

Partners in Care co-design case study

The right to have a key support person in hospital

Location and context

This co-design project is centred on increasing awareness of the key support person (KSP) role at Waikato District Health Board (DHB). This will ensure patients are aware of their right to have someone with them to provide support that is accessible and upheld for patients, whānau and support people who rely on the care and services of Waikato DHB. As identified in the Health and Disability System Review (2019) interim report, consumers have articulated a need for the system to respond to what consumers' value and need.

Waikato DHB is the tertiary provider for patients domiciled in the Bay of Plenty, Lakes, Hauora Tairāwhiti, Taranaki and Waikato DHBs. It is a key provider of integrated hospital and community-based health services within the Midland region, serving a population of approximately 900,000 people (Figure 1).



Figure 1: Map of the five Midland region DHBs

Key support person role

The KSP role is gaining momentum and is an accepted role in many DHBs around New Zealand. There are a number of benefits emotionally, spiritually and physically for patients who are able to have their support person with them during hospitalisation (Waikato DHB, nd).

When admitted into hospital, many people can feel vulnerable leaving the support of whānau, friends and the comfort of their own home while also managing a health event. Isolating patients at their most vulnerable times from the people who know them best places them at risk for medical error, emotional harm, inconsistencies in care, and costly, unnecessary care (Cacioppo and Hawkley 2003). As identified by Netzer and Iwashyna (2017) opening up visiting hours further supports hospitals' ability to provide equitable and just treatment.

Other DHBs both nationally and internationally have implemented similar roles, with the following results:

- no change in the number of security events since allowing 24/7 access
- improvements in perceived patient centredness scores
- 50 percent reduction in hospital acquired infections
- 73 percent reduction in serious safety events since 2007
- children who had undergone surgery cried less, were less restless and required less medications when their parents were present and helped with pain assessment and management.

The Code of Health and Disability Services Consumers' Rights states: 'Every consumer has the right to have one or more support persons of his or her choice present, except where safety may be compromised or another consumer's rights may be unreasonably infringed' (Health and Disability Commissioner 1996). At Waikato DHB, this right is upheld within the KSP role, which allows patients to nominate someone to remain with them to provide support and aid in treatment and recovery. The KSP role has been in place since 2016, and Waikato DHB has a guideline titled *Visiting Patients at Waikato DHB Facilities* (Guideline 0125, 1 July 2017), which has been written in accordance with the Health and Disability Commissioner Act 1994 (reprint 2017), the Health and Safety at Work Act 2015 (reprint 2018) and the Treaty of Waitangi Act 1975 (reprint 2018).

The guideline states:

Waikato DHB acknowledges the difference between key support people and general visitors and the role that each play in the care, recovery and treatment of patients. This guideline provides flexibility for patients to nominate a KSP who may remain present with them beyond core visiting times.

The KSP definition:

This is typically a loved one, for example, a spouse, partner, adult child, parent, sibling, close friend or whānau member. This person will provide emotional and practical support as the patient and key support person wishes during their stay in the hospital or facility. Where a patient is unable to make this decision then the next of kin may identify a key support person. The key support person may change at intervals in response to the patient's wishes and availability of a specific person.

The KSP, at the request of the patient, may:

- participate in clinical conversations and family meetings
- participate in clinical handovers
- help with basic/essential care needs (in agreement with appropriate staff)
- support the patient with decision making
- facilitate transition of care to home.

Project catalyst and intentions

Patients with cancer may traverse many different wards and specialties during their treatment, and approximately 70 percent of treatment for cancer is received outside of the oncology service.

In 2013, the clinical nurse specialist of the Adolescent and Young Adult Cancer Service – Midland region highlighted to Waikato DHB's Quality and Patient Safety team the need for patients to have their right to support upheld as per the Code of Health and Disability Services Consumers' Rights, as variations of support existed depending on the ward that young people navigating a cancer journey were admitted to. As a response to this, in 2016 Waikato DHB's Quality and Patient Safety team embedded the KSP role into the *Visiting Patients at Waikato DHB Facilities* guideline. However, in 2018 the clinical nurse specialist listened to the experiences of a young cancer patient who was not allowed to have their partner's support longer than the general visiting hours during their admission despite this partner being identified as a KSP. This young person had been navigating a long, complex health journey via three medical disciplines, with numerous surgeries and interventions – still without the guarantee of a cure. The support of their partner as part of their recovery was holistically and integrally important to the young cancer patient.

During this time the clinical nurse specialist informed the Senior Nursing Directorate of the lack of awareness of the KSP role. They acknowledged the importance of enhancing the awareness and function of the role. The realisation that there was limited knowledge about the KSP role was the catalyst for this project.

On further investigation, discussions with patients, whānau and staff provided anecdotal evidence highlighting that many were unaware of the KSP role. This emphasised the need to work alongside patients, whānau and staff to help increase their understanding of the KSP role and ensure the patient's right to support is accessible and upheld.

