

Social Protection and Knowledge Sharing Network (SPARKS)

DRAFT Report of progress made against the 2016 Work Plan – May 2018



LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE



Karolinska Institutet



World Health Organization

Planned activities

1. Organize next meeting Q2 2018.

Done (see funding applications)

2. Communication plan, Q2 2017.

In progress - [website](#) created (<http://sparksnetwork.ki.se>) and newsletter planned

3. Evidence generation and methodological innovation

Methods development

1. *To refine the methodology used to measure total costs (direct and indirect) of illness and health care for patients and households in order to identify cost-drivers and enable monitoring of the incurrence of catastrophic total cost.*

- After review of the first TB patient cost surveys using the field testing protocol, the WHO has revised the generic protocol and published it as: Tuberculosis Patient Cost Surveys: A Handbook. WHO/HTM/TB/2017.24. Geneva: World health Organization, 2017. Contributions were provided from SPARKS members who were co-authors of the handbook
- Further analyses of methodological options will be done on additional completed cost surveys, in collaboration with WHO
- Methods adaptation to other condition than TB still needs to be pursued, however a longitudinal instrument is in development in Malawi – adapted from the TB costing instrument - for evaluating household costs for patients and their carers undergoing palliative care for cancer in urban Blantyre. Results on application expected 2019. Bates J, Tomeny E, Squire B, Niessen L
- In the Impact TB project (Nepal and Vietnam) we are also adopting a longitudinal approach using an adapted questionnaire based on the WHO tool to measure patient's costs. In Nepal, the longitudinal approach has been implemented in partnership with Seed award Project (Tom Wingfield)
- Practical work in several countries to adapt the TB patient cost survey questionnaire and incorporate additional methods of measuring income (such as consumption/ expenditure in Ghana and Papua New Guinea) and other efforts to improve the methodology being used to measure TB patient costs

2. *To pursue the assessment of priority research needs based on mapping existing social protection schemes, explore opportunities for making existing schemes more TB-sensitive, and; To develop a check list /guide for the identification of promising interventions and appropriate research design for baseline, impact and process evaluation research*

- Done for selected countries as part of the dissemination and policy translation of patient cost surveys, e.g. in Vietnam, Myanmar, Ghana, and Kenya
- A check-list/guide for the identification of promising interventions and appropriate research design has not yet been developed.

- A symposium at the 48th International Union Against TB and Lung Disease in October 2017 was coordinated by SPARKS members which discussed the current state of play relating to social protection mapping.
- Attendance at the Korean Institute of Tuberculosis organised meeting on pillar three of the End TB Strategy with presentations and draft meeting report in progress: Viney K. Workshop for End TB Strategy Pillar II in the Western Pacific Region: Action towards Universal Health Coverage and Social Protection. Cheongju, Korea. 2017. “Operational steps in designing and conducting patient cost surveys”.
- Attendance at the WHO TB patient cost survey taskforce meeting – Geneva, April 2017
- Workshop on Social Protection and TB Research Meeting in Brazil. April 25-26, 2017 Organized by staff from WHO and National TB Programm/MoH Brazil - Brasília.

3. *To further develop methods for mathematical modelling of the potential impact of social protection on TB burden and TB-related impoverishment.*

This has been a very active work stream, please see publications under the papers and reports section.

Mapping and formative research

4. *To support more countries to do national TB patient cost surveys using the WHO TB Patient Costs Tool.*

- WHO Global TB Programme has continued to coordinate implementation of TB patient cost surveys, several in collaboration with SPARKS partners. There has been impressive progress and to date 11 countries have completed national surveys, surveys are ongoing in 5 and planned in 10, see Figure 1 (not completely up to date).
- Preliminary results were presented in the WHO TB Impact Measurement Task Force Meeting in Glion, May 2018, see Figure 2.
- Attendance at the WHO TB patient cost survey taskforce meeting in April 2017 (Geneva)
- In addition, a symposium at the 48th International Union Against TB and Lung Disease in October 2017 was coordinated by SPARKS members including WHO partners, which discussed development and roll-out of the WHO TB patient costs survey and also methodological issues surrounding catastrophic costs calculations

