

Building Advocacy Competency with the Voice Project

Samantha Khan-Gillmore
Rural Health Advocacy Project
14 April 2016

How many of you have ever seen....?

1. An HIV+ patient on ARVs (including a Protease Inhibitor) whose Aluvia has not been doubled when starting TB treatment?
2. A hepatitis status on a patient not being checked, despite he/she being a candidate for switching ARVs thanks to a persistent viral load?
3. A patient referred with a diagnosis of MDD or schizophrenia but without the appropriate endocrine, metabolic and/or other workup?
4. An HIV+ patient may be managed for acute psychotic episodes with haloperidol with/without a benzodiazapine, but with inadequate consideration of his/her efavirenz as a cause of the neuropsychiatric symptoms

Have you ever.... ?

- Witnessed a patient suffer because you didn't have a certain drug or piece of equipment?
- Been frustrated because your patient's treatment is interrupted because of a drug shortage?
- Had to chose who to bump off a list because there was no linen to do an operation?
- Been frustrated because of a senior colleague who abuses RWOPS?

How do you act when you witness health care system failures in your respective healthcare facilities?

Do you run away?



Or are you part of the solution?



Health care professionals are governed by various pieces of legislation including, but not limited to, the following:

1. National Health Act of 2003
2. The Constitution
3. Health Professions Act of 1974
4. Promotion of access to information Act, 2 of 2000
5. Medicines and related substances Act, 101 of 1965

What exactly is Advocacy?

Advocacy is an ongoing process to change values, attitudes, actions, policies and laws by influencing decision-makers and opinion leaders, organisations, systems and structures at different levels” (measuring up, 2010)

How can this relate to health??

CANMEDS IS A GUIDE FOR HEALTH PROFESSIONALS

Advocacy requires action. Physicians contribute their knowledge of the determinants of health to positively influence the health of the patients, communities, or populations they serve.

Physicians support patients, communities, or populations to call for change, and they speak on behalf of others when needed. Physicians increase awareness about important health issues at the patient, community, or population level. **They support or lead the mobilization of resources (e.g. financial, material, or human resources) on small or large scales.**



THE
CANMEDS
ROLES FRAMEWORK

Health Professionals Council of South Africa: Core Advocacy Competencies for Medical Practitioners

- Respond to individual patient/client health needs and related issues as part of holistic patient care
- Respond to the health needs of the communities that they serve
- Respond to patient's health needs by advocating with the patient within and beyond the clinical environment

So how are we doing?

- The country's medical schools produce approximately 1 200 doctors annually. But, over their career, half of these doctors will move overseas.
- This leaves about 600 doctors in South Africa.
- Three quarters of these doctors will work in the private sector.
- Only 150 doctors will be left to work in the public healthcare sector.
- Of those remaining in public service, the vast majority will work in urban centres.
- This leaves as few as 35 doctors from any single year of graduation to serve the rural areas of South Africa.

And what is the need?

- 43,6% of South Africans live in rural areas (StatSA)
- Six out of ten poor people live in rural areas
- The most deprived districts in South Africa are all rural
- Medical scheme coverage is lowest in rural provinces
 - National average: 16,9%
 - 8,3% in Limpopo, 10,8% in EC
- Catastrophic transport costs (up to 60% of household income) and delayed health-seeking behaviour (Harris et al, 2011)
- HRH shortages highest in rural areas (NW and LP worst)
- 60% of the nurses and 40% of the doctors serve 85% of the population using the public health sector

Poor health outcomes

- Under-five mortality: EC (62.0), KZN (60.0), national average: 46,7, ASSA 2008 in 2013
- 8 out of the top 10 TB-HIV Hotspot Districts are rural (SAHR 13/14)
- Early infant HIV diagnosis coverage: NW (61.1), EC (61.8), LP (63,8), national average (73.9), Gauteng (86.7) (SAHR 13/14)
- Disability prevalence highest among the poor and in rural areas (WHO, 2011). Highest in NW, FS, NC (GHS, 2012)

**What kind of actionable impact
and change can health
professionals make to these dire
statistics?**

World Medical Association:

Medical Practitioners have an **ethical** duty and a **professional responsibility** to act in the best interest of their patients. This duty includes advocacy for patients, both as a group (such as advocating for public health professionals) and as individuals”

Ethical Frameworks

- HPCSA ethical rules
- Code of Conduct for the Public Service

Dual Loyalties and Human Rights:

HCWs may experience spilt loyalties and it shows up in the conflicts between the ethics of the profession, duty to the user and duty to the state/employer

Dual loyalties

According to the SA Public Service Regulations of 2001, updated 2012:

“Health care providers are expected to raise any problems with their immediate supervisor and are **not to criticise government policy** “irresponsibly” in the public domain.”

