



TB Champion Empowerment Index

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Acknowledgements

The TB Champion Empowerment Index was developed by REACH, an India-based non-profit organisation, with support from the Stop TB Partnership/UNOPS through the Challenge Facility for Civil Society mechanism (CFCS Round 9). REACH gratefully acknowledges the support of the United States Agency for International Development (USAID) and the Global Fund to Fight AIDS, Tuberculosis and Malaria to the Stop TB Partnership's CFCS mechanism.

Dr. Manjot Kaur, Consultant, REACH led the development process and drafted the Index. Dr. Ramya Ananthakrishnan, Director, REACH and Anupama Srinivasan, Asst. Director, REACH conceptualised the Index, reviewed the draft versions and provided strategic inputs.

We express our sincere gratitude to the TB Champions and members of TB Mukta Vahini, Bihar's TB survivor-led network, for their active involvement in the development of the Index.

Table of Contents

I Introduction and Rationale	6
II Methodology: How the TB Champion Empowerment Index was Developed	7
2.1 Desk Review	8
2.2. Data Collection and Analysis	9
2.3 Limitations	9
III The TB Champion Empowerment Index	10
3.1 Key Indicators.....	10
3.2 Levels of Progress	11
IV Pilot Testing and Analysis	13
4.1 Analysis of Empowerment	13
4.1.1 Empowerment Scorecard	13
4.1.2 Empowerment by theme	14
4.2 Inferences and Findings	15
V Looking Ahead	19
Annexures	20
A Data Collection Tool (English).....	20
B Data Collection Tool (Hindi).....	22
C How to use the Data Collection Tool	25

I. Introduction and Rationale

Tuberculosis (TB), despite being a disease that is both curable and preventable, remains one of the leading causes of death globally. Every year, over ten million people are affected by the disease. India bears over a quarter of this burden, the highest mortality, and the highest number of people diagnosed with drug-resistant TB.

The Government of India is working in mission mode to achieve TB elimination through the National TB Elimination Programme (NTEP). As a result, the last few years have seen the development and adoption of India's most ambitious National Strategic Plan (NSP) to date, the introduction of new policies and strategies, strengthened data systems and inclusion of IT-enabled services. The engagement of TB-affected communities, often identified as a missing dimension of the global TB response, has steadily grown, with increased domestic and donor investment.

This is in keeping with the Political Declaration from the 2018 UN High-Level Meeting (HLM) on TB (which India is a signatory to), that recognises the role of communities and community-centered approaches as central to achieving all ambitious TB elimination targets. The 2020 Deadly Divide: TB Commitments vs TB Realities report by the Stop TB Partnership emphasised the need for sustained engagement and empowerment of TB survivors. This is also echoed in India's NSP which calls on all stakeholders to acknowledge and support communities not as passive recipients of care but as active and motivated stakeholders in the nation's response to TB.

In alignment with the goals of the Government of India, Resource Group for Education and Advocacy for Community Health (REACH), a Chennai-based non-profit organisation, has been working relentlessly for 25 years with the objective of ending TB in India. Established in Tamil Nadu in 1999 in response to the roll-out of the then Revised National

TB Control Programme, REACH works across the country for a multi-sectoral and comprehensive response to TB, in close collaboration with the TB programme, private health care providers, business leaders, celebrities, the media, people with TB and affected communities.

In 2016, with support from the United States Agency for International Development (USAID), REACH began working with TB survivors, building their capacities and empowering them to become TB Champions. What began with a small cohort of 45 TB Champions has now grown to a pan-India movement, adopted and led by the NTEP, with thousands of committed and passionate TB Champions. Capacity-building has been ongoing, through a combination of in-person meetings, virtual learning sessions and learning resources via digital media like WhatsApp. Select TB Champions are trained on various other aspects – communication skill building, undertaking stigma assessments, implementing a community accountability framework, providing tele-counseling support, leadership training and more.

The engagement of TB Champions has positively influenced the lives of people with TB and helped to fundamentally shift the way communities engage with the public health system. This peer support model has led to the availability of psychosocial support, treatment literacy, stigma redressal and provision of person-centered care. TB Champions have also been successful in mobilising their own communities, galvanising influencers and local leaders to participate in the TB response, thereby

creating a more enabling environment for TB elimination.

There is a small but growing body of evidence on the impact of the TB Champions' efforts. Several indicators have been developed and are being utilised to measure the TB Champions' impact on India's TB care delivery system. These indicators measure both quantitative and qualitative aspects:

- Input indicators such as the number of TB survivors trained as TB Champions, number of awareness generation meetings organised etc.
- Outcome indicators like number of people with TB who received information and support services from TB Champions, improvement in treatment outcomes etc.
- Perception of quality of care and services available to people with TB.

Over the last few years, what has also emerged as a recurrent theme is the impact of the intervention on the lives of the TB Champions themselves. Anecdotes and case studies from the field have shown that in addition to the impact on treatment outcomes and experiences, impact has also been created among the TB Champions themselves. The efforts of the various interventions, particularly capacity-building, have empowered the TB Champions in multiple aspects of their lives, including both personal and professional dimensions.

Through an ongoing process of multimedia documentation and qualitative assessments, REACH has been trying to understand better the exact nature of this empowerment. TB Champions have undergone a transformation themselves – they have frequently related experiences around increased self-worth, agency, and socio-political power.

This growing understanding of empowerment in TB Champions was the genesis of the TB Champion Empowerment Index (TBCEI), described in this publication. This Index will facilitate a transition from anecdotal evidence to more tangible measurement in terms of empowerment and will help in the quantification of experiences. This is critical as the TB Champion movement expands in scale across India.

The TB Champion Empowerment Index provides users with a unique opportunity to quantify and measure (what has so far been believed to be) abstract experiences of individual and shared power. The Index will support mapping and measurement of qualitative indicators which were previously only regarded as anecdotal, and which can have a significant impact on how India's TB care delivery system engages with TB survivors and Champions.

II. Methodology: How the TB Champion Empowerment Index was Developed

An informed and systematic process was followed to construct and develop the TB Champion Empowerment Index. This included secondary research, one-to-one interviews and group discussions with TB Champions and stakeholders, development of a data collection tool, piloting of the tool, analysis of responses received and finally, construction of the Index.

2.1 Desk review

As a first step, the development of this Index drew on REACH's own work in engaging TB survivors and undertaking the Communities, Rights and Gender Assessments (in 2018), using the Stop TB Partnership's assessment tools. The next step was a detailed examination of existing tools and guidelines for measuring empowerment in any aspect of work in the development sector (including but not limited to healthcare). Some of these are briefly described below:

i) UN Women's 2020 report: "Women's Empowerment in Kenya – Developing a measure"

The report describes how the Kenya National Bureau of Statistics (KNBS) developed a model to measure empowerment among Kenya's women using five domains - (a) Attitudes toward wife-beating, (b) Human and social resources, (c) Household decision-making, (d) Control over sexual relations, and (e) Economic domain. Each of the domains was assigned equal weights, and the weight of the domain was then distributed equally to each of its constituting indicators to construct the Women's Empowerment Index (WEI) which was then used to analyze the Kenya Demographic and Health Survey (KDHS) 2014, thus helping to build a composite picture of women's empowerment in the country.

ii) World Bank 2005 document: "Measuring Empowerment – Cross-Disciplinary Perspectives"

This book brings together perspectives of economists, anthropologists, sociologists, psychologists, demographers, and political scientists to explore and describe a multi-faceted approach to measuring empowerment. It places at its core the framework from the World Bank's Empowerment and Poverty: A Sourcebook, which has identified four key elements that can change power relations between poor people and powerful actors: access to information, inclusion and participation, social accountability, and local organizational capacity. It examines approaches and challenges around examining empowerment at various levels –

household, community, and national levels, for example – and acknowledges the value of including subjective experiences in the measurement.

iii) SIDA 2010 report from Bangladesh: "Measuring Empowerment? Ask Them – Quantifying qualitative outcomes from people's own analysis"

This paper presents the experience of one social movement in Bangladesh, which managed to find a way to measure empowerment by letting the members themselves explain what benefits they acquired from participating in the movement and by developing a means to measure change over time. The paper is one of the most detailed guides on how to start the process of quantifying qualitative outcomes in a manner that is rights-based, rational and respectful of communities. The description of SIDA's experiences in Bangladesh have strongly influenced the approach to constructing the TBCEI.

