# Phase 2: Pre-intervention evaluation of healthcare worker and patient-guardian materials

Part 1 of this document presents the views of healthcare workers, Part 2 presents the views of parent/guardians, and Part 3 presents the views of Indigenous Liaison Officers.

#### Materials

The intervention materials under review included different flow charts regarding antibiotic conversion eligibility and identification of suitable oral antibiotics, fact sheets, chart labels, and patient-guardian material.

Table 1.2 Proposed intervention materials

Material	Description
?STOP chart	A simple IV to oral guide to aid in practitioner's decision-making.
Flowchart	Detailed chart for identifying those eligible for IV to oral antibiotic conversion
Medication tables	One table included suitable medications and dosages, and another included comparable IV to oral antibiotics for switching.
Patient chart labels/stickers	Reminders to prompt a medication review.
Fact Sheet	A general IV to oral conversion fact sheet for healthcare workers.
Patient-guardian information sheet	Information for patient-guardians regarding switching from IV to oral antibiotic medication.

## Part 1: Considerations for tailoring healthcare worker materials

In this section, we present views from the 15 healthcare workers views and recommendations regarding the materials designed for healthcare workers. Specifically, healthcare workers were asked to review the content and design of the intervention materials, and consider their relevance and utility within their personal practice and that of their colleagues.

# Overall impressions of the intervention and anticipated uptake among healthcare team members

The intervention materials received strong endorsement from participants, who acknowledged the importance of the issue being addressed, along with the appropriateness of the materials. Several participants also shared their anticipation for its implementation.

"I'm wholly on board with it and yeah it looks like great material so far..." (HCW05 paediatric pharmacist)

"I mean from point of view that I've actually been part of the judicious use of antibiotics at [the] Hospital and I'm pleased to see that we are heading in the right direction. And I would entirely endorse the recommendations and selection of antibiotics as prescribed in this protocol." (HCW07 Paediatric director)

"I'm looking forward to being able to use it I think it's good..." (HCW12 paediatric consultant)

A few participants also noted the relevance of the intervention for regional hospitals, where access to specialists tends to be limited and staff turnover higher.

"Definitely a big help...in a regional centre where they are the only doctors, this can really impact on how they would practice" (HCWO2 paediatric registrar)

"...we have a lot of locum doctors. And it is good to have an in your face recommendation of what the expectation of medication is [locally]...rather than to come along with their practices elsewhere" (HCW07 paediatric director)

While participants indicated the relevance of the materials for all healthcare team members, there was strong agreement that the greatest uptake could be anticipated among nurses and pharmacists, followed by junior doctors. For nurses, it was felt that the materials would clarify the IV to oral conversion process and support them in appealing for timely clinical reviews of IV antibiotic use. Pharmacists were considered most likely to use the materials to aid in decision-making and help foster shared understandings about best practices in antimicrobial stewardship. Similarly, it was felt that junior doctors would use the materials to support decision-making and communication with team members. Most participants felt that senior practitioners, in particular doctors, would have minimal engagement with the materials, due to their already established practices. However, some senior doctors highlighted the importance of the materials for formalising their practice and serving as prompts for reminding them to undertake timely medication reviews.

## Personal preferences and recommendations for optimising the content and design

Participants relayed clear and consistent understandings of the underlying message being portrayed through the intervention materials. While general satisfaction with the materials was evident, most indicated personal preferences for specific materials. When asked to consider the content and design of each material, some diverse views were shared regarding their effectiveness, as well as important, although at times conflicting, recommendations for improving their utility.

#### Flow chart and table of suitable antibiotic agents (flow chart)

The flow chart was particularly favoured by junior doctors and pharmacists, who highlighted its utility for aiding their decision-making, particularly around the selection of appropriate oral antibiotics.

"[the flow chart is] probably the main thing that I would prefer and would be using because that's the most helpful for me. Like I want to go to a doctor with a recommendation I don't want to say look we just need to change it without giving them [a recommendation]." (HCW05 paediatric pharmacist)

"...definitely a big help. Because sometimes when we are in doubt there is no... direct guideline... this can really impact on how [we] would practice... it's going to be quite a good resource for we healthcare providers." (HCW02 paediatric registrar)

"...it helps me to decide whether or not I have to put in another IV cannula if a cannula tissue is in a kid... it shows you whether or not oral is possible." (HCW04 paediatric intern)

One pharmacist also shared how using the material would affirm confidence in their decision-making process, while a senior paediatrician shared how it formalised the approach they already practiced.