There were various interventions conducted between 2018 and 2019 to assist progression, but it was not until this project was initiated by the DHB, the Health Quality & Safety Commission and the Midland Cancer Network that it gained impetus. As a co-design project group, we collaborated with patients, whānau and staff member stakeholders to understand their experiences and explore their ideas for improvement to enable Waikato DHB patients and whānau to 'have a safer and more supported experience'.

There is a range of evidence that identifies the importance of a nominated support person for those patients who require hospitalisation (Bélanger et al 2016; Kent et al 2015).

Figure 2: Waikato Hospital



Project aim

Using a co-design approach, we sought to:

1. understand staff, whānau and patients' current awareness of the patient's right to have a KSP, and to identify challenges and opportunities
2. identify and test new ideas for improvement to ensure widespread awareness and function of the patient's right to have a KSP.

To achieve our aims, we needed to:

- gauge patient and whānau awareness of the KSP role and build on this knowledge by co-designing resources to inform patients, whānau and staff of this role
- work with patients, whānau and consumers to identify the best messaging to increase awareness of the KSP role
- understand the impact on patients when a KSP is not being enabled to stay and support them
- work with staff to identify the best messaging to increase awareness and knowledge of the KSP role and guideline
- work with staff to understand any reservations/challenges they may have in relation to this role
- work with Waikato DHB to implement identified key learnings.

Start up

Following approval from the Senior Nursing Directorate, we formed our core group incorporating consumers, charge nurses from different wards, the director of Te Puna Oranga, clinical nurse specialists, the business manager of Faster Cancer Treatment, and the project manager of the Midland Cancer Network. The co-design team was established via engagement with Waikato DHB, Ko Awatea and the Health Quality & Safety Commission. It initially comprised 12 members from the health sector, with two additional senior stakeholders and three consumers.

During this initial phase, team members discussed and agreed on the following set of principles to guide our work.

- **Ōritetanga – equal opportunity.** The project must capture the voice of all consumers and team members, and address agreed components.
- **Whakaurutia – inclusion.** Ensure all team members feel safe and have the ability to contribute to team discussion via attendance at meetings and/or emails.
- **Tino rangatiratanga – self-determination.** Governance that defines and manages the outputs, outcomes and benefits from this project.
- **Whai i ngā tukanga a te rōpū** – working together respectfully following the group's processes.

To ensure we were correct in our assumptions and discussions, we completed a review of baseline data. We accessed local and national data, including policies and learnings from other DHBs, on the KSP role in order to increase our understanding of what was currently available elsewhere. This included:

- **The Code of Health and Disability Services Consumers' Rights**
Right 8: 'Every consumer has the right to have one or more support persons of his or her choice present, except where safety may be compromised or another consumer's rights may be unreasonably infringed.'
- **Review of complaints**
We reviewed complaints that had been received over the last 12 months that may have related to having a KSP support a patient within the DHB. While this provided a lot of background information, there were no specific complaints regarding not being able to become or have a KSP.
- **Incidental feedback**
Even though no formal complaints had been received by the DHB through our day-to-day work within the DHB, staff members and patients described negative experiences relating to patients not being able to have a whānau member support them during hospitalisation.
- **Review of existing projects**
Within the DHB we reviewed the current projects that were being undertaken to assess for alignment and potential incorporation with existing projects. Table 1 details these findings.

Table 1: Details of project alignment and policies reviewed

Project alignment and policy review		
Project	Relevance	Communication
Welcome Pack to Patients project	The need to ensure clear KSP communication in all information	Project leads updated on project progress as required
Care Partner project	Increase awareness of KSP role and how this can interface with Care Partner project	Project leads updated on project progress as required
Local and national policies	Foundational documents: <ul style="list-style-type: none"> • Counties Manukau information: <ul style="list-style-type: none"> – visiting and supporting inpatients – policy – procedure • Waikato DHB information: <ul style="list-style-type: none"> – Waikato DHB family care plan – Waikato DHB visiting guideline • Bay of Plenty DHB: <ul style="list-style-type: none"> – visiting guideline/policy 	Project leads to feed back and share our learnings and outcomes with those DHBs that shared policies, guidelines and information with our KSP group

Engage

We discussed as a group who we should engage with and what was the most appropriate method to capture this work. Therefore, we collaborated with patients, whānau and staff member stakeholders to investigate what support and education they required to ensure increased awareness of the KSP role. To engage people with this project, we developed the following elevator pitch to help patients, whānau and staff understand what we were aiming to achieve:

We are always looking at ways to improve patient care here at Waikato DHB. We would appreciate time to hear from you about your understanding of the Key Support Person right.

Capture of experiences

Capturing experiences was an iterative process. It involved a range of different mechanisms (surveys, face-to-face discussions, group discussions) that were piloted and adjusted following feedback from consumers and stakeholders. We explored how patients, whānau and staff knew about and understood the right for patients to have a KSP with them in hospital, and we asked for their advice on how to improve awareness.

Surveys

Initially, we trialled the survey on nine patients, whānau and staff within the hospital to assess the flow and suitability of the questions. Only minor tweaks were needed before we progressed to using the survey on the four pilot wards. Our learnings from patient stories and staff feedback during this pilot demonstrated that there were inconsistencies to what patients, whānau and staff were aware of regarding the KSP role and also across the different areas of the DHB. We approached the deputy director of Nursing to share our findings and gain support for a proposal to socialise and raise awareness of the KSP guideline, which already existed within the DHB but was not well understood or used. The deputy director was happy to support our request.

