PART 2 "EVIDENCE AND CASE STUDIES"
HEALTH LITERACY

Action Guide Part 2
“Evidence and Case Studies”
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FOREWORD

The World Health Communication Associates (WHCA) Health Literacy Action Guide Part 2, “Evidence and Case Studies”, is presented as a practical resource for use by local, national and international health, education and development advocates and agencies that are working on and/or planning to take action to enhance people’s health literacy. It builds on Part 1, “The Basics”, which was published on the occasion of the United Nations Economic and Social Council (ECOSOC) meeting in Geneva, Switzerland in July 2009. Ministers of State and Finance who were gathered at that meeting called for action plans to enhance health literacy on all levels. To assist in this process, Part 2 of the WHCA Health Literacy Guide series includes a more detailed review of evidence and, importantly, case studies of interventions that have been taken in a variety of settings in many different countries.

As with the WHCA Health Literacy Guide Part 1, “The Basics”, actions described not only focus on individual behaviour change but also look at initiatives being taken to strengthen and adjust systems in order to address institutional and structural deterrents to health literacy, make information more accessible and understandable, and make ‘navigation’ through health, education systems and work, community and policy-making settings easier. In so doing, the guide builds on the interactive health literacy framework first presented by Ruth Parker at the US Institute of Medicine Roundtable on Health Literacy in 2009.

The case studies included in Part 2 have been gathered by the International Alliance of Patients’ Organizations (IAPO), the Liverpool Healthy City Project, and through a review of relevant literature, particularly submissions to the Communication Initiative (CI) website (http://www.comminit.com/). The guide writing group wishes to thank Warren Feek, Deborah Heimann and the whole team of CI for their support to this project and to the many others who use the CI site as a prime source of health communication information and exchange. We also want to thank Jeremiah Mwangi, Julia Taylor, Kate Hodgkin, Mike Jempson and Carinne Allinson for collecting case studies and editing guide materials. The authors are grateful to all those people, projects and agencies who have shared their work with us. Special thanks to Stacy Cooper Bailey and Michael S. Wolf for use of their materials in sections 2 and 4. Additionally, we wish to thank Tuuli Sauren for her creative design work, Steve Turner, Erik Luntang, Kara Jacobson and the International Council of Nurses for use of their pictures and posters.
Part 2 of the WHCA Health Literacy Guide series also includes the ICN Advocacy Guide as an annex. The action framework presented in this Advocacy Guide serves as an excellent ‘tool’ and resource for enhancing efforts of those working on health literacy, particularly in the policy making arena. We are grateful to David Benton and Linda Carrier-Walker from the ICN for their support of the development of the Advocacy Guide and for permission to reprint it here. We also thank Scott Ratzan for allowing us to reprint his health communication glossary. Finally, we wish to thank WHCA, IAPO, Johnson and Johnson, ICN and the Liverpool Healthy City Project for their support to this project.

The guide has been developed through a process which has involved all the authors and their extended networks and continues to be a work in progress. Updates will be posted on the WHCA website: www.whcaonline.org. In addition to sharing our approaches with you, we would like to invite readers to give us some feedback about whether the conceptual approaches described herein make sense in your contexts and to contribute case studies for inclusion in future editions of the guide. For Part 3 the development team is particularly interested in gathering evidence and case studies about the relationship of Health Literacy to Health Inequities and identifying useful interventions which address both of these challenges.

Please forward any comments to: franklin@whcaonline.org.

For the Guide Development Team

Franklin Apfel
Poor health literacy skills are very common. Based on studies in several countries one can assume that 20-50% of the people in this picture will have trouble obtaining, understanding and using health information.
SUMMARY

Health Literacy at a Glance

WHO IS THIS GUIDE FOR?
This guide is for health professionals, educators, policy makers and advocates who wish to improve individual and population health literacy. This Health Literacy Action Guide summarises current knowledge on why health literacy is important and how we can improve health literacy.

WHAT IS HEALTH LITERACY?
Health literacy refers to a person’s capacity to obtain health information, process it and act upon it. Health literacy skills include basic reading, writing, numeracy and the ability to communicate and question. Health literacy also requires functional abilities to recognise risk, sort through conflicting information, make health-related decisions, navigate often complex health systems and ‘speak up’ for change when health system, community and governmental policies and structures do not adequately serve needs. People’s health literacy shapes their health behaviours and choices—and ultimately their health and wellbeing.

WHY IS HEALTH LITERACY IMPORTANT?
There is strong scientific evidence that shows that poor health literacy leads to less healthy choices, riskier behaviours, poorer health, more hospitalisations and higher health care costs. Poor health literacy has been shown to be a major public health problem in all countries where the issue has been studied. Very large numbers of people in both developed and developing countries have poor health literacy skills. In the US, for example, about 90 million adults—half of the adult population—are thought to lack the literacy skills needed to effectively use the US health care system.

WHY THIS GUIDE?
Poor health literacy is not just an individual problem but a systemic societal problem. It is best addressed when information, education and all types of communication from health and other services are aligned with the skills and needs of their users. While poor health literacy skills are common and have been found to be a significant determinant of health, to date there has been little systematic corrective action in
most countries. Meeting in Geneva in July 2009, the United Nations Economic and Social Council (ECOSOC) acknowledged this deficiency and called for the development of health literacy action plans at all levels. This guide provides a framework for such action and identifies useful interventions that people and agencies can take to strengthen health literacy.

**SIX KEY AREAS FOR INTERVENTIONS**

This guide focuses on action in six key systems or settings: health and education systems, media marketplaces, home and community settings, workplaces and policy-making arenas at all levels. Actions and structures within these settings may either facilitate or be a barrier to the development and expression of health literacy skills. Case studies, from all six WHO Regions, are included that describe a wide variety of interventions in each of these six areas.

**ORGANISATION OF THE GUIDE (6X6)**

The guide is organised into six sections, addressing six key questions:

**Section 1: What is health literacy?**

This section defines health literacy and describes the demands and complexities of different systems and settings, which shape people’s ability to access, integrate and act on health information.

**Section 2: Why is health literacy important?**

This section looks at the size of the problem and briefly reviews evidence of its impact on health, wellbeing and health system costs.

**Section 3: How is health literacy measured?**

This section looks at measurement tools for assessing individual health literacy skills and competencies, as well as the health literacy ‘friendliness’ of the systems and settings where health information is obtained.

**Section 4: What can individuals, agencies and systems do to strengthen health literacy?**

This section looks at interventions in six key systems and settings: health systems, education, media health information marketplaces, home and community, workplace and policy-making arenas.
Section 5: How can we advocate for more attention, investment and action to strengthen health literacy? Messages to Key Stakeholders.

This section identifies messages to key stakeholders and describes specific health advocacy communication strategies.

Section 6: What should be the components of a national or local health literacy strengthening action plan? Building national and local health literacy action plans.

This section suggests steps that can be taken to develop systematic approaches to enhancing health literacy.
SECTION 1: WHAT IS HEALTH LITERACY?

This guide defines health literacy as “The capacity to obtain, interpret and understand basic health information and services and the competence to use such information and services to enhance health.”

(Ratzan & Parker 2000; IOM 2004)

Health literacy ‘capacity and competence’ is not just determined by an individual’s basic literacy skills. It is also defined by the interaction (or alignment) of these skills with the demands and complexities of the systems within which information is sought, interpreted and used (see Figure 1). Health literacy ‘capacity and competence’ varies by context and setting. It is dependent on individual and system factors. These factors include both user and provider communication skills and knowledge of health topics, culture and the specific characteristics of the health care, public health and other relevant systems and settings where people obtain and use health information (Healthy People 2010). When these services or systems, for example, require knowledge or a language level that is too high for the user, health will suffer.

![Health Literacy Framework](image)

Figure 1. Health Literacy Framework (Parker R, in Hernandez 2009, p.91)

Over 300 studies in the US and UK, for example, demonstrate that printed materials, including consent forms, and web-based information sources are written in language above the average reading ability of most of their adult populations (IOM 2004).

**Action to enhance health literacy, therefore, has to focus on both improving individual skills and making health service, education and information systems more health literacy friendly.** Health literacy friendly
systems and settings are ones which actively measure, monitor, evaluate and adjust their communications to meet the needs (and skills) of their users.

**SYSTEM DEMANDS AND COMPLEXITY**

This guide identifies six key systems and settings—‘domains of influence’—which help shape both the development of health literacy skills and their expression (see Box 1).

Navigating increasingly complex health systems is a challenge for all users. Those with poor health literacy skills are particularly challenged. Health care and other agencies can help by ensuring their signposting, consent forms and other written materials are clear and understandable. If you were looking for the pharmacy, does this sign help or confuse?
BOX 1: SIX DOMAINS OF INFLUENCE ON HEALTH LITERACY
(adapted from Kickbusch & Maag 2008)

Health systems — Health systems play a major role in developing individual and population health literacy skills. Health systems can be made more health literacy friendly in a variety of ways. Workers may be trained to recognise the specific needs of users and assist them in navigating systems. Information—such as forms, signs and letters—can be made more accessible and understandable. If done appropriately, this can help align system demands to user skill levels and improve user ability to access health systems, assess risks, select appropriate pathways of care and engage in self-care. Health systems can also advocate for and shape the ‘health literacy friendliness’ of other systems and settings. They can do this by raising awareness of the negative health consequences of weak health literacy skills and, importantly, identifying good practice and advocating for more effective policies and interventions.

Educational systems — Schools and other formal and informal educational establishments play a major role in developing literacy skills and fostering literacy in all countries. They help children and adults to learn about what influences their health, the impact of the choices they make and where to find reliable information to support decision-making. Learning may have benefits in terms of improving attitudes to and competencies for engaging in positive health behaviours and making best use of health services. Literacy improves employment prospects (with associated health gains), either by helping individuals to move out of unemployment or through aiding progression in the labour market. Adult participation in learning may also be beneficial for the next generation in terms of improving their chances of learning and health outcomes. The development of such literacy skills should be a priority and included in all school and adult education programmes, with particular emphasis on parental involvement in early years education.

Media marketplaces — For many people, media marketplaces are a main source of health information. These marketplaces shape people’s health perceptions, behaviours and choices. Commercial and political interests often dominate, with interested parties using sophisticated communication techniques to sell their products and ideas. Public health advocates need to learn from commercial advertisers and marketers. They can use the same approaches to help people make healthier decisions when choosing goods and services. This could also serve to counteract the negative influences of industries—tobacco, alcohol and fast food.
companies—which glamorise and promote unhealthy products and lifestyles.

**Home and community settings** — People are called upon to make daily health-related decisions in their homes and communities. Families, peer groups and communities can be primary sources of health information. They help to shape functional health literacy skills related to product and service choices. These sources can provide important information about health-promoting, health-protecting and disease-preventing behaviours, as well as ‘alternative therapies’, self- and family care, available support services and first aid.

**Workplace settings** — By providing clear and consistent health messages to employees, employers can help prevent accidents and lower the risk of industrial or occupational diseases. Health-promoting work environments go further with specific health and wellbeing policies and dedicated support for employees to address lifestyle choices, such as alcohol and drug use and stress factors, including job security, demand–control, effort–reward in the workplace and issues related to achieving an appropriate work–life balance.

**Policy making arenas** — Policies at all levels—institutional, community, national and regional—shape the social and structural factors which determine health literacy and health. The engagement of citizens in policy making processes is a fundamental democratic principle. A key trend in many health system reforms is the empowerment of patients, the development of patient-centred care, and efforts to address the social determinants of health which shape differential access to information and care across a social gradient.

**BUILDING INDIVIDUAL SKILLS**

Building health literacy skills and abilities is a lifelong process, and no-one is ever totally health literate (or illiterate). People develop their health literacy over time and from a wide variety of sources. These may include their family and work settings;

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This guide intentionally avoids use of the term ‘health illiteracy’, as it is both inaccurate and an emotionally loaded term which all too often causes stigma and shame.
primary, secondary, higher and adult education; health providers; print and on-line health information; the media; and a wide variety of community-based resources, such as support groups to assist in quitting smoking.

Health literacy skills (see Box 2) include basic reading, writing, numeracy and the ability to communicate and question. Health literacy also requires functional abilities to recognise risk, sort through conflicting information, take health-related decisions, navigate often complex health systems and ‘speak up’ for change when health systems, community and governmental policies and structures do not serve needs.

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**BOX 2 : HEALTH LITERACY—FOUR INDIVIDUAL LEVEL SKILL SETS**

*Health literacy related skills can be categorised as: cognitive (knowledge), behavioural (functional), advocatory (proactive) and existential (spiritual).*

**Cognitive skills** include general literacy, numeracy, information gathering skills and analysis. These skills are used for health-related actions like reading health warnings and food labels, filling in forms, deciphering prescription drug instructions, as well as the ability to understand written and oral information given by health care professionals.

**Behavioural skills** include more interactive literacy and social skills used to make health risk assessment and lifestyle choices; system ‘navigation’ (finding the way to services or negotiating complex systems); self-care; and interpersonal communication and negotiating (e.g., asking for and receiving information, filing complaints or understanding health care charges, costs and bills).

**Advocacy skills** include critical competencies to analyse health information, understand the political and economic dimensions of health, and take action to express opinions and make changes at institutional, community and political levels. This may include ‘speaking up’ for oneself and others, taking action to promote new or change existing policies, lobbying and organising campaigns.

**Existential skills** include the ability to make sense of a life with illness, live with uncertainty, and avoid descending into depression, self-pity, hopelessness or helplessness. It includes the ability to grieve and to prepare for and die in a peaceful way.
Health literacy is best viewed as a dynamic continuum of skills. People’s needs change over time as they face different health challenges. Some of these changes are predictable based on life stages or whether preventive, disease care or rehabilitative information is being sought. The need for other skills arises when new behaviours are required: for example, to respond to the emergence of new health threats like pandemic influenza, climate change related heat waves and floods. But no one is ever totally health literate. Everyone at some point needs help in understanding or acting upon important health information. Even highly educated individuals may find systems too complicated to understand, especially when made more vulnerable by poor health.

Times of illness often provide ‘teachable’ moments and opportunities to enhance health literacy skills and knowledge.
SECTION 2: WHY IS HEALTH LITERACY IMPORTANT?

1. POOR HEALTH LITERACY SKILLS ARE VERY COMMON

In the United Kingdom, United States, Australia and Canada surveys have shown poor health literacy skills in 20-50% of the population. A National Consumer Council survey in the United Kingdom (NCC 2004) found that one in five people had problems with the basic skills needed to understand simple information that could lead to better health. US studies estimate that 90 million adults—almost half of the adult population—may lack the literacy skills needed to effectively use the health system. The majority of these adults are native-born English speakers. Literacy levels were found to be lower among the elderly, those who have lower educational levels, those who are poor, minority populations and groups with limited English proficiency, such as recent immigrants (Kutner et al. 2006).

2. POOR LITERACY SKILLS AND LOWER EDUCATIONAL STATUS ARE ASSOCIATED WITH POORER HEALTH AND WEALTH

Literacy—along with primary and secondary school attendance—is positively correlated to personal income, economic growth, female empowerment, life expectancy and having fewer children (Wils 2002). There is also a positive relationship between education and income (Cassen 2002). A global study by Barro (1991) showed that each percentage increase in primary school enrolment resulted in a 0.025 percent higher annual GDP growth rate in the subsequent 25 years. Household surveys of developing countries consistently find that those households headed by illiterate or less educated individuals are more likely to be poor. Simple literacy may not be sufficient to completely erase the possibility that a household is poor, but it can reduce the probability and the depth of the poverty experienced (Wils 2002).

Health education affects health outcomes in many ways. Enhancing a mother’s educational level reduces infant and child mortality in developing countries (Ratzan 2001). The number of years spent in formal education have been found to be inversely related to age-adjusted mortality in many countries, such as Norway, England and Hungary (Ratzan et al. 2000). A review of the health impacts of education found low educational level was associated with an increased risk of death from lung cancer, stroke, cardiovascular disease and infectious diseases, as well as a number of illnesses including back pain, depression, dementia, asthma and diabetes. Even in countries
where the average life expectancy for all has increased, the gap between those with the highest and lowest levels of education has remained (Higgins et al. 2008).

Clear links between education level and health behaviours have been shown. The likelihood of becoming a smoker is increased among less educated populations. Those educated to Level 2 or below are 75 per cent more likely to be a smoker at age 30 than a similar individual educated to degree level or higher (Wilberforce 2005). Higher educational levels are related to decreases in smoking prevalence and higher rates of smoking cessation in Europe (Cavelaars et al. 2000). Having a higher level of education is associated with consuming more fruit, vegetables and fibre and less fat (Johansson et al. 1999; Fraser et al. 2000 cited in Higgins et al. 2008). And higher educational level has been related to more ideal body weight in Europe, Russia and China (Molarius et al. 2000).
3. POOR HEALTH LITERACY IS ASSOCIATED WITH MANY ADVERSE HEALTH OUTCOMES²

Health literacy has been directly linked with acquisition of health knowledge, health behaviours and compliance with medication and self-care regimens (Baker 1999; DeWalt et al. 2004; IOM 2004). Empirical data supports an association between limited health literacy and numerous adverse health outcomes (see Box 3).

