

## Executive Summary - Seminar 2012 on People-Centred Care

### Ways towards individual and collective wellbeing in North and South

#### *Intro*

The achievements of modern medicine over the last century are impressive. The development of new medication, the evolution of and new insights in molecular biology and gene therapy, advances in diagnostic procedures,... Due to all these rapid changes, the scientific approach to health has gained importance. Often at the expense of a human or empathic approach of the patient. The psychosocial and cultural aspects are often not taken into account at the time of diagnosis and treatment. This in turn can lead to bad communication, a patient ill at ease, non-compliance and bad results...

Therefore the Be-cause Health network decided to dedicate its 8<sup>th</sup> annual seminar to people-centred care. The objective was to exchange ideas and best practices between health care workers in the North and South and to come up with solutions that really meet the needs of the people. Because the health and the well-being of all people are still the central goal of health care. Health systems therefore need to change and take on a more holistic and people-centred approach. But how to put that into practice? What are preconditions and obstacles? Are there positive experiences to learn from? These and other questions were tackled in the different sessions of this one-day seminar focusing on formulating recommendations for achieving more people-centred health systems, striving for both individual and collective wellbeing at an operational and organizational level.

*Lut Joris, Coordinator Be-cause health*



Keynote speech by Hernan Montenegro, WHO | Active session on Concept Mapping | The interested public

## **Opening session & key note speech**

**Peter Decat**, International Centre for Reproductive Health, Ghent University, and coordinator of the working group on people-centred care, introduced in an original way the right mind-set of this seminar. He compared people-centred care with the paintings of Michelangelo on the roof of the Sistine Chapel. In these famous paintings Adam & God are nearly touching each other on an equal basis, embedded in a large crowd, the community. Similarly, people-centred health systems consider patients, health providers and communities as equal partners who contribute to the promotion of universal health. To illustrate the importance of the community, Peter gave the example of Nicaragua, where community pressure was needed to convince health workers to make contraception available for adolescents.

In his key note speech **Hernan Montenegro**, Health Systems Advisor at WHO, explained the policy, mandate and work of WHO on people-centred care. He urged all the participants to read some of the work that already has been done: the 2008 WHO report on *Primary Health Care now more than ever*; the 2010 WHO report on *Health Care Financing* and resolution 62.12 of the World Health Assembly on Primary Health Care and the WHO glossary on people-centred care. He promoted universal coverage with its three basic elements: who is covered, in what proportion, and for what problems? He, and both speakers after him, also underlined the importance of a unified understanding of the concept of people-centred care, to properly study and measure it. He stressed that WHO advances people-centred care through research, guidelines, monitoring & evaluation.

## **Promoting individual well-being**

For **Joep Grosemans**, International Projects Coordinator at the PHL University College of Hasselt, patient-centred care finds its origin in doctor-patient interaction. It is about seeing the patient as a biopsychosocial (and cultural) whole, as an individual person, with whom a doctor needs to form a therapeutic alliance, characterized by shared decision making. Some models also include other aspects like education, prevention and health promotion. In a broader managerial context, patient-centred care is also the design of patient care where institutional resources and personnel are organized around patients rather than around specialized departments. People-centred care takes the concept out of the physician's office, into the person's living conditions. This is currently done in residential and chronic care, but much less than needed in family medicine and preventive care. There are plenty of examples to demonstrate that patient- and person-centred care should be adopted in many other healthcare settings and are essential in community and preventive care settings in developing countries. Innovative projects for patient- and person-centeredness should be supported by the management of their institution, should be embedded in existing social structures and should pay attention to documenting the effect on the patients' health, quality of life and economical outcomes.

**Paul Van Royen** from the Department of Family Medicine, University of Antwerp, assessed people-centred care in Belgium. There is hardly any research, but he showed that the medical encounter has always been more disease- and hospital-oriented. Only recently, it has become more patient-centred. But there are also currents against this: evidence-based medicine and more technology. The law on patient rights in 2002 (on choice, information, consent, privacy, right to complain) is uniformly implemented but health workers preferences go against giving choices. And chronic patients are not involved in making guidelines as in the UK and the Netherlands. Broad active listening and team work are now being taught to medical students and central medical records improve the continuity of care. But there are obstacles. One of them is the therapeutic alliance: patients never learned to talk to their medical doctor. And another important aspect related to this is the self-care of the doctor, to be able to strike the right balance between too much emotional involvement and emotional blunting.

