

PROJECT: LONDON



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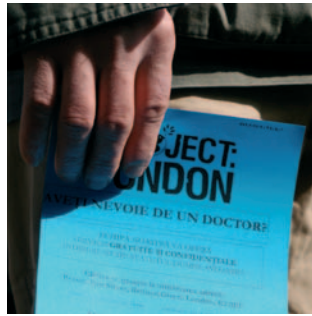
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PROJECT: LONDON



REPORT AND RECOMMENDATIONS 2007

Improving Access to
Healthcare for the
Community's Most
Vulnerable



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would be possible
without the
dedication and
commitment of
our volunteers.
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EXECUTIVE SUMMARY

Our work

For the last two years we have operated a free clinic in East London, reaching out to the community's most vulnerable in order to ensure access to healthcare. The clinic was designed to provide care on a temporary basis, while we work to get patients registered with the NHS. This report combines data from the first two years and provides a brief history of the issues surrounding access to care within the NHS. We examine proposed changes to the regulations which govern access to primary care. And drawing upon the data we collected and the independent research of others, we make recommendations relative to the proposal.

The regulations, explained

GPs currently have the discretion to treat anyone as an NHS patient. But in 2004 the government consulted on a proposal to change the health regulations to bar some migrants from accessing free primary care. The changes would essentially remove this discretion. And as a result people would be turned away from GP care on the basis of immigration status.

At the same time that the government consulted on the proposal, it introduced a change to the regulations which barred the same group of migrants from accessing secondary care. The timing has led to some confusion and we have seen this first hand. Although GPs themselves were usually well informed, the administrative staff responsible for registering patients were often uncertain and confused. In some cases they applied the proposed regulation as if it were already in force. In other cases they even applied the proposed regulation wrongly, extending it to those who it did not apply to - asylum seekers and citizens of EEA countries.

This misunderstanding highlights areas of concern in two important ways:

- It gives us a picture of the kind of people who would be excluded from care and the potential impact of their exclusion.
- It shows that we can expect these restrictions to primary care to be misapplied, by being extended beyond the group they were meant to target.

THE IMPACT OF EXCLUSION

No evidence of health tourism

Two years of data shows that our service users had, on average, been living in the UK for three years before they came to the clinic to see a doctor or to get help accessing healthcare.

No great burden on the NHS

The health problems seen in Project:London service users are broadly reflective of the conditions seen among the general population in general practice. The majority needed help to access primary care or antenatal services rather than expensive specialist treatment. This confirms other independent research with the same results.

No cost savings

It may sound logical to argue that cutting off access to primary care will save money and take pressure off the NHS. But an examination of our findings, alongside other independent research, makes it clear that the opposite is true. Providing early and preventive care through primary care is a means of avoiding costly hospital treatment at a later date.

Prevention

An ounce of prevention is worth a pound of cure, a fact which was the subject of a report from public health experts in 55 countries which pointed out that preventable diseases now cause 60% of deaths worldwide and urged policy makers to take concerted action to move “health systems towards prevention rather than cure”.¹ The report estimated that by doing so 36 million deaths could be prevented by 2015.

The benefits of prevention were recently highlighted in the Prime Minister’s proposal to launch a national screening programme aimed at preventing heart attacks, strokes, kidney failure and diabetes.

As a result of growing rates of hepatitis B, urgent calls have been made for wider vaccination efforts.²

Lack of access also has an impact relative to wider social issues including domestic violence, since the GP surgery is often the first port of call for a victim who is too afraid to contact the police.

Early detection and diagnosis

Failing to prevent or detect a condition only means that it continues to get worse. As a consequence:

- the individual suffers
- he/she becomes less able to work, study, and care for their family
- his/her condition becomes more difficult and more expensive to treat
- if he/she has an infectious disease, it can spread to others

Diseases which are easy and affordable to control, and expensive to ignore

People with diabetes occupy one in ten hospital beds, at a considerable cost to the NHS.³ But recent studies have shown that proactive intervention can facilitate more appropriate care and help save money. A trial which took

such a proactive approach resulted in a cost savings of more than £110,000. If replicated nationwide this would result in a savings of nearly £100 million.⁴

Diseases which spread easily – posing public health concerns for us all

Infectious diseases do not respect borders, nor do they discriminate on the basis of status. We are all at risk from the spread of diseases and we all have a stake in preventing that spread.

Pressure on Accident & Emergency

If people are barred access to GPs, they will be left with no other choice than to seek care at A&E centres. As research has already shown, this places unnecessary pressure on A&E centres, many of which are already short staffed and inadequately equipped to handle the cases that require emergency attention.⁵

The “pull factor”

Debate about healthcare for migrants in the UK tends to be underpinned by a belief that, because NHS care is free at the point of need, Britain is the only country where migrants would have access to publicly-funded care. In fact, this is not true. Most European countries provide migrants with better access to healthcare than the UK does.⁶

Our legal obligations

By virtue of being a signatory to the International Covenant on Economic, Social, and Cultural Rights, the UK government has a duty to respect, protect and fulfil the “right of everyone to the enjoyment of the highest attainable standard of physical and mental health”.⁷ While the realisation of these rights is a process that takes time, the government has committed to their “progressive realisation”. This means that government policies should ensure progression towards attaining the right. The proposed regulations would in fact do the very opposite by further limiting this right to access.

1. Daar A, Singer P, Persad D, Pramming S. et al. Nature (22 November 2007).
 2. See, Rising Curve: Chronic Hepatitis B Infection in the UK, Hepatitis B Foundation, 21 November 2007.

3. “Diabetes nurses would cut costs”, BBC News; 5 March 2008.
 4. “Diabetes nurses would cut costs”, BBC News; 5 March 2008.

Conclusion

Rather than saving money, the proposed changes would only result in greater costs.

There are already problems applying the regulations which limit access to secondary care, a fact poignantly highlighted by the numbers of pregnant women who are denied care.

