

2014-2016 Consultation Report: Just in Case Box

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Background

As part of the Better Access to Palliative Care project hospice@HOME was provided funds to implement an Emergency Medical Kit (EMK) for Tasmanians whose preference was to die in their own homes. In January 2014, hospice@HOME began the initial phase of state-wide consultations around the development of EMK Guidelines and implementation plans.

The initial phases of the consultation process identified that there was little perceived need for an EMK amongst Specialist Palliative Care Services, some Community Health Services and the Department of Health and Human Services. Therefore on completion of Phase 2 in October 2014, consultation ceased until a needs analysis and literature review was undertaken.

Six months of hospice@HOME data (Jan 2015-June 2015) were analysed by a team of researchers based at hospice@HOME in July 2015. The data analysis focussed on a cohort of patients who had expressed a preference to die at home but had died in a facility (hospital or hospice, public or private) one week or less following admission. From that cohort it was found that approximately 60% had been admitted for symptom management at end of life. The team then conducted some 'deep dives' into that cohort and found that there were occasions when access to medications had proved difficult, time consuming and distressing. The findings of the hospice@HOME needs analysis was consistent with findings in the literature review from published papers in Australia and overseas.

In October 2015, Phase 3 consultations commenced with the objective of obtaining broad and extensive input into an EMK. In collaboration with the Specialist Palliative Care Service (South) through an iterative process, the draft Guidelines were developed and the name of the EMK change to Just in Case Box. This draft Just in Case Box Guideline went out to public consultation in March/April 2016.

This consultation report provides details of the reach and key themes emerging from the three consultation phase activities.

Phase 1

Phase 1 of the consultation was conducted in January 2014.

Consultation activities included;

- Consultations with state-wide key stakeholder groups,
- The email distribution of a survey that could be completed online.

Through those consultation activities, hospice@HOME sought to;

- Scope the need for an Emergency Medical Kit (EMK) in Tasmania,
- Identify the enablers and barriers to EMKs,
- Understand the landscape of community palliative care in Tasmania,
- Collect baseline information about current practices,
- Seek information on workforce skills and capacity,
- Understand the needs of remote and rural palliative care in Tasmania.

Consultation Approach

Through January and February 2014 hospice@HOME sought feedback from individuals through a range of state-wide consultation activities. This included;

- Face to face, telephone and consultations with all regional Specialist Palliative Care Services (SPCS) and the Department of Health and Human Services (DHHS),
- Face to face consultations with all Community Health Nursing Services (CHNS) across the state (excluding Flinders and King Islands),
- Face to face, telephone and email consultation with Tasmanian Ambulance Service, General Practitioner's (GP), the Deputy Chief Pharmacist and the Chief Nursing Office,
- An online survey sent to 59 state-wide stakeholders in SPCS, CHNS and GPs.

Survey Reach

A summary of the characteristics of individuals who responded to the Phase 1 survey is included below;

- The survey had a response rate of 35% (n=21),
- Responses were received from each regional area with Southern response rate of 38% (n= 8), the North 38% (n=8) and North West 24% (5),
- Responses were received from at least one SPCS Consultant in each region,
- Respondents identified as Nursing Unit Manager (33%), Community Nurse (17%), Palliative Care Specialist (17%) and General Practitioner (17%),
- 86% of respondents did not use an EMK in their clinical practice.

Consultation themes

Themes arising from Phase 1 of the consultation activities were identified into the following key themes;

- There was a well stated need for standard and consistent Guidelines, that included governance, procedures, carer education, GP and CHNS education, legal implications (particularly in consideration of the Tasmanian Poisons Act and Regulations), after-hours access, inclusion and exclusion criteria,
- A lack of 24 hour nursing and clinical support would be a barrier to implementation,
- Some responders indicated that there was little perceived evidence for an EMK in Tasmania,
- There was an identified need for consensus on the medications,
- Some respondents highlighted that CHNS have limited time and resources to be providing extra education to families and carers about an EMK.

Next Steps

All recommendations in the consultation were carefully considered and the EMK process was drafted based on stakeholder input. A letter was sent to all stakeholders who participated in Phase 1 in February 2014 which provided feedback about the key themes, which included;

- The draft process for EMK provision which would provide the building blocks in the development of a Guideline,
- The indication that there would be the establishment of a 24/7 after hours telephone service staffed by trained registered nurses,
- The acknowledgement that the Specialist Palliative Care Services (SPCS) would continue to have authority over the medications included in the kit,
- The indication that the Caring Safely at Home resources would be utilised and education would be provided by hospice@HOME.

