International experiences of building social participation and power in local health systems

Spring School, April 2018

Rene Loewenson

Training and Research Support Centre

- 12 international sites and teams
- 5 US sites and teams

KEY

#	Site	Country
1	Athens City-County Health Department, Ohio	USA
2	Blueprint For Health, Vermont	USA
3	Centro Sávila, New Mexico	USA
4	11th Street Family Health Services, Pennsylvania	USA
5	PIH Health, California	USA
6	Bridge for Health, Vancouver	Canada
7	Metropolitan District of Quito	Ecuador
8	Cidade Tiradentes, São Paulo	Brazil
9	Ovalle, La Reina, La Bandera, Pte Alto, Biobio	Chile
10	Lusaka district health office, Lusaka	Zambia
11	African Mental Health Foundation, Makueni County	Kenya
12	Aberdeen City, Grampian region	Scotland
13	CHD Murska Sobota, Pomurke Region	Slovenia
14	Sahbhagi Shikshan Kendra, Varanasi, Uttar Pradesh	India
15	Youth mental health service, Gosford, NSW	Australia
16	Ngāti Porou Hauora	New Zealand
17	Wan Smolbag, Port Vila	Vanuatu

Shaping health

https://www.shapinghealth.org/

No decision about me, without me: Learning from international experience on approaches to community power, participation and decision making in health

Annotated bibliography on country experiences of social participation and power in health systems

Understanding and organising evidence on social power and participation in health systems

Dr Rene Loewenson
Training and Research Support Centre

April 2016

Full briefs of the US sites

August 2016

1. ATHENS CITY-CO
- FOCAL POINT: Ru
2. BLUEPRINT FOR Vermont
- FOCAL POINT: Be
3. CENTRO SÁVILA
- FOCAL POINT: Bil
4. DREXEL UNIVER Services, Philadel
- FOCAL POINT: Pa
5. PIH HEALTH Whit
- FOCAL POINT: \ Health

Produced in the proj Learning from intern community power, p

Project lead: Training With support from a gi America from the Rob

Learning from international experience on approaches to community power, participation and decision-making in health.

Management of change: The Athens City-County Health Department

May 2017

Athens City-County Health Department works to promote health in rural Athens County, Ohio.
Ruth Dudding, Director of Health Education at the health department, working with Ohio University College of Health Sciences and Professions, and the Heritage College of Osteopathic Medicine, the OhioHealth Family Practice Clinic, Integrating Professionals for Appalachian Children (IPAC), and Live Healthy Appalachia to establish a community-based platform to inform and engage community members in establishing a strong Community Health Worker (CHW) network.

Background

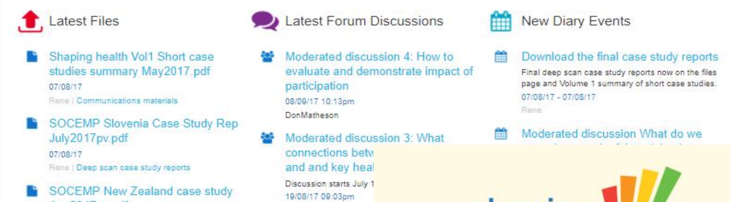
Athens County has the highest poverty rate in Ohio and suffers from disparate rates of chronic disease related to access to healthy food, appropriate health care, health information and other health resources. Athens County is home to Ohio University (OU) a large public university and a small college, Hocking College. The city of Athens has many more resources than the outlying areas. We have found it more

Learning from international experience on approaches to community power, participation and decision-making in health.

Case Study: Lusaka district health office, Zambia

Learning from international experience on approaches to community power, participation and decision-making in health.

Case Study: Wan Smolbag, Port Vila, Vanuatu



What entry points?

