NHS

Commissioning Support for London

The patient perspective

A paper written by the cardiovascular patient panel

March 2010

Contents

1. Executive summary

1 An integral part of the project for improving cardiovascular services in London was the involvement of patients and carers with direct experience of these services. A panel of 11 provided the patient view and experience throughout the project, with two members sitting on the project's three clinical expert panels.

2 Although the project focused on cardiovascular services delivered in hospital, the patient panel asked the project board to recognise that care before, during and after a hospital stay are all of equal importance in the patient experience.

3 Many of the panel's recommendations were incorporated into the model of care, which provides guidelines for commissioning cardiovascular services in the capital. There were some important recommendations from the panel that were outside the scope of the project. As a result, the project board asked the patient panel to carry out a piece of work around improving the patient experience.

4 The task was to highlight top priorities that could easily be implemented by cardiovascular departments without requiring changes elsewhere in the hospital. The report also lists a series of other recommendations which, while possibly taking longer to implement, would significantly improve patients' experience if they were implemented across London.

5 The patient panel recognised that some of the proposals are already part of the services delivered by some cardiovascular providers but recommended this good practice be universally adopted by all providers and form part of performance assessments. Some of the proposals, such as the inpatient consultant appointment and patient passport, could be piloted in cardiovascular units in London and spread to other specialities and regions of the country if they were found to be successful.

6 This paper has been written collectively by the patient panel, putting forward our own views and recommendations on the subjects discussed. As such, it is written in the first person. The views expressed in this publication reflect those of the patient panel and not necessarily those of Commissioning Support for London.

7 Members of the patient panel would be pleased to assist the relevant NHS bodies to develop and implement any of the recommendations made in this paper.

2. Introduction

8 To assist the Commissioning Support for London review of hospital cardiovascular services in London a patient panel was recruited.

9 The panel was made up of 11 members – 10 cardiac patients and one carer. The members were recruited from Commissioning Support for London's Patients and Public Advisory Group and from the patient panels of the existing London cardiac and stroke networks. Some are also active in other patient and public involvement forums, such as LINks.

10 Collectively, the members have experienced a wide range of cardiac events, including angina, heart attacks, valve problems, heart failure and arrhythmia. Some have had just one event; others have experienced multiple events stretching back over 20 years.

11 The two co-chairs of the patient panel sat on the project's three clinical expert panels, providing a patient view as required and reporting back to the patient panel about the detailed progress of the review.

2.1 Background

12 The review was initiated by the London Commissioning Group to consider (in summary) the following issues:

- Cardiovascular conditions are the leading cause of death in London, with nearly 17,000 people dying from conditions, including heart attack, stroke and aneurysms, each year.
- Most London hospitals provide vascular surgery, which often underpins 24 hour emergency surgery. In many cases there is a limited number of surgeons and specialists supporting the service and variable outcomes.
- Surgical outcomes for vascular surgery are poor when compared with national or international good practice benchmarks.
- Better quality and outcomes are produced in centres where there is a critical mass of expertise and a range of supporting specialities.
- The quality of primary angioplasty (door to balloon time) varies across London.

13 Three clinical expert panels – covering cardiology, cardiac surgery and vascular surgery – examined evidence relating to these issues, including comparisons with other countries' (particularly European) results. The studies confirmed that in some aspects of cardiovascular services, particularly but not exclusively the more complex procedures, patient outcomes in London vary widely and in total are not always as good as achieved elsewhere.

14 In short, some cardiovascular patients leave hospital facing a lower quality of life, and die sooner, than could be achieved by adopting best practice.

15 The clinical expert panels' work is reported in two sets of papers:

- A case for change – which sets out how the NHS in London is currently delivering services in comparison with clinical evidence and best practice.
- Model of care – which proposes how commissioners in London could organise services to achieve better outcomes.

2.2 Financial implications

16 At the time of writing this report, it was not yet clear whether the proposals would cost more or save money. Either way, the sums involved are likely to be relatively small. As financial pressure on the NHS is now the subject of much public debate, we consider it important to make clear that our support is based on improving standards, and not on any contribution the project might make to cost saving. Indeed, one of the points we make in this paper is that the project's recommendations should be seen as a whole. They should not be 'cherry-picked' to implement cost saving elements while rejecting the rest.

17 Noting that financial objectives are not the primary driver behind this project, we have confidence that the model of care developed by the clinical expert panels are solely drivers for quality of outcome. It is our view that there **must** be no circumstances in which the project report is used by administrators as a rationale for cost saving and we urge that every effort be made to safeguard the proposals from such motives becoming the focus of public and media belief.

2.3 A comprehensive approach

18 The patient panel would like to declare our unequivocal support for a project, which will **improve standards, reduce deaths and give people better lives**. While we recognise that the project focused on acute cardiovascular services because the model of care and its implementation were required in a very short timescale, we believe that the full benefit will only be achieved by considering a broader range of issues that affect patients' experience in hospital and after discharge. Much like the contented cow theory, a patient who is well treated in all aspects – not just the clinical ones – of a hospital stay will recover better and sooner.

19 Once discharged, it is essential that follow-up support services are properly planned and fully resourced. To put it bluntly, it is pointless devoting costly and skilled hospital resources to saving a life if the patient then dies through inadequate after care. As such, most of this paper is devoted to the wider non-clinical issues, which we believe should be addressed to support the improvements proposed in the model of care.

20 We believe it vital that the organisations responsible for implementing the project's recommendations – commissioners, cardiac networks and individual hospitals – should fully understand our views, the reasons behind them, and what they mean in practice for actual patients. We therefore wish to engage in dialogue with all appropriate bodies.

21 As the first stage we would like to meet the body responsible for approving the implementation of the model of care before they make their final decisions.

3. The patient view

22 At the very start of its work, the patient panel felt that the review's aim of achieving improved standards in cardiovascular services could only be achieved if attention was paid to issues beyond just clinical matters. We were particularly concerned that where services are proposed to be centralised, implying longer and more difficult journeys for many patients and visitors, the NHS should make every effort to provide high quality support services at every stage of the patient pathway.

23 To present our case, the patient panel submitted a paper, The Patient View, to the project board. This paper described what patients expect of cardiovascular services from the point that they experience symptoms beyond those that can be treated by their GP. The views expressed were based on the personal experiences of the panel members and on their wider knowledge obtained from attending other panels, forums and support groups.

24 The Patient View was analysed in detail by the project staff and was circulated for comments to the clinical expert panels. The project board agreed with almost every item raised and provided a formal response to each of them.

