

The Pallium Project  
le projet Pallium



Working Together to Improve the Quality of  
Living and Dying in Canada

Travailler ensemble pour améliorer la qualité  
de la vie et de la fin de vie au Canada

**Transcript from the Participant  
Question & Answer (Q&A) Session  
of the  
Hospice Palliative Care (HPC) Telenursing  
Subproject National Stakeholder Briefing**

A post-conference event to the  
2005 Canadian Hospice Palliative Care Conference  
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**Pallium Project (Phase II)  
Hospice Palliative Care (HPC) Telenursing Protocols Subproject  
Stakeholder Briefing Session**

September 29, 2005

Westin Hotel, Edmonton, Alberta

**Note to Reader:** The following narrative is a written transcript prepared from a recorded stakeholder briefing session. This session took place as an open invitation event for hospice palliative care and telenursing stakeholders as a post-national conference event to the 2005 Canadian Hospice Palliative Care Conference. A companion video briefing by Carolyn Tayler, Chair of the subproject steering committee and a case study by Della Roberts and Diane MacCormack are also available as archival video footage at [www.pallium.ca](http://www.pallium.ca).

Every reasonable effort has been made to accurately record the questions, responses and comments made during the session. Where, upon final review of the transcript, it has been determined that additional commentary would be useful to help situate comments in context, contextual comments have been offered in [ *in square brackets* ] to assist the reader.

**Session Transcript**

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**Marie-Josée Paquin**

Would Fraser Health have been able to implement this project if it wouldn't have had the Palliative Response Nurse (PRN) team available?

**Carolyn Tayler**

Yes, I think there are ways of implementing, and we were just talking about that in the break. If the link were back to an emergency department, somewhere up north, in a hospital, and that emergency department knew that calls might come in, might come back, and you set up a process in place, could that work? I don't see why it wouldn't.

If it were going to a nursing outpost, could it work? Is there anyone that would take the call now? Some people have suggested a family physician who already takes call. And we heard in Manitoba when we were talking to folks there, that in the North they have a roster of family physicians and one of them is on call for everything all the time. So, could a call go back to that person who was the designated on-call health care professional? Yes. The systems would have to be put in place differently than we put them in place – in Fraser Health – but the concept is the same. The concept is that you don't just leave the patient say, "Sorry we can't help you. I hope you make it until morning." Right?

To set that up is almost unfair, I think, to the patient, because you've only taken them halfway. So, what it looks like on the other end, I think, is really the work of the health region who needs to ask themselves, "What do they have in place right now? What could they put in place?" And to some extent, it pushes you to ask yourself if you are meeting the standards that we would say palliative care patients should have in Canada, which would be 24/7 access of some kind. Clearly, there is minimum access and there is maximum access. In Fraser Health, we are fortunate enough to have argued for the dollars for an on-call nurse, we have a CNS and we have physicians, and in some cases the ability to actually go out to that home. So we have been able to say, you might find that as maximum access. Now if you look at Victoria Hospice where they have a PRN team that includes a social worker that can come out and a nurse, they have a high level of access. But we know that many patients in Canada don't have that access and that is the standard. If you are now accredited through CCHSA under the Hospice Palliative Care Standards, they will ask you, "What are you doing about 24/7 access?" So health authorities are going to have to be able to answer that question. And I think it's an important question.

**Ann Syme**

There is a nuance to that, Carolyn, that is important to recognize though, that is important to recognize though that if you do go to that rural and remote notion of how you would set that up, the whole question of being known as palliative is where I think it flounders, because, then what do you do? If your decision, knowledge resources based on the knowledge that you have a patient who is in fact palliative, then how does the call nurse know how to proceed then through her triage?

**Carolyn Tayler**

OK, so maybe I can answer that, and Della may as well.

So the question becomes, and this is certainly a frequently asked question, I guess, that we have talked about is, “How do you know?” So, for example, we don’t have a formal home health program, and the patient isn’t enrolled as a palliative home health patient. If a family physician in a rural and remote area were looking after a patient and knew that they were palliative, they could give them a designated [phone] number. They don’t need to be rostered. They would be given that specialized [phone] number. Now then you could say, “Well, how does the physician in the emergency department who then takes that call know?” They would be triaged back from whatever nurse line that was to say, “We’ve had a call from a palliative patient who phoned our designated line and he is now phoning you.” Does that answer your question?

**Ann Syme**

How does a palliative patient know the designated number?

**Carolyn Tayler**

They would be given it by a health-care provider, any health care provider. It does not have to be a homecare nurse. It could be a family physician.

**Ann Syme** (difficult to hear)

**Carolyn Tayler**

How do we know that patients are palliative?

**Ann Syme**

Not to say that’s going to solve the problem but there are a lot of patients out there who are palliative, and their family physicians never tell them.

**Carolyn Tayler**

Yes. [Acknowledging the “truth telling” challenge and reality]

**Ann Syme**

They insist that they are palliative, they’re wandering out there. Yes, this is beginning to push that in, but there are all those patients, and I would say the further that you move out, I mean it’s an assumption that I have, what if that “wandering patient” becomes more prevalent, and how will we ever capture them?

**Della Roberts (British Columbia)**

I guess that one of the things that I say around that, Ann, is that, and maybe Diane can talk a little bit further about this, patients call the NurseLine, people call the Nurse Line for help. It’s a *known resource*. So there is some spin off for nurse lines. I think it’s been a spin off to patients generally who are calling from BC that say, “I have advanced cancer or my wife has just died.” There is some generalist knowledge within what we have augmented that helps. And also, linking people back in. I think in relation to there is a boundary of service with all of our services. I think that the boundary of service in the NurseLine is if they are going to deviate from their call flow, it has to be a “known” patient [one known to the delivery system as palliative]. So, does that mean that there will be some people that then therefore wouldn’t get as good of direction or whatever? Yes, that’s true. But I don’t think that. I think that there is still the possibility for many people [to receive service] and if you actually were able to establish this service in a remote area where family physicians gave the phone number out, well then the community begins to know. Oh, there’s a special place that you can phone because my aunt’s cousin had that [Service to support end-of-life care via phone]. It creates that same word of mouth, and especially in a rural area. Coming from a rural area I’ll tell you word of mouth works very effectively.

