

Impact case study (REF3b)

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| <p>Institution: Edge Hill University</p> |
| <p>Unit of Assessment: 3 - Allied Health Professions, Dentistry, Nursing and Pharmacy</p> |
| <p>Title of case study: The impact of the revised Minimum Data Set (MDS) on improving composition and delivery of Specialist Palliative Care (SPC) services</p> |
| <p>1. Summary of the impact Accurate recording of adult SPC activity using the revised MDS has resulted in the transformation of SPC services. The MDS provides economic benefits by informing the planning and funding of local services by capturing full service costs and is being used to develop a new NHS funding system for SPC. Informing accurate audit and national benchmarking of services, it shows how revised service composition, enhanced day care, and seven day services, are contributing to reduced hospital admissions. This has both policy and economic benefits. It demonstrates how services are addressing SPC provision for non-malignant disease, a key policy driver.</p> |
| <p>2. Underpinning research The MDS for SPC Services is the only national collection of palliative care activity for adults in England, Wales and Northern Ireland. It was developed in 1996 to provide good quality data to aid service development and the implementation of standards. A revision was undertaken between 2005/6 and launched for data collection in 2008/9. The research element of this revision was led by Edge Hill University (EHU), with the clinical team from Marie Curie Palliative Care Institute Liverpool. Jack, employed at EHU since 1993 and Director of the Evidence-based Practice Research Centre, was the only team member with experience of participatory methodology which was central to the project design and she subsequently first authored the lead paper from the study. The MDS is recognised by the DH as providing “valuable information on hospice and specialist palliative care activity across England, Wales and Northern Ireland”.¹</p> <p>Specific limitations of the original MDS became apparent in 2003, including problems defining data fields, double counting of patients and redundant items. Additionally it did not cover the changing face of palliative care including interventions and service configuration; issues increasingly important with the forthcoming funding review of SPC. An action research methodology was adopted to redesign the MDS. This was to support a partnership between researchers and clinical staff, to ensure clinical needs were met by engaging with the clinical staff who complete the MDS from the outset. Three workshops to assess and redesign different sections of the MDS were held with stakeholders from across England and Wales. To ensure multidisciplinary (MDT) representation of services, stakeholders included: medical staff, community nurses, clinical managers, day care managers, hospice chief executives, cancer service managers, data collection officers and bereavement services teams. The research confirmed the MDS had to be redesigned to show the complexity of SPC services, what they did and what services should be in place across all SPC teams.</p> <p>The research identified five areas previously not recorded in the MDS including:</p> <ol style="list-style-type: none"> i) the expansion of the range of services for example, day therapy, hospice at home; ii) revised SPC team composition for example, including allied health professionals and spiritual care; iii) the wider range of interventions offered in day care including lymphoedema services and blood transfusion therapy; iv) the expansion of palliative care into non-malignant diseases; v) the ‘hidden aspect’ of the SPC teams’ work, including telephone support to patients, families and health care professionals. <p>Prior to piloting, the revised MDS was reviewed by an expert panel comprising clinical leads with a national involvement with SPC organisations, such as Help The Hospices, to confirm fitness for purpose. Piloting was undertaken, minor changes made and the revised MDS was launched in 2008/9.</p> |

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Jack's experience in using participatory research enabled a national consultation exercise to be effectively and speedily undertaken. The approach promoted stakeholder ownership of the revised data set illustrated by the high completion rate of the revised MDS for the 2008–2009 data collection cycle.²⁻⁶ As a result of the research the MDS now provides a data set that reflects current national SPC provision.

3. References to the research

Funding: £60,000 funding was dedicated to this project from the Department of Health Section 63 grant and core funding from the NCPCC

Evidence of the Quality of the Research: The research was published in *Palliative Medicine* (Impact factor 2.609). (2012 Ranking: 15/82 in Health Care Sciences & Services | 26/151 in Medicine, (Thomson Reuters, 2013). The research was presented at the European Association of Palliative Care conference (leading European conference for Palliative Care) 2007/8 with abstracts published in *Palliative Medicine*.

