Integrating community based TB services with chronic lung conditions, including lung cancer

Report of a Consultation Meeting

held on 28-30 June 2017

Johannesburg, South Africa
Acknowledgements

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Declarations of conflicts of interest

All the contributors completed a WHO Declaration of Interest form. The declarations were analysed by the TB/HIV and Community Engagement unit of the WHO Global TB Programme, which found that no significant interest had been declared.

The following interests were declared:

Anita Graham declared that the outcome of the meeting are expected to benefit the respiratory team that she is professionally collaborating with to develop a centre of lung cancer excellence at Helen Joseph Hospital, Johannesburg, South Africa over the next three years (2017-2019). Through this consultation meeting, Anita Graham hopes to better understand the processes needed to design a model of care for patients with lung cancer so they can be referred early to better diagnose chronic lung conditions with focus on lung cancer.

Phangisile Mtshali-Manciya declared that her employer Bristol Myers Squibb Foundation paid all her costs to attend the meeting.

Abduraoof Sayed declared that he received consulting fees of no more than US$1000 in 2015 from the Bristol Myers Squibb Foundation.
I Background

One billion people suffer from chronic respiratory diseases (CRDs) including asthma, respiratory allergies, chronic obstructive pulmonary disease (COPD), occupational lung diseases, sleep apnea and pulmonary hypertension. CRDs kill 3.9 million people each year. Cancer is also a leading cause of death, globally. In 2012, there were an estimated 14 million new cases and more than 8 million deaths (WHO, 2014). Approximately 13% of all cancer-related diagnoses were lung cancer, resulting in nearly 2 million new cases (Torre, 2012).

Tuberculosis (TB) is an important public health concern. Worldwide, 10.4 million people are estimated to have fallen ill with TB in 2015. With 1.8 million TB deaths in 2015, TB is the top infectious killer. Tobacco use is the most important risk factor for cancer, causing about 70% of global lung cancer deaths (WHO, 2015). More than 20% of TB cases worldwide may be attributable to smoking (Sitas, 2004). A number of retrospective cohort studies also report that previous TB increases risk of lung cancer (Liang, 2009).

WHO’s ENGAGE-TB Approach has been instrumental in guiding and scaling up integrated community based TB activities through the engagement of nongovernmental organizations (NGOs). Demonstration projects initiated in the Democratic Republic of the Congo, Ethiopia, Kenya, South Africa and United Republic of Tanzania helped to develop implementation models that are now part of national strategies and plans in 13 countries. Innovative models have integrated TB into reproductive, maternal, newborn and child health (RMNCH), cervical cancer screening, livelihood development programmes and HIV/AIDS programmes.

The experience and achievements of implementing the ENGAGE-TB approach to date can be tailored to integrate community based TB activities with other chronic lung conditions. Current efforts also draw from the earlier work done by WHO to help management of patients with respiratory symptoms through the Practical Approach to Lung health (PAL).
II Purpose

WHO convened a consultation meeting on 28-30 June 2017 in Johannesburg, South Africa. Its purpose was to develop tools and methods to support increased community based integration of TB and chronic lung conditions including lung cancer in order to secure improved outcomes in prevention, detection, treatment and stigma reduction for chronic lung conditions.

III Operational definition

Within this initiative, chronic lung conditions (CLC) are operationally defined as asthma, COPD, allergies, lung cancer, heart failure, tuberculosis and other conditions.

IV Participants

The consultation participants included representatives from national TB and non-communicable diseases/CRD programmes of Lesotho, South Africa, Swaziland and Tanzania; NGOs and other CSOs; experts in chronic lung conditions, TB and community engagement; academia and staff of WHO both from HQ and countries. A list of participants at this consultation is attached as Annex 1.

V The ENGAGE-TB approach: relevant concepts and terms

Efforts to develop guidance, model and tools for the integration of TB and CLC at community level draw from the experience and evidence gained from the ENGAGE-TB approach. Key concepts and terms of the ENGAGE-TB operational guidance are reiterated hereunder to enable clarity in engaging with the tools and methods.

