Health Quality & Safety Commission New Zealand
Kupu Taurangi Hauora o Aotearoa

Ko Awatea
Health System Innovation and Improvement

Partners in Care co-design case study

Supporting better information for palliative care

Context

The All Seasons Pharmacy team in West Auckland has been serving the Te Atatū South community for over 30 years. The pharmacy offers a wide range of services, including vaccinations, medicine use reviews, home health care, community pharmacy anticoagulant monitoring service (CPAMS) for patients on warfarin, and aseptic dispensing.

The pharmacy supports upwards of 120 palliative care patients and their families/whānau on an annual basis. Many of these patients receive their medications in syringes (pre-drawn doses), which are prepared aseptically on-site at the pharmacy. The majority are enrolled with the local hospice (Hospice West Auckland), and the pharmacy works closely with them to deliver these services.

Demographics

Te Atatū South, which comprises the statistical areas of Te Atatū South-Edmonton, Te Atatū South-Central, Te Atatū South-McLeod North and Te Atatū South-McLeod South, had a population of 15,138 at the 2018 New Zealand Census.

Ethnicities were 52.2% European/Pākehā, 15.6% Māori, 17.6% Pacific peoples, 29.3% Asian, and 3.7% other ethnicities (totals add to more than 100% because people could identify with multiple ethnicities).

Problem statement

The pharmacy staff noted that patients' and family/whānau understanding of some of the medications dispensed to them and other aspects relating to palliative care was limited at times despite information sheets being provided to them. This was concerning, and through this project we explored the experiences of patients, whānau and pharmacy/hospice staff to find out more.

Equity aim

It was important for us to recognise the experiences and needs of our richly diverse community and especially those who were supporting patients requiring palliative care.

Our aim was to:

- understand the experiences of family/whānau of Māori and Pacific palliative care patients in primary care who collect, store and administer medications, and explore ideas that they may have to improve our medications services for them
- work with the Hospice West Auckland palliative care team to learn from their experiences and ideas for improvement

- utilise the ideas to make improvements to enhance the care and service provided and increase the confidence of Māori and Pacific families/whānau to manage the medications for their whānau.

Start up

A number of seemingly small but important events prompted us to explore the experiences of people who were receiving palliative medications.

- A family member called the pharmacy requesting additional medication (pre-filled syringes and 24-hour syringe drivers), but the pharmacist who took the call knew they should have had enough supply for the next two days. Upon investigation, it was discovered that there were more supplies of syringes stored in a paper bag in the family's fridge (where they should be stored). The family member had not realised they were there because another person had actually collected the syringes from the pharmacy and had placed them on a different shelf to the one that was usually used.
- On multiple occasions we heard that extended family members of palliative care patients take food in to support the patient and family. In order to accommodate the food in the fridge, they take the syringes out of the fridge and place them elsewhere in the house in unsuitable temperatures. This storage is not optimal and could result in risk to the patient.
- On more than one occasion we learnt that syringes which have past their expiration date were still being used up to a month after the expiry date. It is standard practice for all palliative care syringes to have an expiry date label, and this is checked by two pharmacists before the syringes leave the pharmacy.
- Information is provided (in paper format) at the time of medicines being handed over to family members. However, when the main carer of a patient had time off and other family members took on the responsibility for collecting and providing medications to the patient, there was often confusion about the medications.

There were also specific challenges noted from the staff pharmacist's point of view.

- Communication
  - Delayed notification to the pharmacy following death of a patient. This results in waste relating to the time it took to prepare medications and the cost of the medications themselves.
  - On multiple occasions more medication syringes have been requested by family members just before a scheduled medication review (when dose/medication changes are likely). This can also lead to waste if the review results in a change in dose or medication.
- Indication for medication use
  - Prescriptions are sometimes sent to the pharmacy without a clear indication of the symptom it has been prescribed for. For example, palliative care patients are often prescribed morphine 5 mg every hour as needed. It is not always clear whether this medication has been prescribed for pain or for shortness of breath. This causes challenges when the pharmacist dispenses the medications to family members.

Project team

We created a small core team. The All Seasons Pharmacy owner was the sponsor. Other core members included two pharmacists and two consumers who had recently experienced the palliative care journey. In addition to the core team, we engaged with other stakeholders as needed (Table 1).

Table 1: Stakeholders

Stakeholders
Staff Pharmacist
Hospice Medical Officer
Hospice Nurse
Hospice Pharmacist

Engage

To help people to understand our project, we developed an elevator pitch, a short narrative that helps to engage people so they can contribute to the project. This also helps in generally socialising and promoting the work.

