases, illness and frailty (e.g. the health, public health, and social care systems).

Each section of the chapter ends with a summary and a review of health literacy research and practice. Throughout the chapter, we illustrate our points through ‘vignettes’ (case studies) from around the world.

2. International policy and health literacy research, theory and practice

The year 2016 marked the introduction of the United Nations Sustainable Development Goals (SDGs), a new global agenda for human development [6]. The 17 SDGs are accompanied by targets and indicators that guide local and global efforts to end poverty, fight inequalities and tackle climate change. The SDG agenda pledges to ‘leave no one behind’ and acknowledges the interconnectedness of efforts across development domains and the need to ensure that ‘development’ does not take place at the expense of health and social equity [5,6]. The SDGs call for an unprecedented coordination effort across sectors, countries and regions.

With the launch of the SDGs, analyses have explored lessons learned from the Millennium Development Goal (MDG) experiment. The global MDG targets for HIV, TB and malaria were met, and child and maternal mortality have seen a sharp decline [7]. While many targets were not achieved, significant global progress was made. The success of the MDGs have been widely attributed to several key drivers: 1) the use of a limited number of time-bound, measurable and easy to communicate goals as a mechanism for targeting and motivating action and partnerships; 2) the intensity of focus and investment as a driver of innovation; 3) measurement and the development of monitoring systems; and 4) national public commitments to achieving specific targets and the associated political pressure and accountability. The SDGs redouble the efforts associated with the MDGs and set an ambitious global agenda.

In this section, we apply SDGs 3 ‘Ensure healthy lives and promote well-being for all at all ages’, 4 ‘Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all’ and 6 ‘Ensure availability and sustainable management of waste and sanitation for all’ as exemplars of the role and influence of international policy in shaping national priorities, and to highlight the relationship between health literacy and development progress. They also provide exemplars of approaches to system strengthening, and the potential of the SDGs to focus attention upon issues of inequity. We then explore the role of cross border collaborations, focusing on the movement of people and disease across borders. We then explore the role of research in supporting the development and evaluation of international policy.
2.1. Health literacy and Sustainable Development Goals 3 and 4

The two goals that most clearly highlight the relationship between development and health literacy are SDG 3 ‘Ensure healthy lives and promote well-being for all at all ages’ and SDG 4 ‘Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all’. Goal 3 highlights the need to strengthen the quality, coverage and accessibility of disease control and prevention programs, medicines and vaccines, healthcare services, and mental health care. Empowered, health literate citizens and communities can act as key drivers of the needed reform and support effective engagement with developed systems and services. Goal 4 highlights the importance of education across the life course, with emphasis on the education of children (both boys and girls) and women. Reforms in education provide significant opportunities to develop health literacy capabilities.

An example from Ethiopia (Box 1) shows how the realization of SDG 4 supports development of health literacy, and how health literacy is fundamental to the achievement of SDG 3. Ethiopia is blighted by trachoma; an infectious blinding eye disease, which is spread through contact with linen, hands and flies carrying the infection. Those that develop blinding trachoma, predominantly women/mothers, are often unable to carry out productive work and are reliant on the care of family members. In these households, additional duties often fall to girls/daughters, who then miss out on education and other opportunities. Ending the epidemic of trachoma requires improved health services, particularly improved access to surgical services and antibiotics, and enhanced engagement of the community in facial cleaning and environmental sanitation behaviors. Engagement of community members with services and effective hygiene practices requires development of awareness, an understanding of how trachoma transmission can be interrupted, and the skills, resources and motivation to persistently act to minimize the risk of transmission.

Childhood education that empowers and supports development of literacy and language skills can be seen here as fundamental in enabling access to the required information and to social interactions that assist to shape attitudes and encourage adoption of positive health behaviors. Effective basic childhood education may therefore be an important prerequisite for public health programs requiring significant
changes in citizen behavior. Upon a foundation of basic childhood education, interventions targeting development of specific health literacy capabilities are likely to enable the generation of community led solutions to local health problems that are more likely to be enacted, relevant, and sustainable than those conceived and imposed upon communities from the outside.

This dual health literacy and SDG focus assists to ensure that, globally, population health is being improved, while locally the freedoms, capabilities and health literacy of individuals are being developed. This approach also acts to bridge

| Box 1. Developing health literacy and achieving Sustainable Development Goals 3 (Good health and well-being) and 4 (Quality education): An example from Ethiopia. |
| Mrs E is a 35-year old married woman with five children, aged between one and fourteen years. She lives in a remote Kebele (village) in the Oromia region of Ethiopia. Oromia has the highest prevalence of blinding trachoma in the world. Mrs E has been experiencing eye pain, vision loss and severe headaches now for two years. These symptoms are common in her community and she believes it is hereditary and nothing can be done. The nearest primary health service is 150 km away, but Mrs E has no knowledge of this service and no way to reach it as her only means of transport is by foot. Mrs E and her husband make a living growing Teff (a local grain) and selling it at the local market. They earn enough money to feed their family and purchase basic supplies. Public transport is not affordable, nor is soap, clothing, towels, bedding or linen. In anticipation of losing her sight completely, Mrs E has removed her ten-year-old daughter from school to teach her household management skills and to receive support with childcare and other chores. Mrs E and her family live in a compound with four single room mud structures – one to live and sleep in, one to house the large livestock, one for smaller livestock, and a kitchen. The eight household members share a single room, two mattresses, and three blankets. There is no source of electricity and the nearest water source is 30 minute’s walk. There are restrictions on the amount of water Mrs E’s family can take from the local water pump, and they prioritise this for drinking. They use the river for bathing and laundry once per week. Last year Mrs E’s husband constructed a latrine for the family after receiving some donated supplies and education from an international NGO. Mrs E and her husband use the latrine occasionally, but Mrs E feels she is too busy to encourage the children to use it, and so they continue to defecate around the periphery of the mud structures. The flies breed readily in the human excrement. |

the actions taken to progress health related targets, and efforts to progress the interconnected environmental, education, legal, economic and social welfare targets.
2.1.2 Other Sustainable Development Goals and health literacy

While the SDGs most closely linked with health literacy are 3 and 4, many other goals can also be closely related. As examples, our Ethiopian story shows that SDG 6 ‘Ensure availability and sustainable management of waste and sanitation for all’ could also be promoted through the development of health literacy. It is only through community understanding of the health risks of poor water quality and sanitation, and the benefits to be gained from addressing those risks, that such policies will be effective. Box 2 gives another example, this time from India.

These examples demonstrate the need to develop coordinated approaches across policies, as espoused in WHO’s ‘Health in All Policies’ (HiAP) [8]. HiAP is discussed in more depth in the context of national policies in the next section, where it