The same regulations also state health care providers must put the public interest first in the execution of her or his duties....

What about the confidentiality clause in my contract?

- The contract is invalid if it conflicts with the PDA and Public Service Act which says

“An employee, in the course of his or her official duties, **shall** report to the appropriate authorities, fraud, corruption, nepotism, maladministration and any other act which constitutes an offence or which is prejudicial to the public interest.”

"shall" is mandatory language, it means "must" not "should"

What to disclose: “impropriety”

- Crime, failure to comply with any legal duty (including negligence, breach of contract, breach of administrative law), miscarriage of justice, danger to health and safety, damage to the environment, discrimination and the deliberate cover-up of any of these. It applies to concerns about past, present and future malpractice.

What am I protected against?

- Occupational detriment
 - Very broad, definition includes: harassment, dismissal, transfer against the will of the employee, non-promotion, a denial of appointment, or “otherwise adversely affected”
 - But, there are limits to the reach of the law

However all of this is not easy:

Can be scary to speak out because of

- Lack of support
- Intimidation
- Fear of disciplinary action/dismissal/victimisation
- Lack of advocacy training

Collective action!

Organise! Organise! Organise!

The constitutional mandate for advocacy

- **Section 9** “Everyone .. Has the right to equal protection and BENEFIT of the law. **Equality** includes the full and equal enjoyment of rights and freedoms.”
- **Section 10** “everyone has inherent **dignity** and the right to have their dignity respected and protected”
- **Section 11** “everyone has the right to **life**.”
- **Section 27** “Everyone has the right to have access to **health care services** ... No one may be refused emergency medical treatment”
- **Section 28** “Every **child** has the right to ... **Basic health care services**..

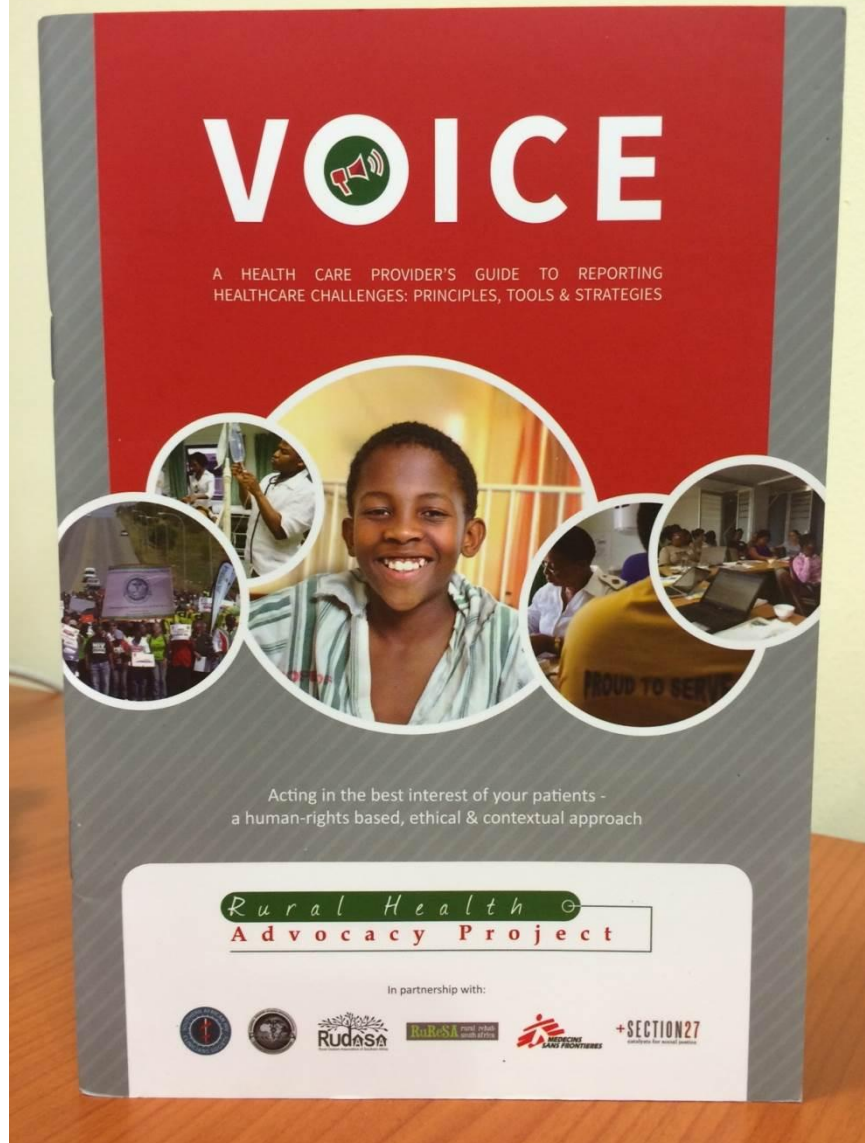
The constitutional rights individual and organisational advocacy

- Section 7 + Section 16 + Section 19
 - The State must respect, protect, promote and fulfil the rights in the Bill of rights..
 - Everyone has the right to freedom of expression ..
 - Every citizen ... has the right to campaign for a cause

What have HCWs done?