BOX 3 : HEALTH OUTCOMES OF WEAK HEALTH LITERACY

- Poorer health choices
- Riskier behaviours
- Less use of preventive services
- More delayed diagnoses
- Poorer understanding of medical conditions
- Less adherence to medical instructions
- Poorer self-management skills
- Increased risk of hospitalization
- Poorer physical and mental health
- Increased mortality risk
- Greater health care costs
- Higher health costs

Less health knowledge. People with limited health literacy have less health knowledge, access fewer preventive services and have poorer self-management skills (Williams et al. 1998a, 1998b). A person with low health literacy is likely, for example, to have poor knowledge about a wide variety of chronic health conditions, including asthma, hypertension, diabetes and congestive heart disease.

Worse self-management skills. People with low health literacy skills demonstrate poorer self-management skills. This has been studied in asthma, HIV infection and diabetic patients (Williams et al. 1998a,1998b; Wolf et al. 2005;

² This section is adapted from Health Literacy: A Brief Introduction by Stacy Cooper Bailey, MPH; Michael S. Wolf, PhD MPH; Kara L. Jacobson, MPH CHES; Ruth M. Parker, MD; Scott Ratzan, MD MPH (ICN 2009).
Kalichman et al. 1999; Wolf et al. 2006b; Schillinger et al. 2002). These studies showed that patients with lower health literacy skills were less able to identify medications, demonstrate proper administration techniques and showed poorer adherence to medication. In the case of people with diabetes, patients were less likely to know the appropriate dosing instructions and dietary restrictions, less able to achieve tight blood sugar control and reported higher rates of retinopathy as the result of poor self-care. HIV-infected patients with limited literacy skills have been found to demonstrate less control of their infection and were less likely to have an undetectable viral load.

**Higher hospitalisation rates.** Patients with limited health literacy have higher hospitalisation rates and a greater number of emergency room visits (Mancuso & Rincon 2006; Baker et al. 2002).

**Poorer health.** People with low health literacy have been found to be twice as likely to self-report poor health, even after adjusting for age, gender, race and markers of economic deprivation (Baker et al. 1998). Health literacy has been found to be a significant, independent predictor of average blood sugar in people with diabetes (measured by serum haemoglobin A1c) (Schillinger et al. 2002). People with low health literacy had a higher prevalence of diabetes and congestive heart failure, reported worse physical and mental health and greater difficulties with daily activities and limitations due to physical health (Wolf et al. 2005).

**Higher mortality.** Sudore and colleagues (2006) reported that in elderly people, low health literacy was associated with greater all-cause mortality risk compared to those with adequate health literacy. Similarly, Baker et al. (2007) found low health literacy to be significantly and independently associated with higher mortality risk in elderly people (see Graph 1).

**4. HIGHER HEALTH CARE COSTS**

Health literacy has a strong economic component. A low level of health literacy can lead to inappropriate use of the healthcare system, reduce effectiveness and efficiency of health care interventions or increase the likelihood of unhealthy lifestyles. One analysis in the US, by the National Academy on Aging Society, estimates that low health literacy costs the US health care system $30-$73 billion annually (1998 dollars). Sixty-three percent of the additional costs attributed to low health literacy may be borne by public programmes (Friedland 1998).
Graph 1: Literacy and Mortality Risk (Baker et al. 2007)
SECTION 3: HOW IS HEALTH LITERACY MEASURED?

Most health literacy measures in current use tend to assess reading skills (word recognition or reading comprehension) and numeracy rather than measure the full range of skills needed for health literacy. Although this is an area of active research, current assessment tools are still weak. There is a need to develop tools that can measure the ability to use health information to attain and maintain good health, including oral understanding, health knowledge and navigation skills (i.e., whether individuals are competent to access services, handle transitions, and find relevant information). Secondly, measures are needed to be able to assess the health literacy friendliness of systems and settings as both a guide to quality improvement and as a way to hold agencies responsible for making health information understandable and actionable (Clancy in Hernandez 2009, p.9).

The 2009 Institute of Medicine Roundtable on Health Literacy Measurement looked at measures of population health literacy, through geo-mapping and other techniques, to determine areas where interventions may be appropriately targeted (Hernandez 2009). The Roundtable pointed to a variety of tools in the pipeline which may help enhance capacities in this area in the near future (see Box 4). The report can be downloaded from http://www.nap.edu/catalog.php?record_id=12690.

BOX 4 : MEASUREMENT TOOLS IN DEVELOPMENT—PATIENT ASSESSMENT

The Consumer Assessment of Healthcare Providers and Systems (CAHPS) is a set of standardized, evidence-based surveys (in the US) for assessing patient experiences with their health care encounters. The CAHPS project not only develops survey instruments, but also provides reports that consumers can use to make decisions about their choices in health care. The project has also started to develop provider reports that can be used by providers to identify areas for quality improvement.

A tool is being developed that will be used to measure patients’ perspectives on how well health care professionals communicate health information. The goal is to gather data to help health providers improve communication skills and patients’ health literacy. It will include measures on:

- Oral communication regarding health problems and concerns, medications, tests, health promotion and forms;
• Written communication regarding medications and tests;
• Techniques utilized by health providers to ensure patient comprehension of health information (commonly referred to as “teach back methods”); and
• Patient-provider relationship.

The plan is to field test the item set in the fall or winter of 2009 with an expected release date of spring 2010 (Ocampo B, in Hernandez 2009, p.81).

3.1 CURRENT MEASUREMENT TOOLS—INDIVIDUAL SKILLS AND ABILITIES

REALM
The Rapid Estimate of Adult Literacy in Medicine (REALM) is a word recognition test. Patients are asked to read a list of 66 increasingly difficult medical terms. The number of correctly pronounced words is subsequently related to approximate grade levels of reading (0-18: third grade and below; 19-44: fourth to sixth grade; 45-60: seventh and eighth grade; 61-66: ninth grade and above). REALM is simple, brief (administered in two to three minutes) and useful for profiling patients’ reading skills (see http://www.ihs.gov/nonmedicalprogrammes/healthed/PDF/PtEd_REALM_Examiner_WordList.PDF).

TOFHLA and S-TOFHLA
Comprehension tests—such as the Test of Functional Health Literacy in Adults (TOFHLA) and the Short Test of Functional Health Literacy in Adults (S-TOFHLA)—were designed to provide a broader assessment of functional health literacy. They take into account reading comprehension and quantitative literacy (numeracy).

TOFHLA uses three passages of prose to assess reading comprehension. These are: (1) instructions for the preparation for an upper gastrointestinal tract x-ray, (2) the patient rights and responsibilities section of a selected application form, and (3) a standard hospital consent form. Each of these passages has about every fifth word eliminated and the respondent is asked to choose the most appropriate word to complete the sentence.

S-TOFHLA uses only the first two passages. For both the TOFHLA and the S-TOFHLA, hospital forms and prescription bottles are also used to assess a patient’s numeracy skills, such as instructions for taking medication, appointment schedules,
blood pressure and glucose monitoring, and obtaining financial assistance for both of these tests.

The number and type of quantitative tasks vary according to the version of the TOFHLA used. TOFHLA and S-TOFHLA have been shown to be reliable and valid measures of functional health literacy. Although TOFHLA and S-TOFHLA are the primary instruments by which reading comprehension and numeracy skills are measured, the time—22 minutes for the TOFHLA and 12 minutes for the S-TOFHLA—and complexity have limited their use to research within health care environments.

**NVS**
The Newest Vital Sign (NVS) test is a health literacy screening tool administered in three minutes. It requires users to read a standard nutrition label from a carton of ice cream and answer a series of six questions. The concept implies that health literacy is a vital sign, just as heart rate and blood pressure are. As with the TOFHLA, there are English and Spanish versions of the NVS. Currently, there is limited experience with the NVS in the published literature.

**One-Item Screening Measures**
While researchers may choose to use one of the above tools, it may be necessary for practitioners in a busy health care environment to simplify the measurement of health literacy. Because of the shame associated with limited health literacy, efforts have been made to identify simple screening questions that avoid the perception of literacy testing.

One study evaluated a series of questions as potential predictors of health literacy as measured by the S-TOFHLA. Three questions emerged from the analysis as best single-item screening measures:

- How often do you have problems learning about your medical condition because of difficulty understanding written information?
- How confident are you filling out medical forms by yourself?
- How often do you have someone help you read hospital materials?

In a follow-up study of the three questions, “How confident are you filling out medical forms by yourself?” was identified as the best predictor of limited health literacy skills when validated against REALM. Using a one-item screening question during individual encounters is simple, less intrusive, and may be a practical alternative to more complex measures.
3.2 MEASURING THE DEMAND AND COMPLEXITY SIDE—HEALTH LITERACY INTERVENTIONS

Some researchers have begun developing tools to evaluate the health literacy friendliness of systems. One such tool is shown in Table 1 (Matthews & Sewell 2002). The evaluation tool is a 5-minute, 15-question, web-based survey. It collects information on whether health literacy is considered in programme development and service activities; the degree to which organisations follow health literacy principles in their programmes; whether organisations pilot test materials for comprehension or cultural competence; evaluation of materials; which activities people associate with health literacy; and lessons learned.

System assessments

In addition to activity/intervention analysis, researchers have used assessment tools to evaluate how well a health service meets the needs of patients with limited health literacy skills. One study applied an assessment tool to a pharmacy setting. It evaluated patient understanding of medications and adherence to prescribed regimens (Jacobson 2008). Additionally, the assessment tools:

- Raise pharmacy staff awareness of health literacy issues.
- Detect barriers that may prevent people with limited literacy skills from accessing, comprehending and using health information and services provided by the organisation.
- Identify opportunities for improvement.

Conducting an organisational assessment may also provide a baseline assessment prior to implementing an intervention. Jacobson identified nine key elements of an organisational health literacy intervention: management, measurement, workforce, care process, physical environment, technology, paperwork and

This assessment tool can be accessed at: http://www.ahrq.gov/qual/pharmlit/.
written communications, culture, and alignment. Evaluating these elements provides a comprehensive audit to assess congruence between patient, provider and organisational perspectives of health literacy. A follow-up assessment allows evaluation of the intervention’s impact on an organisation’s accessibility to those with limited health literacy.

**TABLE 1. FREQUENCY OF UNDERTAKING HEALTH LITERACY-RELATED ACTIVITIES**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Regularly</th>
<th>Sometimes</th>
<th>Do not do</th>
<th>Don’t know</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Simplify language and check readability</td>
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<tr>
<td>Reformat materials to make them more user-friendly</td>
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<tr>
<td>Confirm patient/client understanding</td>
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<tr>
<td>Train agency, staff, or healthcare providers about health literacy</td>
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<tr>
<td>Use audiovisual aids</td>
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<tr>
<td>Provide materials in multiple languages</td>
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<tr>
<td>Use pictographs, cartoons, etc. to instruct and inform</td>
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<tr>
<td>Test for reading levels in clients</td>
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<tr>
<td>Use interactive computer or kiosk</td>
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</tbody>
</table>
3.3 SCORECARDS
The WHCA Action Guide Group has proposed the development of health literacy scorecards for individual and system monitoring of literacy. The individual scorecard would identify a few key health indicators that are associated with a healthy physical and mental state. These might be modelled on the D5 Diabetes Control Scorecard used to assess diabetes control in the US and other countries (see Box 5). A health literacy score might include a mix of physical, mental and social wellbeing measurements, including a literacy score (from one of the above measures); blood sugar; blood pressure; body mass index; cholesterol; tobacco use; immunisation status; exercise measure; wellness self appraisal; sense of social control, etc. Alternatively, the scorecard might measure knowledge of key facts needed to live a healthy life. Individuals could rate themselves against a standard and agencies would be measured on how many of their users successfully achieved the score parameters.

BOX 5: THE D5 DIABETES CONTROL SCORECARD
The D5 represents the five goals needed to reduce a patient’s risk of heart attack or stroke when he/she has diabetes.

A patient achieves the D5 when all five goals are met:
1. Blood pressure is less than 130/80
2. Bad cholesterol, LDL, is less than 100
3. Blood sugar, A1c, is less than 7%
4. The patient is tobacco-free
5. The patient takes a daily aspirin (age 40 and older)

Clinics are then given a D5 score by a designated agency based on the percentage of their patients achieving the D5.


SECTION 3: HOW IS HEALTH LITERACY MEASURED?
3.4 A MEASURE OF HEALTH DEVELOPMENT

Ratzan (2001) and others have proposed that population health literacy should be considered a measure of health development. A population health literacy index which measures a person’s skills and the health literacy friendliness of key systems and settings could provide a useful and unique picture of population health competence. Such an index could provide a new type of health index for societies that complements measures such as the disability adjusted life years (DALYs) and morbidity and mortality data (Ratzan 2001; Kickbusch 2002). The IOM Roundtable 2009 heard several presentations of approaches to population health literacy measurement, including geo-mapping using census data and literacy measures (Lurie in Hernandez 2009, p.66) and another imputing health literacy based on patient sociodemographic indicators such as age, education, etc. (Hanchate in Hernandez 2009, p.61). This is an area for future research.

Social Capital

Links have also been made between health literacy and the concept of social capital. Social capital refers to the features of social organisation—such as networks, norms and social trust—that enable participants to act together more effectively in pursuing shared objectives (Putnam 2000; Coleman 1988). A health literacy index may also serve as a measure of social capital as regards health.

WATCH THIS SPACE

The European Health Literacy Survey (HLS•EU) is a project which will measure health literacy in various European regions and cultures and create awareness of its societal and political impact in Europe. First results are expected at the end of 2010. The HLS•EU is the first international survey of health literacy, yielding datasets for European and national valorization as well as in-depth international analyses.
SECTION 4: WHAT CAN INDIVIDUALS, AGENCIES AND SYSTEMS DO TO STRENGTHEN HEALTH LITERACY?

Health literacy is a society-wide responsibility—it is everybody's business. Useful interventions can be taken in the six domains of activity identified earlier. While health literacy is indeed the product of many societal actors, health care and public health workers have a special responsibility in this area both to enhance their own communication capacities and those of the systems in which they work, as well as facilitating the change and development needed in other sectors and settings.

A NOTE OF CAUTION

While much can be learned from the activities of others, this guide is not promoting the wholesale adoption of any intervention. It is important that any definition of health literacy recognises the potential effect of cultural differences on the communication and understanding of health information (Nutbeam 2000). Native language, socioeconomic status, gender, race and ethnicity, along with mass culture—news publishing, advertising, marketing, and the plethora of health information sources available through electronic channels—all influence health literacy.

4.1 HEALTH SYSTEMS

Complexity of health systems

Advances in medical science, changes in the delivery of care and the adoption of a business approach to health reform in many countries have resulted in less accessible and more complex health systems. These changes all make high health literacy demands on their users. Navigating such health care systems, with their numerous layers of bureaucracy, procedures and processes, can be a challenging task. People often have to choose a provider, make a decision about treatment depending upon the severity of illness, and assess the ease and quality of various treatment options.

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3 The adoption of a business approach to health reform, guided by efficiency outcome measures, has often led to a re-orientation of priorities. Economic values inherent in an industrial and/or for-profit approach have in many places replaced fundamental commitment to access and care for many vulnerable persons, e.g. the poor, elderly and unemployed. Time management of health professional visits, for example, reduces the amount of contact time and opportunities for information exchange between providers (especially doctors) and patients.
They also have to move from community settings to hospitals, and from public to private providers (IOM 2004). An adult’s ability or inability to make these decisions and navigate these systems is a reflection of systemic complexity as well as individual skill levels. Patients, clients and their family members are often unfamiliar with these systems. Their health literacy can be thought of as the currency needed to negotiate the system (Selden et al. 2000); or a compass for what may be a difficult and unpredictable journey (Kickbusch & Maag 2008).

**Health Literacy enhancement interventions**

Health system interventions to improve individual and population health literacy can be divided into four categories:

1. ** Provision of simplified/more attractive written materials
2. ** Technology-based communication techniques
3. ** Navigating health systems
4. ** Training of educators and providers

**4.1.1 Provision of simplified/more attractive written materials**

Health information materials and official documents—including informed consent forms, social services forms and public health and medical instructions—often use jargon and technical language that make them difficult to use (Rudd et al. 2000, cited in IOM 2004). Moreover, studies suggest that health information is often more difficult to comprehend than other types of information (Root & Stableford 1999).

Most of the approaches in this category involve producing patient information materials that are written with simplified language, have improved format (for example, more white space and friendlier layout), or use pictograms or other graphics. Table 2 describes some key techniques (Doak, Doak & Root 1996).

