

Development of new MDS”

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Minimum Data Sets

- Services developed outside NHS
- Need for standardised set of data to capture services
- 1996 NCHSPC developed MDS
- Data manual (electronic only)
- Standardised questionnaire for differing services

7 questionnaires

- Section 1 In patient care
- Section 2 Day care
- Section 3 Home care/community service
- Section 4 Hospital
- Section 5 Bereavement support
- Section 6 Out patient clinic care
- Section 7 All patients

MDS Why do we need them?

- Development and implementation of service standards
- Establishment of resource allocation for commissioners
- Achieving nationally consistent reporting on palliative care provision
- Researching/ evaluating patient needs/ best practice/ service models

Merseyside & Cheshire MDS Subgroup

- Formed in 2002
- Need to show accurate activity across network
- Each ICCN represented
- Network support – SIF(service improvement facilitator) + Data Support analyst
- Multi-professional
- Chose Questionnaire 7 to audit usage

Challenges

- MDS is not inspiring topic
- Differing methods of collection
- Poor IT resources
- Low priority for clinicians
- Voluntary
- Double/triple counting

MDS Difficulties

- MDS returns very variable
- Hospital teams lowest response rate 47%.Why
- Overall response rate 68%
- Some questions never filled in- Ethnicity?
Lives alone?
- Little information collected about non malignant disease
- Far too much detail around neurological disease

Non Malignant disease data

- Neurological
- Huntington's disease
 - Motor Neurone disease
 - Parkinson's disease
 - Alzheimer's disease
 - Multiple sclerosis
 - Other neurological conditions

“Others”

- HIV disease and AIDS
- Cerebrovascular disease
- Other heart and circulatory conditions
- Respiratory conditions
- All other (non cancer) diagnoses

Project start

- Robust
- Consistent
- Useful output and outcome measures for service development/ commissioning
- Expand data for non malignant disease
- 2 phases including expert panel review

Phase One

- Project steering group identified core MDS needed to be updated and refined before being adapted for non cancer areas
- Aim – to revise the core MDS and pilot the revised document in the Merseyside and Cheshire Cancer Network before national dissemination.

Would you tell me, please, which way I ought to go from here?'



That depends a good deal on where you want to get to,' said the Cat.

'I don't much care where--' said Alice.

'Then it doesn't matter which way you go,' said the Cat.

'--so long as I get somewhere,' Alice added as an explanation.

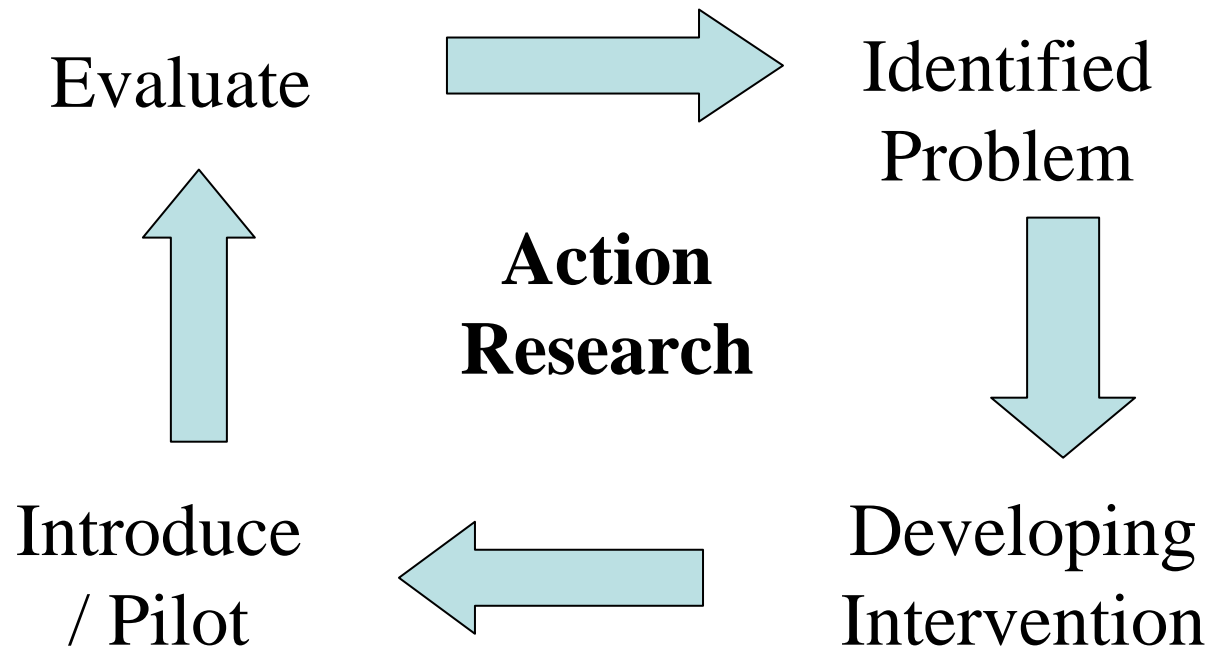
'Oh, you're sure to do that,' said the Cat, 'if you only walk long enough.'

