



RESIDENTIAL SERVICES

Family Engagement Initiative: What We Heard

Summer 2013

Excellent care for everyone, everywhere, every time.



FAMILY ENGAGEMENT INITIATIVE: WHAT WE HEARD

ACKNOWLEDGEMENTS

We would like to thank the many family members, friends and representatives who took the time to complete our survey. Many of you provided additional written comments, sharing your experience and ideas on how we can continue to improve our partnership in the care of clients in residential care facilities. Your input is greatly appreciated.

Thanks go as well to the management and staff in the residential care facilities across the region, for their support and assistance in developing and circulating the survey, and in providing insights and ideas for using the information we received.

This report also benefited from the insight and advice of patient and family representatives from the Continuing Health Services Client Advisory Committee and the Island Health Patient Advisory Council.

Vancouver Island University MBA student, Stephanie Dauncey, designed the survey tool and compiled the large volume of information received as part of her graduate studies, with assistance from Nancy Mayor and Heidi Krebs, administrative assistants at Island Health.

FAMILY ENGAGEMENT INITIATIVE: WHAT WE HEARD

INTRODUCTION

Health care is currently experiencing a major period of change - not only on Vancouver Island, but around the world. The increasing prevalence of chronic disease and the impact of an aging population has major implications for the way that health care is delivered, and means that many people will be managing health challenges over long periods of time.

Living with a chronic health condition is often described as a journey, rather than an event. As we age, the likelihood that we will have at least one chronic health condition increases. Over the course of many years, seniors may manage their own health, with assistance from the family physician, family members and friends – as well as community health services – to remain independent and to maintain their personal lifestyle for as long as possible at home. When a person, or their family on their behalf, makes the decision to move to a residential care facility, it is because care needs can no longer be managed at home, despite all best efforts.

Because of this, people who move to residential care now have very complex health care needs and may require admission as a result of advancing dementia, the loss of a spouse or caregiver, or a need for 24 hour nursing supervision to manage symptoms and activities of daily living.

As the needs of clients admitted to residential care has changed, so has the needs of the family and friends who love and support them. We wondered whether the way facility care staff communicate with families is meeting their needs, and whether there were other factors we should consider to better align with the interests and priorities of family members. We often hear input from individuals or groups on a particular issue or concern – but we wanted to directly ask the families and friends of our clients for their perspectives on engagement in their loved one's daily care at the facility.

The *Residential Services Family Engagement Initiative* was designed to gather this input from family, friends and representatives of people living in Island Health funded residential care facilities. To facilitate this, a short survey was developed to ask for input from the contact person (family, friend or legal representative) on record for all residential care clients across Island Health. The survey asked how respondents participate with their loved one's care, their priorities for receiving and sharing information, and education and support on both an individual and group level. More than 1,000 individual responses were received from 54 of the 61 facilities across the region.

This is what we heard.