"...oral antibiotics might be good but without having something to go with it I'm not as confident in my decision. And especially when I you know I'm not diagnosing and I'm not at the bedside on ward rounds. I think the flowchart would definitely make me more confident in saying "Hey let's look at this"." (HCW08 pharmacist)

"I'm not sure that we weren't doing it in the past, [the flow chart] just formalises the process into the four or five steps." (HCW13 paediatrician)

#### Content considerations

Overall, participants noted that the flow chart and table for suitable antibiotic agents was the most informative of the materials presented. Several also praised it for its clearness and ease to follow.

"I felt like this flow chart is really good... and more like informative." (HCW03 paediatric nurse)

"So I felt like this flow chart is really good because it has got all [of the] exclusion criteria and everything and in this one so...I felt like this one is this is better [than the ?STOP guideline]." (HCW03 paediatric nurse)

"Yeah so as a pharmacist I think having these really clear guidelines... is something that I could definitely use." (HCW08 pharmacist)

Few issues and recommendations for improving the content of the flow chart were shared. One pharmacist felt that the table of suitable antibiotic agents could be described more simplistically, and cautioned against complicating decisions with too many oral antibiotic options.

"...this [suitable agents table] may be a little bit wordy... and then it's got... quite a few [to choose from]... too many options is sometimes difficult for some people... we could look at minimising some of them..." (HCW05 paediatric pharmacist)

Another pharmacist saw the need for more information to be provided in the exclusion criteria.

"...with all of these exclusion conditions [are] there other things that we call any of these conditions... what else could we be looking for?" (HCW08 pharmacist)

Pharmacist HCW08 also felt that the suitable agent chart did not adequately address important barriers to oral antibiotics in paediatrics, such as tablet or liquid dosing and taste.

"...like clindamycin it doesn't come in a liquid, it's only a 150 milligram capsule. [So you need to know] what dose you'd go for and is it practical and is it easy for the parents to give?

Because that could be another thing that makes oral not work... [you may] not realise you can't measure it or there's a foul taste or something like that." (HCW08 pharmacist)

#### Design considerations

Little criticism was received regarding the design of the flow chart. In line with remarks about its content, participants noted its ease and simplicity to follow:

"I think the back flowchart is also good because it has bigger arrows and you can just follow it through." (HCW10 paediatric nurse)

"I find that some of the flow charts that I've seen to date have really complex.... So I like that this is quite short and sweet and concise... Like as the pharmacist, if I were to go and broach a doctor and say "Look I think that we need to switch" it's not too much [to talk through]..." (HCW05 paediatric pharmacist)

While one participant felt the use of colours in the flow chart was appropriate, another felt they were ineffective:

"But you know you've got your green, the colour... obviously matches up with if they do meet those conditions... Overall presentation I think is quite good." (HCW05 paediatric pharmacist)

"I guess the colours don't really stand out on the flowchart to me... [unlike] I guess with the other ones when you've got red for stop.... I just don't know about the yellow for the no?" (HCW08 pharmacist)

Finally, one recommendation was made for improving the readability of the boxes in the flow chart: "The flow chart the only issue that I had with it... [concerned] the box that says are signs and symptoms improving? And if available are sepsis markers decreasing? Which then has a note that would describe bone infections and CRP rises and falls. I think that this box in particular is both asking... two questions and perhaps that could be separated." (HCWO1 paediatric resident)

Recommended location for encouraging uptake

• Pharmacist and acting director (HCW14) advised targeting doctors and pharmacists by placing the material in their personal work spaces, i.e. attached to pharmacist files and doctor's carts.

#### ?STOP guideline chart and lanyards

Participants typically discussed the ?STOP guideline chart and lanyards together. Nearly all participants, representing different modalities and levels of seniority, felt that the guideline chart had the greatest utility of the intervention materials. Most prominently, it was agreed that the guideline could serve as a prompt: to remind practitioners to review IV antibiotic use and encourage timely decision-making, to clarify the decision-making process, and to support shared understandings and clearer communication between healthcare team members.