Following the initial survey conducted with nine participants, a further 40 surveys were completed by patients, whānau and staff in four wards of the DHB. We aimed for 10 surveys per ward: five staff members from various disciplines and five patients/whānau (Figure 3). We also consciously tried to attain the voice of Māori, Pasifika and rural participants (Figure 4).

Figure 3: Number of survey participants

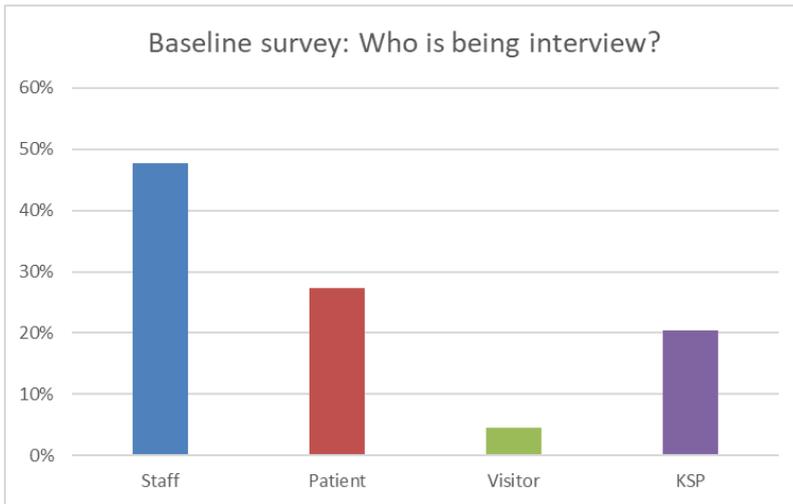
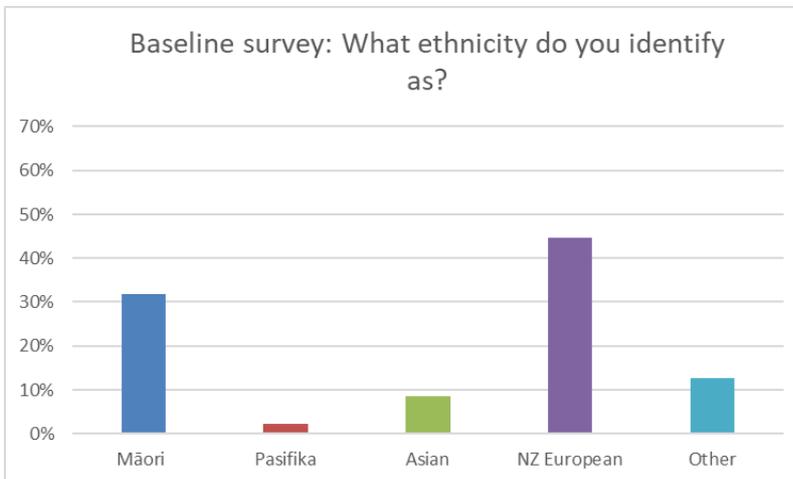


Figure 4: Ethnicities of survey participants



These baseline surveys demonstrated 'little to no' current knowledge or awareness of the right for patients to have a KSP support them in hospital (Figure 5) and when the KSP could be with the patient (Figure 6).

Figure 5: Awareness of the KSP role

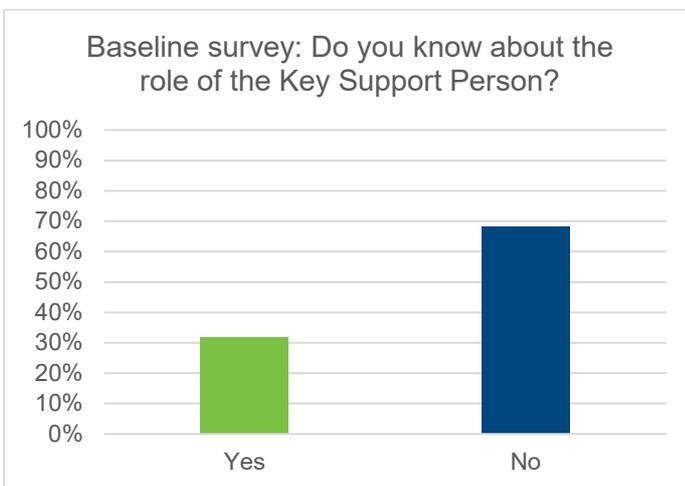
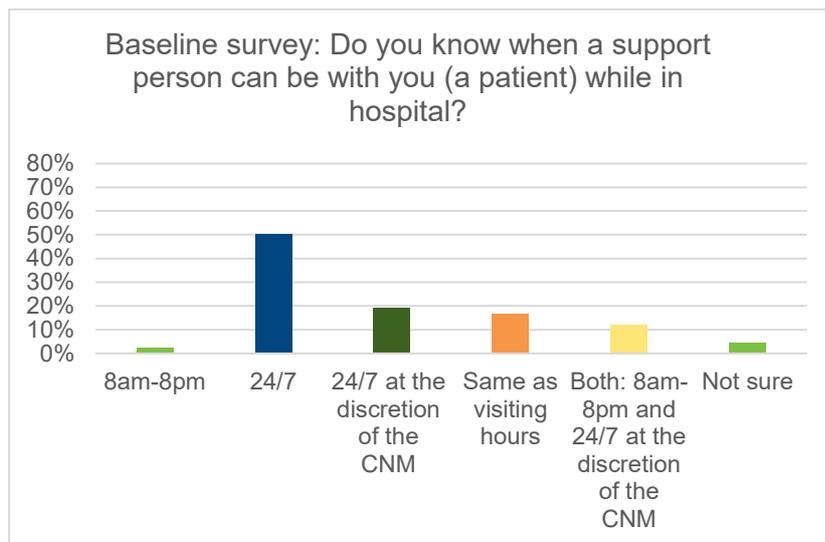


