Cardiovascular disease (CVD), which includes diseases of the heart and circulation such as heart failure, coronary heart disease (angina and heart attack) and stroke, kills more than one in four people in the UK. In 2012, 28 per cent of all deaths resulted from CVD.

Having a choice about where and how to spend the end of life and receiving the support to achieve that, is hugely important to people approaching the end of life. Receiving the right support can also have a lasting positive impact on carers and families.

The British Heart Foundation (BHF) has invested over £18 million in trialling models of care for improving end of life for people with CVD, including our Caring Together programme.\(^1\) Findings from this work have informed our thinking on how we can ensure people with CVD receive the right support at the end of life.

In 2012, the Department of Health in England published the first national VOICES survey of bereaved people. This, and subsequent VOICES surveys show clear discrepancies in the experiences of people whose loved ones died from CVD compared to those who died from cancer.\(^2\)

This finding has also been backed up by information collated by the National End of Life Care Intelligence Network. For most care settings, quality of care was rated as excellent less frequently for those who died of CVD than for those who died of cancer.\(^3\)

In addition, whilst two-thirds of relatives of people who died from cancer felt that the person had enough choice over their place of death (65 per cent) this compared to about 40 per cent of non-cancer deaths.\(^4\) The majority of people, about 70 per cent, indicate that they would prefer to die in their usual place of residence, yet, between 2004 and 2011 a large proportion (59 per cent) of CVD deaths occurred in hospital.\(^5\)

Although the proportion of people with CVD who are able to die in their usual place of residence has been increasing (it stood at 43 per cent in 2011 compared with 37 per cent in 2004)\(^6\) more work is required to ensure that people with CVD receive quality care in the place they choose at the end of life.

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\(^1\) http://www.bhf.org.uk/get-involved/in-your-area/scotland/caring-together.aspx
\(^2\) Department of Health (2012) First National VOICES survey of bereaved people: key findings report
\(^3\) National End of Life Care Intelligence Network (2013) What we know now
\(^4\) Department of Health (2012) First National VOICES survey of bereaved people: key findings report
\(^5\) National End of Life Care Intelligence Network (2013) Deaths from cardiovascular diseases. Implications for End of Life Care in England
\(^6\) National End of Life Care Intelligence Network (2013) Deaths from cardiovascular diseases. Implications for End of Life Care in England
Policy statement
Evidence shows that people with CVD are receiving suboptimal care at the end of life and are not dying in the place of their choice. Care for people with CVD is poorer than that received by people with other conditions, such as cancer. The BHF has invested over £18 million in trialling models of care for improving end of life for people with CVD.

Better identification
Due to the unpredictable trajectory of heart failure, many people with CVD are not identified as needing end of life care. The association of palliative care with the last few days of life, exacerbates this problem.
- In England, the National Institute for Health and Care Excellence (NICE) must adopt the wider term ‘palliative and supportive care’ in the revised End of Life Care Quality Standard, the forthcoming clinical guideline on Care of the Dying Adult and the planned guideline on Palliative Care for Adults.
- In Northern Ireland, the Department of Health, Social Services and Public Safety must update Living Matters Dying Matters to adopt the wider term ‘palliative and supportive care’.
- In Scotland, the Scottish Intercollegiate Guidelines Network must publish guidance on End of Life Care and ensure that the term ‘palliative and supportive care’ is adopted in that.
- In Wales, the Welsh Government must update the End of Life Care Delivery Plan to adopt the wider term ‘palliative and supportive care’.

Better communication
Poor communication between clinicians and people with CVD prevents referral to end of life care and involvement in care planning.
- In England, Health Education England and Local Education and Training Boards,
- in Northern Ireland, the Department of Health, Social Services and Public Safety,
- in Scotland, NHS Education for Scotland
- and in Wales, Workforce, Education and Development services, must review the availability of existing end of life care training programmes and ensure they address communication with people with an uncertain prognosis.

