

EVALUATION OF THE
hospice@HOME
JUST IN CASE BOX PROJECT
FINAL REPORT

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Executive Summary



Many people express the wish to die at home, but few achieve this. Barriers to dying at home include patient concern about the burden this will place on their primary carer; and the challenges of accessing support and appropriate medications when they are needed, including in emergencies.

As part of the Tasmanian Better Access to Palliative Care Initiative, The District Nurses piloted a three-year, statewide, in-home palliative care service, called hospice@HOME, a unique and innovative brokered service delivery approach to in-home, person centred, palliative care.

Early hospice@HOME data identified that 60% of their clients who had expressed a preference to die at home had died in a hospital or hospice one week or less following admission for symptom management, in many cases because access to medications at home had proved difficult, time consuming and distressing.

The District Nurses responded to this issue through the development of the hospice@HOME Just in Case Box (JiCB), which included a package of prescribed medications and related medical supplies, and clinical and non-clinical care during the last days of life through tailored "end of life packages". Lay carers of clients prescribed a JiCB also received a comprehensive and individualised, one-on-one education session to learn about the safe management of the JiCB resources.

KP Health was contracted to evaluate the JiCB initiative by capturing the experience of clients and their primary caregivers, as well as the interdisciplinary care teams involved with the delivery and use of the JiCB.

Evaluation Methodology

Following ethics approval from UniTAS Human Research Ethics Committee, an extensive contact and consent process was undertaken with all identified stakeholders (clients, carers, community nurses, general practitioners and pharmacists). Semi-structured interviews were conducted with all consenting stakeholders.

Interviews

Thirty-nine semi-structured interviews were conducted, either face-to-face or by phone, with 1-3 participants in each interview, as follows: 1 client and 19 carers; 17 nurses; 6 GPs; and 3 pharmacists. All participants consented to the interview being recorded.

Interview Outcomes

The majority of stakeholders were very satisfied with their JiCB experience, although some issues were identified that require further improvement, including the need for more cooperation between service-providers. (See Discussion and Recommendations, below).

Three Case Studies were developed from the interviews:

- Case Study 1 exemplified the extremely beneficial outcome achieved for a terminally ill man and his carers when the JiCB was used as intended, and where all stakeholders cooperated to help him achieve what he wanted, i.e. a good death at home.
- Case Study 2 reported “the client’s voice”; only one of seven clients still alive was well enough, or had capacity, to be interviewed, along with her carer, which provided a deeper understanding of the impact of having the JiCB, and the peace of mind it provided.
- Case Study 3 provided a number of “learnings” and identified areas that need improvement, as it describes a situation where the JiCB was provided too late to be properly effective and, instead, increased the carer’s distress.

Discussion And Recommendations

Many of the stakeholders interviewed for the evaluation were positive about the JiCB and what had been achieved for clients and carers, and in some cases for their nurses and GPs as well. Some stakeholders, in each of the four interview categories, were distressed to think that the service might not continue.

The primary purpose of everyone involved in providing care for clients/patients who are nearing the end of life is to improve the quality of that care, so that it is client/patient-centred. We observed that, where this did occur, the outcome was exemplary care for the client and carer, resulting in the best death possible; where it did not, care was compromised and additional distress was caused to both the client and the carer.

The following themes, identified through this evaluation, provide opportunities to improve the JiCB.

1. IMPROVE THE QUALITY OF THE CLIENT’S END-OF-LIFE CARE PLAN AND CONFIRM THAT THE JICB HAS A PLACE WITHIN THE PLAN

The client’s end-of-life care plan should be client-centred, reflecting their goals and wishes for this stage of their life, within the context of their health condition and the resources available to support them. It should be developed to ensure that it would meet the end-of-life care needs of the client, and by extension, their primary carer.

This is reflected in the JiCB Guidelines (Sept 2016:4), which state that provision of a JiCB “should be part of ... the patient’s overall plan of care (and) should involve the patient, the patient’s family and/or carers, and the patient’s primary care providers”.

Therefore, the fundamental question to be asked in relation to provision of a JiCB is “Will the JiCB help to meet the needs expressed in the care plan?”

We observed that, in some cases, the client and/or carer were not involved in the original discussion; rather, they were only told about the JiCB, and had their first discussion about it, when it was delivered to their home. Some carers found this confronting, and in Case Study 3, where the client was actively dying, the introduction of the JiCB caused additional distress to the carer.

RECOMMENDATION: that a JiCB is not delivered to a client or carer’s home unless: (a) it is likely to assist in meeting the client and carer needs, as expressed in the care plan, and (b) that the carer (and client where appropriate) has been well-informed about its purpose and has agreed that they should have one.

2. IMPROVE INTERACTIONS BETWEEN SERVICE PROVIDERS INVOLVED IN DELIVERING THE PATIENT’S CARE

The JiCB Guidelines (Sept 2016:4) state that: (the contents of the JiCB and the carer training) is fully supported by collaborative and coordinated liaison with the General Practitioner and the patient’s other health care providers with frequent reporting and communication to ensure continuity of care. However, the JiCB was not well-received across organisations.

We observed a culture among Community Nursing Services, particularly at management level, that was not client-centred but was, instead, organisation-centred. The purpose of the JiCB was to help keep clients at home for as long as possible, if that was their wish, and to empower community care providers (whoever they are) to meet the needs of their clients (whatever those needs are). This requires team work and collaboration.

We observed that, not only was there limited cooperation, collegiality and collaboration across the sector, including from some GPs and Community Nursing Services, there were very definite parochial boundary-protection and “turf wars”. For example, there appeared to be little insight among management-level Community Nursing Services staff about the limitations of what they can and cannot provide, which resulted in an unwillingness to work with other services.

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End-of-life client care needs are 24/7 but, except in a small number of location-specific services, Community Nursing Services operating hours are not well-aligned with end-of-life care needs. There appeared to be an acceptance that if the client needed care outside of Community Service hours, the carer should phone for an ambulance. Except in a limited number of cases where the Tasmanian Ambulance Service paramedics could provide emergency treatment, this would result in Emergency Department presentations and/or hospital admissions – precisely what the client and/or carer were seeking to avoid.

Teamwork and collegiality are important components of best-practice end-of-life care among interdisciplinary teams; where this was present, the outcome for clients and carers was greatly enhanced. Where it was absent, the outcome was detrimental for all concerned.

RECOMMENDATION: that all services providing end-of-life client/patient care work together across the boundaries of care to achieve the best possible end-of-life outcomes for the client and carer.

3. PROVIDE GREATER CLARITY TO PROVIDERS ABOUT WHO IS RESPONSIBLE FOR DELIVERING SPECIFIC ASPECTS OF THE PATIENT'S CARE

We observed that providers lacked understanding about who was in the patient's care team and which providers were responsible for each aspect of the patient's care. All members of the care team should be aware of, and contribute to the Plan, and should communicate with other members of the care team in relation to what they are doing to achieve the client and carer goals.

Team members should be aware of who is responsible for:

- discussing the JiCB with the client and/or carer and assessing whether or not the JiCB will support the patient to achieve their goals outlined in their Plan;
- prescribing the JiCB and for informing other team members about this; and
- ensuring that the carer is well-trained in relation to JiCB contents and use.

We observed that poor role delineation between service providers led to multiple services trying to deliver the same care. This poor coordination contributed to decreased service quality and increased carer and patient distress.

Ultimately, someone needs to be responsible for the co-ordination of the patient's care, to be a client and carer advocate and for supporting the client and carer to "navigate the system". This may be the GP, the community nurse or the palliative care nurse, but whoever it is, everyone should know and respect that person's role in the team.

RECOMMENDATION: that all members of the client's interdisciplinary care team recognise, and communicate with, all other members of the team and that agreement is reached about who has ultimate responsibility for specific aspects of the patient's care.

4. IMPROVE COMMUNICATION METHODS BETWEEN TEAM MEMBERS FOR BOTH ROUTINE AND AS-NEEDED COMMUNICATION

We observed poor communication between service provider organisations and between individual team members, which resulted in confusion for everyone concerned and undermined client care.

Planned Communication: All services and team members need to communicate any changes to a client's condition, treatment or end-of-life Care Plan to all other members of the care team and their respective services.

Unplanned Communication: Team members need to feel comfortable to contact other members of the team to ask for advice and/or guidance if they are not sure about particular aspects of the patient's care.

RECOMMENDATION: that all service providers contributing to the end-of-life care of a client establish, and maintain, effective formal and informal communication channels that facilitate information sharing and provision of advice amongst members of the care team, in accordance with patient care needs.

5. IMPROVE INFORMATION SHARING TO ENSURE THAT ALL TEAM MEMBERS HAVE ACCESS TO RELEVANT DOCUMENTS AND RESOURCES

Linked to the issues of communication and collaboration is information sharing. Every member of the care team must receive a copy of the client's end-of-life Care Plan, medication chart, contact details of the carer and other informal client supports, and any other documents or information that might be needed to provide adequate care.

RECOMMENDATION: that all relevant documents and other information be shared with all relevant members of the interdisciplinary team.

6. STANDARDISE AND IMPROVE TRAINING FOR CARERS AND TEAM MEMBERS

The JiCB Guidelines (Sept 2016:4) say: Carers also receive a comprehensive and individualised, one-on-one education session, provided by trained Registered Nurses, to learn about the safe management of end of life medications using the Caring Safely at Home resources.

However, training is needed for everyone involved in end-of-life client care; this includes carers, nurses from all participating organisations, GPs and anyone else who will have direct clinical care of the client.

Training of carers: We observed variable experiences in relation to the training carers received. For some it was excellent, for others it does not seem to have been so effective. An underlying principle of the JiCB project should be that if a carer is going to be provided with a JiCB they need to be properly trained to use it, either when the JiCB is delivered to the home or as soon as possible after that. (Note: this links to the timing of the delivery of the JiCB – see below). The training should be repeated at regular intervals if client care extends beyond two months, or if the trainer thinks that the carer did not comprehend everything that s/he needed to at the first session. Providing the Samsung Tablet with the training videos was helpful to carers who were given it. However, not enough carers received the Tablet for its use to be evaluated.

If it is clear that a carer does not wish to learn how to use the JiCB, this does not necessarily mean that the JiCB should not be provided in that home, as it may enable community care providers to access resources quickly if needed. However, in that case, all members of the interdisciplinary team need to be clear about who will activate the JiCB, and to instruct the carer about what to do if services are not available in an emergency (e.g., phone 000).

RECOMMENDATIONS: (1) that every carer who agrees to receive training to use the JiCB resources receives that training as soon as possible after the JiCB is delivered; (2) that an on-going training schedule be developed, with carers contacted at regular intervals and offered "refresher training"; (3) that hospice@HOME continue to provide the Samsung Tablet containing the training videos but re-evaluate its use when sufficient numbers have been distributed.

Training for GPs and Nurses: The skill-set required to provide high-standard, efficient end-of-life care is not discipline-specific; everyone who is likely to provide clinical care needs to be proficient in, at least, a basic set of skills and procedures likely to be utilised with clients at the end of life, e.g., all clinical care providers attending the client should be able to set up, and maintain, syringe drivers, without needing to call for assistance from another service. These skills should be developed to agreed standards, tested and form a major component of the credentialed "scope of practice" of all end-of-life care service providers. This should address some of the "demarcation and duplication issues" which we observed during the evaluation, e.g., who is "allowed" to set up and maintain a syringe driver.

There is also a safety aspect to such training: given that the JiCB contains a range of (potentially dangerous) drugs, as well as other equipment, everyone involved with its use must be familiar with the contents of the JiCB, the training manual and the medication orders.

RECOMMENDATIONS: (1) that GPs and nurses providing community-based care and support to clients and carers undertake procedure-specific skill training, which, in turn should be reflected in their credentials and scope of practice; (2) that when a patient/client is prescribed a JiCB, everyone providing their clinical care should familiarise themselves with the JiCB and its contents, unless they have already done so.

(NOTE: Resource implications of the training recommendations are acknowledged.)

7. IMPROVE THE QUALITY OF, AND ACCESS TO, AFTER-HOURS SERVICES

We observed that lack of access to efficient and responsive after-hours services caused additional distress to clients and carers. After-hours services in Tasmania are now severely restricted; most of the Community Nursing Services do not have staff available after 9pm and hospice@HOME has been one of the few services available to provide after-hours services to terminally ill clients. There are a small number of after-hours medical services but, in addition to the doctors not knowing the clients, some of the doctors in those services do not have palliative care experience and a number of carers interviewed for this evaluation did not have positive experiences with the after-hours medical services. Although the hospice@HOME clients and/or carers are provided with a 1-800 number, we observed that carers did not always phone the number (calling other after-hours GP services instead) or have a satisfactory response from that service when 1-800 was called. As mentioned above, the JiCB Guidelines stated that the carers would be given a Tablet for 24/7 telehealth or video contact with a hospice@HOME Registered Nurse, but that component of the service had not, in fact, been available for some time. A community nurse noted that the Tasmanian Ambulance Service Extended Care Paramedics provide 24/7 service, which in some cases, but not all, results in the client staying at home.

RECOMMENDATIONS: That all services in Tasmania that provide community-based end-of-life care work together to develop a strategy to ensure that clients and carers have easy and fast access to after-hours contact and advice, including exploring better use of telehealth.

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That further investigation of the user experience of the 1800hospice number be undertaken, to ensure the phone message bank is not hindering care in moments of crisis and the appropriate processes are in place and followed.

8. IDENTIFY THE OPTIMUM TIME IN THE CLIENT'S ILLNESS TRAJECTORY FOR DELIVERY OF THE JICB.

The JiCB Guidelines state that "It is important to anticipate the needs of patient and to place the Just in Case Box in the patient's home in a timely manner." (2016:6). Judging when is the right time to deliver the JiCB is often difficult, as prognosis of time to death is never certain. If the JiCB is delivered too early, it can signal to the client and carer that death is expected in the near future, which can be distressing for all concerned if they have not accepted that this is the case. However, it is more problematic if the JiCB is delivered when the client is actively dying and the carer is in great distress; not only is it probable that, at that point, the carer is in no state to receive training on the use of the JiCB but if the client urgently needs symptom alleviation, that should be delivered immediately by a well-trained community or palliative care nurse.

The JiCB Guidelines (Sept 2016:5) contain the following contraindications for ordering a JiCB:

- The patient is under the age of 18 and/or requires specific dose calculations;
- There is no person in the house who can be responsible for the Just in Case Box;
- There is a clinical improvement and the care plan is re-assessed by a physician.

RECOMMENDATION: That an additional contraindication be added: "When the client is actively dying and introduction of the JiCB would (a) detract from immediate client care requirements or (b) cause undue distress for the carer".

CONCLUSION

The increasing demand for high quality, responsive, community-based end-of-life care requires a whole-of-sector client-centred response. We conclude that the Just in Case Box has an important role to play in that response.

Introduction

Aged and health care in Australia and internationally has moved strongly towards a person-centred approach, with consumer-directed care being introduced into many Australian and State government policies and programs, including those focused on end-of-life care. Many people express the wish to die at home, but few achieve this; additional support and resources are required to help people die in the place of their choice. Barriers to dying at home include patient concern about the burden this will place on their primary carer; and the challenges of accessing support and appropriate medications when they are needed, including in emergencies.

As part of the Commonwealth-funded Tasmanian Health Assistance Package (THAP), funds were allocated to the Better Access to Palliative Care Initiative (BAPC). The overall objective of the initiative is to increase Tasmania's capacity to provide access to community-based palliative care for people with life-limiting illness nearing the end of their life. In 2013 The District Nurses were funded through the BAPC initiative to pilot a three-year, statewide, in-home palliative care service. The new program was called hospice@HOME.

hospice@HOME was a unique and innovative brokered service delivery approach to in-home, person centred, palliative care. hospice@HOME coordinated the delivery of home-based services for people in Tasmania through contracting arrangements with patients' existing service providers, in addition to providing responsive access to equipment and after-hours telephone support. This brokerage model allowed the client's community nurses to continue to provide clinical care, while hospice@HOME non-clinical nurses worked to fill service delivery gaps. The model provided 'wrap around community-based palliative care packages' which essentially met unmet need and provided easy access to palliative care for people in their own homes.

Analysis of six months of hospice@HOME data (Jan 2015-June 2015) focussed on a cohort of patients who had expressed a preference to die at home but had died in a hospital or hospice one week or less following admission. Approximately 60% of these patients had been admitted for symptom management at end of life, in many cases because access to medications at home had proved difficult, time consuming and distressing.

The District Nurses responded to this issue through the development of the hospice@HOME Just in Case Box (JiCB). This included a package of prescribed medications and related medical supplies, and clinical and non-clinical care during the last days of life through tailored "end of life packages", with additional support of 24/7 telehealth and/or video link to a Registered Nurse via a Samsung Galaxy Tablet. Lay carers of clients prescribed a JiCB also received a comprehensive and individualised, one-on-one education session, provided by trained Registered Nurses, to learn about the safe management of end of life medications using the Caring Safely at Home resources. Collaborative and coordinated liaison with the General Practitioner and the client's other health care providers ensured continuity of care. (Precis from the JiCB Guidelines, September 2016).

The JiCB was designed to provide "all Tasmanians who are assessed as having a life limiting illness and are expected to die within 12 months, the choice to die in their own home regardless of their location, socio-economic status, ethnicity, gender or culture".

The evaluation sought to capture the experience of clients and their primary caregivers, as well as the interdisciplinary care teams involved with the delivery and use of the JiCB, and to explore the following issues:

- What additional 'death' conversations (if any) were had as a result of the Just in Case Box?
- Place of care and death outcomes (hospital admissions or transfers out of the home)
- Issues relating to client and/or caregiver safety and quality of care
- Client, caregiver and interdisciplinary team members' satisfaction
- Was there an experiential difference between whether the box was utilised in the home at end of life or was not used?

Evaluation Methodology

The following methods were undertaken:

- the scope of the project was confirmed and the project plan agreed with the hospice@HOME research manager;
- a Social Science Research Ethics Application, which included background information about the project and consultation documents, was submitted to UniTAS Human Research Ethics Committee (HREC) for ethics approval;
- following ethics approval, the JicB Clinical Project Specialist identified the primary (informal) carer, GP, pharmacist and any community nurses who had attended the client, as well as the hospice@HOME non-clinical coordination nurses for each of the 19 clients for whom a JicB was delivered to their home. The Project Specialist then endeavoured to contact all those so identified via phone and/or email and, where contact was established, request their permission to provide their contact details to the evaluation team. Permissions were collected between 31 July 2017 and 29 August 2017, after which time the cut off period was reached and no further participants were sought. (Note: this permission did not constitute consent to participate in the evaluation, only to receive further information about the evaluation).
- contact details for all stakeholders who agreed to further contact were provided to the evaluation team. A detailed email, plus an Information Sheet and Consent Form (See Appendices A, B, C) were sent to all stakeholders for whom an email address had been provided. Where only a phone number was provided, phone contact was made with the stakeholder; if the phone call resulted in an email address being available, the information and other documents were emailed to the stakeholder; otherwise a letter and the documents were posted to the mailing address provided;
- semi-structured interviews were conducted with all consenting stakeholders;
- this report outlines the findings from the consultations and the recommendations from the evaluation.

Note: Community Specialist Palliative Care Nurses (who were involved with some of the clients in this report) were invited to participate in this evaluation, but no acceptances were received.

