

Patient-centred healthcare: the future for care in Africa?

October 30th is to be 'Patient Solidarity Day'. The patient voice is growing. Yasemin Dil and Caroline Staffell report

Discussions are well underway on the United Nation's (UN) post 2015 development agenda which will come into action when the Millennium Development Goals (MDGs) come to an end in 2015. Alongside this, at the World Health Organization's (WHO) 66th World Health Assembly, Member States adopted a resolution to sustain and accelerate efforts towards achieving the health-related MDGs, and to ensure that health remains central to the UN's development agenda after 2015. Furthermore, many countries also expressed support for the inclusion of Universal Health Coverage (UHC) in this agenda, emphasising that UHC requires strong health systems in order to provide quality and affordable care. Central to these conversations are the health of people and how this can be improved; however, such stakeholders are often not at the centre of policy development, or recognised as a voice in providing the solution to health challenges.

In October 2012, the International Alliance of Patients' Organizations (IAPO) published its Patient-Centred Healthcare Indicators Review and accompanying Consultation Report. The review identifies and assesses current initiatives, which aim to measure the patient-centredness of organisations, countries, activities, and any other relevant stakeholders involved in healthcare. It includes examples from WHO and national health systems and hospitals, amongst others. Indicators of patient-centredness relevant to activities, organisations, and countries can support the development and implementation of patient-centred policies and be applied by healthcare providers to measure the extent and quality of their work towards being patient-centred.

The Patient-Centred Healthcare Indicators Review identifies 11 sets of current and proposed indicators for measuring patient-centred healthcare at the system level. These range from the development of specific indicators for the entire health system, hospital settings or primary care settings, to more general indicator recommendations. The review illustrates that there are few well-defined and coherent system level and government indicators currently available.

The key point of reference for the review was the five principles of IAPO's Declaration on Patient-Centred Healthcare.¹ Of the indicators identified, there was an uneven spread across the five principles with emphasis on indicators of access and information, and fewer indicators relating to patient choice, empowerment, and respect. Only two system level indicators identi-

fied included indicators for patient involvement in policymaking. The review highlights that the majority of the literature discussed in the results did not demonstrate patient involvement in the development of these indicators, which IAPO asserts is fundamental to the development of patient-centred healthcare indicators. Furthermore, the large number of self-assessment tools and patient experience surveys may reveal that there is too much focus on organisational improvement through checklists, when patient-centredness should be at the core of any health organisation or system.

As identified by the Patient-Centred Healthcare Indicators Review, indicators with which to measure the impact of patient-centred healthcare and its place in health systems are lacking. In addition, there are global disparities in the availability of indicators to measure patient-centred healthcare, with the majority identified in the review being from developed countries. To address these gaps, the review recommends the use of the 'patient journey' as a framework for measuring patient-centred healthcare. This allows the focus to be narrowed down at specific points along the journey, so that patients' experiences can be measured at points of interaction with different levels of the health system.

Patient-centred healthcare in Africa

In a region with more than 24% of the global burden of disease, while having only 11% of the global population, access to only 3% of the world's health workers,² 70% of the world's HIV burden,³ large inequities in the treatment and prevention of disease, lack of medication, and lack of resources which make even basic patient safety techniques difficult to achieve, one may wonder how patient-centred healthcare can be realised in Africa. In a resource-constrained environment, how can a health system be designed with the involvement of patients, inclusive of patient and community led initiatives? Can this provide the solution to Universal Health Coverage and stronger health systems? While indicators



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for such interventions cannot yet be cited to evidence their effectiveness, the work of patient and community-led organisations in Africa demonstrate the value of these approaches and their potential to create sustainable and long-term improvement to health systems. This depends on whether they are properly recognised and supported as partners in the healthcare system.

While data may be lacking on the outcomes of the involvement of patients' organisations there is evidence that women's groups and health education by peer counsellors can improve the health of mothers and children in low-resource settings.⁴ A systematic review and meta-analysis of seven randomised controlled trials (119 428 births) in Bangladesh, India, Malawi, and Nepal on the effects of women's groups practising participatory learning and action on maternal and newborn health revealed that that exposure to women's groups was associated with a 55% reduction in maternal mortality and a 33% reduction in neonatal mortality.⁵ Such evidence makes clear the importance of community-led interventions in improving maternal and child health, and provides the opportunity for further research into the wider health implications of patient and community involvement in healthcare. At the core of these interventions a patient-centred approach is evident.

IAPO has 27 member patients' organisations and three associate patient-centred health professional organisations, working to improve healthcare in the African region (as defined by WHO). These organisations raise public awareness on key healthcare issues including the control, prevention, and management of both communicable and non-communicable diseases, patient safety, and health literacy. Patients' organisations also promote healthy lifestyles, and facilitate access to preventative services and quality treatments. Their connection with patients at the community level means that they have an in-depth understanding of patients' needs and can provide insights into the most appropriate and cost-effective interventions which will meet the needs of the communities they serve. They are perfectly placed to help their governments and Ministries of Health develop indicators for measuring patient-centredness, which IAPO's review shows are currently lacking in the African region. Putting indicators in place, both quantitative and qualitative, will allow different sectors of the health system from community level to national, to benchmark their work and improve both their approach to providing healthcare and accountability to the patients they serve. This will help improve the quality of care provided to those patients and better health outcomes overall.

The benefits of involving patients' organisations in the design and delivery of healthcare can be demonstrated by IAPO member, the Community Health and Information Network (CHAIN) in Uganda. In 2012 CHAIN reached nearly 27 000 people through its programmes which included:



- promoting health literacy in Uganda through strengthening community partnerships;
- HIV counselling and testing;
- anti-retroviral treatment in partnership with the AIDS Support Organization (TASO) Uganda;
- education on sexual reproductive health and rights;
- support for orphans and vulnerable children;
- community and school outreach to raise awareness on HIV prevention;
- hand washing and sanitation sensitisation in communities.

CHAIN works in partnerships with the WHO Uganda Country Office, Ugandan Ministry of Health, National Drug Authority, members of the Ugandan Alliance of Patient Organizations and IAPO, among others. They provide vital links between patients, communities, healthcare providers and healthcare professionals, working in collaboration towards patient-centred healthcare.

Dialogue with the people that healthcare is meant to serve is the only way that healthcare interventions can be effective, long-term, and sustainable. Patient and community-led organisations are in contact with many of the most marginalised and vulnerable communities in the African region, providing an often unrecognised resource, to strengthen health systems and improve lives. A shift in the emphasis of the UN post-2015 development agenda for health, from top down to patient and community led initiatives, ensuring their involvement in all aspects of healthcare delivery and design, will empower patients' organisations and community groups to make real improvements in health. On 30 October 2013, patients across the African region will come together to celebrate Patient Solidarity Day to raise awareness of patient-centred healthcare in the region. They will call on all healthcare stakeholders to 'Improve lives through patient-centred healthcare' and bring attention to the vital role of their organisations in the communities they serve. We invite you to join us on Patient Solidarity Day. For more information about Patient Solidarity Day please visit www.patientsolidarityday.org.

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