There are likewise problems applying the proposed regulations which limit access to primary care, a fact highlighted by the number of asylum seekers and EEA citizens who were refused access despite the fact that the regulation is only a proposal, and that the proposal does not even apply to them.

When complex legislation is introduced with exemptions that are intended to protect the most vulnerable, these safeguards simply do not work in an organisation as large and diverse as the NHS.

The NHS was not set up to exclude some parts of the population. A central tenet of its design is the provision of care to all, without regard to status. Although there are ongoing challenges, the NHS is facing up to them. It has shown that it can absorb even the most vulnerable within the community, providing them with the care they need.

Recommendation

The experience of Project:London confirms other independent research, including that undertaken by the government. As cited in this report the evidence shows that restricting access to primary care would have a detrimental impact in all key respects: economic, public health, and legal. We recommend that the government reject any changes which would further restrict access.

GLOSSARY

Antenatal care – the care women can expect to receive from their midwives and doctors during their pregnancy. In this report we often use antenatal care to refer to hospital care, namely to hospital outpatient appointments and care during delivery of the baby, although maternity care is also provided at the primary care level.

Asylum seeker – when a person lodges an application for asylum under the 1951 Convention relating to the Status of Refugees they are described as an asylum seeker.

Primary care – healthcare in the UK is divided into ‘primary’ and ‘secondary’ services. Primary care is the first point of professional contact for patients in the community and includes, among others, general practitioners (GPs), dentists, and opticians.

Refugee – in the UK, a person is officially described as a refugee when they have been granted asylum (or refugee status). The 1951 Convention relating to the Status of

Refugees defines a refugee as ‘a person who has a wellfounded fear of persecution for reasons of race, religion, nationality, membership of a particular social group or political opinion.’

Refused asylum seeker – a person whose asylum application and any subsequent asylum appeals have been finally rejected. Sometimes referred to as ‘failed asylum seeker’.

Secondary care – healthcare in the UK is divided into ‘primary’ and ‘secondary’ services. Secondary care is specialised treatment, which is normally carried out in a hospital.

Undocumented migrants – migrants without legal status because they entered the country clandestinely, came into the country using false documents or because their visa has expired. Sometimes referred to as ‘irregular migrants’ or ‘illegal immigrants’.

5. See, e.g. Glendinning, L. “Hospital put on alert as ambulances stack up”, Guardian 22 November 2007; Boseley, S. “Half of trauma patients in A&E receive poor care, say doctors”. Guardian 21 November 2007. “Inadequate care in half of A&E trauma cases” Daily Telegraph 22 November 2007.

6. Chauvin P, Parizot I, Drouot N, Simonnot N, Tomasino A. European Observatory on undocumented migrants’ access to healthcare. Médecins du Monde European Observatory on Access to Healthcare. Paris: Médecins du Monde; 2007.

7. International Covenant on Economic, Social and Cultural Rights.

ABOUT MÉDECINS DU MONDE



Médecins du Monde is an international medical humanitarian organisation whose volunteers provide healthcare to vulnerable populations in both developing and developed countries. Our aim is to provide healthcare for people in situations of crisis or social exclusion around the world.

In order to be effective in the long term, *Médecins du Monde*'s work goes beyond providing healthcare. Based on the information and testimonies collected through our medical practice, we identify and highlight violations of human rights, particularly with regard to accessing healthcare.

Médecins du Monde was founded in France in 1980, dedicated to providing access to healthcare for the world's most vulnerable and marginalised, whether in conflict, deep poverty or natural disaster. Work was likewise undertaken in developed countries where people encountered obstacles to accessing healthcare. In 1998 *Médecins du Monde UK* was established to contribute to the worldwide work of *Médecins du Monde*. After a needs assessment which highlighted the problem of access to healthcare among the UK's most vulnerable, Project:London was opened in January 2006.



INTRODUCTION

History

Project:London was designed to meet the needs of the most vulnerable members of the community, those who were facing the greatest barriers to accessing healthcare. We work primarily with three groups of service users: migrants, the homeless and sex workers. It should be understood that many fit into more than one category, but the vast majority of the homeless and sex workers that we saw are also migrants. And because it is their status as migrants which poses a particular challenge relative to the health regulations which have been proposed, the focus of this report is on the migrant community.

GPs currently have the discretion to treat anyone as an NHS patient. But in 2004 the government consulted on a proposal to change the health regulations to bar some migrants from accessing primary care. The changes would essentially remove this discretion. As a result, people would be turned away from GP care on the basis of their immigration status.

At the same time that the government consulted on the proposal, it introduced a change to the regulations which barred the same group of migrants from accessing secondary care. The timing has led to some confusion and we have seen this first hand. Although GPs themselves were usually well informed, the administrative staff responsible for registering patients were often uncertain and confused. In some cases they applied the proposed regulation as if it were already in force. In other cases they even applied the proposed regulation wrongly, extending it to those who it did not apply to - asylum seekers and citizens of EEA countries.

As a consequence, we saw cases where individuals who were absolutely entitled to registration were denied.

- Firstly, it was sometimes “understood” that the proposals had been enacted and that no discretion remained with the GP.
- Secondly, it was sometimes “understood” that the access exclusion extended to all migrants. We saw numerous asylum seekers and EEA citizens who were denied access to primary care – despite the fact that they are entitled both under the current law and the proposed law.

Mr. G, a 36 year old suffering from leg pain and depression

A friend accompanied Mr. G to Project:London, after trying to help him register in 15 different GP surgeries. As an asylum seeker his entitlement was clear, yet he continued to be rejected. Mr. G came to the clinic complaining of pains in his legs and depression as a result of his imprisonment and maltreatment in his native Georgia. He had been relieving the pain in his legs through medication supplied by a friend. We were able to get him registered with a GP along with a successful referral for counselling services.

This highlights a real concern, that problems understanding the regulations result in the wrongful exclusion of individuals who are entitled to access. This collateral damage is deeply troubling, especially given the vulnerability of the population in question. As we look at the proposed changes to primary care, valuable lessons can be drawn from the way those changes were designed, how they were introduced and how they have been implemented.

