Supplementary Web Appendices for Tuberculosis in hard-to-reach populations 1: Barriers and facilitators to the uptake of tuberculosis diagnostic and treatment services by hard-to-reach populations in countries of low and medium tuberculosis incidence: a systematic review of qualitative literature

Supplementary Material I: PICOS (Population – Intervention – Comparator – Outcome – Study design) and protocol deviations.

1. Review questions

The primary review question was:

What factors help or hinder the uptake of TB diagnosis and treatment services by people from hard-to-reach populations, and how can those barriers be overcome?

Secondary review questions were:

(i) How do views vary between different hard-to-reach populations? and

(ii) What are the views of service providers?

2. PICOS

Population

Hard-to-reach populations, like:

- homeless people
- people with alcohol or other drug addictions
- sex workers
- prisoners or people with a history of imprisonment
- vulnerable migrant populations such as asylum seekers and refugees, including the Roma population
- children within vulnerable and hard-to-reach populations
- people living with HIV

Studies focusing on hard-to-reach populations from Organisation for Economic Co-operation and Development (OECD) countries, European Union, European Economic Area (EU/EEA) countries and the EU candidate countries were included.

EU/EEA and candidate countries

1. Albania
2. Austria
3. Belgium
4. Bulgaria
5. Croatia
6. Cyprus
7. Czech Republic
8. Denmark
9. Estonia
10. Finland
11. France
12. Germany
13. Greece
14. Hungary
15. Iceland
16. Ireland
17. Italy
18. Latvia
19. Liechtenstein
20. Lithuania
21. Luxembourg
22. Malta
23. Montenegro
24. Netherlands

OECD countries

1. Australia
2. Austria
3. Belgium
4. Canada
5. Chile
6. Czech Republic
7. Denmark
8. Estonia
9. Finland
10. France
11. Germany
12. Greece
13. Hungary
14. Iceland
15. Ireland
16. Israel
17. Italy
18. Japan
19. Korea
20 Luxembourg
21. Mexico
22. Netherlands
23. New Zealand
24. Norway

25. Norway
26. Poland
27. Portugal
28. Romania
29. Serbia
30. Slovakia
31. Slovenia
32. Spain
33. Sweden
34. The former Yugoslav Republic of Macedonia
35. Turkey
36. United Kingdom

25. Poland
26. Portugal
27. Slovak Republic
28. Slovenia
29. Spain
30. Sweden
31. Switzerland
32. Turkey
33. United Kingdom
34. United States

Studies that do not specifically look at any of the specified target populations or are conducted in other geographical areas were excluded.

Intervention
Not relevant.

Comparator
Not relevant.

Outcome
Outcome measures were those related to the views of hard-to-reach people regarding perceptions of or attitudes towards TB services.
Primary outcome measures were qualitative descriptions of the views of people belonging to hard-to-reach populations relating to TB services of any kind.
Secondary outcome measures were qualitative descriptions of the variation of views between different hard-to-reach populations, and the views of service providers, relating to TB services of any kind.

Study design
All types of qualitative studies were included in this review.

3. Note on in- and exclusion criteria for this review (Box 1)
We used unspecific/broad inclusion criteria such as "Having a focus on TB services of any kind" (Box 1). This may challenge the reproducibility. Since qualitative evidence synthesis is a more subjective process than the traditional quantitative evidence synthesis, using unspecific/broad inclusion criteria is a legitimate method to appropriately appraise the evidence on the topic.[1] Thus, keeping the inclusion criteria wide allowed us to include any study reporting qualitative evidence relating to TB service - related beliefs or behaviour, regardless of a link to a specific intervention. Using wide inclusion criteria has also been reported in other systematic reviews on qualitative evidence.[2]

4. Protocol deviations
The original protocol was registered under PROSPERO registration number: CRD42015019450. Deviations from the protocol are described below:

Deviation 1
Original statement in protocol: Quality assessments will be performed independently by two review authors for all included studies; disagreements will be solved by discussion or consulting the third review author.

Description of deviation: Two reviewers assessed ten percent of included studies independently; the remaining 90% were assessed by one reviewer and checked by a second reviewer.

References

1. Booth A. Searching for qualitative research for inclusion in systematic reviews: a structured methodological review. *Systematic reviews* 2016; **5**: 74.
2. Lorenc T, Pearson M, Jamal F, Cooper C, Garside R. The role of systematic reviews of qualitative evidence in evaluating interventions: a case study. *Research synthesis methods* 2012; **3**(1): 1-10.

Supplementary Material II: Search strategy

The search strategy for the previous NICE review[1] on the same topic was used as a framework (line 45-88 of the search below) and extended to the European countries that are not Organisation for Economic Co-operation and Development (OECD) countries and to the two extra hard-to-reach groups, HIV positive patients co-infected with TB and children of adults living in hard-to-reach groups (line 1-44 of the search below). The search for the previous NICE review[1] was subtracted from ours so to prevent double screening of records. The search was conducted by René Spijker, Academic Medical Center, Amsterdam, the Netherlands. All studies identified by the search were imported to an Endnote database. The original search was done on the 10th of December 2014 and updated on the 10th of April 2015.

Six databases were used for the search, namely:

- Medline + Medline In-Process (Ovid)
- Embase (Ovid)
- PsychInfo (Ovid)
- Centre for Reviews and Dissemination (CRD) – University of York
- Cochrane Library
- Cumulative Index to Nursing and Allied Health Literature (CINAHL), Ebscohost

Database	**Hits**
Medline + Medline In-Process	1951
Embase	3194
PsychINFO	276
CRD database	33
Cochrane Library	204
CINAHL	257
Total	5915
Total de-duplicated	**4105**

References

1. O'Mara A, Marrero-Guillamon I, Jamal F, Lehmann A, Cooper C, Lorenc T. Tuberculosis evidence review 1: Review of barriers and facilitators. London: Matrix evidence/National Institute for Health and Clinical Excellence 2010. http://www.nice.org.uk/guidance/ng33/evidence/appendix-g8.-ph37-review-1-80851860828 (last accessed February 2016).

1. Search in Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present

Hits: 1951

1	exp Tuberculosis/ or (tuberculosis or tb).ti,ab.
2	(qualitative or focus group$ or case stud$ or field stud$ or interview$ or questionnaire$ or survey$ or ethnograph$ or grounded theory or action research or participant observation or narrative$ or (life and (history or stor$)) or verbal interaction$ or discourse analysis or narrative analysis or social construct$ or purposive sampl$ or phenomenol$ or criterion sampl$).ti,ab. or qualitative research/ or interview/ or Questionnaires/ or Focus Groups/ or phenomenology/ or Interviews as Topic/ or Health Care Surveys/ or Nursing Methodology Research/
3	(view$ or barrier$ or block$ or obstacle$ or hinder$ or constrain$ or facilitat$ or attitude$ or opinion$ or belief$ or perceiv$ or perception$ or aware$ or personal view$ or motivat$ or reason$ or incentiv$).ti,ab. or exp Attitude/ or Motivation/
4	or/2-3
5	((((((((((((((((hard$ adj2 reach) or hard$) adj2 locate) or hard$) adj2 find) or hard$) adj2 treat) or difficult) adj2 locate) or Difficult) adj2 engage) or social$ exclu$ or social inequalit$ or difficult$) adj2 reach) or difficult$) adj2 find) or difficult$) adj2 treat).ti,ab.
6	((geograph$ or transport$ or physical) and barrier$).ti,ab.
7	((low$ or poor$ or negative) and (quality adj2 life)).ti,ab.
8	((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect$ or marginal$ or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma$ or inequitable) and (people or population$ or communit$ or neighbourhood$1 or neighborhood$1 or group$ or area$1 or demograph$ or patient$ or social$)).ti,ab. or Vulnerable populations/
9	poverty area/ or (albania or bulgaria or cyprus or croatia or latvia or lithuania or luxembourg or malta or montenegro or romania or serbia or yugoslav or turkey).ti,ab,hw,in.
10	(Refuser$1 or non-user$1 or discriminat$ or shame or prejud$ or racism or racial discriminat$).ti,ab.
11	social support/ or *social conditions/ or stigma/ or Social Isolation/ or *quality of life/ or Prejudice/ or Socioeconomic Factors/
12	prisoner$1.ti,ab.
13	(recent$ adj2 release$ adj2 (inmate$ or prison$ or detainee$ or felon$ or offender$ or convict$ or custod$ or detention centre$ or detention center$ or incarcerat$)).ti,ab.
14	((prison$ or penal or penitentiary or correctional facilit$ or jail$ or detention centre$ or detention center$) and (guard$1 or population or inmate$ or system$ or remand or detainee$ or felon$ or offender$1 or convict$ or abscond$)).ti,ab.
15	(parole or probation).ti,ab.
16	*prisoners/
17	((custodial adj (care or sentence)) or (incarceration or incarcerated or imprisonment)).ti,ab.
18	(immobile or (disabled and (house bound or home bound)) or ((house or home) and bound)).ti,ab. or Homebound Persons/
19	((hous$ and (quality or damp$ or standard$ or afford$ or condition$ or dilapidat$)) or ((emergency or temporary or inadequate or poor$ or overcrowd$ or over-crowd$ or over-subscribed) and (hous$ or accommodation or shelter$ or hostel$ or dwelling$))).ti,ab. or housing/st
20	(rough sleep$ or runaway$1 or ((homeless$ or street or Destitut$) and (population or person$1 or people or group$ or individual$1 or shelter$ or hostel$ or accommodation$1))).ti,ab. or exp homeless persons/
21	((drug$ or substance) and (illegal or misus$ or abuse or intravenous or IV or problem use$ or illicit use$ or addict$ or dependen$ or dependant or delinquency)).ti,ab. or *Substance-Related Disorders/ or Drug users/
22	((alcohol$ and (misus$ or abuse or problem$ use$ or problem drink$ or illicit use$ or addict$ or dependen$ or delinquency)) or alcoholic$1).ti,ab. or *Alcohol-Related Disorders/ or Alcoholics/

23	(prostitution or sex work$ or transactional sex$ or prostitute$1).ti,ab. or Prostitution/
24	(poverty or deprivation or financial hardship$).ti,ab.
25	((low-income or low income or low pay or low paid or poor or deprived or debt$ or arrear$) and (people or person$1 or population$1 or communit$ or group$ or social group$ or neighbourhood$1 or neighborhood$1 or famil$)).ti,ab.
26	poverty/
27	(low$ and social class$).ti,ab.
28	(traveller$1 or gypsies or gypsy or Romany or roma).ti,ab. or gypsies/
29	(mental$ and (health or ill or illness)).ti,ab. or *mental health/ or Mentally Ill Persons/
30	((((health care worker$1 or health care) adj2 service provi$) or health-care) adj2 provi$).ti,ab.
31	(outreach adj2 worker$1).ti,ab. or Community health aides/
32	(support adj2 worker$1).ti,ab.
33	(case adj2 worker$1).ti,ab.
34	(social adj2 worker$1).ti,ab.
35	social care professional$1.ti,ab.
36	((social care adj2 service provi$) or (social-care adj2 provi$)).ti,ab.
37	(((language$ or communicat$) and (barrier$ or understand$ or strateg$ or proficien$)) or translat$ or interpret$ or (cultur$ and competen$)).ti,ab. or Communication Barriers/ or *Language/
38	(immigrant$ or migrant$ or asylum or refugee$ or undocumented or foreign born or (born adj overseas) or (displaced and (people or person$1))).ti,ab. or "Emigration and Immigration"/ or refugees/ or "Transients and migrants"/ or "Emigrants and immigrants"/
39	or/5-38
40	1 and 4
41	39 and 40
42	animals/ not humans/
43	41 not 42
44	limit 43 to yr="1990 -Current"
45	exp Tuberculosis/ or (tuberculosis or tb).ti,ab.
46	(qualitative or focus group$ or case stud$ or field stud$ or interview$ or questionnaire$ or survey$ or ethnograph$ or grounded theory or action research or participant observation or narrative$ or (life and (history or stor$)) or verbal interaction$ or discourse analysis or narrative analysis or social construct$ or purposive sampl$ or phenomenol$ or criterion sampl$).ti,ab. or qualitative research/ or interview/ or Questionnaires/ or Focus Groups/ or phenomenology/ or Interviews as Topic/ or Health Care Surveys/ or Nursing Methodology Research/
47	(view$ or barrier$ or block$ or obstacle$ or hinder$ or constrain$ or facilitat$ or attitude$ or opinion$ or belief$ or perceiv$ or perception$ or aware$ or personal view$ or motivat$ or reason$ or incentiv$).ti,ab. or exp Attitude/ or Motivation/
48	or/46-47
49	((((((((((((((((hard$ adj2 reach) or hard$) adj2 locate) or hard$) adj2 find) or hard$) adj2 treat) or difficult) adj2 locate) or Difficult) adj2 engage) or social$ exclu$ or social inequalit$ or difficult$) adj2 reach) or difficult$) adj2 find) or difficult$) adj2 treat).ti,ab.
50	((geograph$ or transport$ or physical) and barrier$).ti,ab.
51	((low$ or poor$ or negative) and (quality adj2 life)).ti,ab.
52	((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect$ or marginal$ or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma$ or inequitable) and (people or population$ or communit$ or neighbourhood$1 or neighborhood$1 or group$ or area$1 or demograph$ or patient$ or social$)).ti,ab. or Vulnerable populations/
53	poverty area/
54	(Refuser$1 or non-user$1 or discriminat$ or shame or prejud$ or racism or racial discriminat$).ti,ab.
55	social support/ or *social conditions/ or stigma/ or Social Isolation/ or *quality of life/ or Prejudice/ or Socioeconomic Factors/
56	prisoner$1.ti,ab.

57	(recent$ adj2 release$ adj2 (inmate$ or prison$ or detainee$ or felon$ or offender$ or convict$ or custod$ or detention centre$ or detention center$ or incarcerat$)).ti,ab.
58	((prison$ or penal or penitentiary or correctional facilit$ or jail$ or detention centre$ or detention center$) and (guard$1 or population or inmate$ or system$ or remand or detainee$ or felon$ or offender$1 or convict$ or abscond$)).ti,ab.
59	(parole or probation).ti,ab.
60	*prisoners/
61	((custodial adj (care or sentence)) or (incarceration or incarcerated or imprisonment)).ti,ab.
62	(immobile or (disabled and (house bound or home bound)) or ((house or home) and bound)).ti,ab. or Homebound Persons/
63	((hous$ and (quality or damp$ or standard$ or afford$ or condition$ or dilapidat$)) or ((emergency or temporary or inadequate or poor$ or overcrowd$ or over-crowd$ or over-subscribed) and (hous$ or accommodation or shelter$ or hostel$ or dwelling$))).ti,ab. or housing/st
64	(rough sleep$ or runaway$1 or ((homeless$ or street or Destitut$) and (population or person$1 or people or group$ or individual$1 or shelter$ or hostel$ or accommodation$1))).ti,ab. or exp homeless persons/
65	((drug$ or substance) and (illegal or misus$ or abuse or intravenous or IV or problem use$ or illicit use$ or addict$ or dependen$ or dependant or delinquency)).ti,ab. or *Substance-Related Disorders/ or Drug users/
66	((alcohol$ and (misus$ or abuse or problem$ use$ or problem drink$ or illicit use$ or addict$ or dependen$ or delinquency)) or alcoholic$1).ti,ab. or *Alcohol-Related Disorders/ or Alcoholics/
67	(prostitution or sex work$ or transactional sex$ or prostitute$1).ti,ab. or Prostitution/
68	(poverty or deprivation or financial hardship$).ti,ab.
69	((low-income or low income or low pay or low paid or poor or deprived or debt$ or arrear$) and (people or person$1 or population$1 or communit$ or group$ or social group$ or neighbourhood$1 or neighborhood$1 or famil$)).ti,ab.
70	poverty/
71	(low$ and social class$).ti,ab.
72	(traveller$1 or gypsies or gypsy or Romany or roma).ti,ab. or gypsies/
73	(mental$ and (health or ill or illness)).ti,ab. or *mental health/ or Mentally Ill Persons/
74	((((health care worker$1 or health care) adj2 service provi$) or health-care) adj2 provi$).ti,ab.
75	(outreach adj2 worker$1).ti,ab. or Community health aides/
76	(support adj2 worker$1).ti,ab.
77	(case adj2 worker$1).ti,ab.
78	(social adj2 worker$1).ti,ab.
79	social care professional$1.ti,ab.
80	((social care adj2 service provi$) or (social-care adj2 provi$)).ti,ab.
81	(((language$ or communicat$) and (barrier$ or understand$ or strateg$ or proficien$)) or translat$ or interpret$ or (cultur$ and competen$)).ti,ab. or Communication Barriers/ or *Language/
82	(immigrant$ or migrant$ or asylum or refugee$ or undocumented or foreign born or (born adj overseas) or (displaced and (people or person$1))).ti,ab. or "Emigration and Immigration"/ or refugees/ or "Transients and migrants"/ or "Emigrants and immigrants"/
83	or/49-82
84	45 and 48
85	83 and 84
86	animals/ not humans/
87	85 not 86
88	limit 87 to yr="1990 - 2009"
89	44 not 88

2. Search in Embase Classic + Embase 1947 to 2014 December 2008
Ovid
Hits: 3194

1	exp Tuberculosis/ or (tuberculosis or tb).ti,ab.
2	(qualitative or focus group$ or case stud$ or field stud$ or interview$ or questionnaire$ or survey$ or ethnograph$ or grounded theory or action research or participant observation or narrative$ or (life and (history or stor$)) or verbal interaction$ or discourse analysis or narrative analysis or social construct$ or purposive sampl$ or phenomenol$ or criterion sampl$).ti,ab. or *qualitative research/ or exp *interview/ or exp *questionnaire/ or *self report/ or *health care survey/ or *nursing methodology research/
3	(view$ or barrier$ or block$ or obstacle$ or hinder$ or constrain$ or facilitat$ or attitude$ or opinion$ or belief$ or perceiv$ or perception$ or aware$ or personal view$ or motivat$ or reason$ or incentiv$).ti,ab. or exp *attitude/ or *motivation/ or exp perception/
4	or/2-3
5	((((((((((((((((hard$ adj2 reach) or hard$) adj2 locate) or hard$) adj2 find) or hard$) adj2 treat) or difficult) adj2 locate) or Difficult) adj2 engage) or social$ exclu$ or social inequalit$ or difficult$) adj2 reach) or difficult$) adj2 find) or difficult$) adj2 treat).ti,ab. or exp social exclusion/
6	((geograph$ or transport$ or physical) and barrier$).ti,ab.
7	((low$ or poor$ or negative) and (quality adj2 life)).ti,ab.
8	((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect$ or marginal$ or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma$ or inequitable) and (people or population$ or communit$ or neighbourhood$1 or neighborhood$1 or group$ or area$1 or demograph$ or patient$ or social$)).ti,ab. or *vulnerable population/
9	*poverty/ or (albania or bulgaria or cyprus or croatia or latvia or lithuania or luxembourg or malta or montenegro or romania or serbia or yugoslav or turkey).ti,ab,hw,in.
10	(Refuser$1 or non-user$1 or discriminat$ or shame or prejud$ or racism or racial discriminat$).ti,ab. or exp *social discrimination/
11	*social support/ or exp *social status/ or *social stigma/ or exp *social isolation/ or exp *"quality of life"/ or exp *prejudice/ or exp *socioeconomics/
12	prisoner$1.ti,ab.
13	(recent$ adj2 release$ adj2 (inmate$ or prison$ or detainee$ or felon$ or offender$ or convict$ or custod$ or detention centre$ or detention center$ or incarcerat$)).ti,ab.
14	((prison$ or penal or penitentiary or correctional facilit$ or jail$ or detention centre$ or detention center$) and (guard$1 or population or inmate$ or system$ or remand or detainee$ or felon$ or offender$1 or convict$ or abscond$)).ti,ab.
15	(parole or probation).ti,ab.
16	exp *prisoner/
17	((custodial adj (care or sentence)) or (incarceration or incarcerated or imprisonment)).ti,ab.
18	(immobile or (disabled and (house bound or home bound)) or ((house or home) and bound)).ti,ab. or exp *homebound patient/
19	((hous$ and (quality or damp$ or standard$ or afford$ or condition$ or dilapidat$)) or ((emergency or temporary or inadequate or poor$ or overcrowd$ or over-crowd$ or over-subscribed) and (hous$ or accommodation or shelter$ or hostel$ or dwelling$))).ti,ab. or exp *housing/
20	(rough sleep$ or runaway$1 or ((homeless$ or street or Destitut$) and (population or person$1 or people or group$ or individual$1 or shelter$ or hostel$ or accommodation$1))).ti,ab. or exp *homelessness/
21	((drug$ or substance) and (illegal or misus$ or abuse or intravenous or IV or problem use$ or illicit use$ or addict$ or dependen$ or dependant or delinquency)).ti,ab. or exp *addiction/
22	((alcohol$ and (misus$ or abuse or problem$ use$ or problem drink$ or illicit use$ or addict$ or dependen$ or delinquency)) or alcoholic$1).ti,ab.

23	(prostitution or sex work$ or transactional sex$ or prostitute$1) .ti,ab. or exp *prostitution/
24	(poverty or deprivation or financial hardship$).ti,ab.
25	((low-income or low income or low pay or low paid or poor or deprived or debt$ or arrear$) and (people or person$1 or population$1 or communit$ or group$ or social group$ or neighbourhood$1 or neighborhood$1 or famil$)).ti,ab. or exp *lowest income group/
26	*poverty/
27	(low$ and social class$).ti,ab.
28	(traveller$1 or gypsies or gypsy or Romany or roma).ti,ab. or exp *"Romani (people)"/
29	(mental$ and (health or ill or illness)).ti,ab. or *mental patient/ or exp *mental health/
30	((((health care worker$1 or health care) adj2 service provi$) or health-care) adj2 provi$).ti,ab.
31	(outreach adj2 worker$1).ti,ab. or exp *health auxiliary/
32	(support adj2 worker$1).ti,ab.
33	(case adj2 worker$1).ti,ab.
34	(social adj2 worker$1).ti,ab. or exp *social worker/
35	social care professional$1.ti,ab.
36	((social care adj2 service provi$) or (social-care adj2 provi$)).ti,ab.
37	(((language$ or communicat$) and (barrier$ or understand$ or strateg$ or proficien$)) or translat$ or interpret$ or (cultur$ and competen$)).ti,ab. or *language ability/
38	(immigrant$ or migrant$ or asylum or refugee$ or undocumented or foreign born or (born adj overseas) or (displaced and (people or person$1))).ti,ab. or *immigration/ or exp *refugee/ or exp *migrant/
39	or/5-38
40	1 and 4
41	39 and 40
42	(exp animal/ or animal.hw. or nonhuman/) not (exp human/ or human cell/ or (human or humans).ti.)
43	41 not 42
44	limit 43 to yr="1990 -Current"
45	exp Tuberculosis/ or (tuberculosis or tb).ti,ab.
46	(qualitative or focus group$ or case stud$ or field stud$ or interview$ or questionnaire$ or survey$ or ethnograph$ or grounded theory or action research or participant observation or narrative$ or (life and (history or stor$)) or verbal interaction$ or discourse analysis or narrative analysis or social construct$ or purposive sampl$ or phenomenol$ or criterion sampl$).ti,ab. or qualitative research/ or interview/ or Questionnaires/ or Focus Groups/ or phenomenology/ or Interviews as Topic/ or Health Care Surveys/ or Nursing Methodology Research/
47	(view$ or barrier$ or block$ or obstacle$ or hinder$ or constrain$ or facilitat$ or attitude$ or opinion$ or belief$ or perceiv$ or perception$ or aware$ or personal view$ or motivat$ or reason$ or incentiv$).ti,ab. or exp Attitude/ or Motivation/
48	or/46-47
49	((((((((((((((((hard$ adj2 reach) or hard$) adj2 locate) or hard$) adj2 find) or hard$) adj2 treat) or difficult) adj2 locate) or Difficult) adj2 engage) or social$ exclu$ or social inequalit$ or difficult$) adj2 reach) or difficult$) adj2 find) or difficult$) adj2 treat).ti,ab.
50	((geograph$ or transport$ or physical) and barrier$).ti,ab.
51	((low$ or poor$ or negative) and (quality adj2 life)).ti,ab.
52	((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect$ or marginal$ or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma$ or inequitable) and (people or population$ or communit$ or neighbourhood$1 or neighborhood$1 or group$ or area$1 or demograph$ or patient$ or social$)).ti,ab. or Vulnerable populations/
53	poverty area/

54	(Refuser$1 or non-user$1 or discriminat$ or shame or prejud$ or racism or racial discriminat$).ti,ab.
55	social support/ or *social conditions/ or stigma/ or Social Isolation/ or *quality of life/ or Prejudice/ or Socioeconomic Factors/
56	prisoner$1.ti,ab.
57	(recent$ adj2 release$ adj2 (inmate$ or prison$ or detainee$ or felon$ or offender$ or convict$ or custod$ or detention centre$ or detention center$ or incarcerat$)).ti,ab.
58	((prison$ or penal or penitentiary or correctional facilit$ or jail$ or detention centre$ or detention center$) and (guard$1 or population or inmate$ or system$ or remand or detainee$ or felon$ or offender$1 or convict$ or abscond$)).ti,ab.
59	(parole or probation).ti,ab.
60	*prisoners/
61	((custodial adj (care or sentence)) or (incarceration or incarcerated or imprisonment)).ti,ab.
62	(immobile or (disabled and (house bound or home bound)) or ((house or home) and bound)).ti,ab. or Homebound Persons/
63	((hous$ and (quality or damp$ or standard$ or afford$ or condition$ or dilapidat$)) or ((emergency or temporary or inadequate or poor$ or overcrowd$ or over-crowd$ or over-subscribed) and (hous$ or accommodation or shelter$ or hostel$ or dwelling$))).ti,ab. or housing/st
64	(rough sleep$ or runaway$1 or ((homeless$ or street or Destitut$) and (population or person$1 or people or group$ or individual$1 or shelter$ or hostel$ or accommodation$1))).ti,ab. or exp homeless persons/
65	((drug$ or substance) and (illegal or misus$ or abuse or intravenous or IV or problem use$ or illicit use$ or addict$ or dependen$ or dependant or delinquency)).ti,ab. or *Substance-Related Disorders/ or Drug users/
66	((alcohol$ and (misus$ or abuse or problem$ use$ or problem drink$ or illicit use$ or addict$ or dependen$ or delinquency)) or alcoholic$1).ti,ab. or *Alcohol-Related Disorders/ or Alcoholics/
67	(prostitution or sex work$ or transactional sex$ or prostitute$1) .ti,ab. or Prostitution/
68	(poverty or deprivation or financial hardship$).ti,ab.
69	((low-income or low income or low pay or low paid or poor or deprived or debt$ or arrear$) and (people or person$1 or population$1 or communit$ or group$ or social group$ or neighbourhood$1 or neighborhood$1 or famil$)).ti,ab.
70	poverty/
71	(low$ and social class$).ti,ab.
72	(traveller$1 or gypsies or gypsy or Romany or roma).ti,ab. or gypsies/
73	(mental$ and (health or ill or illness)).ti,ab. or *mental health/ or Mentally Ill Persons/
74	((((health care worker$1 or health care) adj2 service provi$) or health-care) adj2 provi$).ti,ab.
75	(outreach adj2 worker$1).ti,ab. or Community health aides/
76	(support adj2 worker$1).ti,ab.
77	(case adj2 worker$1).ti,ab.
78	(social adj2 worker$1).ti,ab.
79	social care professional$1.ti,ab.
80	((social care adj2 service provi$) or (social-care adj2 provi$)).ti,ab.
81	(((language$ or communicat$) and (barrier$ or understand$ or strateg$ or proficien$)) or translat$ or interpret$ or (cultur$ and competen$)).ti,ab. or Communication Barriers/ or *Language/
82	(immigrant$ or migrant$ or asylum or refugee$ or undocumented or foreign born or (born adj overseas) or (displaced and (people or person$1))).ti,ab. or "Emigration and Immigration"/ or refugees/ or "Transients and migrants"/ or "Emigrants and immigrants"/
83	or/49-82
84	45 and 48
85	83 and 84

86	animals/ not humans/
87	85 not 86
88	limit 87 to yr="1990 - 2009"
89	44 not 88

