People’s Voice Report


Prepared by the People’s Voice Advisory Board to the Lancet Global Health Commission on High Quality Health Systems in the Sustainable Development Era

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The full report of the HQSS Commission is available for download at www.hqsscommission.org and at www.thelancet.com/commissions.

Cover photo: Health workers meeting in Zimbabwe. Photo credit: WRA Zimbabwe
Introduction

The People’s Voice Report is a companion piece to the report of the Lancet Global Health Commission on High Quality Health Systems in the Sustainable Development Goals Era, entitled, “Time for a Quality Revolution.” The Commission is composed of academic and policy leaders from eighteen countries who study, plan and implement healthcare in low- and middle-income countries (LMICs). The People’s Voice Advisory Board to this Commission includes nine civil society experts in healthcare advocacy, citizen-led accountability for quality, and participatory methods in healthcare design and delivery. This report is the advisory board’s response to “Time for a Quality Revolution,” a report that asks academics and policy-makers alike to remember that quality of care is not only a technical issue, but also a political one. The contributors to this report are advocates who understand this acutely. They are masters of making sure that decision-makers understand the experiences and concerns of people as they weigh the value of high quality care against a menu of other socioeconomic and political priorities.

The People’s Voice Report aims to 1) contribute to a fuller understanding of health system quality in low- and middle-income countries by giving voice to people including patients, families, communities, providers, managers; 2) in conjunction with “Time for a Quality Revolution”, to serve as a tool for health system quality advocates, 3) to make people-centric recommendations for future action to better understand and deliver high quality care. This is not meant to be a formal piece of research, nor to be representative of civil society or all people who use and depend on health systems in LMICs.

The role of people in health systems

It is the right of people to be heard at all levels of the health system and the obligation of the health system to listen. What people have to say about the health system is a valuable source of information for planning and improvement. Providers of high quality care also listen to their patients; what they hear helps them diagnose and determine the best treatment approach. The process of listening in the exam room builds the relationships necessary to produce good health. Managers of high quality care listen to people who use facilities, as well as to those who decide not to. They listen to their providers and staff. This feedback helps them identify gaps, monitor performance and use resources strategically to improve services. At the national level informing policy with people’s voices builds confidence and steers the country towards a stronger health system. In research, the voices of people can inform measurement; patient-reported outcomes, for example, are an increasingly important way to measure the quality of care. Qualitative research based on the voices of people helps explain why things are happening. Why has this program not led to improved quality? Why are people deciding to use that service?

People move in and out of health system roles, as providers, managers, as patients, citizens, clients and caretakers. Providers fall ill and transition into the more vulnerable role of a patient. Patients reject formal care when services do not meet their expectations; they become ill community members. New mothers and newborns are often not ill at all, yet dependent on
providers to monitor for complications. Citizens with entitlements to health services become just people-in-need when they are forced to seek refuge in foreign lands. We intentionally use the word “people”, to capture the diversity and multiplicity of experiences and to challenge readers to consider these complexities as they move through the document.

Defining high quality health systems

The Commission defines a high quality health system as one that “optimize health in a given context by consistently delivering care that improves or maintains health, being valued and trusted by all people, and responding to changing population needs”. High quality health systems are equitable, efficient, resilient, and most importantly, for people. Using this definition, the Commission presents evidence that illuminates significant shortcomings in the quality of care in LMICs. People often receive sub-standard or even disrespectful treatment; systems fail to prevent illness; they are not always safe; they leave people waiting and uninformed. Poor countries, and the most vulnerable people in those countries, often fare the worst. As countries expand access to healthcare, basic standards of the quality of that care cannot be assumed.

But what does high quality healthcare mean to people who use and depend on health systems in LMICs? The Commission asked this general question of the People’s Voice Advisory Board who turned to their partners and constituencies for answers. An information gathering tool with more specific questions was collaboratively developed and used to collect thoughts from people, families, community members, providers and health system managers. Board members and their partner organizations used the tool to identify published and grey literature that gave voice to people.

