Public Health England

Protecting and improving the nation's health

Multi Drug Resistant TB Costs Report
Yorkshire and the Humber

Taken to Directors of Public Health Meeting in February 2017

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1. Purpose of report

1.1. To provide:

- Background information on the increasing problems of non-healthcare needs of tuberculosis patients in Yorkshire and the Humber
- An estimate of costs to the system associated with addressing these non-healthcare needs
- Options for discussion to address future non-healthcare needs

1.2. Advice is sought from Directors of Public Health regarding how best to proceed with discussions with Commissioners.

2. Key points

2.1. Tuberculosis (TB) remains a national priority for action and whilst rates of TB are falling the Yorkshire and Humber region has the third highest rate of TB in England and an above average proportion of cases of multi-drug resistant TB (MDR-TB).

2.2. Social circumstances of cases, particularly of those with MDR-TB are becoming increasingly complex, creating difficulties for patients for example where they have no recourse to public funds yet they are unable to work whilst undergoing treatment.

2.3. Costs to public services associated with addressing these complex social circumstances have been estimated for three cases of MDR-TB.

2.4. Costs associated with additional support to address these complex social circumstances were less than the costs associated with staff time ("situational management costs"). Both of these costs were in themselves only a small proportion of the total costs associated with MDR-TB treatment.

2.5. Opportunities exist to reduce future situational management costs and utilise staff time more effectively.

2.6. As local system leaders, Directors of Public Health are requested to consider the evidence and options presented in this paper and advise on the best way forward to progress future discussions with Commissioners.

3. Background

3.1 The "Collaborative Tuberculosis Strategy for England 2015 to 2020" was published in 2015 with the overall aims of reducing the year on year incidence of tuberculosis (TB), reducing health inequalities and ultimately to eliminate TB as a public health problem. The strategy outlines 10 areas for action including improving treatment and care services, reducing drug resistant TB and tackling TB in under-served populations[i].

3.2 Whilst rates of TB in England have been falling over the last 4 years they remain amongst the highest in Western Europe. The majority of TB in the UK occurs in those born abroad, with 60% of all TB cases occurring in non-UK born residents who have lived in the UK for over 6 years. TB disproportionately affects underserved populations including ethnic minorities, refugees & asylum seekers, migrants, those with histories of imprisonment, homelessness or substance misuse and those who are immunocompromised. The proportion of cases with at least one of these risk factors is increasing.[ii]

3.3 In Yorkshire and the Humber, the incidence of TB is below the England 2014 average of 12 per 100,000, falling from 13.2 per 100,000 in 2009 to 9.8 per 100,000 in 2014 with 524 cases recorded in 2014. However the region had the third highest rates of TB nationally behind London and the West Midlands. Additionally, the regional rate masks significant variations within the region ranging from 2 to 20 per 100,000[iii].

3.4 Multi-drug resistant tuberculosis (MDR-TB) is tuberculosis that does not respond to treatment with isoniazid and rifampicin, the two most powerful anti-TB medications. MDR-TB is much more difficult and expensive to treat than non-MDR TB, and patients may require long hospital stays with several months of intravenous medication. Treatment for MDR-TB can last up to two years, occasionally longer, compared with six months for standard TB[iv]. The proportion of MDR-TB cases in Yorkshire and the Humber increased to 2.4% in 2014, above the England average of 1.4%[3]. Whilst absolute numbers are small, the impact of the cases on TB service workload is significant.

3.5 Yorkshire and Humber is leading the way nationally in addressing TB in a number of areas. A Rapid Health Needs Assessment (see Appendix 1) was undertaken in response to concerns about regional negative pressure room capacity required for inpatient treatment of MDR-TB. Some capacity issues were identified in the east of the region and six recommendations were identified (Box 1). Secondly, a narrative report was compiled (Appendix 2), collating case reports and clinician experiences associated with the treatment of complex cases. A number of common themes with significant implications on the ability of cases to complete treatment were identified (Box 2).