3. Search in PsychINFO 1806 to December Week 1 2014
OVID
Hits: 276

1	exp Tuberculosis/ or (tuberculosis or tb).ti,ab.
2	(qualitative* or focus group$ or case stud$ or field stud$ or interview$ or questionnaire$ or survey$ or ethnograph$ or grounded theory or action research or participant observation or narrative$ or (life and (history or stor$)) or verbal interaction$ or discourse analysis or narrative analysis or social construct$ or purposive sampl$ or phenomenol$ or criterion sampl$).ti,ab,md. or *qualitative research/ or exp interviews/ or exp questionnaires/ or phenomenology/
3	(view$ or barrier$ or block$ or obstacle$ or hinder$ or constrain$ or facilitat$ or attitude$ or opinion$ or belief$ or perceiv$ or perception$ or aware$ or personal view$ or motivat$ or reason$ or incentiv$).ti,ab. or exp attitudes/ or motivation/
4	or/2-3
5	((((((((((((((((hard$ adj2 reach) or hard$) adj2 locate) or hard$) adj2 find) or hard$) adj2 treat) or difficult) adj2 locate) or Difficult) adj2 engage) or social$ exclu$ or social inequalit$ or difficult$) adj2 reach) or difficult$) adj2 find) or difficult$) adj2 treat).ti,ab. or exp social deprivation/
6	((geograph$ or transport$ or physical) and barrier$).ti,ab.
7	((low$ or poor$ or negative) and (quality adj2 life)).ti,ab.
8	((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect$ or marginal$ or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma$ or inequitable) and (people or population$ or communit$ or neighbourhood$1 or neighborhood$1 or group$ or area$1 or demograph$ or patient$ or social$)).ti,ab. or exp "at risk populations"/
9	poverty areas/ or (albania or bulgaria or cyprus or croatia or latvia or lithuania or luxembourg or malta or montenegro or romania or serbia or yugoslav or turkey).ti,ab,hw,in.
10	(Refuser$1 or non-user$1 or discriminat$ or shame or prejud$ or racism or racial discriminat$).ti,ab. or exp Discrimination/
11	social support/ or exp social environments/ or stigma/ or exp social isolation/ or exp "quality of life"/ or exp prejudice/ or exp socioeconomic status/
12	prisoner$1.ti,ab.
13	(recent$ adj2 release$ adj2 (inmate$ or prison$ or detainee$ or felon$ or offender$ or convict$ or custod$ or detention centre$ or detention center$ or incarcerat$)).ti,ab.
14	((prison$ or penal or penitentiary or correctional facilit$ or jail$ or detention centre$ or detention center$) and (guard$1 or population or inmate$ or system$ or remand or detainee$ or felon$ or offender$1 or convict$ or abscond$)).ti,ab.
15	(parole or probation).ti,ab.
16	exp prisoners/
17	((custodial adj (care or sentence)) or (incarceration or incarcerated or imprisonment)).ti,ab.
18	(immobile or (disabled and (house bound or home bound)) or ((house or home) and bound)).ti,ab. or exp Homebound/
19	((hous$ and (quality or damp$ or standard$ or afford$ or condition$ or dilapidat$)) or ((emergency or temporary or inadequate or poor$ or overcrowd$ or over-crowd$ or over-subscribed) and (hous$ or accommodation or shelter$ or hostel$ or dwelling$))).ti,ab. or exp housing/
20	(rough sleep$ or runaway$1 or ((homeless$ or street or Destitut$) and (population or person$1 or people or group$ or individual$1 or shelter$ or hostel$ or accommodation$1))).ti,ab. or exp homeless/
21	((drug$ or substance) and (illegal or misus$ or abuse or intravenous or IV or problem use$ or illicit use$ or addict$ or dependen$ or dependant or delinquency)).ti,ab. or drug abuse/
22	((alcohol$ and (misus$ or abuse or problem$ use$ or problem drink$ or illicit use$ or addict$ or dependen$ or delinquency)) or alcoholic$1).ti,ab. or alcohol abuse/

23	(prostitution or sex work$ or transactional sex$ or prostitute$1).ti,ab. or exp prostitution/
24	(poverty or deprivation or financial hardship$).ti,ab.
25	((low-income or low income or low pay or low paid or poor or deprived or debt$ or arrear$) and (people or person$1 or population$1 or communit$ or group$ or social group$ or neighbourhood$1 or neighborhood$1 or famil$)).ti,ab.
26	poverty/ or lower income level/
27	(low$ and social class$).ti,ab. or lower class/
28	(traveller$1 or gypsies or gypsy or Romany or roma).ti,ab. or Romanies/
29	(mental$ and (health or ill or illness)).ti,ab. or exp mental health/ or exp mental disorders/
30	((((health care worker$1 or health care) adj2 service provi$) or health-care) adj2 provi$).ti,ab.
31	(outreach adj2 worker$1).ti,ab. or outreach program/
32	(support adj2 worker$1).ti,ab.
33	(case adj2 worker$1).ti,ab.
34	(social adj2 worker$1).ti,ab. or social workers/
35	social care professional$1.ti,ab.
36	((social care adj2 service provi$) or (social-care adj2 provi$)).ti,ab.
37	(((language$ or communicat$) and (barrier$ or understand$ or strateg$ or proficien$)) or translat$ or interpret$ or (cultur$ and competen$)).ti,ab. or exp communication barriers/ or language/
38	(immigrant$ or migrant$ or asylum or refugee$ or undocumented or foreign born or (born adj overseas) or (displaced and (people or person$1))).ti,ab. or immigration/
39	or/5-38
40	1 and 4
41	39 and 40
42	limit 41 to yr="1990 -Current"
43	exp Tuberculosis/ or (tuberculosis or tb).ti,ab.
44	(qualitative or focus group$ or case stud$ or field stud$ or interview$ or questionnaire$ or survey$ or ethnograph$ or grounded theory or action research or participant observation or narrative$ or (life and (history or stor$)) or verbal interaction$ or discourse analysis or narrative analysis or social construct$ or purposive sampl$ or phenomenol$ or criterion sampl$).ti,ab. or qualitative research/ or interview/ or Questionnaires/ or Focus Groups/ or phenomenology/ or Interviews as Topic/ or Health Care Surveys/ or Nursing Methodology Research/
45	(view$ or barrier$ or block$ or obstacle$ or hinder$ or constrain$ or facilitat$ or attitude$ or opinion$ or belief$ or perceiv$ or perception$ or aware$ or personal view$ or motivat$ or reason$ or incentiv$).ti,ab. or exp Attitude/ or Motivation/
46	or/44-45
47	((((((((((((((hard$ adj2 reach) or hard$) adj2 locate) or hard$) adj2 find) or hard$) adj2 treat) or difficult) adj2 locate) or Difficult) adj2 engage) or social$ exclu$ or social inequalit$ or difficult$) adj2 reach) or difficult$) adj2 find) or difficult$) adj2 treat).ti,ab.
48	((geograph$ or transport$ or physical) and barrier$).ti,ab.
49	((low$ or poor$ or negative) and (quality adj2 life)).ti,ab.
50	((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect$ or marginal$ or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma$ or inequitable) and (people or population$ or communit$ or neighbourhood$1 or neighborhood$1 or group$ or area$1 or demograph$ or patient$ or social$)).ti,ab. or Vulnerable populations/
51	poverty area/
52	(Refuser$1 or non-user$1 or discriminat$ or shame or prejud$ or racism or racial discriminat$).ti,ab.
53	social support/ or *social conditions/ or stigma/ or Social Isolation/ or *quality of life/ or Prejudice/ or Socioeconomic Factors/
54	prisoner$1.ti,ab.
55	(recent$ adj2 release$ adj2 (inmate$ or prison$ or detainee$ or felon$ or offender$ or convict$ or custod$ or detention centre$ or detention center$ or incarcerat$)).ti,ab.
56	((prison$ or penal or penitentiary or correctional facilit$ or jail$ or detention centre$ or detention center$) and (guard$1 or population or inmate$ or system$ or remand or detainee$ or felon$ or offender$1 or convict$ or abscond$)).ti,ab.

57	(parole or probation).ti,ab.
58	*prisoners/
59	((custodial adj (care or sentence)) or (incarceration or incarcerated or imprisonment)).ti,ab.
60	(immobile or (disabled and (house bound or home bound)) or ((house or home) and bound)).ti,ab. or Homebound Persons/
61	((hous$ and (quality or damp$ or standard$ or afford$ or condition$ or dilapidat$)) or ((emergency or temporary or inadequate or poor$ or overcrowd$ or over-crowd$ or over-subscribed) and (hous$ or accommodation or shelter$ or hostel$ or dwelling$))).ti,ab. or housing/st
62	(rough sleep$ or runaway$1 or ((homeless$ or street or Destitut$) and (population or person$1 or people or group$ or individual$1 or shelter$ or hostel$ or accommodation$1))).ti,ab. or exp homeless persons/
63	((drug$ or substance) and (illegal or misus$ or abuse or intravenous or IV or problem use$ or illicit use$ or addict$ or dependen$ or dependant or delinquency)).ti,ab. or *Substance-Related Disorders/ or Drug users/
64	((alcohol$ and (misus$ or abuse or problem$ use$ or problem drink$ or illicit use$ or addict$ or dependen$ or delinquency)) or alcoholic$1).ti,ab. or *Alcohol-Related Disorders/ or Alcoholics/
65	(prostitution or sex work$ or transactional sex$ or prostitute$1).ti,ab. or Prostitution/
66	(poverty or deprivation or financial hardship$).ti,ab.
67	((low-income or low income or low pay or low paid or poor or deprived or debt$ or arrear$) and (people or person$1 or population$1 or communit$ or group$ or social group$ or neighbourhood$1 or neighborhood$1 or famil$)).ti,ab.
68	poverty/
69	(low$ and social class$).ti,ab.
70	(traveller$1 or gypsies or gypsy or Romany or roma).ti,ab. or gypsies/
71	(mental$ and (health or ill or illness)).ti,ab. or *mental health/ or Mentally Ill Persons/
72	((((health care worker$1 or health care) adj2 service provi$) or health-care) adj2 provi$).ti,ab.
73	(outreach adj2 worker$1).ti,ab. or Community health aides/
74	(support adj2 worker$1).ti,ab.
75	(case adj2 worker$1).ti,ab.
76	(social adj2 worker$1).ti,ab.
77	social care professional$1.ti,ab.
78	((social care adj2 service provi$) or (social-care adj2 provi$)).ti,ab.
79	(((language$ or communicat$) and (barrier$ or understand$ or strateg$ or proficien$)) or translat$ or interpret$ or (cultur$ and competen$)).ti,ab. or Communication Barriers/ or *Language/
80	(immigrant$ or migrant$ or asylum or refugee$ or undocumented or foreign born or (born adj overseas) or (displaced and (people or person$1))).ti,ab. or "Emigration and Immigration"/ or refugees/ or "Transients and migrants"/ or "Emigrants and immigrants"/
81	or/47-80
82	43 and 46
83	81 and 82
84	animals/ not humans/
85	83 not 84
86	limit 85 to yr="1990 - 2009"
87	42 not 86

4. Search in Centre for Reviews and Dissemination (CRD)

http://www.crd.york.ac.uk/crdweb/

Hits: 33

((tuberculosis)
AND
(qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or participant observation or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl*)

OR
(view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or personal view* or motivat* or reason* or incentiv*)
AND
((hard* and (reach or locate or find or treat)) or (difficult and (locate or engage or reach or find or treat)) or social* exclu* or social inequalit*)
OR
(geograph* or transport* or physical and (barrier*))
OR (albania or bulgaria or cyprus or croatia or latvia or lithuania or luxembourg or malta or montenegro or romania or serbia or yugoslav or turkey)
OR
(low* or poor* or negative and (quality adj2 life))
OR
((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect* or marginal* or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma* or inequitable or poverty) and (people or population* or communit* or neighbourhood* or neighborhood* or group* or area* or demograph* or patient* or social*))
OR
(Refuser* or non-user* or discriminat* or shame or prejud* or racism or racial discriminat*)
OR
(social support or social conditions or stigma or Social Isolation or quality adj life or Prejudice)
OR
prisoner*
OR
(recent* release* and (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or detention centre* or detention center* or incarcerat*))
OR
((prison* or penal or penitentiary or correctional facilit* or jail* or detention centre* or detention center*) and (guard* or population or inmate* or system* or remand or detainee* or felon* or offender* or convict* or abscond*))
OR
(parole or probation)
OR
((custodial and (care or sentence)) or (incarceration or incarcerated or imprisonment))
OR
(immobile or (disabled and (house bound or home bound)) or (house or home and (bound)))
((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or (emergency or temporary or inadequate or poor* or overcrowd* or over-crowd* or over-subscribed and (hous* or accommodation or shelter* or hostel* or dwelling*)))
(rough sleep* or runaway* or (homeless* or street or Destitut* and (population or person* or people or group* or individual* or shelter* or hostel* or accommodation*)))
(drug* or substance and (illegal or misus* or abuse or intravenous or IV or problem use* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder))
((alcohol* and (misus* or abuse or problem* use* or problem drink* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder)) or alcoholic*)
(prostitution or sex work* or transactional sex* or prostitute*)
(poverty or deprivation or financial hardship*)
(low-income or low income or low pay or low paid or poor or deprived or debt* or arrear* and (people or person* or population* or communit* or group* or social group* or neighbourhood* or neighborhood* or famil*))
(low* and (social class*))

(traveller* or gypsies or gypsy or Romany or roma)
(mental* and (health or ill or illness))
(health care worker* or (health care or health-care and (service provi* or provi*)))
(outreach or care or social or social care and (worker* or professional*))
(social care or social-care and (service provi* or provi*))
((language* or communicat* and (barrier* or understand* or strateg* or proficien*)) or translat* or interpret* or (cultur* and (competen*)))
(immigrant* or emigrat* or transient* or migrant* or asylum or refugee* or undocumented or foreign born or born adj overseas or (displaced and (people or person*)))
NOT
(animal* or badger* or Cow or Cattle or bovine) WHERE LPD FROM 01/01/1990 TO 10/12/2014)
NOT
((tuberculosis)
AND
(qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or participant observation or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl*)
OR
(view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or personal view* or motivat* or reason* or incentiv*)
AND
((hard* and (reach or locate or find or treat)) or (difficult and (locate or engage or reach or find or treat)) or social* exclu* or social inequalit*)
OR
(geograph* or transport* or physical and (barrier*))
OR
(low* or poor* or negative and (quality adj2 life))
OR
((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect* or marginal* or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma* or inequitable or poverty) and (people or population* or communit* or neighbourhood* or neighborhood* or group* or area* or demograph* or patient* or social*))
OR
(Refuser* or non-user* or discriminat* or shame or prejud* or racism or racial discriminat*)
OR
(social support or social conditions or stigma or Social Isolation or quality adj life or Prejudice)
OR
prisoner*
OR
(recent* release* and (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or detention centre* or detention center* or incarcerat*))
OR
((prison* or penal or penitentiary or correctional facilit* or jail* or detention centre* or detention center*) and (guard* or population or inmate* or system* or remand or detainee* or felon* or offender* or convict* or abscond*))
OR
(parole or probation)
OR
((custodial and (care or sentence)) or (incarceration or incarcerated or imprisonment))

OR
(immobile or (disabled and (house bound or home bound)) or (house or home and (bound)))
OR
((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or (emergency or temporary or inadequate or poor* or overcrowd* or over-crowd* or over-subscribed and (hous* or accommodation or shelter* or hostel* or dwelling*)))
OR
(rough sleep* or runaway* or (homeless* or street or Destitut* and (population or person* or people or group* or individual* or shelter* or hostel* or accommodation*)))
OR
(drug* or substance and (illegal or misus* or abuse or intravenous or IV or problem use* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder))
OR
((alcohol* and (misus* or abuse or problem* use* or problem drink* or illicit use* or addict* or dependen* or dependant or delinquency or related adj disorder)) or alcoholic*)
OR
(prostitution or sex work* or transactional sex* or prostitute*)
OR
(poverty or deprivation or financial hardship*)
OR
(low-income or low income or low pay or low paid or poor or deprived or debt* or arrear* and (people or person* or population* or communit* or group* or social group* or neighbourhood* or neighborhood* or famil*))
OR
(low* and (social class*))
OR
(traveller* or gypsies or gypsy or Romany or roma)
OR
(mental* and (health or ill or illness))
OR
(health care worker* or (health care or health-care and (service provi* or provi*)))
OR
(outreach or care or social or social care and (worker* or professional*))
OR
(social care or social-care and (service provi* or provi*))
OR
((language* or communicat* and (barrier* or understand* or strateg* or proficien*)) or translat* or interpret* or (cultur* and (competen*)))
OR
(immigrant* or emigrat* or transient* or migrant* or asylum or refugee* or undocumented or foreign born or born adj overseas or (displaced and (people or person*)))
NOT
(animal* or badger* or Cow or Cattle or bovine)

5. Search in Cochrane library

http://www.thecochranelibrary.com/view/0/index.html

Hits: 204

#1	
	(tuberculosis)
	AND
	(qualitative or "focus group*" or "case stud*" or "field stud*" or interview* or questionnaire* or survey* or ethnograph* or "grounded theory" or "action research" or "participant

	observation" or narrative* or (life and (history or stor*)) or "verbal interaction*" or "discourse analysis" or "narrative analysis" or "social construct*" or "purposive sampl*" or phenomenol* or "criterion sampl*")
	OR
	(view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or "personal view*" or motivat* or reason* or incentiv*)
	AND
	((hard* and (reach or locate or find or treat)) or (difficult and (locate or engage or reach or find or treat)) or "social* exclu*" or "social inequalit*")
	OR
	(geograph* or transport* or physical and (barrier*))
	OR
	(low* or poor* or negative and (quality NEAR/2 life))
	OR
	((vulnerable or disadvantaged or "at risk" or "high risk" or "low socioeconomic status" or neglect* or marginal* or forgotten or "non-associative" or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma* or inequitable or poverty) and (people or population* or communit* or neighbourhood* or neighborhood* or group* or area* or demograph* or patient* or social*))
	OR
	(Refuser* or "non-user*" or discriminat* or shame or prejud* or racism or "racial discriminat*")
	OR
	("social support" or "social conditions" or stigma or "Social Isolation" or (quality NEXT life) or prejudice)
	OR
	prisoner*
	OR
	("recent* release*" and (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or "detention centre*" or "detention center*" or incarcerat*))
	OR
	((prison* or penal or penitentiary or "correctional facilit*" or jail* or "detention centre*" or "detention center*") and (guard* or population or inmate* or system* or remand or detainee* or felon* or offender* or convict* or abscond*))
	OR
	(parole or probation)
	OR
	((custodial and (care or sentence)) or (incarceration or incarcerated or imprisonment))
	OR
	(immobile or (disabled and ("house bound" or "home bound")) or (house or home and (bound)))
	OR
	((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or (emergency or temporary or inadequate or poor* or overcrowd* or "over-crowd*" or "over-subscribed" and (hous* or accommodation or shelter* or hostel* or dwelling*)))
	OR
	("rough sleep*" or runaway* or (homeless* or street or Destitut* and (population or person* or people or group* or individual* or shelter* or hostel* or accommodation*)))
	OR
	(drug* or substance and (illegal or misus* or abuse or intravenous or IV or "problem use*" or "illicit use*" or addict* or dependen* or dependant or delinquency or (related NEXT disorder)))
	OR

	((alcohol* and (misus* or abuse or "problem* use*" or "problem drink*" or "illicit use*" or addict* or dependen* or dependant or delinquency or (related NEXT disorder))) or alcoholic*)
	OR
	(prostitution or "sex work*" or "transactional sex*" or prostitute*)
	OR
	(poverty or deprivation or "financial hardship*")
	OR
	("low-income" or "low income" or "low pay" or "low paid" or poor or deprived or debt* or arrear* and (people or person* or population* or communit* or group* or social group* or neighbourhood* or neighborhood* or famil*))
	OR
	(low* and ("social class*"))
	OR
	(traveller* or gypsies or gypsy or Romany or roma)
	OR
	(mental* and (health or ill or illness))
	OR
	("health care worker*" or ("health care" or "health-care" and ("service provi*" or provi*)))
	OR
	(outreach or care or social or "social care" and (worker* or professional*))
	OR
	("social care" or "social-care" and ("service provi*" or provi*))
	OR
	((language* or communicat* and (barrier* or understand* or strateg* or proficien*)) or translat* or interpret* or (cultur* and competen*))
	OR
	(immigrant* or emigrat* or transient* or migrant* or asylum or refugee* or undocumented or "foreign born" or (born NEXT overseas) or (displaced and (people or person*)))
	NOT
	(animal* or badger* or Cow or Cattle or bovine)
#2	
	(tuberculosis)
	AND
	(qualitative or "focus group*" or "case stud*" or "field stud*" or interview* or questionnaire* or survey* or ethnograph* or "grounded theory" or "action research" or "participant observation" or narrative* or (life and (history or stor*)) or "verbal interaction*" or "discourse analysis" or "narrative analysis" or "social construct*" or "purposive sampl*" or phenomenol* or "criterion sampl*")
	OR
	(view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or "personal view*" or motivat* or reason* or incentiv*)
	AND
	((hard* and (reach or locate or find or treat)) or (difficult and (locate or engage or reach or find or treat)) or "social* exclu*" or "social inequalit*")
	OR
	(geograph* or transport* or physical and (barrier*))
	OR
	(albania or bulgaria or cyprus or croatia or latvia or lithuania or luxembourg or malta or montenegro or romania or serbia or yugoslav or turkey)
	OR

	(low* or poor* or negative and (quality NEAR/2 life))
	OR
	((vulnerable or disadvantaged or "at risk" or "high risk" or "low socioeconomic status" or neglect* or marginal* or forgotten or "non-associative" or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma* or inequitable or poverty) and (people or population* or communit* or neighbourhood* or neighborhood* or group* or area* or demograph* or patient* or social*))
	OR
	(Refuser* or "non-user*" or discriminat* or shame or prejud* or racism or "racial discriminat*")
	OR
	("social support" or "social conditions" or stigma or "Social Isolation" or (quality NEXT life) or prejudice)
	OR
	prisoner*
	OR
	("recent* release*" and (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or "detention centre*" or "detention center*" or incarcerat*))
	OR
	((prison* or penal or penitentiary or "correctional facilit*" or jail* or "detention centre*" or "detention center*") and (guard* or population or inmate* or system* or remand or detainee* or felon* or offender* or convict* or abscond*))
	OR
	(parole or probation)
	OR
	((custodial and (care or sentence)) or (incarceration or incarcerated or imprisonment))
	OR
	(immobile or (disabled and ("house bound" or "home bound")) or (house or home and (bound)))
	OR
	((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or (emergency or temporary or inadequate or poor* or overcrowd* or "over-crowd*" or "over-subscribed" and (hous* or accommodation or shelter* or hostel* or dwelling*)))
	OR
	("rough sleep*" or runaway* or (homeless* or street or Destitut* and (population or person* or people or group* or individual* or shelter* or hostel* or accommodation*)))
	OR
	(drug* or substance and (illegal or misus* or abuse or intravenous or IV or "problem use*" or "illicit use*" or addict* or dependen* or dependant or delinquency or (related NEXT disorder)))
	OR
	((alcohol* and (misus* or abuse or "problem* use*" or "problem drink*" or "illicit use*" or addict* or dependen* or dependant or delinquency or (related NEXT disorder))) or alcoholic*)
	OR
	(prostitution or "sex work*" or "transactional sex*" or prostitute*)
	OR
	(poverty or deprivation or "financial hardship*")
	OR
	("low-income" or "low income" or "low pay" or "low paid" or poor or deprived or debt* or arrear* and (people or person* or population* or communit* or group* or social group* or neighbourhood* or neighborhood* or famil*))
	OR
	(low* and ("social class*"))

	OR
	(traveller* or gypsies or gypsy or Romany or roma)
	OR
	(mental* and (health or ill or illness))
	OR
	("health care worker*" or ("health care" or "health-care" and ("service provi*" or provi*)))
	OR
	(outreach or care or social or "social care" and (worker* or professional*))
	OR
	("social care" or "social-care" and ("service provi*" or provi*))
	OR
	((language* or communicat* and (barrier* or understand* or strateg* or proficien*)) or translat* or interpret* or (cultur* and competen*))
	OR
	(immigrant* or emigrat* or transient* or migrant* or asylum or refugee* or undocumented or "foreign born" or (born NEXT overseas) or (displaced and (people or person*)))
	NOT
	(animal* or badger* or Cow or Cattle or bovine)
#3	#2 NOT #1