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4 This section is adapted from Health Literacy: A Brief Introduction by Stacy Cooper Bailey, MPH; Michael S. Wolf, PhD MPH; Kara L. Jacobson, MPH CHES; Ruth M. Parker, MD; Scott Ratzan, MD MPH (ICN 2009).
## TABLE 2. TECHNIQUES TO SIMPLIFY PRINT MATERIALS

<table>
<thead>
<tr>
<th>Technique</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Write in short sentences</td>
<td>Short sentences tend to be easier to read and understand for patients. Sentence length should be less than 15 words, and ideally less than 10 words. Sentences should be written in a conversational style.</td>
</tr>
<tr>
<td>Print in large, Sans-Serif font</td>
<td>Text should be written in Sans-Serif font (e.g. Arial) with a minimum font size of 12 pt. Use of all capital letters should be avoided; only the first letter of words in text should be capitalized.</td>
</tr>
<tr>
<td>Include sufficient white space</td>
<td>Large margins and adequate spacing between sentences and paragraphs will provide sufficient white space and prevent a document from appearing to be solid text. In general, text should be left-justified for easy reading.</td>
</tr>
<tr>
<td>Select simple words</td>
<td>Words that are commonly used in conversation are the best to include in health messages. Shorter words tend to be easier to understand and more familiar to patients.</td>
</tr>
<tr>
<td>Provide information in bulleted lists</td>
<td>Bullets help to separate information from the rest of the text. Information provided in lists is often easier and faster for patients to read and comprehend.</td>
</tr>
<tr>
<td>Highlight or underline key information</td>
<td>Bolding and highlighting phrases or words can draw attention to essential information for patients. It should be used sparingly to differentiate key sentences or phrases from the rest of the text.</td>
</tr>
<tr>
<td>Design passages to be action and goal oriented</td>
<td>Written passages should be action and goal-oriented, and should provide readers with a clear explanation of the purpose of the written material. Passages should clearly define what actions should be taken by the reader and why these actions are necessary.</td>
</tr>
<tr>
<td>Group and limit instructional content</td>
<td>Consider grouping information under common headings to promote understanding. Place key information at the beginning of a paragraph and be sure to limit the amount of instructional content that is given to what is essential for the patient to know and understand.</td>
</tr>
<tr>
<td>Use active voice</td>
<td>Information written using active voice is easier to understand and more likely to motivate the patient to action.</td>
</tr>
<tr>
<td>-----------------</td>
<td>----------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Avoid unnecessary jargon</td>
<td>Unnecessary jargon can be distracting to patients and often provides little information. Medical terminology should be used as infrequently as possible and, if used, should always be clearly defined and explained to the patient.</td>
</tr>
</tbody>
</table>

Studies have shown that the majority of patients prefer to have print materials provided in clear and concise formats like those described above. All print materials should be simplified regardless of literacy level of target group.

**Utilising visual aids.** It is helpful to use visual aids in print material and during clinical encounters to help patients remember and process health information. One study demonstrated that people who listened to medical instructions accompanied by a pictograph remembered 85% of what they heard in contrast to 14% for patients who did not receive a visual aid (Houts et al. 2001). Visual materials are useful to teach patients about health conditions that cannot be seen easily—for example, cholesterol in the blood vessels—and to demonstrate how to follow steps to complete a task. Visual materials should be tailored to reflect the culture, age and background of the patient population and should be simple, recognisable and clear. Photographs and visual materials depicting how to correctly engage in health activities are useful methods of transferring health information to patients.

### 4.1.2 Technology-based communication techniques

The internet, mobile phones and other telecommunication advances allow for instant local–global linkages and cost-effective information transfer and intelligence gathering. These technologies facilitate health literacy by providing people with a choice of information that can be accessed in their own time and allowing them to put their own information on the web. However, the current digital divide is more dramatic than any other inequity in health or income. Access to internet and mobile phone technologies reflects social and economic differences between and within countries. High income countries—which have 16% of the global population and 7% of the global burden of disease—have 94% of internet hosts. Low-income countries, with 84% of the population and 93% of the burden of disease, have only 6% of internet hosts (Dzenowagis 2004).
Interventions
A wide variety of initiatives have tried to enhance access to technologies and address the digital divide. These initiatives include the introduction of low-cost hardware; the creation of ‘staging posts’ where local intermediaries interpret information for others; language-specific mirror sites (where web pages are regularly translated into local languages); and training programmes for users. Such technologies not only address information access issues for users but can be useful to institutions and governments as an interactive way of gathering feedback on the friendliness of services and information access.

One widely-used type of technology-based communication technique is telephone-delivered interventions (TDIs), in which counselling and health reminders are delivered using the telephone or through text messaging. TDIs can vary by the type of service provider and the extent to which the call is scripted. They may also vary depending on characteristics and responses of the individual, and the extent to which subsequent calls take into account information from other encounters with the individual (IOM 2002).

A systematic review of technology-based communication techniques shows that such decision aids improve knowledge, reduce decisional conflict and stimulate patients to be more active in decision-making without increasing anxiety (O’Connor et al. 1999).

New communication technologies offer educational opportunities that help people to be more involved in their health decisions and treatment. These technologies include web-based learning, audio-visual aids (for example videos, DVDs, spoken word), interactive games and ‘mobile health’ (M-health). ‘Mobile health’ is working on capturing the power of SMS messaging to support literacy. One example of this is in India. ‘Baby Centre’ is a service programme to which mothers can SMS their due dates to a central information centre. They will then receive, on a regular basis, text messages with useful information and reminders about prenatal check-ups, scans, etc. For those with poor literacy, call-in services are provided (Stross & Ratzan 2009, pers. comm.).

On the provider side, computerised profiles of individual patients or target populations can be used to tailor existing materials to fit specific situations. This can be done using computer-based algorithms that take various patient characteristics into account. These characteristics might include language, age, gender, ethnicity,
reading ability, health literacy level, and the needs and goals of the patient at that time (Revere & Dunbar 2001).

### 4.1.3 Navigating health systems

Many health systems, particularly at institutional and community level, have tried to make their services more easily navigable by using case managers and navigators to help patients. Navigators can be community health workers, lay or professional, paid or volunteers, but their role is to help patients through the health or social care system. They can be trained to provide health education, interpret health information and assist in obtaining access to services.

Navigators have been shown to help alleviate financial, communication and medical system barriers. They help patients to overcome fear and emotional barriers by providing support. The navigator can act as the patient’s advocate in the interval between screening and further diagnosis or treatment, assisting with practical issues such as paperwork for financial support, childcare or transportation problems. They may also translate medical jargon into understandable language, provide education about the disease and its treatment, help the patient to communicate with their doctor and be available to listen to fears and concerns. Such services have been found to improve health outcomes, increase adherence to medical treatment, reduce missed appointments and lower health system costs (Freeman et al. 1995).

### 4.1.4 Training of educators and providers

Providers should be trained to communicate more effectively to help them care for patients with limited health literacy. Training should focus on improving clinician communication skills and understanding of cultural sensitivities (Frankel & Stein 2001). Furthermore, the need for improved clinician skills in fostering mutual learning, partnership-building, collaborative goal-setting and behaviour change for chronic disease patients has been identified (Youmans & Schillinger 2003). Training works best when it is informed by users with limited health literacy, who are often under-represented in clinical research (IOM 2004).
Researchers and practitioners at the University of North Carolina in USA have developed several chronic disease management programmes that are designed to identify and overcome literacy-related barriers to care. The programmes, which include interventions for diabetes, heart failure, chronic pain and anticoagulation, are led by clinical pharmacist practitioners and trained health educators, who use evidence-based algorithms, a computerised patient registry and literacy-independent teaching techniques to facilitate effective self-care and assure receipt of effective services and medications. The teaching techniques are used in a one-on-one interaction with the patient during clinic visits and feature:

- A teach-back method in which the patient teaches the content back to the educator
- Practical skills rather than complex physiology
- Written educational materials designed for low-literacy users that the educator reviews with the patient
- Follow-up telephone calls and quick visits by the educator when the patient returns to the clinic, that serve to reinforce the education
- A collaborative learning environment based on sensitivity to the role of literacy in communication with patients

In each area, the programme organisers have systematically measured literacy as well as relevant health outcomes. For diabetes and anticoagulation, completed studies have found that these programmes can offset the adverse effects of low literacy.

A typical training programme might introduce providers to the concept of limited health literacy in patient populations, pointing out the implications for the delivery of healthcare services. It might provide techniques to improve communication with patients who have limited health literacy skills. Programmes may also include direct instruction and role-play exercises, in which the provider practises counselling the patient (in this case the trainer) with an observer providing feedback (Jacobson 2008).
Improving Verbal Communication. It may not always be possible to identify patients with limited health literacy. Health professionals should use plain language with all patients and avoid the use of medical jargon (Paasche-Orlow et al. 2006). When this is not possible, terms and concepts should be clarified when they arise. Techniques for effective verbal communication are shown in Table 3 below (Paasche-Orlow et al. 2006).
<table>
<thead>
<tr>
<th>Communication Technique</th>
<th>Explanation</th>
</tr>
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<tbody>
<tr>
<td>Talk slowly</td>
<td>Slow down the pace of speech when talking with a patient.</td>
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<tr>
<td>Encourage questions</td>
<td>An effective way to solicit questions would be to ask “What questions do you have?” This is an open-ended question and allows the patient more room for possible interactive communication with their provider. Questions such as “Do you understand?”, “Do you have questions?”, and “Do you think you can (check your blood sugars now)?” are vague and give the patient the opportunity to avoid the question with a simple “no” answer.</td>
</tr>
<tr>
<td>Explain things in clear, plain language</td>
<td>Plain, non-medical language should be used. New terms should be defined. Words or expressions that are familiar to patients should be used, such as “pain-killer” instead of “analgesic”. Jargon, statistics, and technical phrases should be avoided.</td>
</tr>
<tr>
<td>Avoid complex numerical concepts and statistics</td>
<td>Many people do not understand percentages. Patients do not understand all the numbers given to them before they make any treatment decision. Instead of saying, “There is a 20% chance that you will experience X outcome,” you can tell the patient “20 out of 100 people will experience X outcome.”</td>
</tr>
<tr>
<td>Use analogies and metaphors</td>
<td>Analogies should be selected to relate complex concepts to things the patient already knows (e.g., “Arthritis is like a creaky hinge on a door.”).</td>
</tr>
<tr>
<td>Limit information provided</td>
<td>Limit information to 1-3 key messages per visit. Reviewing and repeating each point helps reinforce the messages. In addition, it is important that other staff should reinforce the key messages.</td>
</tr>
<tr>
<td>Verify patient understanding</td>
<td>A “teach-back” or “show me” method should be used to allow the patient to demonstrate understanding and for the health professional to verify patient understanding.</td>
</tr>
<tr>
<td>Avoid vague terms</td>
<td>Say “Take 1 hour before you eat breakfast” instead of “Take on an empty stomach.”</td>
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</tbody>
</table>
Health providers should also verify that information provided verbally has been effectively understood by the patient by integrating the ‘teach-back’ technique into clinical encounters with patients. After describing a diagnosis and/or recommending a course of treatment, the health professional should ask the patient to reiterate what has been discussed by reviewing the core elements of the encounter so far. The health professional should be specific about what the patient should teach back and be sure to limit instruction to one or two main points. If a patient provides incorrect information, the health professional should review the health information again and give the patient another opportunity to demonstrate understanding. Using this method, the health professional can gain assurance that the patient has adequately understood the health information presented. Graph 2 shows how the teach-back technique should be conducted (Bailey et al. 2008).

Graph 2: The teach-back method
CASE STUDIES: HEALTH SYSTEMS INTERVENTIONS

1. MEETING THE HEALTH CARE NEEDS OF CALIFORNIA’S CHILDREN: THE ROLE OF TELEMEDICINE

Background

*Digital Opportunity for Youth Issue Brief, Number 3,* describes how telemedicine—the application of information and communication technology (ICT) to provide health care services at a distance—is used to improve the health of children living in the state of California, within the United States, especially those who are low-income or living in medically underserved areas. It also outlines challenges to successful adoption of telemedicine and provides concrete recommendations for action.

Links to health literacy

Telemedicine opens up the health system and creates many new communication options. It can connect providers with clinics and hospitals, schools, a child’s home, a child care centre or juvenile detention centre. It can occur in real time, with simultaneous interaction such as videoconferencing, or ‘store and forward’ transfers of data for review and consultation at a later time. It can potentially enhance the health literacy friendliness of different settings, by making information more accessible.

Lessons learnt

The authors state that telecentres can improve care and information exchange through:

1. screening, diagnosing, treating and monitoring a wide range of paediatric health conditions;
2. treating children in hospitals, especially critically ill children in rural settings;
3. providing dental screenings, treatment and referrals;
4. screening children for early detection and treatment of vision problems;
5. meeting mental health care needs;
6. helping sustain a 24-hour pharmaceutical presence;
7. providing coordination of services for special health care needs, such as autism, genetic diseases, mental retardation, depression, anxiety and behavioural problems;
8. improving the lives of families of chronically ill children by allowing them to keep their children at home;
9. protecting children by conducting child abuse consultations and examinations at a distance;
10. bringing interactive learning tools to parents in their home communities;
11. helping families stay connected when a child has to be hospitalised;
12. managing chronic health conditions;
13. facilitating language translation by bringing translators to the exam room in a short amount of time without needing the translator to be physically present;
14. providing conferences and training without extensive travel for rural health providers; and
15. expanding the capacity of schools and child care centres to address the health care needs of children through connecting school nurses with physicians.

Further Information

There are many challenges to further adoption of telemedicine, including, unclear administration and contractual organisation, legal barriers, provider shortages in subspecialties, and the need for more research demonstrating telemedicine’s impact upon health literacy.

2. NEW ZEALAND ORGANIZATION FOR RARE DISORDERS (NZORD)—WEBSITE RESOURCES

The NZORD website resource was set up to ensure that good quality resources exist online for patients and families affected by rare disorders in New Zealand. The website provides information on rare diseases, a beginner’s guide and offers guidance to navigating the health system in New Zealand. The website also includes a directory of health and disability support groups, and commentary on policy and consultations.

The website was designed to enhance the health literacy of its users by tackling the absence of centrally provided and maintained information about rare diseases (in contrast to the huge amounts of information available for most common conditions). This is achieved through links to a variety of quality databases with information on rare disorders and other resources. To support the use of this information, which is often designed for health professionals and researchers, the site offers guidance on the contents of the databases and how best to navigate and use them.

The website also has an area called “Health & Disability Resources” which contains information on:

- Specialist health services: This area of the website provides information about how specialist health services are controlled, how the process of referrals works and some descriptions of the specialist services to which someone might be referred to help empower patients actively seeking care by demystifying the process.

- Coping with your condition: This area contains links to practical assistance a patient or family may need. This includes links to support networks, training opportunities, counselling, specialist libraries, medicines information, research, income support and needs assessment and service co-ordination agencies.

- Participating in your community: This area provides the details of organizations that offer equipment, housing, transport, educational and vocational assistance to help day-to-day activity and participation in the community.

The resources are aimed at patients and families primarily, but also clinicians and researchers who might need to find groups or connect with NZORD over policy and service delivery issues.

Lessons learnt

A functional understanding of the healthcare system is a key element of health literacy, both empowering patients through a sense of control and ensuring that
care is sought at optimal times at the optimal point of the healthcare system. There is scope to develop similar resources to those provided by NZORD on a country-by-country basis. These, should, of course, reflect the distinct system and service models in each country. However, there is little value in trying to repeat centrally developed information on diseases. There are very good resources out there that should be linked to rather than repeated. In order to meet the needs of different communities, translation of medical information from English to other languages will be necessary.

- It can be time consuming and requires a comprehensive knowledge of the services available.
- The effectiveness of the resource is dependent on regular reviewing and updating of the information.

For more information contact IAPO (www.patientsorganizations.org/contact).
3. PELVIC PAIN NETWORK, DORSET ENDOMETRIOSIS PROJECT, UK

The Pelvic Pain Support Network is a patient-led organization that provides support to and advocates on behalf of those with pelvic pain, their families and carers. The Dorset Endometriosis Project was set up to ensure that patients receive the information they need.

Links to health literacy

The project was initiated after patients reported poor experiences around the quality and availability of information and access to care for their condition. The project worked to enhance both individual provider and agency capacities to deliver information. Focus groups were held to look into the specific information needs of patients. Further research was conducted into the information that was available on pelvic pain worldwide. This involved finding out what information sources patient organizations worldwide had, bringing them together and conducting a patient survey to see how useful they were for patients. The survey was evaluated and gaps in the information and the quality of information available were identified.

Following this survey, a group of patients approached the clinical governance manager at the local hospital about issues regarding patient care. A patient focus group was organized to gather patients’ views. Funding was obtained for an independent facilitator. A meeting of health professionals was convened and subgroups were established, one of which was patient information.