Box 1 – Rapid Needs Assessment: Recommendations

Recommendation 1: NHS England should review commissioning and contractual arrangements for specialist infectious disease provision in Yorkshire and Humber and make a clear recommendation on the number of negative pressure beds required in Hull and East Yorkshire Trust to ensure a safe and sustainable specialised infectious disease service.

Recommendation 2: In line with recommendation 1, NHS England should ensure the Trust have the necessary plans in place to mitigate the likely on-going capacity risks identified in relation to provision at Hull and East Yorkshire Trust, and to communicate this to all relevant stakeholders.

Recommendation 3: NHS England should seek assurance from all providers of specialist infectious disease services in Yorkshire and Humber that formalised protocols for routine transfer of patients and surge capacity where required are in place. These protocols should be agreed with commissioners.

Recommendation 4: NHS England should work with CCGs to ensure signposting and access to relevant services and support which may be required where there is an impact on patient and family experience when transfer between units is required.

Recommendation 5: NHS England to ensure alignment between local pathway work and national work including service reviews and clinical commissioning policy to ensure governance and clinical responsibility relating to specialised TB treatment is clear to providers.

Recommendation 6: TB Control Board to provide on-going oversight of system-wide issues when formally established in Sept 2015.

Box 2 – Narrative Report: Common Themes

- Eastern European Cohort with drug resistant TB – increase in number of patients seen, group is not eligible for screening under the national new entrants programme
- Patients with risk factors – patients e.g. homeless or substance misusers often disengaged from mainstream service provision
- Commissioning complexities regarding multi-drug resistant TB – lack of clarity regarding where costs fall, what costs can be recovered, complications regarding the ability to deliver direct observed treatment, lack of clarity regarding funding for family support
- Insufficient paediatric service provision - to meet the needs of paediatric cases with multi-drug resistant TB
- Cultural and language barriers

- Reference laboratories – complications and concerns regarding pathways, timeliness of reporting and communications
- Social factors – social complexities are "the norm" for cases of multi-drug resistant TB with basic issues such as access to benefits, housing, psychosocial support creating difficulties through support not being available, case not being eligible for support, systems being complex to navigate

3.6 There have been some cases of MDR-TB that have been complex in terms of the management of the situation rather than the clinical management of the cases. The underlying explanations for these complexities have often related to the case's inability to undertake employment during the initial treatment period of the condition, and in many cases, the fact that they have no recourse to public funds. The reasons for non-recourse to public funds often relates to them not being UK residents, and having not contributed sufficiently through the national insurance process either due to not having worked at all, or for too short a period to qualify.

3.7 Local Authorities are encouraged to "ensure commissioning of appropriate access to health and social care support to enable patients to complete treatment" whilst Clinical Commissioning Groups are encouraged to "commission appropriate access to services, treatment and support to enable patients to complete treatment"[2].

3.8 NICE Guidance for TB states that Commissioners should ensure that multidisciplinary teams:

- 1.8.7.1 - "have the skills and resources necessary to manage the care of people with complex social and clinical needs"
- 1.8.7.1 - "have access to funds through local government and clinical commissioning groups that can be used flexibly to improve adherence to treatment amongst underserved groups"
- 1.8.11.2 - "multidisciplinary TB teams, commissioners, local authority housing lead officers and other social landlords, providers of hostel accommodation, hospital discharge teams, Public Health England and the Local Government Association should work together to agree a process for identifying and providing accommodation for homeless people diagnosed with active pulmonary TB who are otherwise ineligible for state-funded accommodation" [v].

3.9 To inform future commissioning arrangements, specifically resources and funds referred to in the NICE guidance, a costing exercise was undertaken for cases of MDR-TB where social barriers to the provision and successful completion of treatment existed.