The three indicator themes that finally were selected for TBCEI (Personal, Social, and Systemic) were inspired by the four indicator categories given in SIDA's report, i.e., Political, Social, Capability, Economic and Natural Resources.

iv) International Center for Equity in Health 2016 report: "Women's empowerment index for Africa and equity analyses on key health and development outcomes in priority geographies"

The report points out that existing empowerment measurement frameworks use individual constructs; for example, agency (either operationalised as self-worth or self-efficacy), decision-making and voice, and that there is a strong need for considering larger themes like partnerships and enabling environments in the measurement.

v) 2017 White paper from BMGF and KIT: "A Conceptual Model of Women and Girls' Empowerment"

This white paper defines empowerment as being made up of a few key elements – resources, agency, and institutional structures, all of which were

observed as playing out in a significant manner in discussions with TB Champion in India.

2.2 Data collection and analysis

Following the desk research, a three-step process was carried out to construct and test an empowerment index. The process was completed over a period of one month in November 2021 and was done in partnership with TB Mukh Vahini (TMV), a survivor-led network based in Bihar which emerged out of REACH's Call to Action project supported by USAID and which continues to be an active partner to the state government's TB care and prevention efforts.

i) One-to-one Interviews and Group Discussions

The first step in the construction of the TBCEI consisted of one-to-one interviews and group discussions with TB Champions and TMV members. The conversations were structured around the ideas of power and empowerment ("shakti" and "sashaktikaran" respectively in Hindi), and what these terms meant to them in their lived experiences. Open-ended questions were asked to generate conversations which led to sharing of stories, thoughts, and hopes for the future. TB Champions were asked to reflect upon how their experiences of their own power have evolved, and to share specific examples from their lives. The discussion was carried out in Hindi. A total of 30 TB Champions, all part of the TMV network, participated in this process.

ii) Identifying groups and patterns and Development of the data collection tool

The second step consisted of translating the statements collected from TB Champions into English and organising them to group similar statements together. The process of organising these statements revealed clear patterns and led to themes and indicators (a total of 10 indicators across three themes).

The indicators were then converted into a data collection tool with a set of ten statements. Each

statement had four options for responses that TB Champions could select from. In all, the draft tool had ten indicators and three levels of progress under each indicator.

iii) Pilot testing and analysis

In the third step, the data collection tool was shared with a group of 55 TB Champions, again all TMV members. They were asked to select the options that would apply to their experiences. The responses were collected and analysed to construct an empowerment scorecard. This is described in Section 4.1.

2.3 Limitations

The data collection tool and the measurement process are an early attempt to measure and understand empowerment and will likely undergo more iterations as they are utilized with a greater number of TB Champions and other survivor-led networks. For the purpose of constructing the Index, inputs from a pilot group of 55 TB champions were used to identify and define specific indicator for the empowerment index. Though valuable, and very likely to be representative, it must be acknowledged that this is a small sample set. As a next step, formal validation of the Index will be undertaken with the required sample size; the tool and process will be updated based on feedback.

III. The TB Champion Empowerment Index

The TB Champion Empowerment Index or TBCEI defines empowerment as an interplay of three interconnected elements: Individual, Social and Systemic. Individual means the self; Social means being part of a family and community; and Systemic means being part of the TB care system.

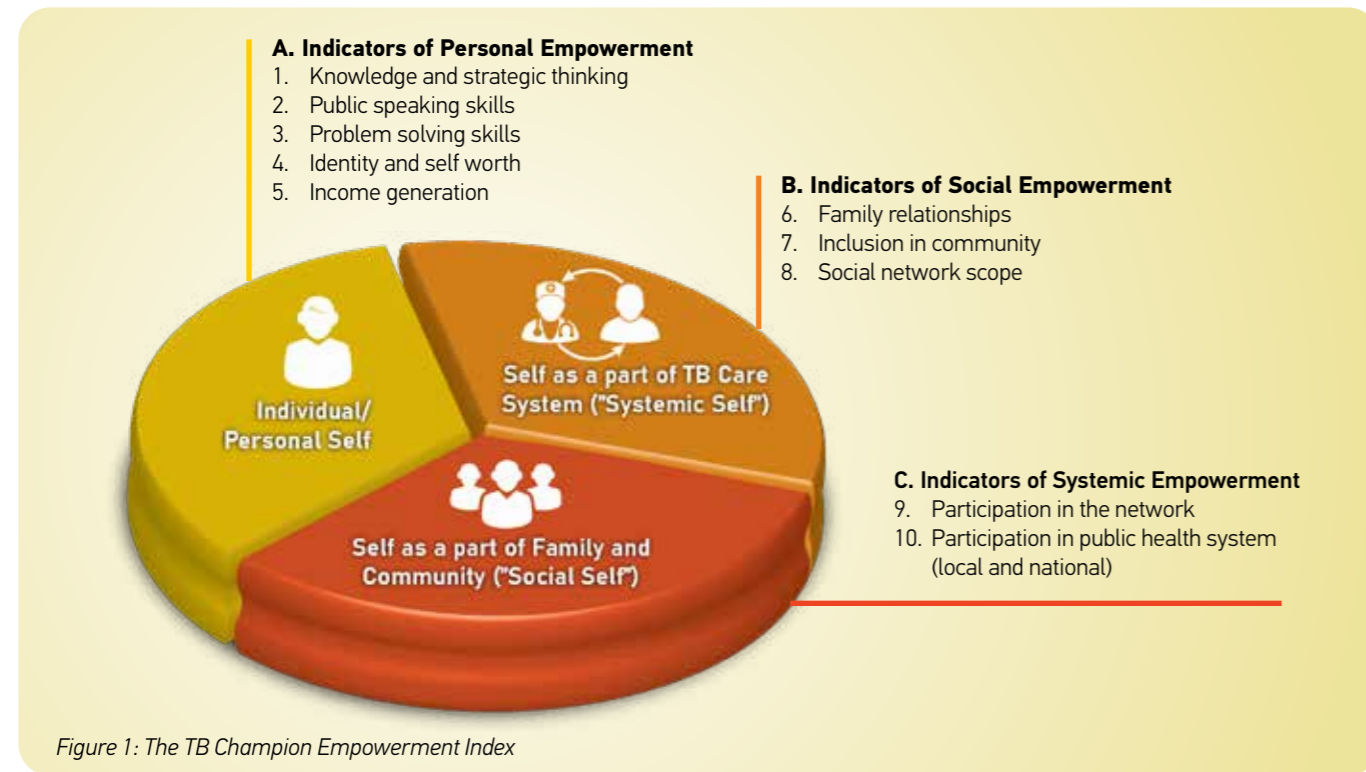


Figure 1 above shows the representation of the three interconnected elements – individual, social, and systemic – that sum up the TB Champions’ experience. The TB Champions who participated in the discussions perceive their selves as being made of these three interconnected elements. Furthermore, they shared anecdotes that pointed to an increased experience of power across all the elements.