Elevator pitch for consumers

> *Hello, my name is _____ and I work at All Seasons Pharmacy. We know sometimes when whānau come to collect medicines, it can be confusing, especially when thinking about what the medicines are for, how to store and use them, how to locate expiry dates, understanding when the next supply is due, and so on.*
>
> *We have set a project up to try to make this better. We would like to have a conversation with you about your experience with the medicines. We are talking to a number of whānau members to understand what works well/not so well to get ideas to make it better. We will then use some of the ideas to see what difference they can make. Would you be happy to share your experience with us?*

A staff meeting was held to ensure staff of All Seasons Pharmacy were aware of and understood the project.

Elevator pitch for staff and palliative care stakeholders

> *Hello _____,*
>
> *You might know that we are working on a project to understand the experiences of whānau who come to collect medication syringes. We are keen to understand a number of things from your perspective and are keen to talk to you about:*
>
> - *what you find that works well in your role of dispensing medication syringes*
> - *examples of any challenges that you/other pharmacists/nurses have had with regard to medication syringes in your dispensing/pharmacy/nursing role*
> - *ideas of what could make things better*

- examples of challenges that whānau have identified to you about managing the medication syringes.

Capture

When considering how to capture experiences of family/whānau members, we worked closely with the consumers, who were core project team members, to jointly develop questions to ask of family/whānau (Appendix A).

In order to capture experiences of whānau, we felt that using the questions in a conversational style was more personal, and we found that by doing this people readily shared their stories. We had these conversations with two Māori and one Pacific whānau of palliative care patients we were providing care for.

For stakeholder experiences, we held two interview-type meetings with five stakeholders. All Seasons Pharmacy staff were interviewed using the prompt questions that we had shared with them as part of the elevator pitch for stakeholders.

Hospice staff were asked to recall their experiences in relation to their role in the provision of medications for palliative care patients. Staff were asked the following three questions, and their responses were recorded in writing.

- What works well currently?
- What does not work well/what challenges are there?
- What are your ideas for improvement?

Following the capture phase, we reviewed the feedback from the discussions and identified three main themes, which are discussed below.

Understand

Information from the capture phase provided rich feedback and detailed understanding about what was working well, what was not working so well, and what challenges there were. We also reviewed the ideas for improvement.

Responses from the three whānau members

Starting point questions

When asked to describe what the syringe drivers are used for, all three described some uncertainty. All three said that they had written instructions but at times they were still unsure.

> *'I get confused about knowing when to use things (syringes and medications) and why.'*

We asked three whānau members to describe on a scale of one to five how confident they were in knowing what each of the syringes were for. Two were 'fairly confident' (level 4 on the scale) and one was 'somewhat confident' (level 2 on the scale).

Question 2: Did you know that the syringes have expiry dates?

One whānau member was unaware that there was an expiry date. Two knew that expiry dates were printed on the bag, and they thought the instructions were clear.

Question 3: Do you know how to store the syringes when you get them home?

All three knew that the medications needed to be stored in the fridge and mentioned that the 'store in fridge' sticker on both the medication pouch and the outside of the main collection bag was a good reminder. They were all unsure if other family members who irregularly care for the patient were aware of this.

Question 4: Do you feel confident about what the medications are for?

All three family members identified a challenge in retaining knowledge about what the medications were for at a time of distress and described being overwhelmed at times.

> *'I think I have understood at the time but then I don't seem to remember afterwards, the situation is all a bit distressing.'*
>
> *'We get good education but don't always remember it, I find when we get home, things get really overwhelming.'*

Question 5: How could we improve the information to make you as confident as possible?

Feedback included:

> *'The written information could be clearer, I don't always understand what is on the paper.'*
>
> *'There are words and things that I don't understand, would be good if you can make them more simple.'*
>
> *'At times there is too much information on the sheet and it is not always relevant to me. That can be confusing.'*
>
> *'Make the information more simple.'*

Two whānau family members said they liked how the pharmacy always phoned them to let them know when more syringes were ready.

> *'I am always grateful when you call – it is one less thing I have to worry about.'*

They said that the information made them aware when the next set of syringes were due and were confident the pharmacy would have them ready. On the odd occasion when things were needed more urgently, whānau knew they could ring the pharmacy and they would help.

> *'When we need more I ring and you guys get them [the medications] ready straight away.'*

Whānau said they valued getting to know the pharmacy staff and felt well treated.

