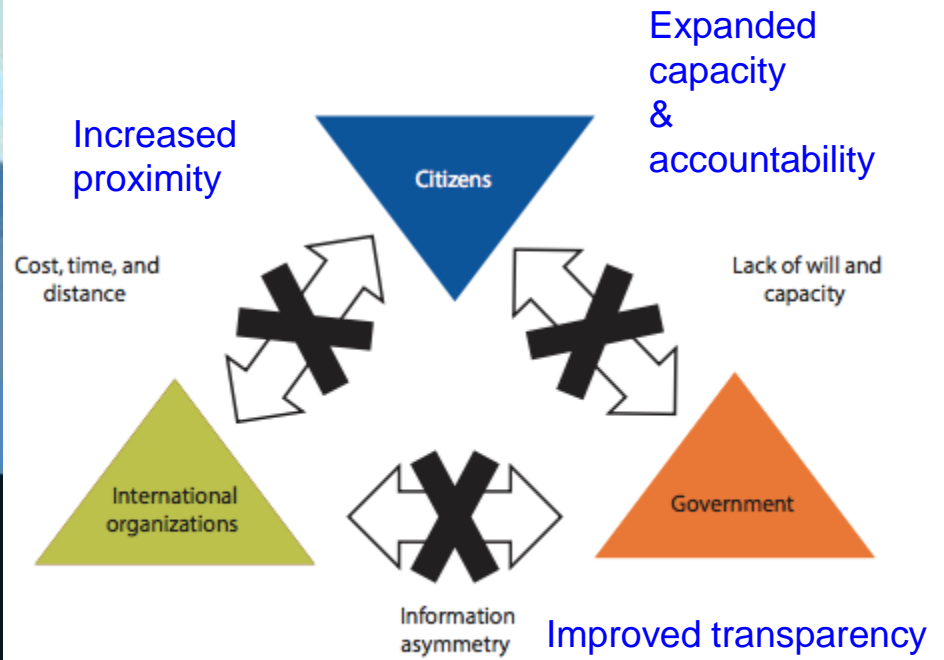
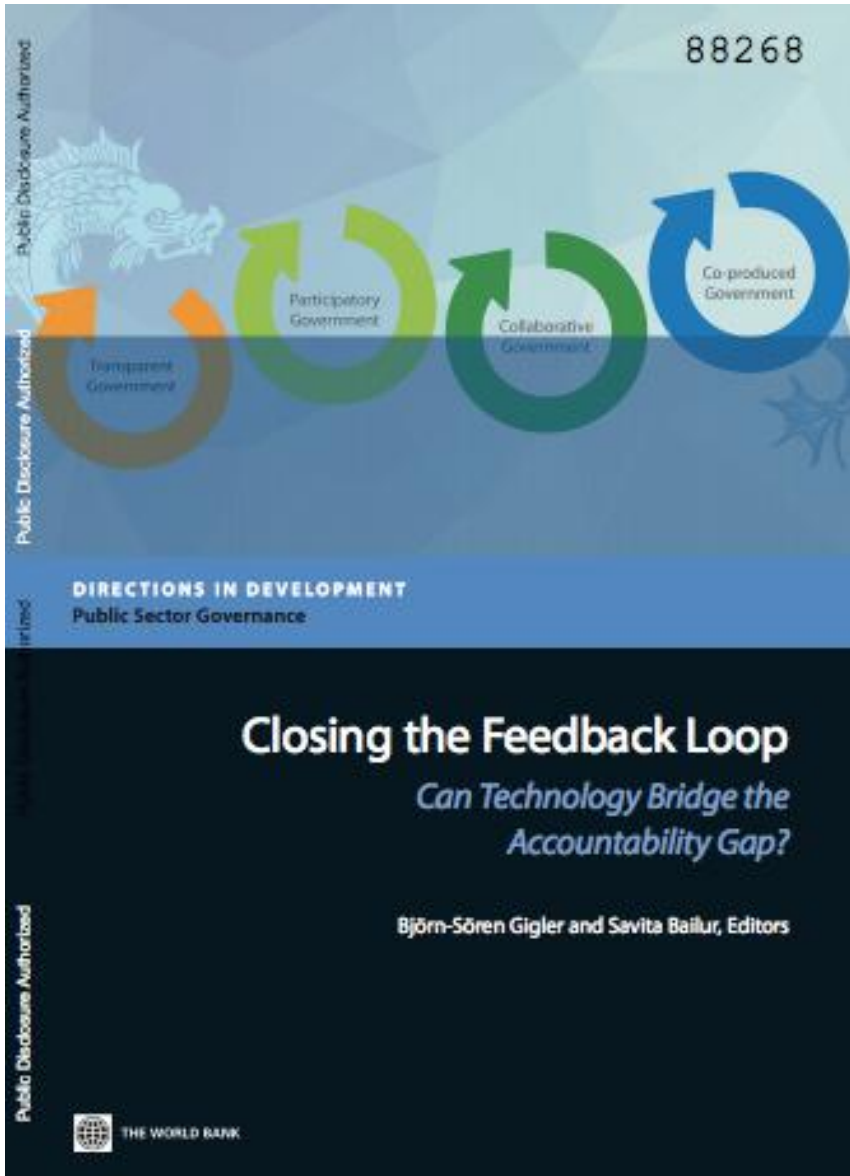


