

Cardiovascular Disease Outcomes Strategy Online Survey Summary Report

Introduction

1. In December 2011, the Secretary of State for Health announced that a new CVD Outcomes Strategy was to be developed.
2. The Department of Health and NHS Improvement have been consulting widely with patients, carers, health professionals and a range of representative organisations on what the strategy should focus on.

This report summarises the feedback received from all the responses to this survey

The survey

3. The Department of Health and NHS Improvement ran an online survey from 18th July 2012 until 28th September 2012 (12.5 weeks) to seek views from patients with cardiovascular disease, carers of people with cardiovascular disease, healthcare professionals, voluntary sector support groups and members of the public. This survey adds to a broad programme of wider engagement activity in the development of the Strategy, including a series of engagement events hosted by the Department of Health and NHS Improvement.
6. The survey asked 10 questions (see Annex A) seeking views on how cardiovascular disease services and care can be improved, and asked respondents to draw out evidence to support views where appropriate..

Responses

8. 302 responses to the survey have been received, all of which were submitted online with the exception of one response by email.
9. The majority of responses to the survey were from patients with cardiovascular disease, and a high proportion from healthcare professionals. The survey also attracted a number of responses from voluntary sector support groups and carers for people with cardiovascular disease. The majority of respondents describing themselves as 'other' category were generally patient or carer, members of the public, or umbrella charity group respondents.

Table 1 : Breakdown by category of respondent:

Respondent	Number
Patients with cardiovascular disease	162
Health care Professionals	65
Voluntary sector support group	21
Carers for people with cardiovascular disease	12
Other	42
TOTAL	302

12. Responses have been categorised into the following areas:-

- Prevention,
- Acute Care,
- Long Term Care, and
- General. (covering cross cutting issues)

These areas correspond with the key workstreams that the Department of Health are using for the strategy. There is also a separate section on responses to equalities issues.

13. This report highlights the key issues within each category and provides further detail about specific comments made. Key issues represent the most commonly reported issues.

Prevention

“Preventing and awareness isn’t emphasized enough to the public - if people could see the damage and blockage in their arteries then I firmly believe that most people would change their life style“

Patient with CVD

14. 188 respondents (62%) highlighted issues relating to the importance of prevention of cardiovascular disease

Key Issues

- Improving access to information and awareness - 132
- Risk factor management – 98
- Regulation – 27
- Local Coordination – 23

15. There was a very strong message that people need more access to information and better awareness of risk factors associated with CVD, to be better equipped to make necessary lifestyle changes, and to take the risk of CVD seriously. People felt better risk factor management in primary care was vital and called for more regular monitoring of risk factors which would in turn achieve earlier intervention when necessary.

People mentioned the need to regulate industry, commented on the success of public health measures such as banning smoking, and called for more food industry engagement to help people make lifestyle changes.

Respondents also drew attention to the need for interventions to be made at community level and how LAs taking responsibility for public health might facilitate this.

16. Improving access to information and awareness – 132

Respondents highlighted:

- The need for increased public awareness of improving lifestyle, diet, encouragement to exercise, and for people to be aware of the risk factors for CVD generally (76 comments)
- The need for public awareness campaigns for risk factor awareness to get people to take risk factors seriously
- Recognition of previous government campaigns like Act FAST, to raise awareness of signs of heart problems/specific diseases/stroke/heart attack
- The need for specific attention to increase awareness of genetic risk which is combined with the need for earlier identification.
- Lifestyle advice needs to be better communicated to patients. Currently, it is 'poorly put across'.
- Translation of lifestyle advice into behavioural change needs to be improved and the support to make those changes needs to be stronger
- Patients need to be encouraged to take responsibility and empowered to self-manage risk factors.
- The importance of education from a young age including the role of schools in providing exercise, cooking lessons, good diet, and getting the message across early in life.