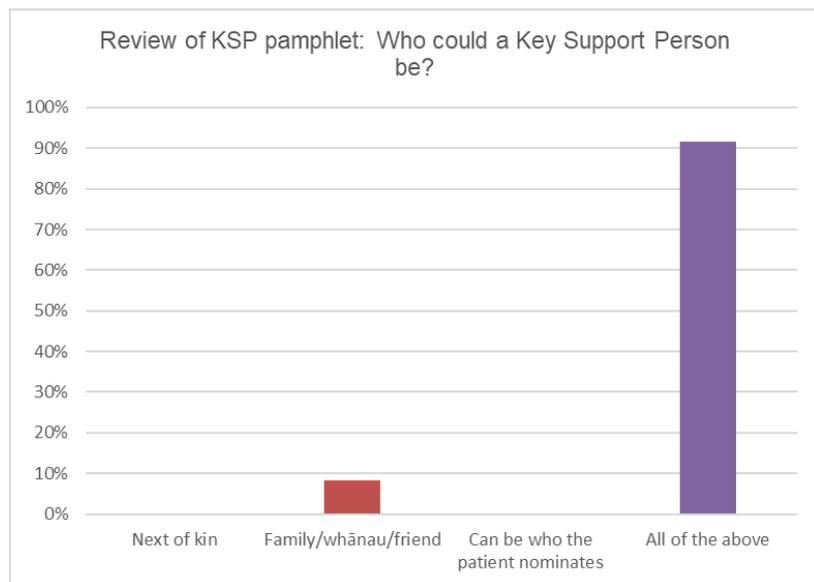
Figure 6: Participants' knowledge of when a KSP can support the patient



CNM = Charge Nurse Manager

The data also identified challenges of implementing the KSP role (eg, confusion between next of kin and KSP) (Figure 7).

Figure 7: Participants' knowledge of who a KSP could be



Post-survey focus groups

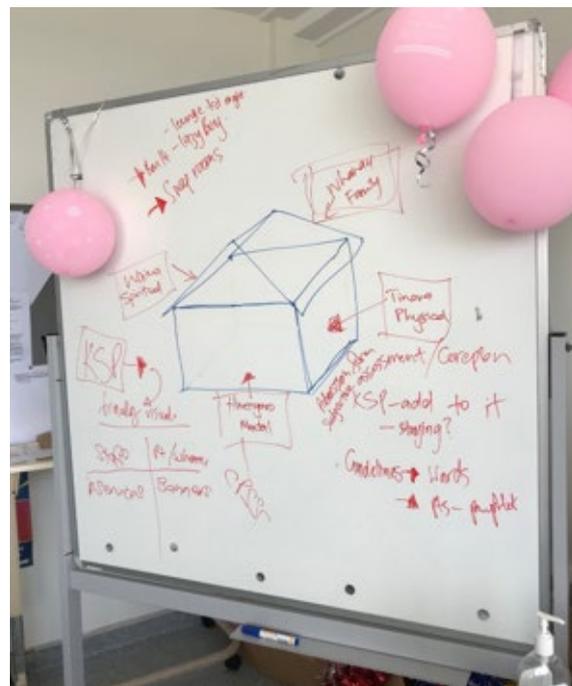
After the surveys were conducted, staff member focus group meetings were then undertaken in the same four wards. Collectively, over 50 staff participated, and at the beginning of each session a quick show of hands revealed only about 15 percent were aware of the KSP role.

There were three reasons why the co-design team held the post-survey focus group meetings. Firstly, to use the opportunity to educate staff members about the patient's right to a KSP. Secondly, to inform them of the survey results conducted on their wards during the previous weeks. Thirdly and most importantly, to listen, acknowledge and learn from the challenges and successes they had previously experienced while implementing the KSP role in their wards.

Figure 8: Clinical staff participating in focus group meetings



Figure 9: Whiteboard exercise looking at Te Whare Tapa Whā and detailing staff feedback on how to increase KSP awareness



These post-survey focus group meetings were invaluable, as we gained a more detailed understanding of what opportunities and challenges each ward previously experienced and/or will have to work through to implement the KSP role in their specific areas.