Lists of sources of information were produced by the Health Information Centre. A basic leaflet was produced for patients about Endometriosis that was to be given to patients on diagnosis.

Lessons learnt

• Patients have a great deal of experience of the information needs in their disease area.
• Information is key to empowering patients.
• It can be a long process to follow such a project through.
• It is useful to use a range of methods for gathering patients’ views—focus groups, surveys, interviews, etc.

For more information contact IAPO (www.patientsorganizations.org/contact).
4. PATIENT UNIVERSITY PROGRAMME (CANCER PATIENTS, PERU)

Since its creation in 2005, Esperantra, a patients’ organization, has been working to improve the quality of life of cancer patients in Peru, through support and information. In Peru, as in many other countries in the world, cancer is the second highest cause of death. The difference between Peru and many other countries is that more than 70 percent of all cancers in Peru are detected at a very late stage. There is an urgent need for prevention campaigns. At the same time, up to half of all the people diagnosed with cancer in Peru will not have access to treatment and care.

Esperantra found there was a critical lack of information for cancer patients in Peru, who do not have access to information and are not aware of their rights and responsibilities. They therefore conducted a study in the three main hospitals that cancer patients attend to find out how well informed patients were. The results showed that 70 percent of all patients were not well informed, 85 percent of the patients surveyed were not aware of their rights and responsibilities, and all the patients and relatives that were surveyed were eager to receive more information. This matched the experience of the organization, which is often contacted by patients for more information and to complain about the lack of comprehensive explanations from doctors, hospital staff and social services. Patients also say that they are often overwhelmed by the obstacles they face when navigating the healthcare system and feel they are left alone to their fate.

Some patients and relatives were willing to act, help others and learn more about what they could do to change things. After working closely with cancer patients for a significant time and participating in the creation of patient organizations and networks, Esperantra created a platform where these practices could be professionalized into an integral training programme. This led to the foundation of the Patient University Programme.

Links with health literacy

The Patient University Programme works to strengthen individual and group capacities and skills of cancer patients. Through specialized courses and workshops covering themes such as up-to-date information on cancer in general, innovative treatments and care, rights and responsibilities of patients, leadership, strategic planning of patient organizations, self advocacy and political action the patients are informed, trained and empowered. By attending the Patient University, patients, survivors and their relatives become protagonists, capable of advocating and defending equality of access to quality treatment and medical services.
The Patient University takes place in the conference room of Esperantra and in other appropriate locations which are situated near the main hospitals. Not only can the patients attend the workshops, training courses and lectures but they can also attend the activities organized by the patient organizations that are part of the Peruvian Patient Coalition. These activities are often organized in local communities, locations reaching a specific public, hospitals and schools.

**Results**

In the pilot phase the Patient University had good results. The patients were eager to learn more about cancer, to learn how to lead, organize and create patient organizations, how to be a representative and teacher for other patients and communicate their needs in a constructive way. The same empowered patients are now participating actively and helping in the realization of the Patient University Programme, other public awareness actions and involvement in health policy making.

Through the training, forums, lectures, and the information and support provided, the patients and their families have been able to access global information on cancer and on the newest technological advances. They have obtained tools to face the situation and move forward. The many activities and support provided by Esperantra and by the patients’ organizations have a positive influence on the quality of life and recovery process of the patients. The patients were able to be stronger self advocates and able to make their own informed choices.

**Lessons learnt**

- Organizing the training and leadership programmes as a university gave the patients more credit and recognition for their efforts and involvement.
- Empowered patients are eager to pass on their knowledge to others and are capable of becoming important self advocates.
- It is often better to train relatively small groups of patients at a time with in-depth trainings and workshops and continuous guidance.
- Some patients feel the need once they feel better to help others who are in the same situation they were once in.

**Conclusions**

The Patient University model can be applied to many other contexts around the world and be a great resource for patients faced with other diseases. In the context of Peru there is a clear need among patients for training in skills such as leadership,
self esteem, communication and many other basic skills, along with up-to-date information and continuous organizational support which gives them the possibility to create or participate actively in a patient organization or simply pass this knowledge on to others.

In other contexts, the needs of the local population can influence the focus of the training and workshops. The members of the patients’ organizations that have been created are strong actors in the Patient University Programme, putting their skills into practice and sharing them with others.

*For more information contact IAPO (www.patientsorganizations.org).*
5. CONCEBIR – FERTILITY CARE CAMPAIGN, ARGENTINA

The Fertility Care Campaign is being run by CONCEBIR, a patients’ organization in Argentina. Through their work, CONCEBIR found that many people do not know what factors can affect their fertility and therefore do not know how to look after themselves and protect their fertility. They found that many people attending an assisted reproduction medical centre find out that their fertility has been significantly reduced because of their age, lifestyle or contraceptive method used.

In response, CONCEBIR carried out a survey in three Argentine cities. Out of 400 interviewees, 25% could not name at least one factor that could affect human fertility and only 6% mentioned a woman’s age as one of the reasons for infertility.

Links with health literacy

CONCEBIR worked to address this by exploring ways to raise awareness of fertility care among the population, providing information on ten factors that may affect fertility. The objective was to make culturally-sensitive information more accessible that could develop people’s knowledge and awareness so as to maximize their chances of starting a family, at the time they choose, without needing assisted reproduction technology.

Methodology

- A survey was carried out in Argentina to evaluate people’s knowledge about fertility (2007)
- A poster was designed, summarizing the ten most important factors that affect human fertility. This was done with the support of two important medical associations in Argentina.
- An information brochure was produced outlining how the ten factors can affect human fertility and how to protect it.
- The poster and the brochure were distributed and a public campaign through the media was organized. The information was distributed in public hospitals, primary medical centres and clinics in the city of Buenos Aires.

The initial target was all the population of reproductive age in Buenos Aires, but the future target will be to reach secondary school pupils as part of sexual education programmes and also run the same campaign in other cities of Argentina.

The immediate result was to create an interest in fertility and the possibility of taking care of it. However, CONCEBIR is finding that, as in the case of any awareness or
public education campaign, it is taking some time to embed these concepts into social culture.

**Lessons learnt**

The most important lesson is to be patient because it takes a long time to achieve the objective and to gather interest and consensus from other organizations in order to work in a coordinated and more effective way, improving the results.

CONCEBIR found that it is not only important to include the patients’ point of view, but also the opinions of doctors and other specialists.

*For more information contact IAPO (www.patientsorganizations.org).*
6. AMERICAN CHRONIC PAIN ASSOCIATION GRAPHICAL COMMUNICATIONS TOOLS, US

The American Chronic Pain Association (ACPA) has sought to offer tools that use graphics to capture critical information and convey it quickly to enhance both initial discussion and longer-term compliance.

**The problem:** ACPA receives many calls from consumers who believe that their health care providers are not taking their pain seriously and that they are not getting the care they need. In addition, many consumers call the ACPA office with questions about how to take medications and otherwise follow their providers’ instructions following a visit.

**Links to health literacy:** This experience aligns with numerous studies that highlight compliance issues among older adults, non-English speakers and others with literacy challenges. Many “graphical tools” were developed to enhance patients’ care management skills.

**The tools:** American Chronic Pain Association Graphical Communications Tools include:

- Pain Log
- Follow-up Sheet
- Care Card Pharmacy Insert (with the American Pharmacists Association)
- In Case of Emergency Sheet (with the American College of Emergency Physicians (ACEP))
- Nerve Man diagnostic aid

**Method:** Before developing the tools, ACPA analysed the kinds of questions they received from consumers and the issues raised by caregivers and identified the problems in the health professional/consumer relationship. In the case of the emergency department project, this involved a survey in partnership with ACEP. ACPA then identified where the lack of understanding or process disconnects occurred.

Drafts of appropriate tools, including text and graphics, were developed and tested with healthcare professionals on the ACPA board, the ACPA Professional Advisory Committee and the partner organization, if any. Once consensus was reached, materials were produced and posted on the web site and printed.

The materials are used in hospitals, clinics and by individuals independently. Target groups include older adults, those with reading or language issues and
anyone wishing to have time-saving tools for better communication with health care professionals.

**Results:** The tools have enhanced communication, reduced frustration and improved relationships between provider and consumer, based on feedback from both consumers and providers. The tools are popular takeaways at ACPA’s stands at professional meetings and are among the most popular downloads on their web site.

**Lessons learnt:** People are eager to communicate better with caregivers and to comply with treatment strategies. These tools give them a greater sense of control and help to build a strong functional partnership between consumer and provider.

ACPA intends to expand the series to address other specific conditions and situations. They feel that tools like these empower consumers and enhance the therapeutic process.

*For more information contact IAPo (www.patientsorganizations.org).*
4.2 EDUCATIONAL SYSTEMS

Schools and other formal and informal educational establishments play a major role in developing literacy skills and fostering literacy in all countries. Literacy skills may improve health in many direct and indirect ways. They help children and adults to learn about what influences their health, the impact of the choices they make and where to find reliable information. Learning may have benefits in terms of improving attitudes to and competencies for engaging in positive health behaviours and making best use of health services. Literacy improves employment prospects (with associated health gains), either by helping individuals to move out of unemployment or through aiding progression in the labour market. Adult participation in learning may also be beneficial for the next generation in terms of improving their chances of learning and health outcomes. The development of such literacy skills should be a priority and included in all school and adult education programmes, with particular emphasis on parental involvement in early years education.

The opportunity to provide health education also exists within institutional and community-based health services. There is sound justification for embedding health literacy instruction into these settings for children and adults. Educational research has documented the impact of context and content on learning, retention and transfer. This research has shown that learners retain and apply information best in contexts similar to those in which they learned it (Bereiter 1997; Mayer & Wittrock 1996; Perkins 1992).

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**BOX 7: CRITERIA FOR HEALTH EDUCATION CURRICULA**

*(Lohrmann & Wooley 1998)*

1. Be research-based and theory-driven.
2. Include information that is accurate and developmentally appropriate.
3. Actively engage students using interactive activities.
4. All students to model and practise relevant social skills.
5. Discuss how social or media influences affect behaviour.
7. Provide adequate time for students to gain knowledge and skills.
8. Train teachers to effectively convey the material.
For example, children and young people can learn about health and hygiene, nutrition and physical activity while learning about sexual and reproductive health. Information about birth control can be given at the same time as information about the prevention of HIV/AIDS and other sexually transmitted diseases—so-called ‘dual protection’. Learning opportunities also exist during immunisation experiences, such that families and recipients understand the disease and the public health benefits of immunisation.

Education and literacy has a positive impact on population health—particularly on women’s health and the health of their children (Sen 1999; Nussbaum 2000). It is estimated that two-thirds of the world’s 960 million illiterate adults are women. There is a strong positive reciprocal relationship between female education and women’s empowerment. Education empowers women by giving them knowledge and a new perspective on their role. It also improves their earning potential. Income for women rises by 10–20% for each additional year of schooling. Educated women are more likely to postpone marriage and childbirth, give better health care to their families, send their children to school and contribute to overall economic growth (Kickbusch 2002; Wils 2002).

The development of literacy skills should be a priority and included in all school and adult education programmes, with particular emphasis on parental involvement in early years education.
The educational intervention should be pitched at a level commensurate with age, mental capacity, gender and environment. Programmes for adolescents, for example, might focus on reproductive health (e.g. use of condoms) along with cancer prevention and detection—breast self examinations, testicular examinations and annual cervical smears. In young adults, the issues of communicable and non-communicable disease and the need for parental and childhood vaccination could be reinforced. Young mothers are receptive to learning about recognising and treating childhood illnesses. And interventions for people in their mature years—especially those with chronic illnesses—might focus on self care.

**Obstacles to health education initiatives**

The World Health Organization (1996) has described several barriers that may impede the implementation of school health programmes. Firstly, policy makers and political leaders—as well as the public at large—often do not fully understand the true impact of modern school health programmes on health. Secondly, some may not support the programmes because the content is considered too controversial, for example those that discuss HIV infection, other prevalent STDs and unintended pregnancy. Thirdly, modern school health programmes require effective collaboration—especially between separate education and health agencies (IOM 2004). Any planned educational intervention will need to address these potential obstacles.

**Understanding barriers and facilitators to adult learning**

According to Hillage et al. (2009), policy actions and interventions to address social inequities in education (and education-related differentials in health literacy) must be based on a clear understanding of why people do not engage with learning activities, as well as knowing the system and structural barriers and policy enablers. Three reasons why people do not take part in learning have been identified:

- **Dispositional:** lack of motivation related to perceptions that the learning is not relevant to them, lack of interest or confidence, and previous negative experiences at school.
- **Situational:** Cost, lack of time and/or transport or childcare and language (especially for non-native speakers) are common situational obstacles.
- **Systemic:** Poor awareness of options, lack of the necessary information or availability of the right type of course or learning environment may further block participation.
Initiatives which have been shown to stimulate demand for post-16 learning (Hillage & Aston 2001) generate demand through targeted publicity, advice and guidance, flexible offerings and funding options in community settings, workplaces and to specific populations (especially to young people, women, people with skill deficits and underserved communities).

Schools and other formal and informal educational establishments play a major role in developing literacy skills and fostering literacy in all countries. Learning to read and understand labels, for example, is a basic health literacy competence.
The study involved nearly 20,000 children in 35 states.

**Links to health literacy**

It gave parents access to essential health information and the confidence to address their children’s basic health care needs.

**Approach**

Parents were surveyed about their family’s health care habits three months prior to the training and six months afterward. At the outset, 60 percent said that they did not have a health book at home to reference when a child fell ill. As part of the study, each Head Start family was given a low-literacy medical guide, *What to Do When Your Child Gets Sick*, by Gloria Mayer, R.N., and Ann Kuklierus, R.N., which offers clear information on more than 50 common childhood illnesses. The Health Care Institute training is adapted to various languages and cultural needs of the participating families.

**Outcomes**

Tracking the Head Start families enrolled in a health literacy programme, researchers found that visits to a hospital emergency room or clinic dropped by 58 percent and 42 percent, respectively, as parents opted to treat their children’s fevers, colds and earaches at home. This added up to a potential annual saving to Medicaid of $554 per family in direct costs associated with such visits, or about $5.1 million annually.

Moreover, parents being better informed about handling their children’s health needs translated to a 42 percent drop in the average number of days lost at
work (from 6.7 to 3.8) and 29 percent drop in days children lost at school (from 13.3 to 9.5). Parents also reported feeling more confident in making health care decisions and in sharing knowledge with others in their families and communities.

Prior to the training, parents said they were “very confident” about caring for their sick children—yet, in reality 69 percent reported taking a child to a doctor or clinic at the first sign of illness. Almost 45 percent said they would take their child to a clinic or emergency room for a cough rather than provide care at home, with 43 percent doing so for a mild temperature of 99.5°F.

Post training, researchers found a marked improvement in parents’ self-confidence, with only 32 percent indicating that they would still go first to a doctor or clinic. More significantly, the number of parents using the medical guide as a first source of help jumped from five percent to 48 percent, indicating a better understanding and higher comfort level in dealing with common childhood illnesses.

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2. SYNCOPE TRUST AND REFLEX ANOXIC SEIZURES (STARS)—SHINE A LIGHT ON EDUCATION, UK

Links with health literacy

The Shine a Light on Education programme aims to make school settings more health literacy friendly for young people with seizures and black-outs by educating teachers, staff and carers on syncope and training them in condition management. The programme also provides information and advice for parents and children on how to cope with syncope in their learning environment.

Every year more than 225,000 young people in the UK experience a blackout. As a result of this STARS established an education programme for use in educational establishments from nursery to university. Many young people diagnosed with a form of syncope (transient loss of consciousness, blackouts, fainting) struggle to either access full-time/full curriculum education. Older students often find access to education is limited/denied.

Based on enquiries, STARS members developed materials and processes:

1) To educate educational establishments
2) To involve families with diagnosed syncope members
3) To initiate and train volunteers

Both educational establishments and STARS members were informed of these new resources. STARS information booklets and sheets were published and the Education section of the STARS website was launched with on-line materials. All of the literature produced for the project is free to patients and educational establishments and it is all endorsed by the Department of Health in the UK.

Results

1. Centres and families responded positively to the publication of support materials and the website. This was evidenced through the rise in requests for booklets and the 1 million hits on the website.

2. Numerous presentations have taken place across the UK and the uptake for these events has been significant.

3. The number of requests from schools for information and presentations has continued to grow. So far, 50 schools have requested presentations which STARS provides free of charge.
The project’s success is illustrated by the fact that across the UK, educational establishments, carers and pupils diagnosed with syncope continue to contact STARS for information and guidance. STARS has received many enquiries from families and schools, seeking advice and support on reflex anoxic seizures (RAS). To date 1,000 information booklets have been sent out following requests; 15 SIR presentations have been made to nurseries, schools and colleges with ten more pending, and requests are coming in weekly.