25 Many of the items have been included in the proposed model of care, either directly or as an implied part of a broader topic (see appendix 1). The patient panel looks to the commissioners to ensure that patient concerns about the procedures they face and other issues are fully understood and do not get lost in the implementation process. In some instances it may be necessary to devise new ways of measuring hospital performance, and patient panel members will be pleased to assist in this.

26 For a few items raised by the patient panel the project board requested more detail. Most of these have been dealt with in discussions with the project team. One suggestion that seems to have gained support within the project team is the proposal that hospital patients should be given the same opportunity as outpatients of having a consultant appointment that can be attended by a carer or relative.

27 Most of the remaining items were deemed by the project board to be out of the scope of the project (see appendix 2). However, we are pleased that the senior officers of the project invited us to submit a further paper dividing our recommendations into categories according to how and where in the NHS they can be implemented. Within these, they have asked us to give a short list of priority items capable of being implemented by cardiovascular departments without needing significant changes elsewhere in the hospitals. This paper – The whole picture: As seen from the patient's perspective – seeks to meet this remit. In so doing we have taken the opportunity to refine and develop our proposals.

28 Many hospitals and other responsible organisations in the NHS already meet some of our recommendations but experience tells us that standards vary widely. To achieve the world-class standards to which the cardiovascular review aspires, we believe that all concerned should systematically review their current practices.

This may be an activity for which the London cardiac and stroke networks can take a lead

29 Consideration also needs to be given to the validity and degree to which hospitals are relied upon to provide self-assessments of their performance.

4. The priority list

30 This section sets out the top eight items on our priority list of improvements to the patient experience, which we believe could be implemented by cardiovascular departments without needing significant changes elsewhere in the hospitals.

31 Some of the items in this section involve spending time with patients before their treatment is decided and delivered. In emergency cases, we recognise that urgency must take priority. These principles should, however, apply to these patients as soon as the immediate emergency has been resolved.

4.1 Our top priorities

Patient care on the wards

32 **Issue one: As far as practicable, there should be continuity of care** with the same doctors for a patient's stay in any one hospital, and the same nurses for their stay in any one ward. We accept that staff roster patterns, leave and the need to second staff for other purposes, such as training, make this difficult. However, it may become easier where wards are staffed by relatively small groups of nurses specialising in cardiovascular work. At the very least, teams of nurses should be as stable as possible, establishments should be maintained to minimise the need to hire agency nurses to meet short term staffing crises, and each patient should have a named nurse on each shift to whom they can address queries.

33 **Issue two: Consultants should clearly demonstrate their interest in all aspects of their patient's situation** – such as bed comfort, feeding, cleanliness and hygiene – and quickly take up any shortcomings with those responsible.

Key quote

The patient knows the pain – the doctor knows the treatment. So a patient – doctor relationship is essential for good treatment.

A patient with 12 years' experience of heart failure

Communication on the wards and patient reassurance

34 **Issue three: When a patient is first admitted to hospital, a consultant's inpatient appointment should be offered at a time suitable for carers and relatives** to attend to support the patient and to make sure that all parties fully understand the situation.

35 **Issue four: As the patient's stay continues, they may welcome the presence of a carer or relative to help them remember and understand what they are told by their consultant, and to ask questions on their**

behalf. We recommend that hospitals facilitate this by publishing details of consultants' ward rounds so carers or relatives can visit while they are in progress. If the ward round schedule is unsuitable for the visitor, further mutually convenient inpatient appointments should be arranged.

36 **Issue five: Without having to be asked, staff should offer explanations of any medical terms and explain the purpose of all medications and treatments.** Verbal information about medical conditions, procedures and future lifestyle advice should be supplemented by easy availability of written information, such as British Heart Foundation booklets (in appropriate languages). DVD material should also be offered if a viewing facility is available.

37 **Issue six: Where patients' condition permits (e.g. ability to move around the ward), staff should encourage them to talk to each over about their condition and treatment.** Sharing information can be mutually supportive.

38 **Issue seven: The prospect of any invasive treatment can be frightening, and the facility to discuss fears with a former cardiovascular patient is valuable, and should be available at all hospitals seven days per week.** Although there may be some provision of counselling and psychological assessment in hospital prior to a procedure, we see this item as one of simpler reassurance from someone who has had personal experience of a similar condition. The aim would be to have a list of former patients willing to visit patients on request or speak with them on the phone, such the buddy system already in use in some departments of some hospitals.

Key quote

Treatment has got better – but explanations have got worse. Patients are often not treated as patients.

A patient with 50 years experience of living with a congenital heart problem

Patient passport

39 **Issue eight: When leaving hospital patients should be encouraged to keep a patient passport or similar wallet with them at all times**, containing up-to-date medical information including discharge letters, latest medication, details of GP and consultants, ECG and Echo results, ICD settings, any later hospital admissions or appointments, and any other papers the patient would like to be readily available in an emergency. This material would be useful for paramedics or other professionals in event of future emergencies. This item could be a quick win for rapid implementation. In the longer term, the wallet should include a copy of a properly structured patient care plan.

Key quote

I've had paramedics, a GP and general nurses all fail to know what my

implanted defibrillator is. Knowledge is all!

A patient with 12 years experience of heart failure

4.2 Other hospital issues

Bedside manner

40 Staff must ensure patients, families and carers understand their condition, the nature and risks of proposed treatment, and future lifestyle requirements and limitations. The importance of a sympathetic and effective 'bedside manner' must be understood by all staff and effective training provided as necessary.

Key quote

This will be a life-changing event.

From a consultant cardiologist to a patient with angina – a cardiac event at the very bottom of the scale of severity

Resources

41 There must be ample resources – staff and bed places – to ensure that operating schedules are maintained in all but most extreme circumstances. Short notice cancellation of operations, for example due to insufficient intensive care beds, is very distressing for patients and costly in staff time.

Food

42 Food must be appetising and served hot. Poor quality and lukewarm food that patients dislike or even reject can inhibit recovery. Uneaten food should be monitored for follow-up by clinical staff.

Enabling nurses to nurse

43 Nursing staff must be able to concentrate on nursing. They should not have to waste time and energy on tasks such as chasing up urgent test results, no-show ambulances or having to guide short-term agency staff. Stressed nurses lead to stressed patients.

Chest surgery for females

44 For some female patients having chest surgery there may be concerns about needing to wear a special support bra – at least until the chest has fully healed. Some hospitals currently offer advice about this but we recommend all do so, and if necessary provide patients help to obtain them.

Stress free outpatient appointments

45 Hospitals must honour appointment times in all but the most exceptional circumstances.

46 At the first visit, the patients' preferences for future communication should be established, for example via letter or email and whether telephone reminders are desired.