Initiated by community/civil society networks

- SSK India - CBOs
- Wan Smolbag Vanuatu- theatre group
- Scotland - Social enterprises

In 'informal' mechanisms engaging formal processes

- Pomurje Regional Action Group, Slovenia

Formal:

By local governments organising innovation

- DMQ Quito, Ecuador
- LDHO, Lusaka, Zambia

In training and dialogue forums

- AMHF and Makueni county, Kenya

All within the community engaging community experience

Community identify their main health issues iQuito. 2016

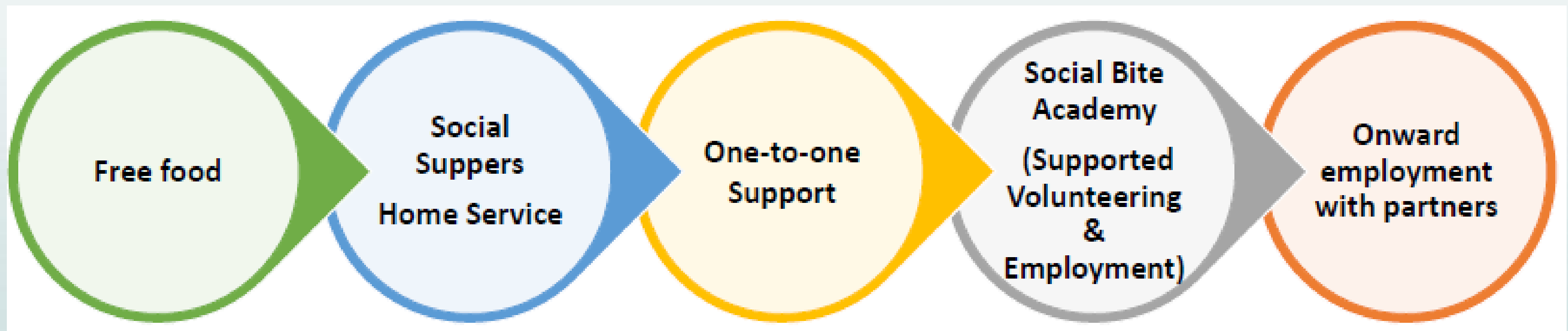
Social Bite Scotland

Social enterprise – serving the public to move our of hunger and homelessness in a pipeline of support

Paying forward meals to support food needs

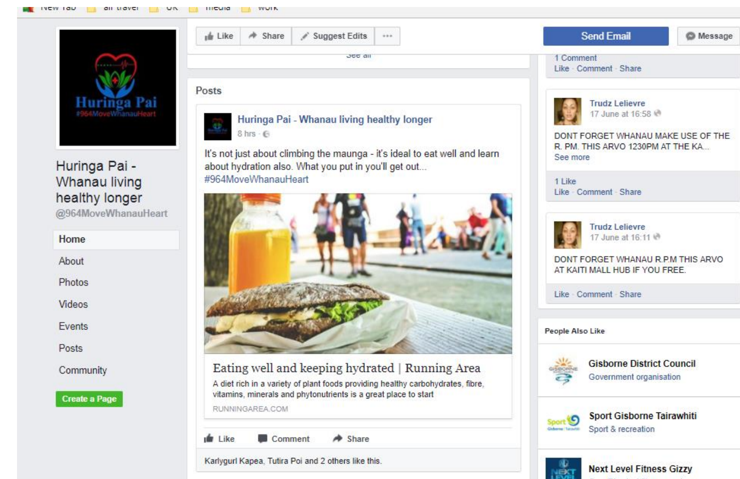
Supporting volunteer, peer led ‘social suppers a vehicle for counselling, skills building and one-to-one support for housing and health care

Linking to skills building and referrals to support employment

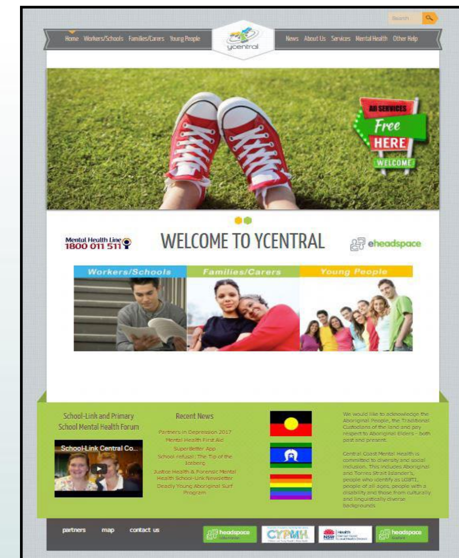


Online media enabling inclusion and voice

- Enables reach and inclusion beyond person to person
- Provides a platform for narrating local experience (eg Social bite Scotland sharing of homeless people's stories)
- Provides spaces for participation where stigma, physical factors discourage it
- Provides information to navigate and engage with services and resources