FAMILY ENGAGEMENT INITIATIVE: WHAT WE HEARD

METHODOLOGY

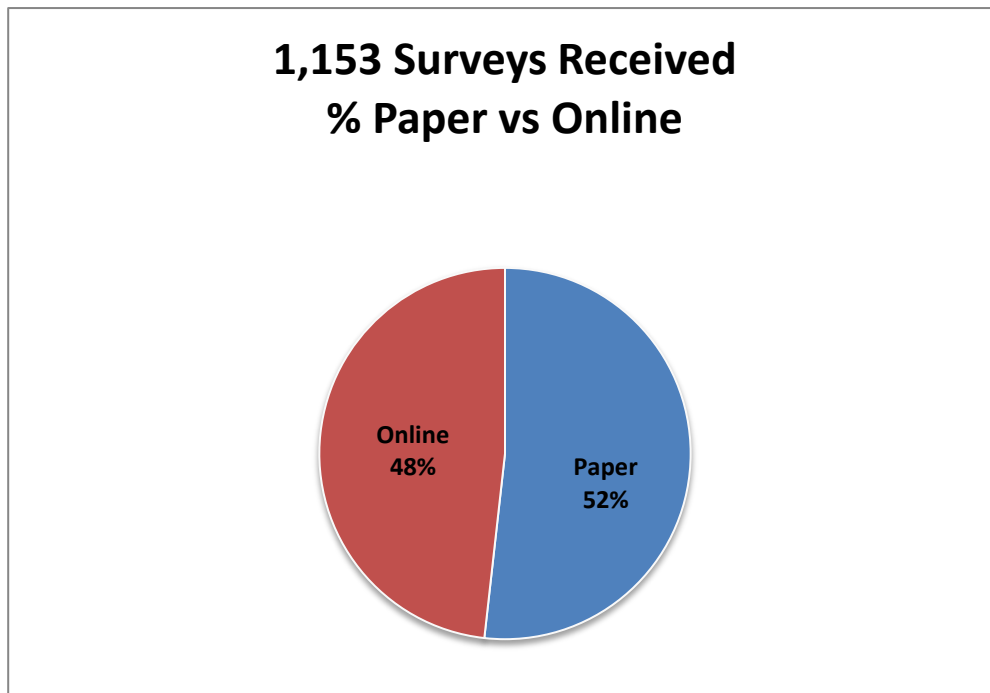
A simple set of survey questions was developed by a small working group consisting of facility managers, program leadership and a graduate student from Vancouver Island University. Further input was provided by staff with expertise in evaluation and communications. The survey was developed in an online format; with paper versions available for those who may prefer to complete the survey that way.

Each facility circulated an invitation to participate in the survey to the individual on record as the main contact for each of their residents. The invitation provided the weblink to the online survey, and let families know how to get a paper version of the survey if they preferred. For those who completed the survey on paper, a mailing address was provided, and facilities also provided an option to collect completed surveys at the facility to return them to the working group.

Survey questions incorporated opportunities for families to provide additional written comments if they wished to provide further feedback or information that may not have been captured in the questions.

Invitations were sent to families in January and February, with several months allotted for the return of completed surveys to ensure enough time was allowed for facilities to get the invitations circulated and for residents' family and friends to participate.

At the close of the survey, 556 surveys were completed online, and 597 paper surveys were returned, for a total of 1,153 responses; a response rate of more than 22 per cent. Although individual facility response rates varied, a fairly consistent rate was achieved in each area of the Island.



FAMILY ENGAGEMENT INITIATIVE: WHAT WE HEARD RESPONSES

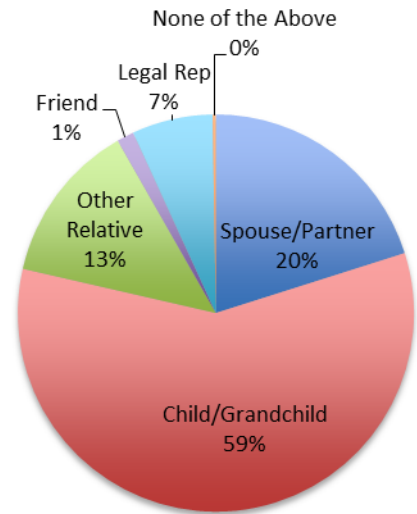
Who are the Primary Contacts?

Information provided by respondents indicates that most of the primary contact persons for residents are family members, most commonly adult children or grandchildren of the resident. Spouses and other relatives, including siblings, nieces and nephews make up the next largest segment of primary contacts, with legal representatives or friends making up the remainder.

This has significant implications and is especially of interest in understanding the information provided regarding challenges to regular visiting, communication needs, and interest in group versus individual activities.