So, I think that there is the potential to have it be a different system, [than the specific Fraser Health model] yet the Nurse Line will still have a boundary of what they can do outside of the protocols. That's just recognized.

**Carol Shemenchuk (Alberta)**

I also want to upfront say that I acknowledge how much work you've done and it's tremendous. I consider you a sister in tele-health triage. I just kind of, in support of all the work that you have done, I would suggest that maybe don't use the word *deviate*. I would really like to see you sort of say that you're not triaging as usual, but that you're using triage principles, and working with specific care plans. I just wonder in general and I don't need an answer to this, but have you explored some of the legal and ethical issues around what we might consider when we do a normal triage, around validating a DNR, is that a standard, or how do you work with some of that? Would that be under the approval or the jurisdiction of the medical director, for example, of each call centre? For example, in Alberta, what we do with our medically approved protocols is he has medical approval, and so we review them within the Alberta context, within actually the Capital Health, Calgary, all of the regions. So within that context, I just wonder about the legal and ethical issues? And again not that I need an answer, I just wonder about that.

**Diane MacCormack (British Columbia)**

Just as I introduce the effect of having the protocols evidence-based and medically approved, we worked with Dr. Doris Barwich, who is Medical Director of palliative care in Fraser [Fraser Health Region]. Then [I] took them to our medical director who signed off each one so they had legal and ethical [status]. And he was aware of each Alert, and every time an Alert is added we have a process through our Q.A. [Quality Assurance] Office that we follow, and then pass across to the doctor to sign off, so it's absolutely supported. Just to speak to what you're saying about "deviate", it's a word that we use, because we are moving away from our traditional line of business, so I appreciate you saying that, because we are still triaging, we're still following [approved] protocols, and we're not deviating in a devious fashion. (laughter)

We're moving away and we're trying to set up a new line [of service]. I just want to speak to what Ann (Syme) was saying to support Della (Roberts). We definitely have to know that the person [a caller] is in a registered palliative program. And what form that takes will be identified by each community, because we can not leave our traditional protocols unless we know we are passing across to someone that will accept that [legal and regulatory] responsibility. So we would be following our traditional protocols, unless the individual was in a registered [palliative] program. There are folks in Fraser [Health's catchment] who will call us. They indicate that they are in this particular state, this is what is happening, and we ask, "Are you having services from a home care nurse?" "Well no, not yet. We haven't got to that point." So we refer them. A lot of folks just don't know the system, so we refer them. They come to the home care office by phone [present to the system] and the nurse comes out.

**Carol Shemenchuk**

I'm just wondering if, in the tremendous work that you have done, are there some health care issues that are not appropriate to resolve through telephone contact?

**Diane MacCormack**

We had spoken about the acuity of certain palliative care situations. Della addressed those for us to recognize. I believe one was [spinal] cord compression. Is that what you're referring to? A symptom set that appears that we can't resolve?

**Carol Shemenchuk**

Or just that it would be appropriate in a face-to-face interaction, or it would be more appropriate?

**Diane MacCormack**

The face-to-face interaction comes the immediate next morning. We're providing the [after-hours] support, as we've said to occupants; we offer the [after-hours consultative] services of a palliative home care nurse. So the face-to-face... we (Della) were talking about that last night actually... and of all the calls we didn't see, that face-to-face would have made an impact as such.

***Della Roberts***

I guess that if they need face-to-face, then you have to figure out where that can happen. Is that going to Emergency [an Emergency department], is that what they need [based on their H.P.C goals of care]? Depending on what the health authorities side, or the health region was to set up for their capacity, you have to work within, and in the boundary of the services, we are able to provide telephone support only. And if they need, because they live up in this rural area, if they need face to face, then they have to go into the Emergency department [of their local hospital].

So, I guess in relation to this, is there anybody that shouldn't phone? If they need help, and it is beyond what that family can manage, then it's a start. It's starting with that phone call and if, as we showed you, if it's a new symptom that is something acute, then the nurse lines are well versed in relation to dealing with that; with getting them connected with emergency services.

***Carol Shemenchuk***

Well I guess that part of that maybe as that home care nurses are telling the caller that you can call the telephone triage nurse, you might have a list of 'here are the things to call about, here's a list of things you need to call your physician, or the ER.' I guess something about educating the families about what is appropriate.

***Della Roberts***

I think that one of the things that you have to remember about these families - look at some of the scenarios we gave you. They are managing very acute changing symptoms. So when they phone, we know that they've gone beyond what they've got and they need some help. And sometimes they don't even know what it is [they need] .You know that from tele-health, that they're not even sure they know what it is that they need until you're part way through the conversation. So, I think what we know is that families need to know what their [point of] contact is and then it's on our side to figure out how to help them; where our help is most appropriate. It can be confusing enough, like Carleen (Brenneis) said, now they've got two

phone numbers. This is what you call during the day and this is what you call during the night. And even that, you know, the ideal system is that you'd call one place all of the time.

***Carleen Brenneis***

Well, you just change your day voicemail that it goes into one line and says call this one, or divert it, you can set up your system so that it goes that way.

***Della Roberts***

I guess one of the things that's important for people that do not have [access to] specialized palliative care programs, which I think is most of the country, is that you also don't want to have on your generalized phone message; the specialized palliative care numbers. You [would] have people calling there that aren't actually within that capture group. The whole, whatever you set up as your interface, has to be thought through quite clearly, and most programs actually are generalist programs.

***Carolyn Tayler (British Columbia)***

And that would be true in Fraser Health. We don't have specialty palliative home care, so it's generalized home care. I don't think that we mentioned that. Other questions?

***Janice Chobanuk (Alberta)***

This is probably my own passion, so you'll have to forgive me if I'm going too far. I keep thinking of the continuum of care and continuity of care, about palliative care and that body of knowledge and how it could benefit people that are in, for example, a long-term care facility. They're not in designated living, they're not in a lodge, so it sort of passes beyond home care, but there's this body of expertise. So, if I was in a long-term care facility and designated palliative, but I'm not quite in that other system, and I had a call, because I didn't know how to manage a symptom, and you have LPN's that might not be experts in this area, or nursing attendants not trained in that area and they make a phone call, could they access this service, "Ah, what to do? Can you give me some advice?" How do you entertain that kind of situation?