Huringa Pai facebook page started by patients to respond to diabetes and heart disease, supported by NPH New Zealand



ycentral website supporting youth mental health, Australia

Community experience is a key entry point. Community leadership a key driver

- **A range of community health activists:** health literacy facilitators, local community leaders; community volunteers and teams; expert patients in peer to peer networks
- Processes that invest in and support **citizen and collective leadership**
- Elected **CHWs** can act as health activists, linking with, complementing, supporting but not displacing other citizen leadership (in addition to service outreach roles)

Iritekura Marae © Ngāti Porou Hauora 2015

Investing in community leadership

Excluded communities, women, female adolescents

Information on entitlements to state benefits, building literacy, market skills, vocational skills in adolescent girls

Citizen leadership programme – builds citizen leaders in CBOs and panchayats to link communities to and engage local governments, health services

Own forums to share ideas

Similar processes in Lusaka Zambia with health literacy facilitators and neighbourhood health committees

Participatory processes more likely to thrive when services go into community settings

- Service personnel going into familiar settings: schools, workplaces, market places…
- Who is the external party? Ngāti Porou New Zealand see the state, as external, participating as equal partner in *community* processes.
- In Pomurje, Slovenia health promotion is embedded in schools, kindergartens, local producers, tourist sites, restaurants….integrating health benefit in benefit to the local economy

Nutrition centre outreach, WSB Vanuatu 2016

Nordic walking, Pomurje, Slovenia. © CHD 2012

Taking health into community settings in Quito

QUITO
ALCALDÍA
SECRETARÍA DE
SALUD

Healthy Markets

Community certification process, made up of an institutional and community evaluation, improvement plan, progressive community "certifications" leading up to the certification by the national government.

How to orient services to support participatory practice?

Combining personal care with proactive, comprehensive PHC, population health focused, intersectoral approaches at frontline level

Chile’s biopsychosocial and community health model

Brazil’s family health teams

Participatory practice is supported by *and elicits* more holistic models of health