Another important aspect identified to us via the focus group feedback was a gap in key stakeholders/co-design members, therefore we included duty managers and a kaitiaki (DHB cultural advisor) in our co-design team. We also conducted face-to-face discussions with receptionists of the four pilot wards and held a group discussion with hospital security. On reflection, we realised including these voices would be crucial to the project's success.

Understand

This phase enabled the team to reflect on all the data collected so far and begin to identify themes.

Themes

Four themes emerged from the patient and whānau participants and six from staff participants (Table 2). Overall, the main theme both groups identified was a lack of awareness and knowledge about the KSP role.

We often heard from patients and whānau that the experience of being in hospital was scary and emotional, and having a support person was important. For example:

...[gain] comfort with knowing that his wife could stay if needed.

...being able to support outside of visiting hours helped immensely.

Having whānau to support cultural needs was also highlighted:

...feeling culturally safe with whānau support, extremely important.

In general, staff described a lack of knowledge of the KSP role, what that meant for the ward, and how they could support it. They described challenges with ward facilities to accommodate a KSP staying for prolonged periods, especially if they needed to stay overnight. Logistically, many wards were not equipped to provide provisions for people to stay overnight. Staff members noted that patients who were supported by a KSP were usually happier, had less fear and anxiety, and were less likely to experience overt racism.

Table 2: Themes emerging from participants

Participants	Themes
Patients and whānau	<ul style="list-style-type: none"> • There was little or no awareness of the KSP role. • Whānau often felt that they have no rights. • Patients and whānau felt they were not listened to. • Many whānau and patients expressed feeling scared or emotional when they had to leave their loved ones.
Staff	<ul style="list-style-type: none"> • There was little or no awareness of the KSP role. • Staff were concerned about: <ul style="list-style-type: none"> – the lack of facilities for the KSP – not enough space and resources such as chairs, mattresses, pillows – the increased number of people who may want to stay after learning about the KSP role – whānau insisting they can stay ‘out of visiting hours’ when they are not a KSP – KSPs wanting to stay in four- to six-bedded rooms with mixed genders – other patients’ privacy.

Throughout the co-design process we actively sought stakeholders’ recommendations and thoughts on how to improve the awareness of the KSP role (Table 3). Once this data was collated and the themes were analysed, we contacted consumers (via email) who consented to being re-contacted, updated and asked for further feedback to prioritise the themes in the order they thought would best help with the socialisation of the KSP role within the DHB. Table 3 also identifies which resources consumers and staff wanted the co-design team to prioritise and begin work on.

Table 3: Stakeholder recommendations for improving awareness of the KSP role via various communication channels

Stakeholder group	Recommendation
<p>Patients and whānau</p>	<p>Poster</p> <ul style="list-style-type: none"> • Develop a KSP poster, such as the ‘Values’ poster in the High Dependency Unit, and make sure you live up to the values stated. • Place laminated KSP info (posters) in rooms, bedrooms, lounges, café (ie, like the ‘Clean Hands’ signs). • Place KSP signage in the front of the ward entry. • Make a simpler version of the Code of Health and Disability Services Consumers’ Rights available. <p>Pamphlet</p> <ul style="list-style-type: none"> • Develop KSP pamphlet. • Provide KSP pamphlet at the end of bed or flyer. <p>Telemedia</p> <ul style="list-style-type: none"> • Develop a KSP advertisement to screen on Waikato DHB telemedia. <p>Admission and nursing documentation</p> <ul style="list-style-type: none"> • Ensure the patient’s KSP is entered into the admission form and send out in the mail and provide on admission. • Discuss KSP role at admission (keep informing at all transition points as an introductory, such as National Health Index and next of kin). • Provide patient information booklet that includes KSP pamphlet alongside other vital information, such as parking voucher. <p>Other</p> <ul style="list-style-type: none"> • Recruit more staff. • Increase staff awareness of KSP role. • Provide verbal information of KSP role. • Provide KSP information to local general practitioner (GP). • Offer and encourage the use of karakia. • Advise National Travel Assistance team to tell patient and whānau of their ability to have someone appointed into KSP role.
<p>Staff</p>	<p>Poster</p> <ul style="list-style-type: none"> • Create KSP posters to increase awareness. • On the Health and Disability Commissioner poster, highlight ‘Right 8’ to ensure staff are aware it is an actual patient right. <p>Admission and nursing documentation</p> <ul style="list-style-type: none"> • Ensure KSP is filled out on admission form and that patients and whānau are informed of KSP process. • Provide cards with the Visitor Guideline information and KSP role. • Create identification and information cards for KSPs (like business cards). • KSP pamphlet to be added to bedside ‘Ward booklets’. • Incorporate KSP role into the Code of Conduct. • Ensure the patient’s KSP is documented in Nursing Care Plan. • Create a KSP contract. • Create formal guidelines so patients and whānau are aware of expected conduct. <p>Pamphlet</p> <ul style="list-style-type: none"> • Develop KSP pamphlets.