The material was initially divided into two categories of voices: health system users and health system employees. As the quotes and stories were read for patterns and themes, it became clear that the division line was arbitrary; users and employees frequently had similar views about quality of care. With this less restrictive framing, the material was re-organized and five themes emerged. These themes speak to the importance of seeing the quality of care received by a patient or delivered by a provider within the broader landscape of people’s lived experiences. They show that quality healthcare means treating patients and their families as partners, it means providers who are capable of treating but also of nurturing and comforting, and it means health systems that prepare and enable providers to consistently deliver the highest standards of quality. Without high quality healthcare, health outcomes suffer, but so do public trust and confidence in the health system.
1. Squandered resources: families and well-informed patients

Though the importance of adequate funding, appropriate and well-functioning equipment and a reliable supply of medications and supplies cannot be underestimated, patients, families and community members point out several missed opportunities to capitalize on resources that exist free-of-cost in health systems. These resources are: 1) the family and loved ones of patients, and 2) well-informed patients.

Health systems have focused heavily on sick people as the target of their services, but people do not fall ill in a vacuum. Their suffering concerns their loved ones, draws them away from their work, and can make them sick too.

“How can I be well with this type of sickness? I cannot sleep. Look at me. I am so emaciated because of my daughter’s illness....My daughter’s illness is really worrying me. I’ve left my trade and everything. Financially, it has ruined my life.”

— MOTHER OF A PERSON WITH MENTAL ILLNESS IN NIGERIA

High quality care means that families are seen as a part of the illness and healing process, as a subject and also as a resource. When people seeking healthcare want their loved ones involved, a high quality health system has the capacity to involve them and has the foresight to view this involvement as an opportunity to provide better care.

“After examining a mother, I would speak to the husband to reassure them, and use the opportunity to encourage them to tell other husbands to bring their wives.”

— PROVIDER IN ETHIOPIA

Unfortunately, family is not always welcome.

“The nurses are just rude. They can ask you: ‘Are you also pregnant? So, go out!”

— A TANZANIAN HUSBAND

“Do not at all allow going into labor room. Inside what is happening with our patient, is she dying or surviving, what problem is she passing through, how is she being treated, we never know. If we ask something we are snubbed.”

— A GRANDMOTHER-TO-BE

A well-informed and empowered patient is also a valuable resource in a high quality health system. However, patients from around the world with various reasons for using the health system report interactions with health workers who withhold information. Given the already vast knowledge chasm that exists between lay people and providers and the close relationship between information and power in healthcare, refusing or failing to share health information strips patients of the little power they may have during a healthcare interaction. The failure to share information is particularly inhumane when it involves invasive physical procedures:
“We have no right to ask questions. I did ask the doctor, ‘how many stitches did I have?’ He said in an aggressive manner, ‘why do you want to know?’ and left. Is this not my right even to know how many stitches I had?”

— PREGNANT WOMAN FROM EGYPT

“The person who was examining me did not tell me what she was doing. She just examined me.”

— PATIENT IN MALAWI

“Doctor checks and says bring the wheelchair and start preparing for operation and people start moving here and there. Only take signatures from husband… The woman is never told, asked or briefed about anything.”

— PATIENT IN PAKISTAN

Patients appreciate when providers take the time to communicate, educate, listen, counsel, explain and share information, when they treat patients as partners who require information in order to actively participate. Two community members in Tanzania were asked how they know that they are receiving good quality care: “The way health providers talk to me” and “When I get good customer care. Doctor to listen me well and give me advice and medicine.”

A patient in China summarized this issue succinctly: “Communication is very important. No matter what the conditions or risks, patients must be completely informed.”

A young woman learns about family planning from a WRA volunteer in India. Photo credit: WRA India
2. The “care” in healthcare

People want their health systems to make them feel better and to help them heal. However, the importance of compassion and kindness cannot be forgotten during the process. Technical expertise does not replace high quality interpersonal care.

“I am an educated girl and I know that the university hospital has lots of resources, technology and professors…after my delivery, I realized that in labour you do not need that technology as much as someone who cares about you.”