Participatory diagnosis

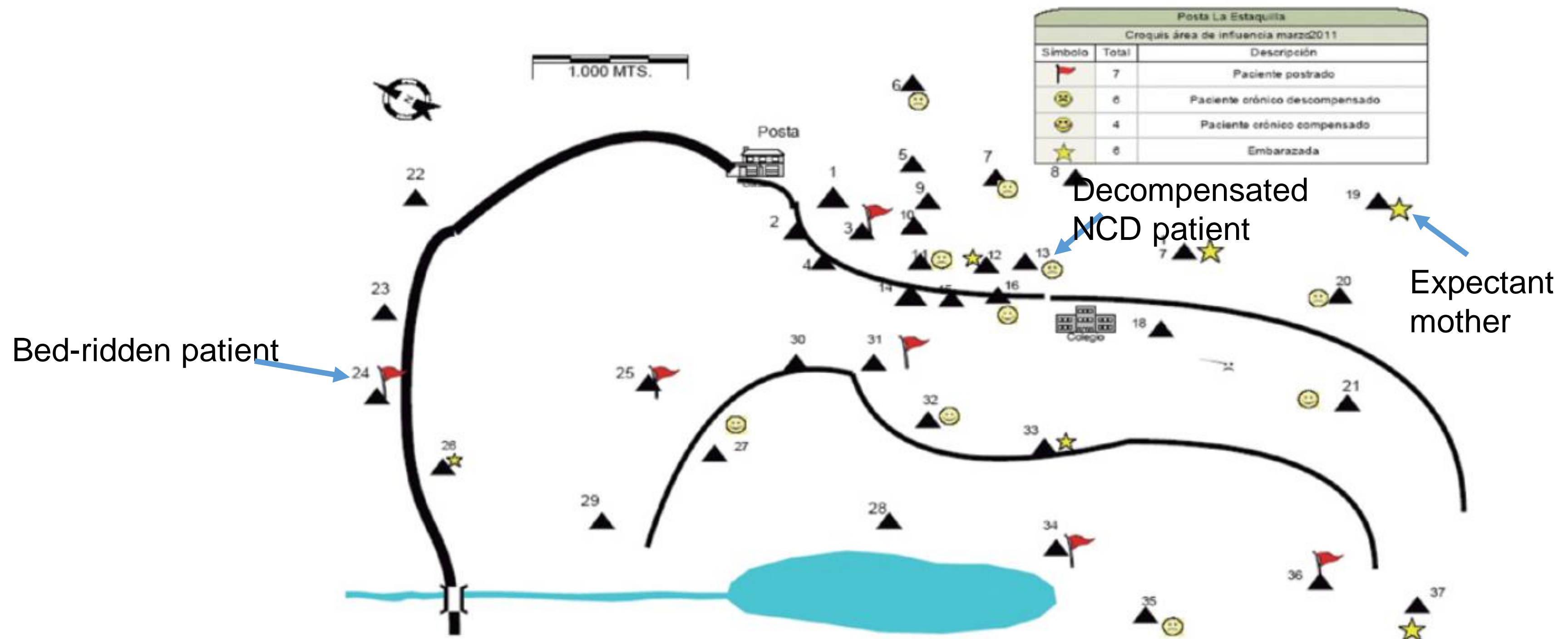
CESFAMs invited people to a meeting

to talk about the community´s health problems and to work together to solve them

As input for the annual municipal health plan and intersectoral action

Epidemiologic map: graphic representation

- Identifies where families live, public institutions and access
- Surveillance tool to identify risks and hazards
- Programming tool for field teams in dialogue with families



How to sustain participatory practice? Formal mechanisms play a key role…

In local government and local health systems:

- Development committees; Panchayati Raj, citizen councils
- Local health facility councils / committees, health centre committees

MDMQ steering committee meeting, Quito LJ Lurado 2016

Methods to link decision making to resources for participatory action such as certification (eg in Quito), community grants, incentive funds (eg Slovenia), participatory budgets (eg in Scotland and Chile).

IDEA
WOODSIDE
WORKING TOGETHER
WINNING BID
TILLYDRONE
ACTION
IMPROVEMENTS
WHO WILL WIN?
YOUR VOTE COUNTS
SEATON
PROJECT FUNDING
BETTER COMMUNITIES
VOTE NOW

U DECIDE
ABERDEEN CITY COUNCIL

We have received an amazing number of bids for funding in Seaton, Tillydrone and Woodside.

Come along to one of our community events to speak to bidders and out find more. The Communities Team will also be on hand to help you register to vote online: **https://aberdeen.participare.io/**

Wednesday 15 Feb 10am – 1pm at Aberdeen Lads Club
Saturday 18 Feb 11am – 1pm at Woodside Community Centre
Thursday 23 Feb 1 – 4pm at Seaton Learning Centre

Announcement day - Saturday 4 March, 1 – 3pm at St Machar Academy

For information, please contact AWoods@aberdeencity.gov.uk
Tel: 01224 523638

Flyer on PB voting event , Scotland

How to sustain participatory practice? Formal mechanisms play a key role…

Local health council meeting in Cidade Tiradentes, Brazil © A Calandrini 2017

Experience from Brazil

- Set in law or guidelines *(but roles not always clear, not always functional)*
- Represent citizens, health workers and health managers (*but indirectly)*
- Representatives elected in public meetings (*but turnout may be low)*
- Members trained- (*but power imbalances, capacities, processes affect how meaningful social participation is)*
- A range of ways for residents to make inputs *(but also depends on how far local facility council members participate outside the LFC)*

So informal mechanisms also play key roles…

Informal mechanisms, such as

- Community and stakeholder forums
- Local community events
- Outreach meetings, theater, cultural activities, photovoice, social suppers
- Workshops