**Carolyn Tayler**

Diane, I'm going to let you answer that one.

**Diane MacCormack**

Yes, we have. We have had calls come in from assisted daily living and nursing homes. We have to refer them back to their system, so we will ask them to contact their nurse because they have a call bell beside them, or contact the supervisor on the floor. We cannot engage because of our duty of care.

**Janice Chobanuk**

Oh, see and that's where my gap is, because those nurses don't have that body of knowledge.

**Diane MacCormack**

Well then, I guess then that speaks to the need to have reinforcement of the body of knowledge in order to support the persons in the facility. They are in care, and we have to return them to the persons [primary healthcare professionals] in their care form. I don't know if Alberta has the same situation.

**Kathy Taylor (Albera)**

Is this the way you set it up? Is this the way you see to go forward? Will you make changes yourself on a go forward basis, based on funding?

**Diane**

**MacCormack**

From the telehealth side?

**Kathy Taylor**

Yes.

**Diane**

**MacCormack**

We are constantly! Our operative word is change! We are taking the lead of the nurses. This is what it looks like right now, and we're at 168 [HPC] calls. We're sitting down now and looking at how far we've come along. We're going to develop focus groups, we're going to develop more on-line education resources, and we're going to be listening to the nurses because they're taking the calls. We're also looking at whether we can start to build a capacity of the nurse in various strategies. I'm very excited! We're opening a new door. We have felt very successful. Velda (Clark) was talking with me. We're looking at how to address the value the

nurses are contributing in the tele-health field and being a virtual member [of the HPC team]. It certainly addressed what I was concerned about for the *window of suffering* that is opened. And I talked to Dr. Barwich about it - immediately two human beings are connected in that space [total end-of-life issues/engagement]. How do we support the nurse in that role? We're looking at how to create strategies, again through focus groups. How do tele-health nurses feel valued... that they're doing valuable work in palliative, and how they want to seek to build their own capacity.

**Carolyn Tayler**

I think that I could comment on the BC situation. We always knew right from the beginning that Fraser Health was first at the door, but clearly there's a provincial mandate to move this forward. The Assistant Deputy Minister is very clear that they [B.C. Ministry of Health] see that this is something that they would want to validate throughout the province. So, Fraser Health was the beginning as a *pilot*, but it was clear right from the beginning that this was seen as potentially a model for the rest of the province.

**Diane MacCormack**

Thanks, Carolyn.

**Kathy Taylor**

Yeah, I was thinking outside [of the Fraser Health region], like how soon will you go to the rest of the province?

**Carolyn Tayler**

As soon as we can.

**Diane MacCormack**

I'm sure that there will be calls coming to Lori Halls quickly, and then how can we start moving forward?

**Kathy**

**Taylor**

Do you have any sense in what the cost of implementing palliative care into your call centre, into your business looks like, orientation, etc....?

**Michael Aherne**

Do you mean the enhanced protocols?

**Kathy Taylor**

Yes.

**Diane MacCormack**

Certainly we can give you that information as far as time, the number of hours. Della documented the number of hours. Certainly we were meeting weekly, and then it moved out into monthly, then of course the start up was a lot of hours.

**Kathy Taylor**

It's kind of tough because you've already established it.

**Diane MacCormack**

But I can certainly think about it for you and take your card and send that information on to you.

**Della Roberts**

I think we spent a lot of time in development. It took us a long time to figure out what were the processes that needed to be augmented to support practice. But in relation to the actual implementation, like Darcie (Bidgood) and I were talking about, there are some practicalities from the health region side: Who would take the call? How would the call come in? Where would take the faxes come? How would they be distributed? How would you have one phone number? One of the things that we tried to do was, and Diane (MacCormack) was really good at pushing back in relation to this: "No Della, that may sound practical from your side, it's not practical from our side. We have to have one phone number. We have to have one fax. We have to have it standardized. From the palliative care side, the learning for us is: "What are the boundaries?" From the NurseLine side, where are your must haves, and where are our must-haves, and where is the interface of that? But I don't know that the time and implementation is around figuring out, from the interface, for the health authority's side, and the nurse line side. It's an education piece. It's an education piece and the mentorship and change management.

**Kathy Taylor**

Diane (MacCormack), I read here that you have a generalist model also.

**Diane MacCormack**

Yes, we do.

**Kathy Taylor**

So every nurse was educated the same then?

**Diane MacCormack**

As I said for the definition of a nurse that could take enhanced assessment calls, she or he had to be there for six months, go through the workshop for three hours, which is now going to be four hours, and have the support through myself initially for mentorship. Now it is out into the team manager group to support. I'm still around to support. A lot of work, for sure, in the beginning, and now I'm feeling, as we have moved on, less work.

**Velda Clark**

[My contribution is] a comment. To be clear here, the [2004 Ipsos-Reid] survey done by CHPCA indicated that 50 per cent of the population said they *would* call a health line [for HPC support]. So there we are like "sitting ducks". If we're wearing the health line hat, the expectation is that we are a resource. *Fifty per cent* of the people, that's overwhelming!

The second thing is that a lot of us are attached to very urban, developed systems and programs. I have to go back to the slide [of the Aboriginal woman in Northern Saskatchewan] because this really came to be for me when I traveled the northern part of the province. And I mean in the northern two-thirds of Saskatchewan. And what kind of palliative care [services] are we offering up there if it isn't through a health line?

The lady that I visited... I was up there with Health Line [in Velda Clark's then capacity as Founding Director of Saskatchewan Healthline] and I ended up doing six home visits to palliative care patients who had no access to direct care but they all had a phone. The lady in the picture, with the fungating tumor... she was using, quite effectively, some moss for. Her access to care other than her telephone was a float plane or the barge that came once every three weeks. Her son drove [the barge] from Fort McLeod. He brought her drugs and dressings as he could. Now, she had a phone. If she could call the

Health Line in our province and have access to developed protocols...wow! And she would have 24-hour access to palliative care protocols. And she was *known* [as palliative] to her outpost nurse who was in Stony Rapids. Now that was way across the top of the province. But she was still registered, if you will, as a palliative care patient. So, there are ways for us to make this happen for all of these people who have no [other] access. But they have phones up there, believe me, they have phones.