Figure 1: Ongoing and planned costs surveys

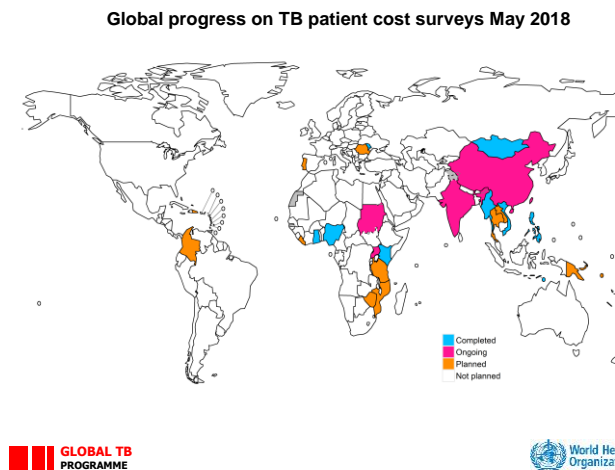
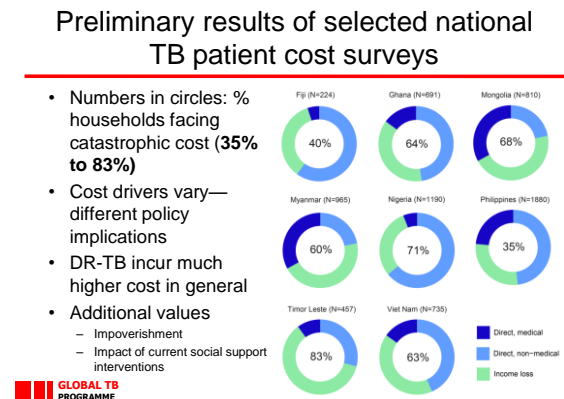


Figure 2: Preliminary results from cost surveys



5. To perform pooled and comparative cross-country analyses of national TB patient cost surveys in order to identify global patterns of cost drivers and determinants of both TB and costs.

- This is planned for Q4 2018, when about 10 countries will have completed surveys.

Evidence generation

6. To evaluate policy changes or pilot interventions designed to reduce patient costs and improve access in selected countries that have performed a situation assessment.

- Studies are ongoing in Brazil, Vietnam, Nepal, Nigeria, Uganda, and Mozambique and planned for Kenya.
- Abstract submitted to Union meeting: Evaluating Catastrophic Costs for Tuberculosis Patients in Brazil: A Multicentre Study in Five State Capitals. Guidoni, LM, Negri LSA, Sales CMM, Zandonade E, Rudgard WE, Lonnroth K, Maciel ELN (paper will be finished in June)
- Pilot intervention designed for Vietnam with funding assured – to be implemented in Q3, 2018
- Two protocols submitted for interventions re social protection and TB in Vietnam and Uganda – if successful will be implemented in Q1, 2019.
- Included TB as a conditionality for access of housing within the Minha Casa Minha Vida (My House My Life) – December 2017 (Law not published yet)

7. To model the extent to which catastrophic costs / impoverishment can be mitigated by social protection.

- See paper: Rudgard WE, Evans CA, Sweeney S, Wingfield T, Lonnroth K, Barreira D, Boccia D. Comparison of two cash transfer strategies to prevent catastrophic costs for poor tuberculosis-affected households in low- and middle-income countries: An

economic modelling study. PLoS Med. 2017 Nov 7;14(11):e1002418. doi: 10.1371/journal.pmed.1002418. eCollection 2017 Nov. PMID: 29112693

- A further manuscript from Peru related to this research area is currently under review: Furukawa N, Wingfield T, Evans CA. The cost-effectiveness of cash transfers for people with tuberculosis: a modelling study using data from Peru.
- A manuscript from Brazil in social protection is currently under second review in Lancet Global health: Effect of the Bolsa Família Program on the outcome of tuberculosis treatment: a prospective cohort study. Oliosi JGN, Reis-Santos B, Locatelli RL, Sales CMM, da Silva-Filho WG, Silva KC, Sanchez MN, Andrade KVF, Araújo GS, Shete PB, Pereira SM, Riley LW, Lienhardt C, Maciel ELN.
- A further manuscript from Brazil: A matter of inclusion: Randomized cluster trial to assess the effect of food baskets on tuberculosis treatment outcomes. Barbara Reis-Santos; Rodrigo Locatelli, Janaina Oliosi, Carolina M Sales; Priya Shete, Christian Lienhardt; Lee W Riley, Ethel L Maciel
- Data from completed patient cost surveys and mapping of social protection schemes will be used to pursue this work further.