17. Primary care: better early detection and risk factor management – 98

“More needs to be done to identify, prevent and assess risk. There is currently no systematic screening to determine who is at risk”

Stroke survivor

Respondents highlighted:

- Primary care should be used to make every contact count by using each opportunity to engage with the patient, and there should be more monitoring of blood/pulse, weight and and risk factor screening. Regular ECG screenings should be conducted in primary care. Either GPs, nurses in clinics in primary care settings, or primary care one-stop-shops should carry out diagnostic tests.
- The important role of early intervention, and that monitoring alone was not enough, and the importance of earlier diagnosis of CVD. (14 comments)
- GP and clinical knowledge and awareness of CVD needs to be improved in order to assist in earlier diagnosis. GPs need to be better at detection of potential problems associated with CVD, and have better diagnostic tools and models for risk management in order to do so.
- NHS Health Check is an important tool and should be implemented, advertised and enforced. They should be better advertised to encourage people to attend if invited, should use risk prediction models, provide more follow up and be taken into non primary care settings (shopping centres, workplaces). They should be more focussed on achieving outcomes than process, and more should be done to ensure local delivery is more consistent.
- That QOF deserves recognition as a ‘fantastic tool’ for managing risk factors in primary care, but it should link across the vascular diseases, and use extended where possible. Tariffs should also be used as a lever.

18. Regulation – 27

Respondents highlighted:

- Legislation, regulation, and engagement with the food industry are key levers to ensure better health of the population. Many felt that regulation was a necessity as self-regulation by industry would be ineffective.
- More attention needs to be given to correct food labelling

19. Local Coordination – 23

Respondents highlighted:

- The importance of access to local services to help risk factor management including access to affordable gyms and sporting facilities

- The important role of local government to work in partnership to help make local services affordable and to play an active role in managing environmental issues and development control e.g. availability of food outlets.
- Community needs should be addressed and multi-agency approaches should be employed in doing so.
- Need to “ensure that there is an inclusive forum for dialogue, local communication, decision making, monitoring and evaluation between clinicians, patients, healthcare managers and local government”

Acute care

“Better management of acute / life threatening issues is needed”

Carer for someone with CVD

20. 101 (34%) respondents mentioned issues relating to acute care

Key Issues:

- Promotion of and access to specialist care – 41
 - Access to services– 26
 - Local Service Inequality – 21
 - Integration of patient information – 17
 - 24/7 services – 11
 - Emergency Care – 7
21. Key issues mentioned concerning acute care include the need for better coordinated access to specialist care, general improvement in access to secondary care services, and a need to address the inequality of disparity in local service delivery across the country. Integration and transfer of patient information is a problem currently leading to inefficiency, which should be addressed. 24/7 services would ensure better access and access to specialists when needed and is deemed as necessary. Specific issues relating to emergency care were also highlighted including the need for better Cardiopulmonary resuscitation (CPR) in general, and ensuring good public access to defibrillators.
22. Promotion of and access to specialist care – 41

Respondents highlighted:

- The need for better access to specialists is a key concern
- The need for heart failure specialists in secondary care
- The importance of specialist stroke units with multidisciplinary teams equipped with specialist interventional radiologists – this has shown key improvements in the treatments available to stroke patients and would improve outcomes leading to improved quality of life
- Hospitals in the North West were viewed as successfully having equality across local services with efficient pathways for cardiac care (one comment)

23. Access to services– 26 (distance/time)

Respondents highlighted:

- accessing secondary care: people having to travel long distances and public transport not being available at all hours to reach secondary care follow up appointments with people in rural areas feel particularly disadvantaged.
- Differing pathways to acute care can cause confusion

24. Local Service Inequality – 21

Respondents highlighted:

- the 'postcode lottery' in acute care
- research by professional organisations to record the disparities in access to services (Atlas of Care map, and study by Heart UK)

25. Integration of patient information – 17

Respondents highlighted:

- Lack of integration of patient information, particularly between primary and secondary care, leaves potential for conflicting advice, duplication and time wastage
- IT systems should bridge the gap between patients records in primary and secondary care
- Opportunities are lost to integrate information because the various professional groups do not link up their services, use a variety of methods for recording outcomes, which are inaccessible to others, and require additional user input (telephone calls, e-mails etc) or are reliant on vulnerable patient-held documentation.

26. 24/7 services – 11

Respondents highlighted:

- the need for 24/7 services to ensure everyone receives the same access to specialists/specialist care irrespective of when the need arises

27. Emergency Care – 7

Respondents highlighted:

- The importance of paramedics' response to CVD events, appropriate CPR attempts, public access to defibrillators and CPR training for the public, "In terms of cardiac arrest care, there is generally a fatalistic approach amongst healthcare professionals. We stop resuscitation attempts far too soon. The NCEPOD report makes this clear. "

Long-term care

"People need continuing care so that they do not feel abandoned when acute intervention is complete."