PROJECT:LONDON ACTIVITIES

This report is based on data and case studies collected at Project:London, a free clinic located in Bethnal Green which is open to the public on Monday, Wednesday and Friday of each week.

Patients are received in two stages: first they meet a support worker who takes them through a series of questions about their social history and helps determine if a medical consultation is needed; second they meet a nurse or doctor who provides a consultation. At the end of the consultation, the support worker and health professional determine what next steps are needed. This normally involves finding and registering them with a GP practice, in order to ensure that there is a long term solution in place. Occasionally this means making a referral to secondary care, as in the case of a woman in need of antenatal care, or to the A&E in the case of someone with an urgent medical condition.

The clinic is not a substitute for ongoing medical care but a provider of temporary services while a permanent solution is being worked out. The idea is for patients to come on a one-off basis and in fact the majority (78%) came only once.

Data collection

The process of data collection is described in detail in Annex page 21.



PROJECT:LONDON FINDINGS

Project:London provided 1074 consultations and saw 893 service users between January 2006 and December 2007.

Access to NHS services

The majority of clients (78%) came to the Project:London clinic only once. We were able to solve the service user's access to healthcare after only one consultation. It is worth noting that the amount of time it took us to do so increased compared to 2006. More contact was needed to ensure registration. This contact broke down as follows:

- calls to a greater number of GP surgeries before successfully booking a registration appointment
- more calls to a particular GP surgery (including contact with receptionist staff, practice managers and GPs themselves)
- more calls made by Project:London doctors, when Project:London support workers' calls were unsuccessful

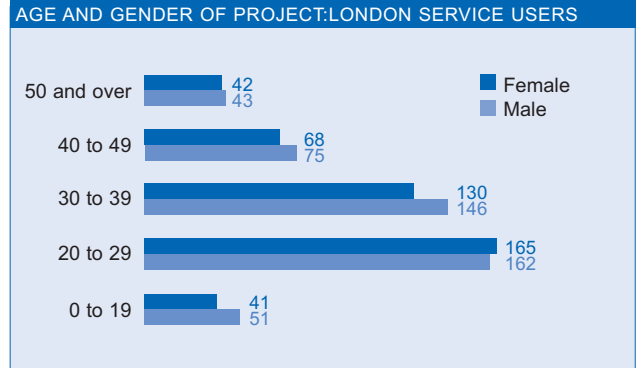
Even after registration appointments were successfully made, we saw an increasing demand for follow up and accompaniment, to ensure that service users were in fact successfully registered. The follow up was needed to overcome the following:

- barriers caused by language
- barriers caused by misunderstandings
- barriers caused by inhospitable and sometimes hostile GP surgery staff
- barriers caused by surgery staff's lack of knowledge and understanding of the regulations.

Age and gender

A roughly equal number of males (48.9%) and females (51.1%) came to Project:London for help. The average (mean) age of persons attending Project:London clinics was 32 years for both men and women. 18 (or 2% of our service users) were under 18, most of whom were children under five who came with their parents. (See Table 1)

TABLE 1



London borough of residence

People from all across London came to Project:London for help. The three most common boroughs of residence for our service users were Tower Hamlets (14.1%), Hackney (10.4%) and Haringey (7.2%). Given the clinic's location in East London, this is perhaps not surprising. It is notable that although we did no outreach or signposting outside of London we saw service users from Surrey and Milton Keynes, indicating that the problems experienced by our service users are not exclusive to London but present countrywide.

Immigration status

Each service user was asked about their immigration status and country of origin, though it should be noted that the information was self-reported. (See Tables 2 and 3) In addition to the migrant community, we provided services to British citizens who were unable to access services. Most came to us by referral from partner organisations who work with the homeless and sex workers. We saw a significant number of citizens from EEA countries who, like asylum seekers, were entitled to primary and secondary care but unable to access it.

TABLE 2

IMMIGRATION STATUS		
Visa expired	144	23.0%
EEA and Swiss nationals	87	13.9%
Irregular entrant	79	12.6%
Refused Asylum Seeker	75	11.9%
Status Impossible to define	58	9.2%
Valid Visa	57	9.1%
Asylum Seeker	52	8.3%
British citizen	47	7.4%
Indefinite Leave to Remain (ILR)/ Exceptional Leave to Remain (ELR)/ Humanitarian Protection (HP)/ Discretionary Leave (DL)	29	4.6%
Total	628	100%

Note: There were 265 non-responses for this question and therefore the total does not reflect the number of service users.

TABLE 3

COUNTRY OF ORIGIN, BY REGION		
Asia	283	33.1%
Africa	265	31.0%
European Union	125	14.6%
Oceania and Americas	91	10.6%
Middle East	52	6.1%
Europe	38	4.5%
Stateless	1	0.1%
Total	855	100%

Note: There were 38 non-responses for this question and therefore the total does not reflect the number of service users.

TABLE 4

TOP 10 NATIONALITIES	
China	131
Democratic Republic of Congo	68
India	45
Brazil	30
Bangladesh	29
Eritrea	25
Nigeria	24
Uganda	22
Poland	17
Phillipines	17

Note: UK was excluded from the top ten list even though we saw 42 people as we came into contact with client group at Crisis Open Christmas 2006, a venue which reaches a predominantly British population of homeless people.

Length of time in the UK

The proposal to limit access to primary care was prompted by the notion that the NHS was besieged by a stream of overseas visitors who came to the UK as “health tourists” with the express purpose of seeking free medical treatment. It is notable that the government itself acknowledged that it had no evidence of the cost, or indeed of the numbers, of “health tourists”.⁸ The data from the first two years of operation of Project:London goes a long way toward rebutting the notion of the “health tourist”. Our service users had, on average, been living in the UK for three years before they came to the clinic to see a doctor or to get help accessing healthcare. (See Table 4)

TABLE 5

LENGTH OF TIME PROJECT:LONDON SERVICE USERS HAVE BEEN IN THE UK (IN YEARS)		
Mean=3.0		
From 0 to 1	244	33.7%
From 2 to 5	347	48.0%
More than 5	132	18.3%
Total	723	100%

Note: There were 170 non-responses to this question in addition to British citizens who were included in the non-responses. As a consequence the total does not reflect the number of service users.