The degree of empowerment resulting from participation in capacity-building and from their work as TB Champions can vary across the three elements. For example, some Champions reported significant increases in their authority as individuals or as members of their community and smaller increases in their power to engage with the system.

The TBCEI, therefore, measures empowerment with a set of indicators under three themes: Personal Empowerment, Social Empowerment and Systemic Empowerment.

3.1 Key Indicators

Across each element, the shifts in power can be observed and measured through a set of specific indicators. A total of ten indicators across the three themes are defined in the TBCEI:



Theme 1: Personal Empowerment

There are five indicators related to Personal Empowerment, as follows:

1. knowledge and strategic thinking skills
2. public speaking skills
3. problem solving skills
4. identity and self-worth
5. income generation

Theme 2: Social Empowerment

There are three indicators related to Social Empowerment, as follows:

6. family relationships
7. inclusion in community
8. social network

Theme 3: Systemic Empowerment

There are two indicators under Systemic Empowerment, as follows:

9. participation in the network
10. participation in public health system

The key indicators clarify, to a considerable extent, the ways in which the experiences of “choice”, “voice”, and “agency” have been evolving in a TB Champion’s personal, social, and systemic experiences over time (as they continue to participate capacity-building efforts). Further, these indicators provide a method to observe and measure empowerment by noting how different TB Champions can experience each indicator in a different manner.

3.2 Levels of Progress

Three ascending levels of progress are defined for each of the ten indicators, as described below:

• Level 1: “Knowledge for self”

At this level, there is a newly experienced, and rapidly expanding understanding of the TB Champion’s own ability to first, take charge of their own lives (each of them had experienced varying degrees of loss of control over their lives as a result of having had TB), second, to help other people in the community, and third, to impact the public health system in small but definite ways. Most TB Champions appear to arrive at this awareness of their strength within a few months of beginning their work and joining survivor-led networks.

• Level 2: “Knowledge for Action”

At this level, usually arrived at after a TB Champion has been working for some period of time (can vary from a few months to 2-3 years), there is a high degree of self-confidence in their position in society and their capabilities in each of the three selves; this self-confidence is demonstrated through acts of courage and persistence.

• Level 3: “Knowledge for sustainability”

At this level, the key features are independent thinking and awareness of responsibility towards TB-affected communities and others in the network. This responsibility is demonstrated through taking initiative and expressing interest in making the network self-sustaining. When TB Champions arrive at this level for any indicator, it becomes fairly evident that they are self-driven and can demonstrate qualities of leadership whenever necessary.

Broadly speaking, each level includes the capacity of the previous, i.e., TB Champions move sequentially from Level 1 to 3.

Table 1 shows the TB Champion Empowerment Index, with the key indicators and levels of progress.

Indicator	Level 1	Level 2	Level 3
THEME 1: PERSONAL EMPOWERMENT			
1 Knowledge and strategic thinking	Understands the science around TB – the disease, diagnosis, and treatment; also understands the structure of the TB programme	Understands what needs to be done when the needs of a person with TB are not being fulfilled; can engage with the public health system	Understands the need to be patient and persistent in engaging with the public health system
2 Public speaking skills	Speaks effectively in network events and with small groups of people with TB and overall community, with some help from other network members	Frequently organises and addresses large community events	Communicates effectively with leaders in the community and the public health system
3 Problem-solving skills	Can respond to most questions from people with TB, sometimes needs help from senior network members	Responds to issues raised by people with TB with minimal help from other TB Champions; escalates via effective channels	Advises and supports other, newer TB Champions in solving their problems
4 Identity and self-worth	Has been able to regain the dignity that was lost when faced with the stigma of having had TB; can now talk about their TB journey without shame	Able to speak about personal TB experiences to increasingly larger groups with confidence; aware that their work is helping people with TB	Experiences a sense of identity and pride in themselves and their work; aware that they are playing an important role in their communities
5 Income generation	Has been able to increase their income to a small extent, which has brought some level of economic independence	Have become eligible for new employment opportunities or increased their income-generation capacity	Their work in TB has resulted in a full-time career that allows them to support their families
Theme 2: SOCIAL EMPOWERMENT			
6 Family relationships	No longer experiencing stigma from family (or reduced stigma)	Family members are accepting of their work as a TB Champion	Family members are supportive of and proud of them and their work as a TB Champion
7 Inclusion in community	No longer experiencing stigma from community (or reduced stigma)	Their community respects them for their work	Their social power has positively impacted their families' standing in the community
8 Social network scope	No longer experiencing isolation because of the connection with other TB survivors	Their network of connections in their community has expanded significantly	Feel confident being part of and supported by a wide social network; think of the network as family
THEME 3: SYSTEMIC EMPOWERMENT			
9 Participation in network activities	Carries out one or more of the following activities – provide peer support and person centred care and/or organise local community awareness generation meetings	Represents networks at meetings with government bodies; takes initiative to add more TB survivors into the network	Actively reaches out to, supports and mentors fellow TB Champions in their work; participates in problem solving for the network; takes initiative for network-related activities
10 Participation in public health system	Can communicate with local public health stakeholders	Recognized and accepted by local public health actors	Seen as a partner by public health partners; invited to key meetings and forums and given opportunities to speak

IV. Pilot testing and Analysis

4.1 Analysis of Empowerment

Responses collected from the 55 TB Champions using the data collection tool were scored and an empowerment scorecard was developed. Analysis of the responses and scorecard helped construct the Empowerment Index.

4.1.1 Empowerment Scorecard

The data collection tool had 10 indicators and three levels of progress under each indicator. The responses of the data collection tool were scored using a simple formula:

- Every level 1 response (i.e., Knowledge for Self) was given a score of 1
- Each level 2 response (i.e., Knowledge for Action) was given a score of 2
- Each level 3 response (i.e., Knowledge for Sustainability) was given a score of 3

If a participant selected the option of “none of the above applies to me”, a score of 0 was given.

Given the distribution of indicators under each theme, the scoring was as follows:

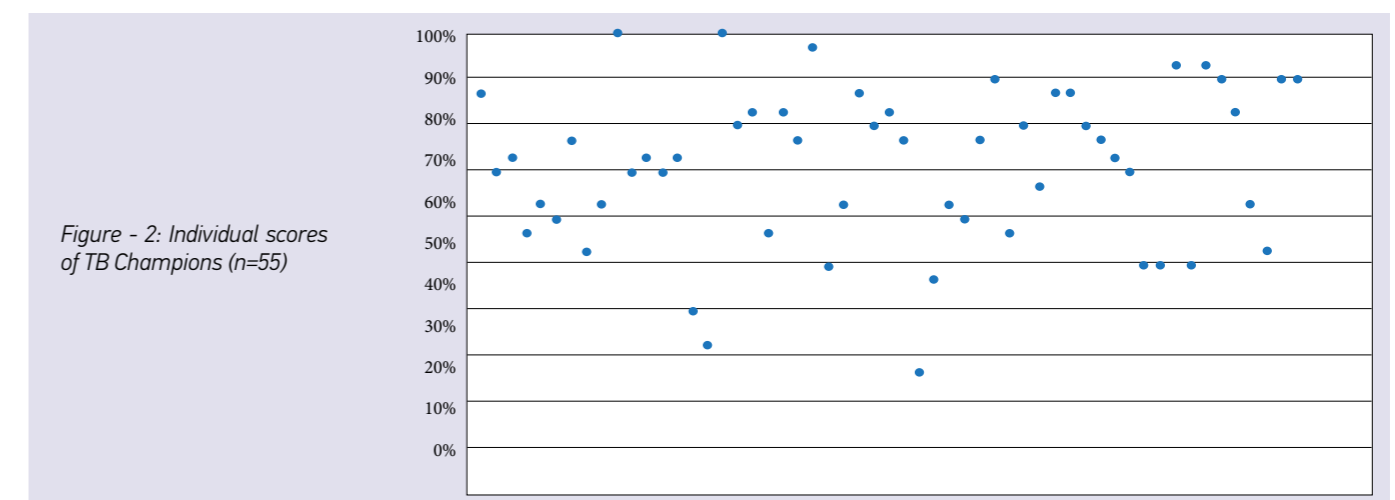
- The theme of Personal Empowerment, measured along 5 indicators, could have a maximum score of 15 points
- The theme of Social Empowerment, measured

