Research Protocol - TB&ME: Examining the views and experiences of MDR-TB patient bloggers and TB programme staff on their interaction with blogging

Authors	Horton, Shona; du Cros, Philipp; Venis, Sarah; Collin, Beverley; Shanks, Leslie
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RESEARCH PROTOCOL

Médecins Sans Frontières

TB&ME: Examining the views and experiences of MDR-TB patient bloggers and TB programme staff on their interaction with blogging

Research question: What are the perceptions, views and experiences of MDR-TB patients and staff on their interaction with blogging?

Study Site: London and various relevant MSF project sites involved with blogging

Proposed start date for data collection for study: July 2012

Primary Investigators: Shona Horter

Email: shona.horter@london.msf.org.uk / shona_horter@yahoo.co.uk

Co-investigators:

Philipp du Cros, Head of Manson Unit, MSF-UK

Sarah Venis, Medical Editor, Manson Unit, MSF-UK

Beverley Collin, Health Policy and Practice Advisor, Programmes Unit, MSF-UK

Leslie Shanks, Medical Director, MSF OCA

Glossary

DR-TB	Drug resistant tuberculosis
DST	Drug sensitivity testing
DS-TB	Drug sensitive tuberculosis
ERB	Ethics Review Board
HIV	Human Immunodeficiency Virus
MDR-TB	Multi-drug resistant tuberculosis
MoH	Ministry of Health
MSF	Médecins Sans Frontières
OCA	Operational Centre Amsterdam
PLHIV	People living with HIV
SSI	Semi-structured interview
TB	Tuberculosis
WHO	World Health Organisation

Background

Multi-drug resistant tuberculosis (MDR-TB) is resistant to the two most powerful first-line anti-TB drugs: rifampicin and isoniazid. It is an emerging problem globally, with 440,000 cases of MDR-

TB and 150,000 deaths due to MDR-TB in 2008 (WHO, 2010). Just 7% of the estimated burden of MDR-TB has been diagnosed, and fewer than half of those diagnosed receive treatment that meets World Health Organisation (WHO) guidelines (Burki, 2010).

Diagnosis and treatment of MDR-TB

The most widely used method of MDR-TB diagnosis is conventional culture drug sensitivity testing (DST), which requires complex laboratory infrastructure and cannot be done outside of reference facilities (Boehme et al, 2011). One of the most significant constraints to rapid expansion of diagnosis and treatment for MDR-TB is laboratory capacity, with DST being done for fewer than 10% of previously treated TB cases in all regions other than Europe and the Americas (16% and 36%, respectively) (WHO, 2010). This is a long way from the WHO target of providing DST for everyone previously treated for TB by 2015 (WHO, 2010). DST is also extremely lengthy, with results taking 2-4 months. While awaiting results patients are often treated with the standard regimen for drug-susceptible TB (Albert et al, 2010), which can lead to resistance amplification (Umubyeyi et al, 2007; Streicher et al, 2012; Blower & Chou, 2004). Increasingly, DR-TB is being diagnosed using rapid molecular tests such as GeneXpert, which can diagnose TB and resistance to rifampicin in just a few hours (WHO, 2011). Improving the coverage of diagnostic DST is urgently required, which involves strengthening laboratory capacity and investing in the introduction of new rapid diagnostic tests.

The WHO recommended treatment regimen for DS-TB is highly efficacious, with 90% cure rates in HIV-negative patients. However, this regimen involves 6 months of treatment with first-line drugs (2-month combination of rifampicin, isoniazid, ethambutol and pyrazinamide followed by a 4-month continuation phase of rifampicin and isoniazid), with patients often feeling better long before treatment completion (WHO, 2011). MDR-TB treatment is more complex, with patients requiring treatment with second-line drugs that are less efficacious, more toxic and more costly (on average US$2,000 – 5,000 per patient) (WHO, 2010). WHO recommended regimens for MDR-TB treatment require at least 20 months of treatment and are associated with multiple, often serious, side-effects and lower cure rates of around 60-75% (WHO, 2011). This treatment is rarely available nationally, with just 9% of TB basic management units worldwide providing curative services for MDR-TB patients (WHO, 2011). There is urgent need for new TB drugs that shorten and simplify treatment, improve efficacy and tolerability of treatment for MDR-TB and improve interactions with HIV drugs (WHO, 2011). This should not only raise cure rates and facilitate increasing access to treatment; but also enable improved adherence and treatment outcomes.

Patient involvement

Over recent years there has been increased emphasis on the need for patient participation in the evaluation and development of all health services; as well as recognition of the need for patients to have more say in decisions relating to their care (Daykin et al, 2004). Governments across Western Europe and North America have encouraged patients' contribution through the development of specific policies, with the belief that involvement of patients will result in more accessible and acceptable health services and improved health outcomes and quality of life (Crawford et al, 2002). In developed countries such as the UK the involvement of service users in the planning, delivery and evaluation of care is an essential component of health-care philosophy, integral to clinical governance and evidence-based practice (Anthony & Crawford, 2000). There are several examples of patients' involvement improving care provision, such as the development of cancer network partnership groups in the UK. These groups have been credited with enabling more effective and responsive cancer services through health-care professionals working with service users (Atree et al, 2010). People living with HIV (PLHIV) have been especially active in gaining knowledge about the infection and advocating for access to treatment. Treatment outcomes of PLHIV are improved by sharing decisions relating to their health with their HIV treatment provider (Beach et al, 2007).