“I came here because I heard that it is a clean hospital that has highly sophisticated equipment. But what does the equipment do without nice, kind and sensitive people looking after you?”

— PATIENTS IN EGYPT

Regular monitoring appears to be an important marker of this caring from the perspective of patients. Not only is there instrumental clinical value in gathering data about the patient’s condition, but it signals that the provider is paying attention, that they care:

“When I came to deliver... They allowed me to stay with a person that I chose. Health workers were coming frequently to check on my progress.”

— PATIENT IN MALAWI

“The doctor was wonderful. I think she gave me a lot of attention and was very dedicated when she spoke to me so I wasn’t uncomfortable to talk to her about my problems.”

— PATIENT IN BRAZIL

The reverse of showing caring and checking on patients can feel like abandonment:

“Once I went for delivery, a woman was already lying uncovered in delivered position...The midwife had gone with the newborn to receive gift (money) from the attendants and then took the baby to nursery. That poor woman kept lying alone there for quite a time. It was midnight.”

— PATIENT IN PAKISTAN

Kindness and compassion in work was raised by providers as well. People-centered care requires the healthcare provider to connect with the patient beyond a technical level. It is a relationship built on trust and respect, and it goes both ways. Patients and providers benefit.

“The midwife takes time with this woman, with this family, with this adolescent. She listens to them, provides respectful maternity care. That way, she will be able to understand the challenges, the hidden challenges, that people have and know how she can help them.”

— MIDWIFE IN MALAWI
In China a healthcare provider stated that they are more effective when they are able to comfort their patients “psychologically, even offering a hug or slightly tough love, to make patients feel better rather than to prescribe drugs.”

“They [pregnant women] mostly want to give birth in CHS because the midwives are friendly.”

— MIDWIFE IN VIETNAM

Providers find more joy in their work when the patient-provider relationship is compassionate. A study in Ghana found, “People are now working with their heart. They are working not because of what they are getting, but they are working because of a certain satisfaction.”

3. Good outcomes motivate providers but are difficult to achieve without strong health systems

Healthcare providers are motivated in their job by a myriad of factors. Many, however, come into the profession because of a desire to help people live healthy fulfilling lives.

“Serving people in remote areas motivates me, especially when you see them smiling, especially when the outcome is good.”

— PROVIDER IN ETHIOPIA

In Kenya a provider commented that despite the many barriers to providing high quality care “what has kept me going is the results.”

In Ghana a health worker echoed the desire to improve the quality of care and make things better: “We have been told by the authorities to really do it for love and that thing has been preached so many times, to do it for love. That is what is keeping most of us moving with the hope that one day it would be better.”

However, high quality services are challenging to deliver at the point of care when the surrounding system is broken. A theme for both patients and providers was the need for systems-level change. In Tanzania a qualitative study of health worker’s perspectives noted the frustration they feel when performing inadequate care:

“To sterilise [when chlorine is not available], after delivery you just wash with normal water then you boil them [equipment]. I’m not accepting this method, but it is our circumstance.”

A surgeon in Central Asia echoed a similar frustration that “The hospital is not connected to centralized hot water, difficult to scrub with cold water (cold country!). We are not able to organize [and keep a] clean area separated from [the] infectious area.”
These broken systems often require providers to go above and beyond in order to provide adequate care.

“If you [the surgeon] can’t get blood, you can drive to the blood bank and donate your own blood, and then drive it back to your patient. We have done that on many occasions.” — SURGEON IN EASTERN SUB-SAHARAN AFRICA

In a study in Malawi a nurse commented that her work circumstances had become overwhelming: “Maybe the council [the Nurses and Midwives Council of Malawi] can decide to take my certificate because I ‘mishandled’ but it’s not mishandling, it’s that the work is too much.”

This sense of having too much to handle was also noted by a provider in Latin America: “Many doctors and surgeons need to work in three or four places at once, and therefore are not 100% focused.”