8. Evidence of Miss Melanie Johnson, Minister for Public Health to Health Select Committee Enquiry (Questions 211 – 215) in Health Select Committee (2005) New Developments in Sexual Health and HIV/AIDS Policy. House of Commons, Oral and Written Evidence, HC252-II. See also Evidence of Liam Byrne, Minister of State to Joint Committee on Human Rights Enquiry (Questions 492-493) The Treatment of Asylum Seekers (2007). House of Commons, Oral Evidence, HC 60-vi.



There is absolutely nothing in the Project:London data to support the idea of large numbers of overseas visitors coming to the UK specifically to seek out free treatment. In this regard, our findings mirror those of numerous other studies. See for example the studies which found that the vast majority of people with HIV and AIDS were not aware of their status until after leaving their home country.⁹

Service users' health

Over the last two years Project:London has seen 893 service users and our medical team provided 1,074 consultations. Through these consultations the team was able to make a preliminary assessment of each service user's health. The top ten health problems assessed by the medical team are shown as a percentage of the service users who received a medical consultation over the last two years (See Table 5).

This data shows that the health problems seen in Project:London service users are broadly reflective of the conditions seen among the general population in general practice. The most common health problems identified are similar to the ten most common reasons for consulting a GP in the last national survey of ill-health in primary care, with the exception of psychological problems.¹⁰ Given the stresses caused by poverty and uncertain immigration status (either or both of which applied to most of our service users), it is not surprising that they reported psychological problems at a rate higher than that of the general population.

Of the service users who had medical consultations, less than one third even required prescriptions. The majority needed help to access primary care or antenatal services rather than expensive specialist treatment. The conclusions from the last two years' data accord with those of a study in the London Borough of Newham, known to have a very diverse population and sizeable migrant population, which found that the impact of "overseas visitors" on primary care was "minimal in terms of absolute numbers" and raised questions about the cost-benefit of expanding the hospital charging scheme into primary care."¹¹ The results are like

9. Cherfas, L "Negotiating Access and Culture: Organizational Responses to the Healthcare Needs of Refugees and Asylum Seekers Living with HIV in the UK", October, 2006; Barton, J "Challenging the Myth of "Treatment Tourism": Is Access to Medical Treatment for HIV a Pull Factor in Migration to the UK?" March 2006; "Recent Migrants Using HIV services in England," London, Report from data

TABLE 6

LIST OF HEALTH PROBLEMS AS ASSESSED BY PROJECT:LONDON MEDICAL TEAM	
Health problems (analysed by system, classified according to the International Classification of Primary Care ICP-2)	%
Pregnancy, childbirth, family planning	22.4
Psychological	19.9
Musculoskeletal	19.6
Digestive	19.1
Respiratory	11.8
Skin	10.7
Female genital	9.2
Neurological	7.8
General and Unspecified	7.4
Cardiovascular	7.4

Note: Pregnancies were excluded from the top 10 list of complaints.

TABLE 7

LIST OF TOP 10 COMPLAINTS FOR PROJECT:LONDON SERVICE USERS
Feeling depressed
Headaches
Feeling anxious / nervous
Back symptoms / complaints
Sleep disturbance
Lower back symptom / complaint
Depressive disorder
Teeth / gum symptom complaint
Abdominal cramps
Cough

wise consistent with the 2007 study by the Audit Commission which noted that "most migrant workers are relatively young and healthy" and that had little need for public services.¹²

These indicators should be considered in conjunction with the well-known cost-effectiveness of providing early and preventive care through primary care, as a means of avoiding costly hospital treatment at a later date.

compiled by Terrance Higgins Trust and George House Trust, 2003.
 10. McCormick A, Fleming D, Charlton J. Morbidity statistics from general practice. Fourth national study 1991-2. Office for Population Censuses and Surveys, Series MB5 no 3. London, HMSO; 1995.
 11. Hargreaves S, Friedland JS, Holmes A, Saxena S. The identification and charging over overseas visitors at NHS services in Newham: a consultation. Final Report. London: Newham Primary Care Trust; 2006.
 12. Audit Commission. Crossing borders – Responding to the local challenges of migrant workers. London: Audit Commission; 2007.

Considering the proposed changes – in light of the Project:London findings relative to primary care

While NHS England is projected to have a £1.8 billion surplus for 2007, it is nonetheless prudent to consider the financial implications of continuing to allow access to primary care. Cost savings were, after all, given as justification for the proposal.¹³ It may sound logical to argue that cutting off access to primary care will save money and take pressure off the NHS. But an examination of our findings - alongside other independent research – makes it clear that the opposite is true.

It is with good reason that the NHS was designed with GPs as the central element. In its 2006 white paper the government noted that the NHS must build on this vital core. “We must set out a new direction for health and social care services to meet the future demographic challenges we face. We must reorientate our health and social care services to focus together on prevention and health promotion. This means a shift in the centre of gravity of spending. We want our hospitals to excel at the services only they can provide, while more services and support are brought closer to where people need it most.”¹⁴

Research draws our attention to the following:

Prevention

An ounce of prevention is worth a pound of cure, a fact which was the subject of a report from public health experts in 55 countries which pointed out that preventable diseases now cause 60% of deaths worldwide and urged policy makers to take concerted action to move “health systems towards prevention rather than cure”.¹⁵ The report estimated that by doing so 36 million deaths could be prevented by 2015.