WHO launched the global *Stop TB Strategy* in 2006, as the internationally recommended approach to reducing the burden of TB. This strategy has six major components, of which component 5 is: *'Empower people with TB, and communities through partnership'* (WHO, 2006). There are a few examples of TB programmes that aim to give TB patients a voice in decision-making, in developing and implementing TB programmes or in taking more control of their care process (Macq et al, 2007). However, general consensus about how TB patients can best be involved in treatment and care is lacking, and research into this area limited.

Involving people living with TB is vital in order to gain insight into how the disease affects people's lives and to tailor a response that meets their needs and therefore achieves the best possible outcomes. Component 5 of the WHO Stop TB Strategy aims to build greater commitment to fighting TB through enhanced advocacy to influence policy change and to sustain political and financial commitment. It also aims to ensure two-way communication between care providers and people with TB, as well as communities, in order to improve knowledge and TB programme success, with TB services hopefully being more responsive to community and patient needs (WHO, 2006). The Patients' Charter for Tuberculosis Care was developed by TB patients with the purpose of empowering people with TB and communities; and facilitating mutually beneficial relationships between patient and provider (World Care Council, 2006). This was linked to the International Standards of Tuberculosis Care in 2009, of which Standard 9 states that '*a patient-centred approach to administration of drug treatment, based on the patient's needs and mutual respect between the patient and the provider, should be developed for all patients',* which is seen to be essential to achieving adherence (TBCTA, 2009).

Despite these efforts, the empowerment of patients in the fight against TB remains an underdeveloped area and TB patients have limited experience in initiating the empowering role and expanding these activities (Macq et al, 2007). By contrast, patient involvement has become well established in the field of HIV with huge activism campaigns in the 1980s and lobbying groups arguing that personal experiences with HIV could and should inform and guide the response to the epidemic. These campaigns are thought to be born out of the association of HIV with the civil and gay rights social movements of this time (Morris & Mueller, 1992). This formed the Denver Principles which were voiced at a national AIDS conference in Denver, USA in 1983, in which HIV-positive people claimed the right to "*be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations"* (International HIV/AIDS Alliance, 2003). In 1994 at the Paris AIDS Summit, 42 countries agreed to "*support a* *greater involvement of people living with HIV at all… levels… and to … stimulate the creation of supportive political, legal and social environments”.* The greater involvement of PLHIV has been critical in halting and reversing the HIV epidemic. It aims to realise the rights of people living with HIV (PLHIV) including their right to participate in decision-making processes which affect their lives and thus improving the quality and effectiveness of the response to the epidemic (UNAIDS, 2007). For the 10 or so years between the Denver Principles and the Paris AIDS summit the involvement of PLHIV was a principle which PLHIV themselves advocated, but which had little formal response from governments (Simon-Meyera & Odallob, 2002).

Although reference has been made to the involvement of PLHIV, a similar pattern of activism and advocacy has not occurred for TB, possibly because of the absence of a deeply rooted social movement. It has been said that the ‘empowerment of TB patients seldom comes from the TB patients themselves’ and that policies and operational guidelines must be developed and implemented in order to increase patients’ involvement in TB control programmes (Macq et al, 2007). Consideration must be given to the relationship between structure and agency linked to the sociological concept of duality, shifting the agenda led by a patient perspective and providing patients with a platform that best fits their particular condition, thus contextualising the patient voice (Giddens, 1984).

Using new technology such as social media to share patients’ stories and link patients’ experiences with the medical response to conditions or diseases is an uncharted area, with little research having been done into how this might be achieved and its potential benefits and harms. Jamie Heywood gave a *Ted Talk* on the launch of the ‘patientslikeme’ website, where 45,000 patients share their stories about diseases they are living with. These stories are then transformed into data, with the aim of enabling more informed and targeted responses to patients’ needs (Ted, 2012).

TB&Me Blog

The TB&Me blog was established in March 2011 as a project with the aim of giving MDR-TB patients around the world a voice. The original objectives were to:

- Assist people undergoing MDR TB treatment to document and share their experiences via web-blogs in order to raise awareness about MDR TB
- Support advocacy efforts to increase access to MDR TB care now (including price reductions)
- Support advocacy efforts to increase research and development for TB diagnostics and drugs

Thus far 13 MDR-TB patients have blogged on TB&Me, from India, Australia, Swaziland, Philippines, Uganda, UK, Armenia, Central African Republic and South Africa. 10 of these bloggers are patients on MSF projects and 3 are non-MSF patients. Bloggers are invited to make a blog entry once a month for roughly 6 months; but can stop blogging whenever they wish. It is clearly explained to potential bloggers that their choice to partake or not and to voluntarily stop blogging, will not affect the services they receive in any way. Informed consent is received prior to blogging commencement.

Over 75,000 people visited the TB&Me project online in the last 6 months. The project has been very well engaged with 267 comments being made on 94 posts on the blog alone. You can multiply this number by ten if you include comments on Facebook and Twitter which have been much more widely used for comments but are not as easily tracked. This demonstrates that the blog has provided a platform to reach a wide audience.