4. Treatment and support costs for MDR-TB

4.1 The costing exercise was undertaken in order to identify:

- costs associated with the provision “additional support” for these cases
- costs associated with the multi-agency situational management for these cases where multi-agency discussions were held with a view to overcoming identified barriers
- costs of treatment and necessary treatment support e.g. transport and translation services

4.2 Two situations covering three cases of MDR-TB were costed for treatment and provision of support. Cases occurred within the last two years within the Yorkshire and Humber region; situation 1 occurred in Hull, situation 2 occurred in North East Lincolnshire. The approach to costings and assumptions utilised are detailed in Appendix 3.

4.3 Situation 1 involved a single case of MDR-TB in a female migrant from Eastern Europe with chaotic social circumstances. In order to minimise the risk to public health it was necessary on a number of occasions to obtain Part 2a orders from a Magistrate under the Public Health (Control of Disease) Act 1984 and the Health Protection (Part 2A Order) Regulations 2010 so as to ensure that the case undertook treatment. The use of these orders across the country is relatively rare and they are enforced by Local Authority Environmental Health Officers. The case had no recourse to public funds so it was ultimately agreed that funding would be provided for accommodation and food so as to ensure that the case was able to complete their treatment.

4.4 Situation 2 involved a case of MDR-TB in a female migrant from Eastern Europe (Case One) with three children. The three children were cared for by family members whilst the case was receiving inpatient treatment for nearly 7 months at a hospital which was a substantial distance from the children. There was a lack of funds available to support visits by the children to the case in hospital. Interim funding for a weekly taxi from the Local Authority and TB Alert was eventually agreed before a voluntary driver was arranged, with a Local Authority vehicle provided and funding for fuel from the Clinical Commissioning Group. Nine adult and eight child contacts with latent TB were identified and required screening on a quarterly basis, for at least 2 years. One adult case of latent TB, a female migrant from Eastern Europe converted to active MDR-TB (Case Two). Difficulties in accessing public funds on discharge from inpatient stays were experienced for both cases with both being advised that they had no recourse to public funds. On discharge Case Two had no accommodation and “sofa surfed” in addition to undertaking employment that was detrimental to their physical health, whilst also supporting one child. Support from the local Housing Association, following multi-agency meetings and further staff input, ultimately enabled public funds to be provided regarding housing though support for food was limited, with Case One relying on food banks and donations from staff involved in managing the case whilst outpatient treatment continued. Both cases were fully compliant with treatment.

4.5 The total cost for Situation 1 is estimated at £174,650 while the total cost for Situation 2 is estimated £398,200. Table 1 provides a summary of costs by Situations, with a further breakdown of costs for each situation illustrated in Figure 1.

Situation	Total	Inpatient Costs	Outpatient Costs including Directly Observed Therapy (DOT)	Treatment Support (transport / translation)	Additional Support	Situational Management
Situation 1	£174,650	£84,125	£ 54,075	NA	£11,250	£25,200
Situation 2 – Case 1	£398,200	£80,850	£118,075	£2725	£3425	£14,575
Situation 2 – Case 2		£37,500	£139,750	£1075	£225	

Table 1 – Summary Costs

4.6 While treatment costs vary significantly across the three cases, these differences can be attributed to differences in the length of inpatient stay in Situation 1, due to the complexity of the social situation which necessitated an increased number of case conferences with broader membership than for Situation 2. In Situation 2, Case One required a longer inpatient stay for clinical reasons than Case Two. Delivery of Direct Observed Therapy through Community Pharmacy in Situation 1 accounts for the substantially lower Outpatient Costs when compared to Situation 2. This is accounted for through the TB service having negotiated an arrangement with a local community pharmacy to provide DOT for an agreed daily charge.

4.7 Treatment costs including inpatient, outpatient and treatment support are addressed through existing commissioning arrangements within the health service. Remaining costs for additional support and situational management, for both situations, fall beyond existing commissioning arrangements and are detailed further in Figure 2.