Better care planning
Multidisciplinary, person centred care is essential for people with CVD at the end of life. Many people with CVD have co-morbidities and all require assessment of their holistic needs. Everyone approaching the end of life must:
- Receive an holistic care assessment.
- Be involved in their own care planning.
- Have an allocated care manager who is responsible for leading and co-ordinating their care.
- In England, NICE must ensure that all of these are included in the revised End of Life Care Quality Standard and the planned guideline on Palliative Care for Adults.
- In Northern Ireland, the Department of Health, Social Services and Public Safety must update Living Matters Dying Matters to ensure that all of these are included.
- In Scotland, the Scottish Intercollegiate Guidelines Network must publish guidance on End of Life Care to ensure that all of these are included.
- In Wales, the Welsh Government must update the End of Life Care Delivery Plan to ensure that all of these are included.

Better access to social care
Social care provides help with essential daily living activities that support people at the end of life to die in the place of their choice. Accessing social care, however, can be both costly and bureaucratic.
- The UK Government must legislate to scrap the means test for social care at the end of life in England.
- The Northern Ireland Government must legislate to scrap the means test for social care at the end of life in Northern Ireland.
- The Scottish Government must legislate to extend free personal care to those under 65 at the end of life in Scotland.
- The Welsh Government must legislate to scrap the means test for social care at the end of life in Wales.

Better specialist care
Research shows the value of specialist cardiac nurses for people with CVD. A BHF study found the work of heart failure nurses led to a 35 per cent drop in admissions. Currently, however, too many people receive no specialist input at the end of life.
- In England, clinical commissioning groups and local authorities,
- in Northern Ireland, the Health and Social Care Board,
- in Scotland, NHS boards and local authorities
- and in Wales, local authorities and local health boards
must include provision of heart failure specialist nurses in their plans for end of life care.

Better incentives
Current incentive structures fail to motivate commissioners to improve end of life care for people with CVD.
- NICE must consider the inclusion of an indicator on preferred place of death in the Quality and Outcomes Framework (QOF) and NHS England must include that indicator in the QOF.
- The Department of Health in England must include a measure on death in the preferred place of care in the Adult Social Care Outcomes Framework.
**Heart failure**

Heart failure is often the final outcome of a variety of cardiac diseases. So although all cardiovascular conditions are covered in this statement, heart failure is the focus.

Heart failure currently affects hundreds of thousands of people in the UK and thousands more are diagnosed each year.7

Heart failure patients are often living with other conditions (co-morbidities) which make treatment and management complex. These co-morbidities commonly include hypertension, diabetes, chronic obstructive pulmonary disease (COPD), depression, arthritis, Alzheimer's, renal failure and liver failure.

Despite therapeutic advances, heart failure is a progressive clinical syndrome. For those that make it out of hospital to be discharged, the mortality rate is 37 per cent within three years and it is higher still for women, older people and those who did not receive the best specialist care whilst in hospital.8

**Identification**

Although heart failure survival rates are worse than for some cancers, unlike cancer patients, very few people with heart failure receive specialist end of life care.

If individuals are recognised as approaching the end of their life there can be proper planning for their needs and wishes. Yet, research from Scotland, published in 2013 by Marie Curie Cancer Care, the University of Edinburgh and NHS Lothian, reveals that only 20 per cent of patients diagnosed with heart, lung, liver or kidney conditions (organ failure) or dementia, either requested or were identified for palliative care before dying, compared to 75 per cent of cancer patients.9 This research also found that those patients that were identified for palliative care were identified too late to fully benefit, on average only eight weeks before dying.

The National Heart Failure Audit shows that only 3.1 per cent of heart failure patients were referred to palliative care services following the first admission, and 7.3 per cent following a readmission.10

**Managing uncertainty**

The relatively small numbers of people with CVD receiving end of life care is due, in large part, to the unpredictable trajectory of heart failure. GPs say that introducing palliative care was fairly straightforward for those with cancer, who typically had a clear terminal decline but much more difficult for patients with other life-threatening illnesses.11

Some patients with heart failure have repeated acute and severe exacerbations that respond effectively to treatment. For others, the decline is relentless with worsening symptoms that are distressing and debilitating. Some die suddenly without warning yet others can show signs of being at the end of life for over a year.

Prognostic tools, however, can help to identify people with heart failure entering the end of life phase of their illness. BHF pilots have shown that by assessing patients against certain criteria, including existing needs, Heart Failure Specialist Nurses can identify a significant proportion of those in their final months of life.

