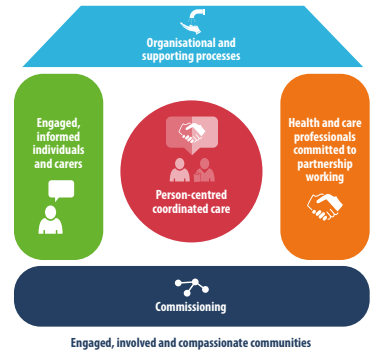




END OF LIFE CARE – SUMMARY OF RESEARCH



PERSON-CENTRED COORDINATED CARE

UNDERSTANDING INDIVIDUAL VIEWS, NEEDS AND EXPERIENCE

- > Palliative care needs and experiences of BME groups
- > Understanding complexity, experience and organisational behaviour
- > Understanding characteristics for best place for good death
- > Understanding care for elderly with and without dementia
- > Understanding experience of people with cancer and advanced diseases

- > Understanding the experiences and needs of people with major stroke
- > Spirituality and religion
- > Preferred place of care vs. preferred place of death
- > Future care planning for people with advanced heart disease
- > Palliative care approach for people with advanced heart failure

ENGAGED AND INFORMED INDIVIDUALS AND CARERS

QUALITY OF LIFE

- > Self-management
- > Symptom management

VOLUNTEERS AND SUPPORT WORKERS

- > Home based care
- > Community support
- > Experience of hospice volunteers
- > Community experience
- > Evaluating volunteer support

IMPROVING COMMUNICATION

- > Concordance
- > Compassion
- > Spirituality
- > Mental capacity
- > Palliative care effectiveness
- > Barriers to tissue donation

CHOICE

- > Advance Care Planning
- > Decision making

- > Choice – policy into practice
- > Supporting staff and people in decision making
- > Decision making for children
- > Young adults experience of participation in decision making
- > Supporting carers with discharge to home

TARGETED GROUPS

- > Elderly
- > Children and young adults
- > Dementia
- > Cancer

OTHER

- > Socio-politics and the elderly
- > Palliative care and health promotion
- > Funeral costs and role of the state



ORGANISATION AND SUPPORTING PROCESSES

TREATMENT, SYMPTOM AND PAIN MANAGEMENT

- > Understanding sedation in palliative care
- > Palliative care prognostic index
- > Systematic reviews: interventions for pain and symptoms management and control
- > Invasive neurodestructive procedures in cancer pain
- > Trans-dermal nitrate
- > Reliability of proxy symptom assessments
- > Artificial nutrient and decision making
- > Clinically assisted hydration
- > Measuring hydration to understand symptoms
- > Anticoagulation
- > Dalteparin and survival in lung cancer
- > Cancer carer medicines management intervention
- > Indwelling drainage catheters
- > Continuous subcutaneous infusion drugs
- > Early palliative care

POLICY AND GUIDANCE

- > Concordance of services for children and young adults with policy and guidance
- > Policy into practice
- > Recruitment guidance for children in studies
- > Benefits and drawbacks of policy recommendations for identifying those with end of life care needs

MANAGING AND SUPPORTING CARERS AND VOLUNTEERS

- > Systematic approach to identification, support and assessment of carers

- > Systematic review organisation support for carers
- > Educational interventions for informal carers
- > Volunteers at the end of life

UNDERSTANDING PATTERNS OF CARE

- > Variation in place of death in relation to location of services in London
- > Emergency presentation of palliative care patients
- > Variation of hospital use in last 12 months of life
- > Data linkage and patterns of care
- > Specialist palliative care and other forms of care interface
- > Optimal contextual conditions end of life care in acute sector
- > Decision making process of adults who die within three days of admission

COMMUNITY AND HOSPICE CARE

- > Delivering integrated palliative care to the community
- > Hospice rapid response community service – hospice at home model

IMPROVING EXPERIENCE

- > Improving experience of palliative care in emergency department
- > Helping people address and manage uncertainty
- > Barriers and facilitators to Advance Care Planning
- > Advance Care Planning for children



COMMISSIONING

UNDERSTANDING NEED

- > Children and young adults
- > Patient centred case-mix classification
- > Palliative care approaches
- > Carer Support Needs Assessment Tool in palliative home care
- > Advanced dementia: symptom burden/health and social care
- > Survival in children and young adults
- > Supportive care in the community for people living with advanced liver disease

ECONOMIC EVALUATION

- > Economics of family care giving
- > Assessing benefit in hospice setting

EVALUATING SERVICES

- > Rehabilitation on quality of life

- > Evaluation of Macmillan Specialist care at home
- > Evaluating telemedicine
- > Impact of Route to Success
- > Effectiveness of services for bereaved children and young adults
- > Impact of palliative care day services on quality of life
- > Variation in place of death and quality of care

EVALUATING INTERVENTIONS

- > Evaluating fatigue management intervention
- > Impact on hospitals admission of Advance Care Planning



HEALTH AND CARE PROFESSIONALS COMMITTED TO PARTNERSHIP WORKING

PARTNERSHIP WORKING

- > Multidisciplinary interactions
- > Doctor-patient relationships
- > Engaging patients and families
- > Understanding experience – patients, staff
- > Supporting staff
- > Leadership
- > Transfer home
- > Decision making
- > Views in shared decision making
- > Data/information sharing

EDUCATION

- > Learning needs of staff

MEASUREMENT AND EVIDENCE

- > Outcome measures
- > Quality of life measurement

- > Clinical scoring system for children and young adults
- > Evidence base
- > Improved evidence base for care in last hours

SYMPTOMS: UNDERSTANDING, RECOGNISING OR MANAGING

- > Fatigue
- > Breathlessness
- > Holistic assessment
- > Prognostic factors in survival
- > Recognising dying

OTHER

- > Gold Standards Framework evaluation