Open innovation

Patients as catalysts for change



Source: Samantha Custer, adapted from Custer, Novin, and Palumbo 2011.

CONCEPTS

- **Citizen feedback loop** (sharing information, giving feedback, tacking action): successful planning, management & evaluation of development projects
- **Citizen participation:** understanding citizenship as ‘the rights and responsibilities’ of individuals (Aristotles); participation is not mere ‘accountability’, it implies ‘ownership’ of projects.
- **Civic engagement:** civic society as ‘the multiple organizations buffering between citizens and the state, including political parties, news media, traditional interest groups [...]’ (Norris, 2003)



Patient Research
Exchange



United Patients
Online academy

SICPA Contributes to a World Bank Pilot Project to Fight Falsified and Sub-Standard Medicines

WASHINGTON, October 28, 2014

Marking a further step in the cooperation between SICPA and International Organizations, Anne-Marie Leroy, Senior Vice President and General Counsel of the World Bank Group, and Pierre Viaud, Senior Director Public Affairs & Government Relations of SICPA, signed during the Law, Justice and Development Week 2015 an agreement confirming SICPA's contribution to a Pilot Project developed by the Global Forum on Law, Justice and Development (GFLJD).



RareConnect.ORG
A PARTNERSHIP OF EURORDIS AND NORD

An open innovation system for rare diseases in Brazil

Towards a bottom-up approach with patients
as innovators

Agenda

A decorative graphic consisting of a series of overlapping, light blue chevron arrows pointing to the right, starting from the left edge of the slide and extending towards the center.

