

Commissioning for quality in end of life care

Summarising the NICE Quality Standard



Overview

This briefing summarises the National Institute for Health and Clinical Excellence (NICE) Quality Standard for end of life care for adults.¹ It illustrates how Marie Curie Cancer Care's experience as the leading organisation in end of life care can help commissioners to deliver excellent services to their local communities while meeting the anticipated outcome framework around quality. It also suggests further reading for commissioners of end of life care.

Marie Curie's reputation is based on our well-established UK-wide nursing and hospice services. The wide ranging expertise we have gleaned in these areas is further enhanced by our experience in service design, through the Delivering Choice Programme, and our palliative care research.

This unique position makes Marie Curie the ideal choice for commissioners who are looking for support in understanding their local end of life care needs and in developing high-quality reliable end of life care services.

National Institute for Health and Clinical Excellence: Quality Standard for end of life care for adults, 2011

Meeting the NICE

Quality Standard

will help patients

by reducing

unscheduled

hospital admissions

and increasing

time spent in their

preferred place

of care.

1. Summarising the NICE Quality Standard

The recently published NICE Quality Standard for end of life care for adults sets out specific statements describing 'aspirational but achievable standards for end of life care for adult patients across the NHS in England'.

The NICE Quality Standard, together with the accompanying commissioning guide³, supports commissioners in implementing the Department of Health End of Life Care Strategy⁴, enabling them to be confident that the services they are providing are high quality and cost effective.

The NICE Quality Standard contains 16 quality statements for the care of adults with advanced, progressive, or incurable conditions approaching the end of their lives and expected to die within the next 12 months. The statements are grouped under six overarching themes:

| NICE Quality Standard for End of Life Care for Adults | |
|---|---|
| Theme | Quality statements |
| Identification, information and assessment | QS1 Identification QS2 Communication and information QS3 Assessment and care planning |
| Holistic support | QS4 Physical and psychological QS5 Social, practical and emotional QS6 Spiritual and religious QS7 Families and carers |
| Access to services | QS8 Coordinated care QS9 Urgent care QS10 Specialist palliative care |
| Last days of life | QS11 Last days of life |
| Care after death | QS12 Care of the body QS13 Verification and certification QS14 Bereavement support |
| Workforce | QS15 TrainingQS16 Workforce planning |

Delivering end of life care services which meet the Standard is expected to contribute to a number of overarching outcomes for people approaching the end of life:

- The care that patients receive is aligned to their needs and preferences.
- Increased length of time spent in preferred place of care during the last year of life.
- Fewer unscheduled hospital admissions leading to death in hospital (where death in hospital is against stated preference).
- Fewer deaths in inappropriate places such as hospital A&E departments or in ambulances.

From 2013/14, it is anticipated that the NHS Commissioning Board will use the NICE Quality Standard to develop the annual Commissioning Outcomes Framework, which they will use to hold commissioners to account.

- National Institute for Health and Clinical Excellence: Quality Standard for end of life care for adults, 2011
- National Institute for Health and Clinical Excellence: Guide for commissioners on end of life care for adults, 2011
- Department of Health: End of Life Care Strategy for Adults, 2008

2. Commissioning end of life services to meet the NICE Quality Standard

The NICE Quality Standard and commissioning guidance set out a number of measures which commissioners can use to monitor whether services in their area meet the required quality standards.

Commissioners can use the NICE Quality Standard, as well as other quality standards and measures, as tools for understanding and monitoring the quality of end of life care services in their local areas.

Providers should be able to prove that they have a robust quality assurance framework in place which demonstrates how their services meet the Quality Standard. Providers which do not demonstrate that they meet the Standard are likely to fall short in other key areas – resulting in risk to patients and NHS organisations.

As the leader in end of life care, Marie Curie has developed a robust quality assurance framework which helps us to demonstrate how our services deliver against the NICE Quality Standard.

We have illustrated how Marie Curie can help commissioners to meet the NICE Quality Standard on pages 7–15. We have also included a key to Marie Curie's services on page 6.