6. Search in Cumulative Index to Nursing and Allied Health Literature (CINAHL)
Hits: 257

S1	TI ((tuberculosis) AND ((qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or participant observation or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl*) OR (view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or personal view* or motivat* or reason* or incentiv*)) AND (((hard* and (reach or locate or find or treat)) or (difficult and (locate or engage or reach or find or treat)) or social* exclu* or social inequalit*) OR (geograph* or transport* or physical and (barrier*)) OR (low* or poor* or negative and (quality N2 life)) OR ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect* or marginal* or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma* or inequitable or poverty) and (people or population* or communit* or neighbourhood* or neighborhood* or group* or area* or demograph* or patient* or social*)) OR (Refuser* or non-user* or discriminat* or shame or prejud* or racism or racial discriminat*) OR (social support or social conditions or stigma or Social Isolation or quality N life or Prejudice) OR prisoner* OR (recent* release* and (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or detention centre* or detention center* or incarcerat*)) OR ((prison* or penal or penitentiary or correctional facilit* or jail* or detention centre* or detention center*) and (guard* or population or inmate* or system* or remand or detainee* or felon* or offender* or convict* or abscond*)) OR (parole or probation) OR ((custodial and (care or sentence)) or (incarceration or incarcerated or imprisonment)) OR (immobile or (disabled and (house bound or home bound)) or (house or home and (bound))) OR ((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or (emergency or temporary or inadequate or poor* or overcrowd* or over-crowd* or over-subscribed and (hous* or accommodation or shelter* or hostel* or dwelling*))) OR (rough sleep* or runaway* or (homeless* or street or Destitut* and (population or person* or people or group* or individual* or shelter* or hostel* or accommodation*))) OR (drug* or substance and (illegal or misus* or abuse or intravenous or IV or problem use* or illicit use* or addict* or dependen* or dependant or delinquency or related N disorder)) OR ((alcohol* and (misus* or abuse or problem* use* or problem drink* or illicit use* or addict* or dependen* or dependant or delinquency or related N disorder)) or

	alcoholic*) OR (prostitution or sex work* or transactional sex* or prostitute*) OR (poverty or deprivation or financial hardship*) OR (low-income or low income or low pay or low paid or poor or deprived or debt* or arrear* and (people or person* or population* or communit* or group* or social group* or neighbourhood* or neighborhood* or famil*)) OR (low* and (social class*)) OR (traveller* or gypsies or gypsy or Romany or roma) OR (mental* and (health or ill or illness)) OR (health care worker* or (health care or health-care and (service provi* or provi*))) OR (outreach or care or social or social care and (worker* or professional*)) OR (social care or social-care and (service provi* or provi*)) OR ((language* or communicat* and (barrier* or understand* or strateg* or proficien*)) or translat* or interpret* or (cultur* and (competen*))) OR (immigrant* or emigrat* or transient* or migrant* or asylum or refugee* or undocumented or foreign born or born N overseas or (displaced and (people or person*)))
S2	AB ((tuberculosis) AND ((qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or participant observation or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl*) OR (view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or personal view* or motivat* or reason* or incentiv*)) AND (((hard* and (reach or locate or find or treat)) or (difficult and (locate or engage or reach or find or treat)) or social* exclu* or social inequalit*) OR (geograph* or transport* or physical and (barrier*)) OR (low* or poor* or negative and (quality N2 life)) OR ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect* or marginal* or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma* or inequitable or poverty) and (people or population* or communit* or neighbourhood* or neighborhood* or group* or area* or demograph* or patient* or social*)) OR (Refuser* or non-user* or discriminat* or shame or prejud* or racism or racial discriminat*) OR (social support or social conditions or stigma or Social Isolation or quality N life or Prejudice) OR prisoner* OR (recent* release* and (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or detention centre* or detention center* or incarcerat*)) OR ((prison* or penal or penitentiary or correctional facilit* or jail* or detention centre* or detention center*) and (guard* or population or inmate* or system* or remand or detainee* or felon* or offender* or convict* or abscond*)) OR (parole or probation) OR ((custodial and (care or sentence)) or (incarceration or incarcerated or imprisonment)) OR (immobile or (disabled and (house bound or home bound)) or (house or home and (bound))) OR ((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or (emergency or temporary or inadequate or poor* or overcrowd* or over-crowd* or over-subscribed and (hous* or accommodation or shelter* or hostel* or dwelling*))) OR (rough sleep* or runaway* or (homeless* or street or Destitut* and (population or person* or people or group* or individual* or shelter* or hostel* or accommodation*))) OR (drug* or substance and (illegal or misus* or abuse or intravenous or IV or problem use* or illicit use* or addict* or dependen* or dependant or delinquency or related N disorder)) OR ((alcohol* and (misus* or abuse or problem* use* or problem drink* or illicit use* or addict* or dependen* or dependant or delinquency or related N disorder)) or alcoholic*) OR (prostitution or sex work* or transactional sex* or prostitute*) OR (poverty or deprivation or financial hardship*) OR (low-income or low income or low pay or low paid or poor or deprived or debt* or arrear* and (people or person* or population* or communit* or group* or social group* or neighbourhood* or neighborhood* or famil*)) OR (low* and (social class*)) OR (traveller* or gypsies or gypsy or Romany or roma) OR (mental* and (health or ill or illness)) OR (health care worker* or (health care or health-care and (service provi* or provi*))) OR (outreach or care or social or social care and (worker* or professional*)) OR (social care or social-care and (service provi* or provi*)) OR ((language* or communicat* and (barrier* or understand* or strateg* or proficien*)) or translat* or interpret* or (cultur* and (competen*))) OR (immigrant* or emigrat* or transient* or migrant* or asylum or

	refugee* or undocumented or foreign born or born N overseas or (displaced and (people or person*)))))
S3	MW ((tuberculosis) AND ((qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or participant observation or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl*) OR (view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or personal view* or motivat* or reason* or incentiv*)) AND (((hard* and (reach or locate or find or treat)) or (difficult and (locate or engage or reach or find or treat)) or social* exclu* or social inequalit*) OR (geograph* or transport* or physical and (barrier*)) OR (low* or poor* or negative and (quality N2 life)) OR ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect* or marginal* or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma* or inequitable or poverty) and (people or population* or communit* or neighbourhood* or neighborhood* or group* or area* or demograph* or patient* or social*)) OR (Refuser* or non-user* or discriminat* or shame or prejud* or racism or racial discriminat*) OR (social support or social conditions or stigma or Social Isolation or quality N life or Prejudice) OR prisoner* OR (recent* release* and (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or detention centre* or detention center* or incarcerat*)) OR ((prison* or penal or penitentiary or correctional facilit* or jail* or detention centre* or detention center*) and (guard* or population or inmate* or system* or remand or detainee* or felon* or offender* or convict* or abscond*)) OR (parole or probation) OR ((custodial and (care or sentence)) or (incarceration or incarcerated or imprisonment)) OR (immobile or (disabled and (house bound or home bound)) or (house or home and (bound))) OR ((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or (emergency or temporary or inadequate or poor* or overcrowd* or over-crowd* or over-subscribed and (hous* or accommodation or shelter* or hostel* or dwelling*))) OR (rough sleep* or runaway* or (homeless* or street or Destitut* and (population or person* or people or group* or individual* or shelter* or hostel* or accommodation*))) OR (drug* or substance and (illegal or misus* or abuse or intravenous or IV or problem use* or illicit use* or addict* or dependen* or dependant or delinquency or related N disorder)) OR ((alcohol* and (misus* or abuse or problem* use* or problem drink* or illicit use* or addict* or dependen* or dependant or delinquency or related N disorder)) or alcoholic*) OR (prostitution or sex work* or transactional sex* or prostitute*) OR (poverty or deprivation or financial hardship*) OR (low-income or low income or low pay or low paid or poor or deprived or debt* or arrear* and (people or person* or population* or communit* or group* or social group* or neighbourhood* or neighborhood* or famil*)) OR (low* and (social class*)) OR (traveller* or gypsies or gypsy or Romany or roma) OR (mental* and (health or ill or illness)) OR (health care worker* or (health care or health-care and (service provi* or provi*))) OR (outreach or care or social or social care and (worker* or professional*)) OR (social care or social-care and (service provi* or provi*)) OR ((language* or communicat* and (barrier* or understand* or strateg* or proficien*)) or translat* or interpret* or (cultur* and (competen*))) OR (immigrant* or emigrat* or transient* or migrant* or asylum or

	refugee* or undocumented or foreign born or born N overseas or (displaced and (people or person*)))))
S4	S1 OR S2 OR S3
S5	TI (animal* or badger* or Cow or Cattle or bovine)
S6	AB (animal* or badger* or Cow or Cattle or bovine)
S7	MW (animal* or badger* or Cow or Cattle or bovine)
S8	S5 OR S6 OR S7
S9	S4 NOT S8
S10	S4 NOT S8
S11	(MH "Tuberculosis+") or TI(tuberculosis or tb) or AB (tuberculosis or tb)
S12	TI (qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or participant observation or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl*) or AB (qualitative or focus group* or case stud* or field stud* or interview* or questionnaire* or survey* or ethnograph* or grounded theory or action research or participant observation or narrative* or (life and (history or stor*)) or verbal interaction* or discourse analysis or narrative analysis or social construct* or purposive sampl* or phenomenol* or criterion sampl*)or (MH "Qualitative Studies+") or (MH "Interviews+") or (MH "Questionnaires") or (MH "Biophysiological Methods+") or (MH "Phenomenology") or (MH "Surveys")
S13	TI (view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or personal view* or motivat* or reason* or incentiv*) or AB (view* or barrier* or block* or obstacle* or hinder* or constrain* or facilitat* or attitude* or opinion* or belief* or perceiv* or perception* or aware* or personal view* or motivat* or reason* or incentiv*) or (MH "Attitude+") or (MH "Motivation+")
S14	S11 AND S13
S15	(AB ((((((((((((((((hard* N2 reach) or hard*) N2 locate) or hard*) N2 find) or hard*) N2 treat) or difficult) N2 locate) or Difficult) N2 engage) or social* exclu* or social inequalit* or difficult*) N2 reach) or difficult*) N2 find) or difficult*) N2 treat) orTI ((((((((((((((((hard* N2 reach) or hard*) N2 locate) or hard*) N2 find) or hard*) N2 treat) or difficult) N2 locate) or Difficult) N2 engage) or social* exclu* or social inequalit* or difficult*) N2 reach) or difficult*) N2 find) or difficult*) N2 treat OR TI ((geograph* or transport* or physical) and barrier*) or AB ((geograph* or transport* or physical) and barrier*) OR TI ((low* or poor* or negative) and (quality N2 life)) OR AB ((low* or poor* or negative) and (quality N2 life)) OR TI ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect* or marginal* or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma* or inequitable) and (people or population* or communit* or neighbourhood? or neighborhood? or group* or area? or demograph* or patient* or social*) or AB ((vulnerable or disadvantaged or at risk or high risk or low socioeconomic status or neglect* or marginal* or forgotten or non-associative or unengaged or hidden or excluded or transient or inaccessible or underserved or stigma* or inequitable) and (people or population* or communit* or

	neighbourhood? or neighborhood? or group* or area? or demograph* or patient* or social*) or (MH "Special Populations") OR (MH "Poverty Areas") or TI(albania or bulgaria or cyprus or croatia or latvia or lithuania or luxembourg or malta or montenegro or romania or serbia or yugoslav or turkey) OR AB(albania or bulgaria or cyprus or croatia or latvia or lithuania or luxembourg or malta or montenegro or romania or serbia or yugoslav or turkey) or AF(albania or bulgaria or cyprus or croatia or latvia or lithuania or luxembourg or malta or montenegro or romania or serbia or yugoslav or turkey) OR TI (Refuser? or non-user? or discriminat* or shame or prejud* or racism or racial discriminat*) or AB (Refuser? or non-user? or discriminat* or shame or prejud* or racism or racial discriminat*) OR (MH "Support, Psychosocial+") or (MH "Stigma") or (MH "Social Isolation+") or (MH "Quality of Life+") or (MH "Prejudice") or (MH "Socioeconomic Factors+") OR TI prisoner? or AB prisoner? OR TI (recent* N2 release* N2 (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or detention centre* or detention center* or incarcerat*)) or AB (recent* N2 release* N2 (inmate* or prison* or detainee* or felon* or offender* or convict* or custod* or detention centre* or detention center* or incarcerat*)) OR TI ((prison* or penal or penitentiary or correctional facilit* or jail* or detention centre* or detention center*) and (guard? or population or inmate* or system* or remand or detainee* or felon* or offender? or convict* or abscond*)) or AB ((prison* or penal or penitentiary or correctional facilit* or jail* or detention centre* or detention center*) and (guard? or population or inmate* or system* or remand or detainee* or felon* or offender? or convict* or abscond*)) OR TI (parole or probation) or AB (parole or probation OR (MH "Prisoners") OR TI ((custodial N (care or sentence)) or (incarceration or incarcerated or imprisonment)) or AB ((custodial N (care or sentence)) or (incarceration or incarcerated or imprisonment)) OR TI(immobile or (disabled and (house bound or home bound)) or ((house or home) and bound)) or AB(immobile or (disabled and (house bound or home bound)) or ((house or home) and bound)) or (MH "Homebound Patients") OR TI((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or ((emergency or temporary or inadequate or poor* or overcrowd* or over-crowd* or over-subscribed) and (hous* or accommodation or shelter* or hostel* or dwelling*))) or AB ((hous* and (quality or damp* or standard* or afford* or condition* or dilapidat*)) or ((emergency or temporary or inadequate or poor* or overcrowd* or over-crowd* or over-subscribed) and (hous* or accommodation or shelter* or hostel* or dwelling*))) or (MH "Housing") OR TI(rough sleep* or runaway? or ((homeless* or street or Destitut*) and (population or person? or people or group* or individual? or shelter* or hostel* or accommodation?))) or AB(rough sleep* or runaway? or ((homeless* or street or Destitut*) and (population or person? or people or group* or individual? or shelter* or hostel* or accommodation?))) Or (MH "Homeless Persons") OR TI((drug* or substance) and (illegal or misus* or abuse or intravenous or IV or problem use* or illicit use* or addict* or dependen* or dependant or delinquency)) or AB ((drug* or substance) and (illegal or misus* or abuse or intravenous or IV or problem use* or illicit use* or addict* or dependen* or dependant or delinquency)or (MH "Substance Use Disorders") or (MH "Substance Abusers+") OR TI((alcohol* and (misus* or abuse or problem* use* or problem drink* or illicit use* or addict* or dependen* or delinquency)) or alcoholic?) or AB((alcohol* and (misus* or abuse or problem* use* or problem drink* or illicit use* or addict* or dependen* or delinquency)) or alcoholic?) or (MH "Alcohol-Related Disorders+") or (MH "Alcoholism") OR TI(prostitution or sex work* or transactional sex* or prostitute?) or AB(prostitution or sex work* or transactional sex* or prostitute?) or (MH "Prostitution") OR TI(poverty or deprivation or financial hardship*) or AB (poverty or deprivation or financial hardship*) OR TI ((low-income or low income or low pay or low paid or poor or deprived or debt* or arrear*) and (people or person? or population? or communit* or group* or social group* or neighbourhood? or neighborhood? or famil*)) or AB ((low-income or low income or low pay or low paid or poor or deprived or debt* or arrear*) and (people or person? or population? or communit* or group* or social group* or neighbourhood? or neighborhood? or famil*)) OR (MH "Poverty+") OR TI(low* and social class*) or AB(low* and social class*) Or (MH "Social Class") OR TI(traveller? or gypsies or gypsy or Romany or roma) or AB(traveller? or gypsies or gypsy or Romany or roma) or (MH "Gypsies") OR TI(mental* and (health or ill or illness)) or AB (mental* and (health or ill or illness))or (MH "Mental Health") OR

	TI(mental* and (health or ill or illness)) or AB(mental* and (health or ill or illness)) OR TI(outreach N2 worker?) or AB(outreach N2 worker?) or (MH "Home Health Aides") OR (MH "Community Health Nursing+") OR (MH "Community Health Workers") OR TI(support N2 worker?) or AB (support N2 worker?) OR TI(case N2 worker?) or AB (case N2 worker?) OR TI(social N2 worker?) or AB (social N2 worker?) OR TI(social care professional?) Or AB(social care professional?) OR TI((social care N2 service provi*) or (social-care N2 provi*)) or AB ((social care N2 service provi*) or (social-care N2 provi*)) OR TI(((language* or communicat*) and (barrier* or understand* or strateg* or proficien*)) or translat* or interpret* or (cultur* and competen*)) or AB(((language* or communicat*) and (barrier* or understand* or strateg* or proficien*)) or translat* or interpret* or (cultur* and competen*)) or (MH "Communication Barriers") OR TI(immigrant* or migrant* or asylum or refugee* or undocumented or foreign born or (born N overseas) or (displaced and (people or person?))) or AB(immigrant* or migrant* or asylum or refugee* or undocumented or foreign born or (born N overseas) or (displaced and (people or person?))) or (MH "Transients and Migrants") or (MH "Emigration and Immigration") or (MH "Refugees") or (MH "Immigrants+"))
S16	S14 AND S15
S17	S14 AND S15
S18	S14 AND S15
S19	S18 NOT S10

Supplementary Material III. Evidence tables

Study details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Note by review team
Year: 2010 **Authors:** Amy Bender, Gavin Andrews, Elizabeth Peter **Citation:** Bender, A., et al. (2010). "Displacement and tuberculosis: recognition in nursing care." Health & Place 16(6): 1069-1076.[1] **Quality Score:** -	**What was/were the research questions:** How does the experience of client displacement shape the relational work of TB nurses? **What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):** "Interpretive phenomenology" (Benner, 1994; Benner et al., 1996) "*Seeking understanding through this methodology means seeing the phenomenon not as something external and objective, but as something in which we actively participate (Benner, 1994). Thus TB*	**What population were the sample recruited from:** Not clearly reported: "*The study setting was Toronto, Canada; a large multicultural city with a large immigrant population. The participants included nine female nurses and 24 of their clients. In terms of nursing specialties, there was representation from the Case Management, Directly Observed Therapy (DOT), and Homeless Teams, with the majority being DOT nurse.***"** **How were they recruited:** NR	**Brief description of method and process of analysis**: A focused analysis on displacement was done. 1. From observations of the usual visits between nurses and clients; across an average of five visits. Observation notes were taken; reflective notes were made afterwards. 2. Additional data from individual interviews with all nurses and 7 of 24 clients; audio-recorded and transcribed. 1 & 2 were combined in the focused analysis; all data concerning immigration, contagiousness and isolation were selected for reanalysis. "Thematic analysis" (Brenner 1994) was used to guide the analysis. **Key themes (with illustrative quotes if available) relevant to this review**: **<u>Clients</u>** <u>*Diminishing the social displacement of immigration*</u> Coping with prejudice and discrimination was evidenced in several client stories in relation to race, ethnicity, language and being identified as an immigrant, which all seemed to be negatively reinforced social markers of being from a different place. <u>*Connecting here with there*</u> Conversations with nurses served for many clients a way to learn about Canada; often providing information well beyond their clinical role.	**Limitations identified by author:** - The data analysis (thematic analysis) had challenges: "*Thus the challenge of this process was not to jump to theoretical conclusions too quickly."* **Limitations identified by review team:** - No description of study group or health care context - Not mentioned when research has been done Time has a big influence on perceptions and might change overtime - No reflection of researchers and possible bias mentioned during interviews. Position of researcher unclear

	care was approached, not according to any theoretical ideal or professional standard, but as a phenomenon lived out daily by nurses and clients." **How were the data collected:** 1. From observations of the usual visits between nurses and clients; across an average of five visits. Observation notes were taken; reflective notes were made afterwards. 2. Additional data from individual interviews with all nurses and 7/24 clients; audio-recorded and transcribed. **<u>What methods</u>** **By whom:** NR	**How many participants were recruited:** 9 nurses, 24 of their clients **Were there specific exclusion criteria:** NR **Were there specific inclusion criteria:** NR	Most clients were dealing with feelings of 'being alone', re-placing themselves, being separated from family. Acknowledging the difficulties and different feelings was emphasized to being very important in the nurse relationship. *"Because, now, if somebody has never even asked, to ask about 'how is your family back home? Have you communicated to them these days?', then it means you are not concerned. What your only concern is, am I taking your medication… But [Leslie] is now a lady [who] really shows you even more than the nurses to be interested.., 'How are they getting on? Do you have any worrying issue as far as you family is concerned?" (Akello, interview)* <u>*Minimizing the displacement of contagiousness*</u> Masking and isolation are described as measures with big impact on people's lives; some clients reported losing friendships, employment, or were unable to look for work. Masking were described as identifiers of disease, barriers between people: *"You know, taking the pills you still have to wear the mask I had gone to the hospital and I had to wear it and I was panicking, like I would scare myself if that was me. I understand the feeling around it that so many people have (Afua, interview,p.4)."* For some participants it was important to distinguish Canada from the home country as the place where she 'got sick': *Aliya says that she wants me to clearly understand that she didn't get sick in [Asia]; that she only got sick when she came to Canada. She explains that she wants this to be clear because she has felt there is an automatic*	- No ethics permission described **Evidence gaps and/or recommendations for future research:** The study aims to demonstrate how place-sensitivity and qualitative research can be applied equally to health/illness and the practice of formal health care, for they are highly related domains. **Source of funding:** NR.

	What setting(s): Toronto, Canada. Data collection in variety of settings: homes, nurses' cars, street, other public settings including a motel room. **When:** NR		*assumption that because she is an immigrant she must have caught the bug in her home country,''that TB is not in Canada, but it is in Canada"… [the nurse] returns and comments, "remember what I told you about how you can carry the bug for a long time without being sick?'' Aliya says she remembers, but turns back to me and again insists that she got sick in Canada (Linda and Aliya, observation notes).* **<u>Nurses</u>** <u>*Diminishing the social displacement of immigration*</u> Nurses expressed an acute awareness whilst visiting their clients of the privileges they enjoy in their lives afforded to them largely through their place of birth. *"a number of clients have asked where I come from and what my background is. I always feel they're not going to like the colour of my skin, they're not going to like the fact that I'm not from another country. I haven't had adversities perhaps like they have had in their life so I'm always worried that my lack of colour (laughs) and my lack of other languages will cause me not to be accepted by them. But in terms of me accepting my clients, I am open and [have] a big desire to find out about everybody (Nurse L, Interview).* <u>*Connecting here with there*</u> Nurses acknowledged being important in the process of adapting to life in Canada; their relationships with immigrant clients were infused with particular attention to displacement. *"It's usually like that unfortunately, you don't ever find yourself saying ;oh it's so eeeasy and oh easy peas', no, it was very difficult, they're leaving their families back*	

			home.. And it's been an extremely eye-opening experience that way" (Nurse P, interview). This asked for particular kinds of support, e.g. informal therapy roles, listening to the clients' stories, worries, or loved ones back home. <u>*Minimizing the displacement of contagiousness*</u> Effects of masking and isolation on psychological and emotional well-being (low-mood, depression, loneliness) were often noted by nurses. Nurses tried to actively minimize displacing feelings: *"I would always attempt to sit where ever she sat down first, like, I would never sit away from her, y'know?... I'm always like that with my patients, especially regardsless if they're infectious or not. If I'm going in, I'm masking, they're already aliented and the stigma attached, 'ooh you're dirty and nobody wants to touch you.' I try not to do that with my body language when I meet them (Paulette, interview)."* Clients' expressions of fear and stigma (due to masking, isolation) were minimized by nurses' attention to proximity and positioning during visits.	

Study details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Note by review team
Year: 2010 **Authors:** Coreil, J. Mayard, G. Simpson, K. M. Lauzardo, M. Zhu, Y. Weiss, M. **Citation:** Coreil, J., et al. (2010). "Structural forces and the production of TB-related stigma among Haitians in two contexts." Social Science & Medicine 71(8): 1409-1417.[2] **Quality Score: +**	**What was/were the research questions:** To identify the components of stigma perceived as important within non-affected Haitian community samples in two study populations in Haiti and Florida; and second, to understand the contextual influences on these stigma components across sites. **What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):** Cultural epidemiology **How were the data collected:**	**What population were the sample recruited from:** Haitian origin in Broward County and in Palm Beach County **How were they recruited:** Organization-based quota sampling (Bernard, 2006) in churches, schools, businesses, civic/cultural organizations and social service agencies. Health care providers and TB patients were recruited from tuberculosis clinics (health department, refugee and private clinics).	**Brief description of method and process of analysis**: Field notes from participant observation, transcripts of interviews and focus group discussions, and demographic data were entered into the database. Finally, documents collected through field research and media monitoring were indexed and catalogued. In-depth content analysis of ethnographic data was undertaken to identify thematic priorities of importance for the study populations. **Key themes (with illustrative quotes if available) relevant to this review**: Phase 2 of the study is not represented in this review since it contains only quantitative data. Only the results for patients in Florida are presented. **<u>Narrative accounts of tuberculosis-related stigma</u>** Themes of shame, social isolation, and discrimination were invoked when discussing the impact of a TB diagnosis. Consequences such as being avoided by others, taking efforts to conceal the condition, effects on family relationships, and repercussions experienced by others. The theme that many people assume that someone who has TB is also HIV-infected was recurrent. *"I find that within the Haitian community. when someone has TB, you will find that it is because they have been diagnosed with HIV or AIDS, and therefore it is part of the whole process. I am finding most of the times that they are both related to each other."* (Interview with	**Limitations identified by author:** NR **Limitations identified by review team:** - no reflection or limitation mentioned by authors - Influence of stigma reinforcement by this research on recruitment and answers of respondents: Even conducting the research study itself may have contributed to reinforcing images of Haitians as **"**unhealthy,**"** associated with **"**stigma**"** and a **"**contagious**"** threat to the community. Sending out teams of interviewers into the Haitian community of South Florida to ask

	What methods: Qualitative data collection techniques included participant observation at clinics (20h each) and 3 health fairs, in-depth interviews (N = 81 in Florida), focus groups (N=12), and media monitoring (local radio, television, newspapers). **By whom:** NR **What setting(s):** Broward County and Palm Beach County. **When:** Between 2004 and 2007	**How many participants were recruited:** Only participants in Florida are presented. N = 81 Community members: 24 Providers: 24 Patients: 33 **Were there specific exclusion criteria:** NR **Were there specific inclusion criteria:** **NR**	community resident, Florida) The threat of court-ordered institutionalization in South Florida's tuberculosis hospital (A.G. Holley in Lantana, Florida) figured significantly. Respondents compared being sent to A.G. Holley to being put in jail for a crime. The risk of loss of confidentiality and privacy related to help-seeking for TB were voiced in interviews among all groups. The organization of TB services may expose patients to the risk of having their conditions revealed to others. In Broward and Palm Beach counties TB clinics are separate and located in the same building as HIV and sexually transmitted disease services, thus exposing patients to identification with other stigmatized diseases. Furthermore, being visited by outreach workers for Directly Observed Therapy (DOT) is viewed negatively because it reveals one's condition to neighbours. Perceived TB stigma was related to both economic and political issues; it was related to poverty, but had a distinct association with Haitians being a socially marginalized and disadvantaged minority group. Themes of discrimination, particularly in relation to immigration policy, surfaced in stigma narratives. *"The media portray us as last class, bad people that we have nothing to offer, because this is all they can reflect to the community, which is false because they don't get to know us. The themes that are emphasized are that we carry all kinds of diseases and we come here to take away people's jobs."* (Interview with community resident, Florida) *"When they say Haitian, they put everything on us. If you*	people about tuberculosis had the unfortunate effect of reinforcing the stereotype of Haitians as purveyors of infectious disease. **Evidence gaps and/or recommendations for future research:** - Future studies might explore further the intersection of social identity and stigma processes through comparative research designs - Better understanding of the institutions that influence the social production of stigma, including the media, public health services, workplaces, immigration regulations and related government programs, is necessary to inform culturally competent services.

			are Haitian you will feel that pressure. Everybody targets you e for no reason e Why? Health issues, immigration, everything, social background, everything because there were some things bad for Haitians." (Interview with Haitian social worker, Florida) "Haitians are victims of double prejudice; first they are black and then they are also Haitian so that has a double negative impact on them. " (Interview with TB patient, Florida) Social attitudes toward Haitians included stereotypes of Haitians having brought HIV to the U.S., being sources of contagion for TB and other infectious diseases, and being unfairly targeted for TB screening "just because we're Haitian." *"The stigma of being responsible of spreading HIV in the U.S. has marked Haitians with a 'stamp,' and those who have TB think that if they state it openly they will be given the responsibility of bringing TB in the U.S as well."* (Focus group with community residents, Florida) *"You know with the stigma that we have, what we were saying about the HIV and everything, and on top of that the color of our skin. In this country it is not very much respected. I think they're treated like a second-class citizen."* (Interview with Haitian physician, Florida) *"You must come [to the TB clinic]. Otherwise, you will have problems with immigration if your documents are not right."* (Interview with TB patient, Florida) <u>Summary</u> The ethnographic findings highlighted commonalities between Haiti and the U.S. with regard to the association of TB with shame, social isolation, discrimination,	**Source of funding:** No. 1-R01- TW06320 from the NIH Fogarty International Center (2003e2008), Hôpital Ste. Croix, Haiti and Broward and Palm Beach County Health Departments and EducaVision, Florida.

			concealment and HIV co- infection. However, in the U.S. the social contextual influences on perceived stigma were more closely associated with the political aspects of Haitians being wrongly portrayed as sources of contagion, being the target of racism, and being unfairly treated through immigration policy.	

Study details	**Research parameters**	**Population and sample selection**	**Outcomes and methods of analysis** **Results**	**Note by review team**
Year: 2011 **Authors:** Dejana S Vukovic and Ljudmila M Nagorni-Obradovic **Citation:** Vukovic, D. S. and L. M. Nagorni-Obradovic (2011). "Knowledge and awareness of tuberculosis among Roma population in Belgrade: a qualitative study." BMC Infectious Diseases 11: 284[3] **Quality Score: +**	**What was/were the research questions:** Exploring the knowledge and beliefs about TB transmission, symptoms and treatment, opinions on appropriate preventive measures, and attitudes towards people with TB among the Roma population **What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):**	**What population were the sample recruited from:** The Roma population in Belgrade **How were they recruited:** Three separate focus groups were to be held, each with 6-8 participants; selected according to living conditions: 1. Living in the worst conditions (slums) 2. Living conditions similar to the general population in Belgrade 3. Living conditions	**Brief description of method and process of analysis**: All sessions were recorded and transcribed verbatim. Data were analyzed and categorized into the objective or topics determined in advance. Interviews were read to become familiar with the text. Then key issues were identified in the text related to the topics. In the third step, key issues were sorted according to the five central topics. Finally, the session data were arranged into new categories within each topic. All three authors discussed the categorization to achieve consensus about the content and the categories. **Key themes (with illustrative quotes if available) relevant to this review**: All participants knew that TB is a pulmonary disease that can be contagious. The participants cited laboratory blood analysis as the most appropriate method to establish if someone is contagious. **<u>Knowledge of modes of transmission</u>** Saliva and mouth-to-mouth contact were the most frequently mentioned modes of transmission	**Limitations identified by author:** NR **Limitations identified by review team:** - Roma populations with different living standards were interviewed, but the text does not mention the different outcomes, or differences in outcomes. This could be an interesting point to be able to target the respective populations better - No information on TB services directly - Only one data collection method

	NR **How were the data collected:** **What methods:** Focus-group discussions addressing 5 main topics **By whom:** A trained psychologist with experience in moderating focus groups **What setting(s):** NR **When:** NR	between 1 and 2 Researchers approached people that satisfied predetermined criteria (living in selected Roma community, aged 19-55) and provided them with information about the aims of the research and asked them if they were interested to contact the researchers at certain time and place in the community. At the initial contact with the researcher further information was given about likely dates and venues, transport arrangements, and that refreshments were to be provided. **How many participants were recruited:**	Participants thought that TB could be transmitted by blood and among family members with the same blood type. Some of them even thought that TB could be hereditary. *"If my mother has TB, I am more likely to get the disease than my wife. My mother and I have the same blood type."* *"There was a man with TB. After a while his sister got TB as well. Maybe they got it from each other because they have the same blood type. As I heard it could be obtained through blood, it is hereditary. "* Some participants thought TB could be transmitted through handshaking, others did not see that as a possible mode of transmission. *"It is possible to get TB through hand shakes. If I cough out bacteria in my hand, because I put my hand on the mouth when I cough, TB bacteria stay on my hand, and if I hand shake with you, bacteria pass on your hand, you touch your mouth and that 's how it is transmitted. "* Rats were also seen as possible vectors for some participants. *"There are a lot of rats, big as cats, they bite. It is possible that rats transmit TB, they put there noses everywhere, in garbage and then pass over our dishes because we do not have closets in which to hide them."* <u>Factors contributing to TB occurrence</u> Participants mentioned poor living conditions, low quality and lack of food, and stress as factors	(focus group discussions) > no triangulation of study findings - It is not clear what the following statement (methods section) is based on: "The focus-group method was considered to be appropriate for exploring the knowledge and beliefs about TB transmission, symptoms and treatment, opinions on appropriate preventive measures, and attitudes towards people with TB among the Roma population." **Evidence gaps and/or recommendations for future research:** - Outreach activities should be provided in Roma settlements - Knowledge should be improved –health care professionals

		24 Roma people aged 19-55 years **Were there specific exclusion criteria:** NR **Were there specific inclusion criteria:** - Living in selected Roma communities - Aged 19 to 55 years	contributing to TB. *"TB is acquired from bad food, nervousness and worries.* *Yes it is; when you worry too much then disease appears. "* The participants thought that, if untreated, the common cold and pneumonia could lead to TB. Furthermore, the participants thought that, if untreated, TB could develop into lung cancer. <u>Knowledge about symptoms</u> Participants quoted: chest pain, cough, haemoptysis, loss of appetite, loss of weight, weakness and sweating as symptoms of TB. Haemopthysis was thought to be indicative for TB. *"It is hard for me to say if someone has TB. If you have chest pain, it could be that you have some virus, flu, asthma or pneumonia, it is not always TB. But you must take care. It is TB if you see someone coughing out blood or has bad pain in the lungs."* <u>Knowledge about treatment</u> Roma people do not visit a doctor until the symptoms of the disease are so severe that they are unable to work *"We Roma do not go to see a doctor while we can work; only when we lay in bed do we ask for doctor's help"* Regarding effectiveness of treatment, views varied. Some thought that TB is a very serious, lethal disease; others thought that it is an unpleasant, long-lasting disease but that it is curable owing to medical advances.	should investigate knowledge & attitudes about TB and provide accurate information - This should be done by the healthcare professionals as they are considered trustworthy - Attention should be paid to folk medicine as this can cause delay **Source of funding:** The study is a part of the Ministry of Health of the Republic of Serbia project "Control of tuberculosis in Serbia", which is supported by the United Nations Global Fund to Fight HIV/AIDS, TB and Malaria. The study was supported by the Ministry of Science Republic of Serbia under the project No 175042.

