LONDON NETWORK OF PATIENTS' FORUMS

RESPONSE TO THE DARZI REPORT

"HEALTH CARE FOR LONDON"

INTRODUCTION

1. The report we are now commenting on was commissioned by NHS London, the strategic health authority for London, from Professor Sir Ara Darzi (now Lord Darzi) and was presented by him just as he became a peer and a junior Minister in the Department of Health. For that reason he is referred to here as Professor Darzi. This report of his, relating almost solely to London, should not be confused with further reports by him on national issues.

2. The first thing that must be said about the report is that **we welcome its mere existence**. NHS London was obviously right to commission a report on London's health but that could not have been done without the existence of a single strategic health authority for London. Since 1948, London has been bedevilled by superior health authorities, none of which covered more than a part of London, save for a period of six months. The latest episode of this sorry story saw London divided into the artificial areas of the five former so-called strategic health authorities. **We supported their amalgamation into one authority for the region and welcome this report as one of its results**.

3. Having said that, it is clear that no sensible person could regard Professor Darzi's report as 100% good or bad. It requires careful consideration of its details and to achieve this, the 31 Primary Care Trusts have launched, under NHS London's supervision, a consultation process in which we have had some share.

4. NHS consultation has been clarified by the decision of Mr Justice Collins in the case involving the former North-East Derbyshire Primary Care Trust. He pointed out that the statutory duty of consultation on NHS changes is a wide one, which should include Patients' Forums as well as other relevant bodies or persons. After an attempt to limit this duty in the recent Local Government and Public Involvement in Health Bill failed as the Bill passed through Parliament, the law remains for the moment as Mr Justice Collins left it. The same Bill, now an Act,

enables strategic health authorities to take a more formal and direct part in future NHS consultations.

5. Whilst we understand that the law, prior to the very recent Act, prevented NHS London being the direct consulting authority, we appreciate the very considerable efforts it has put in to involve patients and the public in the consultation process. There was a focus group of individual members of the public chosen by a consultancy involved in the Darzi report's preparation. This group has been combined with the Executive Committee of the London Network of NHS Patients' Forums to form a consultative group for NHS London. The Executive Committee has been elected by and from the 70-odd Patients' Forums which monitor London's NHS Trusts, all of whose members are unpaid volunteers. This group in turn appointed three of its members to attend NHS London's Joint Commissioning Group (mainly of PCT Chief Executives chaired by NHS London's Chief Executive) as observers.

6. The authors of this response to Professor Darzi's report therefore bear some responsibility for the consultation document used in this consultation. We should like to apologise in advance for its complexity (though there is a summary version) which inevitably corresponds to the complexity of Professor Darzi's report itself. Already a criticism has surfaced in the consultation, that too much money is being spent on it, which could be better spent on patient care. The budget is, of course, decided by the NHS, not us, but we would defend them against this charge. Parliament and the courts have determined that there should be consultation on NHS changes and it would be a breach of the law to do it cursorily. **We believe – as did the makers of this law – that changes which involve thousands of NHS staff and the health of millions of people can best be done by persuasion and genuine consultation. It is important to recognise that consultation is about healthcare with consent. We therefore welcome the efforts of NHS London and the 31 Primary Care Trusts to achieve this**.

THE CASE FOR CHANGE

7. Professor Darzi begins by making a case for change in healthcare in London. In making his report he was assisted by six clinical working groups. We are not primarily clinicians (though a few of us are or have been) and have no intention of challenging his main argument that there is a need to improve Londoners' health, that the NHS is not meeting Londoners' expectations, that there are big inequalities in health and healthcare, that hospital is not always the answer, that there is need for more specialised care, that London should be at the cutting edge of medicine, that the workforce and buildings are not being used

effectively and that we are not making the best use of taxpayers' money.