**Lessons learnt**

It is important to anticipate growth in demand. The current popularity of the programme means that STARS needs more trainers to provide equal support across all areas of the UK.

Better education about a condition leads to improved communication between families and schools, care and management improves and education is more successfully accessed, especially for those previously denied or limited from activities.

*For more information contact IAPO (www.patientsorganizations.org).*
3. REGIONAL CHILDREN’S ANTIRETROVIRAL THERAPY (ART) LITERACY TOOLKIT, AFRICA

Background
The ART Literacy Toolkit is also known as the Kid’s ART Literacy Toolkit. It seeks to enable children to gain a comprehensive level of literacy around HIV and ART issues pertinent to them. It aims to empower children (primarily aged between 6-11 years, though also relevant for teens) who are living with HIV and ART, helping them gain an appreciation of HIV and ART in context.

Links with health literacy
For use in educational systems, this Toolkit is designed for children and members of their ‘circle of care’, including:

- teachers within school-based programmes;
- parents and guardians within the family environment;
- leaders within the religious sector; and
- health care workers, social workers, community workers and counsellors within a service provision context.

Lessons learnt
Using a cascade method, the model was able to be spread throughout community members, who used and adapted it. The booklets helped children unpack both the specific and practical issues related to HIV and ART through ‘edu-tainment’ activities, encouraging them to take action within their own lives to make a difference. Simple cartoons taught children to overcome challenges and changes in the body and helped them learn how to integrate treatment into daily living. Children were encouraged to identify their fears and develop solutions as well as plan for their future hopes and dreams.
**Further Information**

Each toolkit contains:

- an 8-booklet series with narratives, and edu-taining activities to address basic facts about HIV and ART, testing and disclosure, support for a child on ART, stigma and discrimination, positive living, adherence, supporting other children on ART, and suggested ways of using the toolkit;
- a child’s adherence calendar and a watch, to enhance adherence responsibility amongst children;
- an interactive poster that engages the child to actively process ‘Respect’ as a foundation of being responsible, not violating rights and alleviating stigma and discrimination;
- a brochure on tuberculosis (TB) and HIV co-infection, ART, and children;
- three advocacy stickers;
- an HIV and ART knowledge board game; and
- a pack of 20 quiz cards on HIV and ART issues.

The Toolkit is published by Southern Africa HIV and AIDS Information Dissemination Services (SAfAIDS).

4. BEAT IT! HIV/AIDS TREATMENT LITERACY SERIES, SOUTH AFRICA

Background
The Beat It! HIV/AIDS Treatment Series is a training resource consisting of a series of 21 programmes on DVD or VHS and accompanying workbooks. The series was designed to support discussion and workshops on HIV/AIDS treatment.

Links with health literacy
Used in educational systems, the series provides an introduction to the core information needed to respond creatively to people living with HIV/AIDS in their environment. It combines personal documentary accounts of people living with HIV/AIDS with expert advice and explanations. Each programme has an accompanying workbook that provides additional information and a summary of the topic.

Lessons learnt
The workbook can help facilitators prepare and present HIV/AIDS treatment information, offers questions to stimulate discussion and offers methods of checking whether the information has been understood.

5. SPEAKING BOOKS, SOUTH AFRICA

Background

Books of Hope, in association with the South African Depression and Anxiety Group, designed and produced these interactive, multilingual speaking books that can be seen, read, heard and understood by the reader regardless of their reading ability. These hard-backed books feature a sound track, read by well-known local personalities, to take the reader on a step-by-step guide to wellness and encourage readers to build self-confidence through a simple action plan.

Links with health literacy

The Books of Hope series has been created to meet the Health Care Education needs of Africa’s rural and disadvantaged communities and as a means of overcoming the low levels of literacy. Speaking books are distributed in the communities they serve and paid for by government departments, foundations and organisations.

Lessons learnt

The concept of a Speaking Book can be applied to meet a whole range of needs from educating young children on health care issues such as diabetes and asthma, and how they can cope with their illness, to direct mail promotional material to support a product or service where the novelty factor will ensure that the recipient will get the message.

Topics of the books include:

- Teen suicide prevention
- HIV and AIDS doesn’t mean living with depression
- Living free of Tuberculosis (TB)
- Mobilising against malaria
- Treating trauma and Post-Traumatic Stress Disorder (PTSD)
- HIV and AIDS medication – taking the first step
- Allies against substance abuse
- Help for child-headed households

6. Open, Distance and Flexible Learning (ODFL) in HIV/AIDS Prevention and Mitigation for Affected Youth, South Africa and Mozambique

Background
Education is a key protective factor against HIV; however, school dropouts are increasing in many affected countries. This paper, based on field studies in Mozambique and South Africa undertaken by the Institute of Education, University of London, looks at the potential of open, distance and flexible learning (ODFL) to increase access to education for youth who are out of the formal education system.

Links to health literacy
Through the educational systems offered by ODFL, learners can choose the time, place and pace of their study. A significant proportion of the teaching is done by someone removed in space and/or time from the learner. In health education, ODFL has helped to:

- increase access to education (especially for remote or marginalised groups)
- enhance school quality to increase child survival and family health
- raise public awareness and action on health initiatives
- encourage people to practise healthy behaviours.

In this research of ODFL in Mozambique and South Africa, researchers found that AIDS has been declared an emergency threatening development, peace and stability and that the response of the education sector has focused largely on the curriculum to provide relevant information, life skills and the teacher training to deliver them through schooling. There are few strategies to address the needs of out-of-school youth, even though children are increasingly missing lessons, dropping out of school and unable to access the national curriculum or develop basic literacy, numeracy or livelihood skills.

In South Africa, ODFL efforts to prevent the spread of HIV have largely relied on television and media campaigns such as Soul City, LoveLife and Khomanani. In Mozambique, where lack of infrastructure reduces opportunities for mass media campaigns, HIV prevention methods are mostly face-to-face with some ODFL support materials, such as My Future My Choice and Geracao Biz. Experience with these programmes has shown that to be successful young people must participate in the design and implementation of the activities to make sure they are tailored to their literacy levels and real-life contexts.
Lessons learnt

There is now a real opportunity to change policy, accelerate the educational response and transform ineffective systems. But for this to happen there is a need to radically rethink ways that education can be delivered. ODFL could play a much greater role in such educational reforms by sharing the burden schools face and helping to integrate responses to learners’ needs more effectively.

7. POSITIVE ACTION FOR TREATMENT ACCESS (PATA), NIGERIA

Background
Positive Action for Treatment Access (PATA) is a non-governmental organisation working to ensure that every individual has access to treatment education and every person can access qualitative, affordable, ethical and humane treatment. The organisation conducts advocacy, trains media and organisations and works to provide information for treatment literacy.

Links with health literacy
The organisation's objectives are to:

- promote access to treatment education;
- advocate for access to affordable qualitative diagnostic tests and drugs to treat HIV/AIDS;
- ensure non-discriminatory gender-based responses to HIV/AIDS prevention and treatment;
- support the full participation of people with HIV/AIDS in all responses;
- work in partnership with other persons and institutions including governments to facilitate information sharing and build platforms for networking;
- build capacity of people and institutions at all levels to ensure an increase in treatment access; and
- facilitate sector-wide HIV/AIDS prevention, testing and treatment of HIV/AIDS.

Lessons learnt
Objectives are met through a number of differing initiatives that cover a broad range of communication and advocacy strategies. Action can be taken in a variety of settings, including through varying educational systems, both formal and informal, through media, workshops, programmes, newsletters and other means. Examples include:

- The Frontiers Project – A programme designed to reach middle and upper class people living with HIV/AIDS, as most HIV/AIDS programmes in Nigeria focus on the economically poor.
- Media Education Project – PATA has developed a 10-episode Health Tip segment for a national network programme with over 30 million viewers and facilitated a
number of training workshops for Nigerian journalists. PATA also has a column in a leading Nigerian newspaper.

- Treatment Advocacy – PATA helps to keep treatment issues on the front burner of the HIV/AIDS agenda and help communities to understand what is available and can be strengthened.

- Resource Mobilisation Project – PATA has introduced a Buyers Club to help alleviate the financial burden of purchasing drugs for HIV/AIDS treatment. This aims to start a drug revolving fund for the purchase of tax-free drugs to help those who cannot afford the expensive drugs and/or have no access to free and/or subsidised government programmes.

- Public Education – PATA has been involved in a lot of treatment literacy programmes in health facilities and other support groups of people with HIV in various parts of the country. PATA has also given talks in churches, schools, Alumni associations and other clubs and societies. They have been involved with training staff of organisations on treatment literacy and HIV prevention.

- People for People Project (Stigma Fighter) – In June 2004, PATA conducted a training of 50 people from organisations and support groups on HIV/AIDS related stigma and discrimination, formulating a stigma fighter corps who made a commitment to challenge and address stigma and discrimination wherever they see it manifest.

- Positive Moments – PATA’s newsletter aims to fulfil the organisation’s vision of ensuring universal knowledge about HIV/AIDS and universal access to affordable, ethical treatment.

4.3 MEDIA MARKETPLACES

For many people media marketplaces—including print, radio, television, internet, mobile phones and public advertising spaces—are a main source of health information. These marketplaces shape people’s health perceptions, behaviours and choices even though they often contain information of variable quality that can be more confusing than helpful. Separating fact from fiction requires some well-developed health literacy skills. National health information services, like the NHS Direct in the UK (http://www.nhsdirect.nhs.uk/), can help people decipher the variety of health information. Some quality standards and certifications, such as the Health On the Net (HON) standards (http://www.hon.ch/HONcode/Conduct.html), have been developed for quality control of health web pages but have not yet been applied globally and have not been shown to make websites easier to understand.

Commercial and political interests often dominate the media marketplaces. Industries such as tobacco, alcohol and fast food companies use sophisticated communication techniques which glamorise and promote unhealthy products and lifestyles. Recognising and countering these negative health messages require literacy skills to distinguish credible, reliable and independent information from sales-driven product marketing and advertising.

Interventions

Increasingly, public health advocates and educators are using a wide range of technologies, media and social marketing approaches to get independent evidence-based information to stand out and shape people’s perceptions, choices and behaviours.

People need credible, reliable, accessible and understandable information so that they can avoid risky behaviours. This might be about lifestyle choices, mental wellbeing, the control of infectious diseases and environmental threats to health. Such information can help raise people’s understanding of risks, enable them to make healthy choices and counteract the negative influences of some industries. Interventions can also be used to shape the development of policies and structures that can protect health—for example smoking bans in public places.

This domain of health literacy activity has been a very active intervention area in all countries. Public information approaches which support health literacy are thought to provide a necessary basis for:

- informed decision-making
• understanding of bias and levels of evidence
• statistics and probabilities, and
• critical thinking skills

Ratzan (2001) points out that in designing effective and understandable health communications it is important that the context and content reflect the realities of people’s everyday lives and communication practices.

It is also essential to include the viewpoints and experiences of the target population in the design, implementation and evaluation of all interventions (IOM 2004).

Furthermore, health information that is developed from an interdisciplinary approach, which includes a variety of different health, education, social and cultural perspectives, is more likely to be effective, adopted and successfully diffused within individual communities (Allen 2001; Manderson 1999; Watters 2003).

Social Marketing

Social marketing uses marketing principles alongside socio-psychological theories to develop behaviour change programmes. It takes the planning variables from marketing (product, price, promotion and place—see Box 8 below) and reinterprets them for health issues. It seeks to address and adjust where needed the psychological, social and economic contexts that surround behaviour choices (NSMC 2007a; Hastings 2007\(^5\)). Social marketing approaches focus on the needs of well-defined consumer groups—a shortcoming of ‘traditional’ public health communication. A key principle is that if you try to reach everybody, you reach nobody.

\(^5\) Gerard Hastings’ book provides a series of instructive case studies, to which the reader is referred.
BOX 8 : THE ‘FOUR PS’ OF SOCIAL MARKETING

Product refers to something the consumer must accept: an item, a behaviour, or an idea. In some cases, the product is an item like a condom, and in other cases it is a behaviour such as not drinking and driving. Price refers to psychological, social, economic, or convenience cost associated with message compliance. For example, the act of not drinking in a group can have psychological costs of anxiety and social costs of loss of status. Promotion pertains to how the behaviour is packaged to compensate for costs—what are the benefits of adopting this behaviour and what is the best way to communicate the message promoting it. This could include better health, increased status, higher self esteem or freedom from inconvenience. Finally, place refers to the availability of the product or behaviour. If the intervention is promoting condom use, it is essential that condoms be widely available. Equally important to physical availability, however, is social availability. Condoms are more likely to be used when such use is supported and reinforced by peer groups and the community at large.

(Wallack et al. 1993, p22)

Edutainment

Educational entertainment approaches—so-called ‘edutainment’—have been shown to have a positive impact upon learning and action by target audiences. For example, studies indicate that discussions of immunisation on soap operas in some countries have actually increased the number of mothers seeking vaccinations for their children (Glik et al. 1998).
CASE STUDIES : MEDIA MARKETPLACE INTERVENTIONS

1. SOUL CITY, SOUTH AFRICA

Links to health literacy

Soul City, a non-governmental organisation (NGO), uses mass media campaigns to change health practices at the individual, interpersonal and community levels. The project used television and radio entertainment-education programmes that were broadcast nationwide. The television programme consisted of a 13-part

Soul City’s Violence against Women Booklet.
Soul City is a dynamic and innovative multi-media health promotion and social change project. Through drama (soap opera) and entertainment, Soul City reaches more than 16 million South Africans. For more information see www.soulcity.org.za.
drama, broadcast weekly on prime-time national television. The radio programme was a 45-part drama broadcast daily. These were supplemented by printed materials distributed nationwide through newspapers and a national advocacy strategy involving lobbying of government and decision makers.

The media campaign addressed issues in HIV/AIDS and youth sexuality, domestic violence and sexual harassment, hypertension, and small business development and personal finance.

**Impact:** Soul City entertainment-education broadcasts were received by more than 80% of the target audience; perceived as credible source of health-related messages; and effective in increasing health literacy, especially with reference to domestic violence and HIV/AIDS.

Specific findings include:

**Reach:** The television and radio programmes reached diverse audience segments in terms of education, age, sex and geographical location. Forty-two percent of the television audience and 54% of the radio audience lived in rural areas; 66% of the television audience and 67% of the radio audience were women; 38% of both audiences were youth aged 16-24; and 22% of the television audience and 26% of the radio audience had no formal schooling or some level of primary-level education only.

**Audience reception:** A qualitative assessment of focus group and interview responses in six sites revealed that the entertainment-education was perceived as a relevant, credible and entertaining educational vehicle. The audience members reported that the broadcasts conveyed constructive and pro-social modelling of attitudes and behaviours and showed plausible alternatives or coping strategies in realistic and familiar settings.

**Lessons learnt**

**Impact on creating a supportive environment:** The findings provided evidence that Soul City contributed to creating a supportive environment for facilitating behaviour change, particularly in the areas of domestic violence and HIV/AIDS. Soul City had impacts on lobbying, media advocacy and community mobilisation (e.g., public marches) that led to the successful legislation of the Domestic Violence Act in 1999. The findings pointed to synergetic effects of Soul City, such as the television and radio dramas’ positive impacts on the usage level of the Stop Women
Abuse Helpline and the AIDS helpline, and the enhanced communication between community leadership and their constituencies who used the television and radio dramas as common reference points.

**Impact on social and interpersonal environment:** The findings suggested that the Soul City entertainment-education contributed to the empowerment of local communities. It raised collective health consciousness, facilitated a sense of collective empowerment to effect change, facilitated collective action and the formalisation of community structures, reinforced social networks, and provided positive vision and hope for a better future.

**Impact on individual change:** The exposure to the Soul City entertainment-education was associated with the greatest improvement in knowledge and awareness of the Domestic Violence Act, condom use, community action against domestic violence, knowledge and awareness of where to find support regarding violence against women, and intention to do something to stop violence against women. There was no quantitative evidence of an impact on personal attitudes pertaining to sexual behaviour, sexual behaviour itself, and attitudes and subjective social norms around sexual harassment. The study concludes by discussing the factors that contributed to the positive outcomes of Soul City including: the multimedia format, the drama edutainment format, the synergy of multiple, mutually reinforcing intervention components, historical dealing with multiple issues, an understanding of the importance of collectivism, and a theory-based intervention strategy.

2. PROJECT RADIO, MADAGASCAR

Background

Implemented in 1999 by the Andrew Lees Trust (ALT), in collaboration with 71 local partners, non-governmental organisations (NGOs) and service providers, Project Radio is a rural radio communications network for development funded by the European Commission. The project aims to deliver education and information to isolated rural populations in the South of Madagascar via radio broadcast empowering rural producers, women and children who live in some of the economically poorest areas of the South. It strives to improve their food security, alleviate the effects of poverty and increase general standards of living.