The audience added two other elements: patients have not learned to take on an active role and a law alone cannot change that; and secondly that a condition for success in treating a child is by getting the family on board.

To conclude this session **Vincent Mubangizi**, Mbarara University of Uganda, put some experience from the field next to all the theory. He talked about patient-centred care in Uganda, about the long way there still is to go since there are many constraints and difficulties. He started from the definition of patient-centred care (as described by Stewart) and applied this to the situation in Uganda. He more specifically highlighted the problems of high workload and under-staffing in health services, the

poor communication skills of health workers, but above all the fact that the bio-medical paradigm in medicine and health care is still very much prevailing. He quoted a health worker saying: “we are trained to treat and cure, but not to care”. But he did end on a positive note with recommendations and ways forward, like for example the need to integrate people-centred care in the curricula of all health professionals, to promote patients’ rights and empower communities.

### ***Promoting Collective Well Being***

Before summarizing some key elements of people-centred care, **Wim De Ceukelaire**, Third World Health Aid in Belgium, introduced both historical and recent conceptual developments on the topic. He recalled how in the 1960s-70s community-based approaches started off with barefoot doctors and village health workers, mostly in Asia and Latin America. But it was the South-African Sidney Kark who coined the concept of Community-Oriented Primary Care. Community diagnosis, popular education and indeed collective action were considered to be inherent to these community-based approaches. The Alma Ata declaration (1978) as well as the Ottawa Charter on Health Promotion lifted these experiences to an international level. The latter insisted on the transition from intersectoral action to health as public policy. Neoliberal health sector reform throughout the 1980s and 1990s pushed these insights back, as cost effectiveness and individual health came to the fore. Combined with the social and economic impact of neoliberalism this caused increasing inequalities. The consequences of neoliberal policies yielded resistance from below, where concepts like empowerment, community participation and the right to health gradually found their way back. This was reflected in 2008 by the World Health Report insisting on primary health care and the conclusions of the WHO’s Commission on Social Determinants of Health. It is now widely acknowledged that the collective aspect of people-centred care has to include equity, understood as social justice.

To add to this, some experiences from the South were put to the forefront. First **Jovita Montes**, Programme coordinator for health and services at the organisation Gabriela in the Philippines, talked about the experience of this alliance of Filipino women. Gabriela was founded in 1984 as a militant women’s movement that took on national economic and political issues as women’s issues. She stressed the social and economic inequalities in the Philippines: the net worth of the 25 wealthiest Filipinos is equivalent to the combined yearly income of the 55 million poorest. Yet, the government’s development plan insists heavily on public-private partnerships in the delivery of social services, which traditionally tend to favour those better off. The national program for health is also dominated by the privatization of both services and ownership of public health centres. The Department of Health is rapidly removing almost all of its service outlets and changing itself into a mere policy, regulating and research centre. Thus pushing all its services into privately-operated hospitals. High prices for out-of-pocket treatments result in further reduction of household incomes, thus making families less fed, housed, clothed and schooled. Classic factors that make individuals prone to infections, malnutrition, mental health issues. For Gabriela promoting people-centred care starts with the empowerment of women through education and collective action to take care of their immediate needs and to urge the government to take up accountability for the people’s well-being and health.

**Ariel Frisancho**, Coordinator of ForoSalud in Peru, highlights the high diversity and inequality in Peru. While it is a middle-income country, its population is plagued by inequities, discrimination and poverty. National averages show advances on the MDGs, but there is a high incidence of avoidable sicknesses and deaths amongst the poor and a lack of integral approaches. Unequal access to and poor health services’ responsiveness worsen this further. A major civil society platform on health established in 2002, ForoSalud has over a 100 member organizations and 1000 associates at the national and regional level. All members are volunteers who attempt to build national and sub-national alliances to strengthen advocacy efforts. Working with a range of partners, ForoSalud emphasizes the importance of citizens’ participation as a means to influence policies, but also as an end in itself, for building citizenship. The organization tabled a health sector reform proposal and insists on strengthening participation at national, regional and international level, raising awareness through the public opinion (for example ‘informed watchdog’ for media) and implementing social auditing. This relates to the creation and support of grassroots citizens’ surveillance mechanisms to monitor health service delivery and demand governmental accountability and health system responsiveness.