**NGOs and other CSOs** are non-profit organizations that operate independently from the state and from the private for-profit sector. They include a broad spectrum of entities such as international, national and local NGOs, community based organizations (CBOs), faith based organizations (FBOs), patient-based organizations and professional associations. CBOs are membership based non-profit organizations that are usually self-organised in specific local areas (such as a village) to increase solidarity and mutual support to address specific issues. For example, these include HIV support groups, women’s groups, parent-teacher associations and micro-credit village associations. CBO membership is comprised entirely of community members themselves so these organizations can be considered to represent the community most directly. NGOs and other CSOs engage in activities that range from community mobilization, service delivery, and technical assistance to research and advocacy.
**Community-based TB activities** represent a range of activities contributing to prevention, diagnosis, improved treatment adherence and care that positively influence the outcomes of drug-sensitive, drug-resistant and HIV associated TB. They also include community mobilisation activities to promote effective communication and participation among community members to generate demand for TB prevention, diagnosis, treatment and care services. While the diagnostic tests for TB continue to be carried out in clinical settings for lack of simpler diagnostic methods, community based TB activities are conducted outside the premises of formal health facilities (hospitals, health centres and clinics) using community based structures (e.g. schools, places of worship, congregate settings, etc.) and homesteads. Such community based TB activities could and should be integrated with other community based activities supporting primary health care services, including maternal and child health, HIV and noncommunicable diseases to improve synergy and impact.

**Community health workers and community volunteers** carry out community based activities depending on national and local contexts. Community health workers are people with some formal education who are given training to contribute to community based health services including TB prevention and patient care and support. Their profile, roles and responsibilities vary greatly between countries and their time is often compensated through incentives in kind or in cash. Community volunteers are community members who have been systematically sensitized about TB prevention and care, either through a short and specific training scheme, or through repeated and regular contact sessions with professional health workers.

Six components of ENGAGE-TB
Examples of what each component could help address:

- **Situation analysis**
  - Map households, community workers, clinics
  - Review burden of diseases (clinic records, surveys)
  - Identify stakeholders – what existing community workers are addressing TB or NCD

- **Enabling environment**
  - Existing government policy and practice with respect to community health workers
  - Policy with respect to engagement of NGOs in community based TB and CLC services
  - Policy and practice supporting integration of TB with CLC
  - Availability of funds to support integration and associated costs

- **Guidelines and tools**
  - Guidelines needed to support integration
  - Development of a standardized training curriculum in TB and other chronic lung conditions
  - Adaptation of CHW tools for integration of TB and other CLC

- **Capacity Building**
  - Train CHWs
  - Sensitise community about implementation of the integrated method
  - Sensitise and train facility health workers on the integration method and on the diagnostic algorithm including appropriate referral

- **Monitoring and Evaluation**
  - Adopt and adapt global implementation tools for integrated community-based TB and other CLC activities

**VI Pre-requisites to integrate TB and CLC**

The consultation participants noted the integration of community-based TB and CLC activities will only be successful if all of the following six pre-conditions are satisfied:

1. **Primary Health Care (PHC) facilities should be equipped with all needed materials and PHC staff should have adequate training in TB and CLC screening and referral**
2. **There should be a clear description of the role and functions of CHWs formalised in writing**
3. **A designated person in the PHC must be responsible for supportive supervision of the CHWs linked to that facility and should visit field locations periodically to support CHWs effectively**
4. **Training for CHWs, their supervisors and for PHC staff should be locally tailored and contextualised**
5. **A clear referral system to hospitals and specialised facilities should be established with feedback that is linked to the national reporting and monitoring system**
6. **A national policy or guideline should be in place to provide a conducive, enabling policy environment and to attract financial resources by way of funded national plans**
### VII Integration methods

The consultation participants agreed on the following recommended methods for integrating community based TB and CLC based on experience and evidence gained from support to the ENGAGE-TB approach:

<table>
<thead>
<tr>
<th>Theme</th>
<th>Possible activities</th>
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| Prevention                   | Awareness-raising, information, education, communication (IEC), behaviour change communication (BCC), infection control, training providers  
**Key messages:** tobacco use and smoking cessation; improved cough hygiene; ventilation; infection control at homesteads and congregate settings   |
| Detection                    | Screening, contact tracing, sputum collection, sputum transport, training providers  
**Key messages:** multiple causes of cough; red flag symptoms need emergency attention; TB negative diagnosis with continuing cough as a sign of possible CLC  |
| Referral                     | Linking with clinics, transport support and facilitation, accompaniment, referral forms, training providers  
**Key messages:** first referral of all presumptive cases to PHC. If initial treatment fails and symptoms continue, re-referral either back to PHC or to hospital/specialized facility for CLC |
| Treatment adherence support  | Home-based DOT support, adherence counselling, stigma reduction, pill counting, training providers, home-based care and support  
**Key messages:** both TB and CLC need treatment support especially psycho-social support whether for smoking cessation or moderation in alcohol intake or for completing course of medication or proper use of inhalers and spacers |
| Social and livelihood support| Cash transfers, insurance schemes, nutrition support and supplementation, voluntary savings and loans, training providers, income generation  
**Key messages:** Malnourishment is a problem for all conditions. Poor people need special support to successfully transit through their illness and should be linked to all possible sources of financial and livelihood support |
| Advocacy                     | Ensure availability of supplies, equipment and services, training providers, governance and policy issues, working with community leaders  
**Key messages:** If the defined pre-requisites are not fulfilled, integration will fail. Advocacy is particularly needed at local levels to ensure PHCs are adequately stocked and CHWs and PHC staff trained to screen and refer TB and CLC presumptive cases |
| Stigma reduction             | Community theatre/drama groups, testimonials, patient/peer support groups, community champions, sensitizing and training facility and CHWs and leaders  
**Key messages:** stigma deters presumptive cases from seeking help and confirmed patients from completing treatment. It should be addressed wherever it exists |
The entry point for these community based activities could be through existing TB services or through NGOs or other CSOs implementing the ENGAGE-TB model of integration with other sectors such as HIV or RMNCH or even livelihoods or water, sanitation and hygiene programmes. As far as possible, it was stated in the consultation, integration should build on existing community based systems rather than create new systems.

**VIII Integrated community-based symptomatic referral approach**

The meeting participants highlighted the importance of the chronic cough as a key symptom of underlying problems and the entry point for the integration of TB with CLC. For the purposes of standardisation, any cough longer than two weeks will need to be investigated. If tests for TB are negative but cough persists, further tests for CLC will need to be undertaken.

Smoking is a major risk factor for CLC; smoking needs to be reflected on the referral sheet and all person confirmed with CLC need to be offered smoking cessation therapy and counselling.

Furthermore, the consultation underlined the need for adequate training for CHWs and PHC staff to recognise signs and symptoms of TB as well as of CLC. CHWs should normally screen and refer those with signs and symptoms to the PHC as the first step. The PHC should determine whether patients need further diagnosis for conditions that cannot be managed at the PHC and, if so, refer them further to the nearest hospital or specialist facility.

A mechanism will need to be established such that patients receiving treatment continue to be monitored by the CHW. When treatment fails and/or symptoms persist, the CHW must again refer the patient. Depending on the signs and symptoms, such re-referral may be to the same PHC unit or to a hospital or specialist facility. For persons with confirmed CLC, facility staff at any level of the health system will need to offer smoking cessation therapy and counselling.

At the consultation, it was agreed that some conditions are potentially life threatening and should be treated as “red flag symptoms.” CHWs will need to learn how to recognise such signs and have a tool to assist them ask the right questions in order to ensure such “emergency” cases are rushed to the nearest health facility. This might be fairly straightforward for conditions such as chest pain but may be more difficult to judge for symptoms such as patient confusion.

The participants stressed that the enhanced screening of persons with cough by CHWs should not result in the CHW being viewed as a diagnostician either by themselves or by others. Rather, their general awareness of causes of cough should be raised and they should recognise that chronic cough is a sign of a range of possible diseases or conditions.