I just have to say what Fraser [Health and B.C. Ministry of Health] is offering the rest of us is rare gift. They have done the work. They're living the experience and they're bringing to us a "wow"! They've done the prototype. Yeah, we have to put different wheels on our vehicle perhaps [reference to automobile metaphor/visual imagery in Carolyn Tayler's briefing slides], but what a gift that these people [from B.C.] are sharing. And isn't that what palliative care is about? And with the emerging health line business, it's here! It's now! Let's connect and go for the benefit of those people [who currently have limited HPC service access].

### **Carol Shemenchuk**

Is there any project money left, or to for example role this out in Alberta. For example, orientation, development, all of that?

### **Velda Clark**

So far, all of our funding from this [sub-project] other than what Fraser's already developed (their ministry) came through the impetus of Pallium. So I think Michael (Aherne) needs to talk about that.

### **Michael Aherne**

I can say the short answer is no, not at this point. The project, our particular funding envelope like other PHCTF-related, has a "best before" date of March 2006. We, like other projects, have put in for our six month, one-time extension. But the Project Steering Committee that guides the Project has said that this needs to be oriented, if it is granted, to doing the writing and the evaluation work to take it to the level where people can actually say, "Oh, there was that project and whatever happened to it?" to, "There

was that project, there were these learnings, and here is how other people can uptake them." So, the short answer, not from the current Phase II funding of the Project. And I frankly don't know without actually asking the health lines multi-jurisdictional project if there would be any.

### **Kathy Taylor.**

There's not.

### **Michael Aherne**

Then it's not there either. So, maybe it's a good idea that there's sort of a sequel that may be required.

### **Velda Clark**

And realistically do we know what the costs are? What are the costs? Are they big or are they small?

### **Kathy Taylor**

See, we do know that. We know what it costs to implement these programs, so I could tell you a dollar, what it would cost to do that.

### **Michael Aherne**

Excellent. We'll be calling you.

### **Marie-Josée Paquin**

I have a passion for this too. I have some ideas and I'm seeing my vice-president right after this meeting. We have some interface dollars [special purpose funding] through funding. We may look at the interface. How can we interface cancer care and palliative care in Alberta? So, this is a creative way and the committee is willing to look at the criteria, and this is really seed money. Usually, interface dollars are going at \$5,000 at a time. I am willing to bring it forward for Alberta to my vice-president and the interface project funding committee.

### **Several voices**

**(hard to hear)**

### **Michael Aherne**

And that's what I was actually about to say. Sharon (Baxter) [Executive Director, CHPCA] is in the other room. She is sort of messaging the same thing that ought to be here. With the

exception of the Quebec health minister, of course, she has got this letter that she waves around all the time, saying that the other health ministers have made a commitment to certain things and this [Palliative Home Supports] falls within the scope of those, before December of 2006.

I know that, with the exception of Ontario who is actually doing some very active work according to what I've recently learned, there are some opportunities, I think, for governments saying we have this problem, and the field coming forward and saying, by the way we may have a solution here and putting it together. There is this interactive dance that happens. I would say not from us directly in this Phase [of the Pallium Project], but there's a possibility of a sequel here if there's interest.

**Kathy Taylor**

I think that the multi-jurisdiction group felt that we would actually be part of this, and we would actually try to implement this. But what you are saying is in fact that there will be no room for that.

**Michael Aherne**

*What I am saying is, and this has always been very clear from the first time that Carolyn [Tayler] came to Vancouver in February 2005], our commitment and our scope was around what would be involved in developing the enhancements; really scoping that out very clearly.*

But because of the nature of our [National Envelope Funded] project and the nature of the relationship [with provinces/territories], we are certainly not in any position to bind any one jurisdiction to actually doing implementation. Nor have we ever said that. What we have said is that we will actually work together to leverage the learnings of Fraser [Health/BCNL] and to work across jurisdictions to essentially put together a really good thought piece that would, as part of the transitional investment model, say that if we were to do this, let us help pay for your learning curve. And that's really the piece that we are working here. If somebody said, "That's a good idea and they did it in BC. Why aren't you doing

that here?" Then we've got a piece where we can say, "Here are the considerations that would go into doing something like this." So that, as you two were talking about, you spent a lot of time, blood, sweat and tears, as did your colleagues, to figure this out in concept. And I think that's what Velda (Clark) is saying in part, you know, "we've had some really good early leadership about one way that this can be done." But the one way, in addition to having model elements, raises all sorts of issues generation that others would need to consider. I think that's a real gift that you (i.e. sub-project steering committee) bring in terms of the final document. Well and I'm part of that too, as a steering committee to the table is to say "Here is the developmental thinking. Here is a framework for approaching it. But at no point did we ever commit to implementing it" [jurisdictionally, through the National Envelope of the PHCTF].

**Elaine Marrington**

What I want to do is, I'm in support Velda (Clark). I come from an area where a lot of our people are quite away from where the expertise would be in symptom management, so this type of project would really be supported in our area [B.C. Interior].

But my question to you (i.e. Carolyn Tayler) is, how do you envision this, like it is in BC NurseLine. I heard what Michael said, but would it be part of BC NurseLine if we decide to develop through TCS? What would be our commitment to become a part of that? Is there dollars involved? Do we work, or does our health authority, get a hold of you or...

**Carolyn Taylor**

Well, just specifically in BC what we had planned to do is that there is a home and community care council which consists of representatives from each of the health authorities that meets with the Ministry of Health. And we'll be taking, just because everything is moving along so fast, we've written up a report in Fraser Health, we have this Pallium document, we're going to take it that group and really *that* group then is the engineers of moving it forward. The health authorities will have to do the pieces on their side. But, and I

haven't heard otherwise, the Ministry of Health expects that other health authorities will take this up. And we've had lots of calls. People are sort of saying, "Send us out the protocols now." And I'm saying "no, whoa, we have to go through due diligence." We have to finish our pilot project and we have to sort of give that report back to the BC NurseLine, but the understanding is that the uptake can then occur after.