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8 John Cleland et al. (2012) National Heart Failure Audit
10 John Cleland et al. (2012) National Heart Failure Audit
Referral criteria used in our Caring Together project were:

- The patient has advanced heart failure\(^{12}\)
- The patient has distressing or debilitating symptoms despite optimal tolerated medical therapy
- The patient has supportive or palliative care needs.

Supplementary considerations include:

- Increasing age (>75)
- Co-morbidities (one or more)
- Increasing symptom burden/symptomatic
- Hospital admissions or requiring increased home visits in last year
- Assessment for transplant/advanced specialist intervention
- Question: “Would you be surprised if this patient died in the next year?”

**Defining end of life care**

In order to ensure that heart failure patients are identified for end of life care, and at a time far enough in advance for them to fully benefit, we believe that patients must be identified when they reach end stage heart failure. This will likely be in their last months rather than days of life.

Palliative care, however, is often associated with the last few days of life. The Leadership Alliance for the care of Dying People, for example, a group established by NHS England to set out a new approach to care of the dying, have recently published their final report which sets out ‘the priorities for care which express the common principles of good palliative care’. The report is entitled ‘One chance to get it right: Improving people’s experience of care in the last few days and hours of life’\(^{13}\). Following on from this report, NICE are currently consulting on a new guideline on Care of the Dying Adult that proposes to focus on the last few days of life\(^{14}\).

For this reason, the BHF and others recommend using the more inclusive term ‘palliative and supportive care.’ We believe that this wider term will help to prevent the reluctance exercised by GPs in referring patients for end of life care when a prognosis is not entirely certain.

**Communication**

People with life-limiting conditions need to know that they have a life-limiting condition in order to have the opportunity to share their preferences and develop plans. Currently, however, too often, people with heart failure are informed that their heart is not pumping as effectively as it should, though are not informed of the stark details: that 30 - 40 per cent of patients will die within one year\(^{15}\).

Research by Marie Curie showed that some GPs found it difficult to raise and discuss death and dying with patients, particularly with patients with a non-cancer diagnosis\(^{16}\). Further research studies have explored GP communication with people with heart failure approaching the end of life. The studies found that:

- End of life care is rarely discussed, with conversations focusing largely on disease management.
- Clinicians are unsure how to discuss the uncertain prognosis and risk of sudden death, fearing they may cause premature alarm and destroy hope.
- Clinicians wait for cues from people before raising end of life care issues\(^{17}\).

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\(^{12}\) New York Heart Association Heart Failure classification categories III or IV  
\(^{13}\) Leadership Alliance for the Care of Dying People (2014) *One Chance to Get it Right*  
\(^{14}\) https://www.nice.org.uk/guidance/inddevelopment/GID-CGWAVE0694/consultation  
\(^{15}\) NICE (2010) *Guideline on Management of chronic heart failure in adults in primary and secondary care*  
\(^{17}\) National End of Life Care Intelligence Network (2013) *What we know now*
The VOICES survey found that 30 per cent of people whose loved ones died from cardiovascular disease felt that the patient definitely didn't know they were likely to die, compared to just five per cent for cancer.\(^8\)

While it is important to recognise the difficulty of prognosis in heart failure, it is important too to talk about death in order for patients and carers to have appropriate discussions about care planning.

**Care planning and delivery**

Multidisciplinary working across health and social care is vital to the delivery of quality, person-centred care for people with CVD at the end of life.

Large numbers of people dying from CVD have coexisting medical conditions and with an ageing population, this looks set to increase. It is also vital that not only physical health needs but also the spiritual, psychological and social needs of patients are considered and addressed at the end of life. Primary, secondary and out-of-hours services and social care are all be required to work together to support people approaching the end of life. Yet, only 40 per cent of people whose loved ones died from cardiovascular disease felt that community services worked well together.\(^9\)

The BHF Caring Together programme’s approach works across the acute, community and out-of-hours care teams enabling the delivery of consistent and coordinated services to people with heart failure and their carers in all care settings.

**Person-centred care assessments and planning**

When someone is referred to our Caring Together programme, they not only receive a cardiological review to ensure optimisation of medical treatment but an holistic assessment is also carried out. This assessment looks at the physical, social, psychological and spiritual aspects of the person’s needs and involves discussion with the patient on the types of care they are getting and other support that they and their carer might need.