<table>
<thead>
<tr>
<th>Box 2: Developing health literacy to promote Sustainable Development</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Goal 6 (Clean Water and sanitation)</strong></td>
</tr>
<tr>
<td>Mrs Chaudhari is a 22-year old mother who lives with her three</td>
</tr>
<tr>
<td>sons and her parents-in-law in a rural village. She knows that</td>
</tr>
<tr>
<td>vomiting and diarrhoea is a big problem; all her children have</td>
</tr>
<tr>
<td>had severe diarrhoea at some points in their lives, and her</td>
</tr>
<tr>
<td>younger sister died of this when she was a child.</td>
</tr>
<tr>
<td>When listening to the radio with her family she heard about</td>
</tr>
<tr>
<td>the ‘Nirmal Bharat Abhiyan’ (or ‘Clean India’) campaign to</td>
</tr>
<tr>
<td>help reduce the risk of diarrhoea through building toilets,</td>
</tr>
<tr>
<td>and persuading people to use them. Mrs C has heard about the</td>
</tr>
<tr>
<td>new toilets coming to the village, but does not know why they</td>
</tr>
<tr>
<td>are needed or why she and her family should use them. The</td>
</tr>
<tr>
<td>nurse on the radio talks about how open defecation causes</td>
</tr>
<tr>
<td>illness, and how using the new toilets will make it far less</td>
</tr>
<tr>
<td>likely that she and her family will get diarrhoea. Her local</td>
</tr>
<tr>
<td>Panchayat (local administrator) talks about how everyone can</td>
</tr>
<tr>
<td>benefit, and the whole village will work together. The</td>
</tr>
<tr>
<td>Panchayat says that there will be a Swechhata Doot (cleanliness</td>
</tr>
<tr>
<td>ambassador) in every village and that half of them will</td>
</tr>
<tr>
<td>be women. Each Swechhata Doot will earn RS 22,000 ($330) a</td>
</tr>
<tr>
<td>year.</td>
</tr>
<tr>
<td>After listening to the radio show, Mrs Chaudhari understands</td>
</tr>
<tr>
<td>about how the new toilets will help, and wonders whether she</td>
</tr>
<tr>
<td>could become the Swechhata Doot for her village.</td>
</tr>
</tbody>
</table>

is evident that coordination across health, education, economic, infrastructure development and environmental policies (amongst others), is vital for effective and sustainable development. Again, ensuring that health literacy is a central consideration assists co-ordination, a focus on equity, and consideration of the needs of individuals, families and communities.

2.2 Cross border collaborations

In this subsection, we explore the movement of people across borders, the related health risks and their management. We examine both the way that health literacy is currently conceptualized and operationalized in cross border health issues, and the role it potentially can play in the future.
2.2.1 Movement of people across borders

The increasing global mass movement of people across borders creates several policy challenges for host governments, and the need for international collaboration and coordination. Countries receiving migrants and refugees have responsibilities to develop and implement policies that promote equitable access to care, issues that have implementation implications for health literacy, human rights and medical economics.

Current evidence reveals a ‘migrant health decline’ [9-11], which appears to result from the disconnect that emerges, following migration, between the social, economic, and healthcare opportunities available in the host country, and the skills, knowledge and beliefs (health literacy) of migrants. The cumulative impacts associated with the erosion of pre-migration lifestyles, and barriers to healthcare access due to language and cultural factors, appear to be substantive and observable two years following migration [12]. The burden that poor migrant health may pose to host countries because of global inaction, and failure to collaborate on global health issues, is likely to emerge as a significant issue of public debate in coming years.

While there is a growing tendency within immigration debates for developed countries to favor a closed-door solution, migration and temporary movements between borders is likely an irreversible phenomenon, especially in the context of globalization, and ongoing within and across border conflicts. Health systems will need to find a way to respond to, and overcome migration related challenges over the coming decades. Such a response is illustrated by the example from Israel shown below in Box 3, reproduced from Levin-Zamir et al. [1].

This example, which can also be contributing to SDG 3 ‘Ensure healthy lives and promote well-being for all at all ages’, illustrates that rather than expecting migrants to fit with current systems, adaptations can be made to support migrants to learn to navigate their new environment. Both linguistic and cultural liaison between the individual and those providing his/her care appear important to ensure new migrants can effectively access healthcare. The expense of providing such liaison is likely to be offset by the health savings arising from more effective and streamlined care, with fewer wasted health appointments, and the longer-term benefits arising from improved illness self-management. In addition to the potential benefits of specialized liaison roles to support new migrants, health providers within host countries would benefit from education that enhances their understanding of the health systems, cultural practices and norms, and common health beliefs and conceptualizations held within countries of origin.
2.2.2 Movement of disease across borders

There is now widespread recognition of international influences on health. Increasing globalization, growth in international travel, migration and displacement have implications for the way both communicable and non-communicable diseases (NCDs) are managed. The example from Israel discussed above highlights some of the issues for NCDs. Increasingly, though, infectious diseases are presenting new challenges. This is complicated by the fact that while it is inevitable that new acute infectious disease crises will occur, such as the recent Ebola and Zika virus outbreaks, the nature and site of the outbreaks cannot always be predicted. In its recent review of the Ebola epidemic, the US Center for Disease Control (CDC) highlighted the need for international collaborations, and the development of strong partnerships and systems to provide personnel and skills, and contribute to research and development (such as developing new vaccines [13]). Such partnerships between high-income countries and their middle- and low-income neighbors are critical to generating speedy identification of, and responses to, incipient epidemics. Consideration of health literacy within the development and operationalisation of policies assists in ensuring that responses are

| Box 3. The impacts of migration upon health literacy and the challenges created for health systems in host countries. |
| Asmara and his six children and their families immigrated from Ethiopia to Israel 10 years ago. He came expecting to encounter the perfect health support system. Feeling tired all the time, he sought help from the local community clinic. He quickly realized that the health providers not only speak a different language from the one he speaks, but they also arrange the way they provide health and medical treatment to people very differently from what he knew in Ethiopia.

When Asmara approached the family doctor in the community clinic, he was first sent to have a blood test, on a completely different day, and still received no treatment. He was expected to return to the physician to receive the test results, however this time he understood from neighbors that he was to make an appointment through the telephone or an online system, which he was unsure how to do. He finally decided to return to the clinic and just wait until the doctor could see him. He sat in the waiting room for a long time and watched how other people who arrived after he did, could see the doctor before him. He finally decided to go home. Concurrently, the clinic office had been trying to reach him by phone to make an appointment, as his test results reflected why he was feeling so exhausted.

A week later Asmara heard from his neighbors that a new service is offered in the community clinic, called “Refuah Shlema”. Casia, a specially trained health liaison and cultural mediator, now greets Asmara each time he comes to the clinic, seeks to understand what Asmara is feeling, and helps him to communicate his needs and experiences to the clinic staff. She also helps to interpret the recommendations, in culturally appropriate terms, and sits with Asmara to explain to him more in depth his condition, one that he never heard about in Ethiopia – diabetes.

citizen focused. Further discussion of this, illustrated with an example from Brazil on the response to the Zika virus epidemic, is provided below (Box 7).

2.3. Health literacy research and international policies

Robust data are needed for making a case for policy changes, and to monitor the impact of such changes. In recognition of the power of data, significant work is being directed by the WHO towards establishing indicators of SDG progress. Equity data feature prominently as critical to ensuring within-and-across-country initiatives ‘leave no-one behind’. Effective indicators, high quality data collection approaches, central data registries, and coordinated dissemination efforts, in combination, act to support policy initiatives, and keep governments accountable [14]. Health literacy capabilities do not feature in the SDGs, their targets or indicators. However, complementary thematic indicators are being developed by experts in the field, and encouraged as a means of collecting the input and process data required to make meaning of any observed change. There is an opportunity to advocate that health literacy capabilities be represented effectively within these thematic indicators as they evolve over the next two years. Development of health literacy indicators across thematic areas of global significance, and effective advocacy at national, regional and global levels, is required to build awareness of the role of health literacy in the attainment of the health-related SDGs, and of the critical role that effective policy plays in ensuring community engagement and health care access. The importance of international metrics as drivers for change at a national level can be seen through recent policy and system changes in Austria (see Box 4).

Box 4: Using health literacy data to make the case for changing policy: an example from Austria.

The Austrian government was surprised and disappointed by the results from the 2011 European Health Literacy survey, which found that a high proportion of Austrians had ‘problematic’ or ‘inadequate’ health literacy. On reflection and after discussions with the survey leads, the government concluded that part of the problem was that it is difficult for Austrian patients and citizens to gain information and meaning from the complex health system.