The benefits of prevention were recently highlighted in the Prime Minister’s proposal to launch a national screening programme aimed at preventing heart attacks, strokes, kidney failure and diabetes. As proposed, “over time everyone in Britain will have access to the right preventive health check”.¹⁶

13. Hawkes, N and Rose, D “£1.8 bn surplus forecast for NHS after cutbacks in patient care”; The Times 4 March 2008.

14. “Our health, our care, our say”, White Paper: London, January 2006.

15. Daar, A et al. *op cit*.

Mr. T, aged 41, suffering from high blood pressure.

After being refused registration with a GP, Mr. T came to the clinic with elevated blood pressure. He had been self monitoring his BP and using a friend’s medication to try to control it. He was beginning to experience chest pains and palpitations when he finally saw a Project:London doctor. We were able to get him registered with a GP so that he could get the ongoing care he needed.

The issue of prevention was also highlighted in a recent study aimed at assessing the impact of the regulation which limited access to secondary care. Consultants reported that the regulation had a “negative impact on HIV prevention and early diagnosis in immigrant communities”.¹⁷

The government has unveiled a new cancer strategy which focuses on prevention and radiotherapy rather than expensive drugs.¹⁸ As a result of growing rates of hepatitis B, urgent calls have been made for wider vaccination efforts.¹⁹

Baby girl, three months old, in need of immunization:

Baby J was brought in by her mother who was a refugee with exceptional leave to remain. When the mother moved, she had great difficulty getting herself and her daughter registered with a GP. After being registered, she was told that her daughter was not eligible for immunisations and she was not given any further information about where she could go to access immunisations. Fortunately the child had received her first round of immunisations through her previous GP and there was still time to advocate on her behalf in order to ensure receipt of the second round.

16. Hencke, D. NHS screening programme takes centre stage in Brown fightback, Guardian; 7 January 2008; “Gordon Brown pledges a “new age” for the NHS”. The Times; 7 January 2008; “Doctors’ surgeries to offer all patients screening for range of common diseases” Daily Telegraph, 6 January 2008.

17. Wood et al (2007) *Op cit*.

18. See, e.g. Bosely, S New cancer plan to focus on prevention and surgery rather than expensive drugs. Guardian, December 2007.

19. See, Rising Curve: Chronic Hepatitis B Infection in the UK, Hepatitis B Foundation, 21 November 2007.

Lack of access also has an impact relative to wider social issues, including domestic violence, since the GP surgery is often the first port of call for a victim who is too afraid to contact the police. As studies have noted, it takes courage as well as support for a woman to leave a violent partner or a violent situation. “The very point at which a woman leaves is widely recognised as a key moment of risk. Support and protection at these times is essential”.²⁰

As is clear, none of these prevention efforts is possible without access to primary care. By circumventing access we waste the opportunity to maximise prevention, and the considerable cost savings that come with it. In its programme for tackling health inequalities, the government highlighted the importance of the provision of primary care services, indeed half of the programme’s indicators relate to primary care.²¹

Early detection and diagnosis

Failing to prevent or detect a condition only means that it continues to get worse. As a consequence:

- the individual suffers
- he/she becomes less able to work, study, and care for their family
- his/her condition becomes more difficult and more expensive to treat
- if he/she has an infectious disease, it can spread to others

Diseases which are easy and affordable to control, and expensive to ignore

People with diabetes occupy one in ten hospital beds, at a considerable cost to the NHS.²² But recent studies have shown that proactive intervention can facilitate more appropriate care and help save money. A trial which took such a proactive approach resulted in a cost savings of more than £110,000. If replicated nationwide this would result in a savings of nearly £100 million.²³ A study in which the medical records of more than 3.6 million patients in the

UK were examined, estimated that more than half a million people could have diabetes or a high risk of developing diabetes. The researchers urged a roll out of their pilot, noting that “the earlier people are diagnosed, the earlier they can get on with managing the condition and reducing their risk of developing complications”.²⁴

Mrs. L aged 42, diabetic

After being unable to register with a GP, Mrs. L came to the clinic when she could no longer control her diabetes. With the help of the clinic team she was able to register with a GP and begin medical treatment to get her condition under control, avoiding complications.

Diseases which spread easily – posing public health concerns for us all

Infectious diseases do not respect borders, nor do they discriminate on the basis of status. We are all at risk from the spread of diseases and we all have a stake in preventing that spread. That is why, with regard to secondary care, there are exceptions built in to ensure treatment for such diseases. Similarly, since the law governing primary care leaves it to the discretion of the GP to decide whether to accept a patient, one would assume that someone with an infectious disease would not encounter barriers when trying to register with a GP. But for any infectious disease to be diagnosed the patient must first have access to a GP and a recent study published by Coventry PCT documented the case of an individual who presented with TB and was refused registration by six different GP practices over a period of two months, during which time his TB treatment was damaged.²⁵

21. Tackling Health Inequalities: 2007 Status Report on the Programme for Action, Department of Health, March 2008 (wherein reference is made to cancer and circulatory disease, teenage pregnancy, flu vaccinations, smoking and diet, whose prevention and early detection fall within the purview of primary care).

22. “Diabetes nurses would cut costs”, BBC News; 5 March 2008.

23. “Diabetes nurses would cut costs”, BBC News; 5 March 2008.

24. Holt, T et al. The British Journal of General Practice 24 February, 2008.

25. Janmohamed, K. Health Care Needs Assessment for Refugees and Asylum Seekers in Coventry; 7 November 2007.

20. See, e.g. “No recourse, no safety” Amnesty International and Southall Black Sisters March 2008.

HIV and AIDS

Although medically classified as an infectious disease, HIV/AIDS are specifically excluded from the guaranteed treatment for all infectious diseases. As it stands, the NHS provides free testing but no treatment for those with HIV/AIDS who have been restricted from secondary care. It is estimated that approximately one-third of HIV positive people living in the UK are currently undiagnosed.²⁶ But it is not realistic to expect people to be tested when there is no treatment available to them. This is a lesson that public health and development professionals learned in the developing world more than ten years ago. In a European study, Médecins du Monde documented access to HIV treatment and it is notable that only the UK and Germany restrict access to treatment on the basis of status.²⁷

A number of studies have found “no evidence of significant levels of HIV health tourism”.²⁸ One study found that 75% of migrants were tested more than nine months after entering the UK and that the most common reason for testing (58%) was onset of symptomatic HIV.²⁹ Others were tested as part of antenatal care, or as prompted by the death or diagnosis of a partner. Very few already knew their status before coming to the UK.