**Question**

Do you have a timeframe?

**Carolyn Tayler**

I think I was going to try and get on about the November meeting, so hopefully before the end of the year, yes. Other questions?

**Julie Lachance (Health Canada)**

I think this is really exciting. As I work in developing a strategy with all of you to ensure that we have 24/7 access, this is a really essential piece and one that I have been trying to help my colleagues understand - that we cannot always have inter-professional, face-face care. We have to look at all the possible models that are going to be necessary to make sure that all Canadians have access. As you (i.e. Elaine Marrington) were just saying, this might be the best that we can do in some areas and that's great that we can make it work.

I have a couple of questions about where you'll go with this, and what you're able to extract around evaluation. I heard you talk about the nurses themselves who are involved and whether it might be possible to evaluate their experience. The patients, their experience, but also the outcomes. And not only the outcomes for their eventual symptom control and death at home and that kind of thing, but also cost factors. Because, again, if I'm going to argue that this is really an essential piece, it would great if I could know what this would cost to have a nurse line compared to an emergency room visit, which would be the alternative in many situation.

**Michael Aherne**

Plus the medical transportation costs...

**Julie Lachance**

Sure, all of that. So if you can get that from your pilot study, or if you can get that from the next phase, do a before and after study, a controlled study or something like, that that would make it all the more powerful, and much easier to carry the argument forward that this is really necessary.

**Carolyn Tayler**

I can tell you that, certainly Della for the first four months anyways, we did do...what was the disposition of the call? Would they have had to go to emergency?

**Della Roberts**

We've got it actually. We've got it right through. We've got eight months of data.

**Carolyn Tayler**

So we can say, who would have gone to emergency? Were they still alive 24 hours later? 48 hours later? Who then died at home subsequently? So, I mean it certainly isn't randomized or anything but we can tell you our outcomes.

**Julie Lachance**

That would be wonderful. If you could just keep me apprised of that, that would be wonderful.

**Ann Syme**

Just on the notion of research, seeing as that begs more...sorry. Well no, I see it's going to grow. It's going to proliferate. We know our own province particularly. I don't know in each other jurisdiction. Our own province has a great investment in the whole business of how we serve our entire population.

But, from a population-based point of view, you guys have got such a great opportunity to capture data about patients that you're seeing, that goes to a repository of data around symptom management, interventions, where people are sitting with that.

Do you have any thoughts about how you could capture that? Or, could there be some dialogue about how that could happen in terms of picking

clinical tools and being consistent about their application? And the tools that they are using in the community, and that they communicate well, but that they also lend, like when you talk about your activity level, well could we add a palliative performance scale?

**Carolyn Taylor**

We are using that.

**Ann Syme**

OK, so are we capturing that data? And are we capturing the way that can mine it later and link it, and do some research around it so that we don't lose this opportunity?

**Della Roberts**

We have established some fundamental things that we captured like – what was the problem of the person who called? What was the disposition?

**Carolyn Taylor**

Palliative Performance Scale [PPS of Victoria Hospice Society].

**Della Roberts**

And from the disposition you extrapolate what would have been the recommended alternate to transfer to the Palliative Response Nurse [PRN]. What was the palliative performance of the person at the time of the call? What did they do at the end of the NurseLine call? What did they do at the end of our call, like did they stay at home, did they go to the emergency department or whatever?

Then, and I think this is where we have to be careful, we decided 24 hours later. Because with palliative care, after 24 hours there can be so many things that happen that could have been unrelated to that call, so all we did was look at, in 24 hours was that person still at home? Had they gone to the hospital? Had they gone to the emergency room? Trying to say that, did that call not only help them get through the night but actually assist in to stabilizing some transfer of care? So we've collected a fair amount of that data already.

**Ann Syme**

What I'm asking then is beyond that. That's great. That's the beginning. But in your assessment are you getting an ESAS [Edmonton Symptom Assessment Scale] score? Are you looking at perhaps being able to stage your pain? There are different things that you could, from a research point of view, look at.

**Della Roberts**

I think that there are. I think that also we have to be grounded in where these families are at when they call? They're actually at the end of their rope, I would say, most of them. That's why they're calling at three in the morning, because people don't call at three in the morning, and they don't want to wake and bother people. That's how people inherently are.

So, the information gathering piece, I would say, already for the families is when they make the call to provide even their demographics to the NurseLine and all of that thing, the NurseLine has a standardized way. In relation to home health, and the tools that we need, I think we can tell you that one of the gaps we discovered right away was, "Do we have palliative care telehealth protocols? Do they exist in the world somewhere, for telehealth management?" And they don't, so that we've had to use proxies.

So I think in relation to looking at, yes what we can do in relation to research, but also mindful that we're seeing people at a very vulnerable time in relation to – what kinds of things would you want to do to ask them even more questions? Do you know what I mean?

**Ann Syme**

Well, I do, but I also know that is always the point that's on the table through. We can't do palliative care research because...

**Della Roberts**

No, no, I think that then you pick out what are things that you can do that are still meaningful.

**Ann Syme**

Sometimes it's not that you're going to add data, but if you're going to talk to a patient about their dyspnea, you're going to ask them about the severity of it, and if you're going to do that...

**Della Roberts**

Oh yes, and we've already got that at a basic fundamental sort of...

**Ann Syme**

But then you want to use a standardized measure, so it's not necessarily change your questions. It's how you capture the data and record that you really...

**Della Roberts**

And we've even, in the beginning of this, tried to have some standardized [information gathering], making sure that the information that we're gathering is standardized enough. So I think that there are all kinds of opportunities to look at that down the way and if we're doing that in a broader setting.

**Carolyn Tayler**

And I think even in BC it would be very interesting to partner with another health authority that now comes on, and look at what are the differences right. In terms of the calls that come in, are they different, rural or urban? All of that is potential.

**Michael Aherne**

I just want to respond to Julie's (Lechance) comment about cost. That's a very important consideration, but I actually think there's a public confidence and trust issue that is starting to emerge about publicly-funded systems. And maybe we're a little more sensitized to it in some ways in Alberta right now because of all the talk about the "Third Way."