The key stakeholders in designing and running the system – the federal government, the nine Austrian states (Länder), and the social insurance companies – agreed to develop and then implement a strategy to improve communication. Talks with the major health care providers – the hospitals – and those training health care professionals – the universities – are ongoing to develop and implement concrete interventions to improve health care communication practice. The main pillars will be training and improvements to the healthcare culture, that encourage communication to be understood as an important clinical skill. Improvements in organizational practice driven by self-assessments and toolkits are expected to enable organizations to improve.

The strategy was launched in Autumn 2016 and will be implemented from 2017. Interventions to implement the strategy will be selected and designed together with key stakeholders, and there will be an accompanying monitoring system.
Health literacy researchers and advocates have important roles to play in identifying robust indicators that support collection of meaningful data to both drive SDG progress, and to lobby for their incorporation into monitoring frameworks. The choice of indicators is crucial; they should capture both the capacities of individuals, families and communities, and the capacities of the health, social care and education systems to work with citizens and communities to promote health. These connections (between the capabilities of citizens, and global and national health policies and population health targets) are easy to lose sight of. However, effective operationalization of policies requires an understanding of the mechanisms of change, at personal and interpersonal levels.

Collective change is the culmination of individual change and the social momentum that can be created once a tipping point is reached [15]. It is the health literacy capabilities of citizens and communities, and the extent to which healthcare services respond effectively to their needs, that represent the key focal points of interventions geared towards the attainment of the SDGs. The SDG targets form the more distal population level outcomes that will signal medium to long-term progress. Once robust health literacy indicators are successfully included in monitoring frameworks, associations between health literacy, health and social outcomes, and economic progress may be explored. Techniques such as Social Return on Investment, a method that enables the capture of extra-financial value (such as environmental and social value) not captured well in more conventional cost-benefit analyses, [16] are useful in this regard. Qualitative work should be a key component of any evaluation research undertaken, and include gathering insights from those developing or implementing policies, and those experiencing the impacts of policies.

Work is also required to analyse policies with regards to the extent to which they facilitate development of health capabilities and optimise ease of choice and access to health services, products and environments. Comparison and critical analysis of policies can facilitate information exchange, and shorten the development process if countries can adapt policies known to work elsewhere. Trezona et al. (under review) for example propose a framework that supports assessment of the degree to which a policy effectively prioritises and resources health literacy. Policy can be assessed across three categories: the extent to which health literacy or related concepts are mentioned or defined within the policy; the extent to which health literacy is prioritised within the policy; and the extent to which health literacy is operationalized through specific actions and whether these actions are supported through the allocation of resources and establishment of monitoring mechanisms (see Table 1). Policy analyses across a range of sectors and settings will enable policy makers to improve the effectiveness of their policies, and will support advocacy efforts and raise awareness of the role of public policy in addressing the issues contributing to inequities.
Table 1. Framework for analysing health literacy in public policy documents

<table>
<thead>
<tr>
<th>Category</th>
<th>Prominence of health literacy</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Category 1</strong></td>
<td>Health literacy is not explicitly mentioned, nor is a related concept</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>A concept related to health literacy is mentioned, but health literacy is not explicitly mentioned</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Health literacy is mentioned, but not defined or explained</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Health literacy is defined or explained</td>
<td>3</td>
</tr>
<tr>
<td><strong>Category 2</strong></td>
<td>Prioritisation of health literacy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Health literacy is mentioned, but its relationship to health outcomes is not explained</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Health literacy is discussed as a concept related to health outcomes, but is not noted as a strategic priority</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Health literacy is noted as a strategic priority</td>
<td>3</td>
</tr>
<tr>
<td><strong>Category 3</strong></td>
<td>Health literacy actions, resourcing and monitoring</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No specific actions are identified to address health literacy</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Health literacy actions are identified, but no resources are provided to support implementation and no monitoring of outcomes is proposed</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Health literacy actions are identified, resources are allocated to support implementation, OR monitoring of outcomes is proposed (but both are not evident).</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Health literacy actions are identified, resources are allocated to support implementation, and monitoring of outcomes is proposed.</td>
<td>3</td>
</tr>
</tbody>
</table>

2.3. International policy and health literacy research and practice - Summary

In this section, we have described how international policy can promote health literacy, using the example of the United Nations Sustainable Development Goals (SDGs). Of the 17 goals, the two most closely related to health literacy are goal 3 ‘Ensure healthy lives and promote well-being for all at all ages’ and goal 4 ‘Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all’. Using the example of trachoma in Ethiopia, we explored the relationship between health literacy and achievement of the goals. We also discussed how health literacy, with its placement of people and communities at the center of development activities, can shape development of policies that promote equity and ensure ‘no-one is left behind’.
In relation to the needs for future research, we explored the opportunity for development of health literacy indicators and of monitoring frameworks that effectively communicate the link between health literacy and the SDGs. In addition to this we highlight the opportunity for analysis of existing health policy and the extent to which health literacy is considered and strategies for responding to health literacy issues operationalized.

International policies are thus crucial in setting frameworks for international collaboration and joint action, and for the development of coherent national policies with complementary foci. It is, however, national governments, and the policy decisions they make that will determine the systems within which people ‘live, learn, work, play and love’ [3]. That is the focus of the next section in this chapter.

3. National policy and health literacy research, theory and practice

National policy plays a critical role in not only endorsing principles of equity and quality, but also in driving the establishment and maintenance of the many prerequisites of an integrated, people-centered health system. A key challenge for national health departments, and other bodies responsible for driving health policy, is developing and implementing policies that enable strengthening of health systems such that they deliver responsive local care, while also ensuring consistency of standards and ease of navigation across jurisdictions [17].

To complement its guidance role in relation to health systems, WHO recently released a Framework for Integrated People-Centered Health Services (See Figure 3) [17]. This organizational level guidance provides policy makers with support to understand how to approach the task of service design and reorientation. The Framework seeks to ensure that “all people have equal access to quality health services that are co-produced in a way that meets their life course needs, are coordinated across the continuum of care, and are comprehensive, safe, effective, timely, efficient and acceptable; and all carers are motivated, skilled and operate in a supportive environment”. Five interdependent strategies are proposed: in the following section each of these is explored in turn. We then explore the need for a ‘Health in All Policies’ (HiAP) approach to ensure effective co-ordination. We end this section with a discussion of the role of health literacy research in developing and monitoring national policies.
3.1 Empowering and engaging people and communities

The earlier example from India (Box 2 above) provides an example of the benefits of empowering and engaging people and communities. In some ways, the situation in India in regard to sanitation is similar to that in Ethiopia (Box 1 above). In both cases, there is a public health problem arising from transmission of infectious diseases due to lack of safe sanitation facilities and access to water. It is reasonable to hypothesize that the issues continue in these countries, in large part due to limited health literacy regarding opportunities to minimize the risk of infection and illness. The Indian case study describes the potential benefits of developing health literacy on the issue within the community; Mrs. Chaudhari comes to understand how open defecation causes disease, and can share that information with her family and friends. In parallel, issues such as poverty, gender equality, and community engagement may potentially be addressed, at least in part, through the Indian approach.
3.2 Strengthening governance and accountability

Rwanda provides an example of how having strong, accountable systems, which place the citizen and community at the center, can have remarkable impacts on health (Box 5, information gathered from [18-21]). While Rwanda’s health system has its share of

<table>
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<th>Box 5: Strong governance and accountability leading to effective, health literate, systems.</th>
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| The 1994 genocide in Rwanda devastated the country’s health infrastructure and substantively depleted the health workforce. The government established in the aftermath of the genocide commenced reconstruction of Rwanda’s health system and has continued to develop and implement health system reform since this time. Rwanda now has a largely decentralized health system with district health offices responsible for oversight or administration of public and private health services in the localized areas. National programs and policies act to ensure consistency of services across districts. Centrally, policies, strategies and technical frameworks are developed, monitored and reviewed. A minimum package of activities has been defined for common health conditions and the ten most important causes of morbidity and mortality.