1. Report: Department of Health End of Life Care Strategy 3rd Report Sep 2011 (pg 30)
2. Journal Article: Jack, B., Littlewood, C., Eve, A., Murphy, D., Khatri, A. and Ellershaw, J. [Reflecting the scope and work of palliative care teams today: an action research project to modernise a national minimum data set.](#) *Palliative Medicine*, (2009) 23 (1). pp. 80-86. ISSN 0269-2163 DOI [10.1177/0269216308098477](#) (submitted in REF 2)
3. Contribution to Conference: Littlewood C, Jack BA, Eve A, Murphy D, Khatri A Ellershaw JE Dying without data: Modernising the Core Specialist Palliative Care Minimum Data Set. *Presentation at the European Association for Palliative Care 5th research forum Trondheim, Norway 29-31 May (2008)*
4. Contribution to Conference: Littlewood C, Jack BA, Eve A, Murphy D, Ellershaw JE Fit for purpose: modernising the minimum data set collection in the United Kingdom. *Presentation at the European Association for Palliative Care 10th Congress Connecting Diversity Budapest Hungary 7-9 June (2007)*
5. Report: The National Council For Palliative Care (2010) National Survey of Patient Activity for Specialist Palliative Care Services. MDS full report for the year 2008-9 www.ncpc.org.uk (Refers to the modernization process and changes. Available on request).
6. Report: The National Council For Palliative Care National Survey of Patient Activity for Specialist Palliative Care Services full report for the year 2009-2010,2010-2011,2011-2012 www.ncpc.org.uk

4. Details of the impact

The MDS provides an accurate picture of SPC national services. The revised MDS informs policy, including revising SPC service configuration. It enables local, regional, national benchmarking and quality standards comparisons and supports the development of SPC Funding Review data collection methodology. MDS captures the SPC data from over 65% of services in England, Wales and Northern Ireland that completed the return for the year 2011/12 (covered over 38,264 in-patients, 24,981 day care patients, Home care 81,454, Hospice at Home 12,413 patients).

Claim 1: Using the revised MDS enables a more accurate picture of SPC service composition and activity. This enables local/national audit and benchmarking and activity can be used to assess how far national policy drivers are being implemented (*Factual Statements 1 and 2*).

1.1) Accurate audit and benchmarking from the revised MDS is evidenced by:

- The use of the MDS by services as part of national benchmarking of standards of service provision in the sector. Cited in 34 hospices' Annual Quality Accounts, in compliance with the Health Act 2009: 2012/13, for example used by the flagship hospice St Christopher's, London. Use of the MDS was advocated by a Help the Hospices Workshop in conjunction with the Department of Health on Quality Accounts (May 2010) (*Factual Statement 3*).

- National Institute for Health and Clinical Excellence National Quality Standards (NICE) for SPC refer to using the MDS for monitoring purposes to assess for best practice. The Quality Standards also include SPC services providing both telephone advice and access to spiritual care; both now recorded on the revised MDS.¹
- MDS data are being used by the Cancer Networks as part of the National Cancer Peer Review Programme. This supports quality assurance of cancer services by local cancer networks organisations to ensure that national standards are met: for example the monitoring of telephone support and seven day week service, which are now reflected in part of the national Quality Standards for end of life care for adults.²

1.2) SPC services are benefitting because the MDS allows them to demonstrate supporting the DH End of Life Care Strategy of promoting dying at home:

- MDS now records the SPC teams service interventions (including clinical interventions e.g. blood transfusion, hospice at home services). This suggests the positive impact of SPC contributing to supporting dying at home.^{3,4} Midhurst Macmillan SPC Service used these data to evidence a reduction in hospital admissions by 79%.⁵

1.3) MDS demonstrates the increasing access to SPC services for non-malignant disease including neurological, cardiovascular and respiratory diseases (a national policy driver) Previously this data was not captured

- Evidence used by the National Council on Palliative Care to respond to the All Parliamentary Group on Heart Disease, Stroke, Kidney and Diabetes Inquiry recommending Key Priorities for the Cardiovascular Disease Outcomes Strategy, that include access to SPC services. Additionally, MDS data are cited in NHS Outcome Strategy for COPD and Asthma (May 2012), regarding these patients accessing SPC. (*Factual Statement 1*)