47 There must be an easy and efficient system for patients to change appointment times.

Cultural issues

48 Account must be taken of cultural issues, which can affect how members of different ethnic groups may wish to be looked after. For example, there are specific religious and cultural needs of female patients in some communities for service delivery by female health professionals. Other patients, too, may wish to have some choice about who will treat them. We accept that this may need to be a longer-term issue, by reason of training time and resources.

Transfers between hospitals

49 An important feature of the project's proposals is that some patients with an urgent need for specialised treatment will have to be transferred to another hospital. The model of care clearly stipulates that the receiving hospital must provide the necessary service – and associated support facilities – on a 24/7 basis. However, it is also important to emphasise that the ambulance transfer service in such cases must be carried out expeditiously, and accompanied by an appropriate level of paramedic or nursing skill.

50 This may need changes to existing practice. We have concerns that at present the London Ambulance Service would not give such cases the necessary level of priority as they do not classify them as emergencies, and also that some hospitals may use ambulance contractors who provide transport but do not necessarily use staff with the necessary skills or vehicles with the necessary equipment.

51 It is also important in such cases that every possible effort is made to give accurate information to the patient's carer or relatives to minimise the risk of them going to the wrong hospital.

4.3 Issues for patients at and after discharge

Leaving hospital

52 Patient needs vary widely according to their physical and psychological condition, their home circumstances, the availability of family or carer support, and in some cases their financial circumstances. All these aspects need individual consideration by hospital medical teams, in conjunction with the patient and family or future carer, when planning for a patient to leave hospital.

53 Where home circumstances are not suitable for the patient's condition, but remaining in hospital is not appropriate, the possibility of convalescence should be discussed with patients and their family. Hospital staff should have a good knowledge of what services are available, have the time to make bookings and be able to advise and assist with obtaining any financial help that might be available for those who need it.

54 On discharge from hospital every patient should be given a clear care plan, resourced by the primary care system. This should include the contact details of a named individual in the hospital team who has experience of managing the patient's condition. A copy of this plan should be included in the patient passport.

55 When patients return home, the possibility of home visits to check progress and provide reassurance should be discussed.

56 There should be ready availability of psychological support to help come to terms with future lifestyle limitations. In cardiac cases this should be available as part of a cardiac rehabilitation programme. *(Late note: A useful article has been published in The British Journal of Cardiology – "Meeting the psychological needs of cardiac patients: an integrated stepped-care approach within a cardiac rehabilitation setting"[1])*

Key quote

I was brought home then when the front door shut and I was alone, I was frightened because I didn't know what I could or couldn't do. A home visit by my GP helped to give me confidence

From a patient who had cardiac surgery and lived alone

Ultimate discharge

57 Once patients are discharged from hospital, their ongoing care needs should be decided between the hospital team and their GP. Decisions about their ongoing medical care should be made on medical grounds alone and should not involve any sort of means testing. The patient's income or their ability to pay for a service should not affect which services patients can access following their hospital stay.

[1] http://bjcardio.co.uk/2010/07/meeting-the-psychological-needs-of-cardiac-patients-an-integrated-stepped-care-approach-within-a-cardiac-rehabilitation-setting/

58 By ensuring the best possible outcome for the patient, the likelihood of readmission to hospital (with associated additional NHS costs) or even of death will be minimised.

Continuing review

59 Where patient is referred to a GP for continuing review, it must be to a doctor who has training in cardiovascular work, has ready access to a consultant for advice, has an efficient tracking/reminder system to ensure patients attend at the prescribed intervals and has an efficient system for making appointments.

60 Hospitals should keep a database of clinicians and other healthcare professionals working in the community with training in cardiovascular care. This way, the hospital can help patients make an informed choice about where they go for continuing care and, if the patient wishes, assist with making arrangements on their behalf.

61 Where a patient is to continue to see a hospital doctor, they should be offered the opportunity of changing to a more local hospital if the centre where they were treated is a long distance from home.

62 Wherever they are seen, every effort should be made to provide continuity rather than be seen by a different person at each appointment.

63 It is vital that primary care trusts ensure that after-care is fully resourced to support the improved standards and outcomes that hospitals and their clinical staff will achieve as a result of this project. As we have already said, it is pointless to devote costly and skilled hospital resources to saving a life if the patient then dies through inadequate after care.

Key quote

Treat the "whole patient", not just the disease.

A husband and wife who both suffered major cardiac events

Items included in the model of care

64 Appendix 1 shows the items that the project board considers are embraced in the model of care. The model of care paper is a high level guidance document, and much will depend on the detail of how it is implemented. We believe that the contents of appendix 1 will help flesh out some of the detail. We think it important that commissioners pay close attention to these matters, which are very important to patients.

Key quote

Presenting on a Friday and being told one has a heart problem but nothing

will be done until Monday at the earliest is frightening enough; but being left on a ward over the week-end (when nothing happens and staffing levels are at a minimum) one is forced to come to terms with ones own mortality and do it unaided, whilst keeping a brave face on it for the family at visiting time.

I can clearly remember the inhumane experience that week-end and it still happens!

From a patient's memory of events 20 years ago

Finance

65 We note that financial analysis of the project's proposals shows that costs are likely to be reduced in some areas and increased in others. In the current financial circumstances facing the NHS, it might be tempting for commissioners to adopt the cost saving proposals and reject – or at least defer – the others. We believe this temptation must be resisted. The aim of the project is to improve standards, and hence patient outcomes, throughout the areas under study and it would be inequitable to deviate from this objective.

66 At a personal level, as volunteer patient representatives we would be angry if the time we have devoted to the project bore fruit only as a cost cutting exercise.

Carers

67 Slowly, the importance and the needs of those who care for people with long-term health problems are gaining recognition. Many of the needs of people with these problems extend beyond the present responsibilities of the NHS. Of those that are directly relevant to the NHS, most are general for all serious health conditions. However, one particular matter reported to us by the carer member of our panel relates to a unique heart support group called Heartshare, based at St. Helier Hospital.

68 Heartshare's distinctive feature is that, unlike other heart support groups that are for both patients and carers, it is specifically for the partners of heart patients. This enables it to cater much more effectively for both the practical and emotional needs of carers. We commend it as a model that the NHS in London should facilitate more widely.

69 Heartshare is more fully described in A Carer's Story – a paper written for our patient panel and which we believe is worthy of a wider readership (see appendix 3).

5. Going forward

5.1 Future projects

Terms of reference

70 The terms of reference for the cardiovascular services project, set by the London Commissioning Group, are very tightly focused on acute care in hospitals. We appreciate that this was because the model of care and its implementation were required in a very short timescale and this militated against a wider brief.