Another study found that “all respondents whose decisions to migrate would have been influenced by knowledge of their HIV diagnosis prior to leaving would have stayed in the country of origin because of the availability of family support. “In many countries, HIV is viewed as a ‘death sentence’ due to the unavailability of treatment, and they likely would not have known of the possibility of treatment, a perception that is corroborated by other data in a discussion of the difficulties for those diagnosed in the UK to tell their families about their condition”.³⁰

Of those in the study whose decision to come to the UK would *not* have been influenced, all were asylum seekers who were forced to flee and were unable to return due to safety considerations. For them, HIV status did not determine their continued presence in the UK. The study thus concludes that for persons not seeking asylum,

access to HIV treatment is not a ‘pull factor’ for migration to the UK. It is, instead, often a source of real tension. Individuals are confronted with the desire to return to their families and the knowledge that doing so would hurt their chances of accessing life-saving HIV medication.

As the studies noted, a major obstacle for health promoters is that many migrants do not present for testing until they become symptomatic.³¹ This is a particular concern with the ethnic minority and migrant communities, where people tend to present late with their HIV disease with low CD4 counts and more advanced disease. And thus there is the potential for higher morbidity and mortality and increased risk of hospital admission with extended stays.³²

Pressure on Accident & Emergency

If people are barred access to GPs, they will be left with no other choice than to seek care at A&E departments. As research has already shown, this places unnecessary pressure on A&E departments, many of which are already short staffed and inadequately equipped to handle the cases that require emergency attention.³³ Studies have quantified the extent to which A&E centres are treating patients who could and should be receiving primary care, in a local clinic or surgery.³⁴ Two studies looked at the issue relative to the migrant community in particular. One examined the extent to which recently arrived immigrants were accessing services in A&E departments rather than in GP surgeries, concluding that steps could be taken to lessen the impact that the group has on acute services.³⁵ The report of the government’s Migrant Impact Forum noted increased pressure on A&E departments which immigrants were using instead of GPs.³⁶ The results are somewhat surprising, given that this community should in theory be able to access primary care at present. But it is clear that the impact would be far greater if access to primary care were restricted.

26. Wood et al (2007) *Op cit*.

27. Chauvin P, Parizot I, Drouot N, Simonnot N, Tomasino A European Observatory on undocumented migrants’ access to healthcare. Médecins du Monde European Observatory on Access to Healthcare. Paris: Médecins du Monde; 2007.

28. Wood C, Ainsworth J, Hargreaves A, Azad Y. The impact of the April 2004 NHS charging regulations on HIV prevention, treatment and care in the UK: a survey of BHIVA members; 2006.

29. “Recent Migrants Using HIV services in England,” London. Report from data compiled by Terrance Higgins Trust and George House Trust, 2003.

30. Dodds C, Keogh P, Chime O, Haruperi T, Nabulya B, Ssanye-Sseruma W, Weatherburn P, “Outsider Status: Stigma and Discrimination Experienced by Gay Men and African People with HIV”, London, Sigma Research. 2004.

Administrative costs

It is clear that there will be substantial costs associated with the administration of payment systems. What is less clear is whether there is any reasonable expectation that the individuals who have incurred debt as a result of hospitalisation will be able to repay these sums, given their often precarious financial situations. This fact was noted in the report which sought to quantify the economic impact of overseas visitors in Newham.³⁷

Ethical obligation to refuse to implement

The proposal to restrict access has been the subject of considerable debate within the medical community. In the first three months of 2008 alone, more than 650 doctors registered to practise in the UK signed a petition opposing the policy.

The substance of the petition which appeared in *The Lancet*, is as follows:

"This would impose serious health risks on [undocumented migrants] and on the general public. It would also interfere with our ability to carry out our duties as doctors. It is not in keeping with the ethics of our profession to refuse to see any person who may be ill, particularly pregnant women with complications, sick children or men crippled by torture. No one would want such a doctor for their GP.

"We call on the government to retreat from this foolish proposal, which would prevent doctors from investigating, prescribing for, or referring such patients on the NHS.

"We pledge that, in the event this regulation comes into effect, we will: (a) continue to see and examine asylum seekers and to advise them about their health needs, whatever their immigration status; (b) document their diagnoses and required clinical care; (c) with suitable anonymisation and consent, copy this documentation to the responsible ministers, [members of parliament] and the press; (d) inform the public of the human costs, to harness popular disgust at what is being ordered by the government in their name; (e) campaign to speedily reverse these ill-advised policies".³⁸

In some cases health care professionals have already had to fight to protect patients wrongly being denied care. In one case a woman who was 36 weeks pregnant had been de-registered from her GP practice after they received a call from the Home Office. Given that her care was immediately necessary, her midwife refused to stop seeing her. And in the meantime we were able to persuade the GP practice to re-register her.



The cost of a workforce in ill health

The government has estimated that ill health costs the economy over £100 billion a year.³⁹ While this is a problem that must be approached from a number of angles, it is clear that improving access to medical care is among them.

Access to care helps to enable people to use their unique skills and energy to contribute to the economy while helping to build a stronger and more cohesive community.

31. Cherfas, L "Negotiating Access and Culture: Organizational Responses to the Healthcare Needs of Refugees and Asylum Seekers Living with HIV in the UK", October, 2006; Barton, J "Challenging the Myth of "Treatment Tourism": Is Access to Medical Treatment for HIV a Pull Factor in Migration to the UK?" March 2006; "Recent Migrants Using HIV services in England," London. Report from data compiled by Terrance Higgins Trust and George House Trust, 2003.