The blogging process is often assisted by project staff who might collect the blogger's response orally and transcribe it to the computer for those who are not computer literate or who do not have access to a computer (subsequently referred to as assisted bloggers). All non-MSF patient bloggers are not assisted and write blog entries themselves in English. Of the 10 MSF patients 8 are assisted bloggers, of which 6 are also translated (with 1 patient speaking English and 1 blog entry posted in French). 2 patients are not assisted bloggers and write the posts themselves, 1 of these is written in English and the other is translated to Russian and English. Blog entries are minimally edited to address only security concerns, defamatory comments or medically inaccurate information in addition to spelling and grammar. If there is an issue regarding a change this is discussed with the patient and the patient's acceptance of the new version is ensured before the blog is posted.

This blog is an innovative project which aims to improve the diagnosis, treatment and services for sufferers of MDR-TB around the world. It could also potentially provide an informal peer support network, with bloggers sharing the stories of other MDR-TB patients and the comments facility enabling the public to give responses to each entry, which are then shared with the blogger. Two of the TB&Me bloggers have expressed interest in being more involved in helping others with TB.

Background to research proposal

The TB&Me project was proposed to the MSF Ethics Review Board (ERB) during its development and several potential risks were discussed, including programmatic and political ones. Concerns were raised regarding potential risk to the bloggers such as associated prejudice, threats or stigma and querying what benefits people with MDR-TB would receive from blogging. In addition, the ERB suggested qualitative methods as being a potentially useful means by which to obtain information about MDR-TB patient experiences, as an alternative to blogging.

The TB&Me blog has now been running for just over 1 year. In light of the initial concerns and suggestions about the project it is proposed that we conduct a formal evaluation of the TB&Me blogging project impact using qualitative research methods to examine MDR-TB patients' experiences of blogging, project staff experiences of implementing this blog (including clinicians' views on the patient-staff interaction) and TB programme staff wider level experiences in relation to the blog.

The purpose of this research is to assess whether any of the potential risks envisaged in the review process were realised and what the harm-benefit ratio to patients was in reality, as well as examining MDR-TB patient involvement and empowerment, and how best to facilitate that further.

Study Sites

MSF UK office in London, via Skype interviews potentially being conducted with Operational Centre Amsterdam (OCA); WHO European Region; staff in MSF projects and with patient bloggers.

Overall aim:

To evaluate the TB&Me blogging project in order to identify potential benefits and risks associated with blogging and adapt future project activities/proposals as a result.

Primary objective:

To examine MDR-TB patients' experience of blogging to guide both the current and possible future blog proposals and plans.

Secondary objectives:

- To determine if the blogging had an impact, either positive or negative, on project staff treatment of the individual blogger and on their wider approach to the MDR-TB programme.
- To consider potential wider impact of the blog, for example for raising awareness about MDR-TB and advocating for more investment and research into new diagnostics and treatment.
- To develop a better understanding of whether blogging has assisted the empowerment of patients to set the agenda for better TB care.

Methodology:

The research design will be qualitative in focus, as the study aim requires an exploratory approach to understand the views, experiences and perceptions of MDR-TB patient bloggers and those of MSF staff (Pope & Mays, 2006). There will also be a quantitative aspect, with a Monkey tool online survey (subsequently referred to as 'online survey') to provide precision in certain measurements, for example on utilisation figures, which will support the qualitative data (Mason, 2006). A triangulation of the findings will be undertaken to enhance the interpretation of the data. Triangulation enables an accurate representation of reality through use of multiple methods or perspectives for the collection of data (Foss & Ellefsen, 2002).

The methods chosen are:

1. Semi-structured interviews (SSIs) with the bloggers, selected MSF project staff, selected OCA headquarter staff and WHO European Region TB policy advisors. This approach uses a flexible participatory technique for which the researcher bases data collection on a set of interview guides (Appendix 1) and interacts with participants to tailor the research to the local context.

2. An online survey will be distributed to key project staff previously identified as well as OCA head quarter staff (see sampling and recruitment strategy section) via the online survey.

Sampling and recruitment strategy

1. SSI respondents will be identified via purposive sampling, whereby the researcher actively selects participants to form a sample which will best answer the research question (Marshall, 1996). As this study aims to examine the potential impacts of blogging on the blogger, programme staff and programme delivery overall, interviews will be conducted with those deemed to best inform on these topics. All 13 current and past TB&Me bloggers will be approached for interview, with their relevant field health teams recommending whether or not they think each patient should participate (due to health status related factors to ensure patient welfare); but with the patients themselves holding the ultimate decision about whether or not they choose to do so.

   Selected field staff involved with programmes containing TB&Me bloggers will be invited for interview, including clinicians responsible for the patient bloggers' care; as well as certain staff from OCA head quarters involved with TB programme design and delivery; and members of the WHO European Regional Office who focus on TB policy. The total number of participants in this study will only be known when data saturation occurs, which is when new information is no longer being generated from additional interviews (Green & Thorogood, 2009).

   Participation in this study will be voluntary and it will be stressed that interviewees can choose to stop the interview at any point. Respondents' names and any potentially identifying data will not be used to ensure that individuals cannot be identified either by name, contextual details or job. Informed consent will be sought prior to interview commencement with aid of an information sheet stating the purpose of the study and outlining the voluntary nature of their participation (Appendix 2).