through 3 indicators, could have a maximum score of 9 points

- The theme of Systemic Empowerment, measured via 2 indicators, could have a maximum score of 6 points
- The total score for the Empowerment Index, therefore, would be out of a maximum of 30 points

The responses on the data collection tool were thus scored and consolidated to create ‘scorecards of empowerment’ which would provide a snapshot of the group’s perception of their own power. Figures 2 and 3 show empowerment scorecards based on the responses collected in November 2021. Figure 2 represents the responses from TMV members as an aggregated empowerment scorecard, i.e., empowerment as a combined effect of personal, social and systemic experiences. Individual results under the overarching empowerment score could be divided into three parts, in ascending order of progress:

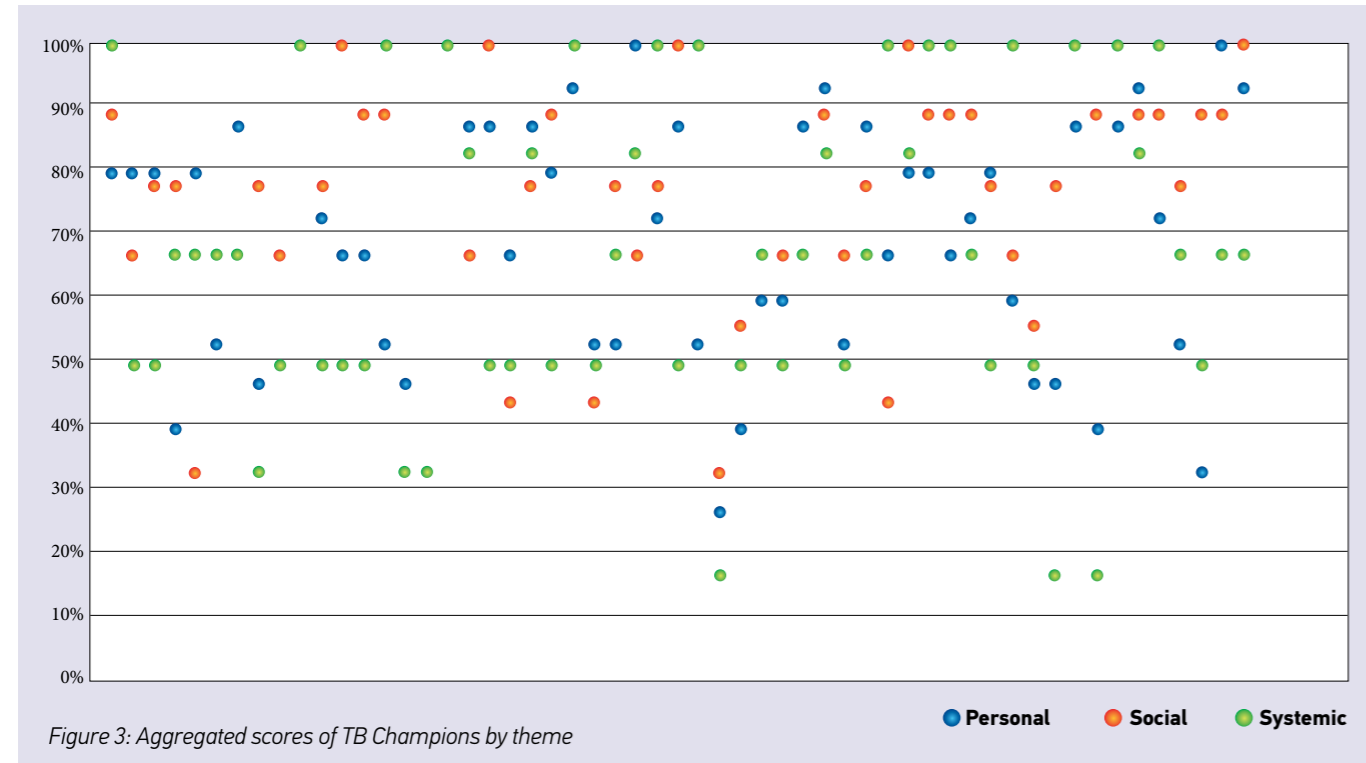
- Only 1 of the TB Champions (out of 55) marked themselves at a score of 30% or below (Level 1 – Knowledge for self)
- A total of 20 TB Champions marked themselves at scores between 30% and 70% (Level 2 – Knowledge for action)
- A total of 34 TB Champions marked themselves at a score of 70% or above (Level 3 - Knowledge for sustainability).



4.1.2 Empowerment by theme

When sliced across the thematic lines, the data shows additional patterns. Figure 3 is an empowerment scorecard which provides further insights on the experiences of power. It can be

seen that low scores were assigned to the theme of systemic empowerment (green dots) much more often than to the theme of personal empowerment, reinforcing the need for more capacity-building in the area of working with systems.



The patterns under each theme are described in further detail below.

Theme 1: Personal Empowerment

The five indicators related to Personal Empowerment were:

1. Knowledge and strategic thinking skills,
2. Public speaking skills,
3. Problem solving skills,
4. Identity and self-worth, and
5. Income generation

As can be seen in Figure 4 under the Personal Empowerment theme:

- 29 TB Champions marked themselves at a score of 70% or above
- 25 TB Champions marked themselves at a score between 31% and 70%

- 1 of the TB Champions marked themselves at a score of under 30%

Theme 2: Social Empowerment

The thematic area of Social Empowerment had 3 indicators

1. Family relationships,
2. Inclusion in community, and
3. Social network

As seen in Figure 5, under the Social Empowerment theme:

- 35 TB Champions marked themselves at a score of 70% or above
- 20 TB Champions marked themselves at a score between 31% and 70%
- None of the TB Champions marked themselves at a score of less than 30%

Theme 3: Systemic Empowerment

The two indicators under the theme of Systemic Empowerment are:

1. Participation in the network, and
2. Participation in public health system

Across the Systemic Empowerment theme (as seen in Figure 6):

- 20 TB Champions marked themselves at the highest level, i.e., a score of 70% or above
- 32 TB Champions marked themselves at a score between 31% and 70%
- 3 TB Champions marked themselves at a score of less than 30%

4.2 Inferences and Findings

This section describes some key inferences from the pilot testing, which helped inform the development process and helped construct the TB Champion Empowerment Index.

i) Need for continued focus on Systemic empowerment: The scorecard revealed something that has frequently been observed (as increasing attention is paid to TB Champions' narratives) - that the greatest increase in perceived power seems to be along the lines of social empowerment, and the one that continues to be most challenging is the theme of systemic empowerment. Just over a third of the respondents marked themselves in the highest level of progress in systemic empowerment, whereas the ratio of respondents marking themselves at Level 3 in personal and social empowerment is 53% and 64% respectively.

ii) Areas of "No change": The indicators where survey respondents had selected "none of the above" were interesting to note. Whenever a TB Champion selected this option, they were indicating that effectively, nothing had changed in their lives for that specific indicator. There were

three indicators, one under each theme, where this "no change" was significant. These were:

- Indicator no. 5 (Income generation) – a total of 9 (out of 55) respondents shared that nothing had changed for them under this indicator
- Indicator no. 7 (Inclusion in community) – 3 respondents shared that nothing had changed for them under this indicator
- Indicator no. 10 (Participation in the public health system) – 5 respondents selected the "no change" option

For the remaining 7 indicators, "no change" responses were either 0 (three indicators) or 1 (four indicators).