Claim 2 Improving management information through accurate data collection and monitoring (*Factual Statements 1 and 2*)

2.1) The MDS provides accurate data for service managers, informing planning and funding of local services, captures accurate service costs and appropriate staffing composition to meet local demand. Consequently, it readily identified the hidden aspects of palliative care interventions to ensure that they are being accurately monitored and can be costed:

- Telephone support is now reported in the MDS 2011/12: day care services provided over 88,240 consultations (p575). In bereavement support services 37.6% of telephone contacts lasted over 10 minutes (21,874 contacts).⁵
- Service use and trends are reviewed including MDT composition and usage of each professional thereby informing staffing composition needs. For example there has been an increase in: pastoral spiritual care telephone consultations in day care has increased and trebled over the last three years⁴. Thus demonstrating the implementation of the Quality Standards For End of Life Care that SPC services had designated access to spiritual service as part of the MDT¹. A further 7% rise was reported in 2011/2.⁵
- Similarly in Day Care, in 2011/12 there were over 285,342 face to face consultations previously not correctly monitored, as did not capture all MDT activity.⁵
- Data can be used to inform workforce planning and service development: for example the PCT Lead Nurse West Midlands “used the NCPC Minimum Data Set to argue with local Commissioners of the need for two more specialist palliative care nurses, which made a major contribution to a small team”⁵
- The data are used to inform the business plan to gain increased staffing with the development of seven day SPC day services. (*Factual Statement 2*)

2.2) Providing accurate data to inform the development of the data sets to be used for the SPC Funding Review 2011 (Factual Statement 4)

- The MDS is key to the Independent Funding Review. The independent review for the Secretary of State for Health 2011 quoted “the only consistent data set for adult services collected at the moment is the Hospice specialist palliative care minimum data set” (pg 73) (Factual Statement 4). Subsequently the MDS has been used to inform the development of the costing methodologies, for the data sets for the pilot sites for the Independent Palliative Care Funding Review drawing upon the categories included in the revised MDS.

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5. Sources to corroborate the impact

1. National Institute for Health and Clinical Excellence National Quality Markers, 2011. <http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-qs13/quality-statement-10-specialist-palliative-care>
2. NHS National Cancer Action Teams National Cancer Peer Review Programme Manual for Cancer Services Specialist Palliative Care Measure. Specialist Palliative Care Resources, 2012 <http://www.cquins.nhs.uk/?menu=resources>
3. National Council for Palliative Care and the National End of Life Care Intelligence Network. Press release 15 August 2012 “More people able to die at home due to community specialist palliative care” <http://www.ncpc.org.uk/news/more-people-able-die-home-due-community-specialist-palliative-care>
4. The National Council For Palliative Care National Survey of Patient Activity for Specialist Palliative Care Services full report for the year 2010-2011 http://www.ncpc.org.uk/sites/default/files/MDS%20Report%201011%20A4_1.pdf
5. The National Council For Palliative Care National Survey of Patient Activity for Specialist Palliative Care Services full report for the year 2011-2012 http://www.ncpc.org.uk/sites/default/files/MDS%20Full%20Report%202012_1.pdf
6. Department of Health Palliative Care – Funding Pilots Guidance 7 Version 9, Final Guidance to support Palliative Care Funding Pilots Data Collection, August 2012 (copy held at University)

Factual Statements

1. The National Council for Palliative Care, Director of Public & Parliamentary Engagement - benefits of use of revised MDS to give an accurate assessment of service composition and activity; improvements to management information and benefits thereof.
2. Royal Liverpool Hospital Specialist Palliative Care Team Directorate Manager - benefits of use of revised MDS to give an accurate assessment of service composition and activity; improvements to management information and benefits thereof.
3. Help The Hospices Information Advisor – advocacy of use of the revised MDS.
4. Head of Palliative Care Funding Programme, Finance Directorate, NHS England – use and benefit of revised MDS in SPC Funding Review, 2011.