32. Wood et al (2007) *Op cit*.

33. See, e.g. Glendinning, L "Hospital put on alert as ambulances stack up", *Guardian* 22 November 2007; Boseley, S "Half of trauma patients in A&E receive poor care, say doctors". *Guardian* 21 November 2007. "Inadequate care in half of A&E trauma cases" *Daily Telegraph* 22 November 2007.

34. See, e.g. Curtis, P. Frequent flyers costing NHS £2.3 bn a year. *Guardian*, 13 February 2006.

35. Hargreaves S, Friedland JS, Gothard P, Saxena S, Millington H, Eliahoo J, Le Feuvre P, Holmes A. Impact on and use of health services by international migrants: questionnaire survey on inner city London A&E attenders. *BMC Health Services Research*. 2006; 6: 153.

36. Treasury, Home Office and Work and Pensions Study, 17 October 2007.

37. Hargreaves S, Friedland JS, Holmes A, Saxena S. The identification and charging of overseas visitors at NHS services in Newham: a consultation. Final Report. London; 2006.

38. Arnold, F et al. "Medical justice for undocumented migrants" *The Lancet*, Volume 371, Number 9608. See petition itself at <http://www.gopetition.com/petitions/medical-justice-for-asylum-seekers.html>

39. "Working for a Healthier Tomorrow" (presented to the Secretary of State for Health and the Secretary of State for Work and Pensions), London:TSO 17 March 2008; 'Sick note culture' costing £100bn every year, *Daily Telegraph*, 17 March 2008; Doctors should write 'fit notes', report says, *Guardian*, 17 March 2008.

SECONDARY CARE - A FOCUS ON MATERNITY

Although the 2004 changes to the health regulations have limited some migrants' access to secondary care, there are clearly stated exceptions:

- Treatment in hospital accident and emergency (A&E) departments and some walk-in centres remain free for everyone
- Treatment for a range of infectious diseases, such as TB and polio
- Treatment for sexually transmitted infections (except HIV/AIDS)
- Compulsory psychiatric treatment for people who are detained under the Mental Health Act
- Any treatment which is "immediately necessary" in the opinion of a clinician

At first glance, this list of exceptions appears extensive. Indeed the problems we have encountered almost all relate to conditions which are *on the list*. It is the implementation of these exceptions that has proven to be the problem. While it is true that patients will indeed be charged even for treatment that is considered "immediately necessary" the Department of Health guidance makes it clear that such treatment must be provided by hospital trusts "whether or not the patient has been informed of, or agreed to pay, charges."⁴⁰

The case of antenatal care

Despite the restrictions, all women are entitled to access antenatal care because it falls under the exception for treatment which is "immediately necessary." The fact that it is "immediately necessary" has been made clear in a number of Department of Health guidances.⁴¹ Despite this absolute entitlement, we have seen an ever growing number of women who have not in fact accessed this care.

40. See, e.g. Families and Maternity Department of Health/Partnerships for Children. Maternity Matters: Choice, access and continuity of care in a safe service, Department of Health. 2007; Caroline Flint. Hansard - Sexual Health (HIV/AIDS) - 9 Feb 2006 : Column 323WH. Department of Health. 2006; London; Rosie Winterton. Hansard (House of Commons Daily Debates) - Column 923W - 2 Mar 2006, House of Commons. 2006; John Hutton. Letter addressed to Brian Sedgemore, MP, Department of Health, Editor. 2005; House of Commons Health Committee. New Developments in Sexual Health and HIV/AIDS Policy: ... >>

The total number of pregnant service users was 118 (39 in 2006 and 79 in 2007). Of the 118, very few were registered with a GP. (See Table 6) 98 women came to the clinic in order to get help accessing antenatal care and 20 needed help accessing a termination of pregnancy. Less than one third of the women had received any antenatal care before coming to the clinic. (See Table 7)

TABLE 8

NUMBER OF PREGNANT WOMEN REGISTERED WITH A GP		
Not registered with a GP	105	90.5%
Permanent registration	9	7.8%
Temporary registration	2	1.7%
Total	116	100%

Note: There were 2 non-responses and therefore the total does not reflect the total number of pregnant women.

TABLE 9

PREGNANT WOMEN WHO HAVE ACCESSED ANTENATAL CARE PRIOR TO COMING TO PROJECT: LONDON		
Yes	32	32.0%
No	68	68.0%
Total	100	100%

Note: There were 18 non-responses and therefore the total does not reflect the total number of pregnant women.



When antenatal care was accessed

Early and regular access to antenatal care is a key to healthy delivery. The government's recent Confidential Enquiry into Maternal Health report noted that 20% of the deaths recorded in the study were "in women with late booking or poor attendance for antenatal care or who had no antenatal care, all of which are associated with a high risk of maternal death".⁴² It is therefore of particular concern that nearly 25% of the pregnant women who came to the clinic were more than 18 weeks into their pregnancies and had never received any antenatal care. (See Table 8) Nearly 5% were more than 30 weeks into their pregnancies. The average number of weeks at which the pregnant women presented to the clinic for antenatal care was 16. (See Table 9) And even among the very small cohort of pregnant women who were able to access antenatal care prior to coming to the clinic, at least 8 women had done so for the first time after 20 weeks into the pregnancy.

Ms. S., 38 weeks pregnant

Ms. S. came to us during her 38th week, having had no prior antenatal care. She had been refused maternity access at her local GP surgery and had been informed that she would not be able to deliver at her local hospital. With delivery imminent, it was vital to secure a bed in the maternity ward of another hospital.

TABLE 10

NUMBER OF WEEKS AT WHICH PREGNANT WOMEN PRESENTED TO PROJECT:LONDON CLINIC			
Mean=15.5	Median=13.0	Min=3.0	Max=37.0
Less than 6	4	5.2%	
From 6 to 11	24	31.2%	
From 12 to 17	21	27.3%	
From 18 to 23	12	15.6%	
From 24 to 29	11	14.3%	
30 or more	5	6.5%	
Total	77	100%	

Note: There were 41 non-responses for this question.