			Others thought it is not totally curable; and treatment can last for 10 years in some cases. *"TB is dangerous but curable. You take antibiotics, doctor tells you what to do, and than you can be cured. It is easier nowadays than it was before. "* *"TB is a really dangerous disease. It is lethal if not treated. Even when treated, it lasts for a long time. My cousin stayed in hospital for 15 months. He was young, only eighteen. He probably didn't go to doctor in time. He barely survived."* Effective treatment was thought to include resting, taking prescribed treatment, inhaling fresh air and eating "strong" food such as bacon and pork. *"Care for TB patient consists of resting, it is necessary take drugs prescribed by doctor. We gave her eggs, honey, bacon and sausages; pork is obligatory. She was sent to the mountains by doctors, where the air is sharp and clean, which is needed for TB treatment."* Not all participants knew the medicines were free of charge. <u>Opinions about most appropriate measures for TB prevention</u> Improvements in hygiene, living conditions, including electricity, sanitation and water are considered as key factors for TB prevention among participants. Participants emphasized that they find it hard to protect themselves from TB, as living conditions are poor. They emphasized the importance of appropriate diet and quality food.	

			"You should have strong food for lungs to function." <u>Source of information about TB</u> The main sources of information are relatives and friends and, to a lesser extent, television. They did not recall seeing anything about TB in the general media. Participants expressed a high level of trust in doctors and believe most of what doctors tell them personally. They would appreciate direct interaction with a doctor who could come and talk to them about preventing TB and, if they are infected, provide advice on how they could protect others from TB. *"I would mostly believe my own doctor, he is treating me. How can I know what they are talking about on TV, it could be only advertising. "* <u>Attitudes towards patients with TB</u> Participants would visit a close relative with TB even if they knew the patient was contagious. Participants emphasize that the Roma people are very close and they often help each other, maybe more than non-Roma populations. *"We are all Gypsies, we protect each other. We wouldn't leave without helping any of us. We visit one when he is sick. It is a shame if another goes to visit and I don t. You are embarrassed. If someone were sick, even with TB, I would come with bottle of juice. We are always one for another, (for each other) solider."*	

Study details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Note by review team
Year: 2012 **Authors:** Kate Gerrish, Andrew Naisby & Mubarak Ismail **Citation:** Gerrish, K., et al. (2012). "The meaning and consequences of tuberculosis among Somali people in the United Kingdom." Journal of Advanced Nursing 68(12): 2654-2663.[4] **Quality Score:** ++	**What was/were the research questions:** To ascertain the socio-cultural meaning and consequences of TB among people of Somali origin living in the UK. **What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):** Data collection; Focused ethnographic approach **Data analysis:** 'Framework' approach. **How were the data collected:** **What methods:** Data collection	**What population were the sample recruited from:** The Somali community in Sheffield, a city with one of the largest (estimated 10,000) and longest established Somali populations in the UK. The population comprised people with varied histories of migration including economic migrants from the 1930s, refugees from the civil war in the 1990s, recent migrants from Somalia through family reunions and European Somalis who migrated mainly from the Netherlands and Scandinavia.	**Brief description of method and process of analysis**: Focus groups and individual interviews were audio recorded with participants' permission and subsequently transcribed. Interviews/focus groups conducted in Somali were translated into English prior to analysis. Data analysis drew on the principles of the 'Framework' approach to qualitative analysis (Ritchie et al. 2003) which involved five stages: • Members of the research team familiarized themselves with the data by reading the transcripts several times. • A thematic framework for coding the data was developed based on the interview agendas and issues arising from initial scrutiny of the transcripts. • Individual transcripts were coded by applying the thematic framework. • The coded data were subsequently organized into major themes. • Data from each phase were analysed separately and then brought together to form a composite analysis. The relationships between different themes were mapped by analyzing the data set as a whole. Initial analysis undertaken by one researcher was checked by a second researcher to ensure consistency in coding and to safeguard against selectivity in the use of data. A reflexive approach was adopted throughout whereby researchers examined their role in the research process and the assumptions that influenced their interpretation of data.	**Limitations identified by author:** - The study was undertaken in one location; however, the extensive social networks that participants reported with Somalis living in the UK and Scandinavia suggest that the findings may be transferable - Sampling strategy relied on social networks and snowball sampling; views may not be representable for wider Somali community - The experiences of TB patients who had been included as participants in the study may not be representative of Somali TB patients more broadly.

	consisted of 4 phases: - <u>In-depth interviews</u> with community leaders from Somali organizations focused on developing an understanding of the Somali community, to include history of migration, family/social networks, health beliefs and behaviours associated with TB. (In quotes as CL) • <u>Semi-structured interviews</u> with members of the wider Somali community explored personal knowledge and attitudes towards TB and related health-seeking behaviours and participants' perspectives of community cultural norms. (In quotes as	**How were they recruited:** - Purposive sampling was used, using the Somali researchers' contacts and snowball sampling (for community leaders / community members) - Patients were recruited by a TB specialist nurse who was involved in their care **How many participants were recruited:** 104 - Ten community leaders from Somali organizations (CL) - Eighty members of the wider Somali community (SCM or FG) - Fourteen patients who were receiving or had recently completed treatment for TB (P)	**Key themes (with illustrative quotes if available) relevant to this review**: <u>Knowledge and beliefs about TB</u> Knowledge varied; many beliefs: Community leaders generally demonstrated a biomedical understanding of causes, transmission, symptoms, treatment and prognosis. The wider Somali population held various beliefs about the nature of TB and how infection spread. They attributed illness including TB to the will of Allah, but did not perceive contracting TB as divine retribution for some demeanour. Some saw it as an airborne disease whereby people became infected by 'breathing in the germ' and once infected, they could pass it on to others. Many thought it was an inherited disease, this was also embedded in patients. *There is inherited TB, it will stay with you forever, your grandfather had it, then your father, then you. (SCM 3)* Some saw a causal link between TB and other diseases: *It starts with flu and then gets worse and becomes a chest infection. If the infection is not treated, it will change to TB. (SCM 9)* Others saw a link with poor socio-economic circumstances or lifestyle: *People get TB because of hunger, living rough, not being healthy, from the environment. Somali men chew khat, even if they are hungry, they don't eat, they don't sleep for 2–3 days and that combined causes TB. (CL 8)*	**Limitations identified by review team:** None **Evidence gaps and/or recommendations for future research:** -Additional research is needed on interventions targeted at empowering people affected by TB to contribute to the development and implementation of strategies to reduce stigma - Additional research is required to develop an evidence-base supporting strategies that nurses might employ **Source of funding:** The research was funded by the Sheffield Health and Social Care Research Consortium England. Grant number ZB63.

	SCM) • Semi-structured interviews with TB patients sought to capture participants' experiences of TB, including strategies adopted to 'manage' their condition, the roles of family and friends and factors influencing their response to the disease. (In quotes as P) • Focus group discussions, based on vignettes developed from earlier interviews enabled a more detailed discussion of health beliefs associated with TB. Focus groups were undertaken with four groups of men and four groups of women. Focus groups varied in size from four to nine participants. Two vignettes that	**Were there specific exclusion criteria:** NR (no informed consent given) **Were there specific inclusion criteria:** NR	Sharing utensils was widespread seen as a cause of infection. Psychosocial factors were also provided as an explanation: *I was a business lady, buying and selling in a village (in Somaliland) before the civil war. When the war started we lost everything. All our assets had been looted. I think that the worry and stress caused my TB. (P5)* Many identified clinical symptoms of pulmonary TB: persistent cough, weight loss, fever and haemoptysis. There was little awareness of non-pulmonary TB. Most knew TB could be treated with a lengthy course of antibiotic therapy and people generally made a good recovery if they completed treatment. There was a prevalent belief that the disease may not be fully cured even after treatment. This was linked to the belief that TB was hereditary and therefore could not be eradicated. *I've taken tablets, it was a long time, 6 months. They tell me I'm cured, but I think it may come back. It's in my family. (P2)* There was little understanding among the general Somali population of the length of time a patient who commenced treatment remained infectious. *Somali people think that anyone who has TB is infectious until he dies. (SCM19)* **Attitudes towards TB**	

	provided a scenario relating to TB in the Somali community were used to prompt discussion relating to community norms and socio-cultural constructions of TB. (In quotes as FG) **By whom:** A Somali researcher and four Somali community researchers were appointed to assist with community interviews. All Somali researchers were fluent in Somali and English and received training in ethnographic data collection and analysis and in TB. **What setting(s):** NR **When:** 2008–2009		Before treatment was available in Somalia, TB brought 'shame on the family', and social isolation of the person, or the whole family, concerned. Personal attitudes differed often from their perceptions of the beliefs and attitudes by the wider community. It was viewed to be stigmatized in the community. *Somali people have stigma (about TB), they feel disgrace to admit that they have TB. They feel ashamed if they have it. (SCM18)* They were likely to face discrimination; manifested by social isolation: *Anyone who has TB, as soon he tells someone, that person will keep a distance because they think they'll get it from him. People will start saying 'he has TB, stay away from him'. They will isolate him. (FG8)* Friends may be reluctant to resume social contacts, due to the belief that TB cannot be cured. *Even when he's had treatment for TB, when he coughs they think he has TB again. They're fearful, they'll keep away. (FG1)* Concerns existed on the impact of TB on employment and marriage prospects, as it was considered hereditary. *TB affects different aspect of your life, even your marriage. You won't be able to marry a woman because you have TB in your family. (FG5)* People also expressed fear of discrimination, leading to	

			isolation (avoiding the distress) or concealment of disease; which was justified by several participants: *People are only human. When they feel they are going to be treated like this, they will hide the disease. If they experience stigma, it might affect them mentally. If you're isolated and everyone keeps a distance from you because you have TB, then you get depressed. (CL8)* There was a big consistency in participants' accounts of the attitudes of the community. Some had other personal views: *TB is seen as taboo illness, but it shouldn't be. It's not a bad disease. It can be cured with treatment. We shouldn't be afraid of it. (SCM18)* Participants who were TB patients indicated that their experiences were less stigmatizing: *Truly speaking, my family and friends are very understanding so they didn't panic or anything like that. (P5)* It was however rare to share the diagnosis outside of immediate family and close friends because of fears of perceived stigma and the possible isolation. One participant encountered a hostile reaction, and others cooling of relations and distancing: *When I said I had TB he was shocked, he stopped eating with us. (P14)* But hostility was often tempered when friends realized that the patient was acting responsibly in taking medication.	

			Few had ben very open about their illness, motivated by the importance of contact tracing. Some discovered individuals that had TB in the past. The variation between individual attitudes and experiences and community norms was attributed to variability in people's understanding of biomedical explanations of the disease. Once members of the community at large became more aware of the transmission, treatment and prognosis of TB, then it was anticipated that the associated stigma would diminish further. Indeed, several community leaders commented that in their view attitudes were changing: *People's attitudes are starting to change. TB is no longer seen with the same stigma. As people become more educated about TB, they aren't so afraid. They'll talk more about it. We're moving in the right direction, but it's a slow process. (CL6)*	

Study details	**Research parameters**	**Population and sample selection**	**Outcomes and methods of analysis** **Results**	**Note by review team**
Year: 2012 **Authors:** Sagbakken, M. Bjune, G. A. Frich, J. C. **Citation:** Sagbakken, M., et al. (2012). "Humiliation	**What was/were the research questions:** To explore patients' and health professionals' views and experiences with DOT in Norway.	**What population were the sample recruited from:** HC professionals: a purposeful sample of doctors, TB coordinators, community nurses and nurses from home-based nursing services.	**Brief description of method and process of analysis**: Verbatim transcription by first author. MS and the third author (JCF) read half of the transcripts independently and developed a coding frame for the analysis. MS coded all the transcripts, and all authors subsequently contributed in the analysis. Data regarding views and experiences related to the exercise of DOT were identified among patients and health workers and were used for systematic text condensation. The analysis followed the following steps:	**Limitations identified by author:**

or care? A qualitative study of patients' and health professionals' experiences with tuberculosis treatment in Norway." Scandinavian Journal of Caring Sciences 26(2): 313-323.[5] **Quality Score: ++**	**What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):** Systematic condensation (inspired by Giorgi's phenomenological analysis) **How were the data collected:** **What methods:** Face-to face, tape-recorded, semi-structured interviews. A semi-structured interview guide was developed on the basis of a literature review and findings in previous research. The interview guide for patients covered five major themes: (i) symptom understanding and acting; (ii) interaction with	Patients: patients from the immigrant populations Somalis and Ethiopians. **How were they recruited:** <u>HC professionals:</u> Written information was sent to hospitals in Oslo/Akershus and to various primary healthcare districts. The first author (MS) subsequently contacted doctors and nurses in relevant positions by phone. Some were recruited by snowball sampling. <u>Patients:</u> Potential participants were approached with written information about the study by a TB coordinator or a nurse. Participants contacted the researcher by	(i) reading all of the material to get an overall impression; (ii) identifying and coding units of meaning related to views and experiences concerning the exercise of DOT; (iii) condensing and summarizing the content of each of the coded groups; (iv) integrating the insights from the condensed meaning units into generalized descriptions that reflected significant factors. **Key themes (with illustrative quotes if available) relevant to this review**: **<u>Information and persuasion</u>** Both patients and health professionals reported that the legal aspect of TB management was emphasized when health professionals informed patients about DOT at the mandatory planning meeting when treatment was started. *Patients* Patients reported that it was difficult for them to question the way treatment was organized; that there was no other way of gaining access to medication. Patients' immigrant status was described as an additional factor making people reluctant to question the treatment. *'People feel that this is not their country and then it is hard to protest. This [DOT] only applies for people coming from the third world'*. Male patient Some participants said that if they tried to question DOT, they had been told that the police would be engaged if they did not cooperate. *I asked [about self-administrating] and the nurse said, 'No, you are not allowed to.' So I was annoyed. 'I am*	- Patients may have had moral or psychological reasons for attributing frustrating experiences to health services - The sample of patients is not representative of all TB patients in Norway - Some of the patients had limited language skills in Norwegian or English, which might have caused misunderstandings during interviews **Limitations identified by review team:** - Only interviews; lack of triangulation might lead to possible bias. - Description of health care system for TB is missing, context not described

	health professionals (iii) information and understanding of the disease; (iv) social support factors; and (v) views and experiences in the context of DOT. The interview guide for health workers covered three broad themes: (i) experiences and views concerning TB-related work at a system level; (ii) experiences and views concerning TB-related work at the individual level (iii) reflections concerning ethical aspects of DOT. **By whom:** The first author. **What setting(s):** <u>HC professionals:</u> The locality where the participant worked or in a room at University of Oslo.	phone, or the researcher contacted patients if they had given their consent. **How many participants were recruited:** <u>HC professionals:</u> - 8 doctors (specialists in lung or infectious diseases) - 5 TB coordinators - 2 community nurses - 5 nurses from home-based nursing services <u>Patients</u> 22 participants: - 15 from Somalia - 7 from Ethiopia **Were there specific exclusion criteria:** NR **Were there specific inclusion criteria:**	*not a child,' I said to her. 'I am an adult. I take the medication for my own sake and not for you.' [...] So she said to me, 'If you don't come and take the tablets, we will report to the doctor, and the doctor will report to the police and the police will force you to take it.'* They did not understand why health professionals, without prior knowledge, suspected them of not wanting to comply with the prescribed treatment. *HC professionals* HC professionals agreed that the planning meeting was executed in ways that could make patients feel disempowered. Often, patients failed to comprehend the information, but abstained from asking questions. The use of persuasion based on subtle threats was often used as means to facilitate patients' acceptance of DOT: *'We do not use force to make patients receive treatment through DOT, but I believe the doctor threatens a little...'.* TB coordinator Health personnel tended to equate potential defaulters with patients expressing scepticism to the way the treatment was organized (DOT). It was common to describe these patients as 'rebels' or 'those being difficult'. **<u>Experiences of care and humiliation</u>** *Patients* Some expressed ambivalence towards DOT: one group conveying humiliating experiences and one group who emphasized that they felt well cared for. All the ten male patients who described DOT implied feelings of humiliation and discrimination. DOT was perceived as a	**Evidence gaps and/or recommendations for future research:** - Create structures and decision-making processes that allow informed patients to consent to treatment and to express their views and negotiate their needs - All potential DOT providers, independent of formal status, should receive adequate training **Source of funding:** Extra funds from the Norwegian Foundation for Health and Rehabilitation (grant number 2005/2/0249) and the Norwegian Heart and Lung Association.

	<u>Patients:</u> Locations chosen by the patient, such as in the patients' home. **When:** Between June 2007 and June 2008	NR	rigid approach where everyone was treated the same based on the assumption that TB patients in general were unreliable. *You feel... you feel a bit strange... first of all because people... they are different. And I felt that I... I am a grown-up and you take responsibility, right? At home, with children and family and everything... But... you feel like someone who is a suspect.* Male patient. Many expressed anger and frustration; argued that DOT should be used only in cases in which patients needed help managing the treatment. Seven of the 12 women described DOT as an expression of care, even if they provided bad examples, such as unpredictability and lack of continuity. They saw it as genuine care for the individual. The daily visits were welcomed in a situation in which many felt isolated. Few reported conflicting needs, like specific hours that they had to attend school or work. The other group of five women described DOT in the same way as men. All had conflicting needs; they experienced to a much larger extent negative impacts of the daily administration of DOT. *HC professionals* A few health professionals emphasized the importance of assisting patients with needs beyond the administration of tablets and described such efforts as means to facilitate the treatment process. *Those who are in a process of seeking asylum have a lot of things going on in their minds that are of more importance to them than tuberculosis. So, I have been accompanying patients to social offices, to the*	

			Norwegian Directorate of Immigration, ... following patients to the dentist [...], I've helped fix a water leakage ... But it creates a bond with the patients. [...] And those who are struggling with other issues, but who receive a bit closer follow-up also in areas beyond tuberculosis, are more easily taken through the treatment. Community nurse None of the five nurses working in home-based nursing services seemed to see the importance of this type of support and explained that even in cases where patients asked questions about the disease and the medication they would refer to the TB coordinator or hospital doctor. **<u>Discontinuity and inconsistency</u>** *Patients* Discontinuity among health workers was a recurrent issue; lack of continuity made it difficult to establish relationships built on trust. Participants regularly met personnel who limited the interaction to an absolute minimum. *Some just arrive, already having the tablets in their hand when arriving, looking at you when you swallow, but not talking to you. [...] I feel like an object, reduced to an object. Those that come, they are like machines.* Male patient There were many examples of personnel not practicing consistently: no action was taken until a patient had failed to come two days in a row, medication was handed to them in the doorway, health workers did not wait to observe the medication being taken; some did not	

			show up at all. Some experienced that guests or neighbours had been offered their medication: *Every day there is a new person [...] They keep ringing on the neighbour's door... they open and then, 'Here you are, your tablets, goodbye.' [The neighbour says] 'I don't expect any tablets' [...] Ah; it's... such a shame.* *HC professionals* Nurses in home-based nursing services claimed that they were only expected to carry out the observation of medication intake. DOT executers were not always registered nurses, but nurse assistants or unskilled personnel in non-permanent positions with limited or no knowledge about TB, the medications or the rationale behind DOT. TB coordinators and hospital doctors were aware of problems caused by discontinuity; one doctor argued that the main source of treatment irregularities was poor routines within the existing health services: *My opinion, anyway, is that where it fails... it is not the patients, it is with the home-based services. It is the patients that call and tell me that the nurses did not show up.* **<u>Loss of autonomy and control</u>** *Patients* Not knowing who or when someone would come to observe the daily medication being taken was described as stressful and humiliating by participants. *They call and say 'where are you living, we can't find you?' They move around on the block, going to the wrong floors, looking at all the doors... I understand and accept DOT from a community perspective, but I do not*	

			accept that all these other people, not even knowing why they are there, are better suited than me to give me my medicine. Male participant Participants, in particular those who were well educated, worried about whether unskilled personnel had the capacity to comprehend the context in which DOT was executed; many expected judgemental interpretations because of their immigrant status. Some participants described DOT as a 'prison' that forces you into a confined and subservient position. Many had problems with their job, because the nurses often came too late, so they were late for work: *I show them that I'm angry [...] but it is not certain that the same person will come tomorrow. So for them it does not matter if they are late today, because they know they won't be coming tomorrow, right? They might not meet me again.* Many patients moved between addresses, not having a permanent residence. Sometimes efforts were made to adjust services; others encountered interrogative questions and were yelled at because of frequent changes of address or because of delays caused by movement between different residences. *HC professionals* Most HC professionals were aware that DOT could cause major problems for patients, but even the nurses in charge of the daily administration seemed to accept DOT without questioning whether it was an acceptable solution for the patients. *She had a very demanding life, I think [...] She often*	

			worked double shifts, and then she slept in other places, and then she had to take a taxi back to her home so that we could see that she took her medication. (Nurse) DOT was referred to as a direct measure of discipline, a good opportunity to 'get up in the morning'. Nurses described those sacrificing the most as the 'dedicated' and 'good' patients, while those who for different reasons resisted by arguing were referred to as 'difficult', 'non-cooperative', or 'rebels'. **<u>Divergent views</u>** *HC professionals* Health professionals had differing views about the rationale behind DOT: an unalterable control measure - equal treatment for all; flexibility and individual adjustment as guiding principles; some doctors argued that social class should not determine which patients were to be treated through DOT. Some admitted that exceptions were made, in particular in cases in which patients gave the impression of having many 'personal resources'. *We present it [DOT] in a somewhat dishonest way I think... because it is not practiced the same for everyone... If there is greater resemblance between me and that person, if we have a common platform, then it is easier to give in.* TB coordinator One doctor suggested that lack of resistance was a consequence of the situation patients were in: *The thing is that many of these [patients] are subservient and they keep quiet. They do what the government says.*	

			They apply for asylum here in this country, right? They know they have to behave. That is what this is about. [...] We manage to implement this [DOT] because those who accept it are those at the bottom, at the bottom in any society. They are black and poor, insecure and without personal resources. Most health professionals were aware of the consequences the practice of DOT had for patients' daily life, few described the treatment as a system with ethical implications or dilemmas. When prompted, most health professionals agreed that the implementation of DOT was facilitated by the patients being members of groups without power in society.	