Healthcare Professional

28. Long-term conditions management - 186 (62%) respondents raised issues relating to long-term care

Key Issues

- Long term conditions management – 136, and Rehabilitation – 57
- Integrated service model - 41
- Transfer of care - 36
- End of Life care - 7

29. Long term conditions management – 136, and Rehabilitation – 57

"Patients need to be provided with clear information to self manage, understand their condition and make sensible decisions."

Patient with CVD

Respondents highlighted:

- Information/empowerment to self-manage is crucial - 85 people specifically referenced the need for improvement in this area.
- Support groups were highlighted as extremely important to the patient. 60 people mentioned the role of support groups, and importance of access to them, as well as the importance of peer support (patients educating other patients and sharing information to help rehabilitation).
- Support for carers was another strong message, 25 people specifically mentioned the importance of carers having more support, and more information to help patients.
- The role of the third sector in rehabilitation and long-term care was highlighted with many respondents highlighting the excellent services they offer and their benefits in the care pathway.
- The importance of access to local services such as cardiac gyms, and spaces for support groups to meet.
- The need to encourage uptake of rehabilitation both physical and mental, ensure consistent provision of rehab and integrate psychological and emotional support
- The importance of patient representatives, specifically post-patients who could offer individual expertise from experience
- Ensuring gyms and fitness groups were affordable, and suggested partnerships with local companies to lower costs
- The need for timely speech therapy/physiotherapy/occupational therapy and early supported discharge .

30. Integrated service model - 41

Respondents highlighted:

- This is a key area with need for improvement in relation to care pathways/better care planning, involving community care better, having better referral back to specialists when needed, and appropriate multidisciplinary teams, continuity of care.
- The role of patient advocate as a solution to improved communication to the patient.

31. Transfer of care - 36

Respondents highlighted:

- That before rehabilitation, there needs to be a good recovery and a good recovery can be aided by better transfer of care. Currently

people report dropping out of any care pathway, leading to increased feelings of anxiety and vulnerability. People mentioned a need to move away from the culture of 'you are fixed' or 'cured' with a hope that they will not see the patient again.

- Need for increased access to specialists as people had faced long delays before any follow up and/or felt that their GPs were not equipped to deal with specialist issues.
- A need for more follow up from GPs and monitoring of health improvement/decline, better management or information about their medication, care packages including information such as key contacts in social services or what they should do in case of need for further specialist care, and in general better integration with primary care, social care, community care.
- A document or information handover about services such as third sector support is needed.
- Currently no key 'responsibility' for the patient in recovery.
- Stroke early supported discharge is currently only available to under 40% of patients and should be extended to CVD patients.

32. End of Life care - 7

Respondents highlighted:

- The need for better planning of end of life care for cardiovascular disease patients. There was acknowledgement that progress has been made in this area which needs to be built upon. The National Council for Palliative Care explained the need for early planning (due to patients' risk of developing dementia).
- The need to ensure adequate provision of heart failure nurses
- The need for local policies on deactivation of ICDs in the community and share best practice in this area.
- The need to address the low numbers of HF patients referred to palliative care (one comment).

General/Issues across workstreams

34. Many respondents mentioned issues which are appropriate to all stages of the care pathway

Key Issues:

- Patient centred care – 35, and psychological and emotional support (if not mentioned in specific workstreams) - 8

- Integrated service model – 32

Other issues:

- Medicines management – 29
- Data – benchmarking tools – 16
- Workforce - 9

“A revolution in the NHS is needed where the patient is truly put at the centre of care.”

