



WORLD CARE COUNCIL
RAISING THE STANDARDS FOR CARE

Growing Social Mobilization in Community Gardens **Six steps for building mass movements to Stop TB in high burden countries**

Almost two million people from our diverse communities die every year from tuberculosis, although a cure was found some sixty years ago. They are wasting away in the barren lands of poverty, suffering in the dark shadows, mostly unheard and unseen by those 'on the top'. This tragedy is the responsibility of the member nations of the World Health Organization, who in spite of noble words and agreed targets, have not protected their vulnerable populations against this preventable disease. It is also a clear indication of the failure of the affected communities to defend themselves.

Enough! It's time to turn wastelands into fruitful gardens, and to bring fresh air and sunshine into the movement to Stop TB. Now is the moment to grow the mobilization in countries decimated by tuberculosis, leading to a harvest of the human and financial resources needed to scale up the response to the spread of TB-HIV and MDR-XDR TB.

After decades of a top-down approach to TB Control which excluded patient and community involvement, a campaign is beginning, from the bottom-up, to increase access to quality care and contribute to the efforts to turn back the growing pandemic. The World Care Council, an international NGO driven by and for people with the disease, is rolling out a dynamic mobilization system coming from the needs on the ground. Recognizing that the crisis of MDR/XDR is a global threat that most countries lack the needed drugs and diagnostic infrastructure to deal with, it is vital to immediately scale-up the participation of civil society as partners with health providers to improve prevention, detection, and treatment adherence, and to drive TB up the local, regional, national and international agenda.

A key element of the WHO Stop TB Strategy and Global Plan 2006-2015 calls for the Empowerment of People with TB and their Communities, and contains three components: Advocacy, Communication, Social Mobilization (ACSM); Community Care; and the Patients' Charter for Tuberculosis Care. These components are closely related, and although essential in the fight against TB, TB-HIV and MDR/XDR TB, they have lacked an implementation plan in the high burden countries, precisely where it is needed. Mobilization 'on the ground' to improve the well-being of the community is best led by the people most affected, patients and their families, with local allies and partners.

After two years of research and development, the World Care Council has produced an easy to use methodology with a package of technical support that allows social activation to jump-start with immediate results, while the locally designed monitoring and evaluation process will encourage accountability and further stakeholding. By conducting operational research through a one year pilot-project program, with technical assistance from start-up through scale-up, national programs and local communities can work together to produce the fruits of grassroots mobilization to Stop TB.

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Growing Social Mobilization in Community Gardens

Six steps for building mass movements to Stop TB in high burden countries

Outline of the organic process for cooperative gardening

1. Preparation and Groundwork

Framework Agreements and documents (translated in local language):

- Patients' Charter for Tuberculosis Care (PCTC), endorsed and printed by NTP
- Stop TB / WHO Patient Centered Care / Community Care Guidelines
- MOU of WCC with WHO/GDF for distribution of Patients' Charter (PCTC)

Operational research / pilot project basic tools:

- Letters of support of WHO, NTP and civil society partners
- Agreement with regional operational research partner (TRC, MRC, AMREF...)
- Agreement for technical assistance provisions from World Care Council (Regional Offices)
- TEAM-UP Survey (Questionnaire) with support pack
- Community Care Club model constitution and terms of reference
- Stop TB / WHO Strategy and Global Plan 2006-2015

2. Seeds in the Ground

Initiate operational research by conducting TEAM-UP Surveys in target areas

Identify target areas and partners for local pilot projects based on the survey results and consultations

'Head-hunt' a core group of former patients and health professionals to spearhead the drive forward

Distribute 'Help Wanted' poster in clinics/dispensaries - Call for Future Community Champions (leaders)

'Head-build' by finding experts, providers and program managers willing to mentor

Invite local expert participation onto Strategic Technical Advisory Group of regional WCC

3. Forge Gardening Tools

Translate and print PCTC short version with local graphics

Adapt the model constitution for a Community Care Club

Translation of Community Care Guidelines (Short Version)

Adapt and distribute Patient Centered Care / Community Care Guidelines

Identify local providers to host Community Care Clubs and the pilot projects

Organize first training workshop for core group of Community Champions

4. Irrigation and Nutrition

Initiate process of creation / formation / registration of 'patient powered' NGO in-country

Introductory meetings and discussions with local civil society groups

Explore common cause with district, provincial and national health programs and political leaders

Secure meeting spaces for Community Care Club activities

Embed journalist to document mobilization process

5. Growth and Blossom

First General Assembly Meeting of NGO

Organize initial Access Workshops / Teach-in

Establishment of model Community Care Clubs in target areas

Recruitment of Team / Call for TB-Activists

Develop and initiate an action plan including events around WTBD, World AIDS Day, etc.

6. First Harvest

Complete registration of 'patient powered' NGO in-country as focal point organization

Design and conduct KAP study in target areas, and roll out pilot projects in these communities

Begin series of public meetings and social events to raise awareness and raise community smiles

Organize local election campaigns for community representatives to national board

Start outreach from pilot projects on local, regional and national levels

Develop plan for increased output in the next 'growing season'

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