Expectation and Satisfaction

8. We would, however, point out certain things which we feel entirely competent to comment upon. The first of these is Londoners' expectations. **We believe that Londoners basically support a public health service funded from taxation and are well aware that such services do not exist in much of the world.** There is a small but influential minority, supported by a minority of media of communication, who wish to erode the public NHS, leaving it to deal only with marginal healthcare not sufficiently profitable for the private sector. We entirely reject this attitude and believe we speak for the overwhelming majority of Londoners. We know and they know that to consider "private equals good; public equals bad" is mere ideology and quite untrue. **Either private or public may be good or bad, that is a matter of competent administration, though the private sector has to make a profit for its shareholders and will always require monitoring and regulation to uphold the standards desired by patients and carers. In Britain it also tends to be more secretive and less accountable than the public sector.**

9. Beside this general principle, some of the points made by Professor Darzi and others look rather different. Many of the points he makes about Londoners' expectations are really about competence or administrative rigidities. For instance he highlights concern about "hospital cleanliness". Why only hospitals? Most people are concerned about cleanliness of the whole environment and much of that (pollution, for example) affects health. Primary care cleanliness is important too. For years hospitals resisted external inspections by public health inspectors of local authorities. **We note that there was no specific public health pathway in the Darzi report's formulation**. Why not? This is symptomatic of the general decline in official concern over public health. What have we to do? Wait for a great pandemic to restore official priorities?

10. Of course expectations rise. That is a symptom of a prosperous society, as every retailer knows. Therefore, of course, the NHS's delivery has to rise too, as every retailer's delivery has to.

11. It is too crude merely to say “Londoners gave their GP services a lower net satisfactory rating than people nationally”. Londoners on average (though far from all of them) are richer than most people outside SE England but they know that the difficulties they find over access to GPs are caused by administrative incompetence at two levels. The Government negotiated with the doctors without covering all matters involved. Now it has developed into a silly argument in which the BMA says: “doctors are willing to work longer hours”. Who said opening a practice on a Saturday morning is about longer hours? A large practice (and Professor Darzi advocates larger practices) which shuts on a Saturday morning does so because:

    1. It can under the doctors’ contract and
    2. It lacks administrative competence or the will to vary the distribution of doctors’ working hours over 5.5 days rather than 5 days

    Many shops stay open longer hours than individuals work in them. Practices (except the most competent ones) seem unable to grasp this principle, though some individual doctors not working in their practice may work outside it as locums.

Inequalities and Finance

12. There is no finance pathway in the Darzi report. This will be remedied by NHS London but we feel the Darzi report should have mentioned this when vividly describing health inequalities. There are inequalities about many things in London but only a few years ago the NHS was working to increase them. As Sir Ian Carruthers, its former head, pointed out, it was more prosperous areas that overspent their budgets. NHS London has taken control over this bizarre situation but it will be some time before all London clinicians and health administrators realise that **more should be spent per head on deprived areas of London than on prosperous areas**. Londoners’ memories have been scarred by the recollection of health cuts in deprived areas.

MATERNITY AND NEWBORN CARE

13. We cannot fault the Darzi report’s proposals but are puzzled by the apparent ease by which it seems to assume the presence of more midwives, consultants and health visitors. We are constantly told – in the Press and elsewhere – that there is a shortage of midwives, that not enough people are entering the profession and that there is a high

proportion of midwives nearing retirement age. Is none of this true? If it is true what is being done about it? Are there midwives available unable to find jobs? The recent statement by the Secretary of State provides for more midwives to remedy past shortages but does not seem to cover the extra requirements of this Darzi report. It is relevant that the imperfect quality of London's demographic data hinders planning of this service and others.

14. The consultative document only partly covers these points: "we believe we should be able to provide mothers with an excellent service" (which is an imprecise hope) "while still ensuring they can get to a doctor-led maternity unit within a reasonable time". Professor Darzi's recommendations of an increase in midwife-led units, increased home births (if chosen by the mother) and visits seem to have been quietly dropped. If they have not been dropped why is there no mention of steps to secure an increase in trained midwives? We are also puzzled by the chart on page 19 of the consultative document which does not refer to health visitors at all. The Government says it supports health visitors, who visit mothers at home after birth. The document apparently does not support them.