In addition, as part of our Caring Together programme, a ‘one-stop shop’, funded jointly by the local authority, NHS and DWP, has been established in hospital. Here, benefits and social care assessments are carried out at the same time. This speeds up the process, giving patients access to the support they need as soon as possible, which is, of course, crucial at the end of life.

When someone’s care and support needs have been assessed in our Caring Together programme, anticipatory care plans are then developed in partnership with the individual, family and carers, on how those needs can be met. Care plans are held electronically in the acute centre and are forwarded to all involved in a person’s care. Electronic summaries are also accessible by unscheduled care providers (including NHS 24, GP out-of-hours, ambulance service and A&E). This means unscheduled care providers are aware of patients’ wishes and preferences. The patient can also request a copy of the plan.

**Care co-ordinators**

With so many agencies working together to provide quality end of life care, all patients on the Caring Together programme are allocated a care manager to act as the patient’s main point of contact for information, advice and support. Care managers are responsible for leading and co-ordinating patients’ care. They work closely with a patient’s GP, cardiologist, district nurse and others providing their care to make sure they are getting the support they need. The patient can discuss with their care manager how and where they would like their care. Wishes are recorded and, with permission, shared with all those who are providing care for the individual. The care manager also provides details of healthcare professionals that the patient can contact during the night and at weekends so they can get support and advice anytime, on any day.

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\(^8\) Department of Health (2012) First National VOICES survey of bereaved people: key findings report

\(^9\) Department of Health (2012) First National VOICES survey of bereaved people: key findings report
In the Caring Together programme, heart failure nurses predominantly take on the care manager role, though district nurses, ward nurses, social workers or GPs could act as care coordinators depending on where people are being cared for and their condition.

**Social Care**

Social care support includes help with washing and dressing, preparing meals, getting out of bed and getting safely around one’s home. This support allows people at the end of life to die in the place of their choice.

Social care support, however, is not easily available to all. In order to access social care, people must go through both needs and financial assessments. The process is complex and takes time. It often results in unnecessary delays and causes unnecessary stress. For someone who is at the end of life, this is not only unreasonable but also wholly impractical.

**Specialist Care**

The 2012/13 National Heart Failure Audit recommends specialist care input for all people with heart failure. The figures show that for those who received no specialist input, mortality stood at 14.4 per cent, whilst for those who did receive specialist input, the mortality rate was just 7.5 per cent. NICE too, recommend that people with moderate to severe chronic heart failure should have access to a heart failure specialist.

An evaluation of BHF heart failure specialist nurses showed that they significantly improved the quality of life of their patients. The work of heart failure nurses led to a 35 per cent drop in admissions compared to historic data and this led to an estimated £1,826 saving per patient.

Heart failure specialist nurses are a key component of multidisciplinary teams working in secondary care to meet the needs of people living with heart failure. Many heart failure nurses currently, however, only provide care to a proportion of heart failure patients, those with Left Ventricular Systolic Dysfunction (LVSD) and many people with heart failure continue to receive no specialist input at the end of life.

**Incentivising**

Incentives for improving end of life care currently lack a clear focus on delivering improved outcomes for all patients. They fail to encourage the assessment and management of quality of care for all people at the end of life, to encourage multidisciplinary working or to hold CCGs and local authorities to account in a clear and transparent way.

In the Quality and Outcomes Framework (QOF), a voluntary reward and incentive scheme for GP practices in England, for example, there are two indicators for palliative care. These require participating GPs to maintain a palliative care register (on which people with CVD are unlikely to be included due to identification issues) and hold three-monthly multi-disciplinary case review meetings to discuss the people on the register. There are no indicators incentivising improvement in outcomes for all patients at the end of life, such as being cared for in their preferred place. In addition, the Adult Social Care Outcomes Framework, which sets out the indicators for measuring adult social care outcomes, includes no indicators on end of life care.