	<p>Education</p> <ul style="list-style-type: none"> • Provide KSP education (in-services and senior staff information). Charge Nurse Manager to let staff know. • Provide verbal information of KSP role. • Provide carer meals. • Consistency of information is important. • Email KSP information out to staff. • KSP memo to be attached to all staff members' payslips.
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Improve

Recommendations for improvement centred on the feedback that patients, whānau and staff provided through the surveys and focus group meetings. Our primary objective was to improve awareness and function of the KSP role for patients and whānau. We were also aware that in order to implement changes we would require staff support because they would be the people who implement these changes.

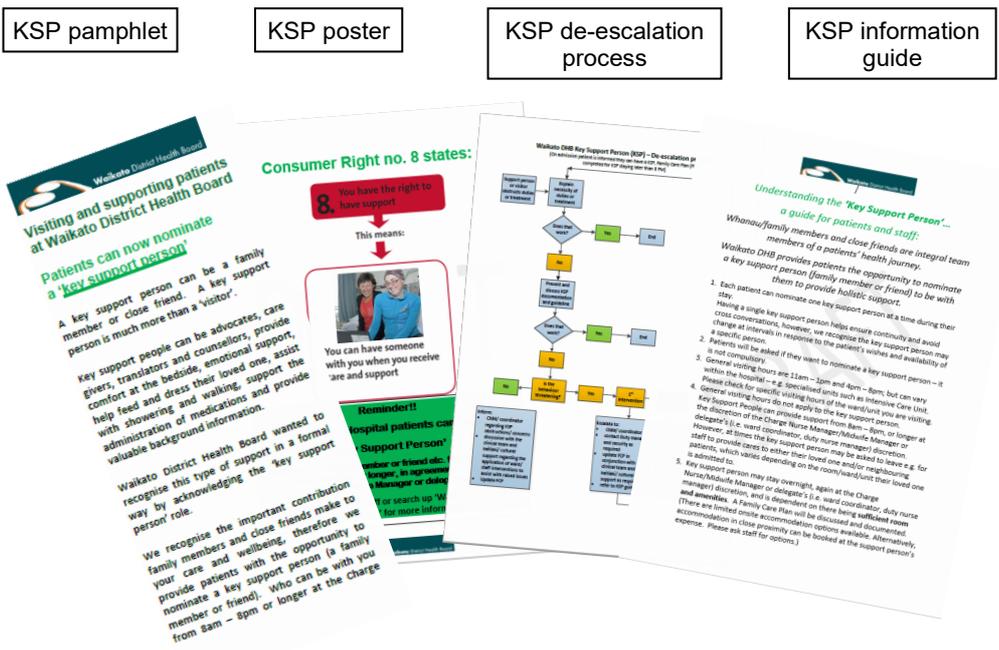
Patients, whānau and staff guided the project by prioritising which recommendations would be most suitable, and the project team agreed to initially begin developing draft materials, including:

- a poster to visually increase awareness about the KSP role
- a pamphlet to provide more detailed information for patients and whānau about the role and expectations
- a de-escalation process form to support and assist staff if any KSP issues arose
- a KSP information guide used to describe the role of the KSP (Figure 10).

Staff also said it would be important for them to be able to easily identify the KSP, so time was spent researching various options, such as a wristband/lanyard/badge. At this stage, a green wristband was identified to test.

The next step was to pilot these resources on the four pilot wards by incorporating them into the daily life of the wards to see if they increase the awareness and function of the KSP role for patients and whānau.

Figure 10: KSP resources developed to assist implementation within Waikato DHB



Measure

The KSP trial was scheduled to go live just as COVID-19 Alert Level 4 lockdown began, which impacted on our ability to pilot the KSP materials that had been developed. To complete this piece of work in the recommended time frame, our team had to be agile, so we decided to seek feedback on the pamphlet from patients, whānau and staff to assess if this resource improved the understanding of the KSP role.

The pamphlets were distributed to two of the four pilot wards, and we asked participants to review the pamphlet and feed back to us ~24 hours later via face-to-face surveys. A total of 24 people were surveyed. The sample included patients, whānau, KSPs and staff (Figure 11).