4. The role of management and education in a strong health system

From the perspective of providers, strong management and good education are critical for a well-functioning and supportive health system. Management can improve the working environment for providers and helps them provide high quality care. In Ghana the high impact of good management on provider morale and productivity was highlighted by a provider:

“Because I have established a nice relationship with management, I will feel better working here than going elsewhere with the same condition... The spirit of the people, our leaders, our colleagues around, they are supportive.”

In Malawi the positive effects of good leadership were also noted by a mother and midwife: “I believe in Malawi — we have a very good environment in terms of policies, guidelines, documents, standards.”
The opposite effects were also mentioned in a study in Tanzania that found that low morale for the providers was a major barrier to providing high quality care.

“I am always alone here [in the health facility] and they [the district health management] are aware of this situation. I went to ask the nursing officer that did you locate me here as a punishment or what? Eeh it is just like a punishment.”

— HEALTH WORKER IN TANZANIA

Failures begin with provider training. Health workers and providers from various countries talk about gaps in skills that lead to poor outcomes. Gaps in technical knowledge have profound effects.

“Sometimes they don’t have those skills to perform certain tasks like emergencies, emergency obstetric procedures. So sometimes you get frustrated because maybe a baby has died, just because somebody has failed to resuscitate that baby. Or even the mother herself has died, not necessarily because there was nothing that could have been done to save her, but because someone didn’t know what to do with the lady because he or she did not have the skills.”

— MIDWIFE IN MALAWI

The deficit starts in the earliest years of training: “Teaching quality in medical schools is terrible. Professors spend five to ten percent [of their] time teaching. Residents learn from residents with poor supervision.”

— FIELD NOTE FROM SOUTH ASIA

5. Poor quality can do harm beyond poor health

Poor quality care can have adverse and lasting effects on the provider, the patient, and the system. When vulnerable people are treated in a disrespectful way, for example, it can lead to a loss of confidence in the health system. Healthcare interactions are influenced by the social structures in which they occur. Providers can reproduce structures that promote discrimination and people can detect differential treatment when entering the system as patients.

“They were treating us differently, in the sense that some were going straight to get the treatment while we were on the queue....Some of them were friends of the doctor but others feel we are inferior to them.”

— PATIENT IN MALAWI

“If you are well dressed then they behave with you in better manner—if you ever go there like a poor devastated rural women then you will realize how bad their behavior can be.”

— PATIENT IN PAKISTAN

“(…) when you find some [care], it’s not good, because the professional that should be assisting people is not prepared for the [disabled] person. He opens the office door, looks at the person, gets afraid.”

— PATIENT IN BRAZIL
Patients actively make decisions about their care. They decide to return, they decide to turn elsewhere, or they decide to stay home. When expectations around quality are not met, trust and confidence are compromised:

“I will not come to that hospital again. I will not deliver here again. It was very hard, hard, hard, I will never do it here again and if I will deliver again, I will deliver at home.”
— PATIENT IN EGYPT

“They sent a woman to the washroom outside. She delivered over there. Thousands of men were seeing her... Having seen this I returned home and decided not to go to hospital for delivery and get my babies delivered at home.”
— PATIENT IN PAKISTAN

Poor quality care, especially poor communication, starts a cycle of distrust aptly described by the mother of a child with malaria in Ghana: “Sometimes when you start discussing your problem, then they begin to shout at you. The next time you go to the clinic, you will find it difficult to tell them the truth or discuss your problem with them because of what happened the previous visit.”

A loss of confidence can also lead to complete abandonment of the formal sector.

“As the tablets that we had received from the health facility hadn’t helped the child to recover, and instead caused the child’s condition to deteriorate, I thought the child had an illness that would be treated by traditional healers and hence chose to return to traditional healers.”
— PARENT OF A 1 YEAR OLD BOY WHO DIED OF AIDS

A midwife examines a pregnant woman inside an Indian health facility.
Photo credit: WRA India
Reflections on Report Key Findings

The following section presents reflections from civil society groups on the Lancet Global Health Commission on High Quality Health System's main conclusions. The primary contributors were the Quality, Equity and Dignity Advocacy Working Group, Walio Katika Mapambano Na AIDS Tanzania (WAMATA), and Support for Advocacy and Training to Health Initiatives (SATHI), three civil society groups that fight for improved quality of care in LMICs. Please see online appendix at http://thelancet.com/commissions/quality-health-systems for full text from these organizations.