Third Report of Session 2004–05, House of Commons. 2005. The Stationery Office Limited: London; Department of Health. Implementing the Overseas Visitors Hospital Charging Regulations: Guidance for the NHS Trusts in England. London: Department of Health; 2004.

TABLE 11

STAGE OF PREGNANCY (WEEKS OF GESTATION) FOR WOMEN WHO HAD NOT ACCESSED ANTENATAL CARE PRIOR TO COMING TO PROJECT:LONDON			
Mean=15.5	Median=12.0	Min=5.0	Max=36.0
Less than 20	14	63.6%	
From 20 to 24	4	18.2%	
From 25 to 29	2	9.1%	
30 and more	2	9.1%	
Total	22	100%	

Note: There were 76 non-responses for those pregnant women who wanted to proceed with their pregnancy. 20 pregnant women were excluded because they wanted a termination of pregnancy.

Access to antenatal HIV screening

Despite the well known risks of mother to child transmission of HIV/AIDS, a very small number of pregnant women we saw had had access to antenatal HIV screening. (See Table 10) Ensuring access to early treatment and antenatal care is known to be cost-effective and can avoid the need for more costly treatment at a later date since every baby born HIV positive in the UK because the mother's HIV status has not been diagnosed during pregnancy is estimated to cost the NHS between £500,000 and £1 million during its lifetime. One in every 450 pregnant women in the UK is HIV-positive, but without access to testing many of these women will not be diagnosed and treated. Without treatment their child is at high risk of also being infected with HIV, when this could have been easily prevented.⁴³

TABLE 12

ACCESS TO HIV SCREENING FOR PREGNANT WOMEN COMING TO PROJECT:LONDON		
Yes	11	25.6%
No	32	74.4%
Total	43	100%

Note: There were 55 non-responses for this question. 20 pregnant women were excluded because they wanted a termination of pregnancy.

41. Implementing the Overseas Visitors Hospital Charging Regulations: Guidance for the NHS Trusts in England. London: Department of Health; 2004.

42. Saving mother's lives: reviewing maternal deaths to make motherhood safer 2003 – 2005. UK Confidential Enquiry into Maternal and Child Health (CEMAH) December 2007.

43. 'A Complex Picture', Health Protection Agency, 2005. If the mother is not treated for HIV during pregnancy and birth, approximately 1 in 3 babies will become infected. However if certain precautions are taken, and in particular the mother and baby are given antiretroviral drugs, the baby is born by Caesarean section and the baby is not breastfed, the risk of HIV transmission from mother to baby drops to less than 1%. For more information see www.aidsmap.com.

The case of accessing terminations of pregnancy **Conclusion**

For those women who came to the clinic to obtain help in accessing a termination of pregnancy, many of the women were unable to access a termination through the NHS. For the majority of these women we were able to help them register with a GP but we found that many were refused access to a free termination of pregnancy at the secondary care level. Some were asked to prove their entitlement to free secondary care or demonstrate their ability to pay. As a consequence, some women went into debt in order to arrange payment while others were forced to proceed with a pregnancy which was unwanted. Because many women who were seeking terminations were quite advanced in their pregnancy, time was of the essence. This highlights an area of particular concern, especially given recent calls to ban terminations after 20 weeks. Such a change would have made terminations impossible in a number of cases, and women would have been forced to proceed to term.

Although the 2004 changes to the health regulations have limited some migrants' access to secondary care, there are clearly stated exceptions including access to maternity care. Yet we consistently see that access is denied. Even where exceptions are clearly stated, they are not applied. This is a fact which the government must keep in mind relative to proposed changes to primary care. Evidence has made it clear that these exemptions simply are not applied correctly. As a consequence, the safeguards which are meant to ensure fair and humane treatment simply do not exist.



RECOMMENDATIONS

Our experience at the Project:London clinic confirms other independent research, including that undertaken by the government. As cited in this report, the evidence shows that restricting access to primary care would have a detrimental impact in all key respects: economic, public health, and legal. We recommend that the government reject any changes which would further restrict access.



Data collection

Project:London provided both support worker and medical consultations. These consultations gave the opportunity to collect data that, in addition to being used for individual support purposes, could be collated to enable Médecins du Monde UK to advocate on behalf of a wider group.

In anticipation of this second use of the data collected, the consent of all service users was sought. In addition, some service users gave more detailed testimonies and consented for these testimonies to be used as case studies.

Most of the information recorded is 'self-reported' in that it is the answer given by the service users and no independent verification of the response is carried out. In addition, much of the information is highly sensitive. We recognise that this could be a source of bias in some of the questions. However, this was recognised from the outset and has been addressed in the design of the project, the training of the team and the data collection. In designing the project and addressing questions of data collection, Project:London was able to draw lessons from the experience of Médecins du Monde in other European countries.

A number of factors were relevant:

- The Project:London team has been fully trained on this issue and always stresses the utmost importance of the confidentiality of all information gathered;
- Médecins du Monde UK's status as an independent nongovernmental organisation has helped to establish trust with the project's client group;
- the primary purpose of both the social and medical consultations is to provide support to the service user. To be able to do this effectively the Project:London team needs accurate information and this is very clearly explained to all service users;
- a service user does not have to provide the information, or answer any specific questions if they are uncomfortable about doing so. A support worker consultation can be provided without any recording of data. For a medical consultation, however, a record of the consultation is required to comply with Médecins du Monde UK's clinical governance arrangements.

These results should be seen as a description of the people seeking help from Project:London. The results concern those people who voluntarily sought the assistance of Project:London. They are not presented as a representative picture of the difficulties of access to healthcare for everyone in the UK, nor of all vulnerable groups in the country. Nonetheless, since such little information exists about these vulnerable groups, particularly of undocumented migrants, these quantitative results allow us to identify some patterns which, despite the need for caution in their interpretation, illustrate and extend understanding of their situation.