STAYING HEALTHY

15. This is as near as the Darzi report comes to public health. Its recommendations seem to be less specific than elsewhere. We support those recommendations but would add some:-

(a) The constant decline in the proportion of PCT expenditure on public health should be reversed or, if PCTs cannot do this, consideration should be given to transferring the public health function elsewhere. It has only been with the NHS for about half the NHS's 60-year existence.

(b) Greater focus on health protection should apply to sex education (and health education generally) in all schools. Heads should be given feedback on the incidence of STIs amongst their schools' anonymised former pupils (no such feedback is presently given). High take-up of free school meals (as an indicator of poverty) should be observed and acted up by PCTs, since poverty is clearly associated with poor health (Black Report).

(c) Health education of adults and children fares very poorly in resources by comparison with those of commercial organisations (including the media).

(d) Much public health is a global or international issue. Even climate change will affect public health in diverse ways. More needs to be done to educate everyone, including the media and

other businesses on this. European Union activities which affect public health should be widely publicised and implemented, not just discussed in secret with influential industry groups. Closer to home, the Department of Health and strategic health authorities should increase their public health activities. Preparing for possible or probable pandemics is, of course, desirable and they do it, but campaigns against pollution, for safe (in more than one sense) sex, against unchecked imports, undesirable food processing with additives for example and other issues are possibly of even more importance because the issues are continuous, not just one great one.

MENTAL HEALTH

16. It is an extraordinary fact that when a minority of non-mental health trusts were cheerfully (or unknowingly) overspending public money, no mental health trust did. The net effect of their competence and others' recklessness was to transfer money away from mental health. This was probably harmful but another fact is that the percentage of PCTs' money spent on mental health varies by 4 to 1 across London which probably partly shows the difficulty of measuring mental health needs (similar percentages for cancer treatment vary by 2 to 1 – they have no relation to outcomes). Our source for the previous sentence was a seminar conducted for us by the King's Fund, which we gratefully acknowledge.

17 We cannot fault the Darzi report's recommendations on mental health but we do feel there is something not quite right in this area. For example, our mental health colleagues tell us that patients often do not have their own care programmes which they are supposed to be given and that some consultants wish this was not required. We need to know that the national mental health seminar framework is being followed and any deviations from it. This is not mentioned by Professor Darzi.

18. Another problem is that the 11 London MH trusts cover, on average, nearly three Borough/PCT areas). The South London and Maudsley Trust even covers an area in two different former SHA areas. Coordination between their commissioners is not always perfect.

19. Finally, MH trusts and users seem to communicate better with each other than with the wider community which pays for them. **We therefore welcome NHS London's decision to set up a new working group on mental health.**

ACUTE CARE – (DARZI pp60-67)

20. The report is quite right that "Londoners do not always know which organisation is most appropriate to call". If "70% of NHS Direct's calls are left unresolved" or passed on to another service", surely there is something seriously wrong with the NHS Direct concept? If "40% of those the ambulance service conveys to hospital could have been cared for in the community", was it not so done because the facilities we not there or not there at night or weekends?

21. The proposed provision of a new telephone service (additional to 999) is to be welcomed but was that not what NHS Direct was supposed to be? It will be interesting to discover how far they successfully "book you an appointment with your (sic) GP". GP administrators find difficulty sometimes in keeping "their" GPs to agreed procedures and it is much more difficult to make an appointment with a particular GP rather than with any GP in a practice. The police have, of course, experience of using telephone numbers additional to 999.