RESPONSES BY AREA			
Area	# Responses	Total Resident Beds	% Resident Beds Responded
North Island	130	602	21.59%
Central Island	394	1811	21.76%
South Island	613	2777	22.07%
Not Named	16		
Total	1153	5190	22.22%

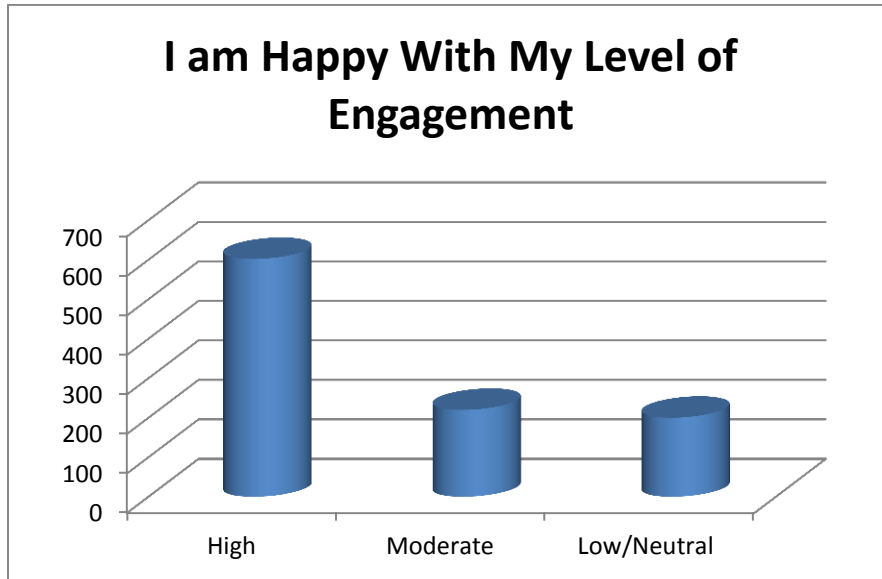
What is Your Relationship to the Resident in Care?



FAMILY ENGAGEMENT INITIATIVE: WHAT WE HEARD

Level of Satisfaction with Engagement

The majority of respondents indicated that they were happy with their current level of engagement and communication with the care team at the facility. Further information provided through the written responses demonstrates both good examples of what has worked well at some sites, and ideas and suggestions to help families connect more easily.



'Visit 2-3 times a week and have good communication from support staff'

'My mom's caregivers are excellent!'

'I would value a time log, initialled by the staff so family would know when they were last checked on.'

'I like the telephone contact when there are changes in my parent's condition'

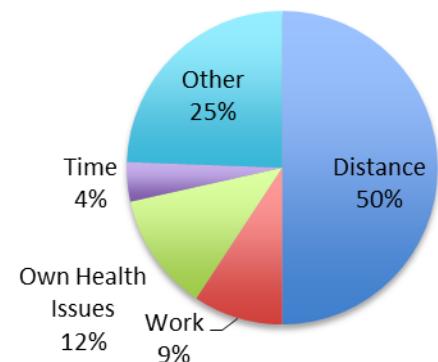
'I find all the staff approachable and informative. The news letters are giving me all the information I currently need and will inquire if I need more.'

Visits from Family

Responses on the frequency with which family members were able to visit their loved one varied significantly- a wide range between several times per week to monthly.

Many respondents indicated they were not able to visit regularly, or as often as they would like, most often as a result of distance, work or family obligations. For some, their own health issues or other factors, such as concerns with upsetting the resident, difficult behaviours, or other family issues have reduced their visits.