**Symptomatic Referral chart**

<table>
<thead>
<tr>
<th>Signs and Symptoms</th>
<th>Possible causes</th>
<th>Action by CHW</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cough more than 2 weeks’ duration</td>
<td>Disease (TB, asthma, COPD, heart failure) Environmental toxins (smoke, silent smoking, dust) Medications (medications that may cause cough as side effect eg, ACE inhibitors as anti-</td>
<td>Referral to PHC/TB clinic</td>
</tr>
<tr>
<td>Symptom/Condition</td>
<td>Associated Conditions</td>
<td>Action</td>
</tr>
<tr>
<td>-------------------</td>
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<td>--------</td>
</tr>
<tr>
<td>Hypertensives)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Allergies (pollen, animals)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cough persisting after treatment</td>
<td>Prior misdiagnosis of disease</td>
<td>Re-referral to PHC or to nearest hospital with details of persistence noted</td>
</tr>
<tr>
<td>Cough continuing with negative TB diagnosis</td>
<td>Possible Cancer or other CLC</td>
<td>Referral to nearest hospital or back to PHC with details of persistence noted</td>
</tr>
<tr>
<td>Wheezing</td>
<td>Asthma</td>
<td>Referral to PHC</td>
</tr>
<tr>
<td>Weight loss</td>
<td>TB</td>
<td>Referral to PHC/TB clinic</td>
</tr>
<tr>
<td>Night sweats</td>
<td>TB</td>
<td>Referral to PHC/TB clinic</td>
</tr>
<tr>
<td>Fever</td>
<td>TB</td>
<td>Referral to PHC/TB clinic</td>
</tr>
<tr>
<td>Change in voice quality persisting over 1 week</td>
<td>Cancer</td>
<td>Referral to PHC/nearest hospital</td>
</tr>
</tbody>
</table>

**RED FLAG SYMPTOMS:**
- Noisy breathing
- Swelling of limbs or face/neck
- Chest pain
- Blood in sputum
- Continuous coughing
- Confusion

Potentially life-threatening symptoms for immediate attention and treatment

Urgent and immediate referral to nearest health facility whether PHC or hospital and follow up

**Smoking is a major risk factor for CLCs**

When screening people for CLC signs and symptoms, it is important to systematically investigate the use of tobacco. Smoking is a major risk factor for CLCs. Stopping smoking can be a powerful preventive measure against developing CLCs. CHWs should provide tobacco cessation counselling to all those who use tobacco in the community and in particular to persons confirmed with CLC.

**IX Implementation Issues**

The consultation participants underlined a number of key implementation issues to consider. These are grouped into relevant sections hereunder.

**Screening tool**

The current screening tool for TB covers key symptoms such as cough for more than two weeks, unexplained weight loss, night sweats and fever. Other signs and symptoms will need to be added to modify the TB screening tool in order to raise the suspicion index for CLC. These should include coughing blood, wheezing, shortness of breath and all the red flag symptoms as well. The history of smoking should be noted and counselling and therapy provided for smoking cessation if applicable. The screening tool should include all TB and CLC. The tool needs to indicate clearly what is to be managed at PHC level; when to refer to district hospital or when to refer to the tertiary hospital.
Alignment with national systems including monitoring and evaluation

CHWs will need to be closely linked to PHCs with a formal system of referral that feeds into the national monitoring and reporting system. PHCs will need to develop a feedback loop so CHWs are provided information about the diagnostic outcome of each presumptive case referred. In addition, CHWs will need to maintain close follow up of all those receiving treatment to ensure that those whose symptoms persist despite treatment completion are re-referred to the PHC or to more specialised facilities or hospitals. Similarly, PHCs will need to develop referral tools to hospitals or specialised TB/CLC facilities and ensure a feedback loop is also provided to them for onward relay to the CHW in whose area the patient resides for follow up and support. Finally, data on contributions from community sources to PHC or higher-level institutional case finding will need to be recorded and reported as part of a single national system for monitoring and evaluation.

Information, education and communication (IEC)

New IEC materials will need to be developed to promote health education among individuals, families and communities. These will need to convey, in simple language, the possible causes of chronic cough while highlighting the need to be screened by a health care worker. Materials showing how TB and CLC may be prevented, particularly relating to common factors such as smoking and second-hand smoke, will also need to be developed and disseminated widely.

Treatment support mechanisms

Peer support groups and other mechanisms to ensure treatment support and reduce stigma will need to grow more familiar with the larger perspective of chronic lung conditions and be able to detect and report red flag symptoms requiring emergency care. Systematic training will be needed and new training manuals enabling this will need to be developed.

Associated risk factor management

It will also be necessary to assess and deal with underlying causes in specific communities whether this relates to environmental factors causing TB and/or CLC or whether it relates to specific factors affecting individuals such as smoking or malnourishment. Based on the assessments, actions will need to be promoted at individual, household and community level. The PHC level supervisor of CHWs as envisaged in the pre-requisites for integration of TB and CLC, will be well positioned to consider these issues in consultation with the CHWs and other PHC staff. A localised response will be needed based on the specific situation analysis.