Other interesting patterns emerged as well and are described under each specific theme.

Personal Empowerment:

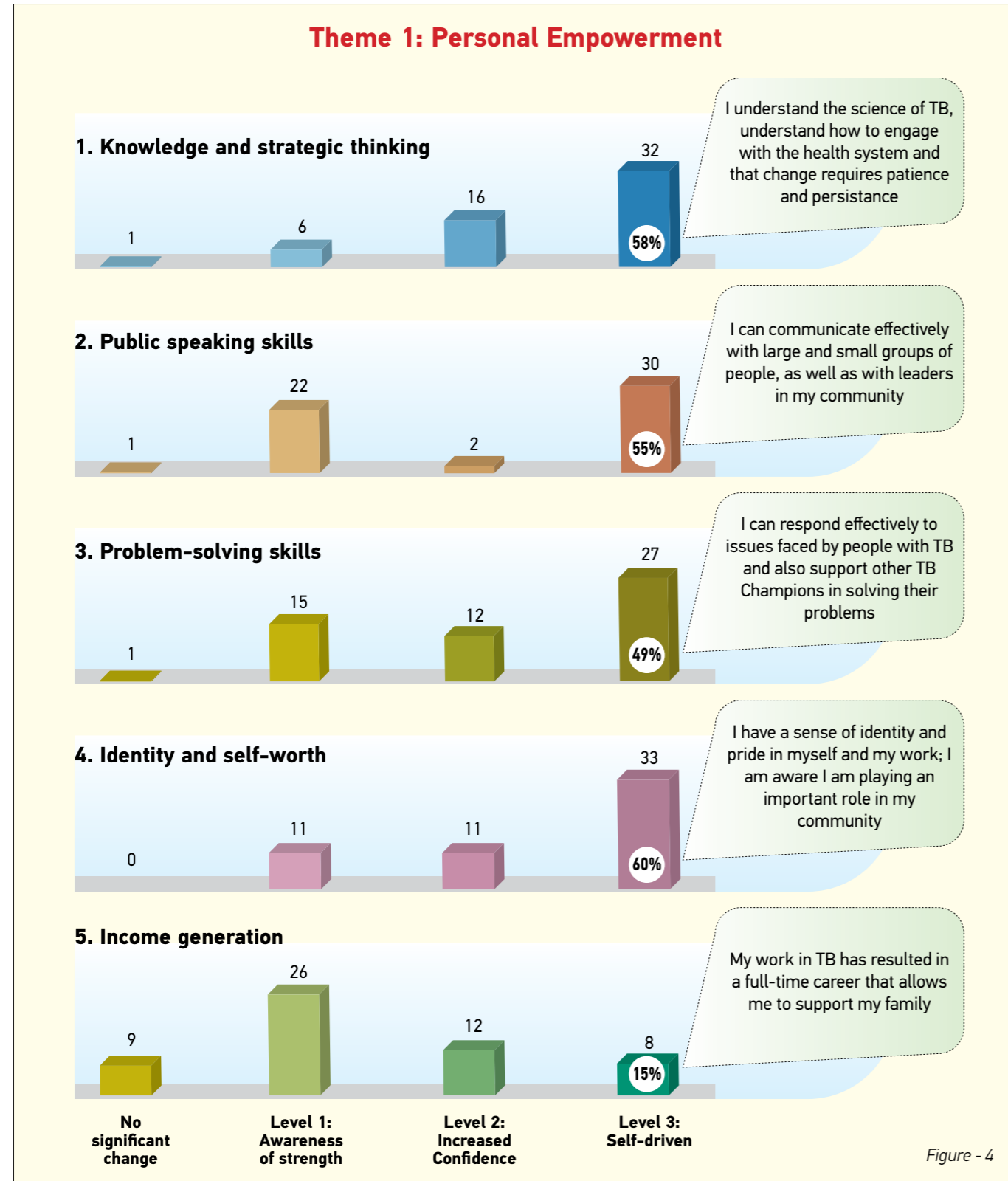
Among the five indicators under this theme, the greatest increase was experienced along the lines of the fourth indicator, i.e., identity and self-worth. This was noteworthy because the words "pehchaan", "maan", and "atma-samman" (translated to identity, esteem, and self-esteem respectively) crop up frequently whenever TB Champions speak about how their lives have changed. This is an indicator that reiterates the interconnectedness of the indicators and themes – an increase in self-respect strongly contributes to the increase in other skills like problem solving and public speaking. Also, this is one of the three indicators (out of the ten total) for which there were zero "no change" responses, meaning that empowerment related to identity and self-worth has been universal.

The lowest increase among the Personal Empowerment indicators was in the indicator related to income generation. As mentioned previously, this indicator is also interesting in that it is the one which received the maximum responses (9 in total) to the statement reflecting "no significant change". Of the 55 TB Champions surveyed, a total of 46 have experienced small to significant increases in their

income, and of these, eight have managed to build full-time careers in TB because of the increased skills and opportunities.

Responses to the other three indicators in this category – public speaking, problem solving and

knowledge and strategic thinking – indicate that about half of the TB Champions surveyed placed themselves at the highest level of empowerment for these indicators.