3. Understanding the needs of your local population

The NICE commissioning guidance recommends that commissioners undertake a comprehensive needs assessment for end of life care for their local population to inform their local end of life care planning. NICE proposes the following information is included:

- Annual number of deaths
- Current distribution of place of death
- Age and gender distribution of the population
- Proportion of deaths from cancer and non-cancer
- Deprivation score
- Number of people with cognitive impairment (dementia)
- Religious or cultural groups in the local community
- Needs of lesbian, gay, transgender and transsexual people
- Needs of children and young adults

Marie Curie understands the different needs of individual health economies. We are working with partners across the UK to develop approaches to meet the needs of specific communities – from isolated rural populations to major cities.

Using our Delivering Choice Programme methodology Marie Curie can support commissioners in undertaking a local needs assessment. We are also developing tools to support a comprehensive analysis of end of life care which will help commissioners to benchmark end of life care in their local area.

Marie Curie understands the needs of individual health economies.

4. Designing high-quality end of life care using a pathway approach

Emerging evidence suggests that redesigning local end of life care pathways to provide high-quality end of life care can result in more people being able to die in their usual place of residence, rather than in hospital. Evidence shows that this can be achieved at no extra cost and has the potential to be a more efficient and effective use of resources⁵.

NICE guidance on end of life care for adults proposes the use of a coordinated pathway approach to commissioning. This is particularly important in end of life care where services are connected and cut across sectors and settings. The guidance highlights the potential for service redesign to produce savings in hospital costs. The NICE online benchmarking tool, based on data from the Hospital Episodes Statistics (HES) database, provides PCT-level estimates on the scale of financial savings that could be delivered by reducing the number of hospital admissions ending in death, and by increasing the number of discharges from hospital before death for patients at the end of life⁶. The tool can be found at: http://www.nice.org.uk/media/607/E7/EndOfLifeCareCABtool.xls

Marie Curie's Delivering Choice Programme works in partnership with the NHS, independent and voluntary sectors to design fully integrated end of life care services. We work across a geographical area to deliver patient-centred 24/7 services which meet local needs. The programme has already changed the way end of life care is delivered in more than 18 localities across the UK.

Marie Curie's experienced service design consultants can work with you to provide tailored advice and support to help you redesign your local end of life services using an integrated approach. For details visit: www.mariecurie.org.uk/commissioning

5. Related quality standards and frameworks for end of life care

- Department of Health End of Life Care Strategy quality markers⁷
- National end of life care workstream of the Quality, Innovation, Productivity and Prevention (QIPP) programme
- End of Life Care Quality Assessment Tool (ELCQuA)
- Quality and Outcomes Framework (QOF)
- Care Quality Commission prompts for end of life care
- The King's Fund: Improving choice at end of life - a descriptive analysis of the impact and costs of the Marie Curie Delivering Choice Programme in Lincolnshire, 2008
- For more information, see the briefing 'Understanding the cost of end of life care in different settings', published by Marie Curie Cancer Care, 2012
- Department of Health: End of life care strategy: quality markers and measures for end of life care, 2009

Key to Marie Curie services

The Marie Curie Nursing Service integrates seamlessly with other local services to enhance or support end of life care in people's homes. Marie Curie Nurses and Senior Healthcare Assistants support discharge, prevent crisis admissions, and provide flexible and responsive nursing care. Some of the locally-tailored services we provide include rapid response, short visits, discharge liaison, fast-track discharge support, coordination of services and health and personal care.

Nine Marie Curie Hospices across the UK provide specialist palliative in-patient and day care services and provide outreach into their local communities. Our specialist teams provide individualised programmes of care, symptom control and end of life care, as well as support for families.

Our **Coordination Centre** can act as a central point of contact for local services arranging care packages for palliative care patients. It also provides administrative coordination and is supported by an experienced Marie Curie Clinical Lead Nurse.