71 However, patients are interested in good outcomes for years ahead, across their entire experience and throughout their pathway, which are not confined to hospital care. This is why the patient panel has considered issues that affect the patient experience both before and after hospital admission.

72 We believe that the desire for speed in dealing with the acute hospital aspects of cardiovascular services could have been met by specifying a wider project but with staged deadlines for different parts of the work. We are pleased that the project board has offered to provide the patient panel with guidance as to where its members can pursue the wider issues we have identified, and would be pleased if a second project was set up to deal with these matters.

Patient representation

73 Although the project started work in July 2009, it was not until mid-October that the patient panel first met. This delay placed pressure on the panel members in getting up to speed. The reason for the delay (presumably) was the need to start from scratch to draft job and person specifications and then invite applications from suitable groups of people.

74 We recommend that, in future, this work should start much earlier so that patient representatives are in place at the very start of a project.

75 We must also draw attention to the skewed experience base of the patient panel members, which did not include anyone with experience of vascular procedures. It is therefore possible that we have missed matters that may be important for vascular patients. Also, although we have a carer on the panel, this was entirely fortuitous in that the lady concerned accompanied one of the appointed members to the first meeting and we invited her to join us.

76 We recommend that for future projects the selection of a patient panel should include people with experience of all the areas to be studied, and should include at least one carer from each of those areas.

77 We also suggest that it would be helpful to have patient representation when project terms of reference are decided. Plainly it is not practical to delay deciding project terms of reference until a patient panel has been recruited – indeed the precise composition of a panel cannot be decided until the terms of reference are known.

78 We therefore recommend that Commissioning Support for London considers the various existing patient representative groups that support the NHS in London, and identifies individuals with suitable backgrounds who are willing to be called upon at short notice to assist in setting the scope of future projects.

79 We would commend one feature of our work for adoption by future projects. This is the decision that representatives from the patient panel should attend the clinical expert panel meetings. This has enabled us to offer strong and timely input at the point where most of the decisions that will affect patients' hospital experience are taken.

80 We understand this is the first time this method of working has been adopted by NHS London, and we would certainly recommend it in appropriate cases for the future.

81 For this project, patient panel attendance at clinical expert panel meetings has been used as an alternative to being on the project board. In this instance, this has not been a problem because the project board has approved all the clinical expert panel recommendations. However, in future projects this may not be the case. To enable patient views to be fully taken into account if a clinical expert panel's recommendations are queried, we consider that patient panels should also be represented on project boards.

Medical jargon

82 Our work with this project has inevitably brought us face to face with the issue of medical jargon and acronyms.

83 We do not dispute that clinicians – like other technical trades and professions – need shorthand terms to describe what they deal with and what they do. However, what has struck us is that it is not just layman who have trouble with jargon. Many health professionals have privately said that they too don't always understand what is being said.

84 Particular vexing features are the use of multiple terms to describe the same thing, (for example, angioplasty and percutaneous coronary intervention) the use of obscure (derived from Latin or Greek?) terms, which are actually longer than the plain English version (for example, myocardial infarction versus heart attack) and (most perverse of all and a cause of real unnecessary worry to patients and relatives) using plain English in a way that is actually misleading. An example is the term heart failure, which implies that the heart has stopped working, essentially death, to describe what is actually reduced heart function or heart weakness.

85 We genuinely believe that the medical profession needs to review and simplify its use of jargon – preferably with patient representatives' input to help select the most easily understood terms. We would like to think that the cardiovascular community is up to the challenge of leading the way.

5.2 Next steps

86 Members of the patient panel will be pleased to assist the relevant NHS bodies with the development and implementation of any of the recommendations in this paper.

87 As a first step, we would welcome a meeting with the sponsors of this project to enable us to flesh out our ideas and answer any queries.

6. Acknowledgements

88 We would like to thank Commissioning Support for London staff who have supported the patient panel's work on this project. Whilst it can be invidious to single out individuals, we feel particular mention should be made of Mark Hindmarsh, the project's principle researcher who, despite having an exceptionally heavy workload, has always found time to assist us in understanding many complex issues.

89 The co-chairs of the patient panel would also like to thank the members of the clinical expert panels, and particularly their chairmen Nick Cheshire, Huon Gray and Steve Livesey, who encouraged us to participate fully in their work and tolerated with good humour our frequent need for explanations of the matters under discussion.

90 Finally we would like to thank Caroline Taylor (project senior responsible officer) and Matt Thompson (project clinical lead) for the very positive reception they have given to the patient panel's work. It is all too easy, when requirements such as patient participation are laid down in directives from on-high, to simply tick the box and no more. This is not a charge which can be laid against their conduct of this project, and panel members feel that we really have been listened to.

Appendix 1 – Items considered by the project board as addressed in the model of care

Item No.	Patient comment	Agree / Disagree	Status	Project response	Action
3	The NHS delivers on the promise of World Class service.	Agree	Included	The project believes that the model of care describes a world class service.	None
5	Pre and post-treatment services which require frequent patient attendance (more than once a month) remain delivered no more than 45 minutes journey from home by public transport.	Agree	Included	Outpatient follow up services should continue to be provided at local hospital units and the recommendation is only to centralise certain specialist procedures. Patients should still be able to access services locally.	None
6	Once a GP refers a patient the aim should be for no more than two visits to a centre for tests, diagnosis, and decision on treatment.	Agree	Included	With more local hospital doctors having access to specialists, it is our belief that patients should require fewer hospital visits. It is difficult however to state a specific number of hospital visits that is appropriate for a given condition.	None
12	It is essential that paramedics can accurately identify the symptoms, to ensure that the patient is taken to the appropriate emergency centre without delay.	Agree	Included	This is absolutely key, and the project will continue to work with the London Ambulance Service to ensure that this happens. This comment will be used to inform discussions with the London Ambulance Service around triage of patients with a ruptured abdominal aortic aneurysm.	Project to continue to work with London Ambulance Service
13	In cases where paramedics are uncertain of the diagnosis, they must have a clear protocol to follow. It is better to go to a hospital with good facilities to assist the diagnosis than to waste time deciding on the best place to go.	Agree	Included	The specific protocols for the ambulance staff to follow will need to be devised and implemented across London. The project will continue to work with London Ambulance Service to ensure this happens and these comments will help to inform discussions with the service.	Project to continue to work with London Ambulance Service
14	The ambulance service must continuously monitor traffic conditions around London. If necessary to avoid delay, paramedics must be authorised to go to an appropriate out of London hospital.	Agree	Included	There is agreement for this in the clinical panels and in the work we have made explicit reference to heart attack centres based outside of London. However it is not in the remit of this work to tell London Ambulance Service to monitor traffic conditions.	None
15	All heart patients should be in specialist wards, treated by cardiac specialists.	Agree	Included	The project believes that the model of care will ensure that this happens. Urgent cardiac patients will be quickly identified and seen by a consultant within 24 hours.	None
19	The decision to transfer a patient out of a specialist unit during post-operative recovery must take into account of the patient's feelings; it should not be dictated by pressure on beds. The principle of short stays being better than long stays is a worthy principle, but it may not be the overriding consideration for every patient.	Agree	Included	In areas of the model of care where we make reference to reductions in length of stay we also make sure to state that patients should only be discharged when it is 'clinically appropriate'. The reductions in length of stay should be achieved by better processes in hospitals and not by discharging patients when they are not ready.	None