Capacity building

Training will be required at all levels, especially for CHWs and their supervisors and other PHC staff. Integration will also require health care workers at the PHC level to be able to screen for CLC and TB
when presented with any patient with associated symptoms. Training of all PHC staff will be needed to secure this outcome. A curriculum on CLCs with simple signs and symptoms should be suited for use of CHWs as well as PHC staff. Existing curriculum and tools available in TB services will need to be revised for CHWs to add other characteristics of cough and age as triggers for referral and further action and follow up.

The consultation also discussed the structure of human resources needed to support such integration. At its core will be the CHWs. Each CHW should have a designated area with a manageable number of families to support. Depending on the local context, this number is usually higher for urban areas and lower for sparsely populated rural areas.

Finally, the meeting participants agreed effective integration also requires appropriate life-saving equipment to be installed and available at PHCs, including bronchodilators in case of emergencies.

The national policy needs to outline the role of NGOs and other CSO who may be able to support integration using CHWs attached to their own organizations and reaching key affected populations that may otherwise not be well connected to the PHC. Linking NGOs and other CSOs with the PHC through district level coordinating bodies will help expand the scope and reach of the integration mechanism. NGOs will need training and the protocol for referral of presumptive cases and their subsequent follow up will need to be clearly defined.

**Supervision**

CHWs should report to a supervisor at the PHC or based within the community. Each CHW supervisor should also be assigned a manageable number of CHWs in order to ensure effective supportive supervision. CHWs and their supervisors should be linked to the appropriate health facility (whether PHC or clinic) to which they report. These should then be linked to the District Health Management Team and a designated person should collate and tabulate all data relating to community based actions.

Consultation participants underlined the importance of integrated supportive supervision at service delivery level to ensure systematic engagement of both the facility staff as well CHWs regardless of the implementer of community-based activity (Government or NGO or other CSO).

**Remuneration of CHWs**

In order to reach universal health coverage (UHC), the consultation participants underlined the importance of integration of CHWs into health system work force as employees with rights and benefits (e.g. health extension workers in Ethiopia). The consultation participants further stressed that, in settings where this is not possible, adequate incentives for CHWs need to be secured.

**X Role definition**

The consultation helped define specific roles of the different human resources involved as follows:

- **Community health workers** (assigned to a specific number of households)
  - Daily visits to households
  - Awareness raising, prevention education, stigma reduction
• Screening of presumptive cases
• Referral of clients to PHC/clinics (escorted/ on their own)
• Reporting to supervisor

**CHW supervisors** (assigned zones and teams of CHWs) in close collaboration with facility supervisors
• Weekly supervision including site visits
• Receiving data from CHWs
• Data collation
• Mentoring and support to CHWs in on-the-job training

**Facility manager** (at PHC/clinic)
• Overall coordination
• Assign CHW teams to communities to ensure coverage
• Mapping of community care services
• Monthly joint meetings with MoH/ NGO leaders

**District supervisor**
• Conduct monthly supervision of facilities
• Data and report compilation from all facilities
• Quarterly joint meetings with NGOs/MoH

**XI Monitoring and Evaluation**

• **Key routine indicators**

  1. Proportion of new patients with TB diagnosed and notified who were referred by CHW

  2. Proportion of new TB patients who received adherence support from CHW and were successfully treated among all TB patients who received adherence support from CHW

• **Special evaluation**

  Special evaluation will be essential part of monitoring and evaluating the integrated community based TB and CLC services. Its aim will be to help assess the contribution of community-based activities to detection of CLCs.

  CHW will be referring persons with CLC symptoms for evaluation and diagnosis at PHC level, health centers, clinics or hospitals. They will record and report on referrals in designated forms and registers. Referral forms with back-referral slips will allow to record the diagnostic outcome of each referred person. These forms and registers will form the basis for special evaluations.

  Special evaluations should be conducted every 1-2 years.
Indicator:

Proportion of new patients with CLC other than TB (one of the following: asthma, COPD, lung cancer) diagnosed and notified who were referred by CHW
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