2. Online survey respondents will also be identified purposively, with an invitation to complete an online survey sent to staff members involved with the TB&Me project; as well as staff who are no longer working on projects with TB&Me patients, those who have been more peripherally involved and medical staff[1]. The study aims to receive between 20 and 30 survey responses. This number is felt to be compatible with the low response number usually expected from online surveys and is linked to the complete number of participants eligible, which is limited by the number of staff who have been involved in the TB&Me project.

   Survey respondents will be invited to take part voluntarily and will be assured of the privacy measures to be taken, with responses being delivered online anonymously so

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[1] Manson Unit staff, operations managers, Public Health Department Staff, South Africa Medical Unit Staff and medical coordinators of involved projects with the invitation for them to disseminate the link to their teams.

that responses are not linked to each respondent's name or email address and only being seen by the listed investigators.

Data collection and analysis

An interview guide with open-ended questions will be used to conduct SSIs (Appendix 1). These will be structured to build trust and rapport, encourage openness and honesty of respondents, with more emotive questions coming later on in the interview. Interview respondents are geographically disparate, as bloggers are located in several different countries; head office staff are located in Amsterdam and WHO European Region respondents in Geneva. Therefore it was decided that it would be more cost and time effective to conduct interviews using Skype, an internet-based software which offers a range of communication options for research including allowing individuals to videoconference from computer to computer using webcams and to call from Skype to a telephone if the respondent does not have access to a computer or the internet (Cater, 2011). It has been said that online interviews are becoming an increasingly viable data collection method, with Skype providing low cost, ease of use, geographic flexibility and synchronous communication. Researchers can also easily record conversations (both computer to computer and computer to telephone) (Saumure & Given, 2010) and this will be done with participants' permission. Some body language is visible in Skype video; but in audio-only mode non-verbal communication is lost. There is also the possibility of technology failing, with the risk of disconnection problems and loss of data. For the purpose of this study it is felt that Skype will provide a useful tool for data collection.

An online survey has been developed to obtain quantitative responses of staff on blog utilisation, quality related to MDR-TB programme issues and the direct value 'blogging' has for patients (Appendix 3). The questions in this survey were developed to avoid bias and optimise value through anticipation of every appropriate answer; categorisation of answers and a consistent ordering of questions throughout the survey. Text response sections were given to allow respondents to personalise and explain their answers. Techniques to increase the likelihood of respondents completing the survey were used, for example asking more emotive or potentially controversial questions at the end. Attempts will be made to establish a connection with the participant being invited to complete the survey so that they feel motivated to respond.

Transcriptions will be made of qualitative interview data and the online text data. Transcriptions will then be coded and thematic analysis of transcripts and codes will be conducted to identify relevant themes, patterns and concepts which emerge. This method of analysis is explorative and may highlight issues or areas of focus that the researcher could not have anticipated or predetermined (Ezzy, 2002); and 'aims to present the key elements of respondents' accounts' (Green & Thorogood, 2009). Grounded theory will also be used to 'generate concepts that make sense of what's going on' (Glaser, 1999).

Online survey responses will be quantified, tabulated and summarised using percentage proportions to explain the results. This will be done by entering numeric data into Microsoft Excel and calculating summary statistics.

Validation

Validity will be maximised by using supporting evidence that includes deviating cases (which do not fit with conclusions), thus testing emerging theory as opposed to selecting examples which reiterate desirable points (Green & Thorogood, 2009). Triangulating qualitative findings with quantitative data will connect the interpretations in such a way as to add to the validity of responses.

Interview language

Interviews will be conducted in English when the respondent is comfortable with this language. Otherwise the interview will be conducted in the respondent's native language with the use of a translator who will be present with the interviewee during the Skype interview, translating the questions and responses as they are asked/given.

Limitations

Although the findings of this study will be informative, relatively small numbers of participants who are not necessarily 'representative' of their respective locations may mean that findings cannot be generalised to all MDR-TB patients and related staff. Concepts, which emerge from this study, are nonetheless likely to be relevant and applicable. The process of translation may risk altering research findings, however it is important that all bloggers have the opportunity to be interviewed in their most comfortable language and the assigned translator should be familiar with the specific context under study in order to translate optimally. Online survey uptake relies on participant literacy with internet use; however this should not pose a problem as all respondents are MSF staff members who will be familiar with computer and internet use.

Inclusion criteria

1. All MDR-TB patient bloggers, past and present, will be invited to participate
2. All MSF medical field staff involved with treatment provision to MDR-TB patient bloggers
3. All MSF programmatic staff involved with TB programme delivery
4. WHO European Region Office TB policy advisors

Exclusion criteria

1. Patients that do not give consent for interview
2. Patients identified by the treatment team as being too unwell for interview
3. Staff members that do not consent to interview

Fair selection of study population

Selection of MDR-TB patient bloggers and practitioners is designed as much as possible to provide all with an equal chance of being selected. All patient bloggers will be invited for interview and all related staff will be offered the option of either an interview or survey depending on their level of current involvement in the project. Participants will be interviewed using Skype at a computer in the MSF field mission with a translator alongside the participant where required.