21	All supporting services must be organised and effectively managed to operate very efficiently. This is very important for minimising patient stress. For example, there should be no uncomfortable and long waits for tests, and if transfer to another site is necessary, then transfer ambulances must arrive at the booked time and with the correct equipment.	**Agree**	**Included**	Our work does make recommendations around how services should be organised and how transfers and referrals for cardiac surgery patients should take place.	None
41	The clear thrust of the review is that many services should be centralised in the interests of better patient outcomes, it is important that the principle is only applied to those aspects of treatment where it is really necessary.	**Agree**	**Included**	The case for change document states in the first couple of pages that, following on from Lord Ara Darzi's work *A Framework for Action*, the project is aiming to 'centralise where necessary, localise where possible'.	none
42	It is one thing for patients and their families, carers and friends to accept travelling long distances for the pre-hospital and inpatient phases of diagnosis and treatment, but much less so of post-operative needs. Our view is that any hospital visits - or combination of visits - which occur more than once a month should be no less local than now. If this means that doctors have to hold clinics at venues away from their central hospital sites, then this is what must be arranged.	**Agree**	**Included**	Although some of the surgical procedures will have to be carried out centrally, it is certainly our aim that follow-up from complex surgery can be done locally. The models of care all talk about establishing networks between sites to share knowledge and expertise and clinicians moving around the network to see patients in different locations. Services should be set up at the convenience of patients and not of NHS staff.	None
43	It is an unfortunate by-product of a system which seeks to drive improvement by tight specifications and by measuring results against targets, that things which are not tightly specified and not measured will tend to receive less management attention.	**Agree**	**Included**	As part of this project, we have worked with patients and clinicians to ensure that the things that we propose measuring and monitoring in the future are the correct ones that will deliver benefits to patients.	None
45	We would expect the results (i.e. outputs from any continuing work by the project) to be included in the future development of models of care and in specifications for patient pathways.	**Agree**	**Included**	Any work produced by the project team to date will form the basis for any future work and will be incorporated.	Patient panel to provide more detail
46	The UK's public service - often intended to benefit disadvantaged ethnic and economic groups - are notorious for their relatively poor uptake by those most in need of them.	**Agree**	**Included**	This is true that there has been much focus on disadvantaged groups over the years. A key component of this work has been around improving the equity of service, so that all patients can access the best quality service more easily. We have also focused on disadvantaged areas of London, particularly in relation to electrophysiology.	None
47	The NHS is of course intended to be a universal service, but it too is characterised by weaker uptake and poorer outcomes for the less advantaged groups. It would boost the chances of the review being translated into a funded plan if it could be demonstrated that it would particularly benefit these groups.	**Agree**	**Included**	Once regional networks are established, they will each have specific problems that relate to them, across a range of issues, including access to services to less advantaged groups. Depending on who these groups are within a certain region, plans will need to be devised locally to address them, and the project will encourage them to do this. The networks will need to provide evidence as to how their existence and plans continue to benefit patients within a specific region.	None

49	Some aspects of the clinical expert panels' work have been hampered by a lack of consistent data collection. In some cases this has resulted in doubt about the validity of comparisons between different NHS trusts. The Department for Health should take a lead to ensure standardised measurements across the UK NHS and to ensure full compatibility it should require the private sector to adopt the same measures as part of their licensing regime.	**Agree**	**Included**	There are have been issues around the validity of data in the project due to a variety of reasons. The project has already started to link the collection of information to payment, which should ensure that hospitals all collect data in the same way. The formation of regional networks should also facilitate this. The project does not necessarily believe that this should be undertaken by the Department of Health, as this would involve a wholesale review of all of their data collection processes and new guidance being given to every NHS organisation in the country.	None
50	As the project proposals are likely to place additional responsibility on the London Ambulance Service to accurately triage emergency patients and then take them to the correct hospital, it will be important that they receive feedback data to enable them to measure their performance and understand the ultimate outcomes for these patients.	**Agree**		Agree. Work with London Ambulance Service is ongoing about how to make this happen	None
52a	Government policy is to encourage patient choice. Both the centralisation of treatment for the more serious conditions, and the proposal that reference to specific consultant should be the exception rather than the rule will militate against government policy on choice. The project board should say how it will reconcile these positions and how they will ensure that the NHS hospitals and NHS patients are treated equally in respect of patient choice of consultant.	**Agree**	**Included**	There is no conflict here between government policy on patient choice and the project recommendations. In relation to centralisation, patients will still choose which hospital they are seen at initially, and this will include which consultant they wish to see. It is important to remember that at present, some patients are 'choosing' a service which we believe to be clinically sub-optimal and therefore, patient choice is already limited to service availability for clinical reasons. Patients should be able to access a service of equally high quality, regardless of where they live. The sub-specialisation of services will reduce the number of sites performing surgery but will add real value to the quality of the service.	none
52b	As above.	**Agree**	**Included**	In relation to the statement around referrals to a 'specific consultant should be the exception rather than the rule' this statement is in relation to non-elective patients for cardiac surgery and not elective patients, i.e. when a patient requires cardiac surgery urgently they should be referred to the surgeon with the shortest waiting time. If the patient, at this point, would like to wait longer for a particular individual then that can still happen and that is their choice to do so.	None