Marie Curie's **Managed Care** service offers a new approach to commissioning end of life care services. It moves away from activity-based contracts to a more responsive outcomes-based model of flexible care delivery. It also gives commissioners overall control of service costs with the assurance that their population's end of life nursing needs are being expertly met.

The **Delivering Choice Programme** brings Marie Curie's expert team of service design consultants together with local NHS and independent providers to improve end of life services with innovative service design configured to meet local needs. We already work with partners in over 18 locations across the UK to improve integration across end of life services and enable more people to die in their preferred place of care.

Marie Curie Helpers volunteer in their local areas to support people with terminal illnesses – signposting information and support services. Helper projects operate in several locations across the UK including Somerset, Nottingham, Liverpool, and East London.

Marie Curie works in **partnership** with organisations that share its values and aspire to increase access to end of life care. **Caring Together** in Greater Glasgow and Clyde brings together NHS and British Heart Foundation partners to help increase access for people with end stage heart failure. The **Self-referral** Project, supported by NHS Derbyshire, encourages people to refer themselves, or their loved ones, if they need end of life care. Our Nurse Assessors arrange care or signpost them to appropriate services.

Identification and assessment

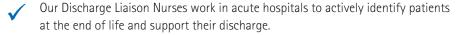
How Marie Curie helps commissioners meet the NICE Quality Standard

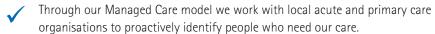
NICE QS1. Identification

People approaching the end of life are identified in a timely way.

Marie Curie helping you meet the statement







 Our Self-referral Project allows people to refer themselves, or their loved ones, for end of life care.

Marie Curie supporting information

- We can help commissioners to calculate local end of life care needs through our Delivering Choice Programme.
- Marie Curie Discharge Liaison
 Nurses undergo regular assessment to demonstrate competency to fulfil their role, including identification of patients at the end of life.

Further reading

Improving end-of-life care: a critical review of the Gold Standards Framework in primary care, Shaw et al, Palliative Medicine, April 2010 End of Life Locality Registers evaluation - Final report, Ipsos Mori Social Research Institute, June 2011 Electronic Palliative Care Coordination Systems (EPaCCS) Overview, National end of Life Care Programme

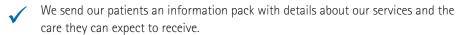
NICE QS2. Communication and information

People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.

Marie Curie helping you meet the statement







Marie Curie Helper volunteers offer information and advice to clients.

Our website contains video guides which focus on personal care towards the end of life.

Further reading

Knowledge and information needs of informal caregivers in palliative care: a qualitative systematic review, Docherty et al, Palliative Medicine, 2008

Effectiveness of a three-day communication skills course in changing nurses' communication skills with cancer/palliative care patients: a randomised controlled trial, Wilkinson et al, Palliative Medicine, June 2008

- We train all frontline staff and volunteers in communication skills.
- Our user survey shows that 95 per cent of our patients felt involved in decisions always, or most of the time.
- Patient information is regularly updated and subject to peer review and user feedback.
- Marie Curie Hospices monitor helpline phone calls for quality.



NICE QS3. Assessment and care planning

People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.

Marie Curie helping you meet the statement



Marie Curie Hospices provide holistic assessment and care planning delivered by a multidisciplinary team.



Our Managed Care Service Nurses provide holistic assessments and care plans for patients.



Marie Curie Discharge Liaison Nurses develop care plans for their patients.



Our Coordination Centre staff plan and book care.



Marie Curie's Clinical Lead Nurses in the community assess patients and prioritise their care needs.

Further reading

Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer: Assessment Guidance, Cancer Action Team, 2007

Holistic Needs Assessment for people with cancer: a practical guide for healthcare professionals, NHS National Cancer Action Team, 2011

- We have a policy which sets out arrangements for safe admission, transfer and discharge of patients which reflects the need of the individual, their relatives and carers.
- Our nurses complete standardised patient care records to ensure patients receive a comprehensive holistic assessment.

Theme 2 Holistic support



NICE QS4. Physical and psychological

People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.