8. *To generate policy-relevant impact and operational evidence in Brazil and India.*

- SOPHIA (Social Protection for Health Improvement and Access): This research program developed by the London School of Hygiene (Delia Boccia) in collaboration with Rede-TB Brazil and the Brazilian National TB control Program. The project aims to understand barriers to access to social protection from TB-affected communities with the scope of designing interventions able to overcome them. The ultimate scope is to promote a better and more cost-effective integration of social protection and TB care and establish synergies to maximise the TB elimination and poverty reduction goals of these programs consistently with the SDGs framework. Funding strategies are being explored.
- **ELISIOS-TB-** Estudo Longitudinal dos impactos do Suporte Social nos Indicadores Operacionais da Tuberculose (Longitudinal Study of Social Support Impacts on Tuberculosis Operational Indicators). This research program developed by the Federal University of Espirito Santo (Ethel Maciel) in collaboration with Rede-TB Brazil (Afranio Kritski and Mauro Sanchez and others), the NTP-Brazil, LSHTM (Delia Boccia) and UCSF (Priya Shete) with funding by Minister of Health in Brazil. The project aims to map existing social protection schemes, explore opportunities for understand and making existing schemes more TB-sensitive, and; to develop a interventions to access the impact and process evaluation of Social Support in TB patient take into to account the income (employment, governmental programs, catastrophic cost), healthy environment, coping and decision making and social networking of TB patients and their contacts.

Other

9. *To determine the impact of social protection on the expression of biomarkers of TB immunity.*

- Together with Immunologists of the London School of Hygiene and Tropical Medicine and social epidemiologists of Kings College (Dr Jennifer Dowd), Delia Boccia has established an interdisciplinary partnership aimed to investigate how vaccine response could be enhanced by combining traditional vaccine R&D strategies with poverty-reduction programmatic actions, such as social protection, using BCG as proof of concept. This

environ-vaccinology approach to the R&D of vaccines for diseases of poverty has recently prompted a successful Pump Priming Grant application sponsored by MRC via the VALIDATE network to undertake 12 months of formative research that is expected to lead to a more ambitious grant application.

- A social protection/biomarkers of TB immunity is also included within a large LSHTM large application under the GCRF: RCUK Collective Fund. Interdisciplinary Research Hubs to Address Intractable Challenges Faced by Developing Countries. The proposal will be submitted by the end of May 2018 and includes a work package on social protection and BCG efficacy led by Delia Boccia. If successful, the work package will entail the implementation of a TB-specific social protection intervention among a cohort of mothers in Uganda to evaluate whether this enhances the BCG response among their children by improving the mental health and the immunological competence of the mothers.
- Development of “*Guidance Document on Nutritional Care and Support for patients with active tuberculosis in India*” for India’s National TB programme. The poor in India suffer a higher burden of TB and its adverse outcomes. TB leads to or worsens pre-existing undernutrition which is the most prevalent comorbidity which confers substantial risk of mortality during treatment, and drug toxicity. The persistence of undernutrition after cure contributes to the higher frequency of relapse, seen in Indian patients. Food insecurity in households with TB is a risk factor for TB in contacts. Anurag Bhargava (Yenepoya Medical College, Mangalore) led the drafting of a policy document on nutritional support for patients with TB in India in association with experts in the field of nutrition, tuberculosis, public health professionals, programme managers. This was released on March 24, 2017 by the National TB Control Programme in association with WHO (India) and Yenepoya University and represents the first country adaptation of the WHO’s Guideline for Nutritional Care and Support for patients with active TB released in 2013. It recommends a food package with good quality protein for patients with active TB, and an enhanced ration for the family through the public distribution system. In 2018, the Government announced an annual budgetary allocation of INR 6 billion for nutritional support of TB patients. The states have been directed to provide it as either a cash transfer of INR 500 per month or in kind.