- Many have spoken and acted out against patient's rights violatins
- Many have been, disciplined, dismissed or victimised
- Many HCWs lack the confidence, skills and knowledge to pursue cases in advocating for patients' rights

A HealthCare Provider's Guide to Reporting Health Care Challenges: Principles, Tools and Strategies



Overview of the Voice Project

- Why it is so vital to advocate on behalf of your patient and encourage patients to advocate for improved health care themselves?

Patient
Complaints
and Adverse
Events



Reporting and
Whistle-
Blowing

- What do we mean by “reporting”
- When reporting, do you have a mandate to report?
- Do you report? Why or why not? How?
- How to report (tools and strategies)
- Strategies to protect against reprisal

Impact of your Action or Inaction

- The impact on individuals, families, and society that are affected by ACTION AND INACTION alike!
- There are hidden costs of inaction that can further perpetuate the culture of fear and intimidation i.e it gives life to the very failure of clinical leadership
- Health professionals are gatekeepers with power and you should use this power to advance patient's rights rather than to abuse this power

Did you know?

- You can make a change!
- There ARE tools at your disposal to make this change
- South Africa had a proud and effective tradition of HCWs and workers in general speaking out, taking risks and making sacrifices to shape effective policies

CASE STUDY: SAVE THE BABIES CAMPAIGN TAC

Patient Rights Charter

- Allows for
 - Participation in decision making
 - Access to healthcare
 - Healthy and safe environment
 - Choice of health services
 - Treated by named HCW
 - Knowledge of your medical aid
 - Second opinion
 - Continuity of care



health

Department:
Health
REPUBLIC OF SOUTH AFRICA

A National Complaints Management Protocol for the Public Health Sector of South Africa

AUGUST 2014

National Complaints Management Protocol

- Assists the patient or his/her family to lodge a complaint about poor service received at a health care facility
- HCP should advocate for the implementation of the NCMP because it assists to improve service delivery, it allows the facility to acknowledge the problem and the patient does not feel neglected or abandoned by the health system.
- The complaint must be acknowledged within 5 working days in writing or telephonically
- If the complaint cannot be resolved sooner, a response to the complainant must be given with 25 working days about how the resolution will proceed
- A complaints register must be available at each facility for record-keeping

How to report health care issues

failures within the public health care system that prevent sound service delivery

- INTERNAL
 - Within DOH
 - Facility (informal and formal written) using the NCMP colleague, manager
 - District or Provincial
 - National
 - Office of Health Standards Compliance
- EXTERNAL
 - Professional Bodies e.g HPCSA, SANC, SAPC etc.
 - Independent Constitutional Bodies eg. SAHRC, Public Protector, Ombud of OHSC
 - Media
 - Legal
 - Advocacy organisations
 - Unions

What are the best “admin- and comms”-related tools and tips?

1. Start as soon as possible with “internal strategy”
2. Gather all the key facts
3. Descalate conflict with superiors, remember the end-game [you still need to deal with your superiors on other issues!]
4. Step 1 is always internal reporting at the level closest to you (at facility) before escalating it
5. Use the established systems to raise concerns (e.g. mortality and morbidity meetings)
6. Follow up in writing
7. Document all effort made to improve the situation, including communications
8. Liaise with others (colleagues, patients, organisations)
9. Organize, organize, organize! Organise to empower yourself and others, there is strength in numbers
10. Talk with the focus on the rights of others, not yourself

Document and keep records of all issues relating to:

1. Patient rights (individual)
2. Danger to health and safety (for the patient, for you, and for others)
3. Relevant laws, policies and frameworks e.g. the National Core Standards or the Patient Rights Charter
4. Your duties in terms of ethical rules of the HPCSA, the Code of Conduct for the Public Service and the Public Service Act
5. The public interest
6. All prior efforts or communications you have made.