Links to health literacy

According to organisers, over three-quarters of the rural population are illiterate and villagers have few means to learn how to improve their situation and reduce their economic and social vulnerability. However, Project Radio claims, aural learning traditions in Madagascar mean that the local people have a far greater capacity than Western audiences to listen to radio and remember details of key messages.

Using the media marketplace, the programmes on Project Radio reach approximately 900,000 people directly at a cost of less than one euro per head per year. They cover a range of topics including cattle rearing, animal husbandry, food security, farming, natural resource management, environment, healthcare, HIV/AIDS awareness, mother and child health, family welfare, education and culture. Since the project’s further expansion in 2006, an average of 30-40 new programmes are produced each month in local languages and distributed to 40 local FM radio stations in Tulear and Fianarantsoa Provinces, which broadcast the programmes in exchange for radio equipment. Villagers are able to listen to the programmes via Freeplay clockwork and solar-powered radios which the project places with village ‘responsables’. Listening groups are formed around these radios and are requested to participate in programme research, production and monitoring.

Lessons learnt

The overall conclusion of the research was that the project is achieving some notable success in changing and enhancing knowledge and attitudes on topics such as HIV/AIDS, family planning, mother and child health, environmental issues, social and administrative issues, and gender inequality. Radio is also reportedly having a positive impact on uptake of health services, enrolment in literacy classes, construction of environmentally-friendly woodstoves, tree-planting, agricultural yields, and awareness of strategies for poverty reduction through income generation and community associations.

3. RADIO APAC, UGANDA

Background
Launched in October 1999, Radio Apac is a community radio station broadcasting in northern Uganda that works to sensitise and educate residents of Apac about HIV/AIDS and other issues of importance to the community. Radio Apac was implemented by a partnership of the Commonwealth of Learning, an Apac-based non-governmental organisation (NGO) called Apac Sustainable Development Initiatives (ASDI) and members of the Apac community. Together they hope to improve the way and speed via which community members access and share information, as well as to improve the livelihood of Apac’s people through participatory initiatives that are inspired by its broadcasts.

How it fits in with health literacy
Through use of the media marketplace, Radio Apac has specific objectives that include:

- Support the community and stimulate rural development by facilitating access to information.
- Stimulate and create capacity-building within the community by providing access to local, national and international information services and resources.
- Import skills in information searching including the use of modern information technologies.
- Generate, record, broadcast and store local information and knowledge from resources available to the community.
- Conduct relevant training for building entrepreneurial skills of the women and youth in the community.

Lessons learnt
The station has learned the importance of engaging with the community in the production of programmes, holding research workshops to identify the broadcast information needs of communities. In an effort to reach as many community members as possible, its programmes are bilingual, multi-cultural and multi-ethnic, responding to the social and cultural needs of minority groups. Furthermore, the station recognises women producers and other minorities in the overall production of its programmes.
Initial programming was educational – including distance education for primary and secondary schools, adult literacy programmes, health education, nutrition based on traditional foods, AIDS awareness and farming practices. Programming has expanded to include agriculture, health, women and youth, environment, business, vocational training programmes and governance. Also, Radio Apac broadcasts programmes provided by Voice of America (VOA).

Further Information: Radio Apac’s partners are National Association of Broadcasters Uganda, Community Multimedia Center Network, World Association of Community Radio Broadcasters, AMARC Africa.


In post-modern society digitalized images and information can be more compelling than reality! Health literacy advocates need to capture the power of the media to help individuals and agencies improve their skills and capacities.
4. MOVING FAMILY PLANNING PROGRAMS FORWARD: LEARNING FROM SUCCESS IN ZAMBIA, MALAWI, AND GHANA. THE REPOSITIONING FAMILY PLANNING CASE STUDY SYNTHESIS REPORT

Background
As part of the Repositioning Family Planning Program, this 26-page evaluation report shares information from three case studies undertaken in countries that were identified as having been successful in increasing contraceptive use and lowering fertility – Ghana, Malawi and Zambia. The case studies found that the programmes were successful not just through supply-side interventions, but also through effective and innovative efforts on the demand side, including both working with the communities and bringing services closer to rural populations. Key messages were developed in consultation with the community to ensure that they were appropriate and meaningful.

Links with health literacy
As an evaluation of the family planning systems in Ghana, Malawi and Zambia, the report shows how each country reacted to an increased use of the media marketplace. In Zambia supply of services was increased and there was a strong emphasis on demand creation through a number of communication activities, such as creation of a family planning logo and radio and television programmes. The TV and radio campaign was particularly successful and the report shows that 24.4% of listeners of any radio programme were currently using family planning compared with only 11.9% of non-listeners. In Malawi, the Contraception Prevalence Rate (CPR) increased from 7% to 26% between 1992 and 2000, across the economic spectrum. On the demand side, communication in many languages was used, such as radio jingles, posters, dramas, health talks and community based activities, flooding Malawi with information, education and communication (IEC) messages developed through community consultations. Under the Ghana Family Planning and Health Program (1991-1996) IEC activities addressed constraints including widespread myths, rumours and health fears. Then in 2001 the Ghana Health Service launched the Life Choices behaviour campaign to reposition family planning in people’s minds and dispel rumours about methods. The campaign gave people the knowledge and tools to see that family planning was directly related to their lives and their personal aspirations for a better future. Vans that brought information, materials and songs moved throughout the country. Nearly 7 out of 10 men and half of the women interviewed in 2003 reported
that they had heard the key slogan of the campaign - “Life choices: It’s your life, it’s your choice.”

Lessons learnt

The evaluation highlighted the importance of addressing the demand side of family planning through effective IEC. Communication activities helped to bring about a shift from seeing family planning as not only a way to limit the number of children (which often led people to associate family planning with not having any children at all) to seeing it as a way to space births and improve the health of women and children. The high levels of knowledge of family planning in all three countries demonstrate that IEC can be effective even in settings with low literacy. Exposure to IEC messages was associated not only with increases in knowledge but also with changes in behaviour, such as increased use of modern contraception. The report concludes that to develop appropriate messages, it is essential to consult the community.

5. ANDREW LEES TRUST, IMPACT EVALUATION OF PROJECT RADIO SIDA, MADAGASCAR

Background
Since 2003, the Andrew Lees Trust (ALT) has collaborated with the National HIV AIDS Awareness Committee of Madagascar (Comité Nationale Lutte contre le SIDA - CNLS) to deliver HIV information via radio to rural populations in southern Madagascar. ALT also distributed 2,000 radios for the CNLS across the Provinces of Toliara and Fianarantsoa, setting up dedicated listening groups to receive national broadcasts about HIV/AIDS as well as locally produced radio programmes on the subject. According to the organisers, explaining complex medical issues to an illiterate audience is challenging, particularly in this region where traditional beliefs attribute illnesses to spirit possession.

Links to health literacy
This project aims to open up the media marketplace by producing radio programmes about HIV/AIDS and creating increased access to radios in the first place. An evaluation of the project found that radio is the most important source of information on HIV/AIDS in Madagascar. During the evaluation, radio was mentioned by 89% of the respondents as most important. Amongst the urban population, 96% mention radio; in rural areas, the percentage is slightly lower at 82%. In addition, 71% of the participants mentioned having heard a radio programme on HIV/AIDS made by Project Radio.

Lessons learnt
The evaluation also found that the programme increased knowledge of three modes of transmission of HIV. Of those surveyed, 75% mentioned both sexual relations and blood, 96% mentioned sexual relations and 78% mentioned blood as methods of transmission. Only 38% mentioned mother-to-child transmission. The survey also found that some false beliefs on transmission continued to be held, the most frequent being transmission by mosquitoes (15%). Also, some people still feared transmission through water or through sharing of clothes.

The evaluation also indicated sound knowledge of methods of prevention. Of the respondents, 77% mentioned both using condoms and being faithful, 95% mentioned using condoms, 81% mentioned being faithful and 28% mentioned abstinence. Furthermore, the evaluation suggests that programmes on stigma and discrimination have a major impact on attitudes towards people living with HIV and
AIDS (PLWHA). It states that people’s first reaction is to isolate and make public the identity of PLWHA, as the community is considered more important than individuals. According to the organisers, after hearing a programme on stigma and discrimination, attitudes changed very fast.


Knowledge of how HIV is transmitted from mother to child may help in the prevention of disease.
6. ALAM SIMSIM OUTREACH PROGRAM, EGYPT

Background

The Alam Simsim Outreach Program is a collaboration between Al Karma Productions (Cairo, Egypt) and Sesame Workshop (New York, USA). Alam Simsim is a multiple episode, half-hour television series, designed to provide children with an opportunity to learn a broad range of literacy, numeracy, cognitive and social interaction skills, using humour, music, fantasy and daily life situations. It is the Egyptian adaptation of the educational television series Sesame Street. Alongside the TV series is an outreach initiative, launched in December 2002, providing parents and caregivers with information about improving the health, hygiene and nutrition of their children. Working closely with local community development associations (CDAs), the outreach team developed a 2-month training component, as well as educational materials for parents and children (such as booklets, flash cards and a healthy habits calendar).

Links with health literacy

The media marketplace was used here to reach children with an educational system in place to back it up. In brief, evaluators found that “both parents and children benefited” from the outreach programme, in that it “had a significant impact on health, hygiene and nutrition practices.” While there was evidence of positive changes for many families, routines requiring commercial items such as toothbrushes were beyond the means of the poorest households. Notably, some families with limited economic means engaged in effective alternative practices such as brushing teeth with fingers. In terms of hygiene the outreach programme had a measurable impact. For example, exposure to the outreach programme was related to reported increases in the frequency of making sure that children washed their hands before eating (a gain of 5% over the control group) and washing face with soap and water (a gain of 15% over the control group). However again, financial circumstances confronting some families can be crucial considerations in the design of future training and outreach programmes. For example, researchers found that “not all parents could afford the additional expenses of separate towels, toothbrush and toothpaste, and having salad, fresh fruits and milk regularly.” They recommended that the Alam Simsim outreach programme continue to model a variety of strategies, including ones that are most affordable and accessible.
**Lessons learnt**

Important health knowledge and behaviours increased after participation in the programme. For example, 32% more parents and caregivers with the experimental group (those exposed to the outreach programme) demonstrated knowledge of the Diphtheria, Pertussis (Whopping Cough) and Tetanus (DPT1) vaccine, whereas knowledge levels of DPT1 remained relatively unchanged within the control group.

Further Information: This outreach initiative reached approximately 10,600 parents, teachers and other caregivers in Minya, Beni Suef and Cairo governorates between April 2003 and January 2004.

4.4 HOME AND COMMUNITY SETTINGS

People are called upon to make daily health-related decisions in their homes and communities. Families, friends, peers and community resources are key sources of health information. These sources model behaviours and shape the early and continuing development of functional health literacy skills related to product and service choices. They also provide basic information about health-promoting, health-protecting and disease-preventing behaviours, as well as self- and family care, ‘alternative therapies’, available support services and first aid.

4.4.1 Challenges

Chronic diseases

According to WHO (cited in Pruitt and Epping-Jordan 2005), chronic diseases—for example diabetes, emphysema, heart disease and cancer—currently account for more than half of the global disease burden in both developed and developing countries. People with chronic diseases have more health literacy demands, such as the need for self-management (see below), the need to coordinate care with multiple providers and the ability to manage multiple, lifelong prescription medications. These people, however, often have poorer health literacy skills.

Patients with chronic diseases and limited health literacy have been shown to have poor knowledge of their condition and of its management. They also experience difficulties with oral communication. A study of patients with diabetes found that poor health literacy was associated with worse blood sugar control and higher rates of complications such as retinopathy, blindness, heart disease and strokes (Schillinger et al. 2004; Williams et al. 1998a, 1998b).

WHO and several international health professional associations have called for major changes in health workforce training to develop the provider skills required to meet the health literacy and other needs created by the prevalence of chronic illness. Skills called for include the ability of providers to support self-managed care, build more partnership-based provider–patient relationships and communicate more effectively (Pruitt & Epping-Jordan 2005).

Self management

In the past, patient health management was primarily the physician’s responsibility. However, in many health systems people are increasingly encouraged to take more responsibility for their own health. To make appropriate self-management decisions,
people must locate health information, evaluate the information for credibility and quality and analyse risks and benefits. Furthermore, people must be able ask pertinent questions and express health concerns clearly by describing symptoms in ways the providers can understand (IOM 2004).

Moreover, people are increasingly challenged to make sound health decisions in many contexts of daily life. For example, they have to read and understand product labels and warnings; make lifestyle choices about food, activity, cigarettes and drugs; and evaluate the safety of chemicals in products they buy. Such decision making requires an understanding of the benefits of being healthy and information about personal health issues. All of these everyday demands require people to be able to assess their current health and consider and deal with the many socioeconomic factors and cultural values that influence it. For all this they need to have health literacy competencies that allow them to take responsibility for their own and their family’s—and, where necessary, their community’s—health (Kickbusch & Maag 2008).

Finally, many people use alternative therapies. This includes traditional healing approaches, nutritional supplements, acupuncture, homeopathy and a wide variety of other therapeutic and healing techniques. The estimated global market for such interventions equals or exceeds allopathic health care markets in many countries. The need to make choices between alternative approaches and standard medical care creates further challenges.

**Community participation**

Community participation aims to identify, shape and advance shared interests in priority issues for community health. This might be investment in education for self-care, increased penetration of vaccinations, elimination of vectors and control of sexually transmitted diseases. Investment in such participatory health literacy skill development can help individuals use systems more effectively and also serve as catalysts for change, when needed, within systems (IOM 2004).
CASE STUDIES: COMMUNITY INTERVENTIONS

1. PALLITATHYA HELP-LINE CENTRE, BANGLADESH

Launched by Development through Access to Network Resources (D.Net), Pallitathya uses mobile phones to both increase access to information for people living in Bangladesh’s rural areas and to create economic opportunities for underprivileged women.

Links to health literacy

This initiative uses face-to-face contact and information and communication technologies (ICTs) to provide information about services such as:

- directory services: basic information about location, availability and cost of health, legal support and agricultural services;
- education information services, such as admission deadlines in different educational institutions; and
- emergency information dissemination services about disease outbreaks, violations of human rights and other natural disasters.

Pallitathya employs ‘Mobile Operator Ladies’ to go from door to door with a mobile phone. Villagers can ask questions about their livelihood, agriculture, health, legal rights, and so on anonymously. The questions are answered by help desk operators at D.Net’s headquarters in Dhaka, who are equipped with a database and the internet. While the service is offered to both men and women, a key strategy involves using technology to increase women’s access to information and economic opportunity. Women were given a crucial role as ‘infomediaries’ in an effort to increase their self-worth, their potential to earn and their knowledge about various issues.

The Pallitathya Help-Line Centre was developed after findings showed that a lack of timely and relevant information was a major bottleneck to rural development and a leading factor in the exploitation of the underprivileged, particularly women.

D.Net notes that there is “disproportionate hype around using computers and Internet for tackling issues of economic deprivation and social injustice”, due to a lack of adequate infrastructure, internet penetration and the inability of many Bangladeshis to use these tools. In contrast, the mobile phone has a 60% geographical coverage in Bangladesh. The help-line is designed to bridge these various information gaps.
Lessons learnt

Among the four villages chosen for the research phase, the village which had the lowest income level and was the most remote was the most active in terms of making calls to the help-line. Furthermore, housewives were the biggest user-group, perhaps because they are the most deprived in terms of access to information. Finally, the research project found that most queries were in the areas of health (majority of which came from housewives) and agriculture (majority of which came from farmers).

2. Societies Tackling AIDS through Rights (STAR)

Background

Operating in Angola, Bangladesh, China, Ethiopia, Gambia, Ghana, India, Liberia, Malawi, Mozambique, Nepal, Nigeria, Sierra Leone, South Africa, Tanzania, Uganda, Vietnam, Zambia and Zimbabwe, Societies Tackling AIDS through Rights (STAR) is designed to be a comprehensive, integrated methodology which combines the strength of participatory learning about HIV and AIDS with empowerment and social change. It focuses on relationships and communication skills with the intention of reducing HIV transmission, improving sexual reproductive health (SRH) and fostering gender empowerment. This is combined with an approach to adult learning that seeks to enable people to plan their development activities based on the local reality. According to the organisers, the STAR methodology evolved from two participatory approaches: Stepping Stones (SS) and REFLECT (Regenerated Freirean Literacy through Empowering Community Techniques). SS is a participatory learning package that focuses on relationships and communication skills with the aim of reducing HIV transmission, improving SRH and fostering gender empowerment. REFLECT is a structured participatory learning process that facilitates people’s critical analysis of their environment, as well as the identification and discussion of problems, resulting in practical solutions relevant to the local context.