Interviews

Consent process: 19 JiCBs were delivered to clients' homes between 17/8/2016 and 1/8/2017. Consent was not received by hospice@HOME staff in relation to 3 clients and/or their carers, so their contact details were not provided to the evaluation team, although 2 GPs and 3 nurses relating to those 3 clients did agree to a general (not client-specific) interview about the JiCB; the remaining 16 clients and/or their carers initially agreed to further contact from the evaluation team, but one then did not respond further:

Of the clients, carers, nurses, GPs and pharmacists who agreed to further contact and were sent an Information Sheet about the evaluation and a Consent Form, 46 in total consented to interview (1 client; 19 carers relating to 15 clients, 17 nurses, 6 GPs relating to 8 clients and 3 pharmacists). Note: 7 clients were still alive at the time of interview but only 1 participated in the interview; reasons for non-participation included insufficient English; being hard of hearing; having dementia; or being too frail. Twenty nurses initially agreed to be interviewed but 3 were unable to find time to do so and one had to take leave for family health reasons; 8 GPs (relating to 10 clients) initially agreed to receive further information but 2 later declined to be interviewed.

Time between delivery of JiCB and death of client or interview date: for the 7 clients who were still alive at the time of interview, the JiCB had been in place between 1-3 months for 6 of them and for 1 year for the 7th person. The JiCB had not yet been activated for any of those clients. For the 8 clients who had died, the JiCB was delivered to their home between 1 day and 4 months prior to death. Timing of the delivery of the JiCB is discussed in more detail below.

Interviews: Thirty-nine semi-structured interviews (see questionnaires: Appendices D, E, F, G) were conducted, with 1-3 participants in each interview, as follows:

- **Client and carers:** 1 client and 19 carers in 15 interviews, 12 face-to-face and 3 by phone;
- **Nurses:** 17 nurses in 15 interviews, 5 face-to-face and 10 by phone (inclusive of direct care community nurses, nurse managers and hospice@HOME non-clinical coordination nurses);
- **GPs:** 6 GPs in 6 interviews, 3 face-to-face and 3 by phone; and
- 3 pharmacists in 3 interviews, 2 face-to-face and 1 by phone.

All participants consented to the interview being recorded and were offered the option of receiving a transcript of the interview; most declined the offer but a transcript was sent to 8 participants who wanted it. Two participants asked for a minor amendment to their transcripts; the other 6 said no amendments were required.

Interview Outcomes

CLIENTS AND CARERS

Clients ranged in age from 49 to 100; seven were still alive at the time of interview, of whom three had dementia. Interviews were held with 1 female client and her husband/carer, plus 18 carers (14 female and 4 male) relating to 14 other clients (10 female and 4 male). Relationship of the interviewed carers to the clients was: wife x 4, husband x 1; partner x 1; daughter x 7; son x 4; friend of the client x 1; and partner of the primary carer x 1.

Not all carers lived with the clients, some lived nearby; one client lives with the carer and her carer's partner at night and on weekends, and in her own home during the day while the carer is at work, so friends can visit (the carer lives out of town).

The person listed as the primary carer was not always the person providing day-to-day care, e.g., for 1 client, her husband provided day-to-day care as best he could but he was unwell and did not undertake the JiCB training; after the JiCB was delivered to the client's home, her son and his wife "went to look at the JiCB and were given an explanation about it" (C2) by the hospice@Home RN who did most of the carer training in relation to the JiCB. In another case, the client's son was listed as the primary carer and although he was providing assistance with financial and administrative matters, the client's wife was providing the physical, hands-on caring and emotional support.

Interviews: The carers (and one client) were invited to give some background to the clients' illness, including diagnosis and length of time that the client had been unwell. The interviews then followed the semi-structured questionnaire (Appendix D), but allowed the carer to tell their story as they wanted to.

Who told carers about JiCB? The majority of carers were told about the JiCB by their GP, one of the hospice@HOME or community nurses who were providing care for the client, or were contacted by a hospice@HOME Registered Nurse during a hospital admission. One carer said "the hospice@HOME people rang me and said that Mum was on the list or whatever and they made an appointment to bring it up and have a chat about it"; another said, "someone brought it to the house" and one carer said that "the hospice nurse arrived with it".

However, one carer actively sought to have the JiCB for the client but faced considerable opposition to this from staff in two hospitals.

I read about (hospice@HOME) in The Mercury and almost simultaneously heard on the ABC Radio that this was a program that was going to be introduced, was going to be trialled, and The District Nurses (sic hospice@HOME) were going to manage it (C4).

The client was in the main city hospital, where the doctor and nurse were insisting, in front of the client and with no prior discussion, that the client could not go home and had to go to a residential aged care facility (RACF). The carer refused and said that the client was to come home and she would look after her. She told them that she had heard about the hospice@HOME program but they insisted that client was not suitable for that. When she asked why not, the doctor said, "Because she isn't" and the nurse said, "No, it's not for people like your mother". The carer explained that, from what she had heard about the program, the client fitted the eligibility criteria. She asked, "Can't we explore whether there's a vacancy." The doctor refused.

The carer arranged for her mother to be transferred to another hospital but again she was pressured to look at 6 RACFs. Eventually, the carer found some respite for the client in a good facility but nothing permanent became available while she was there.

In the last week of respite, I was getting desperate and then I thought about this program again, so I rang (hospice@HOME) and someone came down to see them at the respite centre and it was just wonderful. It was just the best experience, because they said, 'Your Mum can go home. We'll support her' and they did (C14).

Carer understanding/expectations: Some of the carers understood very well the purpose and intent of the JiCB; that it probably would be used by the community nurse but if a nurse could not come, the carer might have to use it, e.g. for pain relief; most were prepared to use it if necessary (i.e., if nurse could not come quickly in an emergency).

We saw the box as being of assistance, to help keep her comfortable if something happened. We didn't see it as going to keep her alive or being used in place of something. It was something we could use if we couldn't get the support we needed (in an emergency) (C14).

Some carers understood that that was the intention but did not think they could use it, and that they would wait for the nurse to come. However, a small number thought that it was only intended for use by the community or hospice@HOME nurses, not for use by them.

I'm not sure that we were authorised to use it, were we? I didn't get that impression. I thought it was here to short-circuit the process of acquiring the drugs, not administering them (C18).

Medical Goals of Care: When asked if the GP had discussed Medical Goals of Care with the client or with them (explained as a discussion about what treatment and/or medications were being or would be given to the client and why that was), a few carers said yes, that this was discussed in detail but most of the carers did not think it had

happened in any formal sense; several said that they were told “in a general way” or “if they asked”.

I did query all the bits of medication and they were all explained to me. Whether it would have been explained to me without the query I'm not sure, because there was quite a lot. There were different things for different things, but they were all explained (C18).

For one carer, the discussion with the GP and other health care providers was extremely helpful; the client's medications had been changed in hospital and reviewed by the GP. The GP and other members of the health care team explained it to the carer.

I know what all the medication is for and why she's on it and what the aim of it is and what needs to be adjusted and changed. The hospital was explaining things to me, the pharmacist was explaining things to me, then the specialist for the pulmonary arterial hypertension explained what medication they're putting her on. The nurse there was able to explain the fluid issues and why and how the medication works (C1).

However, another carer was only given information when the medication was actually required.

I think the doctor thought it was a need-to-know basis but that wasn't very helpful. (On one occasion) I rang the doctor and he mentioned drops in the kit but I didn't know that (previously). And there did start to be reference to the kit, and that's three days before she died (C12).

Timing of JiCB delivery: in relation to deceased clients, the JiCB was delivered to the client's home from 1 day to 4 months before the client died; for those still alive, the JiCB had been in their home from 1 month to 1 year.

Training/Information about the JiCB: Seven of the carers were very happy with the training they received from the hospice@HOME Registered Nurse; in most cases this included being shown the manual and the contents of the bags, and if the carer was willing, having a practice at drawing up the syringe. “It was reassuring and they didn't make you seem silly if you asked silly questions. They were wonderful. I could not fault them” (C15). Three carers also said that they received the tablet which had videos on it showing them how to set up and use equipment. Most were confident at that time that they could do so, especially in an emergency or to relieve distress; in the case of clients who had died, some carers had administered the medication.

Training (to draw up the syringes and provide top-ups as required) was a bit overwhelming at first: We (the carer plus the client's son) were blown away: 'Oh, what do we do? This is all too hard', but once we started using it everything was organised and it worked very well. It seemed complicated until we got started, but it wasn't complicated. The manual that goes with it, the pages are very well set out. It all took so much pressure off us and she was comfortable (C16).

Another seven carers said that they had not been given any training, although four said that they had been provided with good information; one had gone through the manual with the trainer; others had read “the paperwork provided”. In a number of cases the carer was told that when the client reached the stage where the carer might need to administer the medication, the carer would receive more intensive training. One carer commented that this was a good thing, as she would not remember what she was told if it was too long since the JiCB was delivered. Another said, “If I thought it might be getting to there, I would contact them to come and show me” (C3). One carer said:

I don't see myself as using it. I see calling a doctor or a nurse – and I've got that 1800 number and things – and I see them as instigating the use of it and then, if they thought she needed daily injections and there was no one else to come and do it, then they would train me to do that (C6).

A carer who did not live with the client said he was given the bag and asked to put it away safely, although he did look at what was in it. He was told “this is for the nurses if anything happens” (C9). Another carer, whose partner was a nurse, said that she did not receive any training but her partner taught her to draw up syringes.

A “repeating theme” through the carer interviews was that, for some of the carers, when the JiCB was delivered they were already feeling overwhelmed, by the client's diagnosis and prognosis, by the ramifications of that for their own life, and by the fact that they were being inundated with information and paperwork from a number of organisations and services:

When she showed it to us, we were in information overload, my head was swirling with all this and I (was thinking), 'I will not be being responsible for using anything in that Box unless there is somebody here to tell me what to use ... When it got to when things were really starting to ... they would've had to have come back and shown me how to do it (again) (C10).

For one carer, a hospice nurse arrived with the JiCB while the client was actively dying; the carer was in great distress and was in no state to take in anything about the Box.

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Contents of JiCB: In addition to the manual, syringes, medication and other resources, the JiCB Guidelines (September 2016) say that the JiCB contains a Samsung Galaxy Tablet, which includes videos which show the carer how to use the contents of the Box. Only three carers said that they were shown the Samsung Galaxy Tablet; seven stated that they were not given, or shown, it and 6 said that they did not remember being shown one or were not sure if there was a Tablet in the JiCB. Of the three who said that they were shown it, two found the videos very helpful, while the third said that showing her the Tablet was inappropriate as the client was actively dying when the JiCB was delivered and she (the carer) was “in no state to look at the YouTube clips they were bringing up, at such a time” (C19).

A number of carers commented that it would be useful if the JiCB included a monitor (like a baby monitor) to leave beside the client's bed, with the other part near the carer, so the carer could hear if the client called or was in distress. These could be reused by other clients/ carers. Several carers purchased their own.

After hours contact: After hours services in Tasmania have been significantly reduced. Nurses told the evaluation team that none of the specialist palliative care services have an after-hours program for patients. The Southern Region has an after-hours phone service for doctors or nurses but only up until 10pm on weeknights and only until 4pm on Saturdays, Sundays and public holidays. This means that there is a gap for doctors and nurses but an even bigger gap for client and carer access.

The JiCB Guidelines state that, in addition to clinical and non-clinical care, additional support is “provided through 24/7 telehealth and/or video link to a Registered Nurse via a Samsung Galaxy Tablet” (JiCB Guidelines, Sept 2016, p4). hospice@HOME project staff advised the evaluation team that “clients with a JiCB (and their carers) can phone the 24/7 1800 after hours number and activate the box. (Note: the video link was never implemented due to challenges concerning policy adequacy and rigor around its use). The nurse on the 1800 number can liaise with the contact doctor on the nomination form to discuss the situation and determine a plan of care around obtaining drug orders, e.g. for an anti-emetic/narcotic, if the patient is requiring symptom management”.

However, this seemed to be one of the most problematic areas for carers, in particular in relation to keeping the client at home. A carer reported trying to get assistance on a weekend. She called the on-call doctors (a service used by her GP) but no-one came. She phoned back and, having gone through a 15-minute interview the first time, they wanted to go through it all a second time.

I said, 'I've already done that. I just need a doctor to give Mum a sedative.' They're saying, 'We need to take all this information and then we'll call the doctor.' I said, 'Look, Mum is battling me to get out of bed, she's fighting me, she's scratching me. She can't get out because she can't take her weight on her legs and she's going to fall and break something and then she'll be in hospital, which she doesn't want.' They said, 'Well, it sounds like you've got to send her to hospital, we'll send an ambulance.' I said, 'Mum is not going to hospital!'

The carer hung up and rang another on-call service and a doctor came, but he also insisted that the client needed to go to hospital 'to do all these tests'.

I said, 'Mum is not going into hospital'. He said, 'What is the point in calling us if you don't take our advice?' I said, 'Her doctor and I have agreed she's in a palliative care stage'. He said, 'Palliative care for what? What's wrong with her?' (C6).

Note: This carer did not mention calling the 1800 hospice number that all carers of clients with a JiCB were given; it is possible that, had the carer done so, there would have been a more appropriate response.

However, calling the 1800 hospice number did not always meet the carer's need:

One night when (the client) was in a really, really bad way, I tried to get onto his GP, I tried to get an after-hours doctor, too. I tried (the 1800 hospice@HOME number) and I spoke to somebody and they said, 'Try such and such and if you don't get anyone there come back to us,' which I did. But when you've got somebody who is really not well, having to make six phone calls ... I don't find it beneficial. I'm used to knowing that I'll just call the doctor or ring an ambulance or drive in to Emergency (C10).

After experiencing the difficulties and stress with the after-hours services outlined above, this carer decided that the client needed to go into hospital-based palliative care.

A carer who phoned “the after-hours number that they give you” (C15) when the client's haematoma was pouring blood, got a recorded message, which she found frustrating. “Somebody did eventually come on but it seemed to take forever and this blood was going everywhere”. Afterwards, the local community nurses told her that if she needed to phone the after-hours number again, to ask to be put through to them, which she did. “I just knew to ask for them and they came around” (C15).

The after-hours service was also not responsive when a client died at 4am. The carer phoned hospice@HOME "but no one came and no-one phoned back" (C11). The client had a syringe driver and an in-dwelling catheter and although the carer had been giving the client injections, she was too distressed to try to remove these. When the carer's partner, a nurse, returned from night duty 5½ hrs later, she had to turn off the syringe driver and remove it and remove the catheter. The carer's partner said "it's not appropriate for the carer to have to do that. It was barely appropriate for me to be doing that (as a member of the family) but it had to be done" (C13).

Place of care/death: Of the 8 clients who were deceased, 6 died at home, one in a residential aged care facility where she had previously been for respite and where she knew and liked all the staff, and one in a palliative care unit. Both clients who did not die at home were able to stay at home until very close to the end of their lives. Most of the clients had admissions to hospital during the course of their illness; in the majority of cases this was for major treatment, not just for symptom management.

She didn't want to go to hospital; she wanted to die at home. Even when the nurse and the doctor came to the home, she sat straight up in the bed, pointed her finger and said, 'I am not going anywhere. I'm staying right here' (C9).

JiCB Activation: Five carers said that the JiCB was activated, 2 by community nurses, 2 by hospice@HOME nurses and 1 by the client's GP; in 4 of these 5 cases, the nurse or GP set up a syringe driver, which was topped up as necessary by carers, by the carer's partner who was a palliative care nurse and by a nurse friend of a carer. In each case, activation occurred close to the time of death, although hospice@HOME project staff confirmed that it was not intended that it be restricted only to time of imminent death but could be activated in an emergency for symptom control. Several carers said that the community nurses "labelled everything so they knew what to use and when" (C15).

A carer described what happened when one of the community nurses activated the JiCB on the day the client died:

He'd been lying on his back for some time. I'd managed to get a sheepskin under him beforehand but I knew that if he wasn't turned he'd end up with (a pressure ulcer) ... because he was so thin. I wanted to turn him and the (personal carer) was here. The community nurse came just as we were trying to move him. I lifted his leg to put it over the other one so that it would be easy to roll and he cried; it must've been so painful. The nurse came into the bedroom and she said, 'Oh, it's enough,' and she went into the kitchen, to the (JiCB).

She telephoned the doctor and he presumably gave her permission and she came and gave (the client) an injection. We waited (until he was comfortable) and then we were able to turn him (C17).

Best part of being the carer: For the majority of carers, the best things about that role were: having time with the client; the closeness (in some cases closer than when the client was well) and the relationship; the togetherness; doing everything for the client; giving the client the care she needed; getting to know the client at a deeper level; it was a privilege; knowing that the client didn't have to go to an aged care facility or into hospital; that she got her wish and died at home.

Some clients were able to express what they felt towards the carer in a way they had not done previously:

At the moment, he realises that he needs me and he tells me, every half hour probably, 'I love you and I can't live without you' (C3).

I don't know how many times she said to me, 'I wouldn't be here without you' (C12).

I was able to do things for her that she'd done for me all those years ago. She really appreciated it so that was nice, to have that appreciation (C11).

One carer said that the best part was:

Being able to support her. Being able to return some of the support that she gave me. Being able to help her through this, being her advocate - being able to do that for her (C14).

However, for one carer, the client's physical needs were very difficult to deal with, and she said, "there wasn't a best part" (C10).

Most challenging part: Challenges of being a carer included: dealing with the client's dementia; the time demands when carers were still working full time or had other family commitments; dealing with the after-hours doctors and 'others who won't listen'; showering the client; needing to be available 24/7; incontinence issues and smells; and difficulty getting adequate care.

Several carers were glad to be able to keep the client at home, because that is what the client wanted, but it was a big burden, especially if the primary carer did not live with the client; they would be called frequently throughout most nights, by another family member or a personal carer doing "an overnight sit", to come and assist the client. Others did not find the physical demands too challenging (i.e., dealing with the illness-related needs or doing the cooking or cleaning) but some clients were very demanding and thought they were entitled to have the carer do everything for them. For others, it was dealing with

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the client's depression. One carer's son had been providing most of her care and his major challenge was to relinquish that role and allow others to do more when the care needs increased, even though he understood that it was necessary. Receiving the JiCB was the main challenge for a carer because of the sense of finality that it implied.

One client had had a stroke and could not remember anything about it, which the carer found challenging. Some carers found the role of advocate challenging, e.g., when they "had to fight very hard at the hospital for the client to receive appropriate tests and care, and not be immediately discharged" (C14). The physical strength required to care for a large, male client caused his carer some concern, as she was afraid that if he fell she would not be able to get him up. For a carer who had never cared for a dying person before, not knowing what to expect was the biggest challenge e.g., weight loss, the changing skin colour, even though she had the nurses, the hospice team, to guide her and "they were absolutely fabulous" (C16). Constantly being alert at night was a major challenge for one carer:

night time when he said he wanted a pee and (me) being deaf, worrying about not hearing him (which increased her anxiety). But I was getting quite nimble at getting out of bed and then getting around to his side and helping him (C17).

Informal support: Only one of the carers said that she received no informal support from family, friends or others in her community; the majority of carers had occasional assistance, or just visits, from other family members and four carers shared the care with other family members or their partners, which allowed the carer some time to do other things when needed. Three carers had friends (of theirs or the client's) who visited regularly, and some brought meals, but one carer was disappointed that members of the client's church community did not offer any support; by contrast, one carer received both emotional and spiritual support from the female Anglican priest from her church.

Three carers, who were sharing the care of one client, had to deal with the fact that the client did not want anyone else to come and visit her; because of the client's previous experience of relatives trying to take over; they had to make excuses to put people off.

A carer described the situation of a client whose three friends visited her continually right until she died.

At the end, she really didn't look very good and her best friend was very upset about that. But when she passed away everything sort of went back (to how she had looked before she became very ill). It was amazing. I was blown away. I rang her best friend and said, 'Please come back' and she was so thankful that she did, because (the client) looked lovely (C16).

In an excellent example of informal support, a carer had set up a support team of friends, which included nurses and other people who were comfortable with terminally ill people.

We had a crew of people so in those last few weeks we had someone with us 24 hours a day. In our friendship group, we had a roster, so from the time she went into hospital – it was probably (from) about two weeks before she died (right up) until she died - I had someone with me (C19). (The client died at home, a week after coming home from hospital).