4.8 Situation 1 had higher situational management costs than Situation 2, partly due to the case having no recourse to public funds and being considered a potential infection risk. Therefore, a local agreement was made that housing would be provided, in addition to a complex care package that included a weekly stipend for essential living costs. Due to the complexity of Situation 1 there were more case conferences with a broader membership, and the need to serve several Part 2A orders incurred legal costs that cannot be easily quantified as they are absorbed into the corporate charge that the Local Authority Public Health team pay internally for shared services. The case themselves was fortunate enough to secure the services of pro bono legal representation for at least one of the Part 2A orders.

4.9 Situation 2 costs for additional support and situational management require consideration jointly. It is not possible to breakdown these costs by cases but Case One accounted for the greater proportion of additional support, multi-agency meetings and staff time. Transport to enable the children to visit Case One in hospital on a weekly basis was ultimately arranged however significant staff time was required to make this possible. Whilst the actual cost of the transport was low the opportunity costs in staff

time were significant. Despite initially having no recourse to public funds direct support for both cases was limited. Costs such as social support for purchasing food provided in Situation 1 were not provided in Situation 2. Needs did however exist, being partially addressed through support from the local food bank and donations of clothing from staff involved in trying to manage the situation.

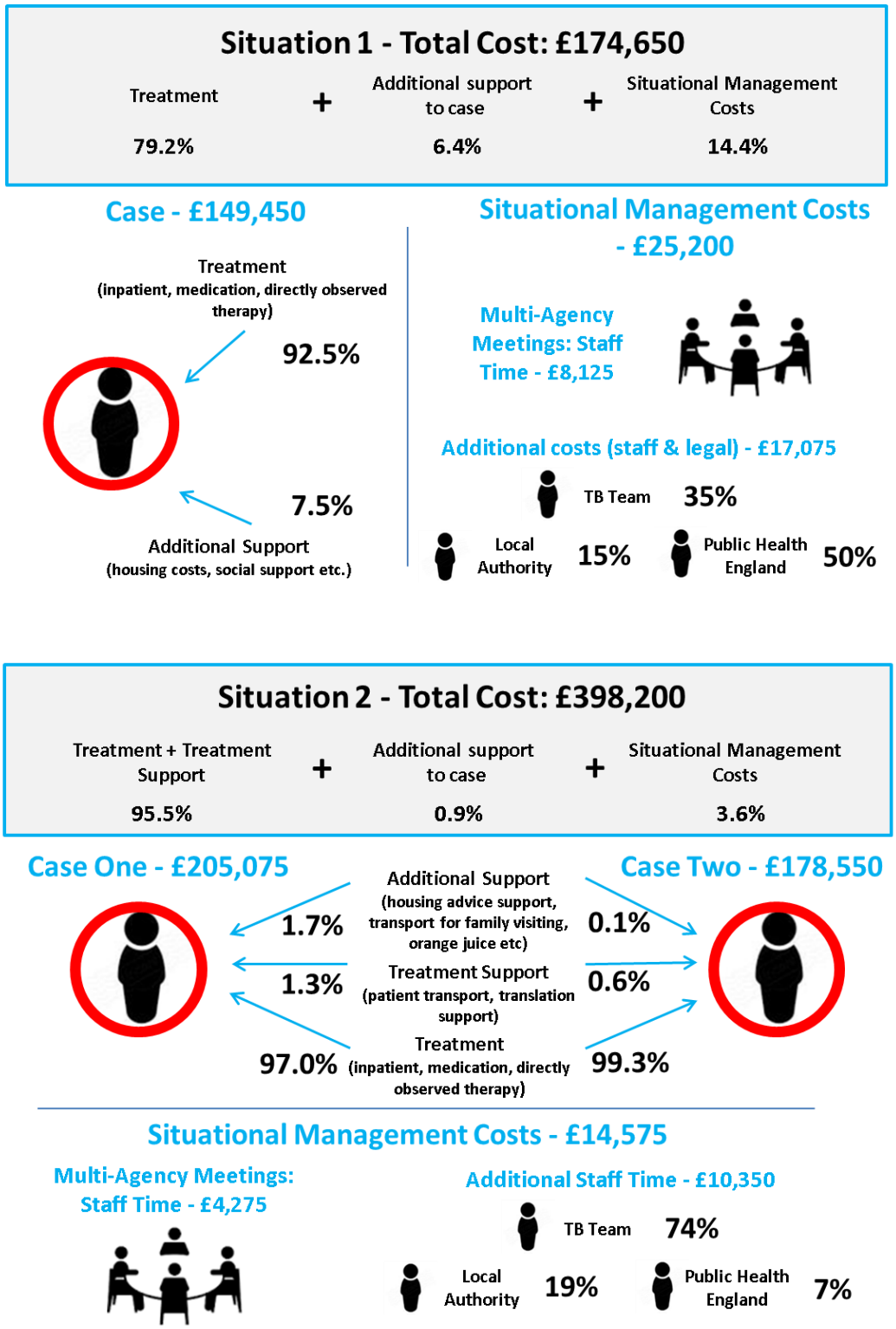

Figure 1 – Total Costs of MDR-TB Situation 1 and 2

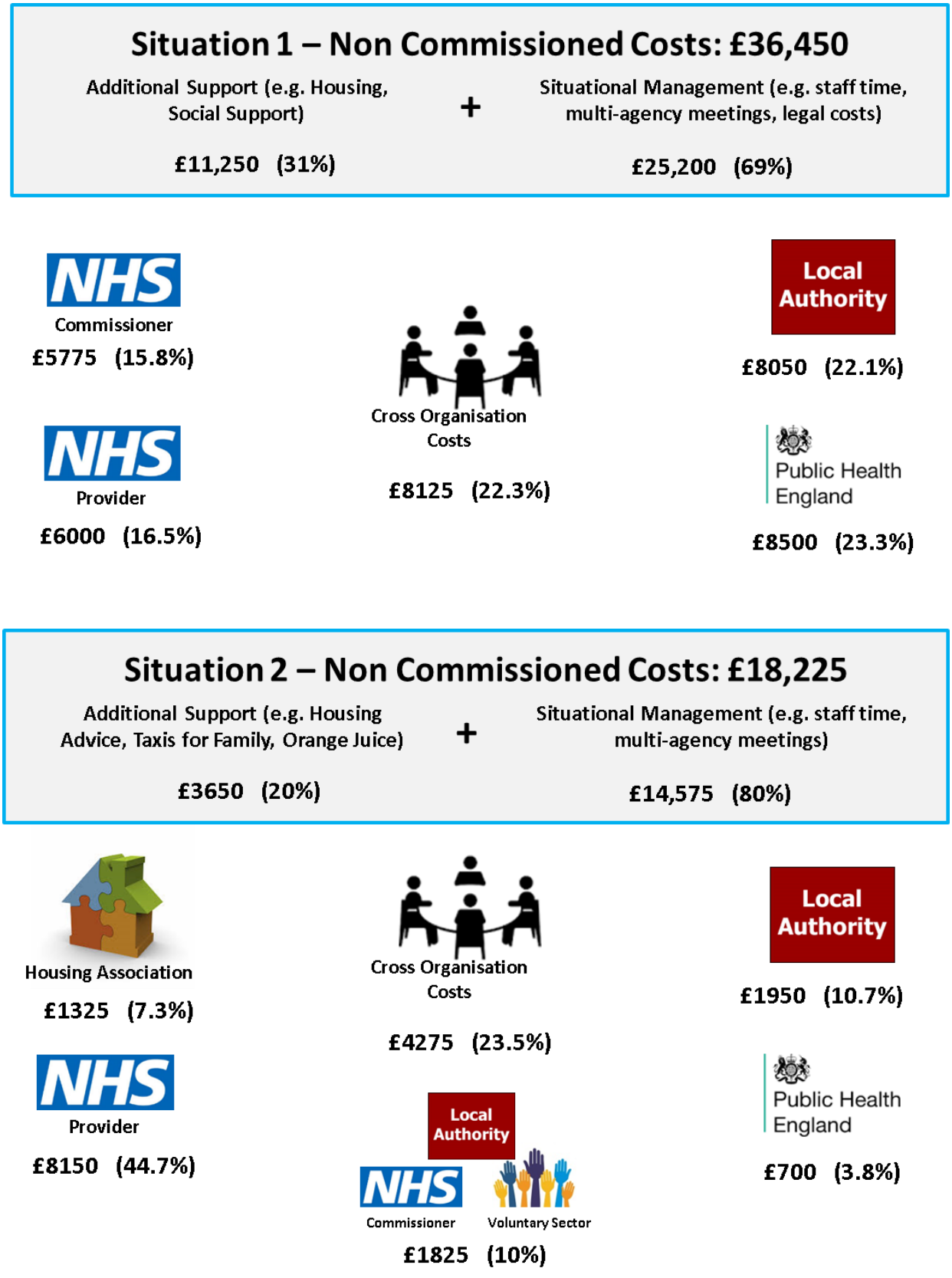

Figure 2 – Organisational Breakdown of Non Commissioned MDR-TB Costs Situation 1 and 2

4.10 All cases were in a similar situation, in that they initially had no recourse to public funds. The costs represented here are not representative of need but the response of the system. Costs shown in Figure 2 highlight that not providing direct financial support for housing and social support does not necessarily reduce costs. Costs continue to be incurred by staff trying to resolve the situation, substantial in case of Situation 2 for the provider. Additionally, costs incurred by the voluntary sector in this instance, for example food banks, have not been captured. Local Authority attributed costs for Situation 1 are primarily the opportunity costs of Public Health staff fulfilling their role as system leaders.

4.11 In both situations, multi-agency meetings were held with a view to establishing a shared understanding of the issues affecting cases, particularly with regard to no recourse to public funds and exploring avenues to address these issues and to manage the associated risks. Situation 1 also included discussions regarding legal measures to ensure that the case completed treatment. These meetings were convened by local staff without supporting guidance or advice regarding how to best address or management such situations. Opportunities exist to learn from the managements of these situations so as to support a future approach which can be structured and streamlined, addressing issues more efficiently. The success of situation 1 relied on the presence of senior members of the relevant organisations, and required a systems leadership approach to be taken; no one organisation was solely responsible for managing the situation, and therefore negotiation and influence across the local system was necessary to ensure that the case, and the population were safe and managed appropriately. The Director of Public Health is often best placed to leverage and manage the necessary relationships within and across the system and has local responsibility around health protection.

5. Options for consideration

5.1 Do Nothing

5.1.1 The current situation leaves clinical staff in a position where they are having to work to resolve non-healthcare needs faced by patients in order to ensure that treatment can be successfully completed. The different approaches in Situation 1 and Situation 2, whilst not directly comparable, show that costs incurred by putting support arrangements in place in Situation 1 are not dissimilar to opportunity costs to the system by not putting such arrangements in place in Situation 2.

5.1.2 Experience gained in responding to issues, whilst helping to create an understanding e.g. of eligibility for housing support, does little to reduce time and effort spent in trying to resolve issues when a future case is not eligible for such support. Opportunity costs across the system are significant particularly when compared to actual costs incurred in providing support. This is not an efficient use of resources and this is not deemed a sustainable approach for the future.