**Abdoulaye Sow**, Fraternité Médicale Guinée in Conakry, **Michel Roland**, Université Libre de Bruxelles in Belgium, and **Chantal Hoornaert**, Maison Médicale Maelbeek in Brussels, talked about the balance between the individual and collective dimensions of patient/person-centred care by presenting their collective project. Fundamental to the project are the values of health care: centred on the patient and the collectivity. These include dignity and respect, information sharing, participation, and cooperation.

The NGO Fraternité Médicale Guinée offered its experience in promoting this in Guinea, which included a mental health program, a long-term and global care project for chronic illnesses (HIV/AIDS), specialized GP training courses, peer observation including North-South exchanges and community health projects. While in the North health care systems generally favour an individual approach to care with a long-term follow-up of patients, in the South community diagnosis and one-shot episodes are widespread. Based on this complementarity, some concrete achievements of the collective North-South project were offered like the introduction of more patient-centred clinical methodologies in health centres in Guinea and an increasing attention for health information systems in the Belgian Maisons Médicales. Michel Roland insisted on how these exchanges also reinforced the training of GPs at the Brussels University ULB.

## ***Ways towards people-centeredness: keynotes and debates in parallel sessions***

### **Session A: Promoting people-centeredness at operational level**

Paul Bossyns (BTC Brussels) presented a number of cases coming from his rich experience as clinician in a variety of (African) settings. He systematically tried to bridge the clinical approach and a number of methodological, organizational and structural elements in the provision of health care. By doing so he clearly illustrated the need for a layered approach to the delivery of people-centred care. There is need for an appropriate clinical method at the micro-level, but also for a conducive organizational environment, for health personnel that is genuinely integrated in the community and for a health system that values the delivery of people-centred care. The case studies illustrated several interesting aspects of people-centered care. The importance of listening was largely debated, including retranslating patients' messages in order to understand symbolic language. Making use of anthropological knowledge on for instance divorce procedures to establish and propose acceptable strategies for the patient was discussed. A variety of clinical cases, like chronic patients, psychosis, family dramas, infertility, divorce and psycho-somatic complaints were touched upon. A lively discussion followed the presentation of these cases. One of the elements raised in the discussion was that people-centred care is not only relevant for the management of complex psychosomatic cases, but also for so-called minor/benign cases a health service is confronted with on a day-to-day basis. People-centred care has to be there for every patient!

### **Session B: Facilitating people-centeredness at organizational level**

**Hernan Montenegro** presented several case studies conducted by WHO in different countries. The key problem that came out of these studies is human resources; and the key elements in successful experiences appeared to be the strengthening of the community and the use of information. He also talked about facilitators and barriers of people-centred care in these case studies. Important elements indicated were the family, again the community that invests in promotion, prevention and outreach and bureaucratic reforms. He ended his intervention by looking at the lessons learnt - focusing on different levels - like the need for strong political will and leadership; the need to link people-centred care with equity, rights and universal health coverage; the need for system wide approaches and strong primary care services. (See presentation for more details.)

**Ariel Frisancho** illustrated the problem of women not going to health facilities. One of the reasons is the demeaning way midwives or nurses talk to them. For him this problem is very much linked to a lack of respect for their culture and their rights. Often in discussing for example maternal mortality these 'missing links' are not taken into account. When talking about linking the national and local levels, he urges everyone to go into dialogue with the community, giving the example of the *vigilantes* in Peru. These are citizen surveillance mechanisms spearheaded by women monitors, surveilling and analysing results of the health facilities. Key here is the creation of systematic dialogue and common analysis. Other important aspects to facilitate this are political will, technical assistance, a gender equality approach and the need to learn to listen.

**Jovita Montes** insisted on how community organizations can facilitate people-centeredness through their programs and actions. She highlighted Gabriela's use of methods of social investigation in the Kampanya kontra Gutom (anti-poverty campaign) as a way to attain a more people-centered approach through community empowerment, education and mobilization. Consultation of leading figures within the community led to an investigation and evaluation of the effect of the living conditions of the slump of the fishing industry on the lives of the people. Social investigation and mobilization efforts contributed to raising awareness within the community about the causes and consequences of their living conditions. This subsequently led to a campaign and a petition that was submitted to the local *barangay* (neighborhood authority) council for endorsement by the city mayor. The campaign, which included demonstrations by local populations, proved a great tool for dialogue with local *barangays* and (provincial) government units. The efforts of mobilization and dialogue with the authorities empowered the people to lobby the authorities and demand concrete care services centered on the population's concrete needs.