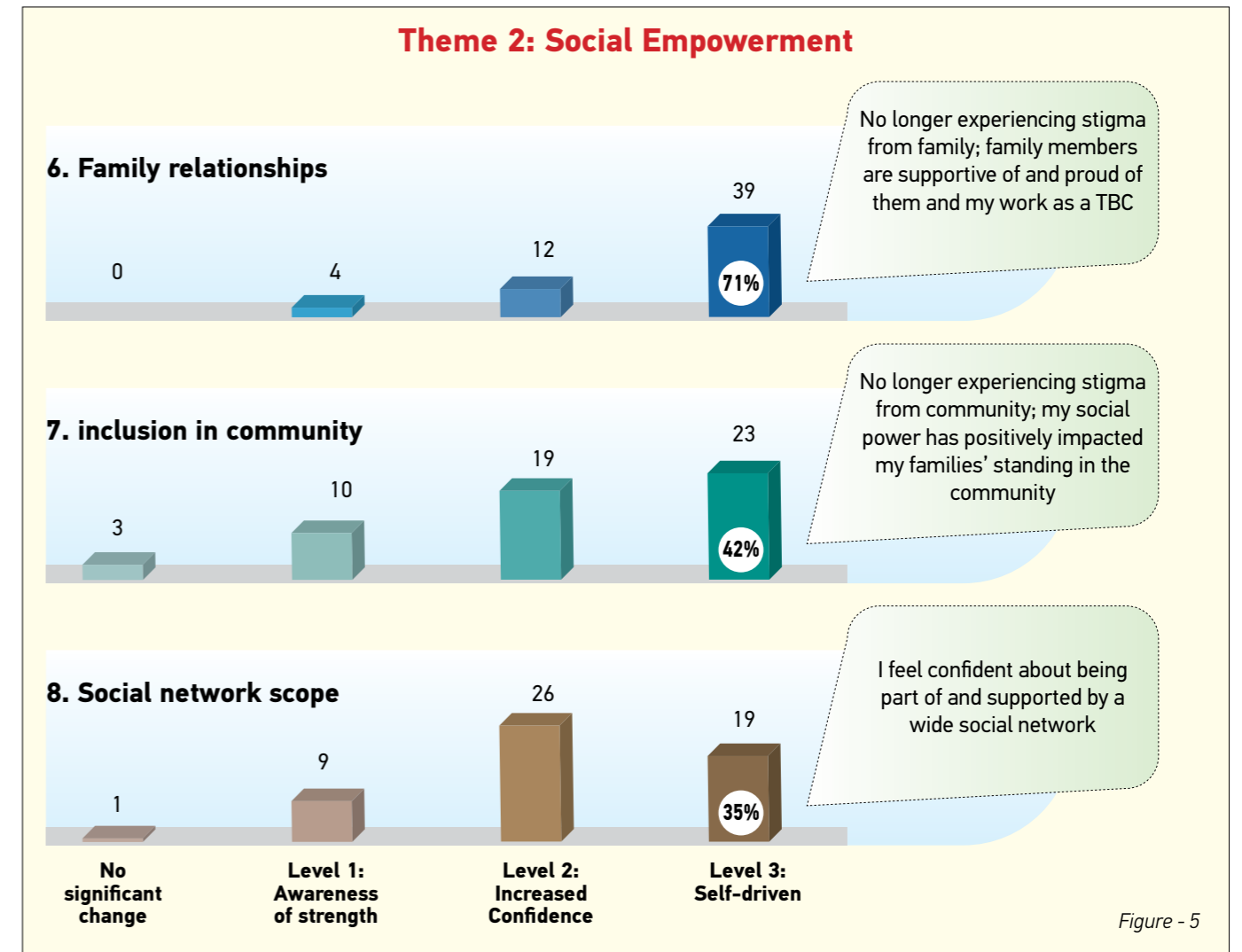


Social empowerment:

The greatest increase in social power, according to TB Champions, has been in terms of the power that comes from family relationships (indicator no. 6). The expansion of power that comes from family has been true for every single member in this network, and 71% of the members placed themselves at the most advanced level for this indicator, making it the strongest among the ten indicators in index. It is

both interesting and poignant that the TB Champions often refer to the TMV network as their family.

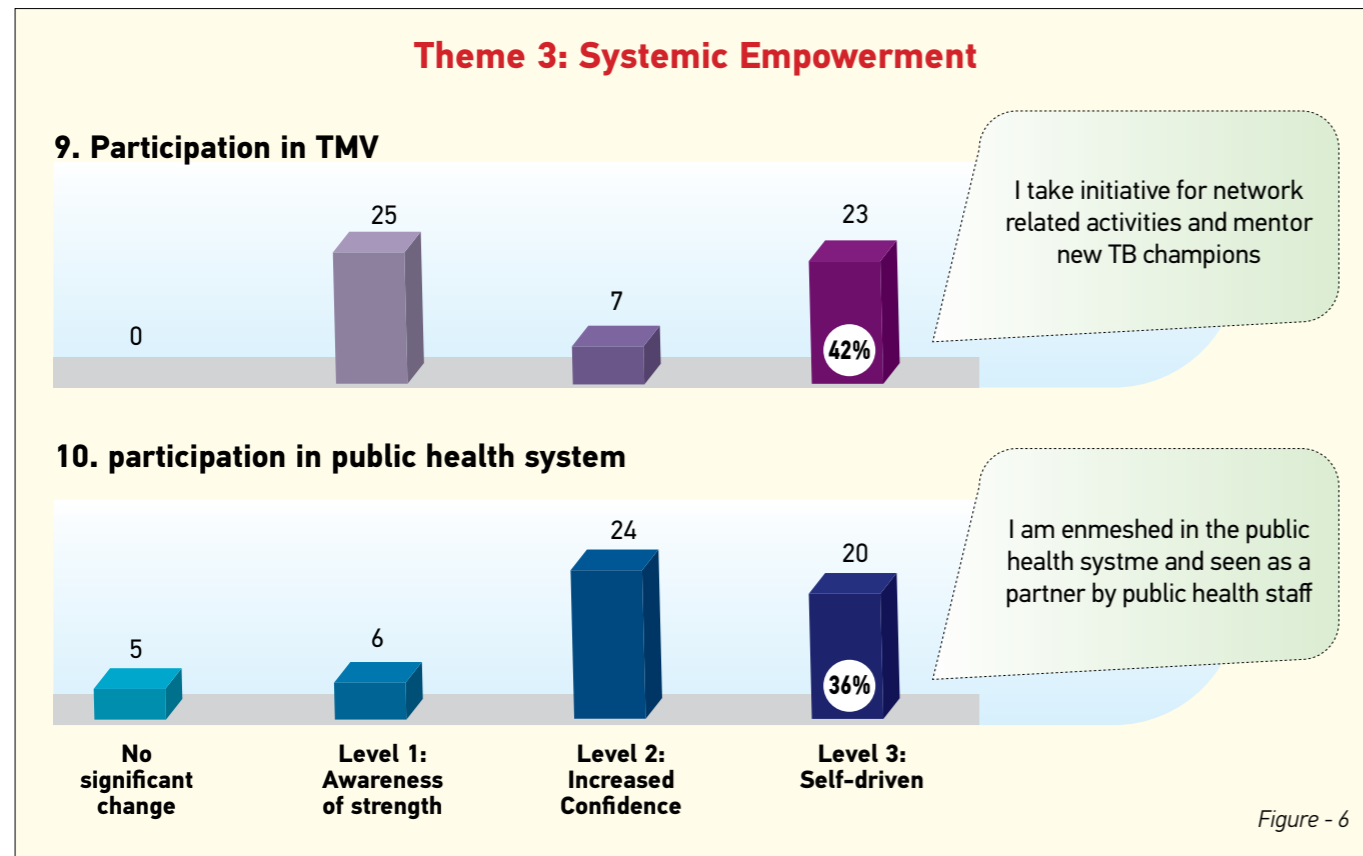
The expansion in each individual's social network is also a source of power (indicator no. 8), and all but one of the 55 TB Champions have experienced an increased sense of support. The area that may contain some vulnerability is that of inclusion in the community (indicator no. 7) where three people shared that they have experienced no significant change in terms of inclusion in their communities.



Systemic empowerment:

Over 42% of the respondents experienced the highest level of power and responsibility of TMV network (indicator 9), and 100% of them experienced some degree of empowerment that comes from participation in the network.

On the other hand, just over a third of TMV members found the full extent of partnership with the public health system (indicator 10), marking this indicator as a clear area of opportunity. For at least five people, there was a clear indication that nothing changed in terms of their power to participate in the public health system.