55	Whilst we hope that as a patient panel we are able to make a useful contribution to this review, our work should not be seen as a substitute for wider stakeholder and public consultation. We would like to hear the project board's proposals for this important part of their work.	**Agree**	**Included**	Whether a public consultation takes place is dependent on certain statutory legal thresholds being passed. If the changes proposed in the work meet these thresholds, then a full public consultation will be necessary. If not, then there will be no pan-London public consultation and the project will not seek to hold a full public consultation if there is no legal requirement to do so. It is also important to note that the consultation for stroke and trauma cost in excess of £1M. The patient panel should note, there is already a full public consultation in the north east sector underway in relation to hospital care, into which this project has contributed. The project has already held an open stakeholder event, and will continue to consult with cardiac networks, patients, clinicians, hospitals and PCTs on the recommendations.	None
56	Patients don't break up their lives in accordance with the NHS organisational boundaries. They are interested in good outcomes for years ahead, not just at the point of entry into or discharge from the hospital system. We therefore regret that the review remit is so limited in this respect, and we hope that the project board recognises this and will make recommendations accordingly.	**Agree**	**Included**	This paper makes recommendations as to where the patient panel can go next to pursue issues that are out of the remit of this project.	Patient panel to provide more detail
57	Three aspects of service are taken as read: 1) Diagnosis and recommendations for treatment are assumed to be the best which well trained clinicians can achieve. 2) National NHS targets for waiting time are met 3) Hospitals meet the highest possible standards of hygiene, cleanliness and avoidance of cross-infections.	**Agree**	**Included**	All hospitals are mandated by the Department of Health and Care Quality Commission to achieve these things, and the work of this project in no way changes this.	None

Appendix 2 – Items considered by the project board as not within the scope of the project

Item No.	Patient comment	Agree / Disagree	Status	Project response	Action
1	Staff to ensure that patients, families and carers understand their condition, the nature and risks of proposed treatment and future lifestyle requirements and limitations. The need for sympathetic and effective 'bedside manner' must be understood by all staff, and effective training provided as necessary.	Agree	Out of scope	It is not within the project scope to define either pan-London or individual provider communications training programmes.	Provide patients with where to go with this issue
2	All sections of the NHS must understand and take account of cultural issues which can affect how members of different ethnic groups may wish to be looked after.	Agree	More detail needed	There are some cultural and ethnic issues that are covered in the documents. The comment would need to be more precise in order for the response to address exactly what is meant by this.	Patient to provide project with specific detail to enable response
4	The wider range of non-clinical services which are an essential part of patients' experience are equally high class.	Agree	More detail needed	Some of the non-clinical aspects of care (e.g. transport, referral systems) are explicitily addressed in the work. If other areas are needed that the project needs to be made aware of what these areas are.	Patients panel to provide more detail
7	At the first visit - agreement to be reached for future communication - letter or email and whether backed up by telephone reminders for appointments.	Agree	Out of scope	It is not the role of this project to define how individual conversations between doctor and patient should be conducted.	Provide patients with where to go with this issue
8	There must be an easy and efficient system for patients to change appointment times.	Agree	Out of scope	It is not the role of this project to define the appointment system that each hospital providing cardiovascular services in London should use. This must be decided locally.	Provide patients with where to go with this issue
9	Hospitals must honour appointment times in all but the most exceptional circumstances.	Agree	Out of scope	The project agrees with this and furthermore believes that this is already the case in the vast majority of hospitals in London. However it is not within the project brief to address issues around outpatient appointment times.	None
10	Time must be allowed for clear explanation of the patient's condition and the proposed treatment. This should be backed up by the offer of booklets, DVDs and NHS website links (including NHS videos). This also applies to emergency patients once the emergency has been resolved.	Agree	Out of scope	This is clearly an important issue, but issues around patient communications in hospitals must be handled locally. This is possibly something that the cardiac networks could look into.	Provide patients with where to go with this issue

11	All patients with any pre-existing condition should be supplied with a patient passport giving brief details of treatment, medication, medical team to be contacted and next of kin. Patients should be strongly encouraged to carry this with them at all times.		**Out of scope**	This is a broad NHS and Department of Health issue that covers a broader area than just cardiovascular disease.	
16	Patient psychology must be recognised as a vital consideration. Being confronted with heart disease – particularly in the circumstances of an emergency admission – can be very frightening. For many people it will be their first serious exposure to the issue of their own mortality.	**Agree**	**More detail needed**	The project need more detail on what is meant by this and what the patient panel would like to change in hospitals. If this is a training issue for medical professionals then it is out of the remit of this project. However, more speedy access to treatment should have a positive impact on the patient psychology.	Patients to provide more detail on what exactly the services are they would like and the rationale for this
17	Equally the prospect of any invasive treatment can be frightening, and the facility to discuss one's fears with someone to one side of the clinical area must be valuable, and should be available at all hospitals seven days per week.	**Agree**	**Out of scope**	Patient access to counseling and psychological assessment in hospital prior to a procedure is out of the remit of this project.	Provide patients with where to go with this issue
18	There must be ample resources – staff and bed places – to ensure that operating schedules are maintained in all but most extreme circumstances. Short notice cancellation of operations – for example, due to insufficient intensive care beds – is very distressing for patients and costly in staff time.	**Agree**	**Out of scope**	This is an issue for hospitals to arrange. The project advocates fewer cancellations and good management of intensive treatment unit beds, but the project will not be issuing London trusts with proscriptive guidance on how to manage their beds and units on a day to day basis.	Provide patients with where to go with this issue
20	There should be continuity of care, with the same doctors for a patient's stay in any one hospital, and the same nurses for their stay in any one ward. Management must secure stable staffing, to absolutely minimise the need to use short term agency staff.	**Agree**	**Out of scope**	It is not possible to guarantee this in every hospital in London. This project cannot get involved with the rotas, timetables and rotations that all clinical staff go on in individual units to ensure that this is the case.	Provide patients with where to go with this issue
22	Nursing staff must be able to concentrate on nursing. They should not have to waste time and energy on tasks such as chasing up on urgent test results, no-show ambulances or having to guide short term agency staff. Stressed nurses = stressed patients.	**Agree**	**Out of scope**	The day to day role and the specific tasks that a hospital asks its nursing staff to do are out of scope. Nurses should of course spend their time doing fewer administrative tasks and our recommendations do include issues that should make services run more smoothly.	Provide patients with where to go with this issue
23	Food must be appetising and served hot. Poor quality and lukewarm food which patients dislike or even reject can inhibit recovery. Uneaten food should be monitored for follow-up by clinical staff.	**Agree**	**Out of scope**	The project understands that there are a range of issues that affect the recovery of patients following surgery, other than the direct clinical care that the patient receives. However, due to timeframes and the specific scope of the project, as set out by the London Commissioning Group in summer 2009, the project cannot address the entire range of other issues that affect a patient's recovery, such as the provision of food.	Provide patients with where to go with this issue