WSB theatre: night show Vanuatu
© D Ragonmal 2017

- Enable community cultures
- Provide spaces for building new interactions and shared plans
- Help to reach, provide safe spaces and processes for stigmatised or marginalised groups (eg social suppers, Scotland, migrant health, Chile)

Mapping family health with Haitian users, Chile © I Riquelme, CESFAM JPII, 2016

Making links between informal and formal processes and spaces

'Bottom-up' interacting with 'top-down'

1. Community representation stronger when reps interact with communities (Brazil LFCs)
2. Community use of other measures for collective voice (social audits, India; protests Brazil)
3. Co-location with community processes improves service access (WSB Vanuatu)
4. Provide more accessible processes to organise input for formal mechanisms (RAG Pomurje)

Inaugural meeting of the RAG Pomurje, © CHD 2012

How to combine service and community evidence?

Information exchange in accessible forms person to person, in social media, in materials developed with communities, in joint training activities

Combining health evidence in Quito's urban zones

PARROQUIAS URBANAS

Indicador	Cotocollao	Centro Histórico	Chillogallo	Iñaquito	La Magdalena	Itchimbía	Rumipamba	San Juan	Chimbacalle	Guamaní	Carcelén	Mariscal Sucre	Chilibulo
Tasa de mortalidad infantil (por 1.000 nacidos vivos registrados) (1) (5)	12,47	2,46	7,20	14,99	9,44	139,04	14,93	65,11	8,74	7,65	14,72	30,46	32,35
Tasa de mortalidad de niños menores de 5 años (por 1.000 nacidos vivos) (1) (5)	13,94	2,46	9,82	17,71	11,01	139,04	18,66	68,45	9,47	9,31	16,68	35,53	32,35
Tasa de mortalidad por diabetes (por 100.000 hab) (1) (5)	95,43	57,72	37,82	27,10	79,73	48,52	79,98	8,13	37,28	12,86	12,48	64,07	10,10
Tasa de mortalidad por tuberculosis (por 100.000 hab) (1) (5)	3,29	5,77	4,54	0,00	0,00	0,00	0,00	0,00	2,66	2,34	0,00	0,00	0,00
Tasa de mortalidad por accidentes de tránsito según lugar de ocurrencia (por 100.000 hab) (1) (5)	26,33	8,66	10,59	6,77	6,93	190,62	9,60	77,21	10,65	8,19	4,68	91,53	14,14
Tasa de mortalidad por cáncer (por 100.000 hab) (1) (5)	490,3	262,63	236,01	158,07	332,78	190,62	249,54	132,07	117,16	63,15	67,09	274,60	20,20
Tasa de mortalidad por enfermedades cardiovasculares (por 100.000 hab) (1) (5)	292,88	155,84	105,90	112,91	190,65	69,32	115,17	42,67	45,27	23,39	34,33	64,07	16,16
Tasa de mortalidad por enfermedades respiratorias (por 100.000 hab) (1) (5)	200,74	106,78	116,49	76,78	124,79	69,32	143,96	58,92	53,25	33,92	28,08	54,92	12,12
Tasa de mortalidad por VIH-SIDA (por 100.000 hab) (1) (5)	16,45	8,66	4,54	9,03	0,00	3,47	6,40	6,10	0,00	0,00	1,56	0,00	2,02
Tasa de mortalidad por homicidios (por 100.000 hab) (1) (5)	16,45	2,89	18,15	6,77	6,93	0,00	6,40	2,03	2,66	4,68	7,80	0,00	2,02
Tasa de mortalidad por enfermedades mentales (por 100.000 hab) (1) (5)	3,29	5,77	0,00	6,77	6,93	0,00	0,00	0,00	0,00	1,17	3,12	0,00	2,02