The care people receive is often inadequate, and poor quality care is common across conditions and countries, with the most vulnerable populations faring the worst

Even while economies and societies may be unequal, health systems must act as equalizing influences, rather than reproducing inequities. Hence poor quality of healthcare for vast numbers of people is a form of injustice which needs to be addressed energetically. And the fact that vulnerable groups face the brunt of poor quality care is an even deeper form of injustice, which should be recognized and addressed as such.

Governments in LMICs may make available some basic health services, even make these geographically accessible, and free or highly subsidized—but if these services are of poor quality then people stay away from them and shift to the private sector, often undergoing catastrophic expenditure. Poor quality services can also do harm. If the patient leaves the hospital
hungry because they had to stay a whole day there, then that’s harm. And at the end of the
day the patient may still not get what he needs. Going to the hospital shouldn’t be a source of
undue stress.

High quality health systems could save over 8 million lives each year
in low- and middle-income countries

If we are going to make high-quality health systems a universal reality and save these lives,
it cannot be business as usual. High quality healthcare can only be achieved when people
and communities are able to voice their demands for the provision and overall experience of
healthcare and when preventable illness and deaths and poor treatment become intolerable.
While investment in quality, equity and dignity is relatively inexpensive, the costs of non-
investment are astronomical.

We also cannot forget the huge amount of preventable morbidity and reduced quality of life
due to poor quality of healthcare. In order to impact these lives, we must erase the rigid line
between the health system and other systems—work needs to be done across sectors.

Health systems should measure and report what matters most to
people, such as competent care, user experience, health outcomes,
and confidence in the system

In addition to the availability of clean facilities and clinically competent providers, we need to
get much better at measuring the quality of the interaction between providers and patients.
This interaction really matters to people who demand respectful care without abuse, discrimi-
nation or humiliation, care without cultural or language barrier, and privacy in healthcare. We
also need to think about providers. Do they feel good doing what they are doing?

People’s confidence in the health system is a particularly important measure of quality. Many
health services have largely lost the confidence of people due to experiences of poor quality of
care. This confidence, once lost, may be very difficult to restore. Humiliation and discrimina-
tion is a ‘catastrophic’ form of negative quality of care, damaging individual and community
confidence in a major way.

New research is crucial for the transformation to high quality health
systems

Research that is able to lead to transformation must include the perspectives of everyday
users of healthcare as well as the people who work in health systems. These perspectives can
help system planners avoid pitfalls, understand barriers, and improve quality. Health systems
research on quality today is heavily focused on numbers which cannot tell the whole story.

New research must also include practitioners in asking and answering questions. Practitioners
may not be trained researchers, but should be incorporated into research teams so that
research is actionable and pertinent to the everyday lives of people. Practitioners and imple-
menters who help shape research on health systems must also be fairly acknowledged for
their contributions in the research process.
Improving quality of care will require system-wide action

System-wide action means that quality improvement processes must reach across multiple levels of the health system—from village and PHC to district and state levels—as well as across sectors. Narrow departmental boundaries and compartmentalization can retard system-wide action. Governments should look beyond facilities and see all the other actors that contribute to health. Non-governmental organizations also need to do their part. We need to see ourselves as a partner in health systems.

This should start with legislation. Legislation shows intention. Action should follow. System-wide action includes improving the way we train our providers. If we do not consider the pre-service education of providers, including how future providers recognize and handle multiple dimensions of marginalization, services that are being provided will not improve. It should include strong accountability systems. Delivering public health services without systematic feedback from its users about service quality leads to some things getting done in a routine or patchy manner, but important areas may get left out.