"I think it's a good prompt and it certainly is something that as a nurse I can prompt a doctor about." (HCW11 paediatric nurse)

"I'm not sure that I would necessarily refer to them every time I wanted to consider changing to orals... I think the steps that need to be taken are fairly straightforward. But it's useful to have a reminder... To do it within the right time limit yeah." (HCW13 paediatrician)

"And I think it might help also to show to the nurses and the parents who are usually the strongest advocates for the kids saying do you have to put in another IV cannula. And I can show them this and say according to this guideline I think we have to put in another IV

cannula and I think everyone will be happier if there's a clear guidelines." (HCW04 paediatric intern)

The guideline was valued by junior doctors for providing direction on the best course of action to make and by nurses for informing them about the treatment being administered.

"It basically helps me, it helps me to decide whether or not I have to put in another IV cannula if a cannula tissue is in a kid. Obviously we're really reluctant we would much rather give oral but it shows you whether or not oral is possible." (HCW04 paediatric intern)

"...I see it useful because it's one making us aware of what we are actually doing with the medication... how long we're giving it for and things like that... clearly it says stop and think about what we're doing." (HCW10 paediatric nurse)

Participants shared mixed views concerning the utility of the guideline lanyards, with some strongly endorsing their use while others dismissing them as ineffective.

"I would see myself using that algorithm sheet a lot. And the lanyard." (HCW06 paediatric intern)

"I'd probably use the guidelines but I don't know we just have so many lanyards... So I probably wouldn't use the lanyard" (HCW08 pharmacist)

#### Content considerations

While the ?STOP chart was the most favoured material of the intervention, it received the most constructive feedback, with some participants suggesting it was limited as a decision-making resource. A few participants criticised its reliance on consulting external sources and its lack of concrete advice regarding appropriate oral antibiotic options. Furthermore, some participants felt that consulting infectious diseases (ID) services could risk delays in making the switch as they perceived the service as being ill-equipped to handle the volume of questions it would receive.

"It's short and simple which is good for like a quick review." (HCW02 paediatric resident)

"I think it definitely makes you think about the decision. However, I don't think it contains everything that it needs for a decision to be made and I would worry that it would just be another thing that we'd look at but not give action on it... There's a lot about consulting ID micro so whether that would happen in an efficient manner? And we don't really have any sort of recommendations on what antibiotics." (HCW08 Pharmacist)

"...if I was working more rurally I'd talk to my senior person, senior medical officer... than a consulting service like infectious disease... I don't think the region is equipped to deal with the amount of IV antibiotics use and therefore questions." (HCW01 paediatric resident)

Pharmacist HCW08 felt that the guideline was lacking critical information about how to navigate the timing of doses when making a switch.

"So when we say moving to oral like when are we moving to oral?... Are we going to start that straight away or are we going to wait till the next day? So I think that's important... I'm not saying it needs to be on that form... you want that to be... succinct. But I think there has to be something that goes with that that would give recommendations of what you would change to if you can't get in contact with someone else. So kind of similar to the paediatric sepsis pathway that there's lots of recommendations on what you'd actually choose." (HCW08 Pharmacist)

Participants HCW11 and HCW13 also advised that the title of the guide be changed to more directly reflect who it was intended for at a glance, stating that it is misleading in its current form.

"I probably wouldn't call it that, guidelines in general I'd probably call that. Because my first thing when I first glanced at it I thought this was something I was giving to the patients." (HCW11 paediatric nurse)

Furthermore, one participant raised a concern that the material does not address common barriers for taking antibiotics or ally among paediatrics:

"[However, it does not consider the issue that]... some patients like in kids... sometimes they don't like to take medicine. So in that case sometimes we normally put a gastric tube and discharge them home... Because sometimes people [have a] hard [time] to get that medicine down." (HCW03 paediatric nurse)

#### Design considerations

Most participants shared positive views about the design of the guideline, in particular noting the appropriateness of the bright colours used and effectiveness of the ?STOP acronym and sign.

"I think the poster with the stop is probably going to be the best, much as I hate acronyms...

Because it's bright, it's easy to read and it isn't overloaded with information." (HCW07 paediatric director)

"...the stop [acronym] is very, it's catchy. I think you know pneumonic[s] are a very good way to help people go through a system..." (HCW12 paediatric consultant)

"...to me [it] looks great. You know it's easy to follow... And then the lanyard version of that which is pretty much the same thing just in a small thing... when you can't find the big version it would be great." (HCW09 paediatric nurse)

One pharmacist, however, raised concern about the ?STOP acronym having to contend with numerous other acronyms in the hospital environment:

"...there's lots of acronyms that float around the hospital it's the odd thing. So whether or not it really stands out from the crowd, because there is... a lot of material out there." (HCW14 pharmacist)

In contrast to praise received for this material, one paediatric resident found the material's layout difficult to read, and highlighted a malalignment between boxes one and two and the questions they relate to:

"It's spread into 3 different columns and the overall readability of it is poor. So the way it kind of looks is that it should be read downwards... [Also] Box 1... doesn't relate to the first question, it relates to the second question which I think decreases the readability of it. Which is similar to Box 2 is... not as related as it could be." (HCW01 paediatric resident)

Furthermore, paediatric resident HCW01 and intern HCW04 raised different issues concerning the use of colour in the material: one recommending traffic light colours to help navigate the chart, while the other cautioned against the use of red.