**Cost-effectiveness**

Providing the right care, in the right place, at the right time is crucial, not only for improving individuals’ wellbeing at the end of life but also economically. Hospital beds are expensive: the

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20 John Cleland et al. (2013) National Heart Failure Audit
mean cost of hospital care in the last year of life for those who died in hospital was £11,298. The mean cost of hospital care for those who died outside of hospital was £7,730.\textsuperscript{23}

Heart failure accounts for two per cent of all NHS inpatient bed-days and five per cent of all emergency medical admissions to hospital. Hospital admissions because of heart failure are projected to rise by 50 per cent over the next 25 years.\textsuperscript{24}

Admissions might be avoided with anticipatory care planning and the provision of community health and social care support.\textsuperscript{25} We know that access to social care services, as part of a package of end of life care, can help people nearing the end of life be cared for and die in their own home, if this is what they want. Yet, an analysis of hospital care and local authority-funded social care services provided in the final 12 months of life found that only seven per cent received just social care during the last year of life, with only 23 per cent receiving social and hospital care and 49 per cent receiving only hospital inpatient care.\textsuperscript{26}

The BHF’s Better Together programme helped manage heart failure symptoms as well as wider care needs.\textsuperscript{27} In addition to reducing isolation and improving quality of life, this scheme was also cost saving. It helped 55 out of 74 patients spend the end of life in their place of choice, which was usually at home.

\textbf{Government activity}

\textbf{England}

- In 2008, the Government published the End of Life Care Strategy.\textsuperscript{28} The responsibility for the End of Life Care Strategy moved to NHS England in April 2013.
- In 2010, the Department of Health commissioned the development of an End of Life Care Intelligence Network, which now sits within Public Health England.
- In 2011, NICE published a Quality Standard on End of Life Care for Adults and a Guide for Commissioners on End of Life Care for Adults.
- The Coalition agreement included a commitment to developing a per-patient funding system for palliative care. This led to £3.6 million funding being allocated to support eight pilot sites up to March 2014.
- The Liverpool Care Pathway (LCP) which was widely recognised as a good model of end of life care came under fire in 2012. As a result, in January 2013 Baroness Neuberger was commissioned to conduct an independent review of the LCP. Following the publication of Baroness Neuberger’s report, in August 2013, the Leadership Alliance for the Care of Dying People (LACDP) was set up to respond. In June 2014, ‘One Chance to Get it Right: Improving people’s experience of care in the last few days and hours of life’, the system-wide response to the Neuberger Report, was published.
- NICE plan to review the End of Life Care Quality Standard in light of the LACDP’s proposals. NICE are also in the process of developing a guideline on Care of the Dying Adult and they plan to develop guidance on Palliative Care for Adults.
- In 2013, the Joint Committee on the Draft Care and Support Bill called for free social care at the end of life to be introduced at the ‘earliest opportunity’. The Care Act provides the statutory framework to implement free social care at the end of life in the future.
- In March 2013, the Government published its new Cardiovascular Disease Outcomes Strategy. This included welcome actions around improving end of life care for people with CVD.
- The 2014/15 NHS Mandate sets an ambition for the NHS in England to deliver a standard of end of life care to be ‘recognised globally’.

\textsuperscript{24} NICE (2010) Guideline on Management of chronic heart failure in adults in primary and secondary care
\textsuperscript{25} Abel J, Pring A, Rich A et al. (2013) The impact of advance care planning of place of death, a hospice retrospective cohort study for over 73,000 deaths in England
\textsuperscript{26} The Nuffield Trust (2010) Social Care and Hospital Use at the End of Life
\textsuperscript{27} http://www.bhf.org.uk/publications/view-publication.aspx?ps=1001308
\textsuperscript{28} Department of Health (2008) End of Life Care Strategy: Promoting high quality care for all adults at the end of life
• The NHS Outcomes Framework for 2014/15 and the Clinical Commissioning Group Outcomes Indicator Set (CCGOIS) for 2014/15, both include an indicator on ‘Improving the experience of care for people at the end of their lives’. NICE also recommend, for future development, further indicators on end of life in the CCGOIS.

• In July 2014 the Department of Health launched a review of choice in end of life care. The review will be undertaken by an independently-led programme board chaired by Claire Henry, Chief Executive of the National Council for Palliative Care (NCPC).

Scotland
• The national action plan ‘Living & Dying Well’ was launched in October 2008 and ‘Living & Dying Well: Building on Progress’ was launched in January 2011.

Northern Ireland
• A five year end of life care strategy for adults, 'Living Matters: Dying Matters', was published in March 2010.