Resources

This research will require the interviews to be performed by the principal investigator with one translator in certain settings where respondents do not speak English. Identification of some key stakeholders and patients will be conducted by the MSF Team. There are no additional budget requirements as study resources are already established in current project planning and interviews will be conducted using Skype which will therefore not require costs associated with the researcher travelling to the field.

Data management, analysis and protection

After transcription all audio files will be destroyed. Information will be stored without any respondent-identifying information and will be stored in a password-protected format which will be accessible only by the principal investigator. Researchers will sign a confidentiality agreement with Ministry of Health (MoH)/MSF. This agreement will state that data gathered may only be used for this research project and that all data will be kept in a manner that respects confidentiality of respondents and protection of data. Data collected will not be shared with others, presented or published without consent of the Medical Director of MSF OCA.

Informed consent

The consent process will be done prior to interview commencement, involving outlining the purpose of the study, stating that participation is voluntary and the respondent can change their mind about participating at any point during the interview. It will be stressed to participants that there is no right or wrong answer; we would like to learn about good and bad experiences and hear how the blogging process has been, how it might be possible to improve the process and ultimately work towards enhancing the involvement of MDR-TB patients. The informed consent procedure will explicitly clarify that participation is not linked to receiving health care or other services. The consent form will be sent to participants via email prior to interview, with the process being outlined verbally during interview and verbal consent being obtained. Participants will be observed signing the consent form which will then be sent to the UK office from field offices via post. There will be two steps to the written consent form – consent for the interview and consent for recording of the interview.

Confidentiality

Participant names will not be included in any of the project reports. Each respondent will be given a code that corresponds to the time they were interviewed so that only the researcher can identify whom they are. Data stored on the computer will be password protected and the UK Data Protection Act (1998) will apply and will be abided by. As the number of bloggers is limited and their identity is public, there is the chance that they could be identifiable from their responses. However, all efforts will be made to avoid this in selection of quotes for report write-up and this will be mentioned to patients during the consent process.

Social value

Project level benefits:

The TB&Me blog has not yet been formally assessed. The research should provide valuable information to help improve the functioning of the project, which could include improving the experience for bloggers and maximising the benefits for the delivery of care in the project.

Community level benefits:

This study should provide a deeper understanding of the potential impact of this blogging project, and examine how the blog might be improved to enable patients to set the agenda and content of advocacy messaging according to their own ‘voice’, which is heard and understood by project staff and beyond. This should then improve programme delivery to current and future MDR-TB patients in each blogging project site, making treatment programmes more patient-centred and better focused around meeting the needs of the patients in each context.

National level benefits

This project aims to look at whether the TB&Me blog has had an impact on overall programme delivery and will examine the potential of this tool to enable patients to play an important advocacy role as well as enhance patient involvement in MDR-TB dialogue. This could potentially have an influence on international TB agenda, policy and programmes, with the aim of enhancing policy makers and funders understanding of MDR-TB patients’ difficult lived experiences and therefore pushing them to prioritise, support and fund what is needed now and in the future to implement effective comprehensive TB care.

Potential risks

Informed consent will be obtained and participant privacy and confidentiality respected as much as possible. There is the chance that patients’ responses may be identifiable due to the public nature of blogging providing familiarity with patients’ individual stories. This will be minimised with full transcriptions being stored securely, careful selection of quotes for use in the report and patients being made aware of this risk during the consent process. This should not be any risk for staff and stakeholder interviews as quotes given in the report will not give specific information which relates to individual staff members and their positions; however the same steps will be taken as for patients, to minimise any risk of identification from occurring. The main burden to interviewees will be the time taken for the interview to be conducted. Undertaking this study should not substantially interfere with routine programmatic activities, however consideration must be made to ensure MDR-TB patient bloggers are not at risk of being over-selected, as some of these patients are already blogging each month.

The questions included in the survey are not deemed to be sensitive, however as it is impossible to predict individual reactions, psychological support through either MSF staff in the case of patients or psychosocial unit in the case of staff will be available in case of need. Interviewees will be free not to answer any question posed or to stop the interview at any time without prejudice to either their care or position within the organisation.

There may be a potential need for disclosure should any information arise as a result of the interview which might indicate risk or harm to the patient (e.g. concerns that would require medical intervention or psychological support). In this instance it may be necessary to discuss with the participant beforehand the need to disclose such information to relevant medical personnel in order to protect their interests

Respect for recruited study participants and study communities

The findings and outcomes of this study will be made available to all participants via feedback mechanisms which respondents can choose to either opt in or opt out of prior to interview commencement. Summary findings of the study will be made available to all participants. Feedback mechanisms will be used to ensure participants are aware of the findings and outcomes of the study. Respondents can choose to opt in or out of this feedback process prior to interview commencement.

References

Albert, H; Bwanga, F; Mukkada, S; Nyesiga, B; Ademun, J. P; Lukyamuzi, G; Haile, M; Hoffner, S; Joloba, M & O'Brien, R. (2010). Rapid screening of MDR-TB using molecular Line Probe Assay is feasible in Uganda. *BMC Infectious Diseases.* **10**: 41-48

Anthony, P & Crawford, P. (2000). Service user involvement in care planning: the mental health nurse's perspective. *Journal of psychiatric and mental health nursing.* **7**(5): 425-434

Atree, P; Morris, S; Payne, S; Vaughan, S & Hinder, S. (2010). Exploring the influence of service user involvement on health and social care services for cancer. *Health expectations.* **14:** 48-58

Beach, M; Duggan, P & Moore, R. (2007). Is patients' preferred involvement in health decisions related to outcomes for patients with HIV? *Society of general internal medicine.* **22**: 1119-1124.