At the health center level, the minimum package of activities includes health literacy promotion activities, preventative care services, and curative activities relevant to each target disease. Health committees have been established in all health centers and district health offices, which act to oversee the financial management of health centers, ensure the health concerns and communities are represented, and to mobilize the community to participate in activities and projects. Since 2000, the committees have included health promoters elected by the population, to ensure better representation of community concerns. The system is financed by a combination of state funds, insurance contributions and direct fees for service. The Community-Based Health Insurance Scheme sees members pay annual premiums of approximately USD$6 per family member with a 10% service fee paid for visits to services. 91% of Rwandans were insured through this scheme in 2010.

Rwandan national life expectancy at birth for both genders increased by 19 years over the period of 2000 to 2012, in contrast to an average increase of 7 years across the Central / Eastern Africa region. Deaths from malaria decreased by 85% between 2005 and 2011, HIV by 78% between 2000 and 2009, and TB by 77% between 2000 and 2010.

ongoing challenges, including poor workforce distribution, poor service integration, and ongoing reliance on international aid, it sits in stark contrast to the health systems of many of its regional counterparts. National leadership and effective policy implementation have played a key role in the health system development and achievement of Universal Coverage (UC) observed in Rwanda. UC is defined as ‘all people receiving the health services they need, including health initiatives designed to promote better health (such as anti-tobacco policies), prevent illness (such as vaccinations), and to provide treatment, rehabilitation, and palliative care (such as end-of-life care) of sufficient quality to be effective, while at the same time ensuring that the use of these services does not expose the user to financial hardship’ [22]. Efforts to provide UC, involvement of the community in the development process and
ongoing management of the health system, successful public health campaigns to address communicable diseases, and inclusion of health literacy development activities as core components of minimum packages of care delivered by district health services, are key features of the Rwandan success story. The Rwandan case example highlights what can be achieved when health policy that seeks to address access inequities and build citizen capacity and engagement is effectively implemented.

3.3. Re-orientating the model of care

Historically, in Western societies, health care systems have been bio-medically focused and hierarchical. A powerful, informed doctor instructs and treats disempowered, uninformed patients who are expected to do what the medical system advises them to. Over the last 20 years, huge strides have been made in re-orientating the model of care to be person-centered, and in empowering patients to control their health and health care. Implementing health literacy focused strategies is one way to promote this change, either through building patient and citizen skills, and/or through building physician knowledge, skills and understanding. See Box 6 for an example (information about teach back from [23]).

Box 6. Re-orientating health care to become health literate and patient-centered

The community health and learning foundation is a UK Non-Government Organisation that works to create a more Health Literate Health and Social Care system. It has developed a training course for General Practitioners (Family Physicians) and their practices, with a face-to-face half- or full-day training course. The course includes practical information about what health literacy is, why it is important, and how it can impact on patients in everyday life, and on patients and doctors in clinical encounters. Those attending the course are also given practical tools to use in the consultation, such as ‘Teach-back’ and using clear language and communication techniques. Feedback from doctors at the end of the course indicated a previous lack of awareness of the issue of health literacy; “Thought provoking – very disturbed by the huge number of people who struggle to read/write/count” and a recognition that improving their health literacy skills will improve their patient care “If I am able to communicate better with clients then their experiences will be better”. The course is now undergoing an evaluation to better capture the impact of the course on patients and the care they receive.

3.4 Co-coordinating services within and across sectors

The 2016 Zika epidemic, centered in Brazil, has highlighted the problems that arise when services are not coordinated. The epidemic had all the features of a ‘perfect public health storm’; the evolution of the virus to a more virulent form with sexual as well as vector-transmission [24], its emergence in a country facing severe social, economic, and infrastructure issues, and the potential for global spread through the very high international travel linked with the 2016 Olympic Games. The following example from Brazil illustrates some of the key factors in that situation.
The public health messages referred to in this example were well distributed and easy to understand, but could not be applied by those targeted by the campaign. An alternative approach that considered the local context, was community led, and that developed the Zika virus-specific health literacy of individuals, families and communities might have had a greater chance of addressing public sanitation issues, reducing mosquito breeding, and reducing the risk of maternal: fetal viral transmission.

3.5. Creating an enabling environment

Health will not be fully achieved unless people are living in health promoting environments. In many countries, culture and stigma inhibit well-being and maintenance of health. HIV is a specific example. Given that, initially, the main means of transmission was sexual contact, being HIV positive carries huge stigma. This has multiple negative effects; Many children and young people with HIV, have contracted the virus pre- intra- or post-partum, and are unaware they have the condition. Even when they are aware, the stigma associated with it makes it very difficult to be open about their HIV status, resulting in adverse effects on attendance at clinics, medication compliance, and disclosure to friends, family, and sexual contacts. Tiwonde’s story (see Box 8, reproduced from Levin-Zamir et al. [1]), from Malawi, is a common one.

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**Box 7. The impact of poorly coordinated services within and across sectors.**

Mrs A is a 34-year old married woman living in Rio de Janeiro (Brazil) with three children. She and her husband live with their extended family in cramped conditions without running water or sanitation. Her husband is unemployed; she is the family earner, working shift hours as a cleaner. She is worried about the Zika virus, and what might happen to her and her baby if she were to become pregnant again, particularly as she will not use contraception on religious grounds, and abortion is illegal. She has talked with her friends and family – they are all very concerned but don’t know what to do. The government messages talk about citizens’ responsibilities for cleaning and avoiding having standing water, but Mrs A’s family have to collect water and store it for use for cooking, drinking and washing, and there are no local plumbed-in toilet facilities. Also, Mrs A cannot follow the government instructions to clean every Saturday as she often must work on Saturdays, and anyway feels that the main issue is not how clean her home is, but the piles of trash and discarded tires and household goods (which often contain stagnant water) in the locality, and urine and faeces in the street and the road.
Changing attitudes is difficult, and may at first glance be beyond the scope of a health system or program – however it is only by challenging myths, misconceptions and stigma, and encouraging openness and discussion, that people with stigmatized illnesses will receive equitable access to health care, be able to effectively control their own health, and future transmission will be reduced. Research with young people with HIV in Malawi (Uwamahoro, in progress) shows high awareness and a desire for empowerment and freedom, in other words the critical health literacy skills [25] to talk openly about their condition to address and reduce associated stigma.

Section 3.6. Health in All Policies

National policies set the contexts within which people live. They will influence the opportunities, capabilities and environments of the population, and the capacity of the health system to adapt to the health literacy of the people it serves. The Health in All Policies (HiAP) approach [8] emerged out of the recognition that, in order to achieve
health, the Social Determinants of Health (SDH) must be addressed. It encourages governments to identify and respond to opportunities across ministries, and to develop or reform services, environments and products in ways that enhance citizen access to information and support. Development of citizen health capabilities and the removal of restrictions upon freedoms to exercise health capabilities requires effort across sectors.

An initial step in operationalizing HiAP is understanding local and national needs and priorities, including the ways in which cultural norms and stigma may be reducing health or causing illness, as in the example of HIV in Malawi highlighted above. Thorough assessment of local health, health system and equity issues, and their relationship to policy and country context, is critical. Addressing complex health issues, particularly those with significant health behavioral components, requires a detailed and contextualized understanding of the personal, interpersonal, societal, cultural political, economic and environmental determinants. Amongst these considerations is the health capabilities (i.e. health literacy) of citizens, families and communities and how these interact with local contexts to influence health decisions, behaviors and outcomes.