Wales
• In April 2013 the ‘Delivering End of Life Care’ three year plan was launched.

BHF activity
• Our flagship medical research programme Mending Broken Hearts is seeking to find a cure for heart failure.

• Between 2006 and 2009 we funded a total of nine heart failure palliative care specialist nurses in eight Trusts across Scotland and England. These posts were established in response to the increasing recognition of unmet end of life care needs among patients with advanced heart failure. Key findings from the external evaluation Included; crisis hospital admissions were prevented and many more patients were able to die at home if they wished.

• In 2007, the Better Together project was launched. This was a two year pilot project in two areas of England, which aimed to provide a service joining the expertise of BHF heart failure specialist nurses with Marie Curie Nurses and healthcare assistants to help with the provision of care at home for patients approaching the end of life.

• In 2011 we funded our intravenous (IV) diuretics in the community project. The project, which operated at ten NHS sites across the UK, enabled patients with heart failure to be treated for excessive fluid retention, a common symptom of heart failure, in their own homes for the first time. An independent evaluation showed that the delivery of IV diuretic treatments, in patients own homes, by existing community heart failure teams is clinically and cost effective, safe, can prevent hospital admissions and is valued by patients and their carers.

• In 2012, we launched an integrated care funding programme. We awarded £1 million to nine projects, six of which supported people living with heart failure.

• In September 2013, we produced a discussion document for healthcare professionals on deactivation of Implantable cardioverter defibrillators (ICDs) at the end of life. ICDs are fitted in people with potentially life-threatening heart rhythm disturbances. If the heart goes into a potentially lethal rhythm, the ICD delivers a shock to restore it to normal. An ICD keeps automatically delivering this shock as required unless you deactivate it. This can be very distressing for someone in their final stages of life whose failing heart is more likely to develop lethal rhythms.

• BHF Scotland, Marie Curie Cancer Care and NHS Greater Glasgow and Clyde are working together to provide better palliative care for patients with heart failure via the Caring Together programme. Between June 2011 and June 2013, 232 heart failure patients were referred to Caring Together across three pilot sites. Caring Together patients are more likely to be cared for and die in their preferred place of care, and less likely to die in hospital. Due to the continuing success of Caring Together it has been decided to extend the current programme and pilot sites to June 2015.

• In May 2014, we funded guidance to help anyone caring for someone with heart failure to open up conversations about their end of life wishes and preferences. 'Difficult Conversations for Heart Failure' was published by the NCPC.
• We are a member of the Richmond Group of Charities. The Richmond Group was represented on the LACDP. We also responded at an organisational level to the LACDP’s engagement document.
• In England, we are an active member of the NCPC heart failure policy group and part of the Dying Matters coalition. In Scotland, we are a member of the Scottish Council for Palliative Care.
• We are also a member of the UK’s End of Life Care Research Interest Group.
• The BHF’s Policy Director, Mike Hobday, is an NCPC Trustee. He also sits on the Government’s programme board for the review of choice in end of life.

Case Study

Michael Jones began suffering with shortness of breath in 2011 and he was admitted to hospital where it was found he had chronic heart failure. He received treatment in hospital for the build up of fluid in his body, one of the symptoms of heart failure. He then returned home and carried on a normal life for an 86 year old.

In December 2012, the symptoms returned as his heart failure progressed. He was readmitted to hospital and received the same treatment as before. On returning home, a few weeks later, it was apparent that Michael could not manage without the treatment he had received in hospital.

At this point, Michael was told by a doctor that they would do what they could, but he was not going to get better. Michael shared his wish to stay at home and as part of Michael’s end of life care plan, he was soon transferred to a local service, funded by the BHF, that could offer him intravenous diuretics therapy at home.

A nurse from the East Cheshire project would visit and administer the treatment for around one hour each day. A friendly, professional relationship was built up between the nurses and Michael’s family. Peter, Michael’s son, said that he and the family cannot praise the team and the project enough. This treatment allowed his father to spend his last few months at home with his wife, Audrey.

Michael passed away peacefully on Thursday 11 July 2013 at 3.35am with his family at his side and just a week after joining in two family birthday celebrations. Being able to stay at home was Michael’s wish and through the East Cheshire project he was able to do so.

Sign off: 11 November 2014
Date for review: 11 May 2015