List of research projects

Funded and ongoing and ongoing research projects

1. **IMPACT TB**

Funding: 3-year grant 2017-2019 (Horizon 2020)

Lead: Liverpool School of Tropical Medicine (PI Maxine Caws)

2. **Locally-Appropriate Socioeconomic Support Package For TB-Affected Households In Nepal: Seed Award Research to inform the BEYOND TB trial**

Funding: 2-year seed Award from Wellcome and Academy of Medical Sciences (2017-2019)

Lead: University of Liverpool (PI, Tom Wingfield)

3. **CHEST - Coordinating Health and Social care for TB patients in Mozambique -**

Funding: 3-years grant from Swedish Research Council

Lead: Karolinska Institutet and University of Tampere (PI, Salla Atkins)

4. **Social support for TB patients in Vietnam: comparison of the acceptability of social health insurance and cash transfers among drug-susceptible TB patients in three cities**

Funding: Seed funding from Stop TB Partnership and European Union

Lead: Vietnam NTP (Viet Nhung, Hoi Van, Binh Hoa) and FIT (Luan Vo)

5. **TB Sequel – Pathogenesis and risk factors of long term sequelae of pulmonary TB defining individual outcomes and public health impact**

Funding: German Government

Lead for the socioeconomic work-package: University of Witwatersrand (PI Denise Evans)

6. **CRESIPT and TB REACH Peru**

Funding: Wellcome Trust/MRC/DFID, STOP TB Partnership

(PI Carlton Evans)

7. **ELISIOS-TB- Estudo Longitudinal dos impactos do Suporte Social nos Indicadores Operacionais da Tuberculose (Longitudinal Study of Social Support Impacts on Tuberculosis Operational Indicators)**

Funding: 4-years grant from Brazilian Minister of Health. (US\$ 700,000.00)

Lead: Federal University of Espirito Santo, Brazil (PI, Ethel Maciel)

8. **From Poverty to Cure: Addressing Socioeconomic Barriers to TB Diagnostic Evaluation in Uganda.**

Funding: 3- year grant from Parker B. Francis Foundation (US).

Lead: University of California, San Francisco, USA (PI, Priya Shete)

Submitted grant proposals

1. **The health, social and economic impact of social protection interventions targeting poor households struck by tuberculosis in Viet Nam: A cluster randomised controlled trial.**

Funding: NHMRC, Australia

Lead: Australia National University and Karolinska Institutet (PI Kerri Viney)

2. ***Evaluating the Impact of Cash Transfers Plus on Tuberculosis Outcomes in Uganda: the ExaCT TB Study***
 Funding: Swedish Research Council
 Lead: University of California, San Francisco and Karolinska Institutet (Leads: Priya Shete and Kerri Viney)
3. ***Development and expansion of the health and social protection action research & knowledge sharing network (SPARKS)***
 Funding: Swedish Research Council
 Lead: Karolinska Institutet (PI Knut Lönnroth)
4. ***Direct benefit transfers and their effect of health and education***
 Funding: Swedish Research Council
 Lead: Karolinska Institutet (PI Vinod Diwan)
5. ***Countering catastrophic costs: Food parcels and transport money via eWallet to support treatment adherence for DR-TB patients***
 Funding: TB Reach
 Lead: South African Medical Research Council and University of Tampere/Karolinska Institutet (Leads: Wanga Zembe-Mkabile, Lieve Vanleeuw and Salla Atkins)
6. ***GEST TB: GEnErating Evidence for Social proTection for TB patients***
 Funding: Academy of Finland
 Lead: University of Tampere (PI Salla Atkins)
7. ***A survey of TB patient costs in north west England: a pilot to inform England's national survey***
 Funding: Royal College of Physicians
 Lead: University of Liverpool (PI Tom Wingfield)
 Collaborations: NIHR (UK), Public Health England, Liverpool School of Tropical Medicine, University of Manchester
8. ***Development and expansion of the health and social protection action research & knowledge sharing network (SPARKS)***
 Funding: Swedish Research Council (Vetenskapsrådet; Development Swedish Links)
 Lead: Karolinska Institutet (PI: Knut Lönnroth)
9. ***Child poverty: measurements and social protection programs as protective factors in Sweden and Finland.***
 Funding: Swedish Research Council (Vetenskapsrådet; Humanities and Social Sciences research project grant)
 Lead: Karolinska Institutet (PI: Kristi Sidney Annerstedt)
10. ***The RATIONS (Reducing Activation of Tuberculosis by Improvement Of Nutritional Status) study: A cluster randomized trial of nutritional support (food rations) to reduce TB incidence in household contacts of patients with smear positive pulmonary tuberculosis in communities with a high prevalence of undernutrition***
 Funding: India TB Research Consortium.
 Lead: Yenepoya University(PI: Anurag Bhargava)