> *'I have never been treated like this from a pharmacy.'*
>
> *'I can't believe you would go out of your way to help me at the weekend.'*
>
> *'You guys are just awesome.'*

Themes from stakeholder experiences

What went well

Timeliness of the pharmacy service

Hospice staff commented that the ability of pharmacy staff to fulfil complicated, urgent prescriptions in a timely manner made a big difference to the hospice's ability to care for and support patients.

> *'Syringes from you [All Seasons Pharmacy] are supplied in timely manner – [we] have done a random audit and some pharmacies make patients wait hours – you guys do your best to get them to the patients ASAP.'*

> *'Things are made in a timely manner. Some places take hours and the patient may not have that time because of their pain.'*

Relationships

Pharmacists said:

> *'Hospice nurses are generally very knowledgeable, helpful, easy to deal with and want to help as best they can.'*

> *'We have a good relationship with the hospice staff, and that makes a big difference.'*

Equally, hospice staff valued the relationship with the pharmacy.

> *'You help me and our nurses to do the best for our patients.'*

> *'You are always willing to help.'*

> *'Patients tell us "At All Seasons I am treated like a person."'*

> *'You are so good – you all care.'*

> *'I am grateful for the way you and hospice work as a team is just awesome.'*

Communication

The hospice team valued the information provided by the pharmacy to all involved in the patients' care.

> *'You let us know when you find out information that may be detrimental to the patient or if you have ideas that can help them.'*

> *'You communicate well with your patients.'*

> *'simple things like helping them to know when their prescriptions are due'*

> *'communicate with us well'*

> *'communicate with families as well'*

> *'You guys are our "go to" – when we need information for us or our patients.'*

Pharmacy staff found it was helpful when they had an idea of how many syringes were being used so they had a good idea of how many to prepare for subsequent collections. One of the whānau

kept a diary of what was being used, and this gave an indication of which medications needed to be more or less prepared. This gave whānau and the pharmacists peace of mind that they wouldn't run out (particularly after hours) and there would be less wastage.

What challenges are there?

Pharmacy staff felt that they received little feedback about their part in the service.

> *'Are our labels clear enough?'*
>
> *'Does the patient really understand the storage conditions?'*
>
> *'Are there any concerns with the quality of the syringes we make from the hospice?'*
>
> *'From a pharmacist perspective there can be difficulties with communication when different family members collect syringes and medications.'*
>
> *'Large families and multiple carers – muddles things, we don't always know who knows what.'*

A hospice nurse felt that there is a need for additional information about when repeat prescriptions are due and will be available.

> *'Information about when next repeats will be due, so we and the family know when they can collect them, would be helpful.'*

Both hospice staff and pharmacists found it helpful to know how many syringes were being used and how often because it gave an indication whether more needed to be prepared for collection, or if doses needed to be reviewed and amended.

Ideas for improvement

Overall, there were eight ideas for improvement. One of the ideas involved system changes between health care professionals around prescribing. This is a complex issue that is being reviewed separately to the others and is not included within this case study.

The remaining ideas were more directly focused on improving communication about medications and syringes for patients and their family. For example:

> *'Introduce Medication Cards (written by Hospital or Pharmacy detailing medications – what for/how to take) to be given to the family member every time medications are collected – as they will be easier to follow.'*
>
> *'Maybe more information on bag of syringes – how they should be stored, when the next prescriptions are due, how many different medications are enclosed, who I can ask for help.'*
>
> *'We need more information on storage, we want to go away at Christmas – will the pump last the time we're away?'*
>
> *'Something that helps to explain things for all the whānau – Hospice is good, but my daughter is coming to help me out and it's all new for her.'*

Whānau said that it would be helpful to have somewhere to record the number and frequency of syringes being used. Ideas included a whiteboard or chart on the fridge, and a notebook, diary or recording on the bag of syringes before placing it back in the fridge.

Improvement, testing and measurement

The predominant theme from the capture phase was communication. This mainly related to detailed information provided to patients and whānau about storage, expiry dates, types of medicines, what they are indicated for and how often to take them.

The core team (including consumers) worked together to create an initial draft information sheet (Appendix B).

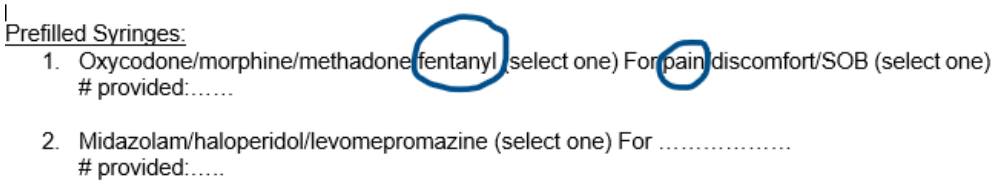
We then engaged with nine patients' families/whānau (4 Māori, 1 Pasifika and 4 European) to gain feedback on the understandability and usefulness of the information sheet.