Figure 11: Number of participants reviewing KSP pamphlet

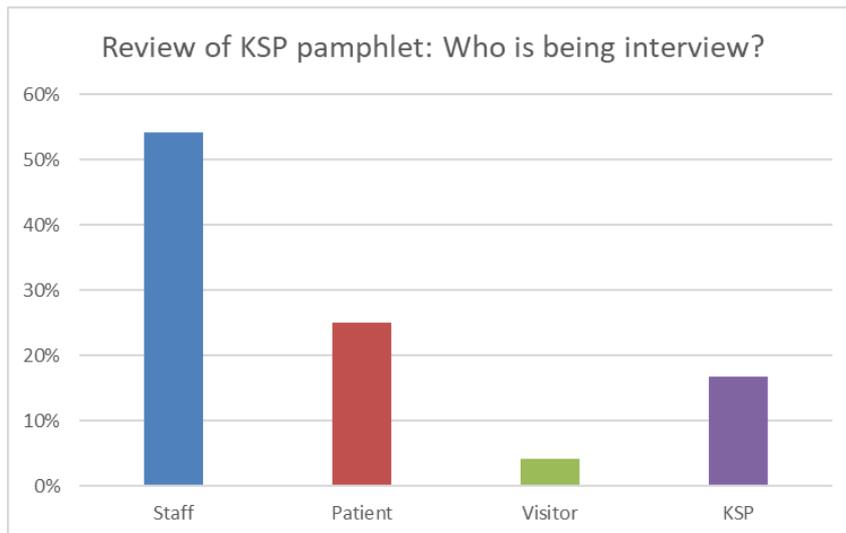
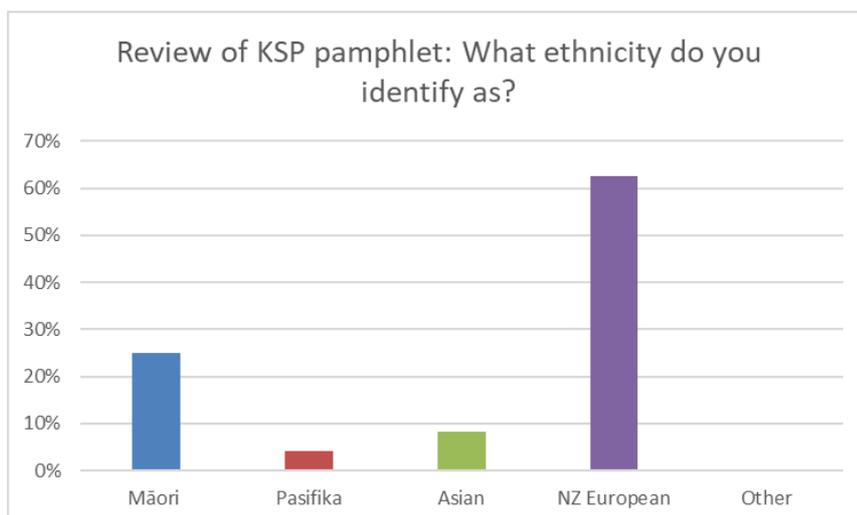


Figure 12: Ethnicities of participants reviewing KSP pamphlet



The survey included the following questions:

- Did the pamphlet help you to understand the role of the KSP?
- Do you have any suggested changes to the pamphlet or other ideas for materials that would help get this message out to patients, whānau and staff?

Patient responses

The responses from patients were positive. They articulated that the pamphlet was a good idea, informed them of their rights, and provided information that they were unaware of. The following are some of the comments we received.

...pamphlet it is helpful...

...yes it was really good, let me know what I was entitled to, outlines everything really clearly, parking a good idea and meals also...

...after 8pm needs work – how do they get in...

...covers basically everything, maybe add it to the website...

Whānau responses

The responses from whānau, visitors and KSPs were positive. It was found to be a welcome resource with no changes identified. The following comments were made by the whānau that were surveyed.

Helpful, self-explanatory, better guidance on managing children as visitors might be good, who can come versus who shouldn't.

...pamphlet was helpful, expectations haven't always been consistent, so a pamphlet would help.

...yes it was helpful.

...very informative and am very appreciative...

...needs to be accessible as can be whakamā/shy...

...social media or word of mouth would be good to get the message out.

Staff responses

Staff members made the following comments about the pamphlet.

...good pamphlet, definitely helpful...

...helpful for patients...

...make it available to GP services/health centres and other NGO...

...maybe available in different languages...

Figures 13–15 indicate that after reading the draft pamphlet, participants demonstrated an awareness of the KSP role, who could act as a KSP, and when the KSP could stay with the patient.

Figure 13: Awareness of the KSP role after reviewing the KSP pamphlet

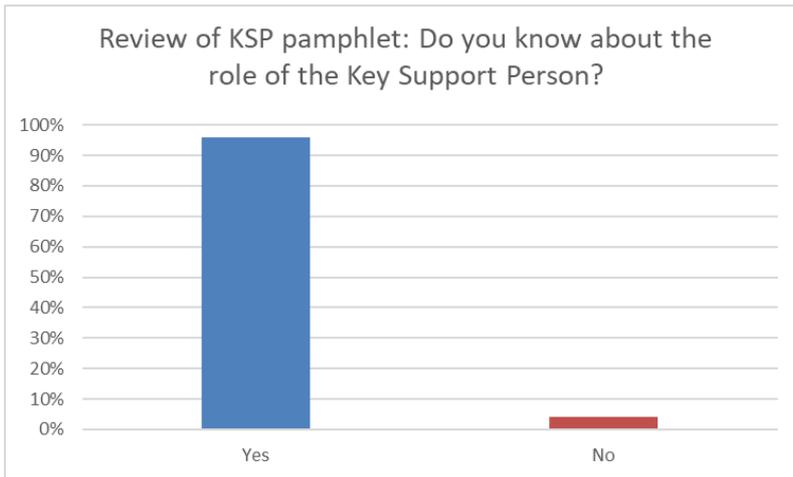


Figure 14: Participants' knowledge of when a KSP can support the patient after reviewing and reading the KSP pamphlet