Indicador	Belisario Quevedo	El Condado	Quitumbe	La Mena	Puengasí	La Ferroviaria	La Argelia	Cochapamba	San Bartolo	La Libertad	Comité del Pueblo	San Isidro del Inca	Jipijapa	Solanda	Kennedy	Concepción	Turubamba	La Ecuatoriana	Ponceano
Tasa de mortalidad infantil (por 1.000 nacidos vivos registrados) (1) (5)	3,23	1,17	20,47	2,83	6,45	4,41	4,32	2,37	4,08	7,81	1,72	2,95	0,00	4,85	2,58	0,00	6,70	5,11	6,17
Tasa de mortalidad de niños menores de 5 años (por 1.000 nacidos vivos) (1) (5)	3,23	3,51	21,49	2,83	9,68	6,61	4,32	2,37	4,08	7,81	4,31	4,42	3,47	8,08	2,58	0,00	6,70	5,11	12,35
Tasa de mortalidad por diabetes (por 100.000 hab) (1) (5)	22,57	5,74	6,45	12,58	5,68	9,39	4,73	4,64	13,76	3,63	11,90	2,04	5,81	5,09	1,44	17,69	4,11	6,69	5,48
Tasa de mortalidad por tuberculosis (por 100.000 hab) (1) (5)	0,00	1,91	0,00	2,10	0,00	1,57	1,58	1,55	0,00	0,00	0,00	0,00	0,00	0,00	0,00	0,00	0,00	0,00	0,00
Tasa de mortalidad por accidentes de tránsito según lugar de ocurrencia (por 100.000 hab) (1) (5)	24,82	1,91	9,21	2,10	7,10	3,13	3,15	0,00	1,53	0,00	3,97	4,08	0,00	1,27	1,44	0,00	1,37	0,00	0,00
Tasa de mortalidad por cáncer (por 100.000 hab) (1) (5)	67,70	22,01	22,11	25,15	26,98	28,17	26,78	30,92	50,47	32,63	27,76	65,33	46,47	21,65	43,11	92,01	16,46	16,06	7,31
Tasa de mortalidad por enfermedades cardiovasculares (por 100.000 hab) (1) (5)	51,90	11,48	15,66	14,67	17,04	9,39	12,60	7,73	15,29	29,00	15,86	26,54	23,24	16,56	15,81	31,85	8,23	5,35	5,48
Tasa de mortalidad por enfermedades respiratorias (por 100.000 hab) (1) (5)	51,90	10,53	9,21	6,29	18,46	14,09	11,03	9,28	6,12	18,13	7,93	26,54	31,95	15,28	14,37	49,54	8,23	12,05	1,83
Tasa de mortalidad por VIH-SIDA (por 100.000 hab) (1) (5)	0,00	2,87	1,84	2,10	2,84	0,00	0,00	1,55	1,53	0,00	0,00	0,00	2,90	0,00	1,44	0,00	0,00	0,00	0,00
Tasa de mortalidad por homicidios (por 100.000 hab) (1) (5)	0,00	0,00	1,84	0,00	0,00	0,00	0,00	0,00	0,00	3,63	1,98	0,00	0,00	0,00	0,00	0,00	0,00	1,34	0,00
Tasa de mortalidad por enfermedades mentales (por 100.000 hab) (1) (5)	2,26	0,96	0,00	0,00	1,42	0,00	0,00	0,00	0,00	0,00	0,00	0,00	0,00	0,00	0,00	0,00	0,00	0,00	0,00

Cuarto cuartil - peores resultados | Tercer cuartil | Segundo cuarti | Primer cuartil - mejores resultados

How to combine service and community evidence?

Various methods for organising community evidence on needs, problems, actions

- Participatory family and social mapping
- Community and online surveys
- Photojournalism and narratives
- Stop drama, problems trees and other tools for analysis, prioritising, planning

Transparent criteria for choices when combining service and community evidence

- Health equity
- Health and economic benefit

Measures for accountability and for assessing progress, with short term wins to build confidence and reporting to widen community and service support

How do we know we are making a difference?

