SURE Rapid Response – April 2010

What are the best methods for involving patients in health system decision making in Uganda?

Background

The importance of patient or community involvement in health care is widely recognized, particularly its potential to improve the availability and relevance of healthcare services to health service users. Community involvement or participation can also be viewed as a goal in itself by encouraging participative democracy, public accountability and transparency.

Key messages

- **Methods for involving patients in health system decision-making vary with respect to their purpose, who is involved, the degree of involvement, the methods employed to support this involvement, and the context.**
- **There is a paucity of evaluations comparing the effects of different methods for involving patients, but there is a large amount of experience and anecdotal evidence that can inform decisions about how to involve patients.**
- **Principles that can guide decisions about how best to involve patients in health system decision-making include:**
    - **having agreed upon roles for patients including their involvement in decision making,**
    - **budgeting for the cost of patient involvement,**
    - **policymakers respecting the differing skills, knowledge and experience of patients,**
    - **acknowledging the contribution of patients,**

Regional East African Community Health Policy Initiative

Who requested this rapid response?

Ms Robinah Kitiritimba

! This summary includes:

- **Key findings** from research
- **Considerations about the relevance of this research** for health system decisions in Uganda

✗ Not included:

- Recommendations
- Detailed descriptions

What is a SURE Rapid Response?

SURE Rapid Responses address the needs of policymakers and managers for research evidence that has been appraised and contextualised in a matter of hours or days, if it is going to be of value to them. The Responses address questions about arrangements for organising, financing and governing health systems, and strategies for implementing changes.

SURE – Supporting the Use of Research Evidence (SURE) for policy in African health systems - is a collaborative project that builds on and supports the Evidence-Informed Policy Network (**EVIPNet**) in Africa and the Regional East African Community Health (**REACH**) Policy Initiative (see back page). SURE is funded by the European Commission's 7th Framework Programme.

www.evipnet.org/sure

Glossary of terms used in this report:
www.evipnet.org/sure/rr/glossary

- **providing training to patients to enable their involvement and to policymakers to enable them to involve patients effectively,**

- **making information underlying decisions and regarding decisions available to patients in formats and languages they can easily understand.**

Summary of findings

Much of the terminology used to describe individuals who come into contact with health systems is problematic. Words such as 'patient', 'client', 'consumer' and 'user' are commonly used, but may be misleading or considered unacceptable by those they are applied to. Individuals affected by health systems decisions include patients, unpaid carers, parents or guardians of patients, users of health services, disabled people, members of the public who are the potential recipients of either health promotion or public health programs, people who believe they have been exposed to potentially harmful products or services, people who believe they have been denied products or services which they believe could have benefited them, as well as those who pay for health services (e.g. as tax payers). Depending on the context, people can be described as 'lay' people, 'non-experts', 'service users', 'members of the general public' or as 'citizens'. In this response, we use the term 'community' to include people in any of these various roles, and the term 'patient' when referring to individuals in any of these roles.

Patients and the community can be involved in health system decision-making in different ways. Involvement may be through consultations to elicit their views or through collaborative processes which involve individuals or groups of patients to allow debate. The groups may be long-term established patient or community organizations or they may be convened specially for a given consultation. They may be organized in different forums and through different media as single events, or repeated events on a large or small scale.

Principles that can guide the selection of options for involving patients and the community include:

- Meaningful participation
- Mutual respect
- Effective communication
- Transparency
- Accountability
- Evaluation
- Adequate resources
- Sustainability

Options or mechanisms of involving the community vary according to their purpose, the patients involved, the degree of involvement, the methods employed to support this involvement, and the context. The degrees of involvement vary from non-participation, manipulation or tokenism to empowerment through partnership, delegated authority or community control.

Consultative methods ask patients for their views or feedback and use these to inform decision-making. For example, policymakers may hold a one-off meeting with patients to ask them about their priorities, or write to patients in accessible terms to invite their views. Patients' views are not necessarily adopted, although they inform decisions.

Collaborative methods on the other hand are active, on-going partnerships with patients or communities. For example, patients may be committee members. There is still no guarantee that patients' views will determine decisions, but there is more opportunity for them to be heard and to influence decisions.

Forum for communication (for either consultative or collaborative methods) may include:
Town or village meetings, written consultation, focus groups, interviews, committee meetings and permanent patient or community panels.

The involvement of patients in decision-making can be implied (e.g., through committee membership), without a clear description of how decisions are made, or explicit (e.g. through voting, ranking or scoring), with a clear description of how decisions are made.

Ways of recruiting patients or community representatives include targeted personal invitations to individuals or organizations and open invitations in mass media or by telephone, mail, email or personal contact.

Training and support for patients and community representatives may be needed to enable them to collaborate effectively. This may include training on how to participate in the forum that are used, education on relevant topics, counselling or mentoring, introductory workshops or orientation days.

Financial support is likely necessary, for example, for administration of the methods that are used, to pay staff to support patient or community involvement, to reimburse patients' or community representatives' expenses, and for honoraria,.

Problems encountered when implementing methods for involving patients

A number of challenges may be encountered when attempting to involve patients or communities in decisions about health systems. Some barriers to involving patients and strategies to address them are summarised in the table below.

Barriers	**Strategies**
It is quite common for governmental ministries to author policy documents that outline and promote participation and involvement of citizens, but not construct the mechanisms for this participation.	Documentation of planned methods for involving patients or communities Training for policymakers to enable them to involve patients effectively Training for patients to enable their involvement
Policymakers and healthcare providers may not appreciate the value of patient involvement view it as providing information to patients rather than obtaining their input into health system decisions.	
Patients may lack health literacy, necessary information, knowledge of legal frameworks, and skills needed to participate effectively.	

Funding for patient or community involvement is often inadequate or short term.	A realistic budget and plan for covering the costs of effectively involving patients
There may be divergent views about problems and solutions.	Involvement of patients or communities in planning programmes for involving them and ensure that they have a sense of ownership Training for patients or community representatives Effective facilitation of meetings Clearly defined roles and responsibilities Adequate funding Reduction of unnecessary bureaucracy to a minimum
Poorly defined roles and responsibilities for individuals or groups may lead to a lack of motivation for patients or the community to be involved.	
There may be geographic and bureaucratic barriers to participation.	

Conclusion

Patient or community involvement in decisions about health systems has the potential to improve healthcare services. However, its effectiveness is likely to depend on having explicit methods for involving patients, clearly defined roles and responsibilities, training for policymakers and patients, and adequate funding.

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Conflicts of interest

None known.

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REACH

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The **Regional East African Community Health-Policy Initiative (REACH)** links health researchers with policy-makers and other vital research-users. It supports, stimulates and harmonizes evidence-informed policymaking processes in East Africa. There are designated Country Nodes within each of the five EAC Partner States.

www.eac.int/health

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