In the discussion afterwards one of the issues debated was the position of traditional healers. The common view was that collaboration between all the providers is key for the continuity and coordination of care. An important part of people-centred care is also to bring everyone together and think about integrated care, like for example joint medical sessions, sharing a single medical record,...

### **Session C: Teaching people-centred skills to health professionals**

This session started with a presentation by **Katrien Bombeke**, Faculty of Medicine, University of Antwerp in Belgium, on fostering patient-centeredness in future doctors and by stressing that this is about more than just skills. She presented the ACE-model and showed how attitude, social influence and self-efficacy affect the intention of the future doctors. Apart from the skills of the doctor and the barriers, there is also the personal context of the doctor that influences his or her final behaviour (emotions, life history, self-care,...). She ended by explaining the idea of transformative learning as a way to overcome some of these barriers.

The session continued with a presentation of **Joep Grosemans** on teaching patient-centeredness to nursing students. Since the competences and teaching methods are similar to those presented by Katrien Bombeke, his part of the presentation focussed more on Marjory Gordon's Functional Health Patterns as a framework for a patient-centred anamnesis.

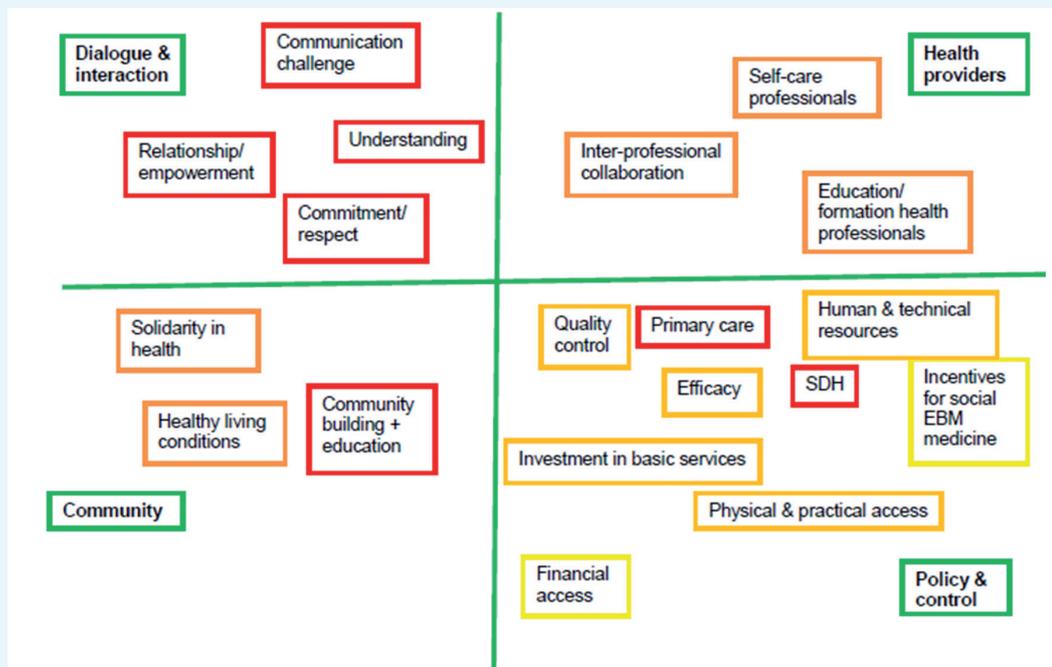
The second part of the session was set up as a fishbowl discussion where people shared experiences or indicated specific problems. The main conclusions of this discussion:

- Education is sometimes a long way from reality. We should be more creative to bring students closer to the reality.
- We need a certain number of doctors and we need to think of quality of care. To achieve both we have to involve a multidisciplinary team and we need investments at the political/organisational level.
- North and South both recognize the importance of training on patient-centred skills. But the education of health professionals should also focus on learning how to work together from the start (interprofessional team) and being creative (for example let the student experience what being a patient is like). Other factors such as attitude, role models and the mentality of the system also have a big impact. In the South, the 'doctor-as-person' factors are recognised as well, but perhaps in a different way. The discussion often focused on basic daily conditions such as workload and payment. On the other hand, it was acknowledged that people-centeredness is also about mentality, an inner motivation.