National tobacco control in Brazil provides a case example (see Box 9: data from [26]) of inter-sectoral cooperation and strong political will to achieve health change. The multi-pronged, multi-level, cross-sectoral approach adopted by the Brazilian government promoted the health literacy of Brazilian citizens with regards to smoking, and constructed environmental, economic and social arrangements that made smoking more difficult, costlier and less attractive to engage in.

<table>
<thead>
<tr>
<th>Box 9. National tobacco control in Brazil</th>
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<td>In 2003 Brazil established the inter-ministerial National Commission for Implementation of the Framework Convention on Tobacco Control. The commission convened representatives from 18 government sectors, and had a broad set of responsibilities to advance tobacco control across Brazil. Some of the cross sectorial actions taken toward tobacco control in Brazil have included the Ministry of Finance raising taxes on cigarettes, changes to legislation that include a ban on smoking in public spaces and on advertising at the point of sale, the Ministry of Agrarian development taking steps to support tobacco growers to diversify their activities, and The National Cancer Institute supporting smoking cessation program development and delivery. Smoking prevalence decreased to 17% in 2009 from 32% in 1989 due to collective action.</td>
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Section 3.7. Health literacy research and national policies

Health literacy has much to add in development, implementation, and evaluation of national policy, much the same as with international policy. Pre-implementation assessment of policies can be used to improve policies before implementation, to maximise benefits for citizens and their health literacy. Timely descriptions and evaluations of a policy’s impacts support future planning, both within the country concerned but also across sister countries facing similar issues and challenges. Health literacy thematic indicators that may be developed to monitor the progress of the SDGs (see section 2.3 above) could also be applied to the evaluation of national policies.
International evaluation frameworks enable direct comparison between countries, and allow assessments to be made about which policies are the most effective in promoting health literacy and associated SDG progress indicators. Inclusion of economic indicators, in particular, will provide countries with information that enables them to effectively decide how best to spend limited national resources. As described in section 2.3, techniques such as social return on investment (SROI) can capture costs and benefits not only within, but also beyond, the health field i.e. increased employment and productivity, and reduced sickness benefits. Finally, qualitative research will bring unique insights into how new policies affect those who receive, as well as those who deliver, services.

**Section 3.8 Summary**

In this section we explored the value of frameworks (such as the Framework for Integrated People-Centered Health Services) and international policy approaches (such as Health in All Policies) in guiding the development of effective policies and approaches to health systems strengthening that incorporate consideration of health literacy issues and contributors to inequity. We also highlight the importance of strong leadership, effective governance structures, effective inter-sector coordination, and consistent effort in influencing how effectively policy acts to reform health systems, respond to health crises, and improve health and citizen capacity.

National policies focused on health, education and social care, have a significant influence upon the nature and qualities of services, structures and systems, and upon how effectively they respond to the health literacy of individuals, families and communities. It is these services, structures and systems that are explored in the following sections of this chapter.

### 4. Services, structures and systems to develop health literacy

The development and maintenance of health literacy is a lifelong process. The importance of education in enabling all to achieve their capacities and capabilities, including health, is highlighted by its prominence within the Sustainable Development Goals (SDG 4). In this section we describe what is known about education, both general and health literacy-specific, and cognitive skills and health literacy, including research into these areas. We follow this with a call for more research to inform the development of health literacy through the life course.

#### 4.1 Developing health literacy through the life-course

Cognitive development capacities start to develop in utero, a fact recognized by the WHO Commission on the Social Determinants of Health, resulting in their focus on ante-natal and early years provision as key to promoting health and reducing health inequity [5]. Learning then takes place throughout childhood, adolescence and adulthood. As societies age, more people will face the challenges of cognitive decline in parallel with the development of multiple health conditions. Education, for both children and adults, is key to developing and maintaining health literacy, as well as for promoting social equity and justice [27]. A fuller description and discussion of the place of education in health literacy is given elsewhere in this book by Levin-Zamir et
al [1]; here we discuss issues in relation to developing coordinated education systems that develop and maintain health literacy through the life course.

Of key importance is building health literacy competencies that recognize and complement cognitive development. Graham and Power describe a model whereby parental background and environment influence childhood cognition, education and health behavior, with ongoing influences in childhood and later adult health [28]. Cognitive development starts before birth and develops most rapidly in early years. Good nutrition and a health promoting environment antenatally and in early years are vital [5], have been shown to improve cognitive performance [29], and are likely to increase capacities for health literacy. High level cognitive abilities, as evidenced by high qualification levels and employment status, are associated with higher health literacy skills [30], and while not everyone with high cognitive abilities will have high health literacy, it is reasonable to hypothesise that they have latent capacities to develop health literacy given the right circumstances.

Building health literacy in childhood and adolescence should link with cognitive developmental stages [31], and can start very early with activities such as hand- and oral-hygiene. As children develop into adolescents, cognitive development enables the capacity to develop critical health literacy. In addition to simply understanding, and being able to discuss, health messages from a wide range of sources, adolescents can be supported to develop critical analysis and decision making skills as relevant for health. They can learn to ask questions such as Where does the information come from? How trustworthy is the source? Are there hidden messages? How do I know that this information is right for me? How do I take the actions that are best for me? [32,33]. Adolescence is a time when people make lifestyle and sexual health decisions that will influence their future health, so investment in building skills in this period will be valuable. In addition, the qualifications that come with a good general education greatly increase employment opportunities and lifestyle chances, all of which are associated with health and health literacy [5,34].

The development of health literacy in adulthood, described in more detail by Levin-Zamir et al [1] can be immensely valuable both for building skills for health, particularly in mental health and in knowledge about lifestyles and health, but also as a vehicle for developing more general literacy and numeracy skills [35]. A currently underexplored area in health literacy is the ‘teachable moment’; where major life changes, both positive (such as having a baby) or negative (such as a diagnosis of a serious health condition) bring opportunities for health-related learning [36]. Cross-generational learning such as family learning, and development of skills within communities, again described by Levin-Zamir et al in this book [1] are also of proven value.

An area where little health literacy teaching or research has been undertaken to date is in older people, particularly during cognitive decline. Wolf et al have shown that much of the loss of health literacy in older people is due to cognitive impairment [37]. However, what is not known is whether health literacy training could benefit this group, or indeed whether effective assessment of health literacy challenges and provision of tailored care is an appropriate way to support older people experiencing these challenges.

There is therefore a need to have ‘Health literacy in all Education policies’. Policies for pre-school, school, and adult learning are usually mutually exclusive. Having health literacy taught at all life stages, tailored to cognitive development and life stage, could do much to promote healthier societies.
4.2 Health literacy education and health literacy research

While there is some research on education in health literacy in adolescents and adults, described above, there is much work still to be done. In particular, there appears to be little or no research into the impact of health literacy training at the extremes of life and cognitive capacities, i.e. early years and during old age with and without cognitive decline. More research is needed on the impacts of health literacy interventions through the life course. This evidence can then be used to make the case for routine incorporation of health literacy into education systems.

4.3 Lifelong learning and health literacy research and practice - Summary

Learning health literacy should be seen as a lifelong activity. A coordinated health literate education system would build health literacy throughout the life course, with the optimal life stages and learning styles identified for different people at different times. There is, as yet, little research into the health benefits of building health literacy at different life stages. Exploration of the benefits of teaching health literacy in preschool, junior, and high schools would be very valuable, as children and adolescents develop the knowledge and skills to move into adulthood. There is some evidence that building adult health literacy, at least at functional and interactive levels, improves health and health behaviors; more research in this area, including the impacts of developing critical and distributed health literacy (in other words, health literacy distributed within networks and social groups [38]), would be very valuable. Finally, more research is needed about the benefits of health literacy training at the extremes of life, both early years and older age, including exploring the extent to which health literacy helps to protect from deterioration of physical and mental health seen with cognitive decline, and whether interventions to build health literacy in these groups are beneficial.