Protected Disclosures Act

Practical guidelines for employees (NO. 702 31 August 2011)

- By remaining silent about corruption, offences or other malpractices taking place in the workplace, an employee contributes to, and becomes part of, a culture of fostering such improprieties which will undermine his or her own career as well as be detrimental to the legitimate interests of the South African society in general. Every employer and employee has a responsibility to disclose criminal and other irregular conduct in the workplace

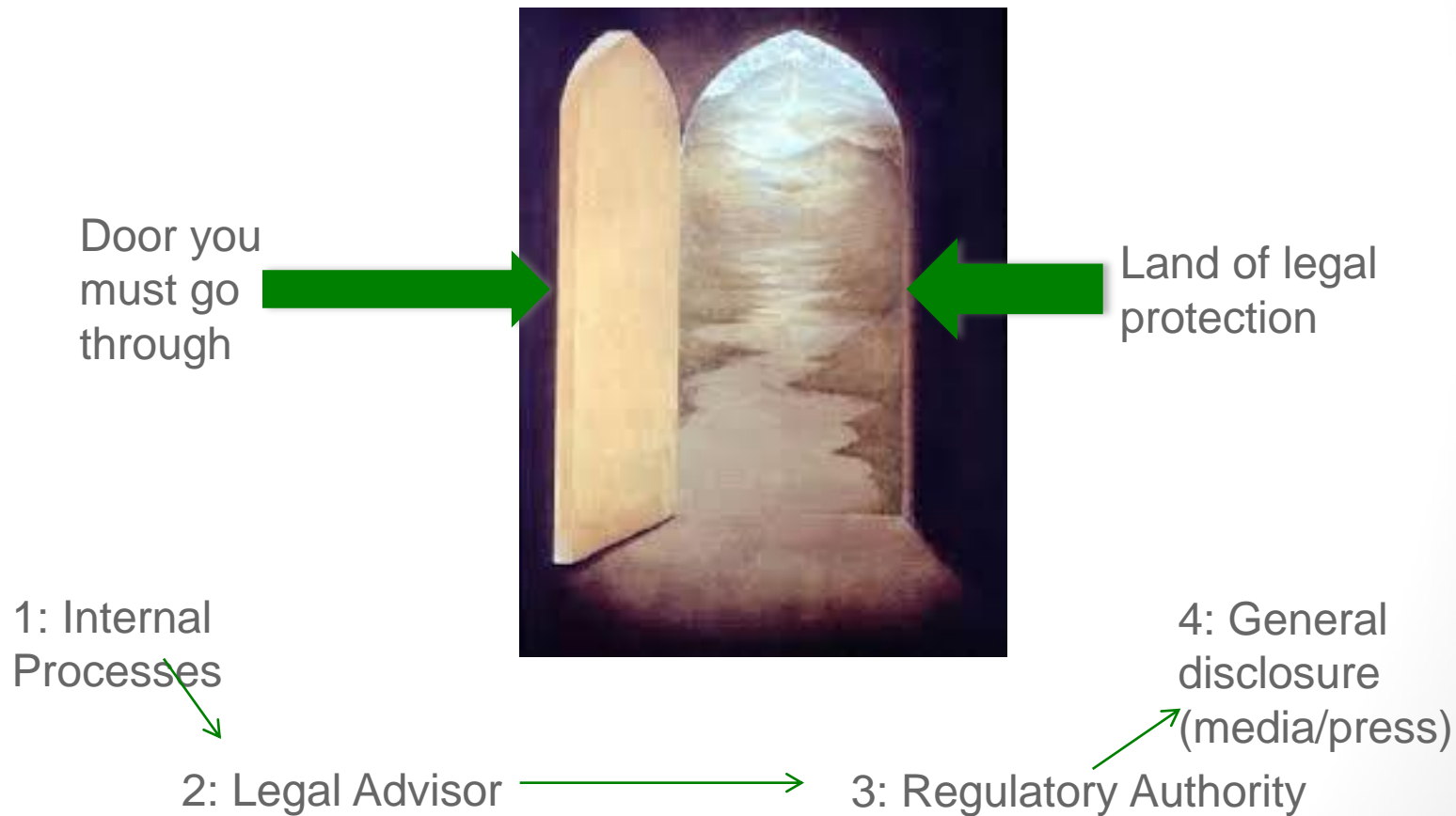
When do you whistle blow?