Patient with CVD

35. Patient centred care – 35, and psychological and emotional support (if not mentioned in specific workstreams) - 8

Respondents highlighted:

- Patients need to have assessments of their healthcare needs which are based on clinical, psychological and social needs as well as physical, and are holistically based on the patient and not the specific presentation
- Need to imbed idea of ‘shared care’ between patient and professional which in turn encourages patient empowerment to self-manage
- Patients need decision aides/decision maps
- Expansion of personalisation as exemplified in adult social care
- People want to have a say in their care, be listened to, and be able to make informed choices
- One suggestion was a ‘my health concerns’ tool, a sheet to ensure patient can record all health needs to be discussed with the consultant
- Ideally people would have more dedicated time with professionals to discuss their needs

35. Integrated service model - 32

Various comments were made about integration across the whole care pathway including:

- Particular attention needed between primary and secondary care and communication between the two
- Particular attention to joining up health and social care
- More effort was needed to avoid duplication across the pathway – e.g. not duplicating blood tests in primary and secondary care
- Movement away from silo working through encouraging a multidisciplinary approach
- There is an important role for community services in delivering care
- Partnership working across the pathway including with the patient, social care, private sector, social enterprise, pharmacists, high street chains
- The development of integrated models of care may be hindered by rewarding performance indicators that are disease-specific. Consideration should be given to outcome measures that are relevant across the vascular disease spectrum and measures that promote maintenance of health.
- Development of joined-up quality indicators may facilitate integrated management of multi-morbidity.

36. Medicines management - 28

Respondents highlighted:

- Concern about the cost effectiveness, and individually experienced side effects, of various drugs statins, aspirin, warfarin, beta blockers, anti-coagulants – some from medical professionals, others patient opinion – specific emphasis was on the newer anticoagulants as an alternative to warfarin which has advantages as warfarin needs to be individually measured and monitored
- Many felt statins should be used more frequently in primary prevention and prescribed more freely by GPs
- Patients' drugs better managed and/or managed more regularly – self management and home management were mentioned as an alternative to travel and time to hospitals

37. Data – benchmarking tools – 16

Respondents highlighted:

- Better data collection for benchmarking purposes should take place, and that where data is collected more effort should be made to use it.
- Better use of PROMS.

38. Workforce – 9

Respondents highlighted:

- The need for appropriate staffing and resources, comments included: specialist nurses currently too busy, need for more community nurses, need for more resources allocated to ensure good discharge from acute care and the need for more rehab teams
- The role of the third sector as part of the wider workforce for people with cardiovascular disease

Equalities

39. Equalities – 149 people (49%) responded to the question asking what the main inequalities are and what we can do to tackle them.

Key issues:

- Local service inequalities - 49
- Socio-economic inequalities – 33

Other issues:

- Age – 13
- Disease specific inequality (and comorbidities) - 11
- BME groups - 9
- Wealth inequality - 8
- Sex/Gender - 7
- Disability -5
- Mental Health - 5
- People in care homes -1

How we should address inequality:

Education – 14

Data Collection – 4

GP Skills - 3

Local service inequalities – 49

As respondents mentioned in response to previous survey questions, local service inequalities are a problem, including access to secondary care, primary care, and practice level/GP referral behaviour. This leads to a feeling that there is a 'postcode lottery' for services

Socio-economic inequalities - 33

Socio-economic issues including poor lifestyle, low educational attainment, and the link between deprived areas and risk factors are key inequality issues – it was commented that there is a lack of choice for people less articulate and educated.

Age - 13

Age inequality needs to be addressed. One comment was that prevention should be for all ages. Other comments were that there are current

restrictions for older people; including issues prescribing medication to over 80s and the need to ensure that older people are still given lifesaving opportunities. Younger people were also highlighted; better stroke treatment is needed for younger people, rehab/support for younger people needs to be better, and there needs to be support for teenagers with syncope.

Disease specific inequality (and comorbidities) - 11

'Disease specific inequalities' were highlighted including:

- Stroke needs to be better recognised in the community
- AF patients need more information
- Rehab is unequal for syncope patients
- Lack of services for heart failure and cardiomyopathy
- Better management needed for heart rhythm disorder

BME groups - 9

There should be increased accessibility for BME groups but were not specific about which services. Other issues raised were:-

- the increased genetic risk in certain ethnic groups.
- language barriers in treatment for non-English speakers
- Afro-Caribbean groups have low adherence to medication.

Wealth inequality - 8

Respondents specifically mentioned issues with wealth inequality including; ability to pay for private treatment, the cost of prescriptions and ability to meet charges for rehab.

Sex/Gender - 7

Respondents mentioned issues relating specifically to inequality between men and women. For women:

- women more often misdiagnosed
- an inequality of access to CR and MDT.