5. Services, structures and systems to promote health, prevent illness, and manage disease, illness and frailty

Citizens within societies will have a range of health capabilities [39,40]. There will certain challenges and barriers they experience, but also skills and attributes they possess that support them to effectively manage their health and engage with health care interactions. Services that seek to promote health, prevent illness, and manage disease, illness and frailty need to be responsive to the health literacy of the citizens they serve. As discussed above, viewing systems through a health literacy lens facilitates the placement of the citizen / patient / client and their family at the center of care, and supports them to design programs that act to reduce inequity. We seek to demonstrate how services and systems that respond effectively to the health literacy of local populations, and work to develop competencies for health, are of key importance in promoting health, and reducing and managing illness. We argue that responsive systems are also more resilient and able to act appropriately and effectively.

In this section, therefore, we discuss those systems of most relevance to health literacy; health, public health, and social services. We then discuss the health literacy research and evaluation opportunities in relation to these systems.
5.1 Health systems

It is only through building and strengthening health systems that it will be possible to secure better health outcomes. To promote the development of strong health systems, the WHO has proposed a framework [41] that describes six key building blocks for strong, resilient services, all of which require attention for maximum benefit for patients. We explore each of these building blocks through a health literacy ‘lens’, and describe how the health literacy concept may strengthen these building blocks.

This section focuses on health services provided to individuals and families. Systems that focus on populations (public health) are explored in the next section.

5.1.1 Health Services

Examining health literacy is a sensitive way to explore the extent to which citizens feel they are receiving the services they need. The European health literacy survey, in addition to highlighting the prevalence and impact of low health literacy across eight countries, highlighted some interesting international differences in health literacy (Figure 4).

In Box 4 above, we describe how these data stimulated the Austrian Government to develop a policy to reduce the complexity of the system, focus on centering care around the patient, and improve communication and service responsiveness to patients’ capacities and needs. This shift in focus was stimulated through high quality international comparative research, which highlighted not only the problem, but also indicated where to focus service reform. The Austrian example also illustrates the need for a planned and coordinated approach across many levels in policy and service. There needed to be a recognition of the problem and willingness to change at three levels – policy (government), organizations (hospitals) and health professionals. This involved recognition of the benefits that could be achieved at these three levels; for the government, there was the potential for increased health of citizens and increased cost-effectiveness of services, for hospitals there was the potential for better patient health outcomes, improved cost-effectiveness due to, for example, fewer missed appointments and unplanned hospital readmissions, fewer patient complaints, and a reduced risk of lawsuits. Health professionals valued the potential for greater patient satisfaction, fewer patient complaints, and better work satisfaction. Finally, for the system to improve there needed to be tools to enable hospitals to assess their ‘health literacy’ and to take action to improve.
Austria is a high-income country with many resources to improve systems; however Box 5 above describes the development of health literate friendly/focused services in the very different setting of Rwanda. What these system developments have in common, however, is a ‘health literacy’ focus that prioritizes communication with the patients and communities served. These two examples show how understanding health literacy capabilities, needs and barriers, and making communication with service users central to the service, can inform health system redesign. Future quantitative and qualitative research should be undertaken to assess the impact of the changed services on patients and the public, and ‘open the black box’ to identify the key barriers to, and facilitators of change, and the extent to which a health literacy focus promotes equity as well as quality in health services.

5.1.2 The health workforce

For the health workforce to be responsive to patients, particularly those with lower health literacy, they need to have health literacy appropriate skills, knowledge and supportive attitudes [42]. In many countries, such awareness and skills are low. For example, in a study involving junior doctors training to be family physicians in the UK, Groene found that health literacy skills, knowledge and attitudes were low, and reflected low levels of inclusion of health literacy in undergraduate and postgraduate medical training [43]. Initiatives to build health literacy skills in the health workforce are emerging, as shown in Box 6 above.

Techniques such as ‘teach back’ have been shown to improve patient understanding in the doctor-patient consultation and improved self-management [44,45]. What is not known is what other benefits health practitioner understanding of, and adoption of best practice in, health literacy, might have in terms of efficiency and fairness. It is reasonable to hypothesise that a health literate workforce would lead to better quality of care and better health service efficiency. There is evidence that people with lower health literacy are costlier to health providers, and use a less efficient mix of health services [30,46]. It is worth examining what impact a more skilled workforce in health literacy would have in these areas.

Figure 4. Health literacy levels in the 2011 European health literacy survey. Reproduced from the HLS-EU Consortium
5.1.3 Health information

Within the WHO health systems strengthening framework, this building block focuses solely on the production of high quality and timely health and health system statistics. While important, this fails to articulate the key importance that health information has for patients as enshrined in definitions of health literacy; individuals and communities need to be able to access, understand, appraise and use information and services to make decisions about health [2], and only by providing information at times, and in ways, that citizens can ‘understand appraise and use’ can health services be truly person-centered. The US has provided international leadership in this area through the promotion of a universal precautions approach, which advocates that services, including health information, are provided in ways that can be accessed and understood by all service users regardless of their health literacy levels [42]. Furthermore, tools have been developed to help hospitals and health centers audit the extent to which their information and systems are health literate, enabling them to plan and implement service improvements [47]. The adult education literature and basic skills surveys have much to teach us about the importance of developing and offering information for health in multiple formats. Preferred learning styles are individual, for example some people prefer learning through specific media (written / audio / visual). Different people have different levels of comfort in understanding and manipulating numbers. For people at the lower end of the skills spectrum, these ‘spiky profiles’ are more pronounced [34], meaning that information must be tailored to individual preferences in order to be understood, and hence acted upon. In practical terms, this means developing information in a range of formats (written, pictorial, audio or video clips, mobile phone apps) so that patients and the public can choose the modality that best suits them.

Digital technology offers exciting possibilities. In developing societies with poor health systems and infrastructure, and often low literacy and numeracy levels, mobile health (m-health), such as the use of cell phone, offers great opportunities for disseminating health information using formats suitable for patient skills. Such technologies also offer potential benefits for populations in more developed countries who face issues of poor health care access (usually societal rather than geographical access issues) and low health literacy. A systematic review of public health cell phone interventions in developing countries found 34 interventions, mostly focusing on reducing the risk of contracting or transmitting infectious diseases. Of note is that only five of the interventions were evaluated, and none were part of randomized controlled trials [48]. One paper from China has described a randomized controlled trial to evaluate an intervention to develop health literacy using SMS. The study found high acceptability (nearly 90%), and a significant increase in health literacy in the intervention group [49]. Making better use of the health literacy opportunities of cell phone technology thus brings rich possibilities for partnership between experienced trialists in developed countries and researchers in developing countries, with outcomes that may be applicable to socially disadvantaged and immigrant populations globally. Furthermore, in cultures where there is stigma attached to certain illnesses or health promotion activities (such as the HIV in Malawi example, Box 8 above), access to online or m-health information can enable people to access the information they need confidentially, empowering them to make the decisions that are right for them. Such interventions could be of use not only in developing countries, but for immigrant populations in transition in new countries. However, in countries with limited...
resources, funding such an infrastructure would take resources away from other health care provision. Research into the impact of m-technologies should therefore include cost: benefit analyses that include the costs of the infrastructure and well as the health benefits accrued.