Factors Influencing Less Frequent Visits

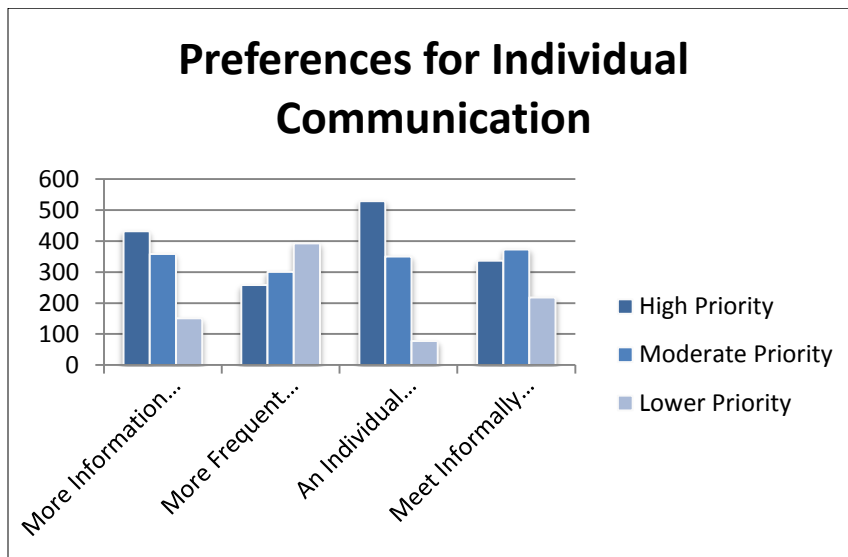


FAMILY ENGAGEMENT INITIATIVE: WHAT WE HEARD

Priorities for Individual Information

For interactions about their loved one's care and status, although respondents were clear that all of the options mentioned were important – having an individual contact who can provide information about the resident was the highest priority.

Written comments provided valuable additional input. Families provided many examples of practical information about daily care and activities they find valuable to receive. These include how well the resident is doing with daily activities such as eating, dressing and mobility, participation in activities, or changes in health, mood or behaviours. Most commonly, families cite telephone contact as their current method of gathering and sharing information with the care team, although many indicated they would like to be able to access options such as email, active website content or other electronic tools.



'I usually just talk to the Unit Nurse or RN.'

'Regular updates via email from the staff would be welcome.'

'Just keep us up to date.'

'I would like more everyday information – which I do get casually from some.'

'We do live out of town so would be helpful to talk to someone on a regular basis.'

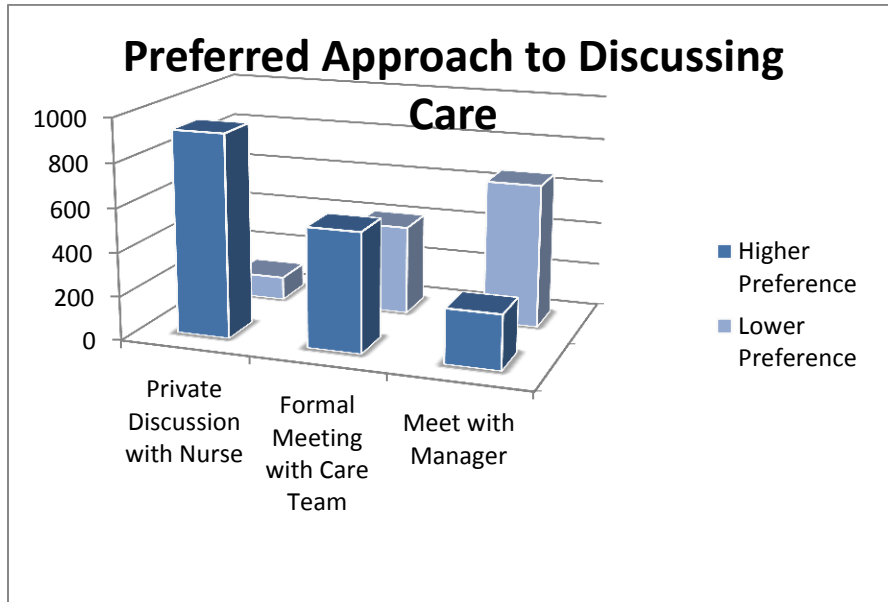
'Some way to have a chart or whiteboard where I can leave messages for caregivers and they can leave messages for me.'

'I live in town, and visit frequently – but would appreciate all of these.'

FAMILY ENGAGEMENT INITIATIVE: WHAT WE HEARD

Discussing Care Needs and Health Concerns

When families need to discuss specifics about their loved one, or any concerns they have with their care or their health condition, they strongly indicate that a private discussion with the nurse or members of the nursing team on the unit is their preferred approach. Text responses confirmed this preference, with many respondents noting that they feel the team that provides the daily care is the best source of information for them.