Marie Curie helping you meet the statement



Marie Curie Nurses provide specialised end of life care 24/7, caring for patients and families with dignity and sensitivity.



Multidisciplinary teams in our hospices provide symptom management and specialist support to meet patients' individual needs. Clinical Nurse Specialists offer outreach, and our Day Services support patients through a personalised programme of care.



Marie Curie Helper volunteers develop close supportive relationships with patients and families.

Further reading

A cluster randomized controlled trial of cognitive behaviour therapy for common mental disorders in patients with advanced cancer Moorey et al, Psychology Medicine, May 2009

Screening for distress in cancer patients: Is the distress thermometer a valid measure in the UK and does it measure change over time? Gessler et al, Psycho-Oncology 2008

Physical Activity as a Supportive Care Intervention in Palliative Cancer Patients: A Systematic Review, Lowe et al, Supportive Oncology, 2009

Marie Curie supporting information

- Our user survey shows that 86 per cent of Marie Curie patients rate relief of pain as very good or excellent.
- We inspect our Hospices twice a year to monitor the quality of care, and also undertake annual environmental inspections. Our Hospices are also audited on health and safety as well as food hygiene by external bodies.
- Our annual Quality Account monitors the quality of our patient care.

NICE QS5. Social, practical and emotional

People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.

Marie Curie helping you meet the statement



Patients' emotional wellbeing is paramount to our staff. They take time to listen to people and help them express their feelings.



Our Hospices offer counselling and social worker services while Day Services offer group activities to support patients' social needs.



Marie Curie Health and Personal Care Assistants can offer integrated health and social care.



Marie Curie Helpers provide emotional support to patients and families.

Further reading

Shared Priorities for the End-of-Life Period, Downey et al, Journal of Pain and Symptom Management, February 2009

- Our user survey shows that 85 per cent of Marie Curie patients rate our emotional support as very good or excellent.
- Marie Curie staff can access diversity and equality training through our development programme or through the Department of Health's end of life training modules to help them meet patients' individual needs.
- Marie Curie Nursing staff work to professional standards and a strict code of conduct.

NICE QS6. Spiritual and religious

People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.

Marie Curie helping you meet the statement



Marie Curie Nurses are trained to offer spiritual advice and support to patients and families.



Marie Curie Hospice chaplains provide spiritual support to patients and families.



Marie Curie Hospices are welcoming places with dedicated spaces for individual reflection, or participation in a multi-faith environment.

Further reading

Spiritual care at the end of life: a systematic review of the literature, Holloway et al, Universities of Hull, Staffordshire and Aberdeen, November 2010

Preventing Ioneliness and social isolation: interventions and outcomes, Windle, Francis and Coomber, Research Briefing 29, Social Care Institute for Excellence, October 2009

Spirituality in nursing care – a pocket guide, Royal College of Nursing: Spirituality in nursing care, 2012

Marie Curie supporting information

- Marie Curie's Spiritual and Religious Care Competencies for Specialist Palliative Care are used internally and are widely respected by external organisations.
- Our user survey shows that 79 per cent of Marie Curie patients rate our spiritual care as very good or excellent.

NICE QS7. Families and carers

Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

Marie Curie helping you meet the statement



Marie Curie's Clinical Lead Nurses work with families to assess their needs and support them.



Our Head of Carer Services and Engagement is dedicated to developing the support we offer to carers and families.



Our Hospices offer specialist counselling and support to the children and teenage relatives of patients.



Our Hospices offer carers complementary therapies to restore their sense of wellbeing.



Marie Curie Helpers offer carers and families short breaks to support them in their caring role.