5.1.4. Equitable access to essential products and technologies

We argue that health literacy is an important driver in promoting equitable access to essential products and technologies. Promotion of health literacy in groups and communities in society means that citizens can become involved in discussions about which products, vaccines and technologies should be available, and how they should be prioritized and funded. In combination with a ‘proportionate universalism’ approach [50], equitable distribution and access can be ensured. It may be that ‘public health literacy’ i.e. ‘the degree to which individuals and groups can obtain, process, understand, evaluate, and act on information needed to make public health decisions that benefit the community’ [51] will emerge as important here. Examples might be public discussions about whether anti-retroviral therapies, which reduce HIV transmission and improve economic productivity, should be prioritized over high-technology diagnostic equipment for diagnosis and management of non-communicable diseases? Or whether investment should be directed towards low-technology but effective products such as mosquito nets, and systems for clean drinking water? Involvement of citizens and communities in such discussion, promotes critical health literacy, can inform government policies, and promote truly person-centered health systems.

5.1.5. Health financing

A central tenet of the global health systems strengthening agenda is Universal Coverage (UC). UC is, to a large extent determined by national health system financing structures, and the need, or otherwise, for patients to pay directly for health care rather than payment through national taxation. The degree to which health care is available and accessible interacts with health literacy capacities to contribute to the degree to which inequities in health are observed within and across countries. Individuals that are both under-resourced and most limited in relation to opportunities to develop health literacy, and exposed to significant barriers to health service access, often fare poorly in both developed and developing country settings.

It is likely that in a health system without UC, those with the lowest health literacy levels are also the most likely to be excluded from health care. Studies comparing the association between capacities, including health literacy, and levels of UC, would provide insights into the cost-benefit of universal coverage and inform decisions about whether, and to what extent, countries should move towards it. It may also be useful to explore in more depth, the impact of health literacy interventions on the health literacy of health service users. It may be that such interventions have less impact on service users within a system that provides better coverage and minimizes barriers to health care. Examples of stark comparisons in levels of UC, and therefore logical natural experiments, would be to compare systems such as in the US where, until recently, a significant proportion of the population had no access to health care, with a health system such as that in Denmark, where a significant proportion of
national revenue from a high-tax system are fed into a health system with UC that is free at the point of delivery.

In the US, the recent introduction of the Patient Protection and Affordable Care Act, providing access to health care for people previously without such care, brings opportunities to explore the impact of policy on the health of people with low health literacy [52]. Ideally such an evaluation should include quantitative measures such as the numbers of citizens affected, their socio-demographic characteristics and health literacy, and the impact on health outcomes and health care costs, as well as qualitative research to understand from citizens themselves what the impact on their life and health has been. Such endeavors will be of great benefit to other countries exploring the costs and benefits of moving towards UC.

Health systems vary in their level of complexity, which is in part due to funding mechanisms for health care. The main health care funding mechanisms are; 1) directly from national tax revenue (such as Denmark and the UK) and 2) from health insurance systems (such as the Netherlands and the US). Interestingly the type of funding mechanism is not related to levels of spending on health. A Commonwealth Fund report showed that the US is an outlier in terms of national Gross Domestic Product (GDP) spent on health care, due largely to high spending on high-technology investigations [53], however the spend in the other 12 countries studied did not relate to the system of health service funding [53,54].

In those systems where funding is based on health insurance, such insurance may be mandatory or optional and may or may not be automatically linked with employment. There may be multiple competing options for insurance, varying levels of cover, for current and previous health conditions, and there may or may not be a ‘safety net’ for those with pre-existing conditions or those unable to afford health insurance [55]. People with low health literacy may have difficulties dealing with the complexities of such systems [56]; they may have insufficient financial resources to afford insurance, they are more likely to be unemployed [40,57], and are more likely to suffer from chronic / longstanding health conditions. [30,58], which may make insurance cover unobtainable. In a report comparing the health care systems and costs for nine countries, the US had the highest proportion of the population (37%) reporting cost-related barriers to accessing needed health care, while the UK National Health Service had the lowest proportion (4%) [55]. In the example from the US described below, the system required college-level literacy and numeracy skills, well above the mean skill levels of US adults [57]. This means that in settings with complex systems, basic literacy and numeracy skills are essential pre-requisites for health literacy. Without these basic skills, citizens are unable to independently access the health care they need.
In such situations, community support systems, including non-government organizations, can provide invaluable help, in particular ensuring that those with knowledge of the complex systems are available to help support those whose lack of skills is impeding access to health resources and services. Complex systems, such as in the US, require integrated health and social systems in which community and non-government organizations have a role in ensuring health related services are available and accessible. The cost of providing assistance in such settings may be high, and may not be covered by health insurance payments. Systems to monitor the costs of different systems should capture these, and wider societal, costs such as loss of economic productivity due to chronic illness.

Box 10. Accessing health care in a complex health system.
Chris W is a 40-year old man living with HIV. He graduated from high school with basic literacy and numeracy levels, and has a good understanding of his condition and the importance of Anti-retroviral therapy (ART) to keep himself well. In his last job, he had low health insurance cover, so used the federal AIDS Drug Assistance Program (ADAP) to help meet the costs of his ART. He has now moved to a higher-paid job with better health insurance cover, but finds that the new scheme will not cover maintenance therapy from his local pharmacy, and that the mail-order alternative does not accept the secondary insurance provided by ADAP, leaving him with an expensive monthly payment he cannot afford. He finds that, despite reading the website and trying to read the information sent to him by the insurance company (reading age of material: 18 years) he cannot understand the new system, and cannot find out who to talk with about this at the insurance company. He is unable to discuss this with his employer as he does not wish to disclose his HIV status.

Chris has now found a community advisor, employed by a local not-for profit organisation, who is experienced in US health insurance systems, and can help. The advisor arranged for a co-payment system directly with the pharmaceutical company providing the ART, which has reduced the monthly payments to a manageable level.

5.1.6 Leadership and governance

The experience from Austria (see Box 4 above) illustrates the critical role that leadership can play; firstly at a policy level where it can enable a health literate system to develop, and secondly at an operational level to build the coalitions required for meaningful engagement of stakeholders, and tools for providers to audit and improve performance. Another useful example is Australia, where the Australian Commission on Safety and Quality in Healthcare has written a report on health literacy that identified professional and organizational legal accreditation requirements of which health literacy is an essential component [59,60]. This approach ensures that action is swiftly taken, without need to introduce new accreditation processes and requirements.
5.1.7. Health systems and health literacy research and practice

The HLS-EU survey has shown how comparative research on health literacy can be a stimulus for system improvement and change. Further comparisons involving more countries will provide great opportunities for stimulating improvements in other countries and settings. In addition, evaluation research has much to add. If service improvement programmes routinely explored the impact of system changes on patients and their health literacy and health, not only would the impact of their changes be known, but also others could benefit from implementing such evidence-based changes in different settings.

As mentioned, the impact of practitioner skills training on patient health literacy and health outcomes is another important area. More research would greatly add to our understanding of which practitioner skills have the most impact, and in which settings they are best applied. Findings from such research could then be fed into practitioner training.

Finally, further research into m-health and e-health, and integration of these into the more ‘classic’ health systems, could bring a wide range of additional benefits to those with low health literacy, or with difficulties accessing health care.

5.2 Public health systems

Public health is ‘The science and art of promoting and protecting health and well-being, preventing ill-health and prolonging life through the organised efforts of society’. It is population based, and emphasises collective responsibility for health, its protection and disease prevention [61]. This emphasis on making decisions that are best for population, rather than individual, health requires different capacities and approaches i.e. ‘public health literacy’ [51]. Because of this fundamental difference from other health services, we look at public health systems separately in this chapter.

As with health-delivery systems, public health systems vary widely around the world. There is variation in levels of funding made available to public health, with some public health systems underfunded in absolute terms or relative to the funding for other health services. In most countries, public health is part of the health system, but, for example, in England, public health services are part of local government authorities, and are thus aligned more closely to education and social services than to health services. Public health services also vary in the extent to which they focus on prevention of infectious diseases, support reduction in substance abuse (smoking reduction services and harmful alcohol drinking services) and/or promote health through support for healthy lifestyles (such as healthy diet and physical exercise promotion), early detection of health problems, and self-care.