'My best communication about my husband comes from the nurses/care aides who know him.'

'The Director of Care and Manager have always made themselves available.'

'We find the care team receptive and responsive. They are usually already aware of concerns we raise, or open to inputs available for my concerns.'

'I find it very frustrating not to have one person I can contact about Mom's care'

'Depends on the issue. Most are resolved with nurses on floor.'

'I have found one-on-one to be unsuccessful.'

FAMILY ENGAGEMENT INITIATIVE: WHAT WE HEARD

Dealing with Concerns or Complaints

Over the past several years, Island Health has worked to improve the availability of information on how to raise concerns or questions about services and care. We wanted to know if this has made a difference – and whether families felt they have enough information to raise any concerns they may have with confidence. In their responses 762 respondents (67%) indicated they have enough information, 296 (26%) indicated they sometimes have enough information, and 78 (7%) responding that they did not have enough information to raise concerns or complaints.

Written comments provided a wide range of additional information – including details of issues of concern, and other aspects of the process of raising concerns that remain an issue. Chief among these were suggestions to ensure that staff ‘close the loop’ on concerns raised so families are informed of the resolution, or the issues involved. Additionally, many respondents requested more proactive information so that families feel they are being kept informed.

‘Would like to be phoned or told if she is having problems without having to ask.’

‘So far staff have been excellent at answering questions, but it would be great to have a 10 – 15 minute review of health and activities.’

‘I don’t get enough information about how my dad is doing.’

‘Sometimes I get conflicting information from different staff.’

‘When we raise concerns, we don’t know if they are handled.’

FAMILY ENGAGEMENT INITIATIVE: WHAT WE HEARD

Family Councils

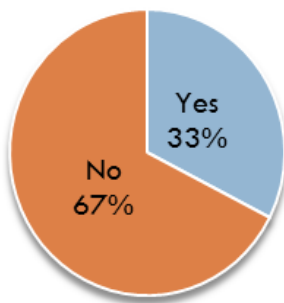
Family Councils are voluntary, self-led, self-determined and democratic groups that can include residents, family, friends, and legal representatives, and staff. Their purpose is to advance the quality of life for the facility's residents. These groups meet regularly to discuss common interests, provide support, education and a forum to voice concerns or issues.

Most respondents indicated that they do not participate in the Family Council at their facility. This is not surprising, especially in light to information provided earlier in the survey. With families juggling personal responsibilities, distance and their own health challenges, attending a separate group meeting can be difficult to do.

Choose to Participate

For those who do participate in their facility's family council, a balance of positive aspects were noted, with family councils valued as a supportive group for discussion of questions or concerns, its role in improving understanding of the facility, sharing health information and providing a venue to connect with other families.

Do You Participate in a Family Council?



'I obtain information that I was not able to find otherwise.'

'Opportunity to meet/raise concerns directly with staff who attend regularly or are invited.'

'Just as it says – a place to discuss questions or concerns about my family member.'

'Ours is small, struggling but consistent and committed.'

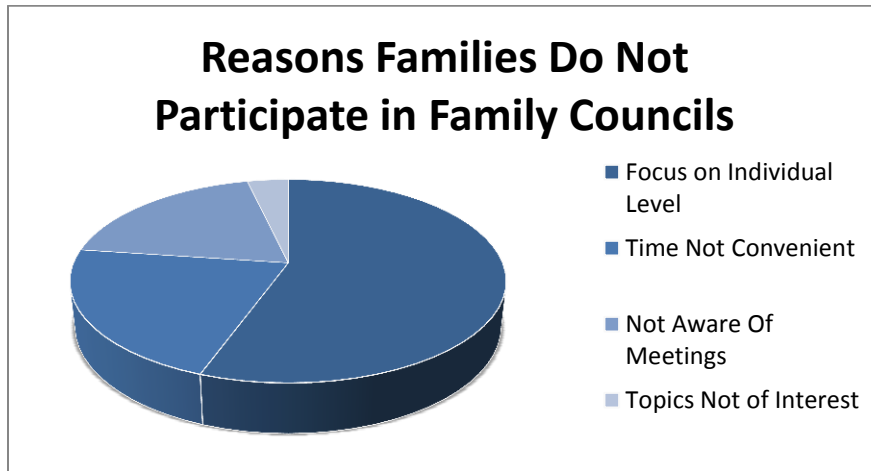
'Being with others who are presently going through the same concerns, seems to lighten the load.'