Formal support services: The majority of clients and carers had Registered Nurses from non-government funded and state-funded and, in some cases, private nursing providers, who attended on an as-needed basis, depending on the client's condition. This ranged from Community Nurses phoning three times a year while the client was well to once a month as the illness progressed, to visiting several times a day towards the very end. For one client, the Community Nurses would sometimes call in for half an hour just to check in on the client and have a chat with her, which the carer was grateful for. Other formal services included an oncology nurse, foot care nurses (not podiatrists), and for one client pathology services came to the home as required. One GP visited every six weeks, others came if needed. However, for one client, the carer said that the GP "didn't have a clue" and it was the Parkinson's Disease specialist who came to the client's home 7 weeks before she died and had a meeting with the carer, and the client's son. He said, "She needs a hospital bed in today. She needs to get into bed and not get out of bed" (C16). They had not realised that she was so close to the end of her life.

Most of the clients also had Home Care Packages or Community and Home Support Program (CHSP) funding, which provided for a personal carer; this ranged from 2-3 times a week to an hour a day for a bed wash or showering, plus in some cases, 1-3 hours a week to do some housework. In one case, because the carer had no informal supports, hospice@HOME brokered extra personal carer hours. Carers said that the quality of the personal carers was variable but most were good. One carer paid privately for a cleaner, a gardener and a cook, who also did the grocery shopping; another carer paid for 5-6 personal carers for 24/7 care.

A problem identified by a carer was that, if a personal carer was sitting with the client overnight (the primary carer did not live at the client's home) and the client needed medication, the personal carer would have to phone for the carer to come to the client's home, because the personal carer could not give medication. This meant that having a personal carer to sit with the client overnight, especially in the last week or so, was not as helpful as it could have been, as it

did not allow the carer to have a full night's sleep. Another carer, who was a retired nurse, found that many of the personal carers were kind but did not have adequate skills for even basic tasks that needed to be done, so she had to do many of them herself.

One of the carers has a number of medical problems and she gets four hours respite once a week, which allows her to go to her own medical appointments and/or have required tests, or go to the dentist. She also uses the respite hours to do the client's grocery shopping.

Advantages of having JiCB/Carer satisfaction: For many carers, the biggest advantage of having the JiCB was that it helped to ensure that, except in extreme cases, the client would not have to go to hospital, and that they could achieve their wish to die at home, or at least, stay at home as long as possible. Carer C6 said: "I gather that a lot of people end up going into hospital at the end of their life purely for pain relief and other things ... and I wouldn't want her to do that". One carer said that it dramatically increased her ability to care for the client.

It just made everything flow well. Nothing was hard. No way could (the client) have stayed at home without (the JiCB and hospice@HOME). No way (C16).

Also frequently noted as an advantage was having the equipment and medication available at home and not having to "run around" to access it. This was considered an advantage even for those carers who did not want to use the JiCB themselves, but who found it reassuring to know that they can phone the nurses and when they come, what they need is there.

The issue of the client and carer being in control, being empowered and having independence was seen as a particular advantage by many carers, as was peace of mind from knowing that what the client might need was on hand. This also reduced carer anxiety.

The hospice nurses were wonderful. (We were) able to negotiate with them to provide all the things that we needed to look after him here, like the hospital bed. The fact that people approached us made it so much more simple (C17/18).

For those carers who did administer top-up pain medication, they were able to witness the relief that it provided to the client, including by reducing agitation and discomfort. This was enhanced when the carer had practiced drawing up the syringes under the supervision of a nurse or, where the medication was drawn up by the nurse, labelled and left in the fridge for the carer to use.

Talking to others about death and dying: Some carers said that having the JiCB helped them to talk about death and dying with family and others but most had already discussed it before they received the JiCB.

Did the JiCB contribute to carers ability to care for client? In relation to the clients who had died and for whom the JiCB had been activated, most of the carers said it had contributed significantly to their ability to care for the clients; another carer said that the client "had a beautiful death" – and the training she'd received included what to do after the client died:

I just went into organisation mode and did what needed to be done, and then she started to look so peaceful and lovely. We didn't rush; we didn't rush her going. One of the nurses came - I had done what I needed to do with her arms and made sure she was straight - she checked what I'd done and it was lovely. We didn't rush the undertakers or anything like that... and we made her look lovely. It really was a great experience (C16).

Where the JiCB had not been activated, it seems it had not contributed to the carer's ability to care for the client, because it was locked away and did not need to be accessed. However, it did reduce fear and anxiety. The carer of a client who was still alive said "it hasn't yet but it's comforting to know that she has got access to pain relief and so forth if she needs it" (C1).

Concerns about safety of having JiCB in house: Most of the carers did not have much concern about the safety of the contents of the JiCB but only told people on a "need to know" basis that it was there, i.e., some family members and the community nurses.

Advance Care Planning: Twelve of the 15 clients had undertaken Advance Care Planning (ACP) in some form, ranging from appointment of an Enduring Guardian and completion of an Advance Care Directive to a statement "attached to the fridge" stating that the person did not want resuscitation and did not want to go to hospital. The carer of client who had not undertaken ACP had been prompted by her caring experience to do her own ACP.

Returning the Box: Several carers were unsure about what they should do with the JiCB after the client had died; most contacted hospice@HOME and were advised to take the medication out of the bag and take it to their local pharmacy or to their GP for disposal. In most cases the Bags were collected by hospice@HOME or returned by the carer to the hospice@HOME office.

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NURSES

17 nurses were interviewed, 11 in relation to specific clients and 5 who were asked to think about their involvement with the JiCB project generally but not to specifically mention any client as consent had not been received from the carers of the clients they attended. Some of the nurses had management roles in their organisations, rather than direct contact with clients or carers; they discussed organisational issues relating to the JiCB and/or what front-line staff in their organisation told them about their direct involvement with the JiCB. Their comments are provided at the end of this section.

Below are the comments from nurses who worked with the client and their carer/family, interacted with the client and carer when the JiCB was delivered and/or activated the box in the home; in most cases these comments are about the nurses' experiences of the JiCB in practice.

What is your understanding of the JiCB project? Most of the nurses understood that the JiCB provided equipment, medications and other resources that were kept securely in the client's home, to be available without delay if and when the client deteriorates, for use by nurses or the GP, or by the carer if health care providers were not able to attend the client. "I suppose it's a safety, a security, a reassurance measure, especially for out of hours when there is limited services" (N3). "It's just something extra ready in the home 'just in case'" (N9). "It's to keep them in their own homes – at any time, not just at the end of their life – any time to keep them safe, pain free" (N12). "(It) gives them the option to manage their symptoms at home independently" (N14).

A hospice@HOME Registered Nurse said that the JiCB assists with "planning ahead for any patient who says that they want to die at home or even that they want to be at home for as long as possible. Whether that happens or not is irrelevant" (N17). She noted that, in relation to carer training, carers of someone who is terminally ill but whose symptoms are well controlled do not always see the relevance of the training but would receive additional information and training if the client's condition deteriorates.

A nurse who works in a somewhat remote location found that having "standing doctor's orders that we can use" particularly helpful because "we don't always have access to palliative care doctors and nurses and, with a signed and dated medication chart, we can access [the medications]" (N2).

One nurse described the JiCB service as follows:

It's around having medications available in the home just in case someone may need them. It's also around educating carers, family members and the client themselves around the medications. I'm also aware that 80% of people present to an Emergency Department because they're in pain. So, having that Just in Case Box in the home prevents those Emergency presentations and it also provides end-of-life care for people that require it (N13).

Another nurse did not know, before going to the client's home, that the client had a JiCB, and did not know very much about it at that time. "I opened the packs up to have a look inside but ... didn't use anything out of it" (N7). The nurse has since found out more about the JiCB and would now be more inclined to utilise it. One nurse did not have any understanding of it at all, and did not know why she was being interviewed. (Note: this was a nurse from a private nursing agency who had only attended the client overnight on one occasion).

How did you become involved in the project? The majority of nurses were advised about the project through hospice@HOME ("Just in Case Boxes were talked about for a couple of years leading up to the implementation of them" (N7)); or from information sent to them, or their service, from hospice@HOME. Some became involved more directly when one of their clients was provided with a JiCB. In one case, a client's daughter (who had lost her husband some time before) "was fully aware of the Just in Case Box and she had been very proactive and set that up" (N2). This nurse said that there was a lot of information in the Health Centre where she worked, including contact information for hospice@HOME. In addition, "I remember somebody coming (to the Centre) with a big box with all the information and it was talked about: where it was going and that this client had consented" (N2). Another nurse said that she was aware that there was a JiCB available for people to look at but she could not do so because it was not in a location she could access.

How many patients in your care received a JiCB? Most of the nurses had only had one client that they were directly involved with, although some of the nurses were aware that other nurses in their organisation had also had clients with a JiCB. One nurse had had three clients with a JiCB; one is still alive and for two who died, the JiCB was not activated. One nurse did not actually know that the JiCB was in the client's home and only found out when another colleague mentioned it after the visit. A nurse said that she had "some" clients with a JiCB but it has not yet been activated for any of them.

Some nurses expressed concern that they were not informed when their clients received a JiCB. They understood that the GP had to

authorise it, but they only found out when they went to the client's home. "They usually just told us: "We've got this box there. We've got this thing there" (N5/6). On one occasion, when they visited a client who had a JiCB, they asked the client if they could see what was in the JiCB.

The bags were well laid out. They had quite a lot of good things – good equipment (the manual) and laminated sheets on how to give drugs, hook them up, which we would be assisting with if we were in there, so there's no problem from that end of it (N5/6).

Did you talk about the JiCB and what was in it to clients or their carers or anyone else? Four of the nurses had discussed the JiCB with clients, carers, GPs and colleagues; two had discussed it with team members and other colleagues and one nurse had discussed it with the client and other colleagues. Six of the nurses had not discussed the JiCB with anyone. One nurse who had discussed the JiCB with colleagues but not with the carer said that, in hindsight, and knowing that the carer did not use the JiCB, she would definitely have that conversation if a similar situation arose in the future:

Maybe get the box out and go through it with them; talk to them about it; see how they feel; can they draw up something? Whether they want to; whether they're confident enough; if they're not, who would they call (for emergency back-up)? That sort of thing (N1).

Another nurse said that, although she has not discussed it with anyone she is very confident to do so, including about the medications in the JiCB. She noted: "As part of the after-hours process, all RNs or people who work after hours had to do the education around the Just in Case Box" (N13).

Do you usually talk to clients, carers and anyone else about the Medical Goals of Care or Advance Care Planning? All of the nurses said that they talk to clients and carers about Advance Care Planning. Comments included:

- I encourage people to do ACP. I think they actually have a sense of relief that somebody's talking about it, because a lot of people have a little bit of fear of the unknown and, just by talking about it, it's comforting.
- to clients, carers and extended family. We had an information session about how much it does impact on having some say in what they want. (She noted that it reduces family friction). Some GPs don't believe in advance care directives. You ask for them to do a Goals of Care: "No! Why would they need that?" They're very indignant about it all. Everyone has to support to make it work.

- I especially talk about advance care planning with someone like this particular client, who wanted to die at home, (in a remote location).
- It's really important, especially with end of life, that we understand that people have a Medical Goals of Care or an advance care directive within the home and that we're aware of it. We have copies of those within our documentation for our hospice@HOME clients.
- As part of our admissions process, we have an advance care directive that we leave with clients. We ask them if they have one. If they haven't, we ask if they would think about one. We describe it; we leave some forms. We follow up in three months. We maybe offer more support if they don't fully understand it, who they can talk to, but we strongly encourage people to have an advance care directive.

Several nurses said that they discuss both Advance Care Planning and Medical Goals of Care, especially with palliative patients.

Did participating in the JiCB project encourage you to talk more about death and dying, with clients, carers or anyone else? Five of the nurses said that having the JiCB in the client's home encouraged them to talk more about death and dying, to the clients and carers and to others; another nurse said that, while it didn't in her case she could see that it might help some people to do so.

For one nurse, although the client and carer were very open and articulate about what they wanted and how they felt, having the JiCB in the house did prompt the conversation. "It's like having another person in the house; it's going to help you. I felt like it was a good opening to conversing with people" (N1). Another nurse said she talks to clients about it as "your insurance policy. You hope you may never need it but, if you do, it's there. There wouldn't be any need for panic" (N3).

When a nurse had the initial discussion with the carer about the JiCB, the carer took the nurse into another room because she did not want the client to listen to them talking around death and dying, "she didn't want to upset him. But she was definitely upset herself in the face of having to talk about his mortality" (N4). The carer is determined to keep the client at home right to the end, even though they are a long way from support.

(The JiCB) opened up the conversation but she needed time between the issue being raised with her, thinking about it, talking to her daughter about it and then coming to the agreement that, yes, that would be good in order to keep him at home (N4).

Interview Outcomes

One nurse noticed that, because of the project, some of her colleagues:

have become familiar with talking more about death, dead, dying – all those types of words – where in the past it's been ... not taboo, but always in the background and people have struggled with talking about death and dying. (However) you have to know when people want to talk about it. (Use your judgement, based on experience). You can't just go in and speak (about death and dying) to clients or carers, or even staff at different times, and be a bulldozer (N13)

Nine nurses said that the JiCB did not encourage them to talk more about death and dying, mostly because they had already done so before the JiCB was delivered to the client and carer. Several said that they judge each case and talk when the person is ready to. One of these nurses, who works for hospice@HOME, said that talking with clients and carers is the main objective of any discussion. However, "in this situation, it made it even more difficult" (N14) (See comments in Case Study 3).

JiCB Activation: While only five carers said that the JiCB had been activated, eight nurses reported that it had been. (This may be because some of the nurses who were interviewed had supported carers who had not agreed to an interview). In most cases it was the Community Nurses who activated the JiCB, usually in conjunction with the carer, in response to signs of pain and discomfort from the client.

Once I became aware that the client needed some relief I went to the client and I suggested that they activate the JiCB. He had a very rapid demise – between 24 and 48 hours. What triggered the activation was the urgent call to me that he was going downhill very fast (N11).

As hospice@HOME is a brokered care model, they can broker other external nurses over and above the client's community services "and we've been able to send nurses out to activate that because the Box is already in the home" (N13). A JiCB had been activated successfully to keep someone out of hospital.

Advantages of the JiCB for the client and the carer: Most of the nurses identified many advantages for both the client and the carer, including: taking away fear and anxiety, and providing reassurance and peace of mind, knowing that everything is there that might be needed; immediate access for comfort of uncontrolled symptoms; keeping clients comfortable in their last days and hours, which gives everybody comfort; providing back-up, especially in remote locations if a nurse can't get there quickly. A major advantage for many clients and carers is that they know it will help to keep the person at home

and prevent them having to go to hospital. Several nurses spoke about giving control to the client and the carer:

It gives them the power or the control; it's available for them to use. The whole thing belongs to the client. The drugs don't belong to an organisation, they belong to the client and it's basically their responsibility that we can access them (N2).

For the client, it probably gives them the feeling of being in the driver's seat as well. Quite often in health care, patients ... (are) not really informed, not in control of their own health. I think the Just in Case Box provides consumer-directed care. For the carer, it decreases their stress level to know that there's something there, in case. It's really important that carers have an understanding and feel part of the process. I'd say both the patient and the carers feel empowered, because they received the education, they have an understanding. I think GPs probably also – who should be at the heart of these patients' care – feel an empowerment, because they're involved, too, with the Just in Case Box (N13).

Nurses noted that the information provided with the JiCB, including the contacts for who to phone if they have any questions or if they're worried about anything, were major advantages for both the client and the carer: "If the carer isn't aware of things they can go and look at all the information" (N9).

When one of the clients died, about a week after the JiCB was delivered, his wife said, "That was the best death." The nurse thought part of this was that, for the carer, everything was contained and no-one tried to insist that he should go to hospital "because she had everything there". However, the nurse thought that other factors, including having her pastoral care person there, not only the JiCB, also contributed to what the carer saw as a good death. "I think things just worked for her as she had perhaps envisaged that they would" (N17).

A nurse gave an example of the challenges of not having something like a JiCB:

A couple of weeks ago, I went in to a lady who was actively dying and it would've been really nice to have had a Box in her home. I had absolutely nothing to give her – no medications, no supplies, no pads, anything like that. It would've been absolutely ideal to have something like that in the home (N7).

Four nurses did not see advantages for the client or carer in having a JiCB; one said that, rather than reassure clients "it would probably make them more nervous actually" (N8) and another nurse said:

I've been providing palliative care (in this location) for 17 years and we have a very good system with lots of good support in place, so I don't see that the JiCB really adds a lot for the client and the carer (N11).

Advantages of the JiCB being there, for the Nurse: Advantages for the nurses included having everything available when needed, which is practical, convenient, efficient and saves time and paperwork, at any time including at night and especially in an emergency. It also means that the nurses can access drugs without having to carry them

because there's all sorts of legal implications about carrying the drugs and the storage of the drugs and how we handle the drugs. ... It was all there, ready to go. A contained box with everything, right down to syringes, the order; it's all very convenient (N2).

One of the nurses said that, with other services now being very limited (e.g., after hours) "we can't just say, 'I'll whip around and get you some morphine or midaz from the chemist (N3). To have the JiCB there with everything prepared is "a huge advantage for nurses" (N3). A nurse described it as "a rapid, wrap-around response to symptom management" (N13).

Everything is there and is set up (although the nurses) still have to get the exact order from the GP at the time of implementation, because they can't be sure what the needs might be – drug dosages and things like that. The drug chart's there. All they have to do is do the faxing and things (N4).

(One nurse said): if there was an emergency, you could open the box and give the GP a call and say, 'I need to use this now. Is that okay?' You wouldn't have to wait for a prescription and go to the pharmacist or whatever. It would, both, save time and suffering for the patient, wouldn't it? (N7).

Another advantage for one nurse was not having to see her client in pain at all. "It was quite relieving to know she wasn't in pain" (N12).

In one case, to activate a JiCB for a patient, "it was just a matter of phoning the GP and saying, 'I'm with this lady and this is happening for her. What do you want us to do?' They just used subcut breakthroughs initially, but they did start a syringe driver within 48 hours (N17).

For another nurse, the advantage related to drawing up extra or stronger doses if there was already a chart written up by the doctor: "If she's in this much distress, give an extra amount of this" (N9).

One nurse did not feel comfortable with the JiCB. She said that if Palliative Care are involved they would usually have everything set up (N8).

Concerns about safety relating to the JiCB having Schedule 8 drugs in it: Most of the nurses did not have concerns about safety in relation to the clients who had the JiCB; "There always has been storage of (Schedule 8) medication in people's homes ... and only a

small amount of Schedule 8 medication is actually prescribed" (N4). Some of the nurses said that there is always a risk but in this case it is a minimal one and it is "less with the JiCB because the drugs are in ampoules and kept well out of sight" (N5/6).

A nurse who did have concerns about her client said: "Yes, there would've been issues in that home, I think – the family dynamics - and the client herself was quite concerned about some things with even her own son" (N7). All agreed that you have to assess the situation in each household and "if you have any issues you just ask if the family are alright with it. Some of them you do have to be a bit careful but, in their own home, what else can you do?" (N12).

If we were concerned about anyone in the household that would be accessing drugs ... as part of our admission procedure we asked the family to consider installing a medication safe to keep the medication in. (If funding for that was an issue) it could come from the client's Package; ... so that there's safety for the client, family members and safety for our staff (N10).

One nurse thought that everyone should check that everything was there but another nurse said:

We have been told we are not to worry about things like [that]. We used to count drugs and sign sheets and we've been told that that is not necessary anymore; they are the clients' worry. So that goes against all my training and feelings but that's the new procedure, so I would not worry about it because I don't have to worry about it (N8).