When we look at some of the stuff out of the Romanow Report and things like that, really I think that the fundamental message for a lot of people in this country that their sending to us, or their concern is, "will the system be there when my family and I need it?" And I think that this kind of initiative [Enhanced HPC Protocols], while it might on the surface not seem like it's really super intensive, and it's going to address all those range of needs, I think it really does very nicely address that [provides public confidence that systems will be there]. If I pick up the phone, am I going to get someone who will listen to me?

Who will help me with some health information? And with some fundamental kinds of navigation questions when the person who is otherwise supposed to be on the end of the line isn't. I think that there is a lot of that issue, sort of, if we start to talk and I'm not suggesting we do that here this morning. But if we were to unbundle what does this [telephone access to HPC enhancements] mean from a public trust and a public confidence perspectives of sustainability of health delivery systems, and their ability to be in there in the moment when one needs it, that there's a tremendous value there that we should probably explore in addition to the traditional cost savings argument that administrators and bureaucrats within provincial and territorial systems often focus on.

**Julie Lachance**

I think we need both.

**Carolyn Tayler**

And I would say that I know, maybe just speaking for Vancouver and the Lower Mainland, but healthcare professionals in emergency departments are just extremely distressed at palliative care patients coming there, because they feel they can't get the kind of care that they need to give them. There's no beds to send them to. I mean, it's a real simple argument when you can go to your executive or the board, here is something. Even if it's one emergency room visit once every two days in Fraser Health, that's seen as very, very positive. And we're under such significant pressure in our emergency rooms, that seems to be the "bell weather" now of the health care system.

**Michael Aherne**

And the [inpatient, acute system] paradigm is completely different. While we still very much talk about hospice palliative care being active, the default response in the emergency room is to cure, to save, to extend.

**Carolyn Tayler**

To have a have a whole bunch of stuff done.

**Michael Aherne**

To intervene. That may not be where the goals of care are. They likely aren't.

**Carolyn Tayler**

No.

**Darcie Bidgood**

That's actually just leads into what I was thinking in terms of outcomes and I know you're going to be looking at disposition 24 hours later, but I'm wondering about satisfaction.

**Carolyn Tayler**

Yeah, and we can talk about that.

**Darcie Bidgood**

Both parts, the tele-health part and if they were referred. And just in relation to Ann (Syme), maybe doing some data capturing of what their pain level was 24 hours ago, if that was the issues or...

**Carolyn Tayler**

We can speak a bit about the satisfaction.

**Della Roberts**

I think that we can use a better tool or whatever, but what we did in relation to the family's experience, we just took a first crack at saying, in relation to process and in relation to just, was this a help to get them through the night kind of thing. And we found that families, the things that we thought were going to, that might have been a barrier, that overall people were grateful to have some place to call.

And one of the things that's hard for families to distinguish is between providers. When we try to identify, you talked to this nurse first about that and how was that for you? And then you talked another nurse about that, how was that for you? We're all kind of mixed up in relation to the system. And we're even mixed up with the home care nurse that comes regularly. We're all just a piece of the palliative care system. It was hard for people to distinguish. And actually the fellow from Manitoba that came to Burnaby, Paul (Nyhof), he had talked about a patient and family outcome tool that he had.

**Carolyn Tayler**

Yes, that the nurse line was using.

**Della Roberts**

You know I think it's a real opportunity for us to use a validated tool for all of us that implement it so that we can start to gather our data together. I think there's a real opportunity.

**Carolyn Tayler**

And we had identified some concern that people had, like if they had to wait too long, that was a problem.

**Della Roberts**

Yes, one of the things, we're actually changing the information that people would get with the [special HPC Nurse Line phone] number, to be able to now change so that it identifies that they may wait on the phone, that there may be a period of time that they're waiting before that NurseLine comes on to speak with them. That they will be asked for some of their demographic information, and that we're giving them the direction that *if* this relates to a medical question, to direct it back to if they're able to contact the physician, contact their physician, that that also is a resource to them. So we're kind of, one of the things that we found was that people didn't, by just giving them the number to the NurseLine, they are expecting that those nurses are part of the homecare system, know their chart, have all of that information so we need give them better information about that.

**Michael Aherne**

To what extent has building your pool of "foster docs" [family physicians that take on "new" palliative patients] been a critical success factor in the hand-off part, like the next day? Because what I am thinking is that a lot of people in this country do not have access to a primary care physician. I think we all know that. But I know that you have worked very, very hard within Fraser to identify that pool of physicians who would take somebody who could benefit from palliative services or who's on your program, that otherwise wouldn't have a family doc. Can you comment on that a little bit?

**Carolyn Tayler**

I think that generally we would be hooking them up with a “foster doc” or a primary physician as they come on homecare, correct? Della?

**Della Roberts**

In relation to the NurseLine piece, it is, like some of the assumptions that Carolyn put out, the reality of your practice is what you’re linking to. So, for that, and one of the things we try and capture in our after hour information is, “Has a palliative specialist physician seen this patient?” Because then you’re able to get some potential different direction from the palliative physician on call so the physician capacity component is an important factor in the delivery of palliative care. And the way that we have set up the link between the NurseLine and the Palliative Response Nurse enables us to link to the palliative physicians on call, but the reality is, it does not change the capacity of the family physician role. But interestingly even, of the first 43 calls that came, six times we actually, between nine at night and eight in the morning, got a hold of a family physician who actually gave some orders or did something. That’s actually pretty darn good. I was quite surprised when heard that. So whatever family physician capacity is there, you certainly want to maximize that.

**Michael Aherne**

And that might play out different in Alberta, for example, with the emergence of primary health care teams, right? And as we, sort of, maybe have some additional conversations about where this may lead, it may be that we want to look at – what does the evolution of that [Primary Healthcare Networks] innovation mean potentially? Because my understanding is that one of their mandated service areas is palliative care.

**Carol Shemenchuk**

Building on that, there has been a lot of interest in chronic disease management. How does this fit in that model?