Blower, S & Chou, T. (2004). Modeling the emergence of the 'hot zones': tuberculosis and the amplification dynamics of drug resistance. *Nature medicine.* **10**(10):1111-1116.

Boehme, C; Nicol, M; Nabeta, P; Michael, J; Gotuzzo, E; Tahirli, R; Gler, M. T; Blakemore, R; Worodria, W; Gray, C; Huang, L; Caceres, T; Mehdiyev, R; Raymond, L; Whitelaw, A; Sagadevan, K; Alexander, H; Albert, H; Cobelens, F; Cox, H; Alland, D; Perkins, M.D. (2011). Feasibility, diagnostic accuracy, and effectiveness of decentralised use of the Xpert MTB/RIF test for diagnosis of tuberculosis and multidrug resistance: a multicentre implementation study. *The lancet.* **377**:1495-1505

Burki, T. (2010). Tuberculosis – resistance, funding, and drugs. *The Lancet Infectious Diseases.* **10**(5): 297-298

Cater, J. (2011). Skype: a cost-effective method for qualitative research. *Rehabilitation counsellors & educators journal.* **4(2)**

Crawford, M; Rutter, D; Manley, C; Weaver, T; Bhui, K; Fulop, N & Tyrer, P. (2002). Systematic review of involving patients in the planning and development of health care. *British medical journal.* **325**: 1263-1268.

Daykin, N; Sanidas, M; Tritter, J; Rimmer, J & Evans, S. (2004). Developing user involvement in a UK cancer network: professionals' and users' perspectives. *Critical public health.* **14**(3): 277-294.

Ezzy, D. (2002). *Qualitative analysis: Practice and innovation.* Routledge: London.

Foss, C & Ellefsen, B. (2002). Methodological issues in nursing research: the value of combining qualitative and quantitative approaches in nursing research by means of method triangulation. *Journal of advanced nursing.* **40**(2): 242-248.

Giddens, A. (1984). *The constitution of society: outline of the theory of structuration.* Polity Press: Cambridge

Glaser, B. (1999). The future of grounded theory. *Qualitative health research.* **9**: 836-847

Green, J & Thorogood, N. (2009). *Qualitative methods for health research.* Sage Publications: London.

International HIV/AIDS Alliance (2003). *The Involvement of People Living with HIV/AIDS in Community-based Prevention, care and Support Programs in Developing Countries.* http://www.popcouncil.org/pdfs/horizons/plha4cntryrprt.pdf - accessed 13/06/12

Macq, J; Torfoss, T & Getahun, H. (2007). Patient empowerment in tuberculosis control: reflecting on past documented experiences. *Tropical medicine and international health.* **12(7):** 873-885.

Marshall, M. (1996). Sampling for Qualitative Research. *Family Practice.* **13**(6): 522-525.

Marston, C & King, E. (2006). Factors that shape young people's sexual behaviour: a systematic review. *The Lancet.* **368**(9547): 1581-6

Morris, A & Mueller, C. (1992). *Frontiers in social movement theory.* Yale University Press: London.

Pope, C & Mays, N. (2006). *Qualitative research in health care.* Blackwell Publishing: Oxford.

Rylance, J; Pai, M; Lienhardt, C & Garner, P. (2010). Priorities for tuberculosis research: a systematic review. *The Lancet Infectious Diseases.* **10**(12): 886-892

Samure, K & Given, L. (2010). Using Skype as a research tool: Lessons learned from qualitative interviews with distance students in a teacher-librarian program. Accessed online: http://www.lrsv.umd.edu/abstracts/Saumure_Given.pdf

Simon-Meyer, J & Odallo, D. (2002). Greater involvement of people living with HIV/AIDS in South Africa. *Evaluation and program planning.* **25**: 471-479.

Streicher, E; Müller, B; Chihota, V; Mlambo, C; Tait, M; Pillay, M; Trollip, A; Hoek, K; Sirgel, F; Gey van Pittius, N; van Helden, P; Victor, T & Warren, R. (2012). Emergence and treatment of multidrug resistant (MDR) and extensively drug-resistant (XDR) tuberculosis in South Africa. *Infection, genetics and evolution.* **12**: 686-694

Tuberculosis Coalition for Technical Assistance (TBCTA). (2009). *International standards for tuberculosis care*, second edition. Tuberculosis Coalition for Technical Assistance: the Hague.

Ted. (2012). Jamie Heywood: the big idea my brother inspired. Accessed online 10/07/12: http://www.ted.com/talks/lang/en/jamie_heywood_the_big_idea_my_brother_inspired.html

Umubyeyi, A; Shamputa, I. C; Rigouts, L; Dediste, A; Struelens, M & Portaels, F. (2007). Evidence of 'amplifier effect' in pulmonary multidrug-resistant tuberculosis: report of three cases. *International Journal of Infectious Diseases.* **11**: 508-512

UNAIDA (2007). *The greater involvement of people living with HIV (GIPA): Policy brief.* http://data.unaids.org/pub/BriefingNote/2007/jc1299_policy_brief_gipa.pdf - accessed 13/06/12

WHO (2006). *The Stop TB Strategy: Building on and enhancing DOTS to meet the TB-related Millennium Development Goals*. WHO: Geneva.