1

Healthcare delivery in Brazil

2

Rare diseases

3

Open innovation

4

Solution

5

Strengths and limitations

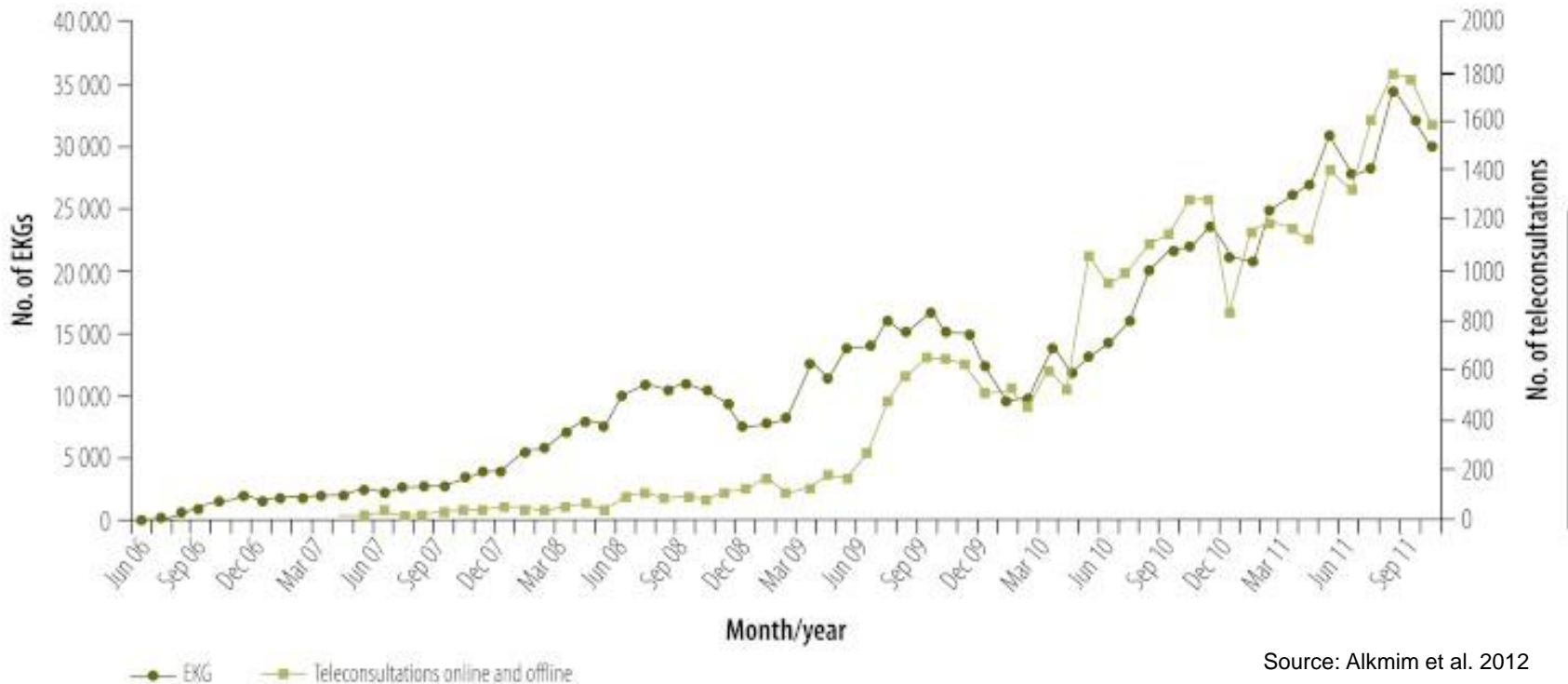
General problem

Low demand
Rare diseases = Poor access to specialized healthcare



Physical (hospitals, clinics and other facilities)
Treatments, diagnostic tests and technologies

Public policies



Source: Alkmim et al. 2012

Rare diseases

- **13 million people** (+ São Paulo, New York, L.A.)
- February 2014: first comprehensive national policy for rare diseases
- The SUS will incorporate 15 new tests to diagnose rare diseases and **accredit hospitals and institutions** for the care of patients suffering from these diseases



DISEASES

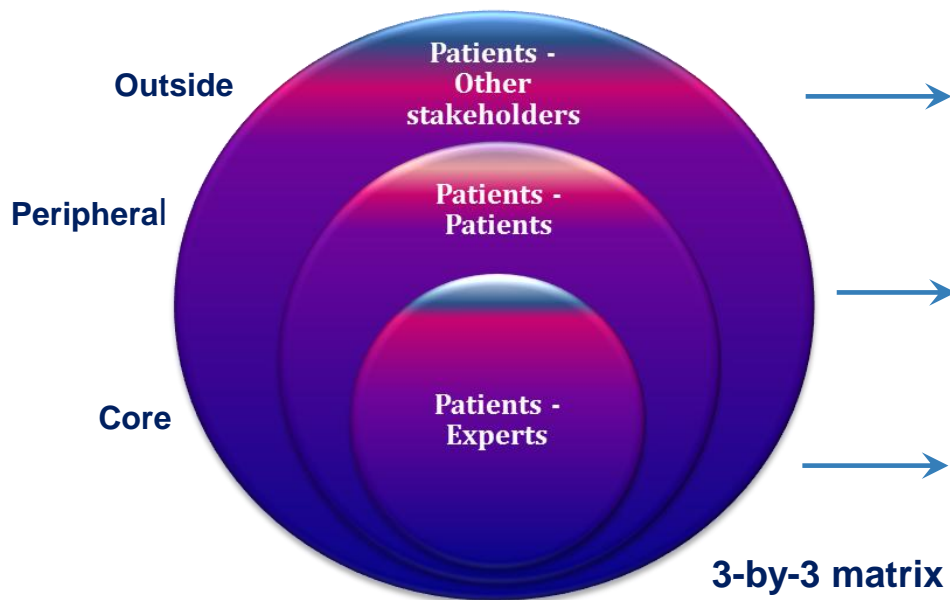
Addison's Disease
Congenital Adrenal hyperplasia
Congenital Hypothyroidism
Crohn's Disease
Cystic Fibrosis of the Pancreas
Pulmonary Cystic Fibrosis
Gaucher's Disease
Hereditary Angioedema
Hereditary ichthyosis
Hypoparathyroidism
Hypopituitarism
Myasthenia Gravis
Multiple Sclerosis
Phenylketonuria
Sickle Cell Disease
Turner's Syndrome
Wilson's disease
Etc.