**Michael Aherne**

Don’t get me started about the “long death.” (laughter) Well, no, I think what we realize, if you think about it, and Joanne Lynn talks about this [see, for example, “Sick to death and not going to

take it anymore!”] a lot. In the course of about 100 years, we’ve gone from what we call the “short life/short death” to the “long life/long death.” And even a lot of cancers, right? We’ve, over the course of the last couple of decades; we manage a lot of cancers as chronic illness. So I think we need to start marrying those two up instead of saying this in our [HPC] silo over here and this is in our [CDM] silo over there, especially with things like end-stage COPD, end-stage congestive heart failure. We’re going to see a lot more stuff and this cuts across “other than cancer” as well.

**Carol Shemenchuk**

And I just ask because I was at the Calgary Global Conference on Chronic Disease and I might have missed it, but there were no plenary sessions, for example, on palliative care.

**Carolyn Tayler**

However, I know that in BC, and I don’t know how far along it is, but there has been considerable discussion about a chronic disease link with the BC NurseLine in terms of primary care. It’s not “go-live” yet as far as I understand it. Would that be correct to say, Diane (MacCormack)?

**Diane MacCormack**

It was “go-live” two weeks ago, actually. The two chronic diseases that we are originally looking at is diabetes and heart failure. So, I know it’s a demonstration project and it’s dated until March 31, 2006, and I know other, will be coming.

**Carolyn Tayler**

So, it’s happening,

**Diane MacCormack**

It’s happening.

**Michael Aherne**

We sure do need to be making the linkage to progressive chronic illness leading to expected death. And of course what we know, that we don’t advertise very well, within the Canadian model is that hospice palliative care, aside from an operational definition around when you get the [palliative care] services, there are things that can be happening much, much earlier when an illness is identified as life-threatening, before it

ever transitions into life limiting. We need to make those linkages more clear.

***Diane MacCormack***

I just wanted to support the research idea that Ann (Syme) brought forward. I think that we always have to remember there are two clients in this relationship. We have the families of the person who is in last days of life and we have the practitioners. And I admire the work that you're doing. I was in palliative care in the early days in Ontario in the 1980's and it's just so exciting to be back in the field again. But we have to look at the value of each practitioner and how he or she views what they're doing to support this family. And that's what I was saying to Della (Roberts), how impressed I was the stability of the families for us to be receiving so few calls.

So then, on the other hand, we have the telehealth nurses who came in from specialties and primarily emergency room, ICU, pediatrics, OBS, and a few of us from the community. Now they're being asked to expand into another role and it is an advanced practice.

So, that's a real goal and passion of mine. To support the practitioner and to listen to them. How can we build their capacity and do the research. I think it's very important to keep watchful for that. I'm actually, with other nurses, leading a project called "Soul in the Workplace." We're looking at how we can maintain the "soul" of the telehealth nurse as our world keeps expanding with your [HPC] world. I think that's something, but I don't know about the literature. If anybody knows I'd love to hear from you. How you can support the practitioner as they support the families [at a time of an expected death]?

***Linda Read Paul***

I'm just thinking about how we're starting to look at palliative care more broadly and getting involved earlier in the course of the disease and these chronic diseases. There may be a good proportion of people that are not necessarily linked to a formal palliative care home care program. But, the way you guide them may be very different depending on their goals of care, and where they're at in terms of their illness. So,

I'm sitting here thinking, the protocol sets almost need to follow that path regardless of who calls. So, yes, you're having pain, but where are you at in the course of your illness? What are your goals of care? What/how aggressive do you want to be treated? So, even if they're not earmarked palliative should you be sending them to emergency? Do you know what I mean? Maybe we're looking at it too narrowly, and especially in a generalist program in rural, where they're not necessarily going to be earmarked this way. But everyone needs to have that same conversation about, "Well, what is important to you and where are you at with your disease?" So, therefore, that's how I guide you, not necessarily what program you are affiliated with.

***Carolyn Tayler***

I don't think that's the role of a nurse line though. I really would question that and I'm saying that entirely as someone who is in the healthcare world.

***Michael Aherne***

Well, there's legal/ethical issues.

***Carolyn Tayler***

Absolutely, and I mean but my sense is that the chronic disease pieces that are being built in the nurse line, that's where it belongs. That's where you have the discussion, but their linked to clinics...

***Linda Read Paul***

So how are you doing that with chronic diseases?

***Diane MacCormack***

We're just starting,

***Linda Read Paul***

But in terms of that goal?

***Diane MacCormack***

We have referrals that are coming into us that's been referred by the outlying community. I can talk with you a little bit more.

***Carolyn Tayler***

Yes, it's really being built into the – how is your diabetes being managed – right from just diagnosis, right? To more through the advanced disease.

**Diane MacCormack**

And the difference is it's an outbound call, we're making outbound calls where this is self-select inbound calls. So these folks are selecting to call us, to the NurseLine for whatever reason they're calling, we're now, when we're going into chronic disease, we're calling out.

**Carolyn Tayler**

And seeing how people are doing.

**Diane MacCormack**

And setting up self-management goal interventions, it's a different model.

**Carolyn Tayler**

So given the time that we have now, which we're almost up, Michael (Aherne,) is there other things that you want to bring to the floor here?

**Michael Aherne**

Yes, I'll explain how I think we should. I think we should eat and break, but what I want to say to you is that you achieved what I hoping we would get out of that last piece [a facilitated session] in there through the "Q and A's", albeit very informally.

So, what I think we're going to do is once we get the rough cut back from Chris (Kindratsky), we'll do a transcript of the Q & A section, but I think one of the things that we needed to hear back from you today is, as we're preparing the final documentation and sort of getting ready to package the work of this sub-project, what I think we really need to know is, from your perspective, what are some of the critical success factors for these enhancements to work? What kinds of messages back do we need to table in addition to those this morning both at a jurisdictional level, jurisdictional level/healthline system level, in some cases those are the same, and at the RHA level?

**Break in the tape 1:00**

So that capturing of wisdom and sort of just set it, in terms of this sub-project Committee saying, here's where we brought it to date, and "voila." It would be helpful to build up a little bit more of what we've captured on the tape this morning around some of the concerns, around some of the navigating change issues.

What, if you were to do this, what would be sort of the words of wisdom or the words of caution? So, I think that when the transcript is ready in a few weeks what we'll do is send that out with a little bit more modified wording around this so that you can respond to it if you choose. Or you can consult internally about it and then furnish a response so that we can kind of capture that and have that as part of the final package of resources that'll we'll have around this.