Key issues that were faced by the client and their carer before they got the JiCB? Key issues included: controlling pain; addressing fears and concern, anxiety and stress (of clients and carers); making the client comfortable; trying to tap into someone quickly; COPD, arthritis; panic because the client couldn't get her breath; that the client would have a comfortable exit; frailty; admissions into hospital; client not eating or more tired. "Physical symptoms: shortness of breath and the fact that he was really, really weak and he found it hard to even get up to go to the toilet. He was completely exhausted" (N11). "(Relating to several clients) – symptom management, medication access, people being short of breath, vomiting, dribbling – all those types of things that medication within the Just in Case Box is designed to ease" (N13).

Concern that if the client deteriorated, you would have to phone the hospice@HOME RN, get the GP involved, do all the runarounds and wait until you get an order or wait until you hear back [as to] what you needed to do for the client. It'd be a lot of time management issues. If it was late at night, where would you get that extra medication? You'd have to wait. Meanwhile, the client would be in distress (N9).

Interview Outcomes

For a client in a very remote location, who wanted to stay at home “not knowing what will happen if (the client) does deteriorate. What do they do? Do they have to pack up and go to the hospital?” (JiCB alleviated those concerns) (N4).

Another client knew she was deteriorating, her mobility was problematic, she had generalised pain and there was “constant dialogue with the GP around appropriate analgesia and medications” (N10). Her primary carer was her husband who was old and frail but “tended not to want to use any of the equipment” that had been provided for the client (N10). The client tried to maintain her independence as much as possible so she wasn't relying on her husband.

Problems relating to after-hours services: Many of the nurses reported problems relating to changes that have been made to after-hours services, which are now severely restricted, and stressed the need for hospice@HOME to continue the excellent care that the service has provided to palliative care patients, particularly after hours. Nurses reported that there is no longer an after-hours palliative care service available to patients, neither in person nor by phone. There is an after-hours advice service available to doctors and nurses, but only until 10pm on weeknights and from 10am – 4pm on weekends and public holidays. In addition, most GPs in Tasmania are not available after 8pm, although there are some who provide the carers of their terminally ill patients with a number for emergencies.

Some of the community nurses said that their service does not have staff available after 9pm, although at least one service does have an after-hours number. In some cases the only after-hours option for carers of terminally ill clients is to phone an ambulance and have the client taken to hospital, which will inevitably lead to more Emergency Department visits or hospital admissions ... (with the risk that) people at end-stage of life ... could be ramped up for (many) hours. On a trolley, it could be 24 hours. Apart from the cost to the client and families' emotional health, the cost to the government is going to be hugely more (N5/6).

Did the JiCB contribute to the quality of the palliative care the client received? Six nurses (3 whose clients had the JiCB activated and 3 where this did not happen) said that having the JiCB contributed to the quality of the palliative care the client received, “especially for night time when things are not so accessible” (N17). Where the JiCB had been activated, it did contribute to the quality of palliative care because the nurses are “able to settle someone's symptoms without sending them straight to hospital” (N17).

Having that box there was just providing her with the ultimate in respect and dignity. And it contributed to the quality of the end-of-life care she received (N12).

The carer had the Just in Case Box ready to go. We could walk straight in there, grab the Box and, while I was drawing up the morphine, I was also talking to (the GP by phone). She was saying, “Give this amount; do this,” and just clarified (everything) (N2).

Where the JiCB had not been activated, the contribution seemed to relate more to the feeling of security that it engendered for both the client and the carer:

One nurse said that she did not think that the JiCB had contributed to the quality of palliative care the client received. Although she acknowledged that having the morphine and midazolam readily available helped to address the client's shortness of breath and make him more comfortable, she said “I don't see that it contributed to the quality of palliative care” (N11). This nurse said that in that location the community nurses offer 24/7 care and were “able to help people before we got the Just in Case Boxes” (N11).

Other benefits that the JiCB provided to clients and carers: Nurses identified other benefits, including: practicality and comfort, peace of mind, having the backup; reassurance that the client won't suffer; that they've got something there; assisting clients to remain at home, not only longer but for end of life; not having to “run around to a pharmacy, get scripts, it's there for them” (N7); and having everything on hand, including mouth swabs and continence pads.

Did having the JiCB there help that person to die at home? For those who had died, four nurses said yes (N1 said “absolutely”) and one client only went into care “to relieve her husband of the burden of care” (N10). Three nurses said no: two said “because we do all that anyway” (N5/6) (but they acknowledged that the JiCB has more resources than they have); the other nurse said “No, the client just urgently needed a syringe driver inserted” (N14) (see Case Study 3).

Comments nurses received from the carer or the family about whether it was a good death? Four nurses said that the carer/other family members had told them it was a good death. “When you can keep someone at home, it is a good death, if that's their wish, and the family really appreciated it” (N13).

(The carer was) very grateful. Once we'd administered that first drug, he just went to sleep and became comfortable straight away. Once she saw that, she was fantastic. She was very stressed before the death but, to see her manage it, she did really well (N1).

“It was a good death, a definite good death. (Her daughter) came in personally to speak to us afterwards and to thank us about everything that had happened and was just over the moon” (N10).

The community nurse involved in Case Study 1 said:

It was not so much that the family told me but I thought it was an absolutely wonderful death. The family told me they were very grateful for my assistance. He was able to be in his own bed with his window open to the beach listening to the waves. He had the music he liked best. He had his dog on the bed and he had a loving family around him. I thought it was absolutely the way most people would want to go (N11).

How was the JiCB retrieved or returned after the patient's death?

Most of the nurses said that hospice@HOME asked the family to take the medications to their local pharmacy; in some cases the nurses took the bag and returned it to hospice@HOME, in others the carer or family did so, or hospice@HOME staff picked it up when they do a bereavement visit.

When is a good time to get the JiCB, at what point in their palliative journey? What's too early? What's too late?

Most of the nurses said that it has to be assessed case by case, on an individual basis but the majority agreed that early is better than later – and even that “too early is better than too late” (N4), with some suggesting it should be when the client is considered to be at the palliative stage. “Trying to find the optimum time is kind of a judgement call, isn't it?” (N14).

It's no good if it's too late, is it? You'd have to get used to it being in the house so I'm not sure how you do time it, whether (it's when) they've had a discussion about not wanting to go to hospital and symptom control. If it's too late it's too late. They've got to get used to it and then revisit what it's used for multiple times. If it's too close to the end then the carer's already so stressed that they're taking less on board (N3).

It has to become part of the household furniture, not just rushed in last minute. It has to be discussed regularly and (the clients and carers) need to feel confident with it obviously (N14).

It all ought to go in at the beginning and be set up and be there. Who knows what could happen on a Saturday night right at the beginning? Everybody's different. If it's “just in case”, then it needs to go in “just in case”. Once they're diagnosed and everything's happening then put it all in there. It doesn't have to be opened (unless it's needed). (Agreed carers would need regular “refresher training”) (N8)

There was some agreement that if the JiCB is delivered early in the client's palliative journey, it would allow the carer to go through the information several times if they want to, and/or watch the training videos. However, some nurses were concerned that “if it was brought in too early it may actually [cause] people to think, ‘Oh, no,

she's not going to live that long’ (N9). While one nurse agreed that the JiCB should be provided early in the process she cautioned that the syringe driver should not be activated too soon.

Concern was expressed by a nurse that there was some restriction from the specialist palliative care services that a client has to be at a certain level on the palliative care rating scale before they can be considered suitable for a JiCB. I think that is really wrong. Everyone should have access and it's not around being a category, it's around what's required for that patient at that time (N13).

Final comments from nurses: Nurses were invited to add any additional thoughts or comments that they had about the JiCB project.

I think the whole concept is really good. It takes a lot of pressure and organisation off my job, knowing that it's there. (The JiCB) legally allows us to have all those resources and medications ready at hand (N2).

The Just in Case Box is perfect for people in remote locations, because it is difficult to access drugs when you need them and the whole point of the exercise is that people's symptoms are well controlled in a timely and appropriate manner. (However) I have had difficulty, barrier after barrier, trying to implement Just in Case Boxes in (the city area). (Possible reasons: more time needed to establish on-going relationships with other services; medications are easier to access in the city areas; misperception by some services that ‘We do this already’ but the JiCB ‘is more than just end-of-life care, it's a carer education program for caring safely at home, with a standardised guideline for teaching people at home to administer medication. Everyone just does that on an individual basis, all differently, so that I think is something that is not done well’) (N4).

A nurse noted that, for the JiCB to be truly effective, the nurses - not just the clients and/or carers - need some training and familiarisation with the contents. “Nurses (from any service involved) also need to know whose homes (the JiCBs) are going into (N7).

Barriers to providing the JiCB identified included: some GPs, who need to prescribe the JiCB, don't see the need for them; and some of the community or palliative care or private nursing services think, “Well, we do that already;” but don't necessarily provide the resources that empower carers, including the training manual and Samsung Galaxy Tablet.

From my understanding, I think there's things in them that would be very worthwhile for a lot of people that we don't actually do now (N7).

Interview Outcomes

One of the nurses suggested that, rather than the resources being in zipper bags with plastic locks, "they need to be in a big box with a lid that you can open up and see what you've got, just like a syringe driver box, (so you could) get it all out and spread it out and see (what's there) (N8). Another nurse thought it would be helpful if the JiCB included a broader range of medications, for example an intranasal spray, such as a fentanyl actuator, for emergency situations where a client is "shutting down" and in great distress.

There appeared to be some confusion among the nurses about whether or not they needed to phone the client's GP and obtain a doctor's order before they accessed and administered the contents of the JiCB. It seems that some GPs had provided a drug order with prescribed dosages and others had instructed that the nurses should phone them for confirmation before administering the medications. For one nurse, the "drug chart was there, signed and indicating for use at end of life" but she still called the GP "because I wasn't really quite sure and it was during the day and it just clarifies what I'm doing. You wouldn't want to do anything that would jeopardise your registration" (N2).

Comments from the hospice@HOME nurse: (Initially), the whole concept has probably seemed really difficult for people. Now, one of the nurses is actually giving the patients flyers and saying, "Take this to your GP," and we're getting GPs ringing us and saying, "The patient's asked me to put a Just in Case Box in." (They have been getting around 2 calls a week). Many of the GPs have been really positive about the project and see it as protecting their patient and enabling the carer. The GPs are sent the JiCB guidelines and the nurse phones them a day or so later. "I had thought that with all the conversation that was happening around all the drugs and the concern around safety and all that sort of stuff that they would only order the merest amount, whereas they haven't actually done that. They've ordered, e.g., two strengths of morphine or hydromorphone and they've ordered their medaz and halo and clonaz and the buscopan. They've done the whole thing". I think the project has highlighted lots of really good things around using the service providers within the local region and the idea of perhaps people co-paying for their package, as they would anything else. Equipment response, from our perspective, has been huge and I think that's something that most people would say was probably one of the hugest things of that project, was that very prompt access to equipment (N17).

A nurse from a remote, somewhat isolated location was very concerned because she had been told that funding for the project had been cut. People often want to stay and die (in that location). "Sometimes that's not possible but, quite often, if they've got the

support of the relatives and the carers then we can go periodically to the house if that's all they need" (N1). The JiCB enables that.

Interviews with Management level nurses from two Community Nursing Services: Although it seems that considerable efforts were made by the hospice@HOME staff to communicate with other service providers, this was not always successful, particularly in relation to some of the Community Nursing services. A Reference Group was set up to help guide the project and although state-wide Community Nursing Services were represented on the Reference Group, it seems that information about the JiCB did not filter down to nurses at other management levels or to front-line staff.

There have been opportunity from several levels for that to be dispersed down to the staff. I think it's around their (internal) communication because they have been invited on a lot of levels (N17).

Four nurses who were interviewed were in management positions at two Community Nursing Services (two from each service). Two nurses from one service said that they had been aware that such a service was being developed but they thought more work should have been undertaken initially to identify who the stakeholders were and to consult with them, particularly as they were the main service providers in their particular region. One of these nurses seemed to suggest that she should have been personally consulted:

I was not included in any of the information rolled out and I found out by accident quite some time into it. I had very little input into it, partly because of lack of availability when the meetings were held to discuss it. For me, I didn't feel that the consultation with stakeholders – well, with this stakeholder – was very strong. So, information was sent out in written form about the development and that was all, really (N15/16).

That Service was also offered a presentation for their staff about the JiCB, but we didn't know anything about the Just in Case Box ... we didn't have any governance over it. It was taken up to senior management, who didn't want the presentation to be given because there was no clarity around its use and we didn't have any governance or safety mechanisms in place, so we didn't have that presentation. We were instructed not to use the Box until further investigation had taken place (N15/16).

A hospice@HOME nurse said that part of the rationale for the JiCB was to get a consistent best practice process across the state. "But most people thought that what they're doing is already best practice, so it's been a little bit hard to engage in that way" (N17).

This was reflected in the interviews; management level staff from the Community Nursing Services did not see the need for the JiCB.

In the majority of cases we are proactive in getting those things in place. When our nurses go in to set up a syringe driver for the client and their families, they provide education to the families about breakthrough medication and they prepare all the breakthrough medication that's required for that client until the next visit. We are actually doing that service for our clients and we have been before the Just in Case Box and we're still doing it now (N15/16).

When asked what they understood about the JiCB project, the Community Nurses thought that it was only intended for use by carers.

The purpose of the Just in Case Box was to provide an avenue for family and carers who were willing and able and confident and competent to access medications and provide them to their dying loved one when it was needed in the final stages of their illness (N15/16).

They believed that they could provide all the support their clients needed because "we have good relationships with our GPs and, at that time, we had after-hours specialist palliative care ... after-hours phone access (N5/6). One of these nurses expressed concern that a client had described the JiCB to a nurse from their service as "my suicide box. That's how he introduced it to her. Probably with a little bit of ironic sense of humour" (N5/6).

Although these nurses did not usually have direct client contact, one of them did ask a client what her understanding of the JiCB was. The client said: 'This is so I won't have to go into hospital'. Although the client had "COPD and back pain from just general degenerative ageing" the nurse thought that she did not need the JiCB because she was "not actively dying". Although the nurses were reminded that the JiCB was not just for when the client was dying, they felt that it had been provided much too early to this client, given that "It's got four drugs in there up in her cupboard for something (that is) probably going to be another couple of years (before it is needed)" (N5/6). These nurses "work in Palliative Care or with the GPs (and) we usually get (pre-emptive medications) in at a later stage: 'They're going to need this soon' not 'They're going to need this sometime.' They also said that they can provide a syringe driver and other equipment very quickly when it's needed.

These Community Nurses supported what they saw as the original purpose of hospice@HOME, i.e., to provide extra services that they could not:

Like personal carers at the drop of a hat; meals; things that there were just no services for, and equipment. They were a really good service, it was fantastic and now it's all just fallen by the wayside. It's 10 times worse than it was before (N5/6).

They also expressed concern that their service was not notified when a JiCB was supplied to one of their clients:

We weren't kept in the loop. On two occasions, we didn't know that a Just in Case Box had been put in. So that was really poor communication, which is quite unusual because the (hospice@HOME) nurses we'd been dealing with generally had been very good but it seemed like there was a bit of a push on. The impression we got ... was that they had to use up this money and they had to get the stuff in. So we wondered if sometimes the wrong people were getting it (N5/6).

They were aware of other nurses in their Service who also had not been informed that their client had been prescribed a JiCB; even though this was a palliative client, they did not think the client was appropriate for a JiCB because they were not seen as close to the end stage of life. They agreed that palliative clients, especially those with COPD, can deteriorate quickly but they said that they can quickly put in syringe drivers and educate carers about how to top them up if necessary.

We've probably discussed (the syringe driver beforehand): 'This is what we can use' and then when (the time comes) we do put it in, and we just tell them why we reload the syringe driver every 24 hours. We draw (the breakthrough drugs) up for them; we label them – actually what it's for and all the rest – and we (get them to) practise how to do it with a bit of saline or something. Again, we'd say, 'Do you want our evening girl to come in until you're used to it?' and they pick up very quickly. And we give them troubleshooting with the syringe driver; how to change the battery and all that sort of thing. So far, no one's had a problem with it (N5/6).

These nurses said that once carers understand that if the client is likely to need breakthrough medication, they can't stay at home unless there's someone willing to do it, then they are usually prepared to be shown how to do it. "Quite often, they're very dubious and apprehensive but, once we've shown them, (and) they've practised (they are okay with it). And because we go every day at that stage, they've got really good support" (N5/6).

The same issues were raised by the other two nurses who had expressed concerns about the project:

Interview Outcomes

That Just in Case Box ... was put in place without our knowledge. As the management, we were not aware that the Just in Case Box was in place until after the client died. (The medication) was used by one of our nurses in conjunction with a hospice@HOME nurse but it was not known to that nurse that it was Just in Case Box-acquired medication at the time. It was only discovered by the next nurses going in when they found the bags in the home with information for the carer and they found the client and the carers in crisis because of the poor management of the situation. This was a very short, sharp episode of care that occurred over only about 24-48 hours (N15/16)

In one case, medications from a JiCB were used "to prepare a subcut infusion for a client" (N15/16) but the Community Nurse, who was asked to attend to assist a hospice@HOME nurse to set up the infusion did not know about the JiCB. (These nurses had said in interview that they were the primary service in their area. They were asked by the evaluators for clarification about this, in relation to hospice@HOME being there).

hospice@HOME were in the space looking after terminally ill clients... (their role) was to be a gap filler for things like personal care for palliative clients and sitting with palliative clients overnight, although they do have some RNs. It was a very grey area. Our understanding was that hospice@HOME were able to initiate syringe drivers and on the day that I got the phone call it was from a hospice@HOME nurse. She asked me if I had a spare registered nurse that I could send out to help her set up a syringe driver. While she had the syringe driver kit and the syringe driver and she had the medication, she didn't tell me that she had a Just in Case Box. I assumed that she had sourced the medication from the GP, like we do, and it was very much their client and we were assisting. However, when our community nurse arrived there, she got the feeling that she was there to attend to the syringe driver and the hospice@HOME nurse was there to assist. However, we didn't initiate it; we didn't instigate it; we didn't get the medication; it was their syringe driver, so it was a very grey area. Then, after the fact, we were told that the hospice@HOME nurses, in fact, weren't allowed to put in syringe drivers; that's why they asked for assistance, but we didn't know that (N15/16).

This also reflected what the other two nurses said; when they see that the client is coming close to the end of life, they have a syringe driver and medications in place a few days or a week before. "Clients are given the scripts and told to get them filled when it looks as if they will be needed soon" (N5/6). They acknowledged that occasionally they do need to go and get the medication, or ask the palliative care nurses to get it for them:

There may be the occasional one that we have to wait for but it's not usually long, maybe overnight. Weekends are probably more of an issue. We'd need to chase up. We'd have to plan that before Fridays (N5/6).

(Note: there did not seem to be awareness or acknowledgement that leaving clients in distress overnight or on weekends while they wait for medication was a major cause for concern).

Two of the nurses who have reservations about the JiCB nevertheless could see some benefits in it for nurses, mainly not having to chase up scripts or find a pharmacy with the needed medications, because not all pharmacies stock all the needed medications, "so in that case it would be an advantage, if they were already there in the Box" (N5/6). They also said:

We don't have to have any responsibility for the drugs really. It really would help us and the client, as long as all the drugs are there that we need. They're usually the standard five. All we'd have to do is get a drug chart/order from the GP for what we wanted.

One of the community nurses said that:

We have Extended Care Paramedics (with the Tasmanian Ambulance Service) that work 24/7 (and) if the medications and a drug chart (are) in the home; if there's advance care directives or Goals of Care in the home, then the paramedics can go in and administer medication off that drug chart for people who are in crisis (N15/16).

She said that their Community Nursing Service does have all of that in the home for a client who is at the end stage of life "and, usually, the Expected Death at Home forms that allow the paramedics to give them that service and not have to transport them to hospital" (N15/16). However, in Tasmania, Extended Care Paramedics are not available in all regions, resulting in inequality of palliative care access through this means.