For men:

- more men die of CVD,
- ED and TDS should be used to their full potential as markers for cardiovascular disease (CVD) in men

Disability - 5

Respondents mentioned inequality for disabled people but were not specific about the current inequalities.

Mental Health - 5

Respondents mentioned mental health specifically: people with mental health needs and CVD are not picked up currently and therefore their needs are not properly served. There is also a lack of psychological support in rehab, which can disproportionately affect people with mental health needs.

Other – patients in care homes - 1

People in care homes needs need to be better managed.

How we should address inequality:

Solutions given to address socio-economic inequality were the need to improve the physical environment, change behaviours, have more lifestyle campaigns, make exercise groups less 'middle class', allocate additional resources to deprived areas, and increase partnership working with the hard-to-reach.

Education - 14

The issue of poor education/poor health literacy was cited as a problem and better education is the solution along with the need to encourage empowerment for patients, emphasise choice and have interventions at local level.

Data Collection - 4

Respondents commented that more data collection is needed to assess where inequalities exist. More integrated IT is needed to compare services, and better risk management is needed – 2 year monitoring for people with risk factors.

GP skills - 3

Respondents highlighted the important role of the GP in encouraging the patient to be an active participant in their healthcare..It was stated that GPs need to be better at communication, limiting jargon and addressing patients' emotional needs, as well as their role to interpret policy guidelines.

Conclusion

40. The key issues highlighted by this survey include:

- The importance of prevention (including encouraging public, individual responsibility, and support to make lifestyle changes, as well as better primary care management of risk factors, and early intervention and diagnosis)
- The need for better provision of rehabilitation services and ensure that the patient is empowered and given information to self-manage in the longer term – and to take particular note of the need for support groups and provision of adequate local services to make lifestyle changes
- The need for holistic patient centred care across the care pathway
- The need to focus on better coordination of the entire pathway which ensures access to specialists when needed and appropriate transfer of care
- The need to address local service inequalities

- The need to address socio-economic inequalities

Annex A

Survey questions

The survey was composed of the following questions:

1. We want to bring all CVD services up to the standard of the best. Are you aware of examples of good practice in cardiovascular service delivery that could be replicated?
2. In your experience in terms of preventing, treating or managing CVD, what doesn't work well at present and why?
3. What action is needed to reduce the number of people dying prematurely from CVD? *Please provide information about the extent to which your suggestions are likely to impact on the number of people dying.*
4. What more needs to be done to improve patients' and carers' quality of life? *Please provide evidence (qualitative and quantitative) about how your proposal improves quality of life.*
5. What more needs to be done to improve patients' and carers' experiences of treatment and care? *Again, please provide evidence.*
6. Bearing in mind there are no new resources available to deliver this outcomes strategy, what do you think is the best way of delivering the proposals you have made for improving CVD Outcomes? *For example, changing tariff arrangements, empowering patients and carers to have greater control over their care and management, improving benchmarking or other things?*
7. Can you give any examples in preventing, treating or managing CVD where it would be better to stop or change practice because that practice is not delivering the results expected? *For example, because it is out of date or a different approach has been found to be more clinically and cost effective.*
8. Do you know of any developments in prevention, diagnosis, treatment or management that will impact on the way in which CVD services need to be commissioned or delivered over the next decade?
9. As we work to improve CVD outcomes, what do you think are the main inequalities and how can we make sure that we continue to tackle them?
10. Any other comments?

AnnexB – Responses by organisation/representative groups

List of Voluntary Sector / Support Groups

Dicky Tickers Heart Support Group

CREW Heart Support Group

Sunderland Cardiac Support Group

Haslar Heart Support Group

Take Heart Leicester

Heart Throbs Cardiac Support Group

Arrhythmia Alliance

LINK in Salford

Hearts in Beds

Cardiac Friends

HEART UK

Kidney Research UK

British Heart Foundation

Syncope Trust and Reflex anoxic Seizures

Children's Heart Federation

Group Responses / Umbrella Charities

National Kidney Federation

National Council for Palliative Care

Cardiac and Stroke Networks in Lancashire and Cumbria

Professional Associations

ADASS

Pharmaceutical

Bayer HealthCare – Anticoagulation Submission

Bayer HealthCare – Men's Health

Devices - neuroscience and neurovascular company

Codman

Other

APPG on Atrial Fibrillation

APPG Vascular Disease Report