Links to health literacy

The STAR approach seeks to address misinformation or lack of information on HIV/AIDS issues and fragmented responses. It is also designed to address issues of gender equity and break barriers to communication by enhancing the capacity of individuals to open up and talk about sensitive issues. The process includes identifying specific actions, for example demanding appropriate information and services from service providers. Some of the actions are intended to be self challenges to the participants themselves, especially around customs and stigma which are considered to fuel the epidemic.

The approach is also designed to strengthen the literacy and communication of vulnerable people, especially women and girls, giving them skills to negotiate, open up dialogue within the household and community and participate in taking decisions. It also intends to help increase the capacity of the economically poor and people living with HIV to advocate for their priorities, particularly around HIV/AIDS, for example, demanding increased access to testing and affordable treatment.
Lessons learnt

In order to facilitate this process, the project included the training of community facilitators and community-based organisations, especially women’s groups, in policy advocacy and rights-based approaches to communication and mobilisation. Methods such as drama, role play and community dialogue were used. According to the organisers, there was systematic and continuous data collection, analysis, learning, documentation, publications and sharing to wider actors to help scale up the approach. Part of the strategy was to facilitate linkage between STAR programmes and other community-based organisations to create mass mobilisation to interact with local government and institutions.


The internet and other media marketplace information sources shape people’s health perceptions, choices and behaviours and can have positive and negative impacts on people’s health literacy.
3. MATERNAL AND NEWBORN CARE PRACTICES AMONG THE URBAN POOR IN INDORE, INDIA: GAPS, REASONS AND POTENTIAL PROGRAMME OPTIONS

The Urban Health Resource Center (UHRC) identified interventions to strengthen maternal-newborn care practices and care of infants aged 2-4 months (feeding practices, morbidity status, immunisation status, and nutritional status) in urban slum dwellings of Indore city, Madya Pradesh (India). The recommendations are based on findings from a study carried out by UHRC between December 2004 and February 2006 in 11 out of 79 slums where its Indore Urban Health Program has been operational since April 2003.

Links to health literacy

The methods used in this research include interviews with mothers of infants 2-4 months old, with mothers of low birth weight infants who were thriving, and slum-based traditional birth attendants (TBAs); assessment of cold stress, hypothermia and associated danger signs in newborns; assessment of under-nutrition amongst infants and newborns; and group discussions (GDs) with citizen-based organisations (CBOs) and mothers of infants. Also discussed in this report are reasons for following these practices, what facilitates and what hinders following optimal practices, and potential programme options for their improvement.

Lessons learnt

Strategies for supporting mothers and newborns through antenatal care in their home and community settings include:

- Enable families to perceive the benefits of appropriate antenatal care practices through persuasive reinforcement of optimal practices by trained slum-based CBOs and involving early adopters as change aides in group meetings/home visits. Early adopters include a progressive early adopter/relative/neighbour/an elder lady of the community.

- Encourage families and/or pregnant women to join a health savings fund group from which they can draw money if needed for health care.

- Train ‘Basti’ Community-Based Organisations (BCBOs) through pictorial and group discussion, accommodating literacy issues, to monitor behaviours of mothers and assess their progress.
• Establish ‘outreach camps’ for individual appointments, particularly in the evenings, and group discussions. Attempt to partner with private medical providers when possible to increase confidence in outreach camps.

• Refresher training for BCBOs and TBAs, related to resuscitation; cutting and tying the cord tie; and thermal protection.

Strategies for supporting mothers and newborns through postnatal care include:

• Health volunteers trained in lactation-related counselling to support and encourage mothers;

• Providing the BCBOs with pictorial material that can enable them to: a) counsel and conduct post-natal visits; and b) maintain records of mothers;

• Specific strategy for mothers who migrate to native villages for delivery, perhaps a take-home pictorial card or poster and persuasive counselling;

• Strengthening of linkage of community with affordable public and private hospitals that are already accessed by slum dwellers.

4. A COMMUNITY-BASED HEALTH EDUCATION PROGRAMME FOR BIOENVIRONMENTAL CONTROL OF MALARIA THROUGH FOLK THEATRE (KALAJATHA), INDIA

Background
Kalajatha is a popular, traditional art form of folk theatre depicting various life processes of a local socio-cultural setting. It is an effective medium of mass communication in the Indian sub-continent, especially in rural areas. This method can be used to carry out a community-based health education programme for bio-environmental malaria control.

Links to health literacy
In India there is no standard format for delivering health education messages on malaria and conventional methods have limited impact. Thus, Kalajatha has been used experimentally as a medium of mass communication to assist the malaria control programme, in community settings. In December 2001, the Kalajatha events were performed over two weeks in a malaria-affected district in Karnataka State, southern India. Thirty local artists, including ten governmental and non-governmental organisations (NGOs), actively participated. Local scriptwriters were involved, writing songs and rupakas (musical dramas) on aspects of malaria, including signs and symptoms of sickness, treatment, health facilities, processes of transmission, role of anopheles mosquitoes and names of the malaria vectors and the breeding grounds of mosquitoes. The role of the community was also a key part of the scripts. Local media followed up with reporting on the events and key messages.

Lessons learnt
Impact assessments held in the focus villages and a random group of villages using semi-structured interviews showed that respondents had significantly gained information and knowledge about malaria, its symptoms, transmission and control methodologies. Although immediate behavioural changes especially in maintenance of general hygiene were not observed, follow up control measures by authorities built on the community’s acceptance to bring about needed behavioural changes.

5. ‘TB CLUBS’, ETHIOPIA

Background
TB clubs were initially formed when, in an effort to simplify organisation, health services requested that TB patients living in a particular kebele come to follow-up appointments at the nearest health facility together and on the same day. As a result, the patients got to know each other and began to form TB clubs. The District Medical Officer promoted the development of the TB clubs and provided advice on organisational arrangements.

Links to health literacy
The success of the project can be attributed to community participation. This is described as the process by which individuals and families assume responsibility for their own health and welfare, and for those of the community, and develop the capacity to contribute to their and the community’s development. The TB club approach makes the patients the principal actors in TB control efforts and shows that even in a remote rural area, and using long-course treatment, high treatment success rates are achievable through a district TB control programme with community involvement and committed leadership. The members of each TB club elect a leader, who is usually literate, who ensures that all members attend the TB clinic on the appointed day and informs the clinic staff if a member is absent. The leader co-ordinates regular meetings of the TB club at least once a week to provide support for each other in adhering to treatment, to share information about the course of the disease and possible drug side-effects, and to help in identifying tuberculosis suspects. They then refer tuberculosis suspects and tuberculosis patients failing to make satisfactory progress or suffering from drug side-effects to the local health facility. The leaders may approach other members of the community for help with encouraging and supporting patients to complete their treatment. The District Medical Officer has supplied the TB club leaders with educational materials written in Amharic, the main language of the region. Members of the TB clubs exchange information on tuberculosis with community members through role-playing and public reading and dissemination of educational materials. Local health workers and community health agents supervise TB clubs regularly and contribute to community education activities and the identification and referral of tuberculosis suspects.
Lessons learnt – Findings

According to a report from 2000, the proportion of tuberculosis patients who came for follow-up during treatment at health facilities significantly increased after the introduction of the TB clubs. The TB clubs referred 181 tuberculosis suspects in the community for investigation, of whom 65% subsequently had a positive diagnosis for tuberculosis. TB clubs identified 69% of all patients and 76% of new sputum smear-positive pulmonary patients diagnosed in the district. Treatment success rates in new sputum smear-positive, smear-negative and extra-pulmonary tuberculosis patients were 83%, 79% and 81% respectively. In 1996 other success rates reported in Ethiopia ranged between 35% and 72%.

Further Information: Although TB clubs do not incur any extra costs from the perspective of the health service provider, an economic analysis is necessary to assess whether the patients incurred any financial costs. Further evaluation of the contribution of the community to tuberculosis control activities in rural Ethiopia through the TB club approach is needed to assess the sustainability of the approach and its feasibility in other settings.

6. LIVERPOOL’S CHALLENGE, UK

Liverpool, like many UK cities, has seen a significant rise in obesity in recent years. In the city, an estimated 40% of the adult population is overweight and 20% obese. It is estimated that obesity results in over 130,000 sick and costs the National health Service and the city’s wider economy an additional £20m a year.

Liverpool PCT launched its Healthy Weight: Healthy Liverpool strategy in April 2008, with the objective of stopping and ultimately reducing the level of obesity in the city from 2010. Liverpool’s Challenge, devised and managed by Liverpool Primary Health Care Trust’s social marketing team, is a strand of that long-term strategy.

The team commissioned extensive qualitative research into the target audience in order to develop an insight into their everyday lives and understand the motivations and barriers to adopting healthy eating and exercise practices. The insights developed from analysis and interpretation of the research showed that people wanted to lose weight and become more active but struggled to change their habits. They needed support – not only in practical terms but in feeling that they were not alone.

And so Liverpool’s Challenge was created – an innovative challenge to residents to pledge to lose one million pounds of weight. A pre-launch ‘teaser’ campaign with the strapline ‘We’ve got one million pounds to lose’ generated curiosity prior to the launch and saw local radio stations holding on-air discussions to guess what the advertisements meant. In September 2008 all was revealed and Liverpool’s Challenge launched with a media campaign that created high levels of awareness and a sense of something ‘big’ happening in the city.

Links to health literacy

The project used a community wide initiative to bring a positive framing to weight loss and make information, support and system navigation easier and more enjoyable for all. The ‘Million Pound Tanker’, a converted milk tanker, provided the focus for the launch event and was a mainstay of the campaign, taking the message out to local people as it toured the city. Inside the tanker, visitors were met by a receptionist and given a goodie bag before meeting with a health professional to have their Body Mass Index measured and receive free, confidential lifestyle advice. Outside the tanker in the ‘Active Zone’, ‘Live Zone’ and ‘Food Zone’, community food workers gave cookery demonstrations and handed out food samples and cookery books, while fitness instructors showed how to use fitness equipment and handed out vouchers for free...
gym or swim sessions. Each community event was run by people from within the community, such as health trainers and community food workers, and featured a wide range of performances by local community groups from armchair exercises to free-running and yoga.

Liverpool Primary Health Care Trust’s social marketing team negotiated partnerships with key local media outlets. Local celebrities lent their support throughout, attending ‘tanker’ events, providing quotes for the press and attending photocalls. The campaign has advertised in Boots stores (Chemists), GP surgeries, job centres, community centres, cafes and other public venues to keep the Challenge at the front of the public’s minds. The frequency of the campaign was increased in areas of the city with high prevalence of obesity.

**Lessons learnt – Initial outcomes**

The collective nature of the challenge helped people to feel that they were joining a club of like-minded people. Residents signed up in their thousands, with 1,500 pledging in the first week and the website receiving 50,000 hits. The campaign is ongoing and will be fully evaluated in early 2010, but interim evaluation shows that at the halfway point it has exceeded its interim targets, with more than half a million pounds pledged by February 2009. Research shows high levels of local awareness, with 13% spontaneous awareness in January 2009 (compared with Weight Watchers 3%), 72% visually-prompted awareness and 58% of participants claiming to have lost weight in December 2009.

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4.5 WORKPLACE SETTINGS

The workplace directly influences the physical, mental, economic and social wellbeing of workers and, in turn, the health of their families, communities and society. It offers an infrastructure to improve health literacy through educational and health promotional interventions.

By providing clear and consistent health messages to employees, employers can help prevent accidents and lower the risk of industrial or occupational diseases. Health-promoting work environments go further, with specific health and wellbeing policies and dedicated support for employees to address lifestyle choices, such as alcohol and drug use, and stress factors, including job security, demand—control, effort—reward in the workplace and issues related to achieving an appropriate work—life balance.

Workplace health promotion

WHO (2008) has defined workplace health promotion as the combined efforts of employers, employees and society to improve the health and wellbeing of people at work. It places particular emphasis on improving the work organisation by increasing workers’ participation in shaping the working environment and encouraging professional development.

Workplace health promotion focuses on a number of factors, such as the promotion of healthy lifestyles and non-occupational factors in the general environment. Non-occupational factors include family welfare, home and commuting conditions, and community factors (and risks) which affect workers’ health.

While some health promotion activities in the workplace tend to focus on a single illness or risk factor (for example, HIV/AIDS or heart disease) or on changing personal behaviours (for example, smoking and diet), there is growing appreciation that there are multiple determinants of workers’ health. In addition to person-focused interventions, workforce health promotion initiatives have moved toward a more comprehensive approach, which goes beyond safety issues and acknowledges the combined influence of personal, environmental, organisational, community and societal factors on employee wellbeing.

WHO has introduced the concept of the health promoting workplace (HPW) as an integrated way of paying proper attention to workers’ health and safety. HPW programmes aim to:
• Help workers make healthier decisions and choices for themselves and their families;
• Reduce workplace-related health risks;
• Enhance awareness and action regarding protecting health from work-related environmental factors (e.g. pollution control);
• Influence occupational health and safety programmes so they help reduce worker and community risks;
• Use the workplace setting for medical diagnosis, health screening and assessment of functional capacities; and
• Link with other community-based activities related to major diseases (e.g., HIV/AIDS, heart disease) as part of larger disease prevention and control strategies. (WHO 2008)
CASE STUDIES: WORKPLACE INTERVENTIONS

1. PREVENTING HIV/AIDS ON ROAD PROJECTS IN CHINA

The Baolong Healthy & Safe Action (BHSA) Project was designed by the Asian Development Bank (ADB) and implemented in Yunnan Province of the Peoples Republic of China (PRC) on the border of Myanmar.

Links to health literacy

Recognising the HIV risk that the Baolong Highway construction project potentially posed to local communities and construction workers, this project integrates a package of health interventions including: behaviour communication change (BCC) strategies, condom social marketing, advocacy, community mobilisation and HIV prevention.

The project sought to reach over 20,000 construction workers in villages and townships along the highway to help prevent HIV/AIDS spread during the construction phase. It was hoped that this strategy could be shared and adapted to other highway construction projects in PRC and elsewhere in the region.

Partnerships were developed with a range of stakeholders. For example, the Bureau of Culture supported film nights in construction sites and local communities; the media communicated HIV and project-related messages through radio, television and newspapers; communication companies developed new strategies such as sending short text messages to highway construction workers; local villages and community-based organisations provided peer educators in entertainment sites and social mobilisers in villages along the highway.

The findings

In the first year of implementation the project has reached over 2,000 people for the first time, 900 people in one-to-one peer education, and over 20,000 people in group and community events. In addition, the Project trained over 300 people to be peer leaders and educators and sold or distributed for free over 80,000 condoms. The findings of the follow-up survey, which was conducted in August 2006 to evaluate impact after the first year of implementation, showed the project had limited impact on changing the behaviours of drivers.
Lessons learnt

The BHSA project found that those who are at most risk of HIV are middle managers, evaluators, subcontractors and drivers, all of whom have more disposable income, are more mobile and are more likely to need to socialize and impress their work colleagues. With the exception of drivers, these populations also have more education and knowledge about HIV/AIDS issues but nevertheless reported higher risk behaviours. This emphasises the need for HIV prevention messages to go beyond knowledge and address attitudinal and behavioural change through compelling motivational messages, address issues of peer pressure, and develop skills that support behaviour change.

2. ADHERENCE TO ANTIRETROVIRAL THERAPY IN ADULTS: A GUIDE FOR TRAINERS, KENYA

Background

This training manual was developed for the Antiretroviral Therapy Program in Mombasa, Kenya by the Horizons Program of the Population Council, the International Centre for Reproductive Health and the Coast Province General Hospital, Mombasa. It consists of four modules to be conducted over four sessions of approximately two hours each.

Links to health literacy

Used in workplace settings this manual aims to provide trainees with a basic understanding of the challenges of Highly Active Anti-Retroviral Therapy (HAART) and adherence to antiretroviral therapy. It is designed for health workers including physicians, clinical officers and adherence nurse counsellors in antiretroviral (ARV) programmes.

The first module provides a background on adherence to ART and is relevant for all health workers involved in ART service delivery. Modules two, three and four provide detailed adherence management of a patient on ART designed for adherence nurse counsellors. Physicians in particular would benefit from attending the session on Module Two. The objective for each session is given at the beginning. The methodology, the materials required, the expected duration and the handouts are given in the margin at the beginning of each exercise. Handouts for the training use actual patient literacy materials, counselling checklists, pill charts and medication demonstration charts being used in the Mombasa ART programme.

Topics include:

- Preparatory Adherence Counselling;
- Patient Preparation for Adherence;
- The Multidisciplinary Adherence Team;
- HIV Infection and Antiretroviral Treatment;
- Strategies and Tools to Enhance Adherence.

The manual uses different techniques in these modules: brainstorming, small group discussion, Power Point presentations, case studies and role-play. Brainstorming, small group discussions and interactive sessions provide an opportunity for a large number of participants to share their views. Power Point presentations are useful in
providing participants with the theory and background on the topics being discussed. Case studies help participants discuss and understand the issues in a practical way. Role-play provides practical training in developing adherence-counselling skills.