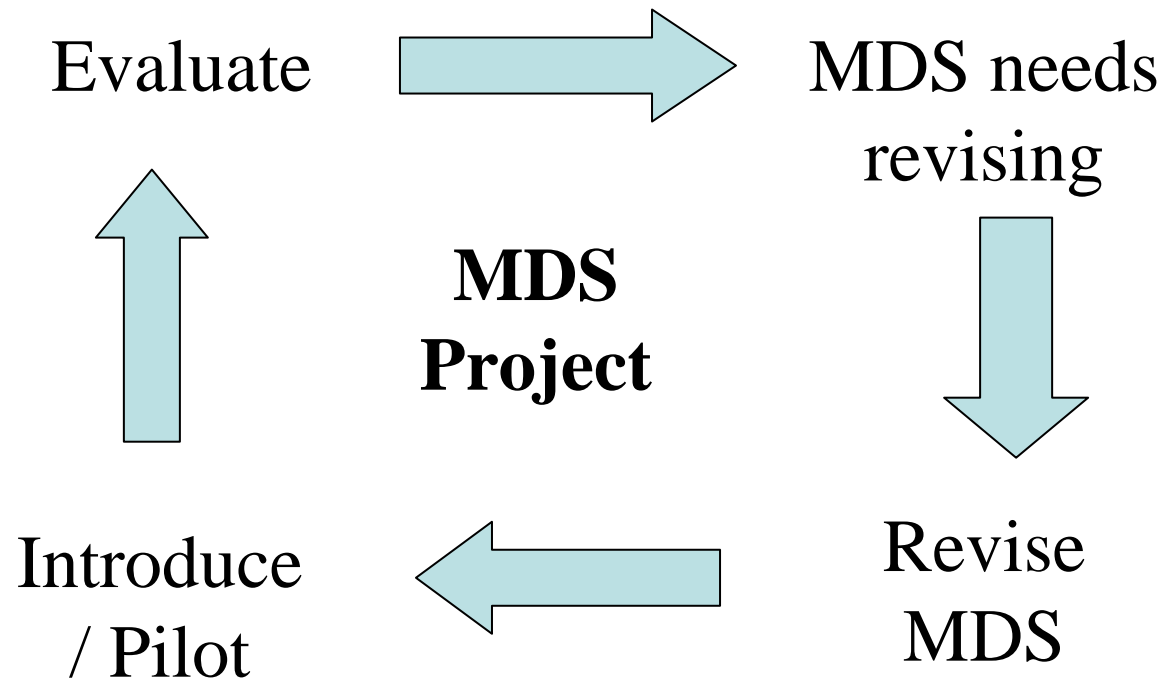
Process

- Identified importance to have a consultation exercise with providers of all palliative care services from across the UK
- Practical issues surrounding this exercise identified
- Consideration made to the project time scale to harmonise with Human Resource Groups (HRG)

Modified Action Research Approach

- A modified Action Research Approach was adopted for the project as it enables:
- *collaboration between all those involved in the inquiry so that knowledge developed in the process is directly relevant to the issues being studied (Sharp 2005)*