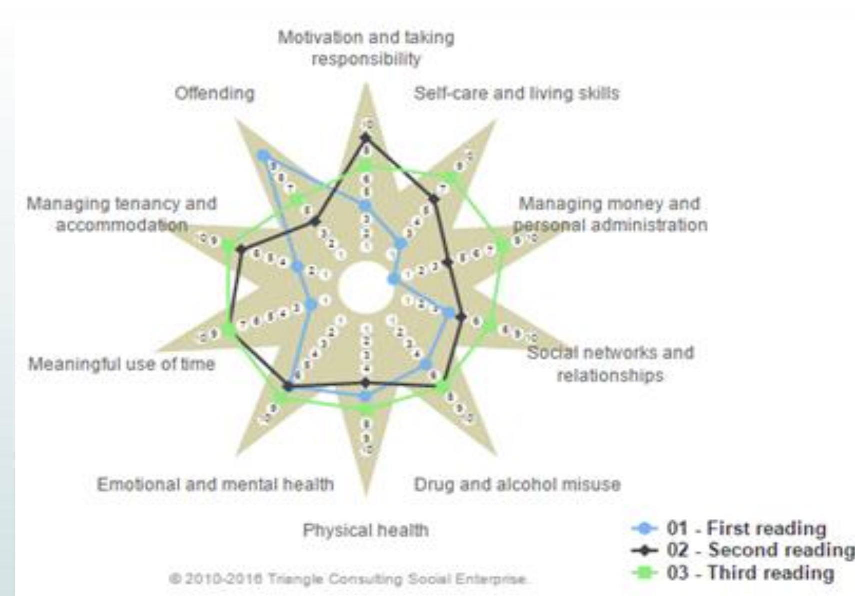
Processes often not evaluated, caution on what is evaluated, lack of relevant routine data, caution on what is transferrable

BUT

Monitoring and reviewing progress / change (against the theory of change) builds confidence and learning, insights that can be shared

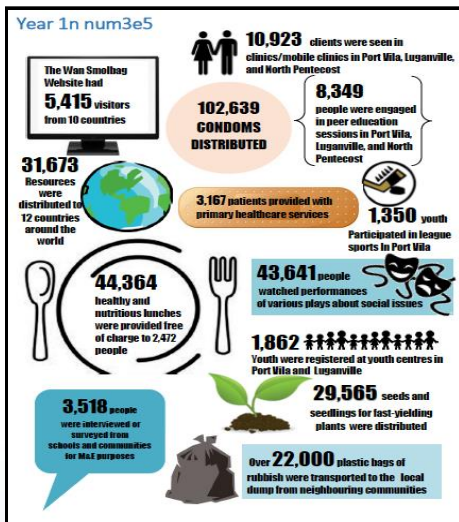
Reflexive methods- test theory of change, track shared outcomes over time for review, such as

- Progress markers (eg Zambia)
- Outcome star (eg Scotland)



Outcomes Star © Triangle Consulting 2010-2016

Mixed methods, shared qualitative and quantitative indicators, narratives, visual media to track and learn from action using process, social, institutional, health system and outcomes