## Session D: Building a concept map on people-centred care

Concept mapping is a structured method for organising ideas of a group or organisation. It helps participants to think effectively as a group without losing the uniqueness of individual contributions. It helps them to organise their ideas and form a common framework that can be used for planning or evaluation. It combines qualitative and quantitative components which can be presented as a visual map.

The concept of people-centered care was addressed in a very participative and structured way by means of this concept mapping session. In the weeks before the session participants were asked to provide statements that describe the preconditions and obstacles for people-centered care. 91 statements from 4 continents were presented for further work at the parallel session. Under the guidance of **Karel Gyselincx**, Belgian Technical Cooperation, assisted by Evelyn Vanderbrugghen en Michelle Ihirwe, 10 participants structured and scored the statements. Due to time constraints, they only initiated the discussion of the final map. Thus **Christine Leyns**, department of Family Medicine, Ghent University, processed and finalized the map afterwards. Actions at the level of policy, the community, the health providers and the interaction between the different stakeholders were identified and put in clusters as shown in the map below. The map demonstrates how the participants perceived the relations between the different statements.



A committed, respectful and understanding health care provider with good communication skills and a strong empowering relationship with patients and the community was highly valued by the 10 participants. Community building and education, strengthening primary care and working on social determinants of health were rated at the same level of importance.

This concept mapping workshop is part of a broader research on people-centered care and more results will be available in the near future.

## ***Final panel on the way forward***

This discussion with Hernan Montenegro, Jovita Montes, Ariel Frisancho, Katrien Bombeke, Paul Bossyns and Abdoulaye Sow focused on two key questions: what are the most important lessons learnt during this seminar and what are your personal recommendations for the future? Apparently it was a very productive day, since many aspects were brought to the fore:

- The broader context and the different societal levels have to be taken into account when assessing and promoting people-centeredness in health care. All actors should be taken in consideration.
- It is a challenge to identify a strategy to promote people-centeredness. Research should focus on the implementation process.
- Attention should be given to reach all actors of the health system.
- Two movements are necessary to promote people-centeredness. A bottom-up movement on the one hand, where communities and patients have knowledge about their rights and stimulate and compel providers, authorities and policy makers to make health care more people-centred. But a top-down approach is also needed. Policy makers and international, national and local authorities should create conditions and develop strategies to promote people-centeredness.
- At the international level people-centeredness should be linked to the agenda of universal health coverage.
- The support of the WHO is important and needed.
- Communication is a key aspect in the promotion of people-centeredness. Communication training should not only address medical students but also other caregivers.
- There is a shared feeling about the need for people-centeredness. However, there is no unanimity about how to reach a more people-centred approach to care.
- There is a unidirectional focus on educating patients and bringing them at the level of health providers. However, for achieving more people-centeredness it is key that caregivers, policymakers and health authorities get into the world of the patients. It is a challenge to achieve this at different levels (local, national, international).
- Interculturality should be included. Traditional healers for example should be included in the health care system.
- Following priorities for research and/or action were mentioned:
  - » Patients should know their rights;
  - » Training and research on training strategies;
  - » How to measure people-centred care? Methods and tools are needed to evaluate people-centeredness;
  - » Much time has been spent on the development of people-centred care concepts. Now it is time to get insights on how these concepts can be implemented. So there is a need for operational definitions, operational research and implementation research;
  - » People-centred care should be integrated within the community work;
  - » It is time for action! People-centred care is like surgery: the more you do it, the more you become an expert.

## ***A parting word for Dirk***

At the end of this long and interesting day, it was time for some words of thanks. To the organizers and all the people who helped to make this seminar a success. But also to Dirk Van der Roost, former coordinator of Be-cause Health and founding father of the network. Thanks to him, the network not only came to being, it also became a unique example of national collaboration of many different actors striving for a common goal: to strengthen the role and effectiveness of all the actors of Belgian development cooperation and to make quality health care accessible worldwide.



Karel Gyselinck & Dirk Van der Roost

## ***Concluding observations***

By **Bart Criel**, Public Health Department of ITM, Antwerp

A very valuable aspect of this seminar was the participation of practitioners, researchers and members of civil society coming from the global South and North, working on the realities of patient/people-centred care in their health systems. There is a lot we can learn from each other. Convinced of this, we decided to invite speakers from both South and North. The seminar has proven us right: there is indeed a lot that we have learned from each other.