FAMILY ENGAGEMENT INITIATIVE: WHAT WE HEARD

Choose Not to Participate

For those who do not participate in Family Councils, information from respondents indicates a primary focus on their loved one at an individual level for a variety of reasons.

A wide range of additional comments were provided to give more information on family perspectives, including challenges of distance, time and availability, the complex health conditions of the residents – and a priority on spending the time they have being with the resident. Several respondents indicated they are involved in volunteering or in other community support programs, which are important to them and provide the support they need.



"I live in Calgary – so not an option for me."

"I volunteer, so already have lots of contact with the staff, other residents and the families of other residents."

"As a full time working parent, my time is short and valuable. My priority is spending time with her."

"I don't want to be involved if there is a negative tone."

"Often the meetings aren't convenient for me."

"Too many other obligations..."

"Between my mother, my family responsibilities, maintaining a home, a 40 minute commute to and from the care facility, managing necessary paperwork, plus Dr. appointments and weekly visits, I am kept extremely busy."

FAMILY ENGAGEMENT INITIATIVE: WHAT WE HEARD

MAJOR THEMES

The outcome of this survey provides us with excellent information on how family and friends are involved, what works for them and what they would like to see in their interactions with the facilities. The information shows us where families would like us to focus, and this feedback will make a significant difference in the way we work together in the future.

From the survey, several themes emerged:

- Primary contacts for residents tend to be children, grandchildren and other family members.
- Many have personal factors which make it difficult to visit as often as they would like; this includes distance, personal health challenges, work and other family obligations.
- Regardless of their ability to visit the facility, families place their highest priority on receiving and sharing information regarding the daily care and health status of their loved one, and are keenly interested in opportunities to expand this.
- Communication between the resident's care team and the family is the primary focus for family members. Most families have a strong interest in regular, proactive updates and information sharing.
- Although most families are satisfied with the relationship they have with the facility, many shared positive experiences and suggestions on how this could continue to improve.
- Family councils are valued by those who participate for the social support, information sharing and education opportunities they provide.
- Most family members do not participate in family councils, primarily focusing their time and support activity around the individual resident.
- Technology options – such as Skype and email - are of interest to many families for providing updates and information on the resident or facility.

'I welcome this survey and the chance to support plans for the residents.'

'I want to be kept in the loop...'

'I cannot stress it enough – Mom is in the best care there is. I wouldn't want her to be anywhere else.'

'My mother receives very good care where she is. She likes it, and thinks of it as home. I can't ask for more than that.'

'Thank you for seeking my opinion.'

CONCLUSION

As the health needs and complexity of people in residential care facilities has increased over the past several years, it has had a significant impact on how facilities share information and participate with families in care. Communication between the care team and families has grown in importance, while factors such as distance, health, work and family obligations have impacted the way that families visit with their loved ones, and communicate with the care team at the facility.

Building good communication based on successful experiences, and seeking new opportunities to enhance information sharing will be a key focus going forward. While telephone calls are currently a primary means of connecting, there are many innovative tools that may expand information sharing in an accessible way and provide families with greater opportunities to be partners in care.

Island Health will continue to use the valuable information from this survey in planning with facility managers and operators, exploring opportunities to incorporate changes, and expand our commitment to families as partners in care based on the many suggestions and ideas shared.