_Further Information: The manual is published by Horizons/Population Council and International Centre for Reproductive Health, Coast Province General Hospital, Mombasa._

_See http://www.comminit.com/en/node/184430 for more information._
4.6 POLICY-MAKING ARENAS

Policies at all levels—institutional, community, national and regional—shape the factors which determine health literacy and health. The engagement of citizens in policy-making processes is a fundamental democratic principle. Furthermore, a key trend in many health system reforms is empowerment of patients and the development of more patient-centred care. To function effectively in politics and policy-making, people need the ability to advocate for policy change; be active citizens (for example, have a vote); be knowledgeable about health rights and responsibilities; and be able to participate in health organisations.

Challenges

Financial crisis

The world is confronting a severe financial crisis at a time when it is also facing major energy and environmental problems and wide social inequalities. While the crisis has global roots, its impact is already being felt unequally between regions and countries (WHO 2009). Many experts point to long-lasting consequences for health all over the world. The crisis may lead to an opportunity to trigger significant changes in social norms, lifestyles and health-related behaviours or it could lead to a widening of social inequalities and further health literacy disparities.

Social determinants and health inequities

The Commission on the Social Determinants of Health (CSDH 2008) makes a strong case for the root causes of health and health literacy inequities as being based on structural societal factors, such as income differentials, lack of social protection or universal health care access. They call for society-wide action to address these factors and to reduce differential exposures to risks, differential vulnerabilities to both acute and chronic disease, and differential outcomes of care that poorer people in every country experience on a socially determined gradient. This social health gradient means that each successive social class is worse off with regards to their health than the class just above them.

Numerous studies (see section 2 above) demonstrate that poor health literacy skills are associated with a wide variety of negative health outcomes. Furthermore, studies point to clear social class differences in health literacy skills (Kickbusch et al. 2008). The CSDH does not deal directly with the issue of health literacy in their report. The relationship of health literacy to socially determined inequities is an important area for further study. This guide sees health literacy as a differential capacity that
results from the same structural factors which the CSDH identifies as underpinning all other health inequities.

Enhancing health literacy and improving the health literacy friendliness of key sectors and settings may help address some of the differential health outcomes of poorer people. Importantly, in the process of addressing health literacy needs of individuals in key societal ‘domains of influence’, greater awareness of the underlying causes of health inequities will emerge and with it broader support and advocacy action for the societal changes being called for by the CSDH.

**Advocacy**

This guide sees advocacy as an important part of the health literacy skills continuum. Advocacy, as discussed here, applies mainly to policy changes in systems. These ‘systems’ include any institution, community, citizen group, association or agency, governmental or non-governmental, public or private, national or international, that can influence individual and community health.

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**BOX 9 : A DEFINITION OF ADVOCACY**

(Alpfe 2008)

Blending science, ethics and politics, advocacy is self-initiated, evidence-based, strategic action that people can take to help transform systems and improve the environments and policies which shape their own and others’ behaviours and choices, and ultimately their health.

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**A note of caution**

The recommendations in this section of the guide focus on advocacy approaches in democratic countries. Advocacy assumes that people have rights and that these rights are enforceable: for example, the right to voice opinions openly as well as the right to adequate health care, pollution-free environments, employment and housing. Advocacy often focuses on ensuring that these rights are exercised, respected and addressed. Advocacy approaches are potentially effective only in political environments where:

- policy-makers can be influenced by public opinion; and/or
- governments can and do take action to protect the rights of their citizens; and/or
there is an open and free media through which people can express themselves/find a voice (Sen 1990).

Where these public freedoms do not exist, the most effective way of changing policy may not be through direct advocacy. It may require action from outside the country, from international agencies, and from actual and potential economic partners, as for example during apartheid in South Africa (Sida 2005). Anyone advocating for change in undemocratic environments may be putting themselves at risk and are advised to take a strategic, long-term perspective and, where possible, strengthen links with appropriate international advocacy groups.

The ICN Guide to Health Professional Advocacy is included as an annex to this report.
CASE STUDIES: POLICY INTERVENTIONS

1. NORTH KARELIA PROJECT: FROM DEMONSTRATION PROJECT TO NATIONAL ACTIVITY, FINLAND

The North Karelia Project was launched in Finland in 1972 in response to the local petition for help to reduce the burden of exceptionally high coronary heart disease mortality rates in the area. In co-operation with local and national authorities experts, as well as with WHO, the North Karelia Project used interventions involving health and other services, schools, NGOs, innovative media campaigns, local media, supermarkets, food industry, agriculture, etc.

The Project included a comprehensive evaluation and has acted as a blueprint for other national and international interventions. Over the years the scope of the project has been broadened to include other major non-communicable diseases and health promotion, as well as prevention of risky lifestyles in childhood and youth.

Main results

The published results of the North Karelia Project show how over the 25-year period major changes have taken place in the levels of target risk factors in North Karelia. Among the male population in North Karelia, smoking has greatly reduced and dietary habits have markedly changed. In 1972 52% of middle-aged men in North Karelia smoked. In 1997 the percentage had fallen to 31%.

In the early 1970s, use of vegetables or vegetable oil products was rare; now it is common. In 1972 about 90% of the population in North Karelia reported that they used mainly butter on bread. Today it is less than 7%. The dietary changes have led to about 17% reduction in the mean serum cholesterol level of the population. Elevated blood pressures have been brought well under control and leisure time physical activity has been increased.

Among women, similar changes in dietary habits in cholesterol and in blood pressure levels took place. At the same time, however, smoking somewhat increased, but from a low level.

By 1995 the annual mortality rate of coronary heart disease in the middle-aged (below 65 years) male population in North Karelia has reduced about 73% from the pre-programme years (1967-71). This reduction was especially rapid in North Karelia in the 1970s and again after the mid 1980s. During the last ten years the decline in cardiovascular (CVD) mortality in North Karelia has been approximately
8% per year. Among women, the reduction in CVD mortality has been of the same magnitude as among men.

**Conclusions**

The results of the North Karelia Project show that a well-planned and determined community-based programme can have a major impact on lifestyles and risk factors. This, in turn, leads quite rapidly to reduced cardiovascular rates in the community. Furthermore, it demonstrates the strength of community-based approaches in changing people's risk factors as well as giving practical experience in organising such activities.

The experiences also actively helped inform comprehensive national action with good results. The decline in heart disease mortality in Finland during the last few years has been one of the most rapid in the world and the overall health of the adult population has greatly improved.

*For more information see [http://www.who.int/hpr/successful.prevention.6.shtml](http://www.who.int/hpr/successful.prevention.6.shtml).*
2. SOUTHERN AFRICA HIV AND AIDS INFORMATION DISSEMINATION SERVICE (SAFAIDS)

Background
Established in 1994 and operating in Angola, Botswana, Lesotho, Malawi, Mauritius, Mozambique, Namibia, South Africa, Swaziland, Zambia and Zimbabwe, SAfAIDS is a regional non-profit organisation based in Harare, Zimbabwe. It works to promote ethical and effective development responses to HIV/AIDS through knowledge management, capacity development, advocacy, policy analysis, and research with special emphasis on gender and human rights.

Links with health literacy
SAfAIDS activities are organised around the following core principles:

- promoting understanding, analysis and focus on the critical impact of HIV and AIDS as a development issue rather than simply as a health issue;
- disseminating information that is effective in promoting changes in knowledge, practice and behaviour of individuals and communities using an evidence-based approach taking into account lessons and best practices;
- promoting the use of multi-sectoral and multi-faceted regional responses and interventions to the epidemic;
- influencing key agencies to mainstream HIV and AIDS and gender-related issues into their development work; and
- promoting the meaningful involvement of people living with HIV and AIDS (PLHIV) in SAfAIDS work in the region.

Its strategies include use of the media, online forums, resource centres, documentation of best practices and various publications. It has also established a Policy Desk whose main purpose is to produce and disseminate HIV and AIDS information to both political and civil society leadership so that they can contribute towards the creation of a conducive HIV and AIDS policy environment. According to the organisers, HIV and AIDS information has been designed for the general public over the years, while political leadership has largely been left out. This created a gap in information levels between the two sections of the population resulting in limited opportunities of engagement to support the development of a comprehensive HIV and AIDS policy and legislative environment.
SAfAIDS partnership approach involves working through identified strategic partners who will contribute to a multiplier effect. The capacity building approach involves strengthening the ability of partners to provide SAfAIDS products and services to grassroots communities, ensuring continuity of services and thus sustainability. SAfAIDS implements its activities through collaborative alliances: increasing diversity, uniqueness and synergy, thereby promoting learning and sharing in a complementary and sustainable manner.

Further Information: http://www.safaids.net/ for more information.
3. WHY LANGUAGES MATTER: MEETING MILLENNIUM DEVELOPMENT GOALS THROUGH LOCAL LANGUAGES

Background

Published in the International Year of Languages (2008) by SIL International, the 16-page brochure provides readers with stories about how literacy programmes in local languages are intending to achieve the Millennium Development Goals (MDGs).

Links with health literacy

The document addresses the policy making arena by posing the questions:

1. Can the development of minority languages become key to helping people create their own way of successfully meeting the challenges in their lives?
2. Can writing systems for mother tongues and multilingual education become tools for people to build a better present and a better future?
3. Are the long-term results worth the investment of money and time?

It uses examples of local language for each of the MDGs to show how “communities are discovering that by using their languages in new arenas of their lives, they can begin discovering solutions to the challenges stated in the MDGs.” Examples include:

- **MDG 1: Eradicate Extreme Poverty and Hunger** – When a language group helped a Democratic Republic of Congo village chief develop his health literacy skills, he learned that “soybeans are rich in protein, [and] he encouraged everyone in his village to plant them. He later learned from another booklet about the components of a proper diet, and again encouraged his community to eat from each food group daily so they could improve their health through nutrition.”

- **MDG 3: Promote Gender Equality and Empower Women** – A Quechua-speaking Peruvian, Margarita, studied at night to finish her primary education and beyond, ultimately earning a university degree in psychology. “Using that knowledge and her skills, Margarita founded a volunteer organization that provides social, psychological and educational help to hundreds of displaced and sometimes abused Quechua women and children – using the language they understand best.”

- **MDG 8: Develop a Global Partnership for Development** – Speakers of several closely-related languages of Vietnam now have a font that is usable on computers and the internet. “The new typeface reflects the traditional hand-written Tai
Viet script that is used informally in several languages spoken in the northwest provinces of Vietnam and surrounding areas. Participants at a United Nations Educational, Scientific and Cultural Organization (UNESCO)-sponsored workshop in Vietnam in 2006 developed a standardized encoding for the script with input from ethnolinguistic communities in Vietnam and immigrant populations in other countries. Funding came in part from the Script Encoding Initiative of the University of California at Berkeley, and the Unicode Consortium accepted the resulting encoding proposal."

## 4. Empowerment and Involvement of Tuberculosis Patients in Tuberculosis Control. Documented Experiences and Interventions

### Background

This 40-page publication from the World Health Organization (WHO) and the Stop TB Partnership describes different national experiences in empowering and involving patients with tuberculosis (TB) in the management of their disease. It presents the results of a review of the available literature with the intention of identifying possible trends and conclusions and suggesting ways of informing policymakers and further research.

According to the executive summary: “The review of documented experience covers the means used to enable patients to take more responsibility for their health and, in particular, for adherence to treatment; organizing TB patients into groups and clubs; ensuring patient-centred TB and general health care; and helping TB patients to use advocacy to improve TB control. It describes the operational definitions of and potential barriers to empowerment and the importance of context, including the characteristics of stakeholders, incentives, the performance of TB programmes and the burden of TB. These issues must be explored carefully in evaluating and planning the scaling-up process.”

### Links with Health Literacy

The document includes strategies for the empowerment of TB patients in their capacity to take control of their own care and lives. It hopes to inform policymakers, so that better decisions are made in the future. Methods include peer support by TB patients and cured patients, counselling, a buddy system, education about pill taking and advocacy and social mobilisation in support of TB control services. The document analyses what hampers TB treatment, including general barriers to accessing health services, particularly for the economically poor, women and other vulnerable groups; stigmatisation and isolation of and discrimination against TB patients; ‘patient control’ in TB programmes; and belonging to vulnerable groups. The document points to programmes that recognise these barriers and either focus on overcoming hampering aspects or match specific interventions for specific populations. Empowering patients includes motivating, informing and enhancing patient economic capacity. This may take the form of motivational interviewing, designing culturally sensitive informational tools for patient-centred care, or providing loans.
or food assistance combined with drug therapy. Self-help groups can be established, in various structures based on social mobilisation, de-stigmatisation, group therapy, support for adherence to treatment, and psychological and financial support from former patients.

In concluding, the document asks for stakeholders – non-governmental organisations (NGOs), activists for persons living with HIV/AIDS, and academic institutions – to empower TB patients through:

- understanding patient motivation and the interventions to stimulate it;
- systematic evaluation of current methods of empowerment;
- attention to successes that might be scaled up; and
- greater involvement of the TB patients themselves, in order to foster the strength of agency of, for example, the community of persons living with HIV/AIDS.

SECTION 5: MESSAGES TO KEY STAKEHOLDERS

General Public
1. Strengthen your own health literacy—engage with formal and informal education systems.
2. Ask and act—seek out information from health providers, systems and other reliable sources. Where access is denied, advocate for change.
3. Support others—join forces with others in patient associations or community groups seeking enhanced alignment between skills and demands.

Policy Makers
1. Recognise the importance of strengthening health literacy and that improvements in health equity, affordability and quality require health literacy.
2. Put health literacy on the agenda. Develop policies that support health literacy development.
3. Fund necessary research.

Health Professionals and Advocates
1. Approach health literacy with ‘universal precaution’: i.e., assume everyone has weak health literacy skills and pay careful attention to all communications. Weak health literacy is common and often undisclosed.
3. Enhance your communications skills. Provide information in accessible, understandable and culturally sensitive ways. Professional schools and professional continuing education programmes in health and related fields, including medicine, dentistry, pharmacy, social work, anthropology, nursing, and public health, should incorporate communications into their curricula and areas of competence.
4. Advocate for system change where needed. Use your professional associations and cultural authority to catalyse policy and structural changes needed to strengthen people’s skills and systems’ healthy literacy friendliness.
**Researchers**

1. Develop and test assessment tools which can measure skills and abilities and demands and complexities. Current assessment tools and research findings cannot differentiate among (1) reading ability, (2) lack of background knowledge in health-related domains, such as biology, (3) lack of familiarity with language and types of materials, and (4) cultural differences in approaches to health and health care. No current measures of health literacy include oral communication, writing, advocacy and citizenship skills and none measure the health literacy demands on individuals within different contexts.

2. Develop causality models that can explain the relationships between skills and demands at different life stages and in different settings.

3. Evaluate interventions. There is a need for more intervention-based evaluations with guidance on efficacy and efficiency.

**Educators**

1. Use all formal and informal settings to teach health literacy. Educators should take advantage of all opportunities to transfer relevant health-related information.

2. Use new approaches and technologies. There is a need to develop more non-reading solutions, recognising that addressing health literacy goes beyond better-written communications.

3. Pay attention to different needs throughout the lifespan.
SECTION 6: BUILDING NATIONAL AND LOCAL HEALTH LITERACY ACTION PLANS

1. Recognise the problem and its significance. Include health literacy on your action agenda.
   - Assess health literacy among your target populations.
   - Measure the alignment of skills/abilities with task demands/complexity. Both must be measured. The goal is for both to be ‘health literate’.
   - Identify and monitor indicators that will reflect progress toward aligning skills with demands.
   - Measure skills and abilities on multiple levels. What gets measured gets done.

   Individual level: reading assessment tools
   Community level: geo coding mapping
   Population level: household surveys

2. Support improvements in education and information access.
   - Make health literacy skills an essential element on school agendas.
   - Help children and adults opt for healthy choices in everyday life.
   - Help people access and evaluate reliable sources for health information.

3. Build health literacy friendly systems that better align demands with skills.
   - Identify the specific health demands/tasks for targeted health actions.
   - Understand and simplify navigational demands.
   - Sensitize and train providers.
   - Identify and communicate essential information and desired behaviours in an accessible, understandable and culturally sensitive way.
4. **Set, measure and evaluate goals for improved alignment of skills/ability with task demands/complexity.**

- **Tasks:** How complex are they?
- **Information:** Is it understandable?
- **Navigation demands:** Can they be simplified?

5. **Engage with members of your target population at all stages of planning, implementation and evaluation.** The real experts in health literacy are those with trouble understanding what they must do to take care of their health.
REFERENCES


ANNEX 1 ICN HEALTH ADVOCACY MANUAL

PROMOTING HEALTH
ADVOCACY GUIDE FOR HEALTH PROFESSIONALS
INTERNATIONAL COUNCIL OF NURSES
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