Planned and possible grant applications under development

Tom Wingfield: Multi-country SP Trial (Wellcome Trust Career Development Fellowship)

Kerri Viney, Knut Lönnroth, Salla Atkins, etc: SE support package (ESRC)

Delia Boccia: SOFIA (ESRC, MRC and ERC) – see above

Delia Boccia; VALIDATE (MRC) – see above

Delia Boccia: Task force for the systematic review of TB-relevant social protection evidence (Target donor to be identified)

Delia Boccia: Working group on the evaluation of the TB –impact of achieving the Sustainable Development Goals (Target donors to be identified).

Kristi Sidney Annerstedt: SPIN: Social protection interventions for non-communicable diseases (Cochrane Review)

Ewan Tomeny, Jamilah Meghji, Bertie Squire – concept note written: potential for extension of disability weights to capture TB Sequelae

Noemia Siqueira, Maxine Caws – Long terms consequences of tuberculosis: a five-year follow-up study in Nepal (ESRC)

Published papers and reports

Submitted

1. Si Thu Aung, Andrew Siroka, Aung Thu, Min Thu, Ines Garcia Baena, Knut Lönnroth. Patient costs due to tuberculosis in Myanmar – a national survey. (Submitted to *Int J Tuberc Lung Dis*)
2. Rachow A, Ivanova O, Wallis R, Charalambous S, Jani I, Bhatt N, Kampmann B, Sutherland J, Ntinginya NE, Evans D, Lönnroth K, Niemann S, Schaible UE, Geldmacher C, Sanne I, Hoelscher M, Churchyard G. TB Sequel: Incidence, pathogenesis and risk factors of long-term medical and social sequelae of pulmonary TB – a study protocol. (Submitted to *BMC Pulmonary Medicine*)
3. Carter D, Daniels R, Torrens A, Bartholomay P, Sanchez M, Maciel E, Rasella D, Barreira D, Barreto M, Rodrigues L, Boccia D. The impact of a governmental cash transfer programme on tuberculosis cure rate in Brazil: A quasi-experimental approach. (Submitted to the *American Journal of Public Health*)
4. Reis-Santos B; Shete P; Bertolde A; Sales CM; Sanchez MN; Arakaki-Sanchez D; Andrade KB; Gomes GM; Boccia D; Lienhardt C; Maciel EL. Tuberculosis in Brazil and cash transfer programs: a longitudinal database study of the effect of cash transfer on cure rates. (Submitted to *PIOS One*).

Accepted and/or published

1. Hoa B. Nguyen, Anh T, Siroka A, Lönnroth K, Garcia Baena I. National survey of costs due to tuberculosis in Viet Nam. *Int J Tuberc Lung Dis* (In Press)
2. Boccia D, Rudgard W, Shrestha S, Lönnroth K, Eckhoff P, Golub J, Sanchez M, Maciel E, Rasella D, Shete P, Pedrazzoli D, Houben R, Chang S, Dowdy D. Understanding the impact of social protection on TB epidemiology and control: The S-PROTECT modelling research framework. *BMC Public Health*. *BMC Public Health*2018**18**:786
3. Rudgard WE, das Chagas NS, Gayoso RC, Barreto ML, Boccia D, Smeeth L, Rodrigues LC, Lönnroth K, Williamson E, Maciel ELN. Receipt of governmental social protection and financial hardship amongst drug-resistant tuberculosis-affected households: A patient cost survey in Rio de Janeiro, Brazil. *Eur Respir J* 2018; 51: 1800274 [<https://doi.org/10.1183/13993003.00274-2018>].
4. Wingfield T, Tovar MA, Datta S, Saunders MJ, Evans CA. Addressing social determinants to end tuberculosis. *Lancet*. 2018 Mar 24;391(10126):1129-1132. doi: 10.1016/S0140-6736(18)30484-7.
5. Carter DJ, Glaziou P, Lönnroth K, Siroka A, Floyd K, Weil D, Raviglione M, Houben RM, Boccia D. The impact of social protection and poverty elimination on the End TB strategy targets: a statistical model of Sustainable Development Goal. *Lancet Global Health* 2018 [http://dx.doi.org/10.1016/S2214-109X\(18\)30195-5](http://dx.doi.org/10.1016/S2214-109X(18)30195-5)
6. Verguet S, Riumallo-Herl C, Gomez GB, Menzies NA, Houben R, Sumner T, Lalli M, White RG, Salomon JA, Cohen T, Foster N, Chatterjee S, Sweeney S, Garcia Baena I, Lönnroth K, Weil DE, Vassall A. Catastrophic health costs averted by TB control: findings for India and South Africa from a modeling study. *Lancet Global Health* 2017; 5: e1123–32