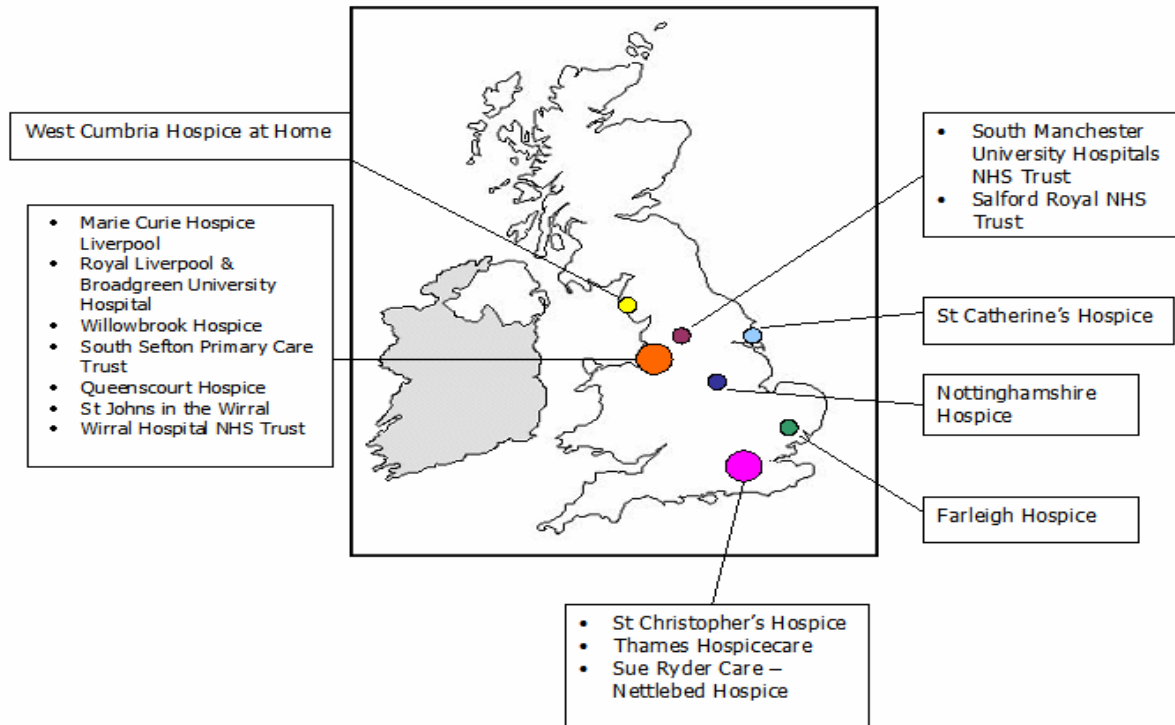




Approach

- Involvement of key stakeholders was paramount
- Purposive sample to include stakeholders from across the UK and different palliative care settings invited to participate
- Workshop format selected to bring stakeholders together
- LREC approval sought but not needed

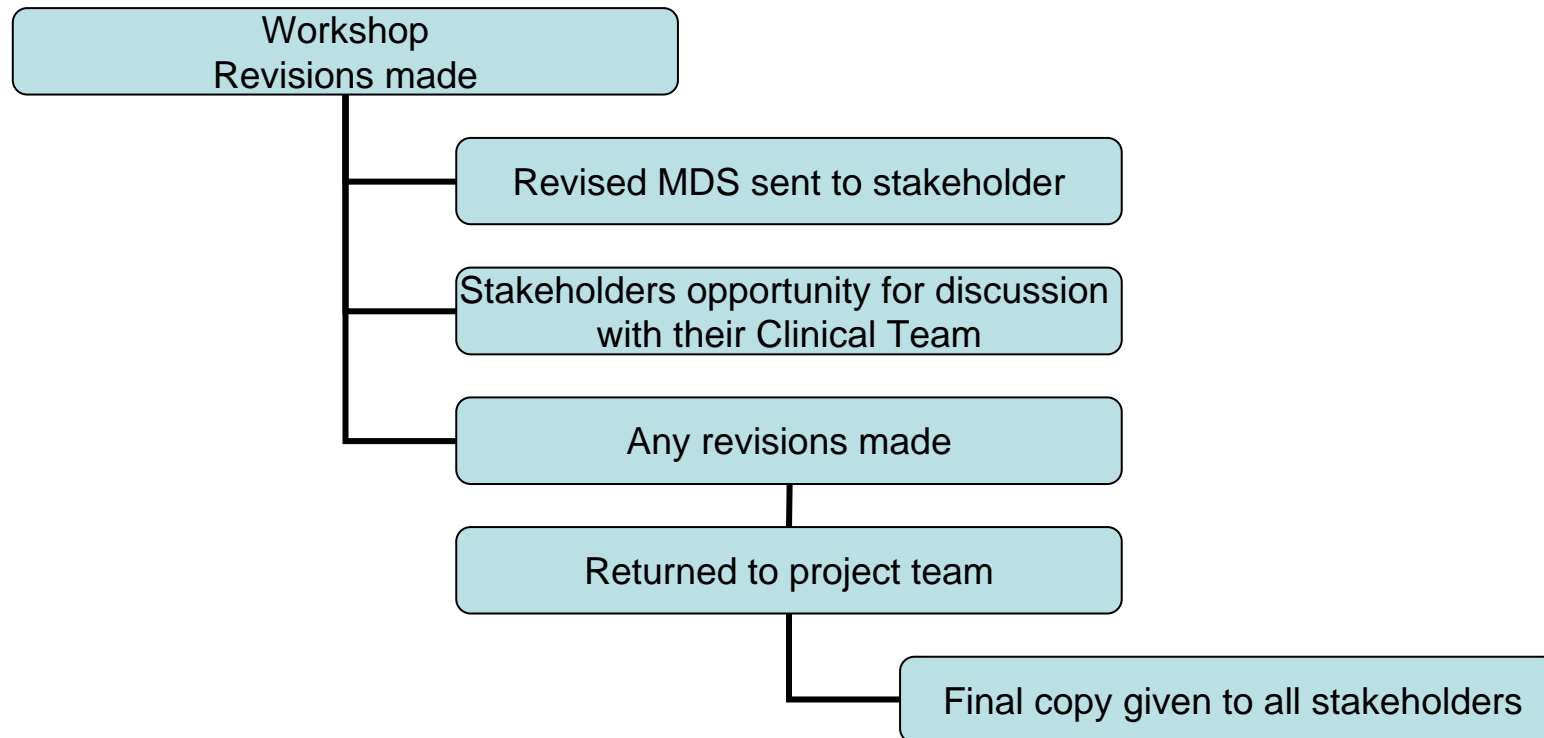
MDS MAPPING FOR PILOT SITE PHASE
16 SITES