Marie Curie's website is packed with information for carers including short video guides covering personal care and publications to support patients' young relatives

Further reading

Supporting lay carers in end of life care: current gaps and future priorities, Grande et al, Palliative Medicine, June 2009

Home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998–2008), Funk et al, Palliative Medicine, September 2010

Interventions for supporting informal caregivers of patients in the terminal phase of a disease, Candy et al, Cochrane Database of Systematic Reviews, June 2011

Committed to carers – supporting carers of people at the end of life, Marie Curie Cancer Care, 2012

- Our user survey shows that 87 per cent of patients feel that Marie Curie support helped carers to continue in their caring role always or most of the time.
- Marie Curie's volunteer visitors and Marie Curie Helpers undergo rigorous selection and training to prepare them to support carers and families.
- Our Hospices assess family and carer needs as part of the patient's holistic needs assessment.
- Our Hospice complementary therapists are registered with the relevant accrediting bodies.

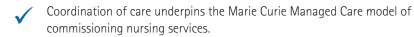
Theme 3 Access to services



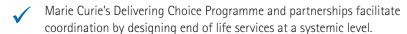
NICE QS8. Coordinated care

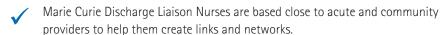
People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.

Marie Curie helping you meet the statement









The Marie Curie Coordination Centre coordinates multiple services, avoiding gaps and duplication.

Further reading

Implementing the End of Life Care Strategy: Lessons from good practice, The King's Fund, October 2010

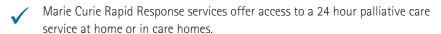
Marie Curie supporting information

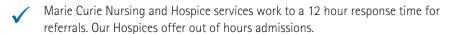
• Our user survey shows that 87 per cent of patients felt that Marie Curie staff had the right information about them, always or most of the time.

NICE QS9. Urgent care

People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.

Marie Curie helping you meet the statement





Marie Curie Discharge Liaison Nurses and fast-track discharge services enable fast transfer to patients' preferred place of care.

Further reading

Improving Choice at End of Life: A descriptive analysis of the impact and costs of the Marie Curie Delivering Choice Programme in Lincolnshire, The King's Fund, April 2008

- A policy covering our Hospice and Nursing service sets out arrangements for the safe and appropriate admission, transfer and discharge of patients including out of hours admissions.
- The Marie Curie Managed Care model provides flexible responsive nursing services according to patients' changing needs.

NICE QS10. Specialist palliative care

People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.

Marie Curie helping you meet the statement



Marie Curie Hospices provide specialist palliative care services for the local community which integrate across other local services.



Our Hospice Medical Consultants also work in local hospital trusts. This helps promote integration across the sector.



The Marie Curie Nursing Service works in partnership with local independent hospices to ensure a skill mix of generalist and specialist palliative care in an area.



Our Delivering Choice Programme design consultants work with local commissioning organisations to help determine optimum levels of specialist palliative care for local communities.

Further reading

Hospice care delivered at home, in nursing homes and in dedicated hospice facilities: A systematic review of quantitative and qualitative evidence, Candy et al, Marie Curie Palliative Care Research Unit, Department of Mental Health Sciences, Royal Free and University College Medical School, December 2009

- Our user survey shows that 94 per cent of users of Marie Curie Hospices rate their overall experience as very good or excellent.
- Marie Curie Hospice doctors, nurses and allied health professionals have qualifications in specialist palliative care. Hospice staff undergo annual professional review and development to ensure competency in specialist skills.
- Marie Curie Clinical Lead Nurses can be based in partner hospices to ensure integrated working with specialist palliative care.

Theme 4 Last days of life



NICE QS11. Last days of life

People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.

Marie Curie helping you meet the statement



Marie Curie's Nursing Service focuses mainly on caring for people at home in the last weeks of life.



Marie Curie Hospices provide specialist care in the last days of life supported by end of life care pathways.



Marie Curie Discharge Liaison Nurses actively identify patients in the last days of life and arrange discharge to a more appropriate place of care in accordance with the patient's wishes.

Further reading

Care of the dying: A pathway to excellence, Ellershaw and Wilkinson (eds), Oxford University Press, December 2010

The integrated implementation of two end-of-life care tools in nursing care homes in the UK: an in-depth evaluation, Hockley et al, Palliative Medicine, July 2010

Marie Curie supporting information

• Marie Curie Hospices adhere to best practice end of life care pathways. Our England, Northern Ireland and Scotland hospices use the Liverpool Care Pathway Version 12; our hospice in Wales uses the All Wales Integrated End of Life Care Pathway.