- Whistle blowing is about ensuring that “malpractice, fraud, corruption, dangers that compromise patient health and safety”* –are dealt with in a manner that promotes individual responsibility and organisational accountability
- It is not only a right but also a duty to report conduct that is prejudicial to public interest

*Protected Disclosure Act

How to whistle blow: the Protected Disclosure Act

- Protected Disclosure Act: four doors to legal protection



Door 1: Internal

- Through your internal process:
 - Good faith
 - “substantial” compliance with relevant procedure

Door 2: Legal advisor

- Legal advisor:
 - To seek advice about the concern and how to raise it
 - Everything you say here is Confidential!
 - Good faith does not apply

Door 3: Regulatory authority

- Office of the Public Protector, South African Human Rights Commission or Auditor General
 - Must be done in good faith
 - Does not have to be raised with employer first
 - It must be substantially true

Door 4: “General Disclosure”

- Police, Media ..
 - This must not be done for personal gain - you must have an honest and reasonable belief that it is substantially true
 - You must show “good cause” for going outside

The 4 good causes

- The concern was raised internally or with a prescribed regulator, but has not been properly addressed
- The concern was not raised internally or with a prescribed regulator because the whistle-blower reasonably believed he or she would be disciplined, dismissed or victimised.

The 4 good causes

- The concern was not raised internally because the whistle-blower reasonably believed a cover-up was likely and there was no prescribed regulator, or
- The concern was exceptionally serious

3 Case Studies

A 52-year-old woman, Mrs Madwe, arrives at a rural PHC in Mpumalanga at 07h00. She has TB and has been on treatment for three months. She has come to pick up her medication for the following month.

A health care worker sees her at 12h40. The clinic does not have two of the drugs that she is currently taking.

- Sr Jafta, a professional nurses, apologises to the woman for the lack of medication, indicates that there is nothing that she can do and asks her to come back the following day by which time she – the HCP – is sure that the drugs will have been delivered.

Case study continued....

Sr Mthembu, a professional nurse asks Mrs Madwe where she lives and feels incredibly frustrated to learn that she has walked over an hour to get to the clinic and still be seen too after such a long wait. She complains profusely to the nurses about the lack of medication and resolves to bring this up at the next sub-district managers meeting.

Once again she wonders about taking up the recently advertised position at the NGO clinic in the nearest town because the strain on patients is taxing on her spirit.

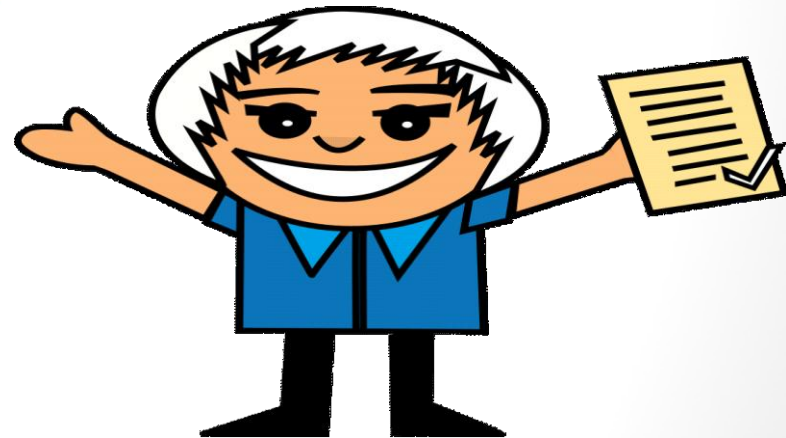
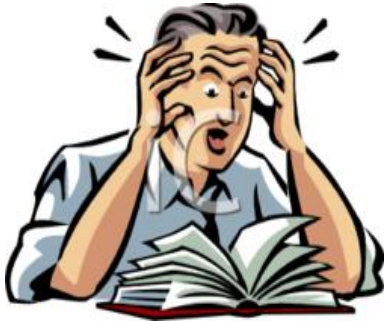
Case study continued....

Sr Phaswana, a professional nurse, rings her immediate supervisor, two neighbouring clinics and the local district hospital to find out if any of them have stock of this drug. She then asks Mrs Madwe where she lives and establishes that there are community health care workers in her village.

She arranges for the community health care workers to deliver the outstanding medication to Mrs Madwe the following Thursday. The health care worker then finds out for how long the medication has been out of stock and why from clinic staff.

She documents the number of TB patients who have been sent home without their drugs. Armed with this information she attends the next sub district managers meeting and raises this as a critical issue.

Which one of the 3 health professionals are you?



Rural Health
Advocacy Project

In partnership with: RuDASA, RuRESA, PACASA, MSF, SECTION27, SA HIV Clinicians Society and our academic partners / Centre for Rural Health

Follow us:

Web: www.rhap.org.za

Twitter: RHAPnews

Facebook: Rural Health Advocacy Project

Subscribe to RHAP mailinglist: Send email with subject "mailing" to info@rhap.org.za

Samantha@rhap.org.za

011 – 880 0995 ext 110

083 3788 120