Workshops

- 3 workshops held in July 2005 and October 2005 and January 2006 in Liverpool.
- 52 participants attended– (including project team) from across the UK
- Each workshop looked at questionnaire with professionals from appropriate sector

Consultation Process



Comments from the stakeholders on the original MDS

‘My teams had previously struggled with the old forms and all produced variations on their own interpretation from each other’

‘We in Wales are a ‘bit behind’- my team has no electronic data collection except for what we have devised ourselves’

Summary of Results

Changes made to the MDS to reflect

- the development of the Multidisciplinary team in palliative care including
 - the range of services provided
 - expansion of the team composition
OT/physio/chaplains/psychology
 - interventions made (day care)
blood transfusion/ bisphosphonates

Summary of Results

- Expansion of services - out patients
- To capture the 'hidden aspects' of the service
i.e. telephone contact with non referrals
- The expansion into the non cancer arena
Heart failure
Chronic obstructive pulmonary disease
Renal failure

Summary of Results

- Amendments to all sections regarding:
 - Terminology used
 - Recording the data on existing and new patients
 - Clarification of out patient clinic rather than attendance day hospice
 - Ethnicity data

Comments from the stakeholders

Revised MDS

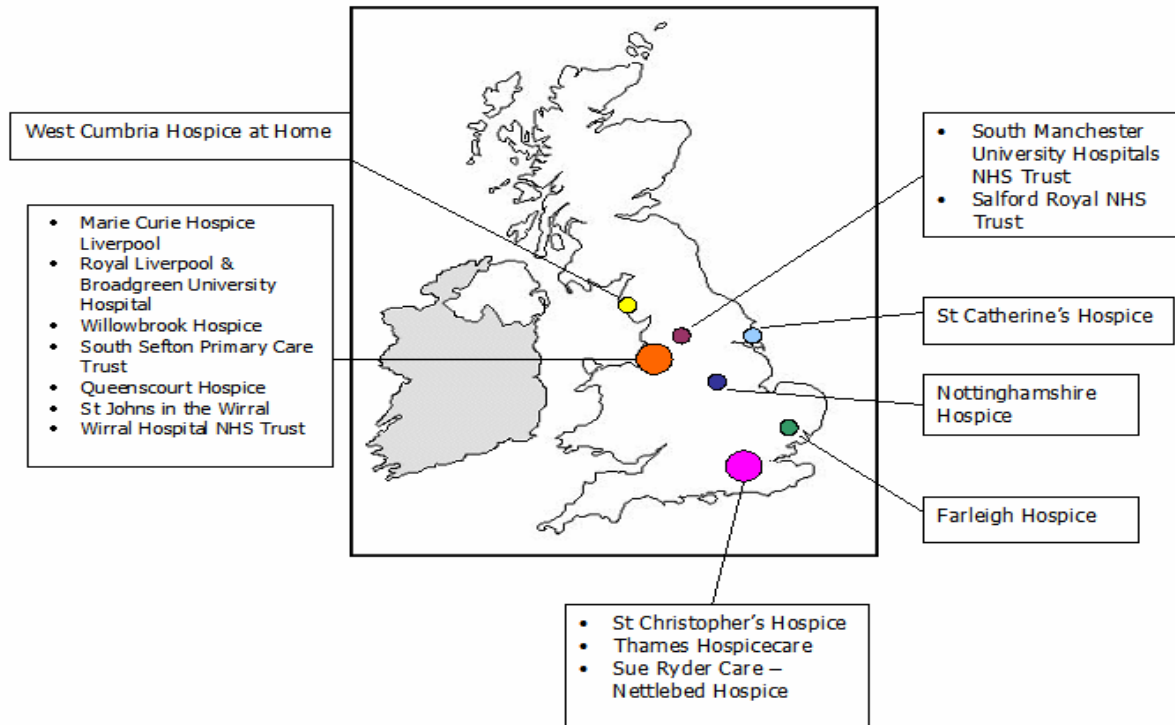
‘The Hospital Team are pleased with the new format as they already collect most of this information but have not been able to include it on the data set in the past’