We discussed above the importance of international and national policy to develop resilience and the ability to respond to public health emergencies, both acute emergencies (e.g. infectious disease epidemics such as the Ebola virus and the Zika virus) and more ‘slow-burn’ emergencies such non-communicable diseases such (i.e. diabetes and cardio-vascular disease) and the challenges of HIV. The reason policy is important is because it determines the public health and health-delivery systems. If there is failure to develop resilient systems, there is a risk of failure of the systems themselves when faced with acute and more chronic emergencies. When a health system fails under such burdens, it is the people with low health literacy who are likely to be the most severely affected, both through increased likelihood of illness,
but also due to reduced health care access. In its review of its response to the Ebola epidemic, the US Centers for Disease Control and Prevention (CDC) highlighted the importance of not only the resilience of local health services, and the need for ongoing international partnerships to respond to such emergencies, but also the importance of health literacy within communities, where misconceptions about the disease and the responders facilitated the spread of the Ebola epidemic and hampered treatment and prevention of transmission [13]. Health literacy research within communities can add much to our knowledge of how individuals, communities and families understand health and illness, and develop health literacy to develop effective and healthy responses to such challenges. It can be argued, therefore, that health literacy should be integral to building both resilient systems, and resilient communities.

The example from Malawi, earlier described by Levin-Zamir et al [1], and repeated in Box 8 above, illustrates some of these issues. People living with HIV in many countries, and their families, face great stigma, exacerbated by public misunderstandings about HIV and its transmission, and the fact that, with treatment, HIV is now a manageable long-term condition rather than the ‘death sentence’ it once was. Public health campaigns to increase public understanding and promote openness and public dialogue could do much to break this cycle of stigma, sub-optimal treatment and unnecessary transmission of HIV. Such campaigns would aim to build distributed health literacy skills i.e. ‘the skills to draw on the health literacy abilities, skills and practices of others as a resource to help seek, understand and use health information to help manage health and make informed choices’ [38]. A focus on building such distributed health literacy skills in schools and families would be of particular help, as Tiwonde’s story suggests that HIV-positive children and young people who are living with the virus are unaware of their condition. In addition, many school children must attend boarding school due to the distance to school from home, therefore informed and engaged teachers can make a real difference both to children’s and young people’s understanding, but also to ensuring that antiretroviral treatment is taken optimally to maintain control of the condition.

5.2.1 Public health systems and health literacy research and practice

Public health systems are thus key to developing resilience and the ability to respond to public health challenges, and thus protect the most vulnerable in societies, including those with low health literacy. Research to help policy makers and practitioners to understand citizens’ views on health and illness, and the approaches that public health should then take to build understanding and action to combat threats to health. Public health literacy requires an understanding of the importance of the health of the wider population. There are times when public health literacy will come into conflict with individual health literacy. What is best for an individual or their family may not be best for society; examples might be decisions about immunization or taking antibiotics for mild infections. Qualitative research is needed to understand current views of citizens and communities on issues of public health importance, and to develop ways in which public health literacy can be developed. This links with distributed health literacy; such skills may be best developed at a community level. Understanding more about these complex and often challenging areas of health literacy would be valuable.
5.3 Social care systems

Social Care concerns itself with helping people live their lives comfortably, particularly those people who require a certain degree of extra practical and physical help [62]. It is therefore of importance to health and autonomy for the more vulnerable in society; those with congenital or acquired physical, mental, or cognitive disability, and those vulnerable through unemployment, severe financial stress, or homelessness. As with the other systems described in this chapter, social care systems vary in their levels of complexity, and also the extent to which they are funded by the state [55]. In addition, in most countries, health and social care systems are separate, with particular impacts on older people, those with multiple health conditions, and those with unemployment and / or low incomes, all groups known to have lower health literacy [30,40,58]. An extreme example of this is the UK where, in contrast to the health service, social care is expensive and disjointed, while at the other end of the spectrum, countries like Japan and Sweden have social systems that are co-funded and coordinated with the health system [55].

An important aspect of the social care system is the extent to which families and communities expect to provide care for the older and more frail in their communities. These cultural aspects to social care will impact on the extent to which the social care system needs to provide a social care ‘safety net’. This issue is also of importance in migration between different settings within a country, such as migration from rural to urban areas, and also migration between different countries and different cultural settings. People who migrate may well bring with them deeply embedded notions of what care and support should be provided by the family or community as opposed to the state. Health literacy is needed to learn about and navigate social care systems in new settings.

To date, no studies have been published exploring the issues around health literacy and social care. As with health, such exploration could approach the issues of health literacy and social care systems from complementary approaches. Firstly, to what extent do people have the health literacy skills to use social care information and systems to access, understand, appraise and use information and services to make decisions about health? Secondly, given that people in receipt of social care are likely to have lower health literacy, to what extent is the social care system responsive to the health literacy of the people it serves? Such studies are urgently required in national settings, and, as with health research, international comparative studies will be very informative about which systems and settings work best from a health literacy perspective.

5.3.1 Summary

Social care systems are of vital importance in supporting the most vulnerable in societies, and their families and carers. As with health, the provision of such systems, and the ways in which they are funded, vary widely between countries. It is likely that health literacy is significant in determining the extent to which people needing care can lead healthy and fulfilling lives. Conversely, the health literacy capabilities of the system will also be important. Health literacy research, both qualitative and quantitative, is vitally important in starting to understand where we are now, and how social care systems need to develop to promote wellbeing and mitigate frailty.
6. National and international policy and systems: implications for health literacy research, policy and practice

In this chapter, we have explored international, and national policies and the systems that arise from those policies through the ‘lens’ of health literacy, looking to see both how policies and systems can develop health literacy, and how health literacy can aid in the development of coherent person-centered policies and systems that will promote equity. We have illuminated these using examples from around the world.

Several key messages arise throughout this chapter. Firstly, there is a need to coordinate policies across the multiple areas of importance to health – health, public health, social services and education to name just some. We argue that policies should be the first area of focus, as policy determines systems – coordinated Health in All Policies means that there will be coordinated well-functioning systems. Secondly, we argue that health literacy theory has much to bring to the development of policies and systems, as situating policy within a health literacy paradigm will place empowered patients, citizens and communities at the center of systems. Person centered policies are more likely to promote equity and reduce inequalities.

Thirdly, we argue that embedding health literacy within policies requires more than simply referring to the concept and its role in health outcomes. Operationalization of the intent to ensure equitable access for all requires policy driven change across all aspects of the health systems, and beyond the health system into other policy domains. Better understanding of the policy frameworks and pragmatic solutions that prove to be effective, and that governments can adopt, can do much to support speedy development of health literacy and health literate systems.

Finally, we identify health literacy policy and systems research as a vital – and yet under-developed – area. The European health literacy survey has shown the power of comparative studies to identify the problem, and act as a driver for change. Incorporation of health literacy into monitoring systems for policies would provide a wealth of information, on which countries can act, singly or collaboratively. Other systems of importance to health, such as social care systems, currently have little or no health literacy research, and citizens have much to gain from a better understanding of the problems, and potential solutions, for the most vulnerable in society. It is reasonable to hypothesize that more responsive systems and services are more effective, more appropriate, and more cost effective. However, these hypotheses are yet to be empirically tested and as such caution is required.

Health literacy theory and practice have much to add to global health systems and policy, through providing a coherent framework for development and promoting citizen empowerment and equity. Embedding health literacy into research and evaluation of systems and policy will not only broaden the field of health literacy enquiry, but also provide opportunities to feed back into, and further improve, policies and systems for health.
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