24	For patients who are elderly, weak or for any other reasons find it difficult to understand or interact with doctors, bed visits should be arranged when a suitable visitor is present to assist.	**Agree**	**Out of scope**	The project agrees with this sentiment, but cannot get involved in defining prescriptive things that units should be doing, such as when bed visits should take place. This is an issue for individual hospitals.	None
25	Staff should offer explanations of any medical terms without the patient having to ask.	**Agree**	**Out of scope**	As stated previously, it is out of the remit of this project to devise or input into communications training for clinical staff.	None
26	Staff should offer to explain the purpose of all medications.	**Agree**	**Out of scope**	This is good clinical practice and should be happening already. Where it is not, this needs to be taken up with individual units and staff.	None
27	Oral information about medical conditions, procedures and future lifestyle advice should be supplemented by easy availability of written information, e.g. British Heart Foundation booklets (in appropriate languages). DVD material should also be offered if a viewing facility available.	**Agree**	**Out of scope**	See answer to item 10	Provide patients with where to go with this issue
28	Consultants must assess – and demonstrate their interest in all aspects of the patient's situation, not just the clinical issues – for example, bed comfort, cleanliness and hygiene and feeding.	**Agree**	**Out of scope**	There is a team of people in the hospital responsible for the full range of issues relating to a patient's hospital stay. Although principally responsible for their clinical care consultants so also already take an interest in all aspects of the patients situation as described. However the project does not propose formallising this in any way.	Provide patients with where to go with this issue
29	There should be ready availability of psychological support to help come to terms with future lifestyle limitations	**Agree**	**Out of scope**	Providers should be explaining to patients where they can access support once they have been discharged from hospital, and this should include a range of local support services.	Provide patients with where to go with this issue
30	Staff should encourage patients to talk to each over about their condition and treatment. Sharing information can be mutually supportive.	**Agree**	**Out of scope**	Having patient support groups that patients can access locally are established across the board for a range of conditions. Some patients find them useful and others less so. This is possibly something that cardiac networks could take forward, if patients felt that access to a patient support group would be a useful thing for them to access upon discharge from hospital.	Provide patients with where to go with this issue
31	What happens after hospital is very important and a review which pays no attention to this aspect would be unacceptable to patients.	**Agree**	**Out of scope**	The project does not believe that patients at large will find the remit of the review 'unacceptable'. The project does believe that what happens after hospital is a crucial part of the patient's care. However, discharge and follow up services for patients have been out of the project remit from the outset. As stated in item 23, the terms of the review were set in summer 2009.	None

32	Patient needs vary widely according to their physical and psychological condition, their home circumstances, the availability of family/carer support, and in some cases their financial circumstances. All these aspects need individual consideration by hospital medical teams in conjunction with the patient and their family or future carer.	**Agree**	**Out of scope**	See answer to item 31.	Provide patients with where to go with this issue
33	Discharge should be to the patient's GP and not to the community at large. This will ensure that the NHS – through the GPs – must deliver patients' needs on clinical criteria. If non-clinical considerations are allowed to influence the post-hospital care plan, then some patients will end up being re-admitted or even dying – which would be contrary to the primary objectives of the project to improve patient outcomes and deliver world class service.	**Agree**	**Out of scope**	It has been clarified that this point is really around ensuring that patients are not disadvantaged, following their discharge from hospital based on how much money they have or a means testing process. The project agrees that when it is not appropriate to discharge a patient home, assessments should be on the basis of clinical need and not the ability to pay. Also, the project would expect that every patient being discharged from hospital following surgery would have a letter written to their GP and them to be informed of the discharge arrangements from the hospital.	Patient panel to provide more detail
35	It is important that the possibility of convalescence should be discussed with patients and families, that hospital staff should have a good knowledge of what is available, have the time to make bookings and be able to advise and assist with any financial help which might be available for those who need it.	**Agree**	**Out of scope**	The project understands the importance of convalescence to patients and families, however the focus of the project is acute focused, and is specifically looking at the services provided in hospitals. The project does acknowledge that discharge planning is key to reducing length of stay and improving patient experience. However, if the project were to look in detail at the issues around social care for cardiovascular patients this would be a project in its own right and would not be finished in time for it to be incorporated into 2010 commissioning standards	Provide patients with where to go with this issue
36	Similarly the possibility of home visits should be discussed.	**Agree**	**More detail needed**	Unsure what kind of home visits are being referred to here.	Patients to provide more information
37	Post treatment review – two issues are that if consultant review appointments are taken by registrars, it is important that there is reasonable continuity. Patients should not find themselves seeing a different person each time.	**Agree**	**Out of scope**	Following on from the answer to item 20, it is not possible for the hospital to guarantee that this will be the case, as there are a range of factors that a hospital needs to consider before deciding which members of staff will be working in a clinic. Continuity of care is an important issue, and hospitals strive where they can to provide this, but it will not always be possible for hospitals to provide this within reasonable constraints, even if the patient remains under the care of the same consultant. Taking this into consideration the project will not be making this explicit recommendation.	Provide patients with where to go with this issue

38	Where patient is referred to a GP for continuing review, this must be to a GP who has training in cardiac/vascular work, has ready access to a consultant for advice, has an efficient tracking/reminder system to ensure that patients attend at the prescribed intervals and has an efficient system for making appointments	**Agree**	**Out of scope**	Care out of the hospital in the community by GPs is out of scope of the review. However the project does agree that patients must be under the care of a GP or community service that has a good understanding of the patient's condition and how best to manage it.	Provide patients with where to go with this issue
39	For some female patients having chest surgery there may be concerns about needing to wear a special support bra - at least until the chest has fully healed. Some hospitals currently offer advice about this. All should do so, and if necessary provide help to obtain them.	**Agree**	**Out of scope**	There are a range of factors that can improve the patient experience of a hospital stay, including this. However, it is not in the remit of this project to be proscriptive to trusts at this level of detail. The clinical expert groups were formed to look at the clinical issues around how cardiovascular services were organised across London, and it is not in our remit to request that every hospital in London provides this specific service.	Provide patients with where to go with this issue
40	As cardiac rehabilitation is reported as being cost effective way of improving patients' medium and long term outcome, it would be perverse for NHS London to spend significant money on reconfiguring its cardiovascular services without also raising its performance on rehabilitation.	**Agree**	**Out of scope**	There is no evidence to suggest that the proposals in the model of care or case for change will result in 'significant' spending. In relation to cardiac rehabilitation, the aspects of care that fall outside of the hospital are not within the scope of the review. However the project accepts that rehabilitation can have a huge benefit for patients.	Patients to provide more detail on why proposals will be more costly.
44	The timescale of the present review is too short for this area to be fully developed. We therefore recommend that a continuing workstream for this purpose should be budgeted, and members of the Patient Panel would be pleased to assist.	**Agree**	**Out of scope**	The short timescales of the project do make it difficult to develop all the issues that relate to cardiovascular care and there are a huge range of issues that could be covered in relation to cardiovascular care. The project will recommend to the patient panel where to take this recommendation.	Provide patients with where to go with this issue
48	The project needs to recognise the cultural and religious needs of female patients in some communities (for example: Southwark has a 37% BME population expected to rise to 45%) for service delivery by female health professionals. We accept that this may need to be a longer term issue, by reason of training time and resources.	**Agree**	**Out of scope**	The project does recognise the needs of training hospital based medical professionals in the future and the importance of cultural and religious needs to all patients in London communities. However, it does not have a role to play medical training or the recruitment of female healthcare professionals.	Provide patients with where to go with this issue
51	The papers place commendable emphasis on the need for patients' treatment to be decided on the basis of clinical need. However where NHS hospitals also cater for private patients there could be conflicts in deciding priorities. Whilst this may not affect the use of consultants time, which is clearly stratified between NHS and private commitments, it can affect support services which are used in common between the two sectors. Clinical need should mean just that, and the Project Board should explain how the NHS hospitals will ensure that NHS patients are not disadvantaged in comparison with the private patients.	**Disagree**	**Out of scope**	The project has not received any evidence to show that NHS patients are disadvantaged in favour of private patients, nor that other NHS resources or support services are used by private patients. In the experience of the project team and expert panels this is not the case.	None