‘I think the data sets are now much clearer in the area of new –patients and new referrals’

Phase 2

- Identification pilot sites (16)
- Delay in pilot due to National Partnership group
- Useful data changes
- 3 month pilot Aug - Dec 06
- Analysis March 2007

MDS MAPPING FOR PILOT SITE PHASE
16 SITES



Phase 2

- All stakeholders who attended the 3 workshops were invited to participate in the second phase of the project
- 16 sites volunteered
- 12 sites undertook the piloting

Phase 2 Assessment

- Participants were asked to use new forms for 3 months and comment upon the new MDS forms on
 - Ease of completion
 - General problems in completion
 - Whether the data required fully represented the service
 - Suggestions for improvement
 - Additionally to identify any amendments to each question in all sections

Phase 2 Results

- **Better Definitions and greater clarity**
 - clarification or better definitions were required for example regarding re referrals. **Action taken**
- **Duplication of Information**
 - issue re 'New Patients' twice within each Section. **Removed**
- **Important data not captured on the present forms**
 - focused into the lack of recording of important telephone activity. **Added**
 - lack of categories to accommodate all referrals to other services
- **Difficulty/Impossibility of providing some of the data requested**
 - Areas highlighted

Pilot Phase comments

- ***Ease of Completion***
 - Respondents were evenly split on the question of whether new MDS form was easier or harder to complete.
 - General agreement new forms were more time consuming
- ***Reflecting Services Accurately***
 - Many respondents felt that the new MDS covered more of their service than previously,
 - some alterations to the forms required to allow coding of all relevant information

Pilot 2 Data Analysis

- The data provided by the pilot sites was analysed as part of the pilot process.
- Areas that were found to be problematic were:
 - Day care
 - Outpatient care
 - Home Care
- With particular problems arising for doctors who see patients in a variety of settings

Expert Panel Assessment

- Revised MDS were assessed by a panel of experts to assess if the information was clear, complete and meaningful.
- Experts were drawn from clinical leads who have a national involvement with palliative care organisation and delivery.

Expert Panel Assessment

- Panels were asked to comment on the following areas
 - Does the revised MDS collect data that covers your service?
 - Would you have any particular problems in providing any of the required data?
 - Do you think the revisions to the MDS help to provide data that is clinically meaningful for palliative care services?
 - Do you think the definitions in the revised MDS more applicable to your clinical service?

Expert Panel Assessment

- **General comments made included:**
- *‘Inclusion of telephone contacts is imperative as these can be just as time consuming as face to face’*
- *‘Inclusion of specific disease data is valuable from an epidemiological point of view’*

Expert Panel Assessment

- **Some areas are not covered in the revised MDS for example:**
- *‘No collection of complementary therapy data and this growing area of work’*
- *‘Would be helpful to have more comparative data specifically for lymphoedema as a separate service’*

Expert Panel Assessment

- **Additional Comments**
- *‘Very positive move. Will provide more accurate data and will be useful to provide evidence of clinical activity which can be costed more readily’*

Summary

- Further revision by NCPC - final forms launched today
- Successful National consultation exercise
- Participation by a large number of stakeholders from all areas of palliative care provision
- Expert panel involved

Summary

- Modified action research approach worked well
- Fast and effective
- Allowed wide user involvement in a major change
- Resulted in a nationally agreed revised MDS to meet the changing face of specialist palliative care

The Marie Curie
Palliative Care Institute

LIVERPOOL

*Thank you for participating in this
national project*

The Royal Liverpool and
Broadgreen University Hospitals
NHS Trust



Reference

***Sharp C (2005) The Improvement of Public Sector Delivery: Supporting Evidence Based Practice Through Action Research Scottish Executive Social Research
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***Waterman H et al (2001) Action research: a systematic review and guidance for assessment
Health Technology Assessment 5 (23)***