GENERAL PRACTITIONERS

(Clients referred to as patients in this section)

Six GPs were interviewed in relation to 8 patients; 3 GPs were interviewed about specific patients but as consent had not been received from all of the 8 carers for a patient-specific discussion, general interviews were held with the other three GPs, who were asked to think about their involvement with the JiCB project but not to specifically mention any patient.

In most cases the GP had been alerted to the availability of the JiCB by a nurse caring for the patient at home, or by a colleague. All but one of the GPs were very positive about the JiCB and the process for accessing it for their patients:

There is a set proforma and it tells you what scripts you have to fill out (but it allowed flexibility and clinical judgement) and what the process of referral is, so it was very straightforward (GP1).

GP1 said that the hospice@HOME Clinical Nurse Manager brought the JiCB to the GP surgery and showed the GP and other staff what was in it. The GP discussed it with the Community Nurses involved with two patients. The JiCB addressed some concerns,

about what happens if the patient can't take oral meds any more, it's the weekend and, e.g., no syringe driver has been set up; the JiCB bridges that gap, it already set up at home, everyone educated, lowers everyone's distress and fear (GP1).

None of the GPs experienced any barriers in relation to supply of the medications or delivery of the JiCB to the carer. The GP who was less positive did not have any problems with the JiCB per se but considered it to be unnecessary in the area in which he worked, because he thought the existing local service worked very well.

We have between 12 and 20 palliative care cases per year which we manage within the local service. (We have) a good local pharmacy service and all of the JiCB drugs are usually available locally (GP2).

GP5 prescribed the JiCB for a 93-year-old palliative care patient whose main problem currently is loss of mobility. She does not want to go to hospital; she wants to stay at home and just be kept comfortable. He thought that having the JiCB seemed sensible "so that she would have medication available for home treatment if her condition deteriorates after hours or on weekends and the GP cannot be contacted".

Several GPs said that they would prescribe the JiCB again and one added that he would like to see another evaluation of the project later, when more patients had used it.

JiCB activation: The patients of three of the GPs for whom the JiCB was prescribed are still alive and to date there has been no need to activate it for these patients. One of these GPs said that it is reassuring to know the medication is there if it is ever needed and another said that he has written on the scripts that if it is ever activated, he is to be contacted before the medication is given. The JiCB was not activated for another patient because she went into respite care and died there. The remaining GP had two patients for whom a JiCB was activated, in one case by the community nurse, with the carer and another family member administering nurse-prepared top-ups as required; for the second patient, neighbours, who were also nurses, accessed the JiCB and administered the medications.

Advantages of the Just in Case Box for the patient, the carer and the GP:

Several GPs said that it was reassuring and comforting for everyone involved to know that the medications, and other accessories in the JiCB, are available when needed. It takes away worry and fear that there would be gaps in the care. The patient feels safer, staying at home, because there is a plan in place if pain or other distress increases. Two GPs mentioned that the JiCB gives carers more control and helps them feel like part of the care team; GP2 added: "that involvement can help them in the bereavement phase". GP5 said that it gave peace of mind to a carer, "knowing that if (the patient) was in pain that they could help her without having her go to hospital, which she gets quite distressed about". GP5 also said that it was more efficient, the process was good and if the patient deteriorates it will not mean having to phone the ambulance. For GP1 a major benefit was that her patient can contact the after-hours phone line if she has any concerns during the night. "It is also good for me to have that back-up, being involved in a model of care like this".

Safety issues, e.g. having the Schedule 8 drugs in the house:

None of the GPs had concerns about the safety of the JiCB being in the patient's home because in all cases they considered that the carers were capable and responsible people. While, theoretically, there can be risks associated with narcotics, the benefits outweigh the risks; community nurses or the GP can carefully assess who is suitable to receive the JiCB and if there were such concerns, that could trigger admission to residential care.

However, a safety concern for one GP was that:

the syringe driver in the kit delivered already had medication in it. It had not been refreshed between the last patient's use and being delivered to my patient. It had been assumed it had been refreshed but it had not (GP4).

Interview Outcomes

Contribution of the box to the quality of palliative care that the patients received: Most of the GPs felt that the JiCB provides reassurance for patients and carers that the services are available to them “and the carer feels in control” (GP3). For GP1, a major benefit was that it gives independence and a sense of empowerment to the carer and to the patient, which takes away the sense of hopelessness and allows the dying person to “be engaged in their own care”; it also assists carers to be confident in their ability to do what was needed. GP4 said that it provided the opportunity for him to talk through the palliative care process with the patient and carer; for GP6 it reduced patient and carer anxiety about what might happen if things got worse. GP5 did not think it contributed in any specific way as he is already comfortable talking about death and dying with his patients, and he had already gone through it with this family and they knew what to expect.

Did the JiCB assist patients to stay at home? Three of the GPs said that JiCB had assisted their patients to stay at home until they died. One patient died in a respite facility, but the GP thought that having the JiCB in place meant that she was able to stay at home longer. “The respite was more about the high level of care that the patient needed”, plus carer fatigue and other factors, completely separate to the JiCB (GP4). For GP2, other factors, including stress and the burden of caring were more important in determining how long a patient stays at home than whether or not they had a JiCB. While GP5 thought that the JiCB had assisted his patient to stay at home until she died, he thought that she would have done so in any case. “She was a fiercely determined lady. Perhaps the very last few days of her life she may have ended up in a palliative care ward but I doubt it”. The GP thought that if her condition deteriorated and she did not have the JiCB, he could have organised community palliative care, but not as quickly, especially if it was a Friday night. “So she may have been uncomfortable for a day or two before we were able to set up syringe drivers and things”

The GPs thought that most of the carers were confident that they could use the JiCB if they had to, for example “if it’s needed and the GP or nurse can’t get there [but] it can be pretty intimidating for family members, giving that sort of medication if they’re not trained in how to do it” (GP5).

The carers of one GP’s patient “were quite confident and thankful that they had a bit of a plan if things were to go downhill, but they also knew that there was additional backup services if needed” (GP6).

Another carer “has many health issues of his own and so the JiCB is mainly in place for Community Nursing to access if needed” (GP2).

(One patient) has requested that the carer is not involved with the JiCB as yet. It is packed away at her house. When the time comes and the patient is ready we can go through the JiCB with the carer (GP4).

Five of the GPs said that the JiCB enabled them to provide better care to their patients:

- GP1: by enhancing the independence and empowerment of the patient and carer; to redress the imbalance of power between the health care providers and the health care consumer.
- GP3: had additional conversations with the patient and carer about some medications that were new for the patient, what each one is and what it is used for. Also enabled more discussion about the dying process.
- GP4: also enabled the GP to have additional conversations with other patients and carers, and interdisciplinary team members, about death and dying.
- GP5: psychological reassurance. “Supportive, more than anything”.
- GP6: it’s really useful. It would be good if it was more widely available to help people who are in that palliative stage to be managed at home. It helps get a realistic conversation going about “this might happen and this might happen and this is what we’re going to [do] and this can help”.

GP2 did not think that it helped him to provide better care because “I am already very involved in palliative care but it may be helpful in other cases”.

Other Comments: Several GPs were aware that funding for the project has been cut and were very distressed about that, as “it is a much-needed service” and two GPs currently have patients for whom they want to prescribe a JiCB. GP5 gave an example of potential cost savings from the JiCB; one of his terminally ill patients “has had four presentations to the Emergency Department in the last two weeks with pain. It was during the day on a weekend but it could’ve easily been managed by having a (service like the JiCB) available.” He noted that “ED admissions cost thousands of dollars while the cost of the JiCB for one patient is hundreds of dollars” (GP5).

(Note: A nurse interviewed for this evaluation said that a GP recently phoned the hospice@HOME service, seeking another JiCB for a patient, and said “we want to have it set up here in our practice so that my nurse practitioner and I can just instigate it”). Other comments included suggestions for improving the material GPs receive, e.g., to streamline prescribing medications, and who is responsible for checking the expiry date on medications if the patient had the JiCB for a long time.

GP2 said: "A local service that is well resourced and adequately funded is a better way of providing care in this situation. Local services have a good team relationship between providers and good access to the Specialist Palliative Care Service. In places where people are keen to do the job, let them do it. Reserve the JiCB for areas that don't have this level of service. The JiCB is a good idea but it should only be applied where it is needed".

PHARMACISTS

Three pharmacists participated in the project; two supplied all of the medications for 18 clients in the Southern region and one supplied the medications for a client on the West Coast. A pharmacist in the Southern Region said that when they were invited to participate in the project, they already stocked a wide range of palliative care medications, as they were based at a major hospital and were looking after a palliative care unit. In the development phase of the project he had also reviewed some of the initial documentation and advised on logistics for setting up the pharmacy contribution to the project.

These pharmacists are able to provide medications at short notice, which many community pharmacies are not able to do. hospice@HOME bring the packs to the pharmacy; the pharmacists insert the combination of medications, as prescribed by the GP, into the pack and put it in a sealed, tamper-proof container, for collection by the nominated person. Prescriptions vary, e.g., in strength of morphine, number of boxes of medications and whether or not repeats are prescribed, depending on the GPs prescribing style. If there is uncertainty about any of the medications prescribed, the pharmacist will phone the GP to clarify.

Drug-specific issues: The drugs on the JiCB request form come from a nationally-approved list. One drug, Fentanyl, has been difficult to get but the pharmacists have been able to access stock. It was suggested that an additional drug, glycopyrrolate, which had been very expensive but had since reduced in cost and become more available, could usefully be added to the list. One of the pharmacists noted that some GPs may need additional information and support to prescribe drugs with which they are not familiar:

Hydromorphone is one of those, where I think the palliative care specialists have sort of "owned it" for a long time and I know there is some concern around that. If the support's there, I think that would probably be the only one that needs further discussion (P1).

The pharmacists do not usually have contact with clients, their carers or family members, there is no clinical component to the service they provide, although one pharmacist said that a carer came in for

additional medication on a weekend and he did check how they were managing. In addition, as the pharmacists do not always receive the Medical Goals of Care form, nor a full list of the patient's current medications, they are not able to assess whether the prescribed medications could interact with the client's normal medications. P3 noted that not being the client's regular pharmacy could be a problem in this regard, especially for a client on a lot of regular medications.

None of the pharmacists were aware of any problems with medication (i.e., drug interactions). Two of the pharmacists understood that when the JiCB was activated, the client's regular medications would cease.

The pharmacists felt that being involved in the Just in Case Box project has assisted them in providing better client care, especially in relation to access and being able to provide medications in a timely manner. P3 said that the JiCB was a straightforward process and his regular work already had a strong emphasis on palliative care, while P2 said that being involved in the project helped him to maintain his knowledge, especially in relation to which drugs are being used and the resources available for people in this situation.

Also, it has helped us remember that palliative care in the home is a growing issue and to help think about how we prepare for assisting in that in the future (P1).

With increasing need for home-based palliative care, it was noted that palliative care specialists will need to support GPs to provide more of this care, and it will also be necessary for community pharmacies to have the medications available to them in a timely manner. "It might mean identifying patients sooner rather than identifying them on a Friday afternoon, when a pharmacy can't get anything in until Monday" (P1).

The pharmacists did not have any safety concerns about the drugs but had put processes in place to record who collected them. One pharmacist noted that the JiCB is straightforward and has a good choice of medications. However, in one case it was set up too far in advance as it was not picked up within the claim period. [Note: Pharmacists are unable to claim for payment by Medicare Australia for items that are dispensed but not collected within the claim period, this means the Pharmacist has to remove the item from the claim and reclaim it in a future claiming period].

Case Study I

The client was a 74-year old man who initially was diagnosed with liver cancer, and later with cancer in his spine, hip and head. He lived for 15 months after his diagnosis. His wife said: "He was extremely stoic". His wife was his full-time carer for that 15 months. They lived in a beach-side area somewhat remote from Hobart. The carer said that the Community Nurses in their location were very good. "People asked me 'How are you going to cope?' I said, 'We'll be right because they're here, instantly.' The Community Nurses kept him comfortable: "They were wonderful and we wouldn't have wanted him to be anywhere else. Hospital would have added what? All those noises – beep, beep, beep – and machines and it's just not nice."

What was the best part about being his carer? The togetherness. We discussed (everything and) got things sorted out, that was good. I didn't mind doing anything; towards the end things got a bit messy but it was all okay. The only thing I was a bit worried about was my physical strength, because even though he'd lost a lot of weight he was still a big man. Once, quite close to the end, he was in the shower and he ... got sort of stuck. The floor was a bit slippery and (the carer was afraid that he would fall on top of her). But I got him out and I sat him on the toilet in a towel and then we managed to get him into the bedroom and in a chair.

Informal support: The client and carer had good support from all the nurses, friends and their two daughters, so that the carer could have some time off. The day before he died, one of his work colleagues and his daughter came for his birthday. After his friend had left, he said, 'I've got to go to bed'.

That is the only time that he ever went to bed during the day the whole time he was sick. When the Community Nurse came in the evening, she said, about his pulse and blood pressure, 'It's barely there' but he lasted another 20 hours. We had little sponges to clean his mouth, so we kept dipping the sponge in champagne and he was sucking it and he had what we classed as a smile on his face.

Formal services: The carer took the client to the oncologist and the GP while he was still able to travel by car; the GP, the Community Nurses and the hospice@HOME nurses came to the client's home towards the end of his illness, when it was too uncomfortable for him to travel by car. The carer spoke highly of all of the support services.

Information/Communication: Throughout the client's illness, he and his carer received sufficient information on what to expect, in particular about his medications and the reasons for those. "He was on quite a lot of pain medication in the end, and an antidepressant at one stage. He just needed that little bit of calm". The Just in Case Box was delivered 4 weeks before the client died; the GP who

prescribed the JiCB said it a simple process. "We simply sent off a letter saying, 'Please can you set this up and educate the family?'" The RN from hospice@HOME talked to both the client and carer about it. The carer said that the information was provided in a way she could easily understand; she did not find it overwhelming. "It was reassuring and they didn't make you seem silly if you asked silly questions. They were wonderful". The training and information made the carer feel more confident, because she knew that there was something already in the home if it was needed. Having already practised drawing up the medication was also reassuring.

The carer talked about the JiCB to her two daughters and the Community Nurses. She found the discussions helpful and they made it easier to talk with the client about death and dying. "Because he was so with it all the time, we'd worked it through". The syringe driver was not used at any time but the Community Nurse put a port in and labelled everything so the carer and her daughter were able to use syringes when the client needed them. The carer found it very reassuring, knowing the medication was there for her to use if necessary. "We'd had a practice and had been shown how to do everything. We actually coped very well." "It was an excellent service. I would recommend it".

Accessing after-hours care: The carer was asked what caused her most concern, what was she most fearful about or what did she need more information about. She replied:

One day he had a fall; he had a haematoma and that night it was pouring blood. That frightened him so I rang the after-hours number that they give you. By the time I got somebody, we were more or less doing what they told us to do with compression. That was frustrating because I wanted to talk to somebody and I got this recorded message. Somebody did eventually come on but it seemed to take forever and this blood was going everywhere. Afterwards, the Community nurse said, "next time just say you want to talk to (X location) nurses, because it's an after-hours number", which I did. When it was all getting a bit close, I just knew to ask for them and they came around.

The JiCB was accessed on the night before the client died, by the two Community Nurses. The carer was confident in the end to give the top-up medications because the Community Nurse had set it all up and labelled everything. There was no delay from when the carer identified that the client needed the medications to when they were given.

At the very end "nobody interfered or anything. (One Community Nurse) was at the house very close to the end and came back as

soon as he died". The carer was asked if the nurse came back too soon or whether the timing was right. She said: "No, it was okay because we'd all been there. We did have some private time. But I didn't feel they were too soon. It was right. They sat as well, just quiet and nice. It was done with a lot of care and thought".

Advantages of having the Just in Case Box in the house:

Huge, really, because it's reassuring. If he was in horrible, screeching pain you've got something you can do about it. And knowing how to use it, it was just a back-up. It was there and it was reassuring. I wasn't scared of it and neither was (her daughter). He knew all about it and what was happening.

It contributed to the carer's ability to care for the client and reduced her anxiety by knowing it was all there, and at the end she could give him the medication. The client's GP said that for the client, the carer and for her (the GP) the main advantage was "not having to worry that there would be gaps in the care. It just took away the 'what if'". The GP also said that the JiCB "gives independence, both to the carer and to the patient; (it gives the patient a sense that) I'm engaged in my own care. I'm engaged in my own process of dying".

That sense of empowerment. We know that the thing that worsens mood, worsens pain, worsens outcomes is the sense of hopelessness and that's what the JiCB takes away. The person who's dying knows that they're dying but they don't have to feel hopeless in the process of dying (GP).

Having the JiCB in place contributed strongly to the client being able to stay at home. The Community Nurse said:

He had had a blood transfusion that day (elsewhere) and we did wonder if he was having a reaction to that, so we contacted Royal Hobart Hospital and talked to the specialists there. They said that if he had been otherwise well and had had a blood transfusion they would have helicoptered him off (from where he lived) to the hospital to see if it was a reaction to the blood transfusion and get that under control. But, given his condition and the fact that he didn't want to be transferred anyway, the client wanted to stay where he was, that didn't happen.

A good death: The carer said:

He was very determined he was going to stay home. We were all here and the last coherent words he said were, 'Don't ring for the bloody ambulance!' I said, "I'm not going to. I'm just ringing (the Community Nurse). He couldn't really have been in a better place. It was night (when he died) but during the day we had all the curtains open so he could see out. He just practically died in his sleep, I suppose. He was ratty but he wasn't distressed. He was very peaceful.

The Community Nurse said that, compared to many people, the client "had the most beautiful death. The window was open and he was able to hear the waves from the beach, having his own music, his dog on the bed and his loving family around him".

In discussing the client's death, the GP commented that:

It's good to be able to return back to the concept that it's okay for death not to be sanitised and on view. It's okay to help others that we love to go through death because, one day, we will as well and, if we get over our fear, we might live what we do live better.

Returning the Box after the client died. The carer had no concerns about having the JiCB in the house, because of the quiet location where they lived. However, after the client died she thought that it was not a good idea to have such medication in the house, "So I got that to the pharmacy as quick as I could and then the hospice@HOME nurse came and picked up everything else, so that was helpful".

Advance Care (and financial) Planning: The client and carer had both appointed Enduring Guardians. The client also discussed with the oncologist that he did not want to be resuscitated. Enduring Power of Attorney for financial matters had also been completed, Wills were in order and names changed on bank cards so carer was listed first. The carer later commented that her biggest challenge since the client died had been taking over the administration of family matters.

Case Study 2

(This was the only interview in which the client also participated).

The client is a 75-year-old woman with emphysema; she is on full-time oxygen and is unable to leave the house. Her husband is her carer; he is still able to occasionally attend social functions but does not like to leave the client alone for very long.

At the time of interview, the JiCB had been in their home for 10 weeks. The carer said that it had not been accessed "so far". They had both been involved with the training/information session when the JiCB was delivered. The carer was given a colour guide for medications, plus guidelines for the Box. There was also a Goals of Care Plan (developed by the specialist, not the GP) in which it was noted that the client did not want resuscitation if that was ever needed. (The carer said that when the client made that statement, it upset him at the time because it brought home to him that his wife was going to die). They were unclear about what other paperwork was included. The carer said that no Tablet was provided with the JiCB.

The client wants to remain at home until the end of her life, if that is possible, and both the client and carer see the JiCB as assisting with that, although the client said that she chooses not to think about it. The carer does feel more secure, knowing that the equipment is there if he needs it in an emergency: "It's nice to know it's here but it's sad to think that the time will come that I've got to use it". He is also aware that he may need to use it to relieve his wife's distress during the course of her illness, to relieve her symptoms, and that it is not only intended to be used at the very end of life:

Yes, that's what they're saying to me, I need to be paying attention to, for example, the noises she makes and things like that so that if there's a change in the sound I can pick up on it and say, "Are you in pain?" and learn, pick up on the signals. And when she can't talk to me and she makes that noise, I know, alright, well, I've got to do so and so".