Study details	**Research parameters**	**Population and sample selection**	**Outcomes and methods of analysis** **Results**	**Note by review team**
Year: 2012, published online 2010 **Authors:** Mark L. Wieland, Jennifer A. Weis, Barbara P. Yawn, Susan M. Sullivan, Kendra L. Millington, Christina M. Smith, Susan Bertram, Julie A. Nigon, Irene G. Sia **Citation:**	**What was/were the research questions:** (1) What are the perceptions and misperceptions about TB among learners and staff at an adult education center? (2) How do relationships and social structures influence these perceptions of TB? (3) What are the	**What population were the sample recruited from:** Students and staff of HEC Rochester Public School District, Hawthorne Education Center (HEC), which provides education with an emphasis on literacy to Rochester adults. This contains of 2,500 learners, 60 staff members, and	**Brief description of method and process of analysis**: Following each session, facilitators debriefed with each other to reflect on key moments in the session. Focus groups sessions were digitally recorded, translated to English, and transcribed. Translations were conducted by a single native-language speaking focus group moderator, and translation integrity was verified by at least one other native-language speaking partner. Each focus groups team created a report with key quotes and themes for each of the questions. An analysis subcommittee of the TB work group was assembled (with community and academic partners); three members independently coded all focus group transcripts initially. Discrepancies were solved in meetings. Coding themes were organized in the context	**Limitations identified by author:** - Application of these descriptive data from a convenience sample of learners at an adult education center may limit applicability of the results in other settings - Sample is derived from a broad diversity of cultures, native languages, and ethnic groups - Some focus groups

Wieland, M. L., et al. (2012). "Perceptions of tuberculosis among immigrants and refugees at an adult education center: a community-based participatory research approach." Journal of Immigrant & Minority Health 14(1): 14-22.[6] **Quality Score: ++**	perceived barriers and benefits to health seeking behavior for TB? **What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):** Health Beliefs Model (HBM) **How were the data collected:** **What methods:** Separate focus groups with students and teachers. Structured focus groups questions were designed by the TB work group and focus groups moderators with edits by adult education specialists familiar with the culture and literacy levels at HEC. Questions were designed to	250 volunteers each year. Adult learners come predominantly from Sub-Saharan Africa (38%), Latin America (21%), Southeast Asia (17%), and Southeast Minnesota (20%). **How were they recruited:** 1. The purpose of the study was introduced to the learners in their classrooms. 2. Recruitment via sign-up sheets in the classrooms and through direct communication with teachers. 3. Word of mouth resulted in a ‘‘snowball’’ sampling within each of the major ethnic groups in the school. 4. HEC program manager finalized list which reflected	of the HBM: perceived susceptibility, severity, barriers, and benefits of TB and its treatment and prevention. These themes were then presented to the broader analysis sub-committee through three cycles of meetings and revisions. **Key themes (with illustrative quotes if available) relevant to this review**: **<u>1. Challenges facing TB control</u>** <u>Misconceptions about TB</u> There were many unsolicited misconceptions about TB; perceptions of transmission and prevention were often inaccurate. Frequent was the misperception that TB is not present in the U.S.: *‘‘I think of (TB as a problem) a long time ago, but not a problem in America anymore.’’* *‘‘… I don’t think Somalis here (in America) have it—maybe people in Africa.’’* Theories on transmission included touch, contaminated food or water, blood, sexual contact, and through smoking and drinking alcohol. Prevention was mostly thought to be through cleanliness, good nutrition, and air pollution control. <u>Feelings and perceptions</u> <u>Fear</u> Fear of the disease and associated repercussions were the most commonly stated feelings: mainly they feared dying from an incurable disease, spreading the disease to	were conducted in English, not the native language of most of the participants. This may compromise the interpretation of some responses - Interpretation of focus groups results are still based on the analysts’ understanding of cultural norms, which may distort the meaning of certain comments **Limitations identified by review team:** - Little distinction in text between cultural / ethnic groups (only Somalis are separately mentioned). - No distinction in text between ages groups, gender, education level **Evidence gaps and/or recommendations for future research:**

	elicit learners' perceptions of TB and perceived barriers to testing and treatment as defined by the Health Beliefs Model. **By whom:** Focus group moderators, with or without professional medical interpreters. **What setting(s):** At HEC in 'a casual setting'. **When:** October 2008 to January 2009	demographic of student body (to many volunteers) **How many participants were recruited:** - Six focus groups with a total of 54 participants were conducted with learners (22 from Somalia + Sudan, 11 from Asia (Vietnam, Cambodia, Laos, China, Pakistan), 12 from Ukraine / Russia / Turkey, 9 from Mexico / Colombia / Puerto Rico). - Four focus groups with 29 participants were conducted with staff (teachers, administrative assistants, interpreters, volunteers, and janitors). (6 from Somalia/Sudan, 4 Asian, 19 United States).	others, and the social isolation that comes from having TB. *''It's a killer disease''* *''TB is fearful thing. The possibility of going away from the family which take place in other countries. We need to put aside on these fears… So, I think there is fear factor level for several fronts; not just cost but the stigma or the shame or the unknown.''* <u>Secrecy and shame</u> The idea that TB is to be kept secret was brought up in all ten focus groups. Secrecy is thought to be a means to avoid the social isolation that may result from others knowing the diagnosis. The label of TB seems to carry a level of shame that is disproportionate to other diseases. *''In Somalis it (TB) is kept a secret or hidden from others.''* *''You have to understand—in our culture (Somali), TB is a very sensitive issue, and a lot of people do not like to talk about it. They do not want to tell people that they have it or they might have had it at one point in their life. They like to be quiet about it. You guys need to understand that first of all.''* *''… People don't like TB. They're not willing to come forth and share their ideas about TB because it's a very sensitive issue. It's hard for you guys to understand because it's something that Somali's don't really like to discuss.''* *''It (TB) was not talked about. If you get it (then you are)*	Recommendations for educational approaches to TB education: - Involve the adult learners in design and implementation of education programs - Address the heterogeneity of TB perceptions by providing multiple approaches to TB education - Link TB education to community resources for testing and treatment - Engage educational content according to perceived susceptibility, severity, barriers and benefits **Source of funding:** National Institutes of Health (NIH) through a Partners in Research grant, R03 AI082703, and by Grant Number 1 UL1 RR024150* from the National Center for Research Resources (NCRR), a

		Were there specific exclusion criteria: NR **Were there specific inclusion criteria:** NR (student or staff at HEC)	*quiet about it because of the fear that he (would be) told leave his family and if there was treatment available it was long track of taking the medication. They rather expose the disease … then go away from the family. You have understood the life expectancy is half in Cambodia than it (is) here. So, it's different perspective but those are things that came with culture that we don't think about.''* <u>Isolation</u> TB associated with social isolation was a theme that emerged from five of the ten focus groups. A diagnosis of TB would wrench people away from their social ties, both within and outside their family. This perception of isolation was cited as a barrier to seeking care. *''Usually, persons with symptoms of tuberculosis may avoid seeking health care, or use simple cough medicine and sometimes deny their illness to others, because of fear of isolation within the community.''* *''First of all, we are Muslims and our belief is that you're not supposed to run away or isolate someone in need. That's what people should understand. If somebody has TB, it's not like you're better than they. So running away or putting them down or ignoring them is what's making this whole issue worse. It's not helpful. So we have to just realize that just isolating someone is not going to cure anything.''* <u>God's punishment</u> Somali women expressed beliefs that TB is considered a punishment for past ill deeds. *''(TB is a) curse or punishment by God for dishonest*	component of the NIH, and the NIH Roadmap for Medical Research.

			conducts.'' **<u>Barriers to testing</u>** Questions regarding barriers to testing largely centered around latent TB screening, which will be discussed elsewhere. People are not generally aware that TB is a problem or that they should be tested. <u>Practical considerations</u> These included difficulties with transportation to testing center, testing centers only being open during work hours, testing takes too much time, and cost of testing. **<u>Barriers to treatment</u>** Access and costs were not large concerns. Cost of medications came up, but most participants were aware of the fact that these medications would be provided free of charge. The two most common barriers to medication compliance were perceived side effects and suspicion over generic medications. Somali participant: *''(treat with) Not generic medicine, good medicine… Generic's no good medicine.''* **<u>Establishing trust when talking about TB</u>** Personal experiences were shared. It was frequently stated that this topic would have been far more taboo in their native countries. *''At the beginning of this meeting (focus group), we were all hesitant. Nobody wanted to talk about TB or say anything. But when people understand the purpose behind this meeting, they will open up. I was able to tell*	

			that I had TB at one point in my life, and I got treated for it. She (pointing to another focus group participant) was able to tell us that she got treated.'' *''It's not as difficult to tell someone or influence someone to get tested. Back home it was difficult because when you tell somebody they may have TB they get offended right away. But in this country that's not the case, I mean you have to put your health first and get treatment… So, it's not as difficult as it was back home.''* **<u>Differences between HEC learners and staff</u>** Separate analysis of HEC learner and staff responses revealed generally consistent themes between the two groups. HEC staff members were far more concerned than the learners about the learners' ability to find transportation to testing centers or pay for the test. The 'negative feelings and perceptions' (about TB) category was disproportionately represented by the HEC learners.	

Study details	**Research parameters**	**Population and sample selection**	**Outcomes and methods of analysis** **Results**	**Note by review team**
Year: 2013 **Authors:** L. A. Croft, A. C. Hayward, A. Story **Citation:** Croft, L. A., et al. (2013). "Tuberculosis peer	**What was/were the research questions:** To understand the motivation and personal impact of being a peer educator on people with experience of anti-tuberculosis treatment,	**What population were the sample recruited from:** TB peer educators in London who raise awareness of TB radiological screening among people using homeless and/or	**Brief description of method and process of analysis**: Semi-structured interviews of 60 minutes were held, using a topic guide developed and tested through a pilot interview. An interview protocol was used to ensure a consistent approach, and interviews were arranged at the convenience of participants. Interviews were recorded for transcription purposes; throughout the interview, the researcher asked for clarification and summarised key points to allow correction and check the participant's meaning.	**Limitations identified by author:** - The small sample size - Positive bias – all interviewees had successfully engaged with the project - Lack of negative analysis

educators: personal experiences of working with socially excluded communities in London." International Journal of Tuberculosis & Lung Disease 17(10 Suppl 1): 36-40.[7] **Quality Score:** +	homelessness and addiction. **What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):** Grounded theory **How were the data collected:** **What methods:** Semi-structured interviews **By whom:** "The researcher" **What setting(s):** NR (London, UK) **When:** NR	drug and alcohol treatment Services. **How were they recruited:** All the peer educators working for: Find & Treat" in London/UK were recruited **How many participants were recruited:** 7, of which 6 were finally interviewed **Were there specific exclusion criteria:** NR **Were there specific inclusion criteria:** Eligible participants must have had treatment for active TB and experience of homelessness and/or drug/alcohol dependency, and have been a peer educator within the	The transcripts were manually coded and identified themes presented to interviewees at a peer group meeting before the final stages of data analysis. **Key themes (with illustrative quotes if available) relevant to this review**: Key themes were identified through the qualitative analysis. <u>Making sense of the past</u> Becoming a peer educator helps building a sense of what the individual can achieve; it can be seen as part of the recovery process: "*Tell me how you became a peer educator*" *" . . and even after I got it [TB] I really didn't want to know and it wasn't until [name of TB worker] said you know, and from there on she invited me to the team, and they invited me back and slowly gradually because I had not done anything for about 20 years, they kind of coaxed me in. (P4)"* *'How did being diagnosed with TB change things for you?'* *It was the TB and the people surrounding me because I had three organisations dealing with my issue, I had the hostel, I had the social workers and the TB services and I had a drugs service as well. So they were working together to basically sort me out. That was a big push, and they disciplined me. I was even told that I could be sectioned as there were times I would not go for my medication because I had a hard time taking my medication. I used to bring up my medication. I mean there are four different antibiotics, fifteen tablets that I*	- Possible bias by researchers characteristics - Possible challenges in transferring findings to other project settings that do not have the same close relationship between the coordinating charity for peer education and the TB service (Find&Treat) **Limitations identified by review team:** - Only semi-structured interviews. Would have been interesting to have done participant observation and/or focus group discussions enabling triangulation. - No clear description of the term "socially excluded communities." - No clear task description of peer educators> how often do they have contact with how many TB patients?

		last 3 years of the project**.** Peers receive ongoing support and counselling from an experienced worker at the coordinating charity who was consulted before inviting individuals to participate to ensure that there were no current social or psychological issues that might preclude their inclusion.	*had to take daily, and my body actually brought them up. So I was on direct observed therapy and that was life-saving in itself, as there is no way, I mean it is hard if you are on antibiotics for a week to take your medication, but taking medication every day for 2ó years, that's how long I was on medication because my TB was so advanced. So there was time for a lot of reflection. . . so you know it just gets you thinking and reevaluating your past and your future.* (P5) <u>Renewed self</u> Being a volunteer affirmed previous beliefs and encouraged empathy and inspiration for future opportunities. It gave some peers more confidence, a reason to come out of bed for. *Did you learn any particular lessons from being a peer educator?' Tolerance, tolerance, and it also what's the word, it also eradicated the ego so to speak. Sometimes there's the tendency to be slightly big headed when one has achieved something, eradicating my habit, there's a tendency to feel big headed. And when you go back into that community and there's that atmosphere it makes you realise how hard it is and you develop sympathy for the people that you are helping, and you see that you are helping from the heart not just from the head. (P5)* *'How long do you think you will be a peer educator for?' I think I stay as long as I stay in London. This place is for me. (P6)* <u>The peer voice</u> Being a peer distinguishes them from professionals, because they can share personal experiences.	**Evidence gaps and/or recommendations for future research:** As indicated in review: - To test the conceptual model that TB peer education provides a positive journey for the peer by using baseline and serial interval measurements on self-efficacy and confidence - Those data could support a quantitative analysis of social returns from investment of the project in terms of the effect on the peers themselves, alongside the evaluation of cost-effectiveness to assess the impact of peers on the health and social care outcomes of TB patients - To explore the extent to which the research findings can be generalised to other

			Most of the peers, most of them have been affected personally, had TB so this makes a difference as people like to listen to you more, when you've had treatment, what happened to you. That's something good you know. If someone knows someone who has suffered or had the same experience you know. Doing it, places we go, constantly people find out you know . . . once people find out that you had treatment they more likely to talk to you, ask you how you solve it. (P3) <u>Project environment</u> Peers showed a strong belief in the project. *'And why did you ask Find&Treat if you could help?' To volunteer for them . . . (P2)* *'To volunteer for them, and why did you want to do that?' She [Find&Treat project worker] took me to the van . . . From the van, to my sickness benefit, to every little thing that happened to me in the past 3 years, I thank Find&Treat. (P2)*	project settings, the methodology could be repeated with peers working in different settings with socially excluded communities **Source of funding:** NR

Study details	**Research parameters**	**Population and sample selection**	**Outcomes and methods of analysis** **Results**	**Note by review team**
Year: 2013 **Authors:** Kate Gerrish, Andrew Naisby & Mubarak Ismail **Citation:**	**What was/were the research questions:** To explore experiences of the diagnosis and management of tuberculosis from the perspective of	**What population were the sample recruited from:** <u>Patients:</u> Somali patients who had received TB treatment in the UK	**Brief description of method and process of analysis**: Interviews were audio-recorded and subsequently transcribed. Framework approach; 1. Team familiarized with data by reading transcripts several times 2. Initial thematic coding framework, based on interview topics, was developed and refined following preliminary analysis of the first few transcripts.	**Limitations identified by author:** - The sample was restricted to one geographical area: it is recognized that the experiences of patients who participated in the

Gerrish, K., et al. (2013). "Experiences of the diagnosis and management of tuberculosis: a focused ethnography of Somali patients and healthcare professionals in the UK." Journal of Advanced Nursing 69(10): 2285-2294.[8] **Quality Score:** **+**	Somali patients and healthcare professionals involved in their care. **What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):** NR **How were the data collected:** **What methods:** Focused ethnographic approach Interviews with: <u>Patients:</u> Single, individual interviews; 30 – 90 minutes; in the preferred language of the participants Somali patients <u>Health care (HC) professionals</u> Individual in-depth interviews; 30-60 minutes.	<u>Health care (HC) professionals:</u> Healthcare professionals with experience of caring for Somali TB patients. **How were they recruited:** By a TB specialist nurse involved in their care. **How many participants were recruited:** - 14 patients - 18 healthcare professionals **Were there specific exclusion criteria:** NR **Were there specific inclusion criteria:** NR	3. Revised thematic framework was subsequently used to code transcripts and coded data were organized into themes 4. Data from patient and healthcare professional interviews were analysed separately and integrated to form a composite analysis. 5. The relationships between different themes were mapped by analysing the data set as a whole. **Key themes (with illustrative quotes if available) relevant to this review**: **<u>Experiences leading up to diagnosis</u>** <u>Patients:</u> All patients found the time leading up to diagnosis distressing. Several patients felt 'anxious', 'stressed', and 'powerless' and this was intensified the longer it took to confirm a diagnosis. Two were unable to continue in employment and loss of income as well as status was distressing. All presented in general practice shortly after initially feeling unwell and a few were diagnosed relatively quickly. Several patients felt that their concerns had not been treated seriously: they lacked trust in their GP and felt 'let down by the system'. *For two years I had problems, I went to GP. I was very worried. Every time I went they told me I was stressed. I had pain in my chest, they prescribed something but it did no good.* (Patient 10) <u>HC professionals</u> TB specialist practitioners acknowledged that diagnosing TB could be challenging when patients presented with atypical symptoms and this made it difficult for GPs to	study may not be representative of Somali TB patients living in the UK more generally. (But, largest Somali community in the UK) - Patients were only recruited via nurses; patients more engaged in HC services. **Limitations identified by review team:** - Focus on established migrants - Lack of triangulation: need of additional data collection method, such as observation or focus group discussions or multiple interviews with respondents in various settings. **Evidence gaps and/or recommendations for future research:** - Further research examining the

	By whom: The research team included a Somali researcher who was a member of the local Somali community and fluent in Somali and English. **What setting(s):** Sheffield; <u>Patients</u>: In the patients' home <u>HC professionals</u> In the workplace **When:** 2008-2009		make a provisional diagnosis and refer appropriately: a situation also recognized by GPs: *It can be hard to diagnose TB. Patients can present with vague symptoms, it may be difficult for them to explain what's wrong and it's harder when there are communication difficulties and different cultural perspectives.* (GP 2) *If a practice has a significant number of patients who are migrants, or at high risk of contracting TB, GPs generally tend to be 'on the ball' in identifying TB as a possible diagnosis. However, it's much harder for GPs who might see very few, if indeed any, cases of TB in a year.* (TB physician 2) Language barriers compounded the difficulty of gaining an accurate account of a patient's symptoms. Most patients relied on relatives to translate, even though it compromised confidentiality and GPs voiced concern about the accuracy of interpretation. Healthcare professionals perceived that some other patients delayed seeking help because of stigma associated with TB. Late presentation was also associated with the use of khat. *Some men who've been unwell for a long time are heavy users of khat. I can understand their reluctance. Heavy use of khat is like heavy use of any drug, it's escapist. Also if they're found to have TB they're going to lose their entire social life because who wants you to go to the Marfesh if you have TB, so they'd be ostracised*. (TB nurse)	challenges of achieving timely diagnosis of TB among Somalis and other migrant communities with high rates of TB is warranted. - Need to raise awareness of TB among established Somali communities and ensure timely referral of patients by GPs to specialist services when TB is suspected. - Studies to compare the stigmatization of TB among recent and established migrants and how the beliefs of new migrants may influence their uptake of services - Research examining the longer term impact of TB in communities where the disease is stigmatized. **Source of funding:** Sheffield Health and Social Care Research

			<u>Response to diagnosis</u> <u>Patients:</u> Patients varied in their response to a diagnosis; many were relieved: *I was happy because I'd been feeling ill for a long time. Every time they did tests they tell me 'we don't know what is your illness'. When the doctor told me it was TB, I was relieved because only known illnesses can be treated.* (Patient 9) For a minority of patients, the diagnosis caused psychological distress because of potential social consequences: *I was very shocked. People are scared of TB because they think they'll die and they can pass it to their families and children. I was very upset because Somali people think TB is very bad and anyone who hides it will suffer a lot and if you tell them about it, they'll stay away.* (Patient 8) All patients had made known their diagnosis to immediate family, but several had been reticent about sharing the information more widely. <u>HC professionals</u> HC professionals were aware of stigma associated with TB among Somalis, but they perceived that this was diminishing: *A few years ago TB was a taboo subject that nobody in the Somali community talked about and if you thought that somebody had TB, if you said that to them, they were horrified. My impression now is that patients would*	Consortium England. Grant number ZB63.

			rather know so I think there's been a change. People come asking 'could I have TB?' whereas we were the ones thinking of it before. (GP 1) **Experiences of treatment** The benefit of support from close family in promoting treatment concordance was stressed by patients and healthcare practitioners. The support of TB specialist nurses and Somali health workers was highly valued by patients and healthcare professionals. Specialist nurses acted as a conduit for patients accessing other health and welfare services. HC professionals In their experience, most Somali patients accepted the diagnosis, adhered to treatment, and had a positive outcome. *My sense over the years has been that it's rare for people not to complete treatment even if they've not wanted anybody else to know they have TB. I suspect the reasons why people don't complete treatment are to do with chaotic things in their lives. There may be all kinds of social difficulties that make it difficult for them to seek treatment.* (TB physician 3) **Living with tuberculosis** Patients: Many patients were well supported by family and friends, but there were considerable sociocultural consequences: Some who had disclosed their diagnosis to their wider social network encountered a degree of social isolation, which caused psychological distress and sometimes loneliness. The social stigma that these patients	

			experienced was attributed to a lack of understanding of TB in the wider Somali community. Some patients experienced economic hardship. One patient, who was particularly ill, had been made homeless and despite support from TB specialist nurses, managing his disease proved difficult due to inadequate temporary accommodation, poor nutritional intake, and lack of social support. The long term consequences of the disease were keenly felt. *I was very ill. It is everything to get back to normal life, to feel fit and strong. It took three years to get back to normal, to find a job.* (Patient 11) Many patients expressed deeply rooted, yet inaccurate, sociocultural beliefs about TB. Several were concerned that they could not be cured completely: a view linked to a belief that TB was hereditary. *I have taken the tablets, they tell me I am cured, but the TB, I think it may come back. It's in my family.* (Patient 4) <u>HC professionals</u> Healthcare professionals also alluded to difficulties in the longer term recovery of patients: *We don't know what happens to people once they are no longer engaging with the TB services. Some still have a long road to full recovery, if indeed they recover completely.* (TB physician 1) *We've a young Somali lady who completed treatment*	

			three years ago. She had TB affecting the spine and has difficulty with mobility. She feels quite depressed; she's concerned that she won't marry because of the stigma of TB. We really know very little about the longer term physical and psychological effects of TB. (GP 2)	

Study details	**Research parameters**	**Population and sample selection**	**Outcomes and methods of analysis** **Results**	**Note by review team**
Year: 2013 **Authors:** Kawatsu, L. Sato, N. Ngamvithayapong-Yanai, J. Ishikawa, N. **Citation:** Kawatsu, L., et al. (2013). "Leaving the street and reconstructing lives: impact of DOTS in empowering homeless people in Tokyo, Japan." International Journal of Tuberculosis & Lung Disease 17(7): 940- 946.[9]	**What was/were the research questions:** To explore the changes experienced by homeless TB patients, and to discuss the possible role of Primary Health Care (PHC)-based DOTS treatment in effecting these changes. **What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):** NR	**What population were the sample recruited from:** Seventy homeless patients who received PHC-based DOTS during the study period between September 2007 and October 2010 at Shinjuku PHC. **How were they recruited:** NR **How many participants were recruited:** 18 (all male, co-morbidities: 3 with	**Brief description of method and process of analysis**: Interpretive content analysis: 1. Familiarisation with the text through review of all the transcripts. 2. Design of a thematic framework using an iterative process. 3. Segments describing any changes that participants had experienced in the context of DOTS were retained for further analysis. 4. Organization of segments by means of open coding and abstraction, 5. A model of empowerment was developed. **Key themes (with illustrative quotes if available) relevant to this review**: **<u>Need to feel cared for as a person</u>** The need to feel cared for as a person was identified by many participants. Many attributed this change to feeling that the nurses genuinely cared for and took interest in them as individuals, and not just as any other homeless person with TB. Participant T07, who assessed himself as reckless and	**Limitations identified by author:** - Not generalizable to other settings; reproduction to other settings not always feasible - Homelessness in Japan different from UK/US: no HIV, no drug use, illiteracy - Defaulters were not interviewed **Limitations identified by review team:** - Setting of interview not clearly described; potential bias

Quality Score: +	(Shinjuku's PHC-based DOTS scheme places emphasis on building a relationship of trust with the patients; patients visit the PHC; they do not only receive drug treatment at the PHC, they are also offered food and drink on each visit, as well as the opportunity to talk about other problems, such as health concerns and social relationship issues. There are 3-4 nurses for 10 patients. At the end of each successfully completed treatment course, a small ceremony is organised by the nurses to congratulate the patient. **How were the data collected:**	alcohol dependence; all homeless at time of TB diagnose, majority unemployed or part-time employed). **Were there specific exclusion criteria:** Serious mental health problems. **Were there specific inclusion criteria:** Homeless patients who received PHC-based DOTS during the study period between September 2007 and October 2010, who: 1) had completed treatment at Shinjuku PHC, 2) were willing and available to participate, and 3) had no serious mental health problems.	cared little about himself or others before developing TB: *LK: 'So how do you feel now?'* *T07: 'Well . . . it's like I'm a completely different person. I'm happy, and I really like the way I am now . . . I used to live a pretty self-destructive life, you know. Didn't care . . . but now I feel I should take a better care of myself . . . I mean, I've never really had people worry about me, so . . . oh, at first . . . I really wondered . . . why on earth they (nurses) cared for me so much? And why are they so polite, and so kind? I didn't understand . . . (but that experience) changed me, like you know, I shouldn't continue like this. I should take care of myself more . . . for example, I'm more careful about what I eat . . . like more vegetables. I also smoke less . . . and trying to cut down on alcohol as well!'* Improved self-worth also had a positive effect on interpersonal relationships. *'Coming here was such a relief . . . I could let it all out, and they (the nurses) would listen. It was so good. They would never look down on me, but were always so kind, so polite. Coming here really gave me strength to continue the treatment. You know, many people just give up (the treatment). But they made me feel I could do it . . . but not just that . . . I also feel much gentler towards other people . . . I can talk kindly, politely . . . not get angry so quickly, like I used to.' (N01)* Several others said that talking to the nurses helped them become milder, more forgiving and less assertive in their attitude towards other people.	**Evidence gaps and/or recommendations for future research:** - Health care providers should be trained to strengthen not only their technical skills but also their interpersonal skills, so that they become more sensitive to the various emotional needs of the patients, and respond appropriately. - How to reach default patient who have no apparent problems but who still disappear and fail to complete treatment is an issue to be considered in future studies. - Although limited, data suggest that PHC-based DOTS could have a similar empowering effect even for those patient with underlying conditions their

	What methods: 60 min in-depth interviews. Participants were asked to talk freely about their experience of and their life after DOTS. All interviews were recorded using an integrated circuit recorder and were transcribed verbatim. Nurses were consulted to triangulate the data regarding changes among the participants before and after DOTS. **By whom:** Researcher LK **What setting(s):** A room without the presence of a nurse **When:** NR		**<u>Need to have efforts recognised</u>** The need for patients to have their efforts recognised was identified from conversations with several participants who said that they had become more confident. *LK: 'You said that you have become more confident . . . is that because you overcame TB?'* *T07: 'Overcoming TB was one . . . but I'm not sure if I'd have finished the treatment by myself. I am really grateful for the nurses . . . they would never use degrading words . . . never demoralise us. You know, sometimes I wanted to give up, and actually once I did try to run away! But they soon found me [laughs]. The nurse got really angry and scolded me, but you know, I didn't feel bad be- cause of the way she got angry . . . I understood that she was worried. And I kind of felt . . . that she knew I was doing my best. That in turn gave me strength, like I have to live up to her expectations . . . she was not always saying 'ganbatte, ganbatte' ('Try harder! Try harder!'). Because I'm already trying hard! I think she (the nurse) got really angry (when I tried to quit treatment) because she knew that I was trying.'* Having treatment completion recognised and praised also seemed to have a similar effect: *'At the end of the long treatment . . . and when I attended the ceremony, I feel, oh I did it! I was able to finish it! I didn't give up and that really gave me a lot of confidence. I feel I can now try other things . . .' (N01)* *'. . . and all the nurses came out and praised me (at the ceremony) . . . sure I felt good. Like a job well done. If I could overcome this (TB), I can overcome other*	specific socio-economic and emotional needs would be identified and addressed. **Source of funding:** Grant-in-Aid for Scientific Research from the Ministry of Health, Labour, and Welfare, Japan.

			difficulties.' (O05) **<u>Need to feel (re)attached to society</u>** The need to feel (re)attached to society was identified from conversations with almost all the participants. After completing DOTS, their thinking had changed and they expressed their gratitude not only to the individual nurses but also to society in general. *'I thought . . . I could do without society but I guess I was wrong. I'm really glad that I overcame TB and I'm really thankful to society for that . . . I realise that I'm part of all this (society) after all.' (S16)* *'It was like DOTS linked me to the society again . . . which I thought I'd left years ago. But I didn't . . . and I am glad that I didn't. Because I'm so glad that I'm alive today, and I admit that is because I was saved by society.' (N01)* A sense of social (re-)connectedness and gratitude made many participants feel that they wanted to give something back to society; become re-employed or do voluntary work. For some reconnecting with society through PHC-based DOTS pushed them to try to get back, or closer, to the life they used to live before becoming homeless. *S16: 'I really think . . . DOTS gave me a second chance . . . To live my life again . . . properly.'* **<u>Five sub-categories of patient empowerment identified by authors</u>** **1. Mental health** Codes: Feel happy; Feel hopeful; Feel confident;	

			Improved self-esteem. *I overcame TB, so now I think I can overcome other difficulties. And also . . . perhaps even try for new things.' (Y09)* *'Sure . . . I feel I have a stronger will. Like, I won't be beaten so easily now.' (S03)* *'Oh before . . . I thought if I die, I just die. But now, I don't want to die like this. I want to live for a long time . . . calmly, and peacefully.' (T13)* **2. Health behavior** Codes: Eat well/healthier ; Drink/smoke less; Seek medical help; Other personal hygiene behaviours *'I try to eat healthier . . . like more vegetables. I also try to eat at regular times.' (Y09)* *'I try to reduce salty food.' (N01)* *'I drink much less now . . . I mean, the most important thing is to stay healthy.' (O05)* **3. Living environment** Codes: Acquire certificate of residence; Move to a better place; Buy furniture/electrical appliances *'I'll apply for a certificate of residence . . . then I can start looking for jobs, like everyone else.' (K02)* *'I bought several kitchen appliances . . . so that I can cook for myself. That way, I can lead a much more decent life.' (M18)*	

			4. Personal relationships Codes: Better able to express themselves; Better able to communicate politely; Able to build relationship of trust; Better able to understand other people's feelings. *'I've learnt to bow my head. And no, I don't hesitate to do that. I feel grateful to other people . . . and I should show that I appreciate them.' (S11)* *'Before . . . I didn't care. I just said what I wanted to say, but that attitude wasn't right. I now try to understand people's feelings . . .' (T07)* *'I now try to think what words mean before I speak . . . what do people feel if I say this or that? Because I don't want to hurt people by my words. Before? I was like, who cares!' (S14)* **5. Attitudes towards society** Codes: Accept social rules and regulations; Feel indebted; Want to give something back *Oh, I feel very indebted now . . . I mean, not just to the doctors and nurses, but to society in general. My treatment was paid for by the country's money . . . and so I feel I should give something back.' (T06)* *'Sure I feel bad . . . my treatment paid for by society's money and now receiving money from society at my age . . . when I'm still supposed to be working. It's a bad thing. When my health fully recovers, I want to start working and return this money.' (O08)*	