Specialist care - trauma, strokes, heart attacks

22. Few will object to more trauma centres though there will be more trusts that want one than are proposed. What a pity though to say it should be "integrating hospital and pre-hospital care" but not mentioning "post-hospital care". We may keep people alive but not in the best condition they could be if the present relatively sharp separation of post-hospital care continues. The Darzi report does not ignore this. (See its paragraphs 173 to 177), but when will improvement in post-hospital procedures take place? **We must add our view to many others and say to the PCTs, NHS London and the Government that whether it be financially to the patient and family or in treatment, the present system of rehabilitation for trauma patients is not satisfactory and needs urgent attention**.

23. Much the same is true for strokes. Few will object to 24/7 stroke centres with proper staff and facilities though their exact location will cause much discussion. A fact sheet giving outcomes from each centre would be desirable. **But when the best immediate treatment has been given how will rehabilitation after that be organised?** The same again is true for heart attack victims and other acute patients. This matter will never be resolved adequately until local authority finance is attended to, but meanwhile local authorities are penalised if they do not take patients from the NHS, even if they have to give them less than desirable care.

PLANNED CARE

24. Access to GPs is a most contentious issue and we deal with it below. Out patient care, we suspect, is not as simple as Professor Darzi makes it sound in his paragraphs 161 and 162. The paragraphs on "diagnostics" (163 to 167) amount to saying that the system for spreading best practice throughout the health service and the private sector should be improved, as should the administration of day cases.

25. Obviously we support the view that good practice on cleanliness should be spread. We hope this is not restricted to NHS hospitals. Private facilities and privately run services should be included automatically. Bugs are neither socialists nor capitalists. GP practices must be included also. There is no doubt that MRSA, for example, is in the community and must be dealt with outside hospitals as well as inside them.

LONG TERM CONDITIONS (LTCs)

26. Many of our members have at least one LTC. We do not all feel we **should** be at the centre of a web of care. We have a higher regard for the NHS than that and often feel that we **are** at the centre of such a web, though obviously improvement is always possible. The "hard to reach" groups may well be people who also find it hard to reach advice and help.

27. There can be little excuse for undiagnosed LTCs. **When reliable tests are available and their cost measured against the frequency of the condition tested, all relevant people should be given them by "their" GP where possible.** Relying on individuals to come along and say: "what is wrong with me?" seems a bit outdated, although it may save money. Everyone has long been aware that without comprehensive testing many cases will be missed until too late. It is relatively simple to calculate the probability of a test revealing an undesirable condition and then the desirability of testing. We suspect that this is not done in some cases because testing would increase the demand for a service. Another factor may lie in the complexities of doctors' contracts. Whether a doctor should gain financially from testing needs careful thought, not just the assumption that different work equals more money. What has happened to the annual health checks of elderly patients? Does it take place as it should in all practices?

END-OF-LIFE CARE

28. We find the percentage (0.7%) (paragraph 232) of London's population dying in 2005 remarkably low and should like an explanation of it.

29. The Darzi report seems to assume that the patients' wishes at the end of life are paramount. We should point out that prospective death is NOT just the same in this respect as any other condition. **A patient's wish to die at home, for example, needs to be balanced against the wishes of carers and family and the provision (which varies) that the relevant local authority makes to support them.**

30. We have strong objection to the artificial boundaries of the former London SHAs continuing in use as "sector" boundaries (Darzi paragraph 250). For example under them, Croydon is in "South-West" London which is a nonsense. If the real South-West London is too small to be a sector, the answer is to have a sector south of the Thames not to try to transport whole boroughs from East to West. Actually London is more readily considered as Inner and Outer, before any other divisions are considered.

CHILDREN

31. We welcome NHS London's decision to create a separate children's (paediatric) workstream.

32. Now that not all diseases are life-threatening, immunisation against them is not compulsory as immunisation against smallpox once was. But if something is not compulsory, one must follow people's wishes in doing it and many people do not wish to subject their children to immunisation aggregated together in a single package. **The Government, NHS London and the PCTs must accept this and provide single immunisations in the NHS if they regard the level of immunisation as sufficiently important.** We realise that patients' (parents and children) may be reluctant to come a second or third time to be immunised but some solution to this should be sought. Is immunisation at school a better possibility?