The carer understood that if he phones for assistance and the nurses are not able to come quickly enough, he will be instructed what to do and how to do it.

The carer and client have a friend whose mother passed away with emphysema, and she explained to them some of what is likely to happen, e.g., that it will get harder for the client to swallow; they said that they will just deal with each step as it happens.

Informal Support: The client and carer have 3 children, a daughter who is a medical practitioner and two sons, one of whom is a paramedic. The client and carer showed them the JiCB; they found it particularly helpful to discuss it with their daughter, who was very pleased that they had it. Their sons did not initially understand the seriousness of the situation but, after their sister explained it to them, they now do and are more supportive. The carer also has a friend who phones him frequently to see how he is coping.

Formal Support Services: Both hospice@HOME and Community Nurses come to the house and each time they do they assess the client's health situation (to see if there is any need to access the JiCB). The client said "We could not praise them enough, both services. They are angels without wings, they really are".

Advantage of having the JiCB: The carer said that the advantage of having the JiCB at home is "that you're not waiting for medicine to arrive – it's right here – and if the situation demands immediate attention you can do it. You're a phone call away from knowing how".

Any safety concerns about having the JiCB in the house, e.g. medication theft? The carer said "Well, we haven't advertised the fact to anyone, other than those necessary, that it's here. We're not advertising that. There's directions on the fridge for any paramedics who come in, they know where the bag is. They're directed to it by the instruction on the fridge. And the crime rate in the area is pretty low".

Advance Care Planning: Neither the client nor carer had undertaken any Advance Care Planning or appointed an Enduring Power of Attorney for financial matters but acknowledged that they need to do that.

The time of death: The client and carer have personal friends who are funeral directors in the area. However, the carer asked, "In the event of her death, the first person I notify is who?" It was explained that, before contacting the funeral parlour, he will have to get a certificate to say that life has ended, from the GP or one of the nurses, but also, that there is no rush and he and/or other family members can have as much time with the client, by themselves, as they want. The client has already written out her death notice to go in the paper. The death notice finishes: "She walks in fields of gold." She accepts that death is a part of life. (The final part of this interview was a discussion about the client's favourite music, and what music she would like played at her funeral).

The client's GP thought that the JiCB contributed to the quality of the palliative care his patient received because "It provides reassurance for the patient and the carer, and the carer feels in control". He thinks that, because of the instruction and training that the carer received, the carer is confident that he will be able to use the JiCB if he ever needs to, but "that hasn't been tested yet". The GP also said that participating in the JiCB project resulted in additional conversations with the client and carer: "It causes you to talk through the medications and the process. There were some medications that were new for the patient, so we talked through each one, what it is and what it is used for."

The Community Nurse was very appreciative of the client's GP: "He's fantastic. He's very supportive of them, whereas their previous GP, if they were to suggest something, I suppose they didn't really believe that they were listened to." She noted that "some GPs don't believe in advance care directives. You ask them to do a Goals of Care and they say 'No! Why would they need that?' They're very indignant about it all. (But) It's all linked together and everyone has to (provide) support to make it work." The nurse said that the JiCB prompted her to have more discussions with the client and carer about their situation and what was in the Box but that "one discussion is not enough" and the conversation needs to be on-going. "People are interested in their own health but how to fulfil a task to make life easier is sometimes hard. (In this case, both the client and carer are intelligent but) I tend not to talk medical. (For example), with injections – it's what they're used for rather than be too technical".

The nurse thought that the main advantage for this client and carer of having the JiCB in place was having a plan. "If they've got the box there and they're calm about it, they know it's going to help; it's probably the carer who feels the benefit more than the client". Also, because the client and carer are "fiercely determined" that the client will stay at home until the end of her life, "the more input into the house that allows that to happen, like the Just in Case Box".

When asked if she thought that the timing of the delivery of the JiCB to this client was appropriate, the nurse said that, while it had been in there home for quite a long time, "It's no good if it's too late, is it? You' have to get used to it being in the house so (perhaps the right time is when) they've had a discussion about not wanting to go to hospital and symptom control. If it's too late it's too late. They've got to get used to it and then revisit what it's used for multiple times".

Case Study 3

(Note: The following information demonstrates some very important learnings; however, it should be noted that this recount does not include perspectives of the client's primary community nurse nor the client's GP or pharmacist, all of whom were unavailable for interview).

The client was a 49-year-old woman who was diagnosed with cancer and died 5 months later. She was cared for by her partner. The client wanted to focus on living as well as she could, not on dying, so the carer was the one who talked to the hospice nurses and got the bed organised. She did not consider herself as "a carer" – it was just an extension of their life together.

as things went down the track that they went, then I walked that journey with her as she became more unwell, doing things that she wasn't able to do any more. My goal was to make her life as easy as possible, so if that meant getting up and getting her fed, accompanying her to appointments, etcetera, whatever that was.

Some of the treatment a few weeks before the client died caused complications, which resulted in the client presenting to the Emergency Department at the hospital on a Sunday because:

she'd had a wretched few days with pain and nausea, so they admitted her and she went into a delirium that night. They weren't sure if she would pull out of that (but she did) and we were in hospital for a few days stabilising things.

On that occasion, she was sent home on a Friday and there was no weekend backup. The carer did not understand what to do in relation to the client's medications, "so it was traumatising". The client ended up in the Emergency Department again for symptom management.

On her last admission, the palliative care doctor at the hospital made a big effort to get the client home on the Thursday so they would have services in place before the weekend. "She was at end of life but we got her home and we had a week (before she died)".

Informal supports: The client and carer had a crew of people, a personal support team, so in the last few weeks they had someone with them 24 hours a day.

In our friendship group, we had a roster, so from the time she went into hospital – it was probably about two weeks before she died until she died – I had someone with me.

Formal services included: the GP, the pharmacist, the cancer clinic, the oncology specialist, a very supportive respiratory team for when her lungs needed draining and the hospice@HOME nurses, community nurses and palliative care nurses. When the client was discharged from hospital, the week before she died, the palliative care service organised the bed and other equipment so that she could go home.

The best part of being her carer: The carer said that the best part was helping the client to have the best death possible.

I loved her and I wanted to be with her and I wanted her to have the most easy (death) ... so my job was to create the most calm and loving and supportive environment for her. I had some control over that and that was never questioned. We went to all the appointments together. I was always with her or someone was always with her. And because she was very open to that, she drew in what she wanted and needed.

The carer explained that their pet dog had died of cancer some months before and the client told her that she wanted to die the same way as their dog had done: "I'm going to wag my tail till the end" and she did. The carer did everything possible to make sure the client was able to do things the way she wanted to, right to the end.

The most challenging part of being her carer: (Note: For this client and carer, the JiCB was delivered too late to be of benefit; some of these challenges may have been addressed if there had been timely access to it).

The carer described feeling out of control, not knowing what was normal in terms of severity of pain and other symptoms and not knowing how much medication was appropriate to give to the client.

and watching her struggle with that: to be in pain, to be confused, to be scared, to have the nausea, and then not feeling able to do anything about it and not knowing what's the normal range. And not feeling equipped to do that and not even realising that 'you don't know what you don't know' (i.e., not knowing what questions to ask).

Friends of the client and carer, who were nurses, came to stay with them, and they were able to explain about some of the medications that the client was taking, but there was also a great deal of written information (not from the JiCB), which was overwhelming; "you can't take in all that stuff at once". The carer found that wanting to make it easier for the client but not always knowing what to do was the biggest challenge, "other than the fact she was dying".

Need for good communication: One area that the carer thought needs to be improved is communication.

It's hard to manage the pain stuff unless you have good communication. I kind of understand the system a bit. I knew who hospice@HOME were; I knew who Palliative Care were; I knew who Community Nursing was; and I knew who my GP was, so I knew that they were all involved. But even I got seriously confused about how those four were in communication.

The carer noted that the discharge planning from the pharmacist at their main hospital was “incredibly good”:

He sat down and he really acknowledged that it was tricky, acknowledged that I'd done the best that I had before, which meant a lot to me. He just went through it and gave me all the time and allowed me to check that I understood it, write notes in my own language and all that. I was really impressed with that.

The fact that the palliative care doctor made sure that they were discharged on the Thursday (a week before the client's death) so that they had Friday to set everything up before the weekend also meant that “I had the hospice@HOME number over the weekend, because weekends and after-hours are really tricky. And I called them a couple of times (and they responded well)”.

When the client was in hospital, a nurse who was part of their support network stayed with the carer at the hospital to support them and explain what was happening, and sit with the carer “while we had the meetings with the oncologists and the oncology team” as a “backup advocate”. Because the client was in a private room, they were also able to organise a 24-hour support roster of friends so there was always someone with the client when she woke up. That gave the carer time to phone everyone and tell them that the client was close to the end of her life.

Delivery of the Just in Case Box: Before being discharged from the hospital, various services made appointments to visit the client and carer at home. hospice@HOME, Palliative Care and Community Nursing came on the Friday (the day after hospital discharge). “Hospice came first and it was to sign up so that I would be on a weekend (list); that was the main thing”. She did not know how all three services fit together (i.e., Community Nursing, the Palliative Care Service and hospice@HOME).

I didn't understand the relationships so all I thought was, 'Some nurse is going to come, put a syringe driver in and then they will come back periodically to make sure she's fine and the doctor will oversee it.'

The carer expressed concern at all of the assessment processes and just wanted phone contact for the weekend, with the rest of the assessment being done during the following week. Over the weekend the GP came and “at some point the doctor initiated the Just in Case Box so we would have a syringe driver; basically, for that final end”.

The day before the client died, two people from hospice@HOME came with the JiCB and it was at this point that some of the communication

kind of fell apart... the box didn't register to me at all other than we were looking at the meds and the next step was a syringe driver and that's what it came in. I would never have known it was called the Just in Case Box, frankly. It just came to the house. The box wouldn't have registered other than as a vehicle of drugs.

The carer had no idea what was happening, did not know that the GP had prescribed the JiCB and did not understand about having to learn how to do the injections or anything else.

I'm going, 'Okay, there's (the client). Put the syringe driver in' and they're sitting me down at the table and they pull out this whole big folder of information and start talking about how to train me to use a syringe driver. They were even bringing up YouTube clips and all that to show. (The client) was at end of life, she was Cheyne Stoking, so clearly it wouldn't have taken much to realise, this is not going to be a syringe driver that's in place for weeks and weeks. In the end, I said, 'I cannot actually take this in'.

The carer rang a friend, a nurse who was part of the support team, and told the friend about not wanting to know how to use the syringe driver; her friend said she would do it instead. Meanwhile, I'm saying, “She's in there. I want the syringe driver in. I want her to be (free of pain) ...”

For this carer, the major problem relating to the JiCB was “that we weren't introduced to that service months before”. This was possibly caused by a communication problem between the cancer clinic, the specialists and the community teams.

There is a need for early communication around the services that are available and when would you pull them in and when would you call them. And particularly the after-hours phone numbers around meds and management. ... You've got those days where you're sitting at home going, 'Is this a normal range of pain and nausea?' (for her illness). There were lots of symptoms where you kind of go, 'Well, do we live with that because that's just the reality of the treatment?'

If the JiCB had been delivered weeks before the carer would have been open to hearing about it and learning how to use what was in it.

There was also a delay, waiting for the syringe driver to be inserted. The carer said that the nurse who brought the JiCB could not do it, and the nurse who was with her could not do it on her own because she had to wait for the community nurse. She thought this related to some partnership arrangement between the services. Eventually the GP set it up, using medication from the JiCB.

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Later that night the carer noticed that the syringe driver was leaking, "because there was a wet patch on the bed, and that was when we called (the Community Nurses)".

They were excellent. They went through the whole ... set all the drugs up, and they were going. 'You should never have had to worry [about this].' They didn't say anything unprofessional but ... they were saying, 'No, you don't need to worry about that. That's our job. We will come in and do it. It's all fine.'

The carer understood from the Community Nurses that something about the way the syringe driver was set up wasn't quite right. "It wasn't quite as easy as it could be because of something that wasn't in the box. But then the community nurses brought some other thing and it was all fine". It was also pointed out that the GP had set up the wrong doses.

When the community nursing team came in later to fix it up again, they had the right ones and so they changed it over so it was all much easier to use.

The carer also was distressed that on that same day (the day before the client died) someone from one of the services (she thought that it might've been hospice@HOME) came to their home and went to talk to the client, who was a little confused and did not want to talk.

At that stage, (the client) hadn't registered that she was so close to death and they started asking her questions about that stuff and she was starting to get agitated. I said, 'Excuse me, can you come out here? You cannot do that. You're distressing her. Why on earth are you talking to her? You can't do an assessment of her at that point. It's just not appropriate.'

A good death: Once the syringe driver was in place, the GP talked to the client and told her what was happening and that she was going to die quite soon. The client was accepting of the situation. She had that kind of high energy that you get just before you die. She had it that night and we had some people that came to see her and she said the things she needed to say. Then, we were looking at photos and kind of doing that and hanging out and then she was kind of drifting in and out of consciousness, not really with it. The following morning, our godson came and he was there with his mum, our dear friend, and another friend and me, we were with her when she died. It was perfect. Well, it was good as it could be. We got enormously good care from a lot of people and she did get to die at home and it was a good death in that sense. We were where we wanted to be and she was comfortable (surrounded by people who loved her). I'm forever grateful for that and my friends, and that we had the systems in place

to do that. Without that network it would have been much more difficult, both emotionally and in terms of physical exhaustion.

The carer understood about who to call after the client died and when to do that:

Because I had nurses with me, the doctor was able to leave the paperwork and then come back after (the client) died but we didn't have to call someone in to sign it off. My friend, who was a community nurse, could sign it off. She was delegated by the doctor and then the doctor came later to check but it meant we didn't have to have people in there and I knew not to call the funeral home until I was ready. I knew that as soon as I called that they were legally bound to come within a certain period. I thought, "Well, I'm not going to call them until I'm ready," I kept her at home till the following day. I also knew that her body would expel stuff, that she would need to be cleaned up, and so we had all that in place. We allowed that to happen and then we cleaned her, washed her and took away her dirty clothes. And we laid her flat so that she wouldn't get stuck in the position, and closed her eyes. Then, I even Facetimed her parents, because they had gone home a few days before ... and they could see her and they said, 'She's got a smile.'

We had a wake. We did everything we wanted to do. We sang her spirit away and I invited people around to sit with her and I had the night with her myself. I just followed my heart and did what was right and I had all the space in the world to do that. I had the information to know that.

The lessons from this case: Two areas that the carer thought could be improved were communication and the assessment processes.

(Communication): the right time and the right way and really simply. How all the services fit together. Most people just think there's a nurse. They wouldn't know which service they came from or what they're doing there. People who work in that system forget how confusing it is.

(Assessment processes): being very much where the situation's at; context. So, saying, 'Okay, this is where it's at. We might have this flowchart of what we're supposed to do with the Box but you've got to read the situation and go, 'Well, that's not what's happening right now. This is not what the person needs right now. They need this'.

Case Study 3 Nurses' Perspectives: A hospice@HOME nurse received a phone call, advising her that a GP was interested in commencing a JiCB with one of their clients. "This client was only recently on our books so it was quite rushed". The next morning, this nurse was asked to coordinate the pick-up and delivery of the

JiCB and commencement of the syringe driver: "When we got to this client, she obviously was in end-stage life. The carer was quite distressed ... so it was a very awkward situation".

The hospice@HOME nurse has many years' experience and she quickly realised that the carer was struggling with the fact that the client was dying. She and another hospice@HOME staff member who was with her tried to pursue some education with the carer, who "was obviously in no state of mind to be receptive to anything we had to say". The carer was aware that the GP had recommended the JiCB but the nurse felt that, given that the client was actively dying, she really wasn't appropriate for a JiCB.

She actually needed a syringe driver there and then – and it should've been through community nursing or palliative care that that all happened, not with the JiCB because it wasn't a 'just in case' situation; it was (a right now situation).

The nurse also realised that the JiCB did not have the appropriate syringes in it so she had to call community nursing in any case. (She later found that she could have used a different type of syringe that was in the JiCB but she thinks that there is a need to ensure that the Box contains everything that is needed). The nurse said that it was a horrible situation for everyone involved. In hindsight, she felt that she should not have attempted to discuss the JiCB with the carer, or to demonstrate the videos. It was her first experience of trying to train someone to use the JiCB but unfortunately, given the condition of both the client and the carer, it was a complex and stressful situation, and very inappropriate. The key issues facing the client and the carer before the nurse arrived were that death was imminent and the client was in pain. The JiCB did not help to address those concerns.

Two nurses at management level in the relevant Community Nursing Service were also interviewed in relation to this client. They were not front-line staff and did not see the client; their information relates to the interaction they had with hospice@HOME when they were asked for a community nurse to provide support, and what they were told by their nurses. It differs in some aspects from the information provided above but supports the fact that, in this case, the JiCB was not appropriate and "that the impact of that has been incredibly negative".

With this particular client, Community Nursing had been referred only a few days before. I think we'd only been in for two short visits. On one of those visits, the nurse who went in felt that the client was at end of life and contacted Palliative Care Service for them to go in and reassess, and the feedback we got was, No, she's got weeks or months to go'. She was actually dead in three days.

Two days later, their service received a call from a hospice@HOME nurse, requesting assistance to set up a syringe driver:

So we deployed a nurse out there to do that. The driver was set up with medications that were in a brown paper bag on the bench. That's why it was not identified as anything to do with the Just in Case Box. It was in the paper bag on the bench from the chemist, which is normally what happens; family pick them up. So there was nothing unusual when our nurse arrived except that she found that she was the person setting it up rather than assisting. There was a syringe driver kit, a syringe driver and some medication that came from a chemist, so this was normal procedure.

Later in the day, the carer called the after-hours triage nurse and was distressed because the client was agitated, in pain, things were not going well at all and they requested some assistance. That triage nurse called the evening community nurse who said, "Yes, we have a plan to visit and we'll get there as soon as we possibly can." Before the nurses could get there, a second call came through from the carer stating that the nurse hadn't turned up yet and what was going on? The carer was quite distressed and that was relayed back to our community nurses who were not very far away at that stage. They arrived at the client's home (and Saf-T-Intima (the part of the syringe driver that goes into the skin) had been removed. (Possibly) the client had become agitated and pulled it out. There was a wetness around the nightgown, which indicated that perhaps medication had not been getting in, (which) may be why she was in the state she was in. Between the two phone calls from the triage service, our nurse did call the carer to find out what the situation was herself and what potential medication was there that they could give and that's when the carer said, "Well, I don't think the syringe driver's working. There's wetness here and she's not getting the drugs." The community nurse advised the carer to give a sublingual – I think it was clonazepam – to help settle the client down until they could actually get there. When they arrived, the client was agitated, appeared to be in pain and distressed.

The carer was very distressed about the whole situation and our two nurses calmed the situation, reinserted a Saf-T-Intima, got the infusion going again, gave a breakthrough dose to help boost that up and then looked at what was actually happening in the home and sat down and talked with the carer. What they found was a syringe drawn up with the vial sticky taped to it. It apparently had been drawn up by the GP who had visited after the syringe driver had been set up. The GP drew up the medication and just said to the carer, "Stick it in the bung (on the infusion line) here and just push it in a little bit if she gets distressed." Our nurses were very concerned

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about that so they discarded that medication and they drew up and labelled some breakthrough doses for the carer to give if she felt that she could and explained how that is done.