We asked three general questions:

- Can you tell me what you liked about the information on this sheet?
- Can you tell me what was not so helpful about the information sheet?
- What would make this information better for you?

The most prominent feedback on the first draft indicated that some aspects were confusing for the patient/whānau. For example, the information sheet detailed a number of different medications. The pharmacist would circle the particular medication that the syringe driver contained and what the medication had been prescribed for (Figure 1).

Figure 1: An excerpt from the Medicines Information Sheet, Draft 1


Prefilled Syringes:

1. Oxycodone/morphine/methadone/fentanyl (select one) For pain/discomfort/SOB (select one)
   # provided:……

2. Midazolam/haloperidol/levomepromazine (select one) For ……
   # provided:…..

Comments included that the sheet was hard to follow, there were too many words, and it didn't help whānau to understand how to give the medication or what it was for.

Once this had been pointed out, the pharmacists realised that while providing all of the information that could be required and enabling them (pharmacists) to circle one part of the information was timesaving for the pharmacist, it was quite confusing for those who were trying to read it.

Generally, the feedback suggested that the information sheet was too complicated and contained too much information. There were also a number of positive comments about the usefulness of some the information, namely the main details about storage, expiry dates, after-hours contacts, and who to ask when syringes would be next prepared.

Two of the Māori patients had a number of carers involved in their support, and they saw the development of a more condensed information sheet as a positive thing to assist them in handing over care between each other.

The sessions with patients and whānau resulted in a number of changes being made, leading to the next version of the information sheet (Appendix C).

Our testing of the next version of the information sheet involved engaging with five consumers/whānau (2 Māori, 1 Pasifika and 2 European) and asking the five questions below.

1. Can you tell me what you liked about the information on this sheet?
2. Can you tell me what was not so helpful about the information sheet?
3. Is the information easy to understand?
4. Is there anything that could be clearer?
5. Have you shared the information sheet with other family members or health care workers?
   - If yes, ask who and what use was it for them.
   - If no, ask if they think it would be useful to do that in the future.

Results

1. Can you tell me what you liked about the information on this sheet?

The majority (4/5) said the information was helpful to them and their whānau and especially liked the pictures and simple layout.

> *'It has a nice flow and I like the pictures.'*
>
> *'It is a good basic thing to keep on the fridge for other carers.'*

2. Can you tell me what was not so helpful about the information sheet?

One mentioned that it was a bit basic, while the rest of the participants said the information on the sheet was all very helpful.

3. Is the information easy to understand?

All five people said that the information was really easy to understand. They particularly liked the pictures and basic phrases. They said it prompted patients/whānau to the main information needed and is easy to follow for all ages and levels of health literacy.

> *'I like the simplicity and think it will be helpful for whānau in the future.'*

4. Is there anything that could be clearer?

On the original information sheet there was information relating to the quantities of medication in the bag. This was removed after the initial feedback from whānau because it was found to be confusing. Although the quantities of medications are provided verbally by the pharmacist to the person(s) collecting the syringes from the pharmacy, this is not immediately obvious on the updated information sheet.

5. Have you shared the information sheet with other family members or health care workers?
   - Only two of the five consumers/whānau had shared the information so far. This is mainly because the prime carers had not taken any respite time so other whānau had not been called to help. All five said that they would share the new information in the future and thought it would be helpful to others.

Reflections

In addition to the specific work we did with consumers/whānau and hospice and pharmacy staff to co-design a new information sheet about medications, two additional and unanticipated improvements also happened during the time of the project. Both of these related to communication and are described below.

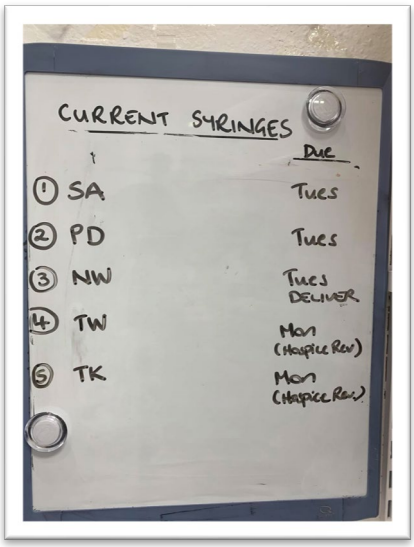
Communication between pharmacy staff

As we were focusing on communication with patients and whānau, pharmacy staff stated that they had been talking about communication between themselves.