(On the flip chart is written: What do we need to know? Understand and report back in the final report as critical success Factors (CSF) for enhancements to work? A) Jurisdiction Level/Health Line-System Level? B) RHA Level)

**Carolyn Tayler**

And, Michael (Aherne), I understand that the tool that you have in front of you (i.e. the framework document) will be on the Pallium website I think our hope was by November. You haven't got the full package in colour, but when you open it up as a PDF file, there'll be the PowerPoint that we use in Fraser Health for education and you'll be able to double click and the tools will all be embedded on the document. Does that make sense to people?

**Michael Aherne**

Yes, that's quite correct. And we'll probably make sure it's available in a couple of different places.

Are there any closing thoughts that you have before I make a concluding statement...(fade out)

**Schedule A**

**Hospice Palliative Care (HPC) Telenursing (Health Line/Call Centre) Protocols Subproject Stakeholder Briefing and Information Exchange Session**

**Working Agenda**

**Leduc Room, Westin Hotel (10315-100 Street), Edmonton  
Thursday, September 29, 2005, 0900 hrs – 1200hrs**

**Note: This session is an optional post-national hospice palliative care (HPC) conference activity to inform hospice palliative care and telenursing health line stakeholders about the HPC Telenursing Protocols Subproject being supported by Health Canada’s, Primary Health Care Transition Fund (PHCTF) through the *Pallium Integrated Capacity Building Initiative*. The session provides an opportunity for information sharing, issue exploration, dialogue and early planning feedback regarding the development and use of provincial health line infrastructure to support HPC at the community-level in Canada.**

<b>Time</b>	<b>Activity</b>
9:00 am	<b>Welcome and Introductions</b> – Michael Aherne, Pallium Project
9:15 am	<b>Hospice Palliative Care (HPC) Telenursing Protocols Subproject briefing</b> (Carolyn Tayler, Chair, Steering Committee, HPC Telenursing Protocols Subproject & Director, Planning and Systems Development, End of Life Care, Fraser Health Authority) <ul style="list-style-type: none"> <li>• Overview</li> <li>• Review of subproject development process</li> </ul>
9:30 am	<b>Case Study – Fraser Health, British Columbia</b> (Della Roberts, Palliative Care Clinical Nurse Specialist, Hospice Palliative Care, Fraser Health Authority; Diane MacCormack, Community Liaison Nurse, British Columbia NurseLine) <ul style="list-style-type: none"> <li>• Background and context</li> <li>• Case Study</li> <li>• Review of process-to-date and utilization/uptake</li> <li>• Outcomes and early lessons learned in Fraser Health – HPC &amp; Telenursing perspectives</li> </ul>
10:15 am	<b>Future Development</b> (Carolyn Tayler, Chair, Steering Committee, HPC Telenursing Protocols Subproject & Director, Planning and Systems Development, End of Life Care, Fraser Health Authority) <ul style="list-style-type: none"> <li>• Future development in BC and other Provinces in Western Canada</li> <li>• Resources developed through the project</li> <li>• Readiness</li> </ul>
10:30 am	<b>Morning Break</b>
10:45 am	<b>Questions and Answers; Dialogue session with participants</b>
11:15 am	<b>Interactive planning session</b> (all participants)
12:00 pm	<b>Review and concluding comments</b>
12:15 pm	<b>Session adjourned.</b> Note: A buffet luncheon will be provided to participants outside of the meeting room at conclusion of workshop.

**Schedule B  
Participants at September 29, 2005 Stakeholder Briefing**

Kathy Taylor  
Manager, Calgary Health Link

Carol Shemanchuk, Clinical Practice Manager  
Health Link Alberta, Edmonton, AB

Julie Lachance, Senior Policy Analyst  
Secretariat on Palliative and End-of-Life Care,  
Health Canada, Ottawa, ON

Elaine Marrington, Coordinator of the T.C.S.  
Hospice Palliative Program  
Thompson Caribou Shuswap Health Authority,  
Kamloops, BC

Darcee Bidgood, Clinical Nurse Specialist  
Vancouver Island Health Authority,  
Saanichton, BC

Patty Greene, Program Specialist,  
Rural Continuing Care  
Calgary Health Region, Carmangay, AB

Linda Read Paul, Clinical Nurse Specialist,  
Department of Palliative and Hospice Care  
Calgary Health Region, Calgary, AB

Daphne Powell, St. Paul's Hospital  
Saskatoon Health Region, Saskatoon, SK

Barb Bracko,  
Manager – Community Care Access  
Capital Health Region, Edmonton, AB

Janice Chobanuk,  
Program Leader Palliative Care  
East Central Health Region, AB

Velda Clark, Director – Palliative Care Services  
Regina Qu'Appelle Health Region, Regina, SK

Ann Syme, Provincial Leader, Pain and Symptom  
Management/Palliative Care  
BC Cancer Agency, Victoria, BC

Marie-Josée Paquin, Provincial Coordinator,  
Hospice Palliative Care Network &  
Project Manager, Medical Affairs and  
Community Oncology  
Alberta Cancer Board –Calgary, AB

Carmen Taylor, Manager, Regional Palliative and  
Hospice Care Program  
Department of Palliative and Hospice Care,  
Calgary Health Region, Calgary, AB

Carolyn Tayler, Director, Planning Systems and  
Development, End of Life Care  
Fraser Health, Surrey, BC

Della Roberts,  
Palliative Care Clinical Nurse Specialist, Hospice  
Palliative Care  
Fraser Health Authority, BC

Diane MacCormack, Community Liaison Nurse  
BC NurseLine, Vancouver, British Columbia  
NurseLine, BC

Shari Young, Nurse Consultant and Regional  
Palliative Care Coordinator  
East Central Health, Lamont, AB

Jacque Béasse, Project Officer  
Pallium Project – Phase II

Michael Aherne, Director,  
Initiative Development  
Pallium Project – Phase II

Carleen Brenneis, Program Director,  
Regional Palliative Care Program  
Capital Health, Edmonton, AB

Jean Kipp, Senior Policy Advisor  
Alberta Health and Wellness (portion?)