WHO (2010). *The global plan to stop TB 2010-2015: transforming the fight towards elimination of tuberculosis.* WHO: Geneva.

WHO (2011). *Global tuberculosis: WHO report 2011.* WHO: Geneva

World Care Council (2006). *The patients' charter for tuberculosis care: patients' rights and responsibilities.* National Tuberculosis Centre: San Francisco

Appendix 1

Semi-Structured Interview Guides

SSI MDR-TB Patient Bloggers

Introduce study, explain consent, explain that discussion is participant led with prompts to keep topic on track.

Blogging process

1. Could you tell me about yourself and your experience of blogging on TB & Me?
2. How did it start? What was the process like?
3. Do you feel that you were adequately prepared for blogging?
4. How do you think the blogging process could be improved?
5. If no longer blogging why did you stop?

Personal experience of blogging

6. What stimulates your blog? Probe reaction/getting followers/fame
7. How does blogging make you feel? Probe what they're getting back/what's lacking/conversation vs monologue
8. What do you think about the option for people to comment on your blog entries? Probe encouragement, usefulness, difficulties, supportiveness, competitiveness/discouragement if no comments, misinformation
9. How do you feel about the fact other MDR-TB patients from around the world are also blogging/sharing their stories? Probe access to other blogs, informal peer support network (anonymity of blog facilitates openness?)
10. Did you have any hopes from blogging? / What did you hope to get from blogging? Probe benefits
    a. Were these realised?
11. Did you have any fears about blogging? Probe risks
    a. Did these eventuate?
12. How did your family/friends/community respond to the blog? Probe stigma
13. Did you show it to people? If so, who?
14. Were there any negative impacts you experienced from blogging? Probe confidentiality, stigma

15. If so, is there anything you think could have been done to mitigate these?
16. Looking back at your past blog entries, is there anything you regret blogging about?

Wider level (empowerment, patient involvement, etc)

17. What has blogging done that's different for you in terms of being able to talk about TB? Has it changed the way you talk about MDR-TB? Do you talk openly about having MDR-TB now??
18. Do you feel you have an audience?
19. Do you think blogging about MDR-TB gives patients like yourself a voice? - Probe patient involvement, empowerment
20. Do you think blogging has led to any changes? Could it? Probe programme changes, research and advocacy
21. How do you think the experience of blogging compares to speaking publicly about MDR-TB? (only ask patients for which this applies). Probe patient involvement anonymity? Control?
22. Had you had the opportunity to speak to other MDR-TB patients/your community/publicly before or after blogging?

Patient involvement

23. Do you think patients should be involved in developing TB programmes, national and/or international treatment guidelines?
24. If so, how do you think this should be done?
25. What about in the design of TB services in your community, should patients like yourself be involved in this? How?
26. If you were given the opportunity to be involved in informing TB guidelines or programmes would you be interested?
27. If you were asked to contribute to MDR-TB treatment guidelines what would you prioritise? E.g. length of treatment, success rate of treatment, side effects, etc
28. Show table from WHO treatment guidelines – do you agree with the order of priorities on this table? Would you change the order of any points?

Anything to add? Any questions?

Thanks and close

SSI Field Staff

1. Could you tell me about your experience working with the TB&Me blog? Probe how often read, how disseminate, if share with people
2. What do you understand as being the main purpose of doing this blog? Probe value of patient involvement/advocacy/priorities
3. Do you personally think MDR-TB patient involvement is important? If so, why?
4. Which other ways do you think MDR-TB patient involvement could be enhanced? E.g. value of speaking publicly versus blogging
5. What benefits (if any) came from the patient blogging?
6. Were there any negative effects of the blog? Probe risks – did those initially potentially foreseen eventuate? Harm/ any other risks not foreseen
7. If there were any bloggers in programme who stopped blogging early, why did they stop? Probe potential harm
8. What do you think about the fact different MDR-TB patients from around the world are all blogging? Does the patient in your project see these/know this? Probe access to other blogs, informal peer support network
9. What do you think about the option for people to comment on the patient's blog entries? Probe encouragement, usefulness, difficulties, supportiveness, competitiveness/discouragement if no blogs, risk of misinformation
10. In what way (if any) did the blog influence/affect/change patient-staff interactions?
11. [clinicians] Did patients' blogging cause any changes to your relationship with them? Were there any effects on patients' care? Prove favouritism versus negativity
12. Did the blog make any difference to MDR-TB treatment programmes? If so, what?
13. How did the communities respond to the blog? Did people in the community hear about the blog/read it/speak about it after initiation? Probe stigma, public disclosure, HIV status discussions?
14. How did local governmental agencies respond to the blog? Probe political sensitivities
15. How did the blog influence project site workload? Probe risk of added burden
16. Lessons learnt: how could we improve blog in future?
17. Do you think MDR-TB patients blogging about their experiences could lead to any changes e.g. research, investment? Probe raised awareness/interest/advocacy