Study details	Research parameters	Population and sample selection	Outcomes and methods of analysis Results	Note by review team
Year: 2013 **Authors:** C. Wannheden, K. Westling, C. Savage, C. Sandahl, J. Ellenius **Citation:** Wannheden, C., et al. (2013). "HIV and tuberculosis coinfection: a qualitative study of treatment challenges faced by care providers." International Journal of Tuberculosis & Lung Disease 17(8): 1029-1035.[10] **Quality Score:** +	**What was/were the research questions:** To understand the challenges faced by nurses and physicians in the treatment of patients coinfected with the human immunodeficiency virus (HIV) and tuberculosis (TB), with special focus on opportunities for information and communication technology. **What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):** NR **How were the data collected:** **What methods:**	**What population were the sample recruited from:** The staff of the out patients clinics for TB and HIV at the Infectious Diseases Department, Karolinska University Hospital, Stockholm, Sweden. **How were they recruited:** NR **How many participants were recruited:** - 4 physicians (one HIV specialist, one TB specialist, two residents at the HIV clinic) - 5 nurses (four HIV nurses, one TB research nurse)	**Brief description of method and process of analysis**: Inductive thematic analysis (Braun et al): 'process of coding the data without trying to fit it into a pre-existing coding frame or the researcher's analytic preconceptions'. Verbatim transcription; coding of portions of transcripts independently by two researchers; discrepancies resolved in discussion. Then, codes were grouped into categories and candidate themes. Codes and themes were refined and further developed in discussions among co-authors. Illustrative quotations were translated into English by the first author. **Key themes (with illustrative quotes if available) relevant to this review**: <u>Theme 1: Complexity inherent to TB-HIV co-treatment</u> Physicians reported that they face their main challenges when diagnosing TB and choosing a treatment strategy (pay attention for comorbidities and patient characteristics). Pharmacological complexity was also mentioned by physicians; physicians and nurses described that side effects, which occur frequently, may be difficult to identify and tackle. *Because it overthrows a little if you have your treatment plan and then suddenly 'Well, no, now this doesn't apply anymore. Now there has been a side effect to the liver. Then we have to start over from the beginning.' So that is also part of the whole process that some patients don't*	**Limitations identified by author:** - The sample used in the study was limited, especially with regard to the setting and the number of participants which limits transferability **Limitations identified by review team:** - Hospital setting might have caused bias, influenced respondents answers - It would be interesting to include perspectives of patients to get a complete view of the situation - Description of hard–to-reach group/migrants is limited **Evidence gaps and/or**

	First author carried out in-site observations and informal discussions at the HIV clinic for 1 week to become acquainted with the clinical context and workflow. One nurse and one physician of each specialty (HIV and TB) participated in the initial task diagram interviews. Identified tasks and challenges were documented in mind-maps and used to guide subsequent CMD-inspired interviews. Then: 1. One nurse and one physician of each specialty (HIV and TB) participated in the initial task diagram interview: applied cognitive task analysis, a streamlined method specifically	**Were there specific exclusion criteria:** NR **Were there specific inclusion criteria:** working in either the HIV or TB clinic of the Karolinska University Hospital, Stockholm,	*follow this train that just rolls on; it is also a part of the treatment that we have these problem situations that sometimes require quite a bit of thinking.* (Physician) <u>Theme 2: Clinical knowledge and task standardization</u> Physicians and nurses working with HIV felt that they had insufficient knowledge and experience of anti-tuberculosis treatment: *Sometimes I think it gets a little difficult that we do not know and then maybe we take tests just in case. It has felt a little bit like one has been a bit uncertain, that I have to say.* (Nurse) Varying routines among care providers and between clinics can be challenging, and some nurses said that they felt confused or irritated by the different opinions among physicians at the clinic. Guidelines and care protocols are of limited usefulness. *Yes, there are memos on our website. But they are not valid anymore, one has understood now. They are not updated and especially not with regard to HIV patients.* (Nurse) A need for guidelines with more detail regarding different patients and treatment alternatives was expressed; guidelines could be more comprehensive and easier to use by means of computer-based guideline support. *. .that there maybe were different memos for different types of patients so you could go in and check . . . if it would be in InfCare or some other support tool it would have been even easier if you just 'beep beep'. 'Ok, now*	**recommendations for future research:** - Educational material and tools need to be developed further to support care providers in making decisions about adequate care as well as to support collaborative activities and communication among patients and care providers - Information and communication technology based solutions **Source of funding:** The study was financed by the Health Informatics Centre and the Medical Management Centre at Karolinska Institutet, Stockholm, Sweden

	developed for professionals without training in cognitive psychology. The purpose is to establish an overview of challenging tasks and to identify difficult cognitive elements. 2. Identified tasks and challenges were documented in mind-maps and used to guide subsequent critical decision method (CDM): in-depth interview method based on the retrospective narrative of a critical incident or non-routine event where the informant has played a key role. It covers four phases: a) An appropriate event for in-depth analysis is identified. b) The sequence of		*we are here, this then'. That's what I think would be much safer.* (Nurse) Informants were generally positive about computer-based support, some physicians were more sceptical: *Well, it's hard to imagine, I think. Because there is so much that we take into account. I think it would be difficult to develop. Also a bit, I don't know. . . . maybe it's possible. But it feels strange and a little bit dangerous that you might stop thinking on your own then. But maybe it's just that I am conservative, I don't know*. (Physician) <u>Theme 3: Care coordination and collaboration</u> Nurses working with HIV emphasized challenges during treatment follow-up, particularly with regard to monitoring and managing the treatment process. There was uncertainty about the division of task responsibilities among care team members and between the HIV and TB clinics; insufficient networking between the HIV and TB specialties, and a need for more collaboration. *But above all, we should have more collaboration across, I think. Regardless of how it is solved, because we don't know . . . I have no idea who has tuberculosis there [at the HIV clinic]. I don't know how they manage [tuberculosis]. And that's not good.* (Physician) Reduced continuity among physicians and challenges related to staff shortages were concerns: *But now the patients see . . . some up to five different physicians in recent years. Before it was between one*	

	events and 'decision points' of the incident are diagrammed on a timeline. c) Key events are probed for additional detail, and d) 'what if' probes are used to illuminate expert-novice differences. **By whom:** In-depth interviews: First author **What setting(s):** Infectious Diseases Department, Karolinska University Hospital, Stockholm, Sweden **When:** May to November 2010		*and two physicians during a treatment. So it has worsened a lot with cutbacks. It is so poorly staffed that it—and one moves, we physicians are moved around and—that it isn't possible to follow your patient.* (Physician) Several informants described that communication between care team members was ineffective. *Some always read what we have written in the medical record, and some never read what we have written. That's actually how it is, to be honest.* (Nurse) <u>Theme 4: Information management</u> There was limited electronic access to some treatment-related information: test results that only arrive on paper, web-based drug information systems with restricted access, medical records from transferred patients, and protocols and treatment plans that are only available in print. The information content in the Electronic Health Record (HER) system was reported to be unstructured; a need for automatic reminders was expressed: *It would have been great to have some sort of flag: 'Now it's time for the vision control'. Because it happens of course that we miss that—'Oops, we should have done a vision control a week ago'.* (Nurse) <u>Theme 5: Engaging patients in their treatment</u> Several informants emphasised the challenge of communicating effectively with patients and engaging them in their treatment. Patients' knowledge and	

			understanding of TB-HIV varied and there was a need for routines for discussing treatment and adherence with patients: *But I think it would be good if we could be a little bit more updated with patient information as well. 'How do we provide information?', 'How can it feel?', 'What side effects are normal in the beginning?' and such things.* (Nurse) The majority of the patients treated at the clinic were of foreign origin; informants stated that communication is challenged by language and cultural barriers. Some described the issues of patients' distrust of interpreters and withholding of information about their symptoms and general condition: *But they [patients] think that it's a burden with the interpreters. Because one is scared anyway. So surely there is some kind of fear there. One does not trust that the interpreters keep quiet. Because it is a small group where everybody knows everybody. It is a problem actually.* (Nurse)	

Study details	**Research parameters**	**Population and sample selection**	**Outcomes and methods of analysis** **Results**	**Note by review team**

Year: 2014 **Authors:** Craig, G.M. Joly, L.M. Zumla, A. **Citation:** 'Complex' but coping: experience of symptoms of tuberculosis and health care seeking behaviours--a qualitative interview study of urban risk groups, London, UK. BMC Public Health, 2014. 14: p. 618.[11] **Quality Score:** ++	**What was/were the research questions:** To analyse patients' knowledge of tuberculosis, their experiences of symptoms, and their health care seeking behaviours **What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):** Wilkinson and Marmot' s ' key facts' model to situate participants' experiences within structures which both place individuals at risk and shape health actions, including: stressful life circumstances, influence of early life, social exclusion, unemployment, addiction, food, opportunities for	**What population were the sample recruited from:** A major TB centre in London, UK, characterized by a culturally diverse catchment area **How were they recruited:** The study was part of a new initiative evaluating the role of a TB caseworker in developing collaborative care pathways. Inclusion was based on a risk assessment (identifying health and social risk factors likely to complicate adherence to treatment (such as homelessness and drug use). If eligible for referral to a TB caseworker, they could then be referred/recruited by nurses or the case worker.	**Brief description of method and process of analysis**: Interviews were audio recorded and transcribed; except for two interviews with interpreters and one in prison when notes were taken. A theoretical thematic analysis was used, (Braun & Clarke 2006). Coding involved three stages: 1. Readings of the transcript to identify segments of relevant text relating to knowledge of TB, recognition of symptoms of TB, and examples of how participants accessed care and contextual information about individual life experiences 2. Comparison across transcripts 3. Linking codes to social determinants **Key themes (with illustrative quotes if available) relevant to this review**: <u>Participant characteristics:</u> 17 participants, 16 confirmed TB cases, 1 suspected TB. 12/17 male; 5 had complex immigration cases (affecting housing and welfare); 3 migrant participants lost their job after diagnosis; 1 homeless man had a job; most relied on benefits / voucher schemes. 9 reported drug use; 7 received methadone maintenance; 3 reported problematic alcohol use but no drug use. <u>Personal accounts of health:</u> Prior to their diagnosis of TB most interviewees described themselves as having good health with no history of illness. On further request co-illnesses such as HIV, epilepsy, hypertension, diabetes, a history of gastric ulcers were mentioned. <u>Knowledge of TB + susceptibility:</u>	**Limitations identified by author:** The authors note that clinical interpreters, rather than bilingual interpreters were used, which may have influenced the conduct of the interviews. Reasons to participate can be biased in vulnerable groups. **Limitations identified by review team:** A clearer comparison / matching between the subgroups could have contributed to the comprehensiveness of the article. A description of the health care system / policy / specific interventions regarding homeless/drug using TB patients would have given a clearer

	healthy lifestyle and access to service **How were the data collected:** Several in-depth interviews (30-60 minutes each) on more than 1 occasion over the course of treatment. **<u>What methods</u>** **By whom:** - Interviews: G.M. Craig (social science background) - Coding & thematic data analysis: G.M. Craig + L.M. Joly (background in nursing and homelessness) **What setting(s):** A major TB centre in London, UK, characterised by a culturally diverse catchment area including migrant,	**How many participants were recruited:** 17 **Were there specific exclusion criteria:** NR **Were there specific inclusion criteria:** - Confirmed or suspected diagnosis of TB - Patients health and social risk factors likely to complicate adherence to treatment (such as homelessness and drug use) - Eligibility for referral to a TB caseworker for enhanced case management and support	Most participants had heard of TB and some knew others had died of the disease. In general, knowledge of personal susceptibility in this group was low. A variety of reasons was given (inside the person / external factors ("illegal immigrants"), personal responsibility (failure to take medicines), poor living conditions or lifestyle factors. Overseas-borns were more likely to discuss risk of exposure by close contacts or health care worker / setting. <u>Recognition of symptoms of TB</u> Common symptoms were reported: tiredness, sweating, cough, loss of appetite, headaches, lethargy, shortness of breath, pain or ache, feeling cold, and weight loss. *'it 's like somebody stick a pipe in your bloodstream and sucking every bit of blood out of you ' [ID02]* However, these symptoms were often attributed to other (undiagnosed) illnesses, to poor diet due to economic reasons, or to drug/alcohol abuse (e.g. weight loss, loss of appetite). *I didn' t have a clue.... sweating at night I put down to alcohol, the coughing down to smoking and um feeling unwell, down to withdrawal from um, the heroin [ID05]*. Older migrant groups, especially from Somalia, had a greater awareness of TB but they did not always associate their symptoms with the disease (e.g. tiredness in a Somali refugee woman was attributed to "a lack of finance to buy good halal food"). The authors conclude that symptoms are affected by the	idea of the medical context. Influence of health care setting and unequal patient-researcher relationship on responses of interviewees not considered. Future research could focus on experience of TB patients not only prior to but also during treatment. **Evidence gaps and/or recommendations for future research:** Authors emphasised the need for protocols on disclosure, guidelines on safety and support for researchers and staff working with vulnerable groups, in addition to referral pathways to agencies with skills to support research participants.

	homeless and drug using populations; the majority of interviews took place in the hospital outpatients' clinic, three took place on a hospital ward, one interview took place in a homeless hostel and one in a prison with the permission of the managers in charge. **When:** NR		social context which can provide alternative, although in these examples, erroneous and misleading explanations for feeling unwell. <u>Examples of how participants accessed care</u> For some patients the first point of contact was the GP. Four did not have a GP, and relied on to the many specialist homeless health services in the catchment area of the clinic. Several people accessed medical help only when they reached crisis point and were taken to hospital by ambulance after collapsing or through self-referral to A&E. In some cases it was only the intervention of friends, a partner, hostel worker or a member of the public (for example when patients collapsed in a public place) that enabled people to access care. One participant 'blacked out' on a bus and the police called an ambulance to take him to A & E. Another collapsed in a hostel and care workers took him to hospital suspecting TB after a recent training course aimed at raising awareness. One man accessed health care through a TB mobile x-ray screening initiative for homeless. Several interviewees sought care late, trying to self-manage the condition or attributing symptoms to other factors. *I ain't got a clue. That was the last thing on my mind, TB, I, I just thought I was having pneumonia trouble. I thought I'd just ruptured something in me chest or something… I didn't have a clue what it was [ID09].* <u>Barriers to seeking care</u> For PWIDs drug dependency and the issue of 'scoring	**Source of funding:** The alumni fund at City University London donated in support of the analysis of the interview study. Further acknowledged for funding (by Prof Zumla): College London Hospitals NHS Foundation Trust, the National Institute of Health Research, Biomedical Research Centre, UCL Hospitals, the EDCTP and the EC-FW7 (RiD-RTI).

			drugs' dominated every day routines. For one participant, the prospect of hospitalization was the issue. *Cos the reason I never came into hospital, was because I was on heroin and like I thought, well if I go into hospital they'll keep me in, I'm gonna withdraw I didn't know, that they give methadone and all that, you know, not everybody knows that, you know [ID06].* Another homeless drug user saw it as a welcome break from the street. In prison being admitted to the hospital wing means a deprivation from a source of income. *The monetary aspect is enough to keep it a secret', ID01* <u>Managing risk to access care</u> Participant reported creative and strategic approaches to managing the risk of drug withdrawal and seeking medical attention. *Anyway this ' when was it Tuesday night and I just. I had the money to score my heroin to be able to keep me, in, the A & E Department until I was to be admitted and to get my methadone. You see that was my main concern. I didn' t want to be in a situation where, I' d maybe be in there mayb', I dunno, maybe ten or twelve hours and start withdrawing, not have any heroin and not have any money to score it. Which would then mean I wasted twelve hours [ID15].*	
Study details	**Research parameters**	**Population and sample selection**	**Outcomes and methods of analysis** **Results**	**Note by review team**

Year: 2014 **Authors:** Julie Ann Zuñiga, Silvia E. Muñoz, Mary Zuñiga Johnson, Alexandra Garcia **Citation:** Zuniga, J. A., et al. (2014). "Tuberculosis treatment for Mexican Americans living on the U.S.-Mexico border." Journal of Nursing Scholarship 46(4): 253-262.[12] **Quality Score: +**	**What was/were the research questions:** Experience of TB treatment among Mexican Americans living in the Lower Rio Grande Valley (LRGV) **What theoretical approach (e.g. grounded theory, IPA) does the study take (if specified):** Merleau-Ponty's (1962) philosophy of phenomenology. **How were the data collected:** **What methods:** In-depth, semi-structured interviews; up to 1 hr and audio recorded. Spanish speaking participants were interviewed in Spanish with the assistance of an interpreter. Field	**What population were the sample recruited from:** Mexican Americans living on the U.S.–Mexico Border. **How were they recruited:** Participants were recruited during their daily appointment at the county clinic. **How many participants were recruited:** 18 (13 men, 5 women). **Were there specific exclusion criteria:** NR **Were there specific inclusion criteria:** English– and Spanish-speaking Mexican American adults who were currently receiving DOT treatment	**Brief description of method and process of analysis**: Data analysis was guided by Cohen, Kahn, and Steeves (2000). A professional transcriptionist and translator transcribed and translated the audio recordings shortly after the interview. Spanish language interviews were transcribed and translated at the same time. Possible concept labels were noted during the interview, and participants were asked to validate them at the end of the interview. Transcripts were reduced: reorganized the data to place similar topics together, and removed vocal tics. Then, line-by-line coding of the revised transcript was completed. Next, a thematic analysis was conducted, guided by Merleau-Ponty's (1962) concepts of culture, embodiment, equilibrium, and relationships, examining the transcript for important phrases and creating tentative concept labels. Labels generated during the interviews were used at this time. Finally, this arrangement was examined to uncover any over-arching themes. **Key themes (with illustrative quotes if available) relevant to this review**: <u>Being observed taking pills every day.</u> Most participants did not go to work because they were too sick, had not been cleared to return to work, or had lost their job due to the illness. Their major daily task was taking their TB medication by going to the clinic to get it or waiting for the nurse to bring it to their home. Most other activities were limited to prevent exposing others in the community to TB. Their daily routine changed; at the beginning of treatment, going to the clinic was many participants' only outing for the day. Some said they felt bad, and others stated they did not mind going to the clinic every day.	**Limitations identified by author:** - Findings are limited to the Mexican Americans who live in the LRGV of the U.S.–Mexico border and may not be generalizable to other settings or cultural groups - Purposive sampling may induce bias because it is not random selection - Some of the participants knew each other or were relatives. This may alter the findings because of the close relationship with other participants in the study. **Limitations identified by review team:** - Methods of analysis partially unclear (multiple researchers coding?). This could lead to a bias - Very broad research question

	notes were written immediately after each interview and included a description of the interview setting, the subject's body language, preliminary thematic labels, and bracketed ideas. **By whom:** Researcher and Spanish two interpreters trained in qualitative research and interview techniques in formal classes as part of their graduate degree programs. **What setting(s):** As agreed by the participants' preference: participants' homes (n = 4), nearby parks (n = 3), the county clinics (n = 5), libraries (n = 3), or restaurants (n =	were recruited from two counties of the LRGV, Cameron and Hidalgo.	The majority of participants took their medications from a nurse at the clinic. A small percentage of patients were brought medication by a nurse to their homes. Most the participants were surprised to learn they would be observed daily. Most stated they were not too concerned with the every-day trip to the clinic but found the schedule frustrating. They did not think they needed direct observation. *The nurse told me they didn't want to give them [the pills] to me because they were afraid I won't take them, and I told them "Why wouldn't I take them if it's for my own benefit? I'll take them until the last day you tell me treatment was completed."* (Participant 8) Taking the pills was no problem for some participants, but some talked about being rushed and pressured by the nurses to go faster. *On the weekends, . . . it was very cool because I took my time, . . . and there was no pressure because there was nobody there hurrying me . . .; and they were always on top of time, you have to take them. They are there . . . That's why I told them to leave them with me, and I would take them alone because I felt the pressure from the nurse watching me.* (Participant 2) After taking their pills, participants returned to isolation at home. They talked about being depressed and sad after coming home with nothing to do. Several spoke of not only isolating themselves in the homes, but also confining themselves to the bedrooms.	- Big difference in men and women not explained and not taken into account during analysis - In discussion no link results and theory **Evidence gaps and/or recommendations for future research:** <u>Implications for practice:</u> - Providing phones with texting ability to TB patients might save direct and indirect costs of treatment by decreasing transportation and staffing needs. - Nurses should counsel and assist patients with disclosure of their TB status to their family and other members of their support system - Nurses should include family members when providing health education about the

	3). **When:** August – October2012		<u>Symptoms and side effects.</u> Participants reported experiencing symptoms pre-treatment and side effects during treatment. The symptoms and side effects were different, but both were extremely negative and shaped their perspective of TB by affecting their physical and mental feelings. *Even with the fan I sweated a lot, I got the sheets wet; and the cold. With this sun I wore a jacket or sweater and trembling, the symptoms were very bad. At that moment that you feel cold and all that, you feel bad. When you're losing appetite, cold, cold sweating at night. I told them how I felt, the cough that didn't let me sleep. Those are the symptoms I had.* (Participant 9, translated from Spanish) Weight loss was seen as a very negative side effect of TB. One participant got tested for HIV because his major symptom was weight loss, not cough. *The first time I lost weight. I didn't have symptoms; the way it was noted is because I lose weight, not because I had cough or the usual symptoms. I lose weight . . . cough, you perspire at night, sometimes phlegm with blood. This second time I've not had phlegm with blood and they say I should and I don't. The food makes you sick; you lose weight again. This time I didn't lose weight as the first time.* (Participant 5, translated from Spanish) The side effects of the medication could be as severe as or more severe than the symptoms of TB for many participants. *I felt that that wasn't a very good treatment for me*	disease and prevention. <u>Implications for research:</u> - A future study should focus on migrant workers' barriers to accessing care for TB treatment. **Source of funding:** Sigma Theta Tau International for research funding through the Doris Bloch Research Grant.

			because I felt that it started affecting parts of my body. I felt nauseous . . . I started feeling the fatigue. My finger started to feel really stiff. The bone ache, the tiredness . . . . I blame the pill treatment. It was all happening because of that because I was fine when I was released [from the hospital]. After that treatment I started feeling all those symptoms. (Participant 2, translated from Spanish) <u>Importance of family (familismo)</u> All participants spoke of the importance of their families to their TB diagnosis, treatment, and process of living with TB; the familismo concept (Marin & Marin, 1991). In general, those who told their families about the treatment found support and acceptance. Those who did not tell their families about their diagnosis and treatment missed out on this familial support and acceptance. *My son and my daughter-in-law accompanied me, and my mother as well . . . . They never rejected me . . . [M]y son who lives here told me to come here to be treated, because I was alone in Mexico so I decided to come here.* (Participant 10, translated from Spanish) Family was the key source of support for participants who told their families of the TB status. *In the treatment for tuberculosis, . . . they did make a difference. Not my friends, but my family present here.. . . And they have been a really good support because they have helped me to do my best, take my pills, finish the treatment because otherwise, you know, if you want a relapse and it will be harder.* (Participant 2, translated from Spanish)	

			Five participants kept their TB status a secret: they did not want to be a burden; they were ashamed; or they were protecting their family members from the stigma of TB. One participant's father had recently died from TB, and her mother had kept it a secret. She kept her TB status a secret: *At home they know that I'm taking medication for my lungs, I haven't told them. No, I don't dare. I'm afraid. [My mother] will be worried, because although I'm under treatment, she only knows that I'm taking medication for my lungs but she doesn't know why.* (Participant 7, translated from Spanish) Some spoke of trying to protect their families, not wanting to be discriminated against by their family, and not wanting to spread the disease to their family: *I will never tell them. I haven't told my brothers. I told them I didn't want them to come and visit me. My sister's son used to come here and stay in a room back there, . . . but I told him I didn't want him to stay here any longer. My sons . . . were disappointed because I told him not to come, but I would never tell them the disease I had.* (Participant 18, translated from Spanish) <u>Stigma</u>. Some participants did not let their family visit or contact them because of the fear of stigma. The resulting isolation plays a key role in the experience of stigma from TB. Participants did not like wearing masks for two reasons: physical discomfort and stigma. *I didn't like it but I had to wear it . . . . I felt like I*	

			couldn't breathe. I felt that everybody looked at me sort of saying, oh, she's infected, she's going to infect me. That's why I tried not to go out. (Participant 7, translated from Spanish) Participants feared that wearing the mask prevented the participants from keeping their TB status secret; if they wore the mask, people would know they were infectious. Most chose to stay at home rather than wear a mask. Even without the mask, participants spoke of feeling stigmatized by family and friends because of their TB. Participants talked about losing friends, their family shunning them, and feeling very depressed. Many accepted being shunned and stigmatized, stating that their friends and family were just trying to protect themselves from a disease. Though many had never heard of TB prior to being diagnosed, some participants talked about being told as children to stay away from people with TB. This made them keep their diagnosis secret and further isolated them from others. *I didn't want to bother people and make them feel bad. I'd know anyway why they didn't want to [visit me]. I knew they didn't look for me and I didn't want to look for them . . . . I'll tell them "It's fine you didn't look for me, and I didn't want to look for you because of my disease" and thank God I'm here.* (Participant 10, translated from Spanish) One spoke of how people would not want to take any food and drink from her or anyone in her house. Others talked about being lonely. *A lot of people, they still don't come around because*	

			they think that we're gonna get sick. They're afraid to come near because . . . it is contagious . . . . [I]t can be treated, . . . but if you don't treat it in time, it is pretty contagious. I guess people are kind of right to be cautious . . . . If I was in there, I wouldn't wanna go near somebody I know who has something that might kill me . . . . No. Depending on who asked. Give me a gas mask and I'll go visit you. (Participant 11) Many reported internalizing others' reactions to their disease and beginning to feel depressed and guilty. Many participants spoke about being a burden. *I was treated again for 9 months. I still got one more month to go. . . . And I feel good. The only problem is that sometimes you feel bad . . . when you first get it. . . the family have to go through all this . . . and it's bad, it's real bad . . . . Because at that time, my daughter was living with me, two grandsons and my wife and. . . I used to feel real bad because of me they were going through that.* (Participant 3) *Isolation seemed to intensify depression.* *At the beginning, when they told me I had tuberculosis and it was a very dangerous disease, I was depressed. Because I thought it was a disease like rabies where you can't speak with anyone; I felt badly.* (Participant 8, translated from Spanish) <u>Reaction to stigma.</u> Reacting to stigma, participants limited their exposure to negative reaction from people by keeping their TB status a secret, extending their isolation, and avoiding intimate	

			relationships. Many kept their TB status a secret from people outside their families. *My friends and my relatives knew about, yeah, but like my coworkers, most of them did not know . . . . [T]hey (friends) see you different, they talk bad about you and they never know it might be them or their family and things can turn around . . . you never know . . . what might happen tomorrow. One of your kids might get it.* (Participant 3) Some kept their TB status a secret from their family; they were trying to protect their family, were embarrassed by the diagnosis, or thought their family would reject them if they knew. *I didn't tell them I had tuberculosis. I have two sisters. . . and I never told . . . . I also have nieces here . . . and didn't want to share it with them because I didn't know how they would react; maybe they would . . . say, "Uncle, don't come over to my house, you might pass it on my children," or maybe they would come to investigate because I belong to their family. Do you understand? This is why I didn't want to tell my family; . . . we decided not to say anything.* (Participant 2, translated from Spanish) Apart from isolation being required, participants isolated themselves so they did not have to feel stigmatized, and others kept their distance; this reinforced the isolation. There was a lack of intimacy with spouses and partners. Some spent the entire duration of treatment isolated from other people.	