The TBCEI is an early-stage attempt to understand and quantify the multi-faceted empowerment that capacity-building and sustained engagement can create. The pilot testing of the TBCEI revealed a few areas of opportunity in strengthening TB-affected communities. For example:

- **Focusing of efforts on specific areas:** As described above, clear vulnerabilities exist for a few areas like income generation and participation in the public health system. These areas need to form the basis of further discussion to expand understanding and creative solution-making.
- **Focusing of efforts on specific individuals:** The pilot scorecard revealed individual variations in the degree of empowerment. There were clear

outliers on both sides – a few TB Champions (9-10 of 55) who scored themselves at 90% or above on nearly all the empowerment indicators, and 4-5 who scored themselves at 40% or below. A few experimental efforts can emerge from these observations – the former group could partner up with and support the latter group, or the latter group could undergo additional, more focused capacity-building.

- **Measurement of change:** It would be interesting to carry out a repetition of the data collection at a few specific intervals to see if/how experiences of empowerment change for the group as they undergo new capacity-building and engagement efforts.

V. Looking Ahead

- What does it mean for a person to say, 'I am a TB Champion?'
- What could motivate a TB survivor to want to become a TB Champion?
- What does the experience of becoming and being a TB Champion mean for an individual, beyond their contribution to the TB response?

These questions were the starting point for the conceptualisation of this Index, which to the best of our knowledge, is a first-of-its-kind attempt to undertake measurement of empowerment among TB-affected communities in India. The TBCEI offers a tangible way to record and analyse empowerment and the impact that sustained capacity-building and meaningful engagement can have on individual lives as well as collective networks, in addition to the impact on people with TB and the overall TB response. The TBCEI also provides an opportunity to track and understand the growth and progress of a TB Champion along the various domains of Personal, Social and Systematic empowerment.

While the TBCEI was designed primarily for use in tuberculosis, and with TB survivors, it can be adapted to other settings for similar use and analysis. The Index can be used to measure empowerment of TB-affected communities in other TB high-burden countries. The process of developing the TBCEI, and

specific elements from this Index, can be potentially replicated or adapted to formulate similar tools for other public health contexts, to measure empowerment of affected communities who have been systematically engaged. While indicators of empowerment are likely to vary based on specific contexts, the process for constructing the Index and indicators could remain broadly the same, as described in this document.

There is growing global recognition of the need to increase investment in communities as part of the 'End TB' strategy. In India, the TB programme's commitment to expanding the TB Champion pool is well established, with the ambitious vision of having two TB Champions at every Health and Wellness Centre. The increasing numbers of TB Champions in India offers an opportunity to use the TBCEI at scale to track and measure empowerment at different stages of capacity-building and engagement. In the future, the Index could possibly be used by survivor-led networks, at multiple time-points and intervals, to discern the needs of their members and identify strategies for engagement. Finally, the use of the TB Champion Empowerment Index can generate evidence that could help strengthen the case for enhanced and more strategic investment in TB-affected communities.

Annexures

A. Data Collection Tool (English)

Note: minor edits were made to the first version of this tool, following the pilot testing.

Instruction for respondents:

Please read the statements below and mark the statements (A, B, C, or D) that are applicable for you. You can mark more than one option in each group of statements

1. Information about TB and the national TB programme

- I have adequate information about TB as a disease and the TB programme
- I know what to do and whom to call when a person with TB is not getting the right care or support
- I know it takes many attempts to change things and I need to be patient in my interactions with the system
- None of the above

2. Public Speaking skills

- I can speak confidently at small community groups, network meetings etc.
- I feel confident addressing large groups of people
- I feel confident about speaking to anyone, no matter what their level of authority
- None of the above

3. Problem solving skills

- I can solve most of the problems that people with TB share with me, but sometimes I need help from other TB Champions
- I can independently solve the problems that people with TB share with me, and I know how to escalate things
- I can independently solve the problems that people with TB share with me, and I sometimes help other TB Champions in overcoming their challenges
- None of the above

4. Identity and Self worth

- I don't feel ashamed of having had TB and I share my TB experiences without shame with other people with TB and the community
- I can share my personal TB experiences with large groups of people because I know by doing this, I am helping others with TB
- I feel proud of myself and my work as a TB Champion. I know that I play an important role in my community
- None of the above

5. Income generation

- I have been able to increase my income to a small extent and this has brought me some level of economic independence
- I have become eligible for new employment opportunities or increased my income-generation capacity because of my work as a TB Champion
- My work in TB has resulted in a full-time career that allows me to support my family
- None of the above

6. Family relationships

- My family does not stigmatise me or discriminate against me (or stigma has reduced)
- My family accepts my work as a TB Champion
- My family members are proud of me and supportive of my work as a TB Champion
- None of the above

7. Inclusion in community and social recognition

- I no longer experience any stigma from my community (or the stigma has reduced)
- My community members respect me for my work as a TB Champion and see me as an expert
- My social power has positively impacted my family's standing in the community
- None of the above

8. Social network scope

- I no longer experience isolation because of the connection with other TB survivors
- I feel confident being part of and supported by a wide network; I think of the network as family
- My network of connections has expanded significantly, I am now connected to people all over the country and I find this useful
- None of the above

9. Participation in networks

- I frequently (at least once a month) carry out at least one of the following activities: provide peer support and person-centred care, organise local community awareness generation meetings
- I frequently (at least once a month) represent the network at meetings with government bodies and/or I take initiative to add more TB survivors into the network
- I actively reach out to, support and mentor fellow TB Champions in their work, and/or participate in problem solving for the network; and/or take initiative for network-related activities
- None of the above

10. Participation in public health system

- I frequently (at least once a month) communicate with local public health stakeholders
- Local public health stakeholders know me and my work
- I am a respected ally of the public health system; they see me as a partner and invite me to key meetings and forums
- None of the above

B. Data Collection Tool (Hindi)

सशक्तिकरण सूचक (Empowerment Index) डाटा संग्रह फॉर्म (data gathering form)

निर्देश: कृपया नीचे दिए गए कथनों को पढ़ें और उन विकल्पों (ए, बी, सी, या डी) का चयन करें जो आप के लिए सही हैं। चाहें तो एक से अधिक विकल्प का चयन भी कर सकते हैं

1. टी.बी. (TB) or NTP के बारे में जानकारी

- मेरे पास टी.बी रोग और TB कार्यक्रम के बारे में पर्याप्त जानकारी है
- मुझे पता है कि टी.बी रोगी को सही देखभाल न मिलने पर क्या करना है और किसे कॉल करना है
- मैं समझता/ती हूँ कि सिस्टम को बदलने के लिए कई प्रयास करने पड़ते हैं और मुझे सिस्टम के साथ धैर्य, साहस और दृढ़ता के साथ काम करना आता है
- इन में से कोई भी विकल्प मुझपर लागू नहीं

2. पब्लिक स्पीकिंग का कौशल

- मैं छोटे सामुदायिक समूहों, नेटवर्क मीटिंग आदि में आत्मविश्वास से बोल सकता/ती हूँ
- मैं बड़े से बड़े समूहों को संबोधित करने का आत्मविश्वास रखता/ती हूँ
- मैं किसी से भी बात करने का आत्मविश्वास रखती/ता हूँ चाहे उनके अधिकार का स्तर कुछ भी हो
- इन में से कोई भी विकल्प मुझपर लागू नहीं

3. समस्या समाधान का कौशल

- मैं टी.बी मरीजों की अधिकांश समस्याओं का समाधान कर सकता/ती हूँ, लेकिन कभी-कभी मुझे अन्य टीबी चैंपियन से मदद की आवश्यकता होती है
- मैं टी.बी मरीजों की सभी समस्याओं का समाधान स्वतंत्र रूप से कर सकती/ता हूँ, और मुझे अपनी बात को सही अधिकारियों के पास पहुँचाना आता है
- मैं टी.बी मरीजों की सभी समस्याओं का समाधान स्वतंत्र रूप से कर सक ती/ता हूँ, और मैं कभी-कभी अन्य टी.बी. चैंपियन को उनकी चुनौतियों को हल करने में मदद भी करती/ता हूँ।
- इन में से कोई भी विकल्प मुझपर लागू नहीं