PRIMARY CARE BY GPs

33. This is our heading for Darzi page 87 onwards. We realise that Professor Darzi chose his headings with care but we wish to make the point that the relationship with GPs is the most important in the public mind.

Size of practices

34. Patients quite clearly prefer to have a primary relationship with one doctor; hence the popularity of small practices. But patients do not expect to see the same general practitioner all the time; they know that "their" doctor may be ill or on holiday. Patients hope to see the same doctor about one condition, since it is irritating to have to repeat the facts to different doctors – notes are never perfect.

35. The diagram in the Darzi report (page 88) on the size of practices is quite deceptive and should be disregarded. It is based on the former SHA areas and on that basis shows the percentage of single-doctor practices as varying from 16% to 36%. In fact it varies much more by PCT area and this fact is concealed by the old SHA-area diagram. In Lambeth, for example, there are only two single doctor practices left because the PCT, over the years, has quietly amalgamated practices as natural wastage occurred. Those two practices are under 5% of all Lambeth practices. In other words, the percentage of single-practices is partly a function of each PCT's attention to removing them – if that is considered desirable by the PCT. Those boroughs with high percentages of single practices have them because their PCTs did not get rid of them, possibly intentionally.

36. It is certainly possible to argue that a small practice is too small but there does not seem to be any legal upper limit to size. The number of partners was once limited to four, until a practice in Sutton and Merton instigated a general change in the law. Patients, however, prefer smaller practices and dislike them more the larger they grow (Picker Institute study).

37. Amazingly, there seems to be no study on the optimum size of practice, determining the size at which they are most efficient. **Therefore we welcome NHS London's proposal to have 10 pilot "polyclinics" as Professor Darzi provisionally labelled his proposed units.** It is to be hoped that they will differ, especially in size, so that the effect of size variation can be studied. Professor Darzi does not propose that all polyclinics should comprise a single practice nor does he propose any model for their governance.

38. It is important that someone does consider this, since existing practices are known to us in which the partners privately consider their own practice to be too large at over 15 FTE GPs. We know practice administrators who consider their GPs to be out of control in administrative respects. Indeed there is no necessary reason why good doctors should be good administrators and they may find the rules which develop to control a larger practice irksome.

Relationship of GP and Patient

39. Size of practice is only one aspect of the relationship between GP and patient. The Department of Health and the medical profession do not seem to realise the distrust caused by the registering of patients with practices in replacement of registering them with individual doctors. It was not discussed with patients at the time. Nor was it widely publicised so that knowledge of it is still seeping out to the community, causing a state of trickling distrust. Who is now responsible for an individual patient's primary health care? The answer: "the partners in the practice" or "the company providing the care" is meaningless to the average patient.

40. This is important because the responsibilities of doctors have suddenly become vaguer than they were. This must not extend to polyclinics. A hospital has a chief executive and NHS London must give each polyclinic a defined head with responsibility for it.
Matters which need to be considered are:-

    (a) Liability for crime. Rare though it is, doctors can commit crimes, Shipman being only the extreme case. But successfully prosecuting companies for manslaughter is almost impossible in the UK, unless they plead guilty. The Department of Health even recommended as consultants three companies convicted of crime outside the UK.

    (b) The cumbersome procedure of suing "the partners" as "the company" in a civil action should be replaced by "no fault" remedies.