System-wide change should include increasing the demand for high quality care. Meaningful change will only occur when demand for quality is so great it can no longer be ignored. This will only happen from citizens holding their leaders accountable and actively seeking the kind of high-quality and dignified care they want, when and where they need it. Limited up-front inclusion of citizens in the creation of a shared vision for and ownership of their health system and with minimal investment in community monitoring and accountability structures, leaves them essentially defunct and hollow.
Next Steps

The following five actions were identified by advocates as necessary next steps to create high-quality health systems.

Generate political will across sectors

This is central for ensuring that health systems—including both public and private providers—deliver quality care. We must not lose sight of the fact that public action on quality of healthcare is a deeply political process. Such political will must naturally be developed at multiple levels—from communities and local elected representatives through legislators and political parties, to state and national governments.

Make demand generation and accountability a priority recommendation for all

Demanding change and holding systems to account should not be a priority recommendation only for civil society and NGOs, but rather the priority recommendation for all. There is a frightening global trend to silence and disenfranchise people’s movements and local civil society in many countries that must be roundly rejected by donors and the global health and development community. More must be done by all to support citizens holding decision-makers and duty-bearers to account and to ensure public health decision-making is conducted in a way that encourages people to participate and to help solve problems that affect their daily lives. ‘Country ownership’ does not mean no questions asked to government leaders, it means helping to ensure priorities are being truly set by and for the people. It means rejecting the false but common viewpoint that public health strategies and plans are highly technical and cannot benefit from citizens’ inputs.

Avoid tokenistic social accountability mechanisms

Tokenistic social accountability mechanisms can harm the relationship between communities and the health system. People need to see that their investments and contributions are truly heard and lead to meaningful change.

There is a need to spell out and ensure core components of an effective, participatory and empowering social accountability framework in each country context. These components should be based on actual community and civil society experiences. Components that should be considered include:

- Publicly declared and displayed quality standards
- Community awareness generation
- Empowering communities to document and communicate their experiences on quality of healthcare
- Local advocacy to ensure effective community dialogue with health functionaries
- Multi-level action for promoting community health priorities.
Rights-based civil society organizations and community groups have a particularly important role to play in facilitating social accountability processes. In addition to existing mechanisms, there is a need to develop innovative and accessible social accountability mechanisms.

**Fund better**

This means three things for governments and donor agencies. First, flexible funds and financial decision-making powers need to be available for health officials at the frontline and lower levels of the system. Such decentralization of powers can ensure a health system that can rapidly and effectively respond to specific quality related issues in a locally rooted manner. Second, project cycles need to be longer. Having whole countries running on short term projects means that you cannot accomplish critical quality improvements like making medical schools better. Third, funding agencies and governments should use indicators that matter most to people (see key finding 3) so that implementers can focus on programs and improvements that will truly lead to higher quality care for all.

**Regulate the private sector**

Minimum standards and effective regulation of the private medical sector is necessary to ensure basic quality of care. This is especially true given that there is a rising trend towards medical consumerism and a healthcare culture that says ‘more is better’, ‘more expensive is better’ and ‘more invasive is better’. This trend needs to be countered by a combination of widespread public awareness regarding rational healthcare and effective regulatory mechanisms across sectors.
Conclusion

Quality healthcare is an issue of social justice and human rights—people deserve high quality care and failing to deliver it, especially to the most marginalized populations, inhibits progress towards a more equitable and just society. In order to achieve high quality care, people, in all of their roles, need to be partners in improvement. As this report demonstrates, people as patients and people as providers often share common goals. Finding these areas of alignment can lead to powerful partnerships and opportunities to advocate for high quality health systems.

The voices of non-health professionals should be recognized as equally valid as any health expert. This means making intentional and well-resourced efforts to both foster and make welcome a widespread and engaged citizenship that positively shapes a country’s growth and development. It means empowering people to recognize the value of their contributions and training them to participate effectively. Perhaps most importantly, it requires a fundamental paradigm shift within the wider health and development community. People are not passive participants in healthcare, they are active decision-makers and experts in their own lives and experiences. Their thoughts and concerns—their voices—are essential ingredients in the design and delivery of high quality healthcare.
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