The carer and the other people there to support the client had felt that they were told that it was their responsibility to draw up the syringes every day and that they would be required to give whatever medication there was; this expectation caused the carer distress. When the first nurse had arrived that morning to start the syringe driver, she looked on YouTube for how to set it up because they didn't know how to set it up and then they called Community Nursing and asked for some help.

(These nurses thought that there was no Tablet in the JiCB with information on the process, or if there was, the carer wasn't aware that it was there).

The carer said that the nurse that morning was watching a YouTube video (on her mobile phone) to try ... to work out how to get a syringe driver going and that was when she called for a community nurse to come and assist. "This all happened in a very short space of time as well and it heightened the deterioration of that client".

(There was some confusion about who actually put the syringe driver in. The carer said that the GP did so but the management-level community nurses said that one of their nurses had done so. The GP for this client was not interviewed as participation cut off time had elapsed prior to seeking permission. The client's primary nurse did give permission to be contacted by the evaluation team but did not respond to email or phone messages from the evaluation team.) In relation to the syringe driver dislodging, the management-level community nurses said:

The community nurse who set it up said the Saf-T-Intima was very secure in the normal way that we do it. Her feeling was that the client, in her agitation, must've pulled it out. The message that the evening nurses received was that the Saf-T-Intima had fallen out but the nurse who put it in said it was impossible for that to happen. It would've had to have been yanked out – and that's fair enough. Clients will get agitated and do that.

Discussion and Recommendations

Many of the stakeholders interviewed for the evaluation were positive about the JiCB and what had been achieved for clients and carers, and in some cases for their nurses and GPs as well. Some stakeholders, in each of the four interview categories, were distressed to think that the service might not continue.

The primary purpose of everyone involved in providing care for clients/patients who are nearing the end of life is to improve the quality of that care, so that it is client/patient-centred. We observed that, where this did occur, the outcome was exemplary care for the client and carer, resulting in the best death possible; where it did not, care was compromised and additional distress was caused to both the client and the carer.

The following themes, identified through this evaluation, provide opportunities to improve the JiCB.

1. IMPROVE THE QUALITY OF THE CLIENT'S END-OF-LIFE CARE PLAN AND CONFIRM THAT THE JiCB HAS A PLACE WITHIN THE PLAN

The client's end-of-life care plan should be client-centred, reflecting their goals and wishes for this stage of their life, within the context of their health condition and the resources available to support them. It should be developed to ensure that it would meet the end-of-life care needs of the client, and by extension, their primary carer. This is reflected in the JiCB Guidelines (Sept 2016:4), which state that provision of a JiCB "should be part of ... the patient's overall plan of care (and) should involve the patient, the patient's family and/or carers, and the patient's primary care providers".

Therefore, the fundamental question to be asked in relation to provision of a JiCB is "Will the JiCB help to meet the needs expressed in the care plan?"

We observed that, in some cases, the client and/or carer were not involved in the original discussion; rather, they were only told about the JiCB, and had their first discussion about it, when it was delivered to their home. Some carers found this confronting, and in Case Study 3, where the client was actively dying, the introduction of the JiCB caused additional distress to the carer.

RECOMMENDATION: that a JiCB is not delivered to a client or carer's home unless: (a) it is likely to assist in meeting the client and carer needs, as expressed in the care plan, and (b) that the carer (and client where appropriate) has been well-informed about its purpose and has agreed that they should have one.

2. IMPROVE INTERACTIONS BETWEEN SERVICE PROVIDERS INVOLVED IN DELIVERING THE CLIENT'S CARE

The JiCB Guidelines (Sept 2016:4) state that: (the contents of the JiCB and the carer training) is fully supported by collaborative and coordinated liaison with the General Practitioner and the patient's other health care providers with frequent reporting and communication to ensure continuity of care. However, the JiCB was not well-received across organisations.

We observed a culture among Community Nursing Services, particularly at management level, that was not client-centred but was, instead, organisation-centred. The purpose of the JiCB was to help keep clients at home for as long as possible, if that was their wish, and to empower community care providers (whoever they are) to meet the needs of their clients (whatever those needs are). This requires team work and collaboration.

We observed that, not only was there limited cooperation, collegiality and collaboration across the sector, including from some GPs and Community Nursing Services, there were very definite parochial boundary-protection and "turf wars". For example, there appeared to be little insight among management-level Community Nursing Services staff about the limitations of what they can and cannot provide, which resulted in an unwillingness to work with other services. End-of-life client care needs are 24/7 but, except in a small number of location-specific services, Community Nursing Services operating hours are not well-aligned with end-of-life care needs. There appeared to be an acceptance that if the client needed care outside of Community Service hours, the carer should phone for an ambulance. Except in a limited number of cases where the Tasmanian Ambulance Service paramedics could provide emergency treatment, this would result in Emergency Department presentations and/or hospital admissions – precisely what the client and/or carer were seeking to avoid.

Teamwork and collegiality are important components of best-practice end-of-life care among interdisciplinary teams; where this was present, the outcome for clients and carers was greatly enhanced. Where it was absent, the outcome was detrimental for all concerned. Case Study 1 exemplifies best practice; the Plan was set up well in advance; the oncologist, GP, community nurses, and the client and carer were all involved and agreed that a JiCB was required. The interdisciplinary team communicated and collaborated well and the outcome was "the best death possible". By contrast, in Case Study 3 it did not appear that anyone was really coordinating care; this was an anticipated death, yet it did not seem that the GP, specialist team or community team had a Plan in place.

Discussion and Recommendations

In addition, the JiCB was delivered at a totally inappropriate time, which greatly increased the distress of the carer. Although the client eventually did achieve a “good death”, this was because of the efforts of the carer and her personal support team, with some input from the community nurses, rather than through a well-functioning interdisciplinary team.

RECOMMENDATION: that all services providing end-of-life client/patient care work together across the boundaries of care to achieve the best possible end-of-life outcomes for the client and carer.

3. PROVIDE GREATER CLARITY TO PROVIDERS ABOUT WHO IS RESPONSIBLE FOR DELIVERING SPECIFIC ASPECTS OF THE PATIENT’S CARE

We observed that providers lacked understanding about who was in the patient’s care team and which providers were responsible for each aspect of the patient’s care. All members of the care team should be aware of, and contribute to the Plan, and should communicate with other members of the care team in relation to what they are doing to achieve the client and carer goals.

Team members should be aware of who is responsible for:

- discussing the JiCB with the client and/or carer and assessing whether or not the JiCB will support the patient to achieve their goals outlined in their Plan;
- prescribing the JiCB and for informing other team members about this; and
- ensuring that the carer is well-trained in relation to JiCB contents and use.

We observed that poor role delineation between service providers led to multiple services trying to deliver the same care. This poor coordination contributed to decreased service quality and increased carer and patient distress.

Ultimately, someone needs to be responsible for the co-ordination of the patient’s care, to be a client and carer advocate and for supporting the client and carer to “navigate the system”. This may be the GP, the community nurse or the palliative care nurse, but whoever it is, everyone should know and respect that person’s role in the team.

RECOMMENDATION: that all members of the client’s interdisciplinary care team recognise, and communicate with, all other members of the team and that agreement is reached about who has ultimate responsibility for specific aspects of the patient’s care.

4. IMPROVE COMMUNICATION METHODS BETWEEN TEAM MEMBERS FOR BOTH ROUTINE AND AS-NEEDED COMMUNICATION

We observed poor communication between service provider organisations and between individual team members, which resulted in confusion for everyone concerned and undermined client care.

Planned Communication: All services and team members need to communicate any changes to a client’s condition, treatment or end-of-life Care Plan to all other members of the care team and their respective services.

Unplanned Communication: Team members need to feel comfortable to contact other members of the team to ask for advice and/or guidance if they are not sure about particular aspects of the patient’s care.

RECOMMENDATION: that all service providers contributing to the end-of-life care of a client establish, and maintain, effective formal and informal communication channels that facilitate information sharing and provision of advice amongst members of the care team, in accordance with patient care needs.

5. IMPROVE INFORMATION SHARING TO ENSURE THAT ALL TEAM MEMBERS HAVE ACCESS TO RELEVANT DOCUMENTS AND RESOURCES

Linked to the issues of communication and collaboration is information sharing. Every member of the care team must receive a copy of the client’s end-of-life Care Plan, medication chart, contact details of the carer and other informal client supports, and any other documents or information that might be needed to provide adequate care.

RECOMMENDATION: that all relevant documents and other information be shared with all relevant members of the interdisciplinary team.

6. STANDARDISE AND IMPROVE TRAINING FOR CARERS AND TEAM MEMBERS

The JiCB Guidelines (Sept 2016:4) say: Carers also receive a comprehensive and individualised, one-on-one education session, provided by trained Registered Nurses, to learn about the safe management of end of life medications using the Caring Safely at Home resources. However, training is needed for everyone involved in end-of-life client care; this includes carers, nurses from all participating organisations, GPs and anyone else who will have direct clinical care of the client.

Training of carers: We observed variable experiences in relation to the training carers received. For some it was excellent, for others it does not seem to have been so effective. An underlying principle of the JiCB project should be that if a carer is going to be provided with a JiCB they need to be properly trained to use it, either when the JiCB is delivered to the home or as soon as possible after that. (Note: this links to the timing of the delivery of the JiCB – see below). The training should be repeated at regular intervals if client care extends beyond two months, or if the trainer thinks that the carer did not comprehend everything that s/he needed to at the first session. Providing the Samsung Tablet with the training videos was helpful to carers who were given it. However, not enough carers received the Tablet for its use to be evaluated.

If it is clear that a carer does not wish to learn how to use the JiCB, this does not necessarily mean that the JiCB should not be provided in that home, as it may enable community care providers to access resources quickly if needed. However, in that case, all members of the interdisciplinary team need to be clear about who will activate the JiCB, and to instruct the carer about what to do if services are not available in an emergency (e.g., phone 000).

RECOMMENDATIONS: (1) that every carer who agrees to receive training to use the JiCB resources receives that training as soon as possible after the JiCB is delivered; (2) that an on-going training schedule be developed, with carers contacted at regular intervals and offered “refresher training”; (3) that hospice@HOME continue to provide the Samsung Tablet containing the training videos but re-evaluate its use when sufficient numbers have been distributed.

Training for GPs and Nurses: The skill-set required to provide high-standard, efficient end-of-life care is not discipline-specific; everyone who is likely to provide clinical care needs to be proficient in, at least, a basic set of skills and procedures likely to be utilised with clients at the end of life, e.g., all clinical care providers attending the client should be able to set up, and maintain, syringe drivers, without needing to call for assistance from another service. These skills should be developed to agreed standards, tested and form a major component of the credentialed “scope of practice” of all end-of-life care service providers. This should address some of the “demarcation and duplication issues” which we observed during the evaluation, e.g., who is “allowed” to set up and maintain a syringe driver.

There is also a safety aspect to such training: given that the JiCB contains a range of (potentially dangerous) drugs, as well as other equipment, everyone involved with its use must be familiar with the contents of the JiCB, the training manual and the medication orders.

RECOMMENDATIONS: (1) that GPs and nurses providing community-based care and support to clients and carers undertake procedure-specific skill training, which, in turn should be reflected in their credentials and scope of practice; (2) that when a patient/client is prescribed a JiCB, everyone providing their clinical care should familiarise themselves with the JiCB and its contents, unless they have already done so.

(NOTE: Resource implications of the training recommendations are acknowledged.)

7. IMPROVE THE QUALITY OF, AND ACCESS TO, AFTER-HOURS SERVICES: (See also Case Study 1)

We observed that lack of access to efficient and responsive after-hours services caused additional distress to clients and carers. After-hours services in Tasmania are now severely restricted; most of the Community Nursing Services do not have staff available after 9pm and hospice@HOME has been one of the few services available to provide after-hours services to terminally ill clients. There are a small number of after-hours medical services but, in addition to the doctors not knowing the clients, some of the doctors in those services do not have palliative care experience and a number of carers interviewed for this evaluation did not have positive experiences with the after-hours medical services. Although the hospice@HOME clients and/or carers are provided with a 1-800 number, we observed that carers did not always phone the number (calling other after-hours GP services instead) or have a satisfactory response from that service when 1-800 was called. As mentioned above, the JiCB Guidelines stated that the carers would be given a Tablet for 24/7 telehealth or video contact with a hospice@HOME Registered Nurse, but that component of the service had not, in fact, been available for some time.

A community nurse noted that the Tasmanian Ambulance Service Extended Care Paramedics provide 24/7 service, which in some cases, but not all, results in the client staying at home.

RECOMMENDATIONS: (1) That all services in Tasmania that provide community-based end-of-life care work together to develop a strategy to ensure that clients and carers have easy and fast access to after-hours contact and advice, including exploring better use of telehealth.

RECOMMENDATIONS: (2) That further investigation of the user experience of the 1800hospice number be undertaken, to ensure the phone message bank is not hindering care in moments of crisis and the appropriate processes are in place and followed.

Discussion and Recommendations

8. IDENTIFY THE OPTIMUM TIME IN THE CLIENT'S ILLNESS TRAJECTORY FOR DELIVERY OF THE JICB.

The JiCB Guidelines state that "It is important to anticipate the needs of patient and to place the Just in Case Box in the patient's home in a timely manner." (2016:6). Judging when is the right time to deliver the JiCB is often difficult, as prognosis of time to death is never certain. If the JiCB is delivered too early, it can signal to the client and carer that death is expected in the near future, which can be distressing for all concerned if they have not accepted that this is the case. However, it is more problematic if the JiCB is delivered when the client is actively dying and the carer is in great distress; not only is it probable that, at that point, the carer is in no state to receive training on the use of the JiCB but if the client urgently needs symptom alleviation, that should be delivered immediately by a well-trained community or palliative care nurse. (See also Case Study 3).

The JiCB Guidelines (Sept 2016:5) contain the following contraindications for ordering a JiCB:

- The patient is under the age of 18 and/or requires specific dose calculations;
- There is no person in the house who can be responsible for the Just in Case Box;
- There is a clinical improvement and the care plan is re-assessed by a physician.

RECOMMENDATION: That an additional contraindication be added: "When the client is actively dying and introduction of the JiCB would (a) detract from immediate client care requirements or (b) cause undue distress for the carer".

CONCLUSION

The increasing demand for high quality, responsive, community-based end-of-life care requires a whole-of-sector client-centred response. We conclude that the Just in Case Box has an important role to play in that response.

APPENDIX A



EVALUATION OF THE “JUST in CASE BOX (JiCB)” PROJECT INFORMATION SHEET FOR CAREGIVERS

1. Invitation

You are invited to participate in the evaluation of The District Nurses hospice@HOME Just in Case Box (JiCB) project. As you are aware, hospice@HOME aims to provide easy access to palliative care, so that people can receive care and die in their own homes, if that is their choice and if circumstances allow that to happen. One component of the service is the JiCB project, which provides medications and related medical supplies to people with a life limiting illness and their primary caregivers, as well as a range of care services during the last days of life. Comprehensive and individualised one-on-one education about the safe management of end of life medications and other resources is provided to the home carer by trained hospice@HOME Registered Nurses. hospice@HOME staff also liaise with the client's GP and other health care providers to ensure continuity of care.

2. What is the purpose of the evaluation?

The District Nurses have contracted the KP Health/University of Tasmania team to evaluate the outcomes associated with the JiCB, from client, carer and clinician perspectives, including whether or not having access to the JiCB enabled people to remain at home longer and/or to die at home if that was their choice. Findings from the evaluation will contribute to on-going development of services for terminally people and their carers in the community.

3. Why have I been invited to participate?

We understand that you have been receiving these services and we would like you to tell us about your experience of having the Just in Case Box in your home, as one of the services you received from hospice@HOME.

4. What will participation involve?

If you agree to share your thoughts and experiences with us, hospice@HOME will provide us with your contact details. A KP Health Senior Consultant will then phone you to make a time that is convenient for you to be interviewed, either face-to-face in your own home or by telephone, whichever you prefer. We expect the interview to take about 45 minutes. With your consent, the interview will be audio-recorded, so we don't miss important information that you provide. Any information that you provide will be kept completely confidential and no names or other identifying information will be used in the evaluation report. You may request the recorder to be turned off at any time. If the person you have been caring for is still alive and would like to be part of the interview, we will be happy for them to share their perspective as well.

Participation is completely voluntary; if you prefer not to take part in the evaluation, that will not have any impact on the services you receive from The District Nurses. If you do agree to the interview you may ask for it to stop at any time. You may also withdraw at any time and any information that you provided will not be used. You may also request that the information you provided be withdrawn, up until 15 September 2017.

5. Possible benefits of participation

Outcomes of the evaluation will contribute to on-going quality improvement in hospice@HOME services. This may benefit you and the person you care for, if they are still alive, and may also improve services for other patients and carers in the future.

6. Possible risks of participation

Talking about your experiences in an interview may be upsetting, or lead to the recall of painful memories. You are free to not answer any questions that you find upsetting, or ask the interviewer to stop at any time. If you do feel distressed the interviewer will be able to assist you or you can also contact The District Nurses for additional support on 1800HOSPICE (1800 467 7423).

7. What will happen to the information when the evaluation is finished?

All information from interviews will be stored securely in a locked filing cabinet in KPHealth office for five years, after which it will be destroyed.

8. How will the outcomes of the evaluation be published?

The outcomes of the evaluation will be provided to The District Nurses in a report. Dissemination will follow the Commonwealth guidelines and protocols for data release under the Better Access for Palliative Care (BAPC) project. Any publication from the project will be made publicly available via the Commonwealth data release schedule. The evaluation consultants and staff from The District Nurses may also prepare one or more papers reporting on the results of the study, for presentation at conferences and/or publication in academic journals. The publications will not include your name or any information that could be used to identify you.

9. Who do I contact if I have questions about the evaluation?

If you would like more information about the evaluation, please contact Professor Colleen Cartwright, Senior Consultant at KPHealth, by email at colleen.cartwright@kphealth.com.au or by phone 0411 048 635. If you prefer you may contact one of the other consultants, Dr Kelly Shaw (kelly.shaw@kphealth.com.au) or Amber Polles (amber.polles@kphealth.com.au).

This study has been approved by the Tasmanian Social Sciences Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on +61 3 6226 6254 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number H0016658.

This information sheet is for you to keep. If you are willing to participate in the evaluation, please read, complete and sign the attached Consent Form.

EVALUATION OF THE “JUST in CASE BOX (JiCB)” PROJECT CONSENT FORM FOR CARERS

1. I agree to take part in the evaluation named above.
2. I have read and understood the Information Sheet for this evaluation.
3. I understand that the evaluation involves participating in an interview of approximately 45 minutes.
4. I understand that the interview will be audio recorded but I can ask for the recording to stop at any time.
5. I understand that there is a risk that talking about my experiences may be upsetting or lead to the recall of painful memories. I understand that I am free not to answer any questions that I find upsetting, and can ask for the interview to stop at any time. I understand that if I feel distressed or in need of help, I can contact The District Nurses for additional support on 1800HOSPICE (1800 467 7423).
6. I understand that all interview data will be securely stored in the KPHealth offices for five years and will then be destroyed.
7. I understand that the interviewer will maintain confidentiality and that any information I supply will be used only for the purposes of the evaluation.
8. I understand that the results of the evaluation will be published but no identifying details will be used, so that I cannot be identified as a participant.
9. I understand that my participation is voluntary and that I may withdraw at any time without any effect.

Participant's name: _____

Participant's signature: _____

Date: _____

Statement by Consultant

The participant has received the Information Sheet where my details have been provided so participants have had the opportunity to contact me prior to consenting to participate in this project.