This is an important lesson and message for all of us involved in teaching, research and advocacy on public health and primary health care: many of the challenges in the organization of health care delivery systems are universal. (Both Professor Van Royen and Vincent Mubangisi used the same subtitle “PCC still a long way to go” in their presentations!) The contexts of course differ (especially when it comes to resources) and the relative weight of the obstacles may and will differ (many of them are also culturally defined). But there are many analytical approaches and solutions that cross-cut South and North and that have global relevance and validity. So let’s not work too much in ‘silos’ and let’s avoid thinking in terms of public health for the South and public health for the North.

The theme of today was patient- and people-centred care. The distinction between the two is not always straightforward. Both are situated on a continuum that goes from individual care for patients, most often in the context of a curative encounter between a patient and a health worker, to care for a community. Many of the tools and methods discussed apply to situations along that continuum: patient/person-centred care is about listening to people, respecting them, showing empathy, engaging in a real dialogue, acknowledging that people themselves have resources/are a resource, allowing patients and people to really make informed choices, promoting autonomy, accepting and embracing the involvement of the community in health policies,... Health systems are there for the people, not the other way round.

I already emphasized the fact that the North can learn from the South and vice versa. There is definitely more room for improvement in our Belgian health system to develop local health care systems that establish a structured and longitudinal relationship with a well-defined population. A relationship in which there is room for proactive action, where structural drivers of ill-health are addressed. There is a strong case to make for primary health care in this country, and in other high income countries, and there is a need to be more ‘political’ and less exclusively technical than is the case today...

On the other hand there is room for improvement in the South to make individual care more patient-centred. There are many obstacles and constraints, some of which have been highlighted at this seminar. Health systems are often under-resourced (especially in Africa); they are fragmented with a supply of care that is too much programme-driven and not enough shaped by people's needs. The organizational culture is often bureaucratic, with strong hierarchical relationships and excessive standardization. Models of training of health workers are still dominated by a biomedical vision which tends to emphasize a strong hierarchical distinction between health workers and people hereby neglecting intercultural aspects. Etcetera...

Changing all this is obviously a huge endeavour. There is clearly a need for a multi-pronged strategy with a long term vision and action at the micro, meso and macro level of the health system. Bridges must also be built between individualized people-centred care and people-centred action at community level. Both are necessary and they can and should create synergies with each other. All this needs good preparation and thinking. I am confident we will return home with a number of good ideas.

Allow me to highlight a few things I find particularly important:

- **Exchange visits and observations.** The power of positive real-life practice is not to be underestimated as a learning process. I refer to our own experience at the Institute of Tropical Medicine with our Master in Public Health students, where we let them visit Belgian GP practices. Patient/people-centred care is a bit of an abstract concept and it may be easier for students/trainees to actually see and recognise it, rather than banking only on a cognitive understanding.
- **A positive attitude of health workers towards people-centred care is important but is not sufficient.** There is a need for necessary skills (which can be taught), but also for a conducive environment (at the micro, meso and macro level of the system) where people-centred care is valued by peers, health authorities and academics. Not in the least, proper working conditions for health workers are part of such a conducive environment. The same goes for the more collective dimension of people-centred care: communities need to be aware of their rights and acquire the capacities to organise themselves and raise their voice in the health care debate.
- **We should disseminate more than we do now the evidence that people-centred care works and that it is effective!** (See the work of the late Barbara Starfield from the USA, the excellent 2008 World Health Report on Primary Health Care and many other pieces of research.)
- **In terms of research it would be relevant to identify more precisely the set of obstacles/constraints that exist in different contexts.** Because that is the basis for subsequent local action and change (i.e. the nature of the obstacles: methodological, organizational, sociocultural, political, institutional and their relative importance/weight in different settings).
- **There is definitely also room for more action-research.** If only to show that more people-centred care is possible, also in contexts where non-medical doctors are the frontline health workers. In line with this, it is important that researchers and practitioners reflect on tools and instruments on how to measure people-centred care and more in particular adapt the existing tools to the context in Low and Middle Income Countries.
- Finally, I voice a plea to **join forces and try and group expertise in South and North.** Perhaps we should consider launching an international centre on the study of people-centred care?

All pictures, presentations & background documents are available on the website: <http://www.be-causehealth.be/en/events/annual-seminars/seminar-2012.aspx>