			Over my dead body I was going to wear a mask . . . . I haven't returned [to church], but when I pass by the church I make the sign of the cross . . . . What I do is when I get home I turn on the TV because they are transmitting a mass. I miss that. (Participant 18, translated from Spanish) Participants talked about their lack of intimate relations since their diagnosis. Participants told they slept separately from their spouses and significant others. *I was dating a girl and had not seen her for a while . . . . I explained to her that I was ill, but I was afraid to be rejected. She said it was fine, she would wait. And I was in doubt if it is right or wrong to have a relationship the way things are right now. That is what I was afraid of because she wanted to hug me and kiss me and I said, "Just wait until I get well" and she said, "I will wait for you." So I don't know if I can have a relationship. I was afraid . . . . In the mean time, no.* (Participant 16, translated from Spanish) Living close to the U.S.–Mexico border influenced participants' perspectives and heightened their isolation. Some of the participants talked about being vulnerable to TB because of the proximity to Mexico, where rates of TB are higher. *There's a lot of people that come over from Mexico, here in the border towns, and that's probably what makes us susceptible to tuberculosis . . . . We're so close to the border. We come into contact with people from Mexico every day.* (Participant 11, translated from Spanish)	

			Many crossed the border in both directions to visit family and friends or to receive treatment. After their TB was diagnosed, several stopped crossing the border either to prevent the spread of TB or because they felt they were discriminated against by the border patrol for wearing a mask during a border crossing. Health care was sometimes first obtained in Mexico and then continued in the United States, perhaps because health care can be less expensive and more accessible in Mexico. *I started with a cough. I couldn't be talking with someone because I would start coughing. I went to Matamoros and they gave me medication for the cough but it didn't disappear. So, the doctor ordered some x-rays and there they discovered that I had water in my lung. They removed the water from my lung and I stopped coughing. Then they sent me to the health centre . . . . My son who lives here told me to come here to be treated, because I was alone in Mexico so I decided to come here.* (Participant 10, translated from Spanish) The border became an additional barrier limiting access to social support, therefore exacerbating social isolation. *I used to go to a bar in Reynosa because it was close to my house and I used to play pool with my friends. I have many retired Mexican friends and we used to get together . . . on Saturdays and Sundays to play pool. I would drink a beer and then back home . . . But I haven't gone back . . . yet.* (Participant 18, translated from Spanish)	

List of Abbreviations

A&E = Accident & Emergency Department; CDM = Critical Decision Method; CL = Community Leaders; DOT = Direct Observed Treatment; DOTS = Direct Observed Treatment Short-course; FG = Focus Group; GP = General Practitioner; HBM = Health Belief Model; HC = Health Care; HEC = Hawthorne Education Center; EHR = Electronic Health Record; HIV = Human Immunodeficiency Virus; IPA = Interpretative Phenomenological Analysis; LRGV = Lower Rio Grande Valley; n = number of participants; NHS = National Health Service; NR = Not Reported; PHC = Primary Health Care; PWIDs = People Who Inject Drugs; SCM = Somali Community Members; TB = Tuberculosis UCL = Univeristy College London; UK = United Kingdom; U.S. = United States

References

1. Bender A, Andrews G, Peter E. Displacement and tuberculosis: recognition in nursing care. *Health Place* 2010; **16**: 1069-76.
2. Coreil J, Mayard G, Simpson KM, Lauzardo M, Zhu Y, Weiss M. Structural forces and the production of TB-related stigma among Haitians in two contexts. *Soc Sci Med* 2010; **71**: 1409-17.
3. Vukovic DS, Nagorni-Obradovic LM. Knowledge and awareness of tuberculosis among Roma population in Belgrade: a qualitative study. *BMC Infect Dis* 2011; **11**: 284.
4. Gerrish K, Naisby A, Ismail M. The meaning and consequences of tuberculosis among Somali people in the United Kingdom. *J Adv Nurs* 2012; **68:** 2654-63.
5. Sagbakken M, Bjune GA, Frich JC. Humiliation or care? A qualitative study of patients' and health professionals' experiences with tuberculosis treatment in Norway. *Scand J Caring Sci* 2012; **26**: 313-23.
6. Wieland ML, Weis JA, Yawn BP, et al. Perceptions of tuberculosis among immigrants and refugees at an adult education center: a community-based participatory research approach. *J Immigr Minor Health* 2012; **14**: 14-22.
7. Croft LA, Hayward AC, Story A. Tuberculosis peer educators: personal experiences of working with socially excluded communities in London. *Int J Tuberc Lung Dis* 2013; **17**: 36-40.
8. Gerrish K, Naisby A, Ismail M. Experiences of the diagnosis and management of tuberculosis: a focused ethnography of Somali patients and healthcare professionals in the UK. *J Adv Nurs* 2013; **69**: 2285-94.
9. Kawatsu L, Sato N, Ngamvithayapong-Yanai J, Ishikawa N. Leaving the street and reconstructing lives: impact of DOTS in empowering homeless people in Tokyo, Japan. *Int J Tuberc Lung Dis* 2013; **17**: 940-6.
10. Wannheden C, Westling K, Savage C, Sandahl C, Ellenius J. HIV and tuberculosis coinfection: a qualitative study of treatment challenges faced by care providers. *Int J Tuberc Lung Dis* 2013; **17**(1029-35.
11. Craig GM, Joly LM, Zumla A. 'Complex' but coping: experience of symptoms of tuberculosis and health care seeking behaviours--a qualitative interview study of urban risk groups, London, UK. *BMC public health* 2014; **14**: 618.
12. Zuniga JA, Munoz SE, Johnson MZ, Garcia A. Tuberculosis treatment for Mexican Americans living on the U.S.-Mexico border. *J Nurs Scholarsh* 2014; **46**: 253-62.

Supplementary Material IV: Evidence Statements

Below are evidence statements based on the current review and the previous NICE review.[1]
Evidence was graded as follows:

No evidence – no evidence or clear conclusions from any studies;
Weak evidence – no clear or strong evidence/conclusions from high quality studies and only tentative evidence/conclusions from moderate quality studies or clear evidence/conclusions from low quality studies;
Moderate evidence – tentative evidence/conclusions from multiple high quality studies, or clear evidence/conclusions from one high quality study or multiple medium quality studies, with minimal inconsistencies across all studies;

Evidence Statement 1·1: Views on Susceptibility (SUS)

Correctly perceived factors among the hard-to-reach groups were: food-related (poor nutrition), interactions with HIV, lifestyle factors, airborne transmission and smoking. Misconceptions included connections with flu and pneumonia, God, hereditary causes, stress, blood and blood type, sharing of utensils, and rats as vectors.

SUS1. **Strong evidence** from ten studies, of which nine were identified by the previous review,[1] suggests that hard-to-reach participants commonly view **smoking** as a risk factor for or cause of tuberculosis (TB). These views were reported by studies with:

- mixed migrant groups in the United States (USA)[2] (Wieland et al. (2012) [++])

Identified in the previous review:[1]

- a range of hard-to-reach participants (e.g., migrants, prisoners) in the UK[3] (BRF, 2007 [++]); homeless participants in the USA[4,5] (Kitazawa, 1995 [+]; West et al., 2008 [+]);
- mixed migrant groups in the United Kingdom (UK)[6] (Brewin et al., 2003 [+]) and Canada[7] (Gibson et al., 2005 [++]); Somali migrants in the UK[8] (Gerrish et al., 2010 [++]);
- Somali and Ethiopian migrants in Norway[9] (Sagbakken et al., 2010 [+]);
- Asian migrants (Chinese, Vietnamese) in the UK[10] (Johnson, 2006 [-]) and the USA[11] (Fujiwara, 2000 [-]).

SUS2. **Strong evidence** from eight studies that hard-to-reach participants commonly view **food- or diet related factors (e.g., poor nutrition)** as a risk factor for or cause of TB, reported in studies with:

- a range of hard-to-reach groups in the UK[12] (Craig et al. (2014) [++])
- Roma migrants in Serbia[13] (Vukovic and Nagorni-Obradovic (2011) [+])
- mixed migrant groups in the USA[2] (Wieland et al. (2012) [++])

Identified in the previous review:[1]

- homeless participants in the USA[4] (Kitazawa, 1995 [+]; West et al., 2008 [+]);
- mixed migrant groups in the UK[6] (Brewin et al., 2003 [+]);
- African migrants in the UK[10] (Johnson, 2006 [-]) and Norway[9] (Sagbakken et al., 2010 [+]); and
- Asian migrants in the UK[10] (Johnson, 2006 [-]).

SUS3. **Strong evidence** from eight studies that hard-to-reach participants commonly assign **hereditary causes** to TB, reported in studies with:

- Somali migrants in the UK[14,15] (Gerrish (2012) [++]; Gerrish et al. (2013) [+])
- Roma migrants in Serbia[13] (Vukovic and Nagorni-Obradovic (2011) [+])

Identified in the previous review:[1]

- a range of hard-to-reach and homeless participants in the UK[10] (Johnson, 2006 [-]);
- mixed migrant groups in Canada[7] (Gibson et al., 2005 [++]) and New Zealand[16] (Van der Oest et al., 2005 [-]); and
- African migrants in the UK[8,17] (Nnoaham et al., 2006 [++]; Gerrish et al., 2010 [++];).

SUS4. **Strong evidence** from eight studies suggests that hard-to-reach participants may believe that susceptibility to TB is higher when a person has **another illness**, such as:

- HIV: A range of hard-to-reach groups in the UK[12] (Craig et al. (2014) [++]); Haitian Migrants in the USA[18] (Coreil et al. (2010) [+])
- flu, common cold or pneumonia: Somali migrants in the UK[15] (Gerrish (2012) [++]) and Roma migrants in Serbia[13] (Vukovic and Nagorni-Obradovic (2011) [+]) and identified in the previous review:[1] African migrants in the UK[8,17] (Nnoaham et al., 2006 [++]; Gerrish et al., 2010) [++]).

Identified in the previous review:[1]

- AIDS[5] (homeless people in the USA; West et al., 2008 [+]);
- low immunity[10] (Asian migrants in the UK; Johnson, 2006 [-]);
- asthma[8] (Somali migrants in the UK; Gerrish et al., 2010 [++]).

SUS5. **Strong evidence** from eight studies that hard-to-reach participants commonly view **poverty (including poor living conditions)** as a risk factor for or cause of TB, reported in studies with:

- a range of hard-to-reach groups in the UK[12] (Craig et al. (2014) [++])
- Somali migrants in the UK[15] (Gerrish (2012) [++])
- Roma migrants in Serbia[13] (Vukovic and Nagorni-Obradovic (2011) [+])

Identified in the previous review:[1]

- homeless participants in the USA[5] (West et al., 2008 [+]);
- mixed migrant groups in the UK[6] (Brewin et al., 2003 [+]);
- Somali migrants in the UK[8] (Gerrish et al., 2010 [++]);
- Somali and Ethiopian migrants in Norway[9] (Sagbakken et al., 2010 [+]); and Vietnamese migrants in the USA[19] (Houston et al., 2002 [+]).

SUS6. **Strong evidence** from six studies suggests that hard-to-reach participants sometimes consider the **sharing of objects,** such as cutlery, as a likely transmission mechanism, in Somali migrants in the UK[15] (Gerrish (2012) [++]) and,
Identified in the previous review in:[1]

- a range of hard-to-reach participants in the UK[10] (Johnson, 2006 [-]);
- homeless people in the USA[4,5] (Kitazawa, 1995 [+]; West et al., 2008 [+]);
- mixed migrant groups in the UK[6] (Brewin et al., 2003 [+]); and
- African migrants in the UK[17] (Nnoaham et al., 2006 [++]).

SUS7. **Moderate evidence** from four studies that hard-to-reach participants commonly view **handshaking, blood, saliva and / or sexual contact** as a mode of transmission of TB, reported in studies with mixed migrant groups in the USA[2] (Wieland et al. (2012) [++]) and Roma migrants in Serbia[13] (Vukovic and Nagorni-Obradovic (2011) [+])
Identified in the previous review in:[1]*:*
A range of hard-to-reach participants in the UK[10] (Johnson, 2006 [-]) and mixed migrant groups in the UK[6] (Brewin et al., 2003 [+]).

SUS8. **Moderate evidence** from three studies that hard-to-reach participants commonly viewed the **'will of God'** as a cause for TB, reported in studies with:

- a range of hard-to-reach groups in the UK[12] (Craig et al. (2014) [++]);
- Somali migrants in the UK[15] (Gerrish (2012) [++]);
- mixed migrant groups in the USA[2] (Wieland et al. (2012) [++])

SUS9. **Strong evidence** from three studies suggests that hard-to-reach participants sometimes consider **lifestyle factors,** as a likely cause, in:

- a range of hard-to-reach groups in the UK[12] (Craig et al. (2014) [++]);
- Somali migrants in the UK[15] (Gerrish (2012) [++]);
- mixed migrant groups in the USA[2] (Wieland et al. (2012) [++])

SUS10. **Weak evidence** from two studies suggests that hard-to-reach participants sometimes consider **their geographical localisation** as a risk (or non-risk) factor for TB; mixed migrant groups and Mexican migrants in the USA[2,20] (Wieland et al. (2012) [++]); Zuñiga et al.(2014)[+])

SUS11. **Moderate evidence** from one study suggests that hard-to-reach participants sometimes consider **airborne transmission** as a likely transmission mechanism, in Somali migrants in the UK[15] (Gerrish (2012) [++])

SUS12. **Weak evidence** from one study suggests that hard-to-reach participants sometimes consider **vectors** such as rats, as a likely transmission mechanism, in Roma migrants in Serbia[13] (Vukovic and Nagorni-Obradovic (2011) [+])

The following topics were only identified in the studies included in the previous review:[1]

SUS13. **Strong evidence** from seven studies suggests that hard-to-reach participants commonly view **environmental conditions** (such as a "dirty" or "wet" environment, or weather-related conditions) as a cause of TB. These views were reported by studies with:

- a range of hard-to-reach participants in the UK[3] (BRF, 2007 [++]);
- homeless participants in the USA[5] (West et al., 2008 [+]);
- mixed migrant groups in Canada[7] (Gibson et al., 2005 [++]);
- Somali migrants in the UK[8,10] (Johnson, 2006 [-]; Gerrish et al., 2010 [++]); and
- Asian immigrants (Chinese, Vietnamese, and Filipino) in the UK[10] (Johnson, 2006 [-]) and the USA[11,21] (Yamada et al., 1999 [++]; Fujiwara, 2000 [-]).

SUS14. **Moderate evidence** from seven studies suggests that hard-to-reach participants commonly view **lack of self-care** ("not looking after yourself") or a health imbalance as risk factors for TB. These views were reported by studies with:

- a range of hard-to-reach participants in the UK[3] (BRF, 2007 [++]);
- homeless participants in the USA[5] (West et al., 2008 [+]);
- mixed migrant groups in the UK[6] (Brewin et al., 2003 [+]) and Canada[7] (Gibson et al., 2005 [++]);
- Somali migrants in the UK[8] (Gerrish et al., 2010 [++]);
- Somali and Ethiopian migrants in Norway[9] (Sagbakken et al., 2010 [+]); and
- Filipino migrants in the USA[21] (Yamada et al., 1999 [++]).

SUS15. **Weak evidence** from two studies suggests that hard-to-reach participants may believe that **stress** is a cause of TB. These views were reported by studies of Somali migrants in the UK[8] (Gerrish et al., 2010 [++]) and Vietnamese migrants in the USA[19] (Houston et al., 2002 [+]).

Evidence Statement 1·2: Views on Severity (SEV)

Members of hard-to-reach groups generally demonstrated fairly accurate views of the symptoms, dangers and methods for prevention of TB; views on curability varied.

SEV1. **Moderate evidence** from six studies suggests that hard-to-reach participants typically understand the main **symptoms** of TB (e.g., persistent cough, weight loss, fever and haemoptysis), and many participants were familiar with other symptoms such as sweating, tiredness, and weakness. Symptoms were discussed by

- Somali migrants in the UK[15] (Gerrish (2012) [++])
- Roma migrants in Serbia[13] (Vukovic and Nagorni-Obradovic (2011) [+])

Identified in the previous review:[1]

- various vulnerable groups in the UK[10] (Johnson, 2006 [-]);
- Somali and Ethiopian migrants in Norway[9] (Sagbakken et al., 2010 [+]);
- homeless participants in the USA had mixed knowledge of symptoms: participants in West et al., 2008 [+] had good knowledge[5] while participants in Kitazawa's (1995) [+] study[4] were generally unaware about typical symptoms of TB.

SEV2. **Moderate evidence** from two studies suggests that participants are aware of the **danger** of TB. Danger was discussed by:

- mixed migrant groups in the USA[2] (Wieland et al. (2012) [++])
- Roma migrants in Serbia[13] (Vukovic and Nagorni-Obradovic (2011) [+])

SEV3. **Inconsistent evidence** arose from six studies concerning participant views on **curability**:
Some Roma migrants in Serbia[13] (Vukovic and Nagorni-Obradovic (2011) [+]) and Somali migrants in the UK[15] (Gerrish (2012) [++]) thought TB was curable, whereas others thought it was incurable. Mixed migrant groups in the USA[2] (Wieland et al. (2012) [++]) feared TB to be incurable.
Identified in the previous review:[1]
Chinese migrants in the USA viewed TB as a curable disease[11] (Fujiwara, 2000 [-]), but a lack of understanding about curability was evidenced by African migrants in the UK[22] (Marais, 2007 [++]) and homeless people in the USA (Kitazawa, 1995 [+]).

SEV4. **Strong evidence** from five studies suggests that participants are aware of the **fatality** of TB. Fatality was discussed by:

- mixed migrant groups in the USA[2] (Wieland et al. (2012) [++])

Identified in the previous review:[1]

- Somali participants in the UK[8] (Gerrish et al., [++]);
- African migrants in the UK[22] (Marais, 2007 [++]);
- various vulnerable groups in the UK[10] (Johnson, 2006 [-]); and homeless people in the USA[5] (West et al., 2008 [+]).

SEV5. **Moderate evidence** from two studies suggests that participants are aware of some **preventive measures** for TB, such as an appropriate diet and improved living conditions. Prevention was discussed by Roma migrants in Serbia[13] (Vukovic and Nagorni-Obradovic (2011) [+]) and mixed migrant groups in the USA[2] (Wieland et al. (2012) [++]).

The following topics were only identified in the studies included in the previous review:[1]

SEV6. **Inconsistent evidence** from five studies discussed participant views on **traditional and modern medicine.** Somalis in the UK[3] (BRF, 2007 [++]), Filipinos in the USA[21] (Yamada et al., 1999 [++]), and Vietnamese migrants in the USA[19] (Houston et al., 2002 [+]) all mentioned acceptance of the use of both traditional and modern approaches to treatment. Somalis in the UK[3] (BRF, 2007 [++]); African migrants in the UK[22] (Marais, 2007 [++]); and Chinese, Maori, and Pacific Islanders in New Zealand[16] (Van der Oest et al., 2005 [-]) generally preferred using traditional medicines first. In contrast, Somalis in New Zealand are happy to seek modern treatments first because of their experiences with TB-related deaths in their home country[16] (Van der Oest et al., 2005 [-]). In other words, different migrant groups in various Western countries had varying opinions about the role that traditional and modern medicines should play in treating TB.

Evidence statement 1·3: Facilitators and barriers to testing and treatment (FABA)

Using the literature, we have identified various potential facilitators and barriers to testing and treatment.

Facilitators

1. Nurse support
2. Family support
3. Hospitalization and care

Additional facilitators identified in the previous review[1] were:

- Religious beliefs and support
- Culturally-sensitive and appropriate care

Barriers:

1. Complications with access
2. Symptoms and side effects
3. Stress, depression
4. Loss of privacy / lack of confidentiality
5. Threat of hospitalization / paternalistic Direct Observed Treatment Short-course (DOTS)
6. Stigma
7. Inadequate service provision
8. Economic struggles

Additional barriers identified in the previous review[1] were:

- Lack of coping mechanisms
- Low standard of care
- Inadequate service provision and access (will be compared with "1. Complications with access")
- Fear, anxiety, and denial
- Language and culture differences
- The difficulties of treatment
- Lack of symptoms (will be compared with "2. Symptoms and side effects")

Potential facilitators

FABA1. **Moderate evidence** from three studies stressed that **nurse support** was identified as an important facilitator for patient treatment compliance.

Nurse support was discussed by:

- migrant TB patients in Canada[23] (Bender et al. 2010 [-])
- Somali migrants in the UK[14] (Gerrish (2013) [+])
- homeless TB patients in Japan[24] (Kawatsu et al. 2013 [+])

FABA2. **Inconsistent evidence** from four studies on **family and friend support** was available.
Family and friend support as facilitators was considered important by:

- Somali migrants in the UK[14] (Gerrish et al. 2013 [+];
- Mexican Americans near the USA-Mexico border[20] (Zuniga et al. 2014 [+])

However, from the previous review,[1] **inconsistent evidence** arose from two studies; for some Vietnamese refugees in the USA, families were identified as key in supporting compliance, while other participants often worried about what would happen to their dependents[25] (Ito, 1999 [+]). HIV-infected patients with TB in respiratory isolation in the USA reported either support or discouragement to continue treatment from family members[26] (Kelly-Rossini et al., 1996 [+]).

FABA3. **Conflicting evidence** from three studies suggested that **hospitalization and strict Direct Observed Treatment** (**DOT) policy** were viewed by some patients as an expression of care and can therefore be considered as a facilitator for treatment compliance. However, this conflicted with evidence in the same studies and one additional study[18] (Coreil et al. 2010) that the **threat of hospitalization and the paternalistic approach of DOT** had a negative effect on patient life and state of wellbeing and how they coped with treatment.
Hospitalization and DOT was discussed by:

- non-infected Haitians in the USA[18] (Coreil et al. 2010 [+])
- various hard-to-reach TB patients in the UK[12] (Craig et al. 2014 [++])
- Somali and Ethiopian migrants in Norway[27] (Sagbakken et al. 2012 [++])
- Mexican Americans near the USA-Mexico border[20] (Zuniga et al. 2014 [+])

FABA4. **Moderate evidence** from four studies found that **culturally-sensitive** and appropriate care increased **access and adherence** to treatment. This topic was discussed by:

- Homeless TB patients in Japan[24] (Kawatsu et al. 2013 [+])

Identified in the previous review:[1]

- Nnoaham et al.'s (2006) [++] sample of African migrants in the UK found that counselling by healthcare providers, personalised care from specialist nurses, and advice from well-informed peers could improve adherence to treatment.[17]
- Many women and men from Muslim communities also noted the ability to access gender-compatible services as a facilitator to service access[22] (Marais, 2007 [++]). Whoolery (2008) [++] suggested that face-to-face support and good rapport with healthcare professionals from the time of diagnosis, appropriate care delivery, and positive hospital experiences were important facilitators in the successful treatment of homeless persons in London.[28]

The following topics were identified in the studies included in the previous review:[1]
FABA5. **Weak evidence** from two studies suggested that **religious beliefs** could be a **source of hope and a coping strategy.** For Somali participants in Sheffield, Islam was a source of hope[8] (Gerrish et al., 2010 [++]). For some HIV-infected patients in the USA, religion offered a coping strategy to deal with respiratory isolation[26] (Kelly-Rossini et al., (1996 [+]).

<u>Potential barriers</u>
FABA6. **Weak evidence** from one study showed that various hard-to-reach groups (migrants, homeless people, drug and/or alcohol users) had **complications with access to care**, caused by drug use or the lack of a GP. As a consequence, they sought care very late. Problems with access to care was reported by:

- various hard-to-reach TB patients in the UK[12] (Craig et al. 2014 [++])

FABA7. **Weak evidence** from one study suggests that hospital delay was caused by people being **unaware that TB was a problem** or by people having **difficulties with transport, time schedules, or duration of testing in testing centres.**
Problems regarding transport, time or recognising TB as a problem were mentioned by:

- mixed migrant groups in the USA[2] (Wieland et al. 2012 [++])

FABA8. **Strong evidence** from eight studies indicated that **difficulties with treatment (e.g., length, side effects**) were a barrier to treatment compliance.
Side effects were reported by:

- mixed migrant groups in the USA[2] (Wieland et al. 2012 [++])
- Mexican Americans near the USA-Mexico border[20] (Zuniga et al. 2014 [+])

Identified in the previous review:[1]

- various migrants in Canada[7] (Gibson et al., 2005 [++]) and
- Vietnamese migrants in the USA[25] (Ito, 1999 [+]).

In the previous review,[1] length of treatment was mentioned to be a concern for:

- vulnerable groups in London[10] (Johnson, 2006 [-]);
- Ethiopian refugee families in Israel[29] (Chemtob et al., 2003 [-]); and
- homeless and drug/alcohol abusers in the USA[5] (West et al., 2008 [+]).

Adhering to TB treatment in the context of substance addiction or use and social exclusion was reported to be difficult for homeless persons in the UK[28] (Whoolery, 2008 [++]).

FABA9. **Moderate evidence** from two studies reported that **stress and depression** complicated TB diagnosis and treatment.
Stress and depression was discussed by:

- Mexican Americans near the USA-Mexico border[20] (Zuniga et al. 2014 [+])
- Somali migrants in the UK[14] (Gerrish et al. 2013 [+]

FABA10. **Moderate evidence** from two studies suggested that **loosing privacy or lack of confidentiality** caused by careless health workers affected patient compliance.
Loss of privacy and confidentiality was reported by:

- Somali and Ethiopian migrants in Norway[27] (Sagbakken et al. 2012 [++])
- non-infected Haitians in the USA[18] (Coreil et al. 2010 [+])

FABA11. **Weak evidence** from three studies illustrated that **discontinuity regarding which health worker is visiting** patients at home and at what time hindered a good patient-health care worker relationship that is important during TB treatment.
Discontinuity was mentioned by:

- Somali and Ethiopian migrants in Norway[27] (Sagbakken et al. 2012 [++])

Identified in the previous review:[1]

- participants in two studies reported feeling stigmatised by attitudes of healthcare staff HIV patients in respiratory isolation[26] (Kelly-Rossini et al., 1996 [+]); African migrants in London[22] (Marais, 2007 [++]).

FABA12. **Conflicting evidence** from two studies mentioned **economic struggles** of TB patients with regards to transport to the clinic, housing, and provision of varied diet. However, another study mentioned that financial constraints did not form a major obstacle. This resonates with the fact that in most OECD (Organisation for Economic Co-operation and Development) countries TB treatment is provided free of charge and most patients were aware of this.
Economic struggles were mentioned by:

- Somali migrants in the UK[14] (Gerrish et al. 2013 [+]
- mixed migrant groups in the USA[2] (Wieland et al. 2010 [++])

FABA13. **Weak evidence** of two studies showed that **masks were identified as a marker of TB** and forced many patients into social isolation because they were afraid to disclose their TB status. Social isolation and non-disclosure of TB patients is a barrier to treatment compliance.
Masks were discussed by:

- Mexican Americans near the USA-Mexico border[20] (Zuniga et al. 2014 [+])
- migrant TB patients in Canada[23] (Bender et al. 2010 [-])

FABA14. **Weak evidence** of one study referred to the **geographical spacing of hospitals (TB and HIV clinic)** speculating the association of **HIV with TB** and aggravating TB stigma.
Geographical spacing of hospitals was reported by:

- non-infected Haitians in the USA[18] (Coreil et al. 2010 [+])

FABA15. **Moderate evidence** of two studies suggests that **internalised stigma** is a big problem among TB patients. Feelings of guilt and shame often lead to reluctance to testing or non-disclosure and can be identified as barriers to diagnosis and adequate TB care. Moreover, non-disclosure hinders contact tracing.
Internalised stigma was discussed by:

- Somali migrants in the UK[14] (Gerrish et al. 2013 [+])
- Mexican Americans near the USA-Mexico border[20] (Zuniga et al. 2014 [+])

FABA16. **Strong evidence** of four articles describes **the consequences that TB stigma** caused among many participants, i.e. psychological distress, because of discrimination, social isolation, not sharing food, sleeping apart from their partners, losing employment and friendships. This occurred both among Somali migrants in the UK, Mexican Americans near the USA-Mexico border, and Haitian community members in Florida.
The consequences of stigma were mentioned by:

- Somali migrants in the UK[14] (Gerrish et al. 2013 [+])
- Somali migrants in the UK[15] (Gerrish et al. 2012 [++])
- non-infected Haitians in the USA[18] (Coreil et al. 2010 [+])
- Mexican Americans near the USA-Mexico border[20] (Zuniga et al. 2014 [+])

FABA17. **Weak evidence** from one study showed that stigma is aggravated in Florida by a **negative presentation of Haitians in the media**. They are presented as a marginalized and disadvantaged social group who are spreading diseases such as TB. These stigmatizing images can lead to non-disclosure of TB patients and influence TB diagnosis and treatment compliance. This evidence was limited to the Haitian group in Florida and did not occur among other hard-to-reach groups.
Negative presentation of Haitians in the media was mentioned by:

- non-infected Haitians in the USA[18] (Coreil et al. 2010 [+])

FABA18. **Strong evidence** from three studies suggested that a **lack of knowledge and avoiding taboos such as mentioning TB within conversations** is a cause for stigmatizing attitudes among community members. They stress the need for more sensitization programmes to educate about TB infection and treatment in order to reduce fear and stigmatizing actions.
Lack of knowledge and taboos were reported by:

- Somali migrants in the UK[14] (Gerrish et al. 2013 [+]
- non-infected Haitians in the USA[18] (Coreil et al. 2010 [+])
- mixed migrant groups in the USA[2] (Wieland et al. 2010 [++])

FABA19. **Strong evidence** from 15 studies indicates that **stigmatisation** is an important concern for people with TB and their families. **Social isolation** is a key feature of stigmatisation for many hard-to-reach groups:

- Ethiopian and Somali TB patients in Norway[27] (Sagbakken et al., 2012 [++]);
- Haitian migrants and TB patients in Florida, USA[18] (Coreil et al. (2010) [+]);
- Somali TB patients in the UK[14] (Gerrish et al. (2013) [+]);
- Mexican TB patients in the USA[20] (Zuñiga et al. (2014) [+]); and
- a group of mixed migrants in Canada[23] (Bender et al. (2010) [-])

Identified in the previous review:[1]

- a range of hard-to-reach participants (e.g., immigrants, prisoners) in the UK[3] (BRF, 2007 [++]);
- Somali immigrants in the UK[8] (Gerrish et al., 2010 [++]);
- mixed immigrant groups in Canada[7] (Gibson et al., 2005 [++]);
- African immigrants in London[17] (Nnoaham et al., 2006 [++]);
- various refugee and minority ethnic groups in New Zealand[16] (Van der Oest et al., 2005 [-]);
- Filipino immigrants in the USA[21] (Yamada et al., 1999 [++]);
- homeless persons in the UK[28] (Whoolery, 2008 [++]).