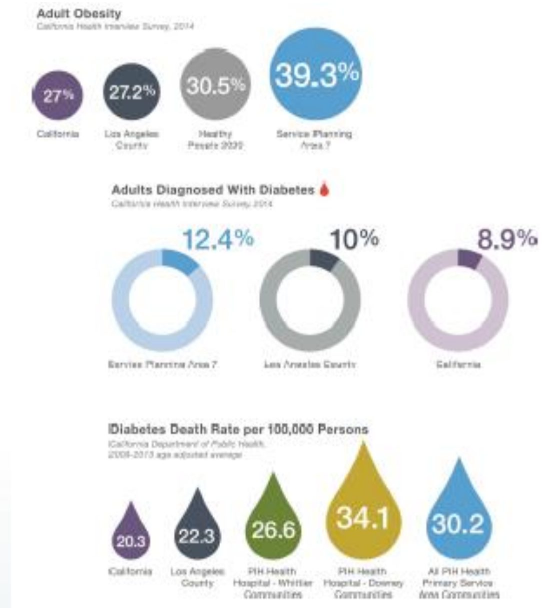
WSB 2016

Embedding assessment, HE2020 Slovenia

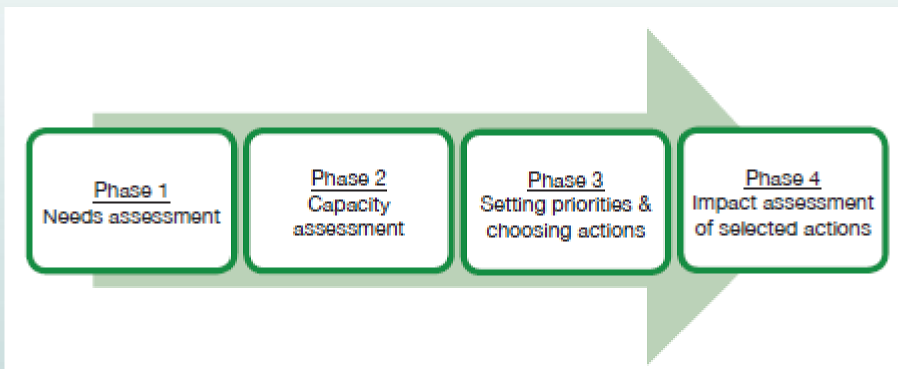
Problem: Inadequate Information And Communication On Planning Progress							
EXPECT To See Progress Markers		Progress Monitoring					
		CLINIC A			CLINIC B		
		1	2	3	1	2	3
1	HC staff meetings with CMs having schedules, agendas & minuites						
2	HC staff & CMs disseminating or sharing information on planning and any other current issues						
3	HC giving CMs feedback on planning activities and any other current issues as soon as it is received						
4	HWs & CMs respecting each others views during meetings & discussions						
5	Participants who attended the 2007 PRA orientation workshop sensitizing or sharing the information with their immediate workmates and colleagues.						
LIKE To See Progress Markers							
1	HC providing necessary materials & simplified guidelines to CMs on planning process						
2	HCs & CMs beginning the planning cycle activities without being prompted by higher level						
3	HC providing & sharing information to CMs on budget allocation & expenditure for HC						
LOVE To See Progress Markers							
1	75% of HWs conversant with planning process						

Key: Done ■ Started/Ongoing ■ Not Started/not done □

Progress markers LDHO 2017



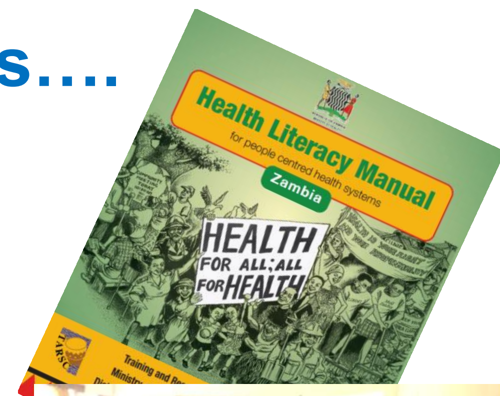
PIH Health population snapshot



*Community members have become part of the change process . Health is no longer seen to be just about taking medication...*KI Zambia 2017

Deepening participation takes capacities….

- For communities: Health literacy (Lusaka), functional skills (Vanuatu, Scotland) for citizen leaders (Varanasi), youth leaders (Canada)
- Training for community representatives (Chile); community health workers (Kenya)
- For services/ facilitators: socio-cultural competencies (Kenya; Chile); management; diverse competencies and disciplines



Training of THPs to detect mental illness Makueni, Kenya © D Ndetei 2017

….time and trust

"You have to tell the community everything, warts and all. Sometimes you will get a pat on the back, other times you will get your butt kicked. At the end of the day people appreciate transparency, and we end up on the same page when all the information is there, because we have the same long term kaupapa (principle)" – New Zealand KI, 2017

Key role of strategic individuals and institutions

It takes time and commitment to "…walk beside people who struggle to navigate systems seen to be hostile to them…" and facilitate their power (Scotland case study)

Stamp series WSB over 25 years, Vanuatu

- Catalysts, mediators and facilitators
- Technically credible, trusted by communities
- Visionary, strategic, participatory management
- Adequate personnel as staff or volunteers;
- Experience of joint work with other agencies,
- Funding or resource strategies to sustain programmes
- Organisational freedom to innovate
- Monitoring and making visible achievement, accepting constructive criticism