Theme 5 Care after death



NICE QS12. Care of the body

The body of a person who has died is cared for in a culturally sensitive and dignified manner.

Marie Curie helping you meet the statement



- Marie Curie Nursing and Hospice staff assist the family in preparing the body for undertakers and support families and carers in making arrangements after the death of a patient.
- Marie Curie Hospices have appropriate facilities, including mortuaries and viewing rooms.

Marie Curie supporting information

- Marie Curie Nurses note religious preferences and customs as recorded on the care plan and adhere to our Care of the Dying policy.
- Hospices use best-practice evidence based pathways including the Liverpool Care Pathway to support care of the body after death.

Further reading

National Care of the Dying Audit - Hospitals, Marie Curie Palliative Care Institute Liverpool and the Royal College of Physicians, 2012

NICE QS13. Verification and certification

Families and carers of people who have died receive timely verification and certification of the death.

Marie Curie helping you meet the statement



Marie Curie Hospices verify and certify death and will issue the medical certificate confirming cause of death and information on how to register the death.



Marie Curie Nurses can verify expected death when it fits with the local model of care.

Further reading

Guidance for staff responsible for care after death (last offices), National End of Life Care Programme, April 2011

Marie Curie supporting information

- Marie Curie Nurses are trained to verify expected death in areas where the local commissioning body and coroner support the practice of nurse verification.
- Marie Curie's training for Healthcare Assistants includes modules on care of the dying and the deceased.

NICE QS14. Bereavement support

People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.

Marie Curie helping you meet the statement



Marie Curie Helpers support carers up to three months into bereavement.



Our Hospices provide bereavement support to families for up to a year after the death and signpost them to other agencies if necessary.



We offer a comprehensive brochure on bereavement to families and carers.



We give families opportunities to keep in touch with us through commemorative events and volunteering.

Further reading

Marie Curie supporting information

- Marie Curie Hospices contact bereaved families and carers within 12 weeks of the death to offer support.
- Marie Curie's bereavement care in Hospices is supported by a bereavement service policy which ensures proactive bereavement support.

Bereavement care services: a synthesis of the literature, University of Nottingham, November 2010

Theme 6 Workforce



NICE QS15. Training

Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.

Marie Curie helping you meet the statement



Marie Curie Nursing and Hospice staff have extensive training in end of life care.



76 per cent of Senior Marie Curie Healthcare Assistants have NVQ level 2 or above.



Our nurse induction programme includes training in communication skills with ongoing robust training and development.



Our Clinical Nurse Specialists offer support and training to care home staff and GPs



Marie Curie Hospices provide palliative care training for medical students.

Further reading

Effectiveness of brief training in cognitive behaviour therapy techniques for palliative care practitioners, Mannix et al, Palliative Medicine, September 2006

Marie Curie supporting information

- Marie Curie has a training policy and a clinical supervision policy to support staff professional development.
- Training and development are part of Marie Curie's strategic agenda. We regularly measure this activity against key performance indicators.
- All Marie Curie staff complete an annual professional development review to keep their skills up to date.
- Marie Curie staff have access to an online training and development site, offering flexible personalised learning and training options.

NICE QS16. Planning

Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.

Marie Curie helping you meet the statement



Our Delivering Choice Programme service design consultants can support commissioners in ensuring the right skill mix and availability of the right level of multidisciplinary staff to provide end of life care for their local population.

Further reading

Better Together: An end of life initiative for patients with heart failure and their families, Marie Curie Cancer Care and University of York, June 2010

Advance care planning for people with dementia: a review, Dening, Jones and Sampson, International Psychogeriatrics, December 2011

- Through the Delivering Choice Programme our service design team can support commissioners with local workforce planning.
- We have recently restructured the Marie Curie Nursing Service to accommodate the increasing demand for our services. A new Nursing Support Centre in Pontypool will vastly improve our operational efficiency.