53	The medical profession needs to review its use of jargon – preferably with patient representatives input to help select the most easily understood terms. Even where jargon is simplified, medical staff should avoid using it when talking to patients, unless they have first explained what it means and the patient clearly understands it.	**Agree**	**Out of scope**	It has been confirmed that this statement is not in relation to the project documents and that they are clear. In relation to improving communications in hospitals, between medics and patients then see answer to items 1 and 10.	Patient panel to provide more detail

Appendix 3 – A carer's story

Perhaps some of you know that this year is the 100th anniversary of MI5 but how many of you know about another Secret Service, which is so important to us all here?

It is the Secret Service of 6 million informal carers who look after such patients as husbands, wives, partners, relatives, neighbours, and children.

Those unpaid volunteers play a vital part in the total care and rehabilitation of those who are, or have been, ill, especially in Cardiac cases with Heart Disease being the number one killer in the United Kingdom. Consider their roles.

Statistics

- A carer could be an adult or a child of 5 to 18 years and may live with the patient or some distance away.
- Of those 6 million in the UK, 4.4 million are of working age.
- Some give 24 hours care daily and respite is badly needed.
- 65% of carers suffer ill health or injury.
- Carers save the country £87 billion per year, equivalent to a second Health Service.
- The number who do not realise they are carers is UNKOWN.
- That number could be known from a 2011 Census question.

What can a person expect in giving cardiac care and rehabilitation?

- **Work:** A sympathetic employer is needed and pay could effect benefits or it could mean loss of job.
- **Benefits:** The means tested Carer's Allowance is £50.55 per week. The carer can also expert to receive other forms of income support and grants for patients.
- **Income:** Carer's income adjustments could mean changes in standard of living, car and clothes.
- **Social life:** Isolation because of health and finance.
- **Lifestyle:** Impact on families. Might mean remaining single. Cause stress leading to a divorce. Just one member of the family involved when patient is elderly.
- **Holidays:** Only change of scenery with same problems, respite care, such as adult sitting, necessary.

So what help can be given to carers? There is…

Legislation

The charity Carers UK is shaping legislation aimed at Carers

- 1995 The Carers (Recognition and Services) Act. The right to receive Local Authority assessment but LA has no obligation to act.
- 2000 The Carers and Disabled Children Act. Local Authority to provide services such as washing machines, mobile phones, and driving lessons but no obligation to act.
- 2003 The Carers Act (Equal Opportunities) passed into law
  - Ensures all Carers are entitled to assessment of their needs.
  - To take into account a Carer's outside interests(work, study, leisure).
  - To provide better joint working between Local Authority and the NHS.
- 2009 Shaping the future of care together: Green Paper that invites views on the principles for improving the delivery of care and on a number of options for reform of the current funding system. (Comments before November 13, 2009).

Other help for patients and carers

Support groups are invaluable for the welfare of carers and patients especially in rehabilitation, which is designed to help heart patients recover quickly and improve their physical, mental, and social functioning.

There are numerous such support groups around the country but one at St. Helier Hospital in Surrey is unique. It is called HEARTSHARE and is exclusively for partners, men or women, of Heart patients.

The group was established in 1999 with the aim of providing support and information to partners of heart patients, partners who perhaps did not realise they were Secret Service carers.

Lucy Grothier, now Director of South London Stroke and Cardiac Network, promoted the idea of a Partners' Service as part of a degree study. This was developed by me, as a volunteer and with support from the Cardiac team, into HEARTSHARE. My qualifications are Cardiac Nurse (Royal Brompton), Health Visitor, Clinical Teacher, Artist, and, deeply important, a CARER for 12 years.

Partners indicated how important it was to be able to meet and talk on their own, without the presence of patients. Points they liked to raise were:

- Information about cardiac events.
- How to deal with fear and stress.
- Highs and lows of patients' moods.

- Medication.
- When to call ambulance?
- Suitable activity.
- Travel insurance.

You may say those subjects are for medical professionals to deal with. But, let's be frank, how many patients and partners get professional psychological advice? How many, indeed, experience full support after a cardiac event when you consider that only 38% of those who qualify for rehabilitation have it. That's the official 2009 National Audit provided by the British Heart Foundation.

Another interesting rehabilitation statistic is that rehabilitation can reduce cardiac mortality by 26% during the first five years of the cardiac event.

Professionals and patients must be made aware of the importance of rehabilitation and the carers who guide them on the health pathway. Greater recognition should be given to the value of the carer's voice.

And greater recognition must be given to support for carers. Too often if the carer is a wife or husband he or she is expected to abide by the traditional philosophy of 'for better, for worse, in sickness and in health'. That does not hold in the 21st Century when carers, despite their love for the patient, can be working 24 hours for nothing.

They need respite provided by professionals. Perhaps they should be paid financial benefits inline with other citizens. Perhaps they should be given pension and tax concessions, …. everything and anything to lighten the weight of their task.

Carers, patients, the public, health professionals and MPs must continue to lobby for help for carers. Who cares for the carers? is a vital question for the whole nation.

SIRKKA THOMAS
CARDIAC REHABILITATION NATIONAL PRIORITY PROJECT,

13 October, 2009.