Phase 2

Phase 2 of the consultation occurred between February 2014 and October 2014.

Consultation activities included;

- Consultations with key stakeholder groups,
- Presentations to key stakeholder groups,
- Health professional forums held in each region in Tasmania.

Through those consultation activities, hospice@HOME sought to;

- Develop a state-wide Guideline that was informed and supported by key stakeholders,
- Gain consensus on a core medication list for inclusion in the EMK.

Consultation Approach

Through February to October 2014 hospice@HOME sought feedback from individuals through a range of state-wide consultation activities. This included;

- Face to face consultation with regional SPCS and DHHS,
- Presentations to the Partners in Palliative Care Reference Group,
- Three health professional information events held in each geographical region hosted by hospice@HOME and attended by SPCS, CHNS and GP representatives
- Face to face consultations with Deputy Chief Pharmacist, Drug and Alcohol Services and Community Pharmacy,
- Email and telephone consultation with Brisbane South Palliative Care Collaboration,
- Email and telephone consultation with Wimmera Palliative Care and Grampians Palliative Care Service.

Consultation themes

- SPCS, some CHNS and DHHS resistant to the draft Guidelines as there continued to be little perceived need for an EMK in Tasmania,
- No consensus reached on a core medications list with individual prescribing preferences being preferred over 'one-size-fits' all approach.

Next Steps

Following Phase 2, hospice@HOME temporarily suspended consultations into the Guidelines to undertake a literature review, a retrospective audit and a needs assessment into an EMK in the Tasmanian context. This was in direct response to the consultation themes and to deliver an empirical evidence base to demonstrate a need for an EMK in Tasmania.

Phase 3

Phase 3 of the consultation was undertaken between October 2015 and April 2016 following the provision of a Just in Case Box Needs Assessment to the Better Access to Palliative Care program partners in September 2015.

NB: the name of the initiative changed from Emergency Medical Kit (EMK) to Just in Case Box on request from Prof Michael Ashby that 'Just in Case Box' better reflected its purpose.

Consultation activities included;

- Consultation with DHHS,
- Consultations with SPCS (South),
- The distribution of a survey that could be completed online.

Through those consultation activities hospice@HOME sought to;

- Develop a Guideline that was directed, informed and supported by key stakeholders.

Consultation Approach

Throughout October 2015 and April 2016, hospice@HOME sought input from SPCS (South), DHHS and interstate experts in Just in Case Boxes through a range of consultation activities. This included;

- face to face and email consultations with SPCS (South),
- face to face and email consultation with DHHS,
- email and telephone consultations with researchers in South Australia, Queensland and ACT,
- email and telephone consultation with the Federal Chief Medical Officer and Federal Grant Management Team,
- An open access online survey with state-wide and interstate distribution.

Survey reach

A summary of the individuals who responded to the Phase 3 survey is provided below:

- 62% (n=19) of respondents identified as Registered Nurses, 16% (n=5) as Medical Practitioners and 23% (n=7) as other (pharmacist [n=2], Social Worker [n=1], Medical Practitioner [n=1], Registered Nurse [n=2] and Nurse Practitioner [n=1]),
- Responses were received from all regional areas and all SPCS,
- 55% (n=17) of respondents were willing for hospice@HOME to contact them about their feedback,
- After reading the Guidelines 63% (n=20) respondents identified strengths,
- After reading the Guidelines 88% (n=28) respondents identified a risk.

Consultation themes

- There is a strong perception of limited stakeholder consultation in the development of the Guidelines,
- Respondents expressed concerns about the legality of the Just in Case Box under the Tasmanian Poisons Act and Regulations,
- Many respondents did identify that the only method for patients to access non-PBS end of life medicines for low cost is if SPCS is involved in their care,
- It was expressed that end of life medications dispensed by the community pharmacy are expensive and act as a barrier to accessing end of life medications for those patients who do not need SPCS but wish to die at home,
- There was a perceived advantage to the Guidelines for those patients who did not required the care of SPCS but could better access non-PBS medications from community pharmacy for the time of the program,
- There was uncertainty about who the Guidelines were developed for and the scope of the implementation.

Next Steps

To clarify the intent, scope and purpose of the Just in Case Box Guidelines hospice@HOME will publish a Frequently Asked Questions page on the website. Additionally, an update of how/where the Guidelines were adjusted to reflect consultations and identified risks will be provided. Following on from that on 28th April 2016, hospice@HOME will host a public forum for all key stakeholders. On listening to the concerns of stakeholders and the perceived lack of consultation, a state wide reference group will be convened to provide external governance on the implementation phase.