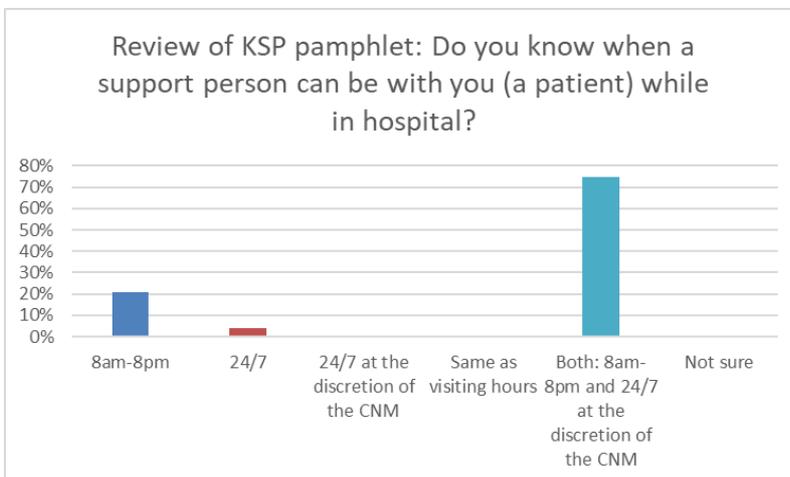
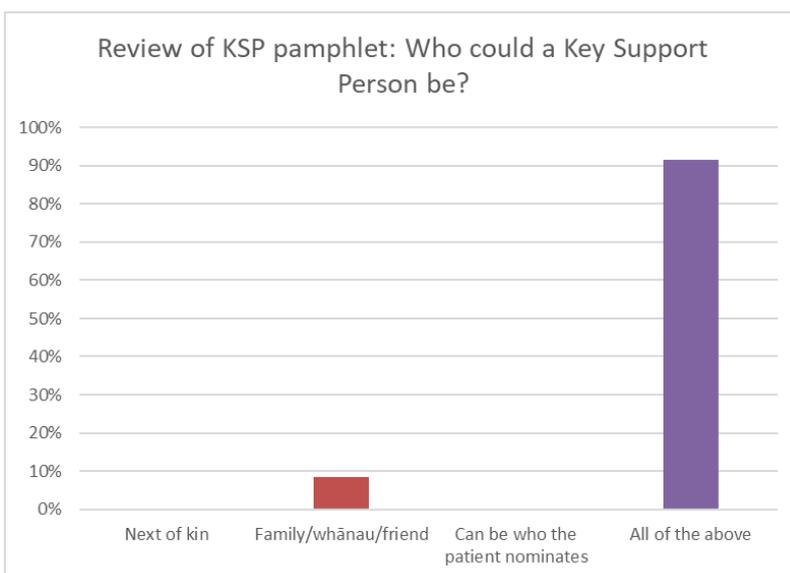


Figure 15: Participants' knowledge of who a KSP could be after reviewing and reading the KSP pamphlet



Feedback just from the KSP pamphlet alone has demonstrated this resource's ability to increase awareness of the KSP role.

The co-design group is committed to this project. We have all decided to continue rolling out the other recommendations, and we will do this by conducting a three-month trial using all the KSP resources together on the project wards. We have also informed the Health Quality & Safety Commission we will update them with the outcomes.

Working as a co-design team

Learnings

- As a co-design team we had to learn to be less solution focused – by actively listening to the voices of patients, whānau, users and consumers to identify what will work for them.
- The use of consistent messaging and acknowledging the importance of clear and concise communication enabled the progression of this project and expectations of the team members.
- We developed stakeholder engagement early on in this project, which enabled stakeholders to develop a good understanding of what we were trying to achieve, collectively. As our stakeholders were often from the health sector, we were open to the need at times to add additional stakeholders along the way.
- Listening to patients, whānau and staff stakeholders describe their lived realities was key to understanding the impact of this project on them. It also provided a forum for these stakeholders to inform and assist the development of this project. This at times meant that the co-design team had to be open to both negative and positive feedback that was received.
- Co-design serves as a mechanism that ensures that services, policy and guidelines are created and designed collaboratively to enhance the health and wellbeing of the community we serve.

Recommendations received by co-design team during the co-design process

- Create a communication pathway to de-escalate any developing KSP issues arising in a timely manner to senior management (ie, ward and daily report to duty managers).
- A comprehensive KSP education package should be developed for peripheral and regional hospitals that transfer patients to Waikato DHB.
- A KSP pamphlet should be added to Ward Orientation booklets for patients and staff.
- Admitting staff should document KSPs on appropriate nursing documentation.
- Staff should be equipped with the adequate skills and responses for de-escalation and communicating to whānau.
- KSP volumes should be collated and integrated via the patient management system.

The project team

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Dedication

In memory of Ihaka Mita, Consumer Team Member – your KSP team members honour and thank you.

Acknowledgements

The KSP project team would like to acknowledge the learnings and knowledge shared by Auckland DHB and Counties Manukau DHB.

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