FABA20. **Strong evidence** from four studies indicates that perceptions of a **link between TB and HIV** increases concerns about stigmatisation for Haitian migrants and TB patients in Florida, USA[18] (Coreil et al. (2010) [+]) and, as reported in the previous review[1], for various migrant groups in the UK[10,17,22] (Johnson, 2006 [-]; Nnoaham et al., 2006 [++]; Marais, 2007 [++])

The following topics were identified in the studies included in the previous review:[1]

FABA21. **Inconsistent evidence** from three studies suggests that some participants viewed the **standard of care** as low. Common themes included feelings of staff being neglectful (HIV patients in respiratory isolation[26] (Kelly-Rossini et al., 1996 [+]); drug users in the USA[30] (Curtis et al., 1994 [+])) or disrespectful[30] (Curtis et al., 1994 [+]). However, one study on Somali migrants in Sheffield reported that patients were generally happy with their TB services[8] (Gerrish et al., 2010 [++]).

FABA22. **Strong evidence** from three studies indicated a **lack of information or awareness** about service availability or access for vulnerable groups in London[3] (BRF, 2007 [++]), Somali migrants in London[22] (Marais, 2007 [++]), or Chinese migrants in New York[11] (Fujiwara, 2000 [-]).

FABA23. **Weak evidence** from four non UK studies suggested that the **cost of TB** services was a concern for some participants, in particular, Chinese migrants in New York (Fujiwara, 2000 [-]); various migrants in New Zealand[16] (Van der Oest et al., 2005 [-]); and homeless people in the USA[5] (West et al., 2008 [+]).

FABA24. **Strong evidence** from five studies suggests that hard-to-reach groups (mostly African migrants) have a lack of confidence in or are concerned about **misdiagnoses or delayed diagnosis by healthcare professionals**. Groups that mentioned these concerns included: Somalis in Sheffield[8] (Gerrish et al., 2010 [++]); various vulnerable groups including HIV patients in London[10] (Johnson, 2006 [-]); African migrants in London[17,22] (Nnoaham et al., 2006 [++];Marais, 2007 [++]); and Somali and Ethiopian migrants in Norway[9] (Sagbakken et al., 2010 [+]).

FABA25. **Strong evidence** from five studies suggests that various hard-to-reach groups felt that **fear of death from TB** was a barrier to wanting to be screened. This was mentioned by: various vulnerable groups in London[3] (BRF, 2007 [++]); Somali migrants in Sheffield[8] (Gerrish et al., 2010 [++]); Filipino migrants in Hawaii and California[21] (Yamada et al., 1999 [++]); homeless people in San Francisco[4] (Kitazawa, 1995 [+]); and homeless people in the North-Eastern USA[31] (Swigart & Kolb, 2004 [+]).

FABA26. **Strong evidence** from three studies shows that **language barriers** between service users and service providers are a concern for many hard-to-reach migrant populations. This was evident for Somalis in Sheffield[8] (Gerrish et al., 2010 [++]); migrant Africans in London[22] (Marais, 2007 [++]); and various refugee and minority ethnic groups in New Zealand[16] (Van der Oest et al., (2005 [-]).

FABA27. **Moderate evidence** from three studies suggests that non-compliance with treatment often occurs when a patient **no longer shows symptoms** of TB, even though their course of treatment has not finished. This was mentioned in relation to Somali patients in Sheffield[8] (Gerrish et al., 2010 [++]); substance misusers in London[10] (Johnson, 2006) [-]); and Vietnamese people receiving treatment in California[25] (Ito, 1999 [+]).

Evidence Statement 1·4: Cues to Action (CUE)

CUE1. **Conflicting evidence** arose from three studies concerning the **timing participants sought care.** Somali migrants in the UK[14] (Gerrish (2013) [+]) reported to have accessed health care early after symptom onset; Roma migrants in Serbia[13] (Vukovic and Nagorni-Obradovic (2011) [+]) stated that Roma people generally seek care late, and drug users in the UK[12] (Craig et al. (2014) [++]) generally looked for help rather late, or they did not look at all; in those instances care had to come to them.

The following topic was only identified in the studies included in the previous review:[1]

CUE2. **Weak evidence** from three studies reported on cues to action. A cue for **Chinese migrants** in London can be a serious symptom (e.g., blood in sputum)[10] (Johnson, 2006 [-]). The most common cue to action among 55 **homeless** people in the USA was family history, while concerns about lung problems, living in a shelter, and the pressures of shelter workers were less common but evident cues[31] (Swigart & Kolb, 2004 [+]). Concerns about the seriousness of TB and concern for others were also mentioned by homeless people in the USA[4] (Kitazawa, 1995 [+]).

Evidence Statement 1·5 Variation of views between hard-to-reach groups (VAR)

No studies comparing the different views between HTR groups were identified; **no further evidence** can be distilled than what was concluded in the previous review.[1]

Evidence statements as cited in the previous review:[1]
VAR1. **Weak evidence** from two studies suggested that **commonalities** emerged across different hard-to-reach groups. These were:

- an understanding of the possible fatal consequences of TB[10] (Johnson, 2006 [-]);
- the stigma associated with diagnosis[10,16] (Johnson, 2006 [-]; Van der Oest et al., 2005 [-]); and
- the importance of language in communicating with migrant and minority ethnic groups[16] (Van der Oest et al., 2005 [-]).

VAR2. **Weak evidence** from two studies noted **differences** between hard-to-reach groups. Differences related to preferences for traditional versus modern medicines and confidence in general practitioners (GPs) or the healthcare system:

- Somalis in the UK had little confidence in GPs, preferring to go to Accident and Emergency[10] (Johnson, (2006 [-]), while Somalis in New Zealand had high confidence in GPs[16] (Van der Oest et al., 2005 [-]).
- Chinese people in the UK visited their GPs, but when they failed to improve they used Chinese practitioners who were seen to have more effective treatment[10] (Johnson, (2006 [-]), while Chinese migrants in New Zealand had a preference for traditional medications[16] (Van der Oest et al., 2005 [-]).
- Maori and Pacific Islanders in New Zealand also had a preference for traditional medications and healers[16] (Van der Oest et al., 2005 [-]).
- people with HIV and prisoners in the UK had little faith in healthcare services, and people with HIV preferred to self-medicate than go to the GP[10] (Johnson, 2006 [-]).

Evidence Statement 1·6: Service providers' views (SPV)

SPV1. **Strong evidence** from eight studies suggested that healthcare workers face challenges to meet the complex care needs of hard-to-reach groups with TB, especially where there are **cultural and language barriers** that make it difficult to interpret symptoms and explain about the disease and its treatment. New evidence was identified in:

- Bender et al. (2010) [-];[23] Sagbakken et al. (2012) [++];[27] Gerrish et al., (2013) [+];[14] and Wannheden et al. (2013) [+].[32]

Identified in the previous review:[1]

- Moro et al., 2005 [++];[33] Marais, 2007 [++];[22] BRF, 2007 [++];[3] and Gerrish et al., 2010 [++].[8]

SPV2. **Strong evidence** from eight studies suggests service providers view a **lack of specialist services and coordination of care** as major difficulty in TB service provision:

- Sagbakken et al. (2012)[++];[27] Gerrish et al., (2013) [+];[14] Wannheden et al. (2013) [+].[32]

Identified in the previous review:[1]

- Jackson & Yuan, 1997 [+];[34] Moro et al., 2005 [++];[33]Belling et al. 2008 [++];[35] and Gerrish et al., 2010 [++].[8]

SPV3. **Weak evidence** from four studies suggested that service providers thought TB-related **cultural barriers and stigma** influenced whether people sought testing or complied with treatment.

- Gerrish et al., (2013) [+] ;[14] Wannheden et al. (2013) [+].[32]

Identified in the previous review:[1]

- Jackson & Yuan, 1997 [+];[34] and Gerrish et al., 2010 [++].[8]

SPV4. **Weak evidence** from one study (Croft et al., (2013) [+]) suggested that **peer education** is a possible effective method for **reintegration in society** for multi-problem ex-TB patients, as well as it is an effective method of **delivering care** for TB patients with similar experiences.[36]

SPV5. **Weak evidence** from one study (Gerrish et al., (2013) [+]) suggested that service providers thought **support from family, TB specialist nurses and health workers** positively influenced treatment compliance.[15]

SPV6. **Weak evidence** from one study (Sagbakken et al. (2012) [++]) suggested that service providers thought **the use of subtle threats** positively influenced treatment compliance.[27]

SPV7. **Weak evidence** from one study (Wannheden et al. (2013) [+]) suggested that service providers thought that the **quality of TB-HIV** care could be **improved by communication between divisions**, **improved guidelines and possibly computer-based support.**[32]

The following topics were only identified in the studies included in the previous review:[1]

SPV8. **Moderate evidence** from three studies[3,35,37] (BRF, 2007 [++], Belling et al., 2008 [++]; and Craig et al., 2008 [-}) suggested that the **complex social and clinical interactions** surrounding a patient with TB can be a challenge to participation and adherence, and that outreach TB link workers or social care workers can facilitate coordination of services.

SPV9. **Weak evidence** from one study[38] of **service providers' views of their own compliance to testing** indicated that service providers can also be afraid of the consequences of contracting TB, including becoming stigmatised. Non-clinical healthcare workers may also have limited knowledge about TB, the need for screening and the implications of a positive test result (Joseph et al., 2004 [+])[38].

List of Abbreviations

AIDS = Acquired Immune Deficiency Syndrome; BRF = Brent Refugee Forum; CUE = Cues; DOT = Direct Observed Treatment; DOTS = Direct Observed Treatment Short-course; FABA = Facilitators and Barriers; GP = General Practitioner; HIV = Human Immunodeficiency Virus; HTR = Hard-To-Reach; OECD = Organisation for Economic Co-operation and Development; SEV = Severity; SPV = Service providers' views; SUS = Susceptibility; TB = Tuberculosis; UK = United Kingdom; USA = United States of America; VAR = Variation

References

1. O'Mara A, Marrero-Guillamon I, Jamal F, Lehmann A, Cooper C, Lorenc T. Tuberculosis evidence review 1: Review of barriers and facilitators. London: Matrix evidence/National Institute for Health and Care Excellence 2010.
2. Wieland ML, Weis JA, Yawn BP, et al. Perceptions of tuberculosis among immigrants and refugees at an adult education center: a community-based participatory research approach. *J Immigr Minor Health* 2012; **14**: 14-22.
3. Knowledge, perceptions and barriers and the social meaning of tuberculosis among asylum seekers, homeless people and refugee communities in Brent 2004–2006. London: Brent Refugee Forum 2007.
4. Kitazawa S. Tuberculosis health education. Needs in homeless shelters. *Public Health Nurs* 1995; **12**: 409-16.
5. West EL, Gadkowski LB, Ostbye T, Piedrahita C, Stout JE. Tuberculosis knowledge, attitudes, and beliefs among North Carolinians at increased risk of infection. *N C Med J* 2008; **69**: 14-20.
6. Brewin P, Jones A, Kelly M, et al. Is screening for tuberculosis acceptable to immigrants? A qualitative study. *J Public Health (Oxf)* 2006; **28**: 253-60.
7. Gibson N, Cave A, Doering D, Ortiz L, Harms P. Socio-cultural factors influencing prevention and treatment of tuberculosis in immigrant and Aboriginal communities in Canada. *Soc Sci Med* 2005; **61**: 931-42.
8. Gerrish K, Ismail M, Naisby A. Tackling TB together: a community participatory study of the socio-cultural factors influencing an understanding of TB within the Somali community in Sheffield. Sheffield: Sheffield Hallam University, 2010.
9. Sagbakken M, Bjune GA, Frich JC. Experiences of being diagnosed with tuberculosis among immigrants in Norway-factors associated with diagnostic delay: a qualitative study. *Scand J Public Health* 2010; **38**: 283-90.
10. Johnson A. Beliefs and barriers related to understanding TB amongst vulnerable groups in South East London. London: Health Protection Agency 2006.
11. Fujiwara PI. Tide pools: what will be left after the tide has turned? *Int J Tuberc Lung Dis* 2000; **4**: S111-6.
12. Craig GM, Joly LM, Zumla A. 'Complex' but coping: experience of symptoms of tuberculosis and health care seeking behaviours-a qualitative interview study of urban risk groups, London, UK. *BMC Public Health* 2014; **14**: 618.
13. Vukovic DS, Nagorni-Obradovic LM. Knowledge and awareness of tuberculosis among Roma population in Belgrade: a qualitative study. *BMC Infect Dis* 2011; **11**: 284.

14. Gerrish K, Naisby A, Ismail M. Experiences of the diagnosis and management of tuberculosis: a focused ethnography of Somali patients and healthcare professionals in the UK. *J adv nurs* 2013; **69**: 2285-94.
15. Gerrish K, Naisby A, Ismail M. The meaning and consequences of tuberculosis among Somali people in the United Kingdom. *J adv nurs* 2012; **68**: 2654-63.
16. van der Oest C, Chenhall R, Hood D, Kelly P. Talking about TB: multicultural diversity and tuberculosis services in Waikato, New Zealand. *N Z Med J* 2005; **118:** U1496.
17. Nnoaham KE, Pool R, Bothamley G, Grant AD. Perceptions and experiences of tuberculosis among African patients attending a tuberculosis clinic in London. *Int J Tuberc Lung Dis* 2006; **10**: 1013-7.
18. Coreil J, Mayard G, Simpson KM, Lauzardo M, Zhu Y, Weiss M. Structural forces and the production of TB-related stigma among Haitians in two contexts. *Soc Sci Med* 2010; **71**: 1409-17.
19. Houston HR, Harada N, Makinodan T. Development of a culturally sensitive educational intervention program to reduce the high incidence of tuberculosis among foreign-born Vietnamese. *Ethn Health* 2002; **7**: 255-65.
20. Zuniga JA, Munoz SE, Johnson MZ, Garcia A. Tuberculosis treatment for Mexican Americans living on the U.S.-Mexico border. *J Nurs Scholarsh* 2014; **46**: 253-62.
21. Yamada S, Caballero J, Matsunaga DS, Agustin G, Magana M. Attitudes regarding tuberculosis in immigrants from the Philippines to the United States. *Fam Med* 1999; **31**: 477-82.
22. Marais F. Towards the improvement of tuberculosis control and participatory research: A multi-method Community-based Participatory Research study of TB in migrant African communities in the borough of Westminster, London. London: Imperial College, Department of Primary Care and Social Medicine 2007.
23. Bender A, Andrews G, Peter E. Displacement and tuberculosis: recognition in nursing care. *Health Place* 2010; **16**: 1069-76.
24. Kawatsu L, Sato N, Ngamvithayapong-Yanai J, Ishikawa N. Leaving the street and reconstructing lives: impact of DOTS in empowering homeless people in Tokyo, Japan. *Int J Tuberc Lung Dis* 2013; **17**: 940-6.
25. Ito KL. Health culture and the clinical encounter: Vietnamese refugees' responses to preventive drug treatment of inactive tuberculosis. *Med Anthropol Q* 1999; **13**: 338-64.
26. Kelly-Rossini L, Perlman DC, Mason DJ. The experience of respiratory isolation for HIV-infected persons with tuberculosis. *J Assoc Nurses AIDS Care* 1996; **7**: 29-36.
27. Sagbakken M, Bjune GA, Frich JC. Humiliation or care? A qualitative study of patients' and health professionals' experiences with tuberculosis treatment in Norway. *Scand J Caring Sci* 2012; **26**: 313-23.
28. Whoolery M. Survivalising among homeless people with tuberculosis: a grounded theory study. Buckinghamshire: Faculty of Society and Health Bucks New University, Brunel University 2008.
29. Chemtob D, Leventhal A, Weiler-Ravell D. Screening and management of tuberculosis in immigrants: the challenge beyond professional competence. *Int J Tuberc Lung Dis* 2003; **7**: 959-66.
30. Curtis R, Friedman SR, Neaigus A, Jose B, Goldstein M, Des Jarlais DC. Implications of directly observed therapy in tuberculosis control measures among IDUs. *Public Health Rep* 1994; **109**: 319-27.
31. Swigart V, Kolb R. Homeless persons' decisions to accept or reject public health disease-detection services. *Public Health Nurs* 2004; **21**: 162-70.
32. Wannheden C, Westling K, Savage C, Sandahl C, Ellenius J. HIV and tuberculosis coinfection: a qualitative study of treatment challenges faced by care providers. *Int J Tuberc Lung Dis* 2013; **17**: 1029-35.
33. Moro ML, Resi D, Lelli B, Nicoli A, Gagliotti C, Falcone F. Barriers to effective tuberculosis control: a qualitative study. *Int J Tuberc Lung Dis* 2005; **9**: 1355-60.
34. Belling R, Woods L, Boudioni M, McLaren S. Pan London Tuberculosis services: An audit evaluation: Institute for Strategic Leadership and Improvement. London: London South Bank University 2008.
35. Jackson L, Yuan L. Family physicians managing tuberculosis. Qualitative study of overcoming barriers. *Can Fam Physician* 1997; **43**: 649-55.
36. Croft LA, Hayward AC, Story A. Tuberculosis peer educators: personal experiences of working with socially excluded communities in London. *Int J Tuberc Lung Dis* 2013; **17**: 36-40.
37. Craig GM, Booth H, Hall J, et al. Establishing a new service role in tuberculosis care: the tuberculosis link worker. *J Adv Nurs* 2008; **61**(4): 413-24.

38. Joseph HA, Shrestha-Kuwahara R, Lowry D, et al. Factors influencing health care workers' adherence to work site tuberculosis screening and treatment policies. *Am J Infect Control* 2004; **32**: 456-61.

Supplementary Material V: Illustrative quotes per theme

Perceived susceptibility		*"It starts with flu and then gets worse and becomes a chest infection. If the infection is not treated, it will change to TB."*[35] *"TB is acquired from bad food, nervousness and worries. Yes it is; when you worry too much then disease appears."*[37] *"There is inherited TB, it will stay with you forever, your grandfather had it, then your father, then you."*[35] *"There's a lot of people that come over from Mexico, here in the border towns, and that's probably what makes us susceptible to tuberculosis . . . . We're so close to the border. We come into contact with people from Mexico every day."*[30] *"(TB is a) curse or punishment by God for dishonest conducts."*[12] *"...there are two kinds of TB: psychological TB and physical TB. Psychological TB is due to too much work, too much worry and stress, which causes TB. Psychological TB does not have microbes … For psychological TB, we need a cure for the mind. For physical TB, we need medicines [antibiotics] and good food"*[57] *"We used the same utensils, shared the same toilet, bathroom, cups and glasses. And we weren't using disinfectants."*[50] *"I thought... he passed it on to me through sex, like HIV."*[50]
Perceived severity		*"Somali people think that anyone who has TB is infectious until he dies."* [35] *"TB is dangerous but curable. You take antibiotics, doctor tells you what to do, and then you can be cured. It is easier nowadays than it was before."*[37] *"It's a killer disease"* [12] *"I didn' t have a clue.... sweating at night I put down to alcohol, the coughing down to smoking and um feeling unwell, down to withdrawal from um, the heroin."* [29] *"You get isolated, people they look at you like you are going to die you cannot getting treated. It is a lack of knowledge obviously that it can get cured."*[47]
Perceived barriers	Difficulties with access	*"I need accommodation and an address first before I register with a GP."*[46] *"It's that once you get to the [shelter], you have to stay there, because if you don't stay there and stand in line, you're not going to get in. And food_s the same way. You have to go stand in line for a couple hours, just so you can get something to eat. So you have to budget your time."*[63]
	Signs, symptoms and adverse effects of medication	*"I felt that that wasn't a very good treatment for me because I felt that it started affecting parts of my body. I felt nauseous . . . I started feeling the fatigue. My finger started to feel really stiff. The bone ache, the tiredness . . . I blame the pill treatment. It was all happening because of that because I was fine when I was released [from the hospital]. After that treatment I started feeling all those symptoms."*[30]
	Stress, depression	*"I was treated again for 9 months. I still got one more month to go. . . . And I feel good. The only problem is that sometimes you feel bad . . . when you first get it. . . the family have to go through all this . . . and it's bad, it's real bad . . . . Because at that time, my daughter was living with me, two grandsons and my wife and. . . I used to feel real bad because of me they were going through that."*[30] *"Some doctor told me I have TB … nightmare … months I am sad, I am cry not in the eye my heart cry [sic]."*[44]
	Loss of privacy/lack of confidentiality	*"They call and say 'where are you living, we can't find you?' They move around on the block, going to the wrong floors, looking at all the doors..."* [36]

	Threat of hospitalization/ paternalistic DOT	*"People feel that this is not their country and then it is hard to protest. This [DOT] only applies for people coming from the third world."* [36] *"You feel... you feel a bit strange... first of all because people... they are different. And I felt that I... I am a grown-up and you take responsibility, right? At home, with children and family and everything... But... you feel like someone who is a suspect."* [36]	
	Inadequate service provision	*"Every day there is a new person [...] They keep ringing on the neighbour's door... they open and then, 'Here you are, your tablets, goodbye.' [The neighbour says] 'I don't expect any tablets' [...] Ah; it's... such a shame."* [36] *"I was coughing lots at night, could not sleep. I went to GP and for 6 months prescribing antibiotics but did not work. After more than 6 months GP sent me to hospital and in examination they said TB."*[47] *"I had chest pain . . . I was brought to the emergency . . . the doctor examined me and gave me a painkiller. As I was about to leave, I coughed and, it was all blood."*[50]	
	Economic struggles	*"I was very ill. It is everything to get back to normal life, to feel fit and strong. It took three years to get back to normal, to find a job."* [32] *"Well, London is hard. Even when I'm at work it's still hard. And now I've been off work with TB it is difficult because like, this month, all my sick pay that they paid me is going to go towards my rent. So this will be a difficult month for me, I must say, it's going to be so difficult."*[47]	
	Stigma	Face masks	*"I didn't like it but I had to wear it . . . . I felt like I couldn't breathe. I felt that everybody looked at me sort of saying, oh, she's infected, she's going to infect me. That's why I tried not to go out."* [30] *"I'm scared… It makes me feel miserable. Makes me feel as if I'm being punished for something that I've done, I don't know what I've done … To start with I didn't really know much about it (TB)… when they started putting masks and that on your face, I never thought I would survive that."*[44]
		Self-stigma / non-disclosure	*"People are only human. When they feel they are going to be treated like this, they will hide the disease. If they experience stigma, it might affect them mentally. If you're isolated and everyone keeps a distance from you because you have TB, then you get depressed."* [35] *"You have to understand—in our culture (Somali), TB is a very sensitive issue […]. They do not want to tell people that they have it or they might have had it at one point in their life. They like to be quiet about it."*[12] *"I will never tell them. I haven't told my brothers. I told them I didn't want them to come and visit me. My sister's son used to come here and stay in a room back there, . . . but I told him I didn't want him to stay here any longer. My sons . . . were disappointed because I told him not to come, but I would never tell them the disease I had."* [30]
		Lack of knowledge	*"The media portray us as last class, bad people that we have nothing to offer, because this is all they can reflect to the community, which is false because they don't get to know us. The themes that are emphasized are that we carry all kinds of diseases and we come here to take away people's job."* [39]
		Consequences	*" [I]t can be treated, . . . but if you don't treat it in time, it is pretty contagious. I guess people are kind of right to be cautious . . . If I was in there, I wouldn't wanna go near somebody I know who has something that might kill me . . . No."* [30]

			"Even when he's had treatment for TB, when he coughs they think he has TB again. They're fearful, they'll keep away." [35] *"When I said I had TB he was shocked, he stopped eating with us.* [35] *"My nephew, who used to come and see me, when he heard that I had TB, started staying away. He thought that if he came close to me, he will contract it and will start dying."*[50] *"Your family member don't come around because they feel you are dirty, and they are afraid that they will be infected by you. They don't want to talk to you."* [60]
Perceived facilitators	Nurse support	*"Coming here was such a relief . . . I could let it all out, and they (the nurses) would listen. It was so good. They would never look down on me, but were always so kind, so polite. Coming here really gave me strength to continue the treatment. You know, many people just give up (the treatment). But they made me feel I could do it . . ."*[33]	
	Family and friend support	*"In the treatment for tuberculosis, . . . they did make a difference. Not my friends, but my family present here . . . And they have been a really good support because they have helped me to do my best, take my pills, finish the treatment because otherwise, you know, you relapse and it will be harder."*[30] *I read the Bible. My husband comes and visits and that helps.*[62]	
	Hospitalization and care	*"I had the money to score my heroin to be able to keep me, in, the A & E Department until I was to be admitted and to get my methadone. You see that was my main concern. I didn' t want to be in a situation where, I' d maybe be in there mayb', I dunno, maybe ten or twelve hours and start withdrawing, not have any heroin and not have any money to score it. Which would then mean I wasted twelve hours."*[29]	
Cues to action	*"We Roma do not go to see a doctor while we can work; only when we lay in bed do we ask for doctor's help."* [37] *"Anyway this w' when was it Tuesday night and I just. I had the money to score my heroin to be able to keep me, in, the A & E Department until I was to be admitted and to get my methadone. You see that was my main concern. I didn' t want to be in a situation where, I' d maybe be in there mayb', I dunno, maybe ten or twelve hours and start withdrawing, not have any heroin and not have any money to score it. Which would then mean I wasted twelve hours."* [29] *"My sister had it [TB] one time. She died from it. She used to smoke, then she had a half a lung ... and she got TB and she died. I thought I better be checked."*[55] *"Um, I figured that since I was passing through, and you know, that I would want to see, that I really didn't pick up nothing from being here."* [55]		

Service providers	*"It can be hard to diagnose TB. Patients can present with vague symptoms, it may be difficult for them to explain what's wrong and it's harder when there are communication difficulties and different cultural perspectives."* [32] *"But above all, we should have more collaboration across, I think. Regardless of how it is solved, because we don't know . . . I have no idea who has tuberculosis there [at the HIV clinic]. I don't know how they manage [tuberculosis]. And that's not good."* [34] *"I think that there are too many people involved in the management of tuberculosis cases."*[52] *"If you see one case of TB every 3 years, does it make a lot of sense for you to invest a huge amount of energy into knowing about this disorder?"* [61] *"Some ethnic minorities are particularly difficult to communicate with: we need cultural mediators."*[52] *"You can't always know everything. You might be used to dealing with Somalians and then get a group of Rwandans, whose health needs are different. I feel fairly comfortable with the Muslims who say, it's Ramadan, I can't take my tablets. I know exactly what to say and I can point to the passage in the Koran where it says it's OK to take tablets if you're ill. But somebody from Vietnam, I know nothing about their health beliefs. And you can't just send people on courses to find out because you just don't know what you're going to get. I've got a middle class mother who won't bring her child in because she doesn't believe in anything. And she's white, middle class. She lives in my suburb and her health beliefs are not available to me."*[42] *"I am sure there [are lots] of TB cases in Canada just treating themselves with Tylenol and cold medicine."*[61]

List of Abbreviations

A&E = Accident & Emergency; DOT = Directly Observed Therapy; HIV = Human Immunodeficiency Virus; TB = Tuberculosis