4. पहचान और आत्मसम्मान

- मुझे इस बात से शर्म महसूस नहीं होती की मुझे टी.बी. की बीमारी थी और मैं अपने टी.बी. के अनुभव बिना किसी शर्म के अन्य रोगियों और चैंपियन के साथ साझा करता/ती हूँ
- मैं अपने व्यक्तिगत टी.बी. अनुभव को बड़े समूहों के साथ साझा कर सकता/ती हूँ क्योंकि मुझे पता है कि ऐसा करने से, मैं अन्य टी.बी रोगियों की मदद कर रहा/रही हूँ
- मैं एक टी.बी चैंपियन के रूप में अपने आप पर और अपने काम पर गर्व महसूस करता/ती हूँ। मैं जानता/जानती हूँ कि मैं अपने समुदाय में एक महत्वपूर्ण भूमिका निभाता/ निभाती हूँ।
- इन में से कोई भी विकल्प मुझपर लागू नहीं

5. आमदनी सृजन

- मेरी आमदनी में कुछ वृद्धि हुई है और इससे मुझे कुछ हद तक आर्थिक स्वतंत्रता मिली है
- मेरे लिए रोजगार के नए अवसर खुल गए हैं या मेरी आमदनी में महत्वपूर्ण वृद्धि हुई है
- टी.बी के काम में मुझे पूरी आजीविका मिल गयी है और यही मेरे परिवार-पालन का संतोषजनक स्रोत है
- इन में से कोई भी विकल्प मुझपर लागू नहीं

6. पारिवारिक संबंध

- मेरा परिवार मेरे साथ कोई भेदभाव नहीं करता (या भेदभाव कम हो गया है)
- मेरा परिवार टी.बी. चैंपियन के रूप में मेरे काम को स्वीकार करता है और मेरा सहयोग करता है
- मेरे परिवार के सदस्यों को मुझ पर और मेरे टी.बी. चैंपियन के काम पर गर्व है
- इन में से कोई भी विकल्प मुझपर लागू नहीं

7. समुदाय में समावेश और मान्यता

- मेरे समुदाय में कोई मेरे साथ भेदभाव नहीं करता (या भेदभाव कम हो गया है)
- मेरे समुदाय के सदस्य टी.बी. चैंपियन के रूप में मेरे काम के लिए मेरा सम्मान करते हैं और मुझे एक विशेषज्ञ के रूप में देखते हैं
- मेरे काम से मुझे ही नहीं, मेरे परिवार को भी मान मिला है
- इन में से कोई भी विकल्प मुझपर लागू नहीं

8. सोशल नेटवर्क

- अन्य टी.बी सर्वाइवरस को मिलने के बाद अब मेरा अकेलापन दूर हो गया है
- मुझे एक विस्तृत नेटवर्क का हिस्सा होने और उसके सहयोग से आत्मविश्वास मिलता है; मैं नेटवर्क को परिवार मानता/ती हूँ
- मेरे सामाजिक संबंधों में वृद्धि हुई है, मैं मेरी जान पहचान देश भर में है और इससे मुझे लाभ हुआ है
- इन में से कोई भी विकल्प मुझपर लागू नहीं

9. नेटवर्क में भागीदारी

- मैं अक्सर (महीने में कम से कम एक बार) निम्नलिखित गतिविधियों में से कुछ करता/ती हूँ: सहकर्मी सहायता और व्यक्ति केंद्रित देखभाल, स्थानीय लोगों के बीच जागरूकता कार्यक्रम का आयोजन
- मैं अक्सर (महीने में कम से कम एक बार) सरकारी नेटवर्क का प्रतिनिधि बनकर सरकारी मीटिंग में भाग लेता/ती हूँ, और/या नए टीबी सर्वाइवरस को नेटवर्क में जोड़ता/ती हूँ
- मैं सक्रिय रूप से साथी टी.बी. चैंपियंस से मिलता/ती हूँ, उनका समर्थन करता/ती हूँ और उनको काम के बारे में सलाह देता/ती हूँ; और/या नेटवर्क की समस्या के समाधान में भाग लेता/ती हूँ; और/या नेटवर्क से संबंधित गतिविधियों में बढ़-चढ़ कर भाग लेता/ती हूँ
- इन में से कोई भी विकल्प मुझपर लागू नहीं

10. स्वास्थ्य विभाग के काम में भागीदारी

- मैं अक्सर (महीने में कम से कम एक बार) स्थानीय स्वास्थ्य विभाग के स्टाफ के साथ बातचीत करती/करता हूँ
- स्थानीय स्वास्थ्य विभाग के स्टाफ मुझे और मेरे काम को जानते हैं
- स्थानीय स्वास्थ्य विभाग के स्टाफ मेरा सम्मान करते हैं, मुझे एक हितधारक के रूप में देखते हैं और मुझे प्रमुख बैठकों और मंचों पर आमंत्रित करते हैं
- इन में से कोई भी विकल्प मुझपर लागू नहीं

C. How to Use the Data Collection Tool

As can be seen in the data collection tools in Annexure A and B, each set of ten statements is presented as a multiple-choice question with 4 responses, of which one needs to be selected. Options a), b) and c) correspond to Levels 1, 2 and 3 of Progress. Option d) provides the respondent to select none of the above if they disagree with the indicator description and free-text space to explain their point of view.

Data gathering: The tool can be used in one of two ways:




- Team-assessment: A person from the project team or a consultant can gather TB Champions' responses to the questions during interviews or group discussions
- Self-assessment: Using data collection tools like Google Forms, TB Champions can be given access to the questionnaire and requested to select one option under each question

Analysis: The response to each question results in a score depending on the level selected.

- For every a) response selected, a score of 1 is assigned, for every b) response, a score of 2 and for every c) response selected, a score of 3 is assigned. If option d) is selected, a case-by-case decision can be taken to give a score of 0 to 3. Therefore, the final score is out of a total of 30.
- If TB Champions carry out self-assessment, they are likely to select multiple options because if c) is true, a) and b) are will also be true (because each level includes capacity of the previous). The score will be calculated based on the highest level that they select. For example, if a TBC selects both a) and b), the score will be 2. Similarly, if a TBC selects all 3 options – a, b, and c – a total of 3 will be given to that response.

The TB Champion Empowerment Index is a first-of-its-kind attempt to measure empowerment among TB survivors in India. Developed through an informed and systematic process, the Index offers a tangible way to quantify and measure abstract experiences of individual and shared power, and to understand the impact that sustained capacity-building and meaningful engagement of TB survivors as Champions can have. The Index defines empowerment as an interplay of three interconnected elements: Individual, Social and Systemic, and offers the opportunity to track progress along a set of ten key indicators in these three domains. The use of the TB Champion Empowerment Index can generate evidence that could help strengthen the case for enhanced and more strategic investment in TB-affected communities.



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HEAD OFFICE

No. 194, 1st Floor, Avvai Shanmugam Salai Lane,
Lloyds Road, Royapettah, Chennai – 600014
PHONE: 044 45565445 / 28132099

DELHI OFFICE

BB-5, 1st and 2nd Floor, Greater Kailash
Enclave II, New Delhi – 110048,
PHONE: 011 49055686

EMAIL US

support@reachindia.org.in

FOR MEDIA RELATED QUERIES

media@reachindia.org.in