Those not directly involved with preparing the syringes for patients, or who work part-time, found it difficult to know what was happening – they felt inefficient and unprofessional when they answered phone calls or queries in-person regarding these patients.

Together, the staff decided that a whiteboard with 'Current Syringe Patients' be installed on the wall in the Aseptic Dispensing Area in the pharmacy. This contains the name of the patient, when the next supply of syringes is due, whether they need a new prescription, and any other relevant information that enhances communication within the team and with patients/whānau. This is updated regularly by the Dispensary Manager each time a new batch of syringes is prepared for each patient (Figure 2). We have 'de-identified' information for privacy of the patients but have included the image as an illustration.

Figure 2: Whiteboard detailing when syringes are next due for palliative care patients



Communication with the hospice team

When we started the co-design work, we engaged with hospice staff in a different way than we had before when undertaking our 'business as usual' activities. Our relationships strengthened and we continued to look for ways we could collaborate to improve processes between the pharmacy, hospice and families/whānau.

As a result, the pharmacy Dispensary Manager now participates in a Consumer Engagement Meeting at the hospice once a month. This is a multidisciplinary team meeting that aims to gather

feedback to enhance the palliative care services provided to consumers. There is a particular focus on Māori and Pasifika patients and their family/whānau.

Two of the pharmacists have also had the opportunity to work alongside the Hospice Nurses and learn the process and techniques they use to review medications and discuss care and quality of life with palliative care patients and whānau.

The hospice now invites pharmacists to education sessions held by them to further enhance their knowledge and delivery of palliative care services within the West Auckland community. Many of these sessions have a strong focus on Māori and Pasifika.

Working as a co-design team

We have seen the real value of involving consumers in decision-making from the initial stage of the project.

The project team

Name	Role	Email	Organisation
Sheenal Kumar	Pharmacist/Project Co-leader	kumar_sheenal@hotmail.com	All Seasons Pharmacy
Belinda Robinson	Dispensary Manager-Pharmacist/Project Co-leader	mr.bean@orcon.net.nz	All Seasons Pharmacy
Consumer 1	Patient	withheld	
Consumer 2	Whānau	withheld	

Note: During the time of this project we worked with different consumers and some of them passed away. We want to recognise their contribution and the value they and their whānau provided to this work. We could not achieve as much as we did without them.

Appendices

Appendix A: Prompt questions used to capture experiences

Starting point questions

I will start by asking some questions about the syringes that you have been collecting from the pharmacy.

- Can you describe to me what the big syringe drivers are used for?
- How do you know that?
- Can you describe to me what the little syringes/prefills are?
- How do you know that?
- Using a scale between 1 and 5, how confident are you about knowing what each of these syringes are used for?

  1 Not confident
  2 Somewhat confident
  3 Confident

4 Fairly confident
5 Very confident

Question 2

- Did you know that the syringes have expiry dates (a time when you cannot use the syringes anymore)? Yes/No

  [If the person said yes, ask]:

  - How do you know this?
  - Do you think the information is clear? Y/N/Partially
  - How can it be made clearer?

Question 3

- Do you know how to store the syringes when you get them home? Yes/No

  [If they say yes, ask them to describe how they would store them.]

Question 4

- Do you feel confident about what the medications are for? Yes/No
  - Can you describe to me what you think they are for?
  - How did you know that?
  - What information helped you to understand what the medications were for?
  - Was that information useful? Y/N/Partially

Question 5

- How could we improve the information to make you as confident as possible?

  [If needed, share some of these ideas as a prompt]:

  - Written information – with their ideas included
  - Providing the information verbally as well as in written format
  - Information written or verbal in their language

Appendix B: Medicines Information Sheet, Draft 1

Syringe Driver Information Sheet – All Seasons Pharmacy

Patient Name:

Date:

Syringes – Store in Fridge. Expiry:_____

Enclosed:

Prefilled Syringes:

1. Oxycodone/morphine/methadone/fentanyl (select one) For pain/discomfort/SOB (select one)
   # provided: _____

2. Midazolam/haloperidol/levomepromazine (select one) For _____
   # provided:_____

3. Buscopan for_____
   # provided:_____

4. Dexamethasone for_____
   # provided:_____

5. Other:_____

We will prepare more syringes on:_____

Syringe Driver #:_____

Other:

New prescription needed/Contact Hospice/Contact GP

Other info:

After hours contact:

Marie: *Phone number provided*

Belinda: *Phone number provided*

Appendix C: Medicines Information Sheet, Draft 2