    (c) Finally the delicate subject of the competence of individual doctors in the practice/polyclinic needs addressing. It is not long ago that there was a doctor criminally harassing his women patients in Lambeth; it took many years to remove and convict him. Quite recently a PCT failed to deal with a failing practice during an interval in the succession to the PCT's chief executive. **If clinics and practices are to grow larger the disciplining of its doctors and other professionals must become more like that of, say, accountants in businesses, i.e. they should be fairly easily dismissible. The mixture of salaried and feed professionals in the public and private sector cannot just be ignored.**

ACADEMIC HEALTH SCIENCE CENTRE

41. Professor Darzi pointed out that London has seven Biomedical Research Centres (three comprehensive and four specialist) none of which meets his criteria for an Academic Health Science Centre. The criteria were integrated governance, internationally-recognised excellence in research and clinical practice, clear integrated funding streams for research and teaching, integrated leadership and career paths, joint programmes which combine research and clinical work and commercial expertise to market research development and benefit the UK's economy. **The last of these criteria seems to us to ignore the possibility that the research developments may be published openly for the use of the world.** Aspirin, though it was developed commercially, was not discovered and copyrighted in that way. There are currently well-known controversies over the use of the human genome and other matters. **Not all research can be purely commercial.**

42. Professor Darzi proposes somewhat vaguely that Biomedical Research Centres "could develop into" Academic Health Science Centres (does this mean all seven?) but "NHS London will have to seek to ensure that research and clinical excellence is not diluted". His report then pointed out that all research must not be concentrated in major acute and specialist hospitals (most of the country might add that it should not all be concentrated in London). Finally, according to the Darzi report: "Work should also continue to build the Global Medical Excellence cluster in South East of England". This involves collaboration between Imperial, University and King's Colleges in London , as well as Oxford and Cambridge. Considering that King's alone is related to two NHS Hospital Trusts on several more sites, there is some way to go in this collaboration and it certainly could not claim the "integrated governance" which is one Darzi criterion for a mere Academic Health Science Centre.

43. The consultation paper does not discuss this issue raised by Professor Darzi. We would point out that it needs more thought than is currently being given to it. Much work is being done based on emotion rather than thought. **There is need for a centre for excellence capable of competing with such institutions as the Mayo clinic in Minnesota and similar institutions in the US, Germany, France and elsewhere. This will not be created in the UK if every existing medical institution seeks to become the world-competing one.** It is clearly a matter for the Government as a whole to consider, since it involves the NHS in the UK, university research and teaching and finance.

CONCLUSIONS

44. We welcome the existence of a report considering London healthcare as a whole, resulting from the creation of a strategic health authority (NHS London) for the Greater London region. We also welcome the efforts of NHS London and the 31 Primary Care Trusts to achieve adequate consultation on this report.

45. We believe that Londoners basically support a public health service financed from taxation and are well aware that such services do not exist in much of the world.

46. There is no finance pathway in the Darzi report. It needs to be made clear that if health inequalities are to be dealt with more needs to be spent on deprived areas of London than on prosperous areas.

47. There should be more emphasis on public health and we welcome NHS London's decision to set up a new working group on mental health. We also welcome the decision to create a separate children's workstream.

48. We welcome the proposed provision of a new telephone service, more trauma centres and 24/7 stroke centres but point out that post-hospital rehabilitation is important too. Planned care proposals on, for example, cleanliness, should include private facilities and GP practices automatically. We find little excuse for undiagnosed long term conditions if tests are available and would be desirable.

49. Patients' wishes to die at home must be balanced against the wishes of carers and family and local authority provision for their support.

50. If immunisation is sufficiently important, parents' wishes as to how it is done must be taken into account.

51. No one has studied the optimum size of practices. Therefore we welcome the 10 proposed pilot "polyclinics" if they do so. Patients and many doctors dislike very large practices and they raise questions not mentioned in the report of the relationship between GP and patient, the responsibility for individual patient primary care, no fault remedies for mistakes, governance of clinics and the dismissability of below-average doctors. These have not yet been addressed.

52. Not all research can be purely commercial. There is need for a world-competing centre of medical research excellence but it will not be created in the UK if every existing medical institution seeks to become the world-competing one.

53. We look forward to the next report on detailed implementation proposals.