5.2 Maintain Strategic Oversight

5.2.1 Decisions to address issues affecting cases of MDR-TB, which have the potential to jeopardise their treatment, need to be made quickly, in the best interests of both wider public health as well as the individual patients. The British Thoracic Society and PHE are in the process of developing a virtual MDT approach for all cases of MDR-TB. Consideration should be given to developing and adopting a formalised local cross-organisation approach to managing future MDR-TB cases where appropriate and necessary, led by the local Director of Public Health. A local cross-organisation approach for appropriate cases would support the need to manage the individual patient, and protect the population, and ensure that the necessary resources are agreed and made available as required. Developing guidance, such as that utilised for Outbreak Control Meetings as an example, would assist in clarifying roles, responsibilities and expectations for all parties and streamline the management of future cases.

5.3 Risk Pool Approach

5.3.1 By adopting a “risk pool approach” across Commissioners, contributions from each Commissioner would be pooled into a central fund (or other agreed arrangements). Funds would be used when cases present with social complexities requiring resolution in order to support the successful completion of treatment. These complexities may include support for family to visit cases in hospital out of the local area, housing and other appropriate support where there is no recourse to public funds. A risk pool

approach could reduce situational management costs associated with staff trying to resolve issues and multi-agency case conferences.

5.3.2 A similar approached has already been adopted in Middlesborough with the CCG and Local Authority contributing to a fund managed by Adult Social Care which addresses accommodation needs and supports compliance with continued treatment on discharge from secondary care for cases who have no recourse to public funds.

5.3.3 This approach has the advantages of:

- Sharing the risk
- Reducing opportunity costs associated with trying to resolve complex social issues enabling resources to be utilised more efficiently and effectively across a number of public sector organisations
- Providing some certainty to cases of a stable environment in which they can complete their treatment
- Aligns services to national recommendations and NICE guidelines

5.3.4 Implementing this option alongside Option 2 would maximise potential gains.

5.3.5 The rolling average of MDR-TB cases annually across the region between January 2011-December 2012, was 5.33, between January 2013-June 2015 it was 6.4[vi]. Housing and social support provided in Situation 1 was costed at approximately £11,250. Applying this to the above averages provides an estimate of a regional risk pool of £60,000-£72,000 annual, assuming all cases would require such support. As demonstrated in Situation 2, Case 2, this is not necessarily the case.

5.3.6 Considerable savings would be made in situational management costs, for example staff time in Situation 2. Though multi-agency meetings are likely to continue to be required this would be at much a reduced frequency and therefore also contribute to cost savings. A regional risk pool of £60,000-£72,000 is approximately half of the difference in costs of DOT between Situation 1 and Situation 2.

Appendix 1: Costings approach and assumptions

Costs associated with enabling successful completion of treatment were identified and encompassed:

- treatment costs associated with inpatient care, outpatient care, medication and medication delivery e.g. through direct observed therapy.
- treatment support costs such as the provision of patient transport services to attend appointments and translation support
- additional support costs such as provision of housing and housing advice support, food, transport support for visiting family
- situational management costs such as staff time for multi-agency management meetings, costs associated with court orders, specific dedicated staff time in organisations spent on resolving social support issues necessary to enable ongoing treatment e.g. housing or enabling arrangements such as provision of transport support for visiting family to be provided.

Actual costs, or charges to Commissioners were identified where possible. Some costs were projected on the basis of treatment completion scheduled for mid-2017. Tariff costs based on NHS Reference Costs were used in the absence of relevant data for treatment provision and staff costs were based application of staff time estimates and hourly rates from either Personal Social Services Research Unit or Agenda for Change Pay Circular for the year 2014-2015. Costs incurred by cases or their families, for example the foster care of children by relatives are not included. Costs associated with support from Food Banks, staff donations etc are not included.

Costs presented are likely to be underestimates as:

- It has not been possible to establish some specific costs e.g. legal services within a Local Authority due to the manner in which these services are internally charged through an annual departmental charge
- It has not been possible to follow-up or obtain estimates of involvement of all staff involved in the situational management of cases

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