7. Rudgard WE, Evans CA, Sweeney S, Wingfield T, Lönnroth K, Barreira D, Boccia D. Comparison of two cash transfer strategies to prevent catastrophic costs for poor tuberculosis-affected households in low- and middle-income countries: An economic modelling study. *PLoS Med.* 2017 Nov 7;14(11):e1002418. doi: 10.1371/journal.pmed.1002418. eCollection 2017 Nov. PMID: 29112693
8. Pedrazzoli D, Boccia D, Dodd P, Lönnroth K, Dowdy D, Siroka A, Kimerling A, White R, Houben R. Modelling the social and structural determinants of TB: opportunities and challenges. *Int J Tuberc Lung Dis* 2017; 21: 957-964.
9. Wingfield T. Mitigating the financial effects of tuberculosis requires more than expansion of services. *Lancet Glob Health.* 2017 Nov;5(11):e1056-e1057. doi: 10.1016/S2214-109X(17)30368-6
10. Tuberculosis Patient Cost Surveys: A Handbook. WHO/HTM/TB/2017.24. Geneva: World health Organization, 2017
11. Siqueira-Filha NT, Albuquerque MFM, Legood R, Rodrigues L, Santos AC. The economic burden of tuberculosis and latent tuberculosis in people living with HIV in Brazil: a cost study from the patient perspective. *Public Health*, 158 (2018), 31-36
12. Guidance Document: Nutritional Care and Support for patients with tuberculosis in India. 2017. Ministry of Health and Family Welfare, Government of India and WHO (India). [Writing team: Anurag Bhargava, Bharati Kulkarni, Anura Kurpad, Madhavi Bhargava, Raghuram Rao, Malik Parmar, Sreenivas A Nair, Padmapriya Darshini, Lalit Mehandru, Shariqua Yunus, Shibu Balakrishnan]
13. Bhargava A. Undernutrition, nutritionally acquired immunodeficiency and tuberculosis control. *BMJ* 2016;355:i5407 doi: 10.1136/bmj.i5407
14. Pedrazzoli D, Siroka A, Boccia D, Bonsu F, Nartey K, Houben R, Borghi J. How affordable is TB care? Findings from a nationwide TB patient cost survey in Ghana. *Trop Med Int Health.* 2018 May 31. doi: 10.1111/tmi.13085

Presentations (including posters) and oral communications

1. Presentation at the Tuberculosis Centre of Research Excellence symposium (The University of Sydney). Sydney, Australia. 2017. “Measuring the financial burden of tuberculosis: Tuberculosis patient cost surveys”
2. Presentation at Karolinska Institutet’s Open House: Stockholm, Sweden. 2017. “Measuring the financial burden of tuberculosis”
3. Doctoral seminar at Karolinska Institutet (with staff from WHO) on Universal Health Coverage, Social protection and TB patient costs: 22 March 2018
4. Global Health Masters seminar, University of Tampere, April 2018: Social protection and health (with a SPARKS advertisement)
5. Panel in BIEN conference in August 2018 featuring Knut Lönnroth discussing why policies beyond UHC are needed
6. Institute for Advanced Social Research/New Social Research seminar series, University of Tampere, May 2018: Social protection and tuberculosis

7. Maximising the impact of social protection on tuberculosis control: from research and modelling to policy change and implementation. Symposium at the 48th International Union Against TB and Lung Disease in October 2017, Guadalajara, Mexico
8. SPARKS: from analytical to action research. Symposium submitted to the 49th International Union Against TB and Lung Disease, October 2018, The Hague, the Netherlands