Consultant's name: _____

Consultant's signature: _____

Date: _____

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APPENDIX B



EVALUATION OF THE “JUST in CASE BOX (JiCB)” PROJECT INFORMATION SHEET FOR HEALTH/ALLIED HEALTH PROFESSIONALS

Invitation

You are invited to participate in the evaluation of The District Nurses hospice@HOME Just in Case Box (JiCB) service. As you are aware, hospice@HOME aims to provide easy access to palliative care, so that people can receive care and die in their own homes, if that is their choice. One component of the service is the JiCB service, which provides medications and related medical supplies to people receiving palliative care and their primary caregivers, as well as a range of clinical and non-clinical care during the last days of life through tailored “end of life packages”. Additional support is provided through 24/7 telehealth and/or video link to a Registered Nurse via a Samsung Galaxy Tablet. Comprehensive and individualised, one-on-one education about the safe management of end of life medications and other resources is provided to the home carer by trained Registered Nurses. hospice@HOME staff also liaise with the client's GP and other health care providers to ensure continuity of care.

What is the purpose of the evaluation?

The District Nurses have contracted the KP Health/University of Tasmania team to evaluate the outcomes associated with the JiCB, from client, carer and clinician perspectives, including whether or not having access to the JiCB enabled people to remain at home longer and to die at home if that was their choice. Findings from the evaluation will contribute to on-going development of services for terminally people and their carers in the community.

Why have I been invited to participate?

You have been identified as one of the health professionals who has been involved in the JiCB service. We would like to invite you to tell us about your experience with the JiCB service, and to share your thoughts about what worked well and what you think could be improved, if anything. Your involvement in the evaluation is completely voluntary. Neither your name nor any other identifying information about you will be provided to KPHealth unless you agree to participate.

What will participation involve?

If you agree to share your thoughts and experiences with us, a KP Health Senior Consultant will contact you to make a time that is convenient for you to be interviewed, either face-to-face in a place of your choice or by telephone, whichever you prefer. The interview should take about 30 minutes. Alternatively, you may prefer to attend a focus group with other clinicians involved in the JiCB service; these will be held in convenient locations and will last for approximately 1 1/2 hours. With consent of participants, interviews and focus groups will be audio-recorded, so we don't miss important information that you provide. You may request the recorder to be turned off at any time.

Any information that you provide will be kept completely confidential and no names or other identifying information will be used in the evaluation report. All focus group participants will be requested to keep any information arising during the focus group completely confidential but we will have no way of ensuring that participants abide by that request.

Possible benefits of participation

Outcomes of the evaluation will contribute to on-going quality improvement in hospice@HOME services. As a clinician in this area of work, you and your clients/patients and their carers may benefit from any improvements to the service.

Possible risks of participation

It is not expected that there would be any risks to clinicians from participation in the evaluation beyond the usual challenges of your work. Nevertheless, you are free to stop the interview or withdraw from a focus group at any time. If so, you may request deletion of information you provided during the interview; however, it will not be possible to delete information provided in focus groups, as that would impact on information provided by other participants.

What will happen to the information when the evaluation is finished?

All information from interviews or focus groups will be stored securely in a locked filing cabinet in KPHealth office for five years, after which it will be destroyed.

How will the outcomes of the evaluation be published?

The outcomes of the evaluation will be provided to The District Nurses in a report. Dissemination will follow the Commonwealth guidelines and protocols for data release under the Better Access to Palliative Care (BAPC) project. Any publication from the project will be made publicly available via the Commonwealth data release schedule. The evaluation consultants and staff from The District Nurses may also prepare one or more papers reporting on the results of the study, for presentation at conferences and/or publication in academic journals. The publications will not include your name or any information that could be used to identify you.

Who do I contact if I have questions about the evaluation?

If you would like more information about the evaluation, please contact Professor Colleen Cartwright, Senior Consultant at KPHealth, by email at colleen.cartwright@kphealth.com.au or by phone 0411 048 635. If you prefer you may contact one of the other consultants, Dr Kelly Shaw (kelly.shaw@kphealth.com.au) or Amber Polles (amber.polles@kphealth.com.au).

This study has been approved by the Tasmanian Social Sciences Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on +61 3 6226 6254 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number H0016658.

This information sheet is for you to keep. If you are willing to participate in the evaluation, please read, complete and sign the attached Consent Form.

EVALUATION OF THE “JUST in CASE BOX (JiCB)” PROJECT

CONSENT FORM FOR HEALTH/ALLIED HEALTH PROFESSIONALS

1. I agree to take part in the evaluation of the JiCB service.
2. I have read and understood the Information Sheet for this evaluation.
3. The nature and possible effects of the evaluation have been explained to me.
4. I understand that the evaluation involves me participating in an interview/a focus group (cross out whichever does not apply) of up to 1 ½ hours.
5. I understand that the interview/focus group (cross out whichever does not apply) will be audio recorded but I can ask for the recording to stop at any time.
6. I understand that there is no risk involved beyond what I would experience in my usual professional work. I understand that I am free not to answer any questions and can ask for the interview to stop at any time, or to withdraw from the focus group.
7. I understand that focus group participants will be asked to keep any information from the group confidential but KPHealth cannot guarantee that they will do so.
8. I understand that all evaluation data will be securely stored in the KPHealth office for five years and will then be destroyed
9. Any questions that I have asked have been answered to my satisfaction.
10. I understand that the KPHealth Consultant will maintain confidentiality and that any information I supply will be used only for the purposes of the evaluation.
11. I understand that the results of the evaluation will be provided in a report to The District Nurses and may be published in academic journals, but if so, only group information will be used and nothing will be included that could identify me as a participant.
12. I understand that my participation is voluntary and that I may withdraw at any time without any effect.

Participant's name: _____

Participant's signature: _____

Date: _____

Statement by Consultant

The participant has received the Information Sheet where my details have been provided so participants have had the opportunity to contact me prior to consenting to participate in this project.

Consultant's name: _____

Consultant's signature: _____

Date: _____

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APPENDIX C



EVALUATION OF THE “JUST in CASE BOX (JiCB)” PROJECT INFORMATION SHEET FOR GENERAL PRACTITIONERS

Invitation

You are invited to participate in the evaluation of The District Nurses hospice@HOME Just in Case Box (JiCB) service. As you are aware, hospice@HOME aims to provide easy access to palliative care, so that people can receive care and die in their own homes, if that is their choice. One component of the service is the JiCB service, which provides medications and related medical supplies to people receiving palliative care and their primary caregivers, as well as a range of clinical and non-clinical care during the last days of life through tailored “end of life packages”. Additional support is provided through 24/7 telehealth and/or video link to a Registered Nurse via a Samsung Galaxy Tablet. Comprehensive and individualised, one-on-one education about the safe management of end of life medications and other resources is provided to the home carer by trained Registered Nurses. hospice@HOME staff also liaise with the client's GP and other health care providers to ensure continuity of care.

What is the purpose of the evaluation?

The District Nurses have contracted the KP Health/University of Tasmania team to evaluate the outcomes associated with the JiCB, from client, carer and clinician perspectives, including whether or not having access to the JiCB enabled people to remain at home longer and to die at home if that was their choice. Findings from the evaluation will contribute to on-going development of services for terminally people and their carers in the community.

Why have I been invited to participate?

You have been identified as one of the health professionals who has been involved in the JiCB service. We would like to invite you to tell us about your experience with the JiCB service, and to share your thoughts about what worked well and what you think could be improved, if anything. Your involvement in the evaluation is completely voluntary. Neither your name nor any other identifying information about you will be provided to KPHealth unless you agree to participate.

What will participation involve?

If you agree to share your thoughts and experiences with us, a KP Health Senior Consultant will contact you to make a time that is convenient for you to be interviewed, either face-to-face in a place of your choice or by telephone, whichever you prefer. The interview should take about 30 minutes. With consent of participants, interviews will be audio-recorded, so we don't miss important information that you provide. You may request the recorder to be turned off at any time.

Any information that you provide will be kept completely confidential and no names or other identifying information will be used in the evaluation report.

Possible benefits of participation

Outcomes of the evaluation will contribute to on-going quality improvement in hospice@HOME services. As a clinician in this area of work, you and your clients/patients and their carers may benefit from any improvements to the service.

Possible risks of participation

It is not expected that there would be any risks to clinicians from participation in the evaluation beyond the usual challenges of your work. Nevertheless, you are free to stop the interview at any time and you may request deletion of information you provided during the interview.

What will happen to the information when the evaluation is finished?

All information from interviews will be stored securely in a locked filing cabinet in KPHealth office for five years, after which it will be destroyed.

How will the outcomes of the evaluation be published?

The outcomes of the evaluation will be provided to The District Nurses in a report. Dissemination will follow the Commonwealth guidelines and protocols for data release under the Better Access to Palliative Care (BAPC) project. Any publication from the project will be made publicly available via the Commonwealth data release schedule. The evaluation consultants and staff from The District Nurses may also prepare one or more papers reporting on the results of the study, for presentation at conferences and/or publication in academic journals. The publications will not include your name or any information that could be used to identify you.

Who do I contact if I have questions about the evaluation?

If you would like more information about the evaluation, please contact Professor Colleen Cartwright, Senior Consultant at KPHealth, by email at colleen.cartwright@kphealth.com.au or by phone 0411 048 635. If you prefer you may contact one of the other consultants, Dr Kelly Shaw (kelly.shaw@kphealth.com.au).

This study has been approved by the Tasmanian Social Sciences Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on +61 3 6226 6254 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number H0016658.

This information sheet is for you to keep. If you are willing to participate in the evaluation, please read, complete and sign the attached Consent Form.

EVALUATION OF THE “JUST in CASE BOX (JiCB)” PROJECT

CONSENT FORM FOR GENERAL PRACTITIONERS

1. I agree to take part in the evaluation of the JiCB service.
2. I have read and understood the Information Sheet for this evaluation.
3. The nature and possible effects of the evaluation have been explained to me.
4. I understand that the evaluation involves me participating in an interview/a focus group (cross out whichever does not apply) of up to 1 ½ hours.
5. I understand that the interview/focus group (cross out whichever does not apply) will be audio recorded but I can ask for the recording to stop at any time.
6. I understand that there is no risk involved beyond what I would experience in my usual professional work. I understand that I am free not to answer any questions and can ask for the interview to stop at any time, or to withdraw from the focus group.
7. I understand that focus group participants will be asked to keep any information from the group confidential but KPHealth cannot guarantee that they will do so.
8. I understand that all evaluation data will be securely stored in the KPHealth office for five years and will then be destroyed
9. Any questions that I have asked have been answered to my satisfaction.
10. I understand that the KPHealth Consultant will maintain confidentiality and that any information I supply will be used only for the purposes of the evaluation.
11. I understand that the results of the evaluation will be provided in a report to The District Nurses and may be published in academic journals, but if so, only group information will be used and nothing will be included that could identify me as a participant.
12. I understand that my participation is voluntary and that I may withdraw at any time without any effect.

Participant's name: _____

Participant's signature: _____

Date: _____

Statement by Consultant

The participant has received the Information Sheet where my details have been provided so participants have had the opportunity to contact me prior to consenting to participate in this project.

Consultant's name: _____

Consultant's signature: _____

Date: _____

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APPENDIX D

EVALUATION OF THE “JUST in CASE BOX (JiCB)” PROJECT SEMI-STRUCTURED QUESTIONNAIRE GUIDE FOR CAREGIVERS

(Prior to each session we will be told if the client is alive or deceased, and if deceased, when did s/he die. We will also know the carer's relationship to the client. Note: 4 clients lacked capacity).

After introductions and some basic conversational exchange, the following questions can be asked. These are only a guide, and the interview will follow where the carer wants to go with “the story”.

1. Can you tell me a little bit about (client)?
 - a. How long had s/he been unwell?
 - b. Were you his/her full-time carer? For how long had you been in that role?
2. What was the best part of being his/her carer? (expand from response)
3. What was the most challenging part of being his/her carer? (as above)
4. Did any other family members, friends or community members provide you with any support in your caring role?
5. What services was (the client)/were you receiving?
6. Who told you about the Just in Case Box? GP? District Nurse? Other?
7. Did the GP discuss a Medical Goals of Care Plan with (the client?) and with you? (Explain: a MGOc Plan outlines the care and treatment proposed for the client, and the benefits that can be expected from such care and treatment)
 - a. (If so), what did you gain from those conversations?
 - b. (If not), would you have preferred it if the GP had discussed it with you (and or the client?)
8. Did you talk about the Just in Case Box to:
 - a. Family members?
 - b. Personal carers?
 - c. Nurses who came to provide care?
 - d. Anyone else?

(If yes) Where these discussions helpful? Did they encourage you/others to talk more about death and dying, and what you were most concerned or fearful about or what you needed more information about?
9. Before receiving the Just in Case Box, had you and/or (the client) completed any Advance Financial Planning/ Advance Care Planning documents? e.g, had (the client)
 - a. appointed you or anyone else to have Enduring Power of Attorney for financial matters?
 - b. appointed you or anyone else as his/her Enduring Guardian to make health care decisions for him/her in s/he lost capacity?
 - c. written an Advance Health Care Directive?

10. (If no), were you encouraged to complete any Advance Planning documents when the Medical Goals of Care was developed, or when you received the Just in Case Box?
11. After receiving the Just in Case box, did you and/or (the client) complete any Advance Financial Planning/ Advance Care Planning documents? e.g., did (the client)
 - a. appoint you or anyone else to have Enduring Power of Attorney for financial matters?
 - b. appoint you or anyone else as his/her Enduring Guardian to make health care decisions for him/her in s/he lost capacity?
 - c. write an Advance Health Care Directive?
12. I understand that you were able to care for (the client) at home (for the whole time s/he was unwell) or (until very close to the end of his/her life) or (until his/her care needs reached a point where the only option was to go into ...palliative care unit/hospital/ residential care/other). (Also explore if there were multiple hospital admissions or transfers out of the home). Can you tell me about that?
13. (Explore role of having JiCB at home in relation to above)
14. I understand that you received (did not receive) training provided by a Registered Nurse to make sure you knew how to give medication out of the Just in Case Box. Can you tell me about this?
15. (For those who did) How did the training make you feel?
16. I understand that the box was used (not used) in (your/the client's) home.
 - a. (if used) Did you give any medications? (If yes) How confident were you to give the medications? if not, who did?
 - b. (if used) How long did you have to wait from when you identified the client needed the JiCB medications to when medications were given? What happened in that time? (e.g., GP came to assess, community health nurse said she was coming to do it etc.)
 - c. (if not used) Why do you think it was not used?
17. What were the advantages of having a JiCB? What concerns (if any) do you have about JiCB? How can these be addressed?
18. In what ways did the JiCB contribute to your ability to care for (client) (if any)?
19. (if client is dead) Were you satisfied that (client) experienced a good (comfortable) death?
20. What did you do with the JiCB after (client) died?

APPENDIX E

SEMI-STRUCTURED QUESTIONNAIRE FOR RNs/ALLIED HEALTH STAFF IN RELATION TO THE JiCB EVALUATION

1. What is your understanding of the JiCB project?
2. How did you become involved with the project?
3. How many patients/clients in your care received a JiCB?
4. Did you talk about the Just in Case Box (the MGOC/ the ACP) to:

Clients?/ Primary carers?/ Family members?

Other team members who came to provide care?/ Anyone else (e.g, the GP, SPC)?

(If yes) Where these discussions helpful? Did the JiCB encourage you/others to talk more about death and dying? Did participating in the JiCB project enable you to have additional conversations with clients and/or their carers about death and dying (more than would have occurred with usual care)? and any information they may have needed?
5. Can you describe any advantages of the JiCB for the client? the carer?
6. What were the advantages of the JiCB (if any) for you? (Possible prompts for interview: did it save time? was it more efficient?)
7. Once you became aware that the client needed symptom relief, what did you do? (Suggest use of JiCB? Go to client?)
8. Was the JiCB activated? (If yes, by whom? If by participant) what triggered the activation?
9. Were there any safety issues relating to the JiCB that caused you concern? What were the circumstances of these? Were they addressed? If so, how? If not, how could your concerns be addressed?
10. In your opinion, what were the key issues facing/faced by the client and/or their carer? (If prompts are needed: was it medication access? Pain? Other distress? Delirium? Did the JiCB help to address these concerns in any way?)
11. What was the contribution of the JiCB to the quality of palliative care the patient/ client received (if any)?
12. Do you think that providing the JiCB to the client (and their carer) resulted in other benefits to them?
13. Do you think the JiCB assisted the patient/client to remain at home longer?
14. For those patients that were admitted to hospital, what was the reason for admission?
15. For the patient(s) who have died;
 - a. Did you receive any comments about the death from family, carers (was it a good death)?
 - b. are you aware of how the JiCB was retrieved/returned after the patient's death?
16. Do you have any further comments you would like to make about the JiCB project? (If time permits, could ask about timing in relation to when the patient received the JiCB: was it too early in their palliative journey? When is a 'good time?')

APPENDIX F

SEMI-STRUCTURED QUESTIONNAIRE FOR GPs IN JiCB EVALUATION

1. Can you describe your involvement with the JiCB project?
2. How many patients in your care received a JiCB?
3. Why was the JiCB prescribed for that patient/those patients? (Ask about each one)
4. What was the process for having a JiCB delivered to your patient and their carer? (e.g., did you have to just complete a form and send it to hospice@Home, or did you contact the pharmacist directly?)
5. What was your experience of the process for getting a JiCB delivered?
6. Were there any barriers to it being supplied to your patient/their carer?
7. Were you contacted for a medication order related to the JiCB?
8. Do you know if any of the drugs from the JiCB were administered?
If yes, do you know who administered them and why they were required?
If no, do you think there were times when they should have been but were not?
9. What was your experience related to the accessing of pre-emptive medications from the JiCB?
10. Were there any barriers to the JiCB being used?
11. What were the advantages of the JiCB for the patient/the carer/you, if any?
12. Were there any safety issues relating to the JiCB that caused you concern? What were the circumstances of these? Were they addressed? If so, how? If not, how could your concerns be addressed?
13. What do you think are/were the key issues facing/faced by the patient and/or their carer?
14. What was the contribution of the JiCB to the quality of palliative care the patient received (if any)?
15. Do you think that providing the JiCB to the patient (and their carer) resulted in other benefits to them?
16. How did the carer feel about receiving the JiCB? Were they confident in their ability to use it if required?
17. Do you think the JiCB assisted the patient to remain at home longer?
18. Did participating in the JiCB project assist you to provide better patient care?
19. Did participating in the JiCB project enable you to have additional conversations with patients and or their carers (or patients/carers outside the project) and/or other interdisciplinary team members about death and dying (more than would have occurred with usual care)?
20. Did it assist you in providing any additional information they may have needed, e.g., what they might expect in relation to pain and/or other symptoms?
21. Are you aware of how the JiCB was retrieved/returned after the patient died (for those who did die)?
22. Do you have any further comments you would like to make about the JiCB project?

APPENDIX G

SEMI-STRUCTURED QUESTIONNAIRE FOR PHARMACISTS IN JiCB EVALUATION

1. Can you describe your involvement with the JiCB project?
2. How many patients/clients did you personally dispense medications for?
3. Of the medications listed in the 'Just in Case Request Form' which medications were routinely prescribed?
4. Were there any medications on the request form that were not dispensed? If yes, why was that?
5. Were there additional medications prescribed that were not on the request form? If yes, why do you think that was?
6. With the JiCB medications prescribed, were there any incidences of drug interactions with the patient's current medications or contraindications with the patient's medical conditions?
7. Did you engage with the client's regular pharmacist/GP (or did they engage with you) for any reason related to the JiCB project?
8. Did you have any direct interaction with the patient/client? The carer? If not, were you aware of any barriers that prevented them visiting the pharmacy?
9. Did participating in the JiCB project assist you to provide better patient care?
10. Do you have any safety concerns have about the use of JiCB into the future? If so, how could your concerns be addressed?
11. Did participating in the JiCB project enable you to have conversations with clients and/or their carers and/or other interdisciplinary team members about death and dying and any information they may have needed?
12. How were the medications retrieved/returned after the patient died (for those who did die)?
13. Do you have any further comments you would like to make about the JiCB project?



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