Anything to add? Any questions? Thanks and close

SSI WHO

1. Could you tell me what you know about the TB&Me blog? Probe knowledge, how often read, if share/disseminate
2. What do you think about the idea of assisting patients with sharing their experiences of MDR-TB via a blog such as this?
3. What effect has the blog had on how you see DR-TB and on how you think DR-TB may be viewed by the wider community?
4. Has the blog provided a more accessible understanding of TB? Humanised TB?
5. Has the blog had any influence on current policy?
6. What do you think about the importance of patient perspectives in policy? Has blog enhanced role of patients' perspective?
7. What do you think the main aim of patient involvement should be? Probe raising awareness/increasing research/investment/development
8. How do you think patient involvement should best be facilitated/enabled?
9. What lessons do you think could be learnt to do the blog better in the future?
10. How do you see the content of what the bloggers are presenting/saying being utilised? Value of blog for doing something with content of what patients are saying. Probe advocacy.
11. Do you think the blog could be used as a tool for raising awareness/informing policy/advocacy
12. Was this initiative helpful towards achieving Component 5 of the 2006 Stop TB strategy?
13. Do you think more consideration of what patients value and tolerate should be made? E.g. MDR treatment guidelines – effectiveness of treatment, cure, lower rate of relapse are high priorities to testing and treatment strategies and cost to patient much lower down list.
14. Do you have any recommendations as to what should be done next? Probe utilise patient voice/empowerment/involvement

Anything to add? Any questions? Thanks and close

Appendix 2 – Informed Consent Form

PART 1: INFORMATION SHEET FOR PARTICIPANTS

TB&Me: Examining the views and experiences of blogging on the MDR-TB patient blogger and project staff

We would like to invite you to participate in this operational research because we feel you can give an insight into this area and value your opinion. You should only participate if you want to, choosing not to take part will not disadvantage you in any way. Before you decide whether you would like to take part or not, it is important for you to understand why the study is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. If anything is unclear, you would like more information or if you have any questions please feel free to ask.

Purpose of the research

This study aims to understand any potential impacts the TB&Me blog has had on the bloggers themselves, on the staff-patient interaction, on MDR-TB programme delivery and on the field of MDR-TB in general. We want to explore your views on MDR-TB patient blogging in order that we can better facilitate patients' experiences being shared and can learn how best to enable patient-centredness. This study hopes to understand any potential risks and benefits associated with blogging so that risks can be mitigated and benefits maximised. Taking part in this research would involve your participation in an interview which will take around 45minutes.

Voluntary participation

Your participation in this research is entirely voluntary. You may stop the interview at any point if you so wish and can skip any question you feel uncomfortable answering. There is no right or wrong answer to the questions asked, we would like to learn about good and bad experiences and hear how it might be possible to strengthen or improve the TB&Me blog. The findings of this study can be fed back to you once it has been completed. We would like to record this interview if you consent to this, solely for the purpose of ensuring we hear everything you say. This recording will only be heard by the interviewer and will be destroyed as soon as it has been written up. You can choose to voluntarily consent to this recording or not below.

Confidentiality

All information collected will be kept privately and anonymously so that no one can link anything you say in the interview back to you. Transcripts of the interviews will only be shared with the principal researchers in compliance with the principles of data protection e.g. anonymous and password protected format.

PART 2: CONSENT FORM FOR PARTICIPANTS

MEDECINS SANS FRONTIERES

Title of study: ***TB&Me: Examining the views and experiences of blogging on the MDR-TB patient blogger and project staff***

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the information sheet above or the explanation given to you please ask the researcher before you decide to join in. You will be given a copy of the information sheet/consent form to keep.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I agree that this research project has been explained to me to my satisfaction and I understand what the research study involves. I understand that if I decide at any time during the research that I no longer wish to participate in this project, I can notify the researchers involved and withdraw from it immediately without giving any reason. I am also free to refuse to answer any question I am asked and this will not affect either my care as a patient nor my ability to blog.

I____

consent voluntarily to being a participant of this study

Signed ____ Date ____________________

I consent to this interview being recorded ☐

Appendix 3: Survey Monkey

1. How often do you read the TB&Me blogs?

   Never / rarely / sometimes /often

2. Do you disseminate/share the blog with people?

   Yes / no / don’t know

   a. If so, who from the following:

      Colleagues / patients / other health care providers / policy makers / donors / friends / other… [text]

3. What do you understand as being the main purpose of the blog?

   Raising awareness / advocacy tool / improved programme delivery / empowering patients / none / other… [text]

4. Do you think MDR-TB patients blogging about their experiences could lead to any positive changes?

   Yes / no / don’t know

   a. If so, what?

5. Do you think patients should be involved in their treatment and care?

   Yes / no / don’t know

   a. If so, why?

6. How best could patients be involved in their treatment and care?

   [Text]…….

7. Do you think the TB&Me blog has resulted in any direct benefits to patients?

   Yes / no / don’t know

   a. If so, what?

8. Do you think the TB&Me blog has caused any harm to patients?

   Yes / no / don’t know

   a. If so, what?

9. Do you think the TB&Me blog has resulted in any direct benefits to treatment programmes you are involved with?

Yes / no / don’t know

a. If so, what…..