Open innovation

- Health 2.0 is the use of Internet or Web 2.0-based technology in health care (Van De Belt et al. 2010)
- The innovation potential of Health 2.0 is still under-researched
- User participation, openness and network effects

Open innovation system (Chesbrough, 2003) that may leverage the participatory practices already promoted by the Brazilian Federal Government in order to strengthen the public provision of health care for rare diseases in conjunction with the patients and other stakeholders, optimizing resources, improving access and quality of health care

Innovation ecosystem – Quadruple helix



Information Incremental Radical

		eDemocracia	
Instituto Baresi	Telehealth		

Platforms

Solution

- Community for patients and affected people of rare diseases that will connect them to a multitude of possible problem solvers like caregivers, researchers, engineers, other patients, and policy makers
- Two focuses: 1) Information dissemination and social support
and 2) Innovation creation –incremental and radical- (market place for exchanging ideas)
- It should start as a pilot, scalable to other Portuguese-speaking countries (+220 million native speakers)
- Inspired by the model of GemeinsamSelten (*Rarely Together*), launched in 2011

The screenshot shows the homepage of the 'Gemeinsam für die Seltenen' website. The header features the logo 'Gemeinsam für die Seltenen' on the left, the title 'Die Initiative zu seltenen Erkrankungen' in the center, and a login form on the right with fields for 'Benutzername' and a password, and buttons for 'Anmelden', 'Registrieren', and 'Passwort vergessen'. Below the header is a navigation bar with tabs: 'Start', 'Probleme', 'Lösungen', 'Projekträume', 'Community', 'Über die Initiative', and 'Mein Profil'. The main content area is divided into two sections. The left section, titled 'Gemeinsam für die Seltenen!', contains a paragraph of text: 'Mach mit bei der Initiative zu seltenen Erkrankungen und werde Teil einer lebhaften Community! Suche gemeinsam mit Anderen nach Lösungen, die Betroffenen seltener Krankheiten helfen. Dein Wissen wird gebraucht, Deine Ideen können etwas bewegen... egal ob Du selbst betroffen bist oder nicht, ob Du täglich mit seltenen Krankheiten zu tun hast oder nicht.' Below this text are links for 'Mehr Info', 'Mach mit!', and 'Folge uns!' with social media icons for Facebook and Twitter, and a 'Berichte über uns!' link. A 'SHARE' button with social media icons is also present. The right section, titled 'So funktioniert's', shows a diagram of five stylized human figures with lightbulbs above their heads, representing a community of ideas. Below the main content are three large buttons: 'Probleme definieren + diskutieren' (green), 'Lösungen beitragen + kommentieren' (blue), and 'Community aufbauen + stark machen' (orange).



Strengths and limitations

STRENGTHS

- The pilot is open to further technological sophistication: i.e. private optical fiber network for connecting research centers, protecting confidential information; biometric identification of the users, digital signature, m-apps, etc.
- It generates demand, previously fragmented
- The supply side would be incentivized (on-line marketplace)
- It overcomes market failures and information asymmetries
- Peer supervision
- Collaborative solutions can be customized and developed faster (R&D)
- Commonalities among different diseases can be found
- Institutional support and awareness about real needs
- Generation of local knowledge
- Easy replicability
- Positive synergies as a result of a high degree of interaction and user's motivation

LIMITATIONS

- Brazilian law bans doctor-to-patient solutions; it only allows doctor-to-doctor consultations
- Privacy concerns
- Systemic inefficiencies in the health system
- Funding
- Incentives to actively participate and ensure adherence
- Intuitive, user-friendly
- Poor infrastructures (no access to broadband) in some areas
- M&E before scaling up the solution

Thank you