"I would anticipate you would be going for like a traffic light system like a green, orange and red. So they're kind of meant to be like an amber light but from the first kind of glance it's not as easy as the flow chart could be to read." (HCW01 paediatric resident)

"Again I don't like red, red means bad, it means dying, it means CPR I don't think we're talking about that at this stage... So blue is good, maybe purple or brown or orange some neutral kind of colour that doesn't scare people yeah." (HCW04 paediatric intern)

Finally, one participant raised specific concern with the readability of boxes one to three on the lanyard due to its fine print.

#### **Recommended locations**

- Place copies of the guideline in the medication section of a patients' chart (HCW04 paediatric intern, HCW11 paediatric nurse).
- Prioritise targeting nurses by posting in areas where nurses would see them most, i.e. near medications (HCW10 paediatric nurse, HCW11 paediatric nurse, HCW14 pharmacist)
- Distribute lanyards to all paediatric staff (HCW14 pharmacist)

#### Patient chart labels

Second to the ?STOP guidelines, participants viewed the patient chart labels as an important component of the intervention, with nurses and pharmacists in particular anticipating their regular use of the material. Participants valued the labels as a prompt for encouraging timely reviews of clinical decisions, supporting clearer lines of communication between healthcare team members and encouraging team decision-making.

"If you forget it we can just put a small sticker in front of the medication chart to remind the doctor so they can have a look... So that's a good thing we are letting the doctors know as well rather than waiting for the pharmacist or like the doctor." (HCW03 paediatric nurse)

"I think it would nudge you to consider it more frequently... formally make you think about it whereas I think most of us think about it informally and possibly not necessarily at forty eight hours but maybe even a bit later than that." (HCW13 paediatrician)

"...I think it actually it encourages... a little bit more of a team approach when it comes to drugs... the nurses and the pharmacists could put these stickers on... and bring it to the doctor's attention and say "Actually do we really need to continue IV"?... it will encourage a team approach having these different resources rather than it being just written [on a guideline]." (HCW12 paediatric consultant)

Despite participant enthusiasm for the chart labels, electronic patient records were noted as a potential barrier for their uptake.

"Probably we won't be able to use this [chart labels] if it's on IEMR [integrated electronic medical record]" (HCW02 paediatric resident)

#### Design considerations

Overall participants shared highly positive views regarding the design of the patient chart labels, describing them as visually appealing and eye catching.

"And I really the IV antibiotics labels I think are excellent and should be implemented as is in my opinion." (HCW01 paediatric resident)

"Having a sticker like that conveys the message quite easily. That's why I like the sticker... I like the design of it personally.... it's a very big eye catching sticker. And like I don't think prescribers could really miss something like that when they open the chart." (HCW14 pharmacist)

Some participants noted the appropriateness of the colours used in the stickers for carrying their intended message, while one participant felt that the black writing on the red sticker lacked visibility.

"And then on the labels page I think they're good colours. I mean the red one obviously saying stop I think that's an appropriate colour. And the yellow one it catches your attention. So if you see it in the chart or wherever your eyes will easily pick it up and it will stop you doing that." (HCW10 paediatric nurse)

"...I like that that stands out the red one. And I'm not sure whether it's just the way it's on the form or not but I don't know how clear often black on red is not very clear." (HCW11 paediatric nurse)

#### Recommended location

Patient medical charts were the agreed location for the labels among participants.

#### Fact sheet

While the fact sheet for practitioners drew little consideration from most participants, both in regards to its content and design, its relevance for informing practice was particularly noted by those participants whose work included education and/or leadership elements (in particular: HCW09 paediatric nurse, HCW08 pharmacist, and HCW14 pharmacist). These participants valued the sheet's utility as an educational resource for informing students and interns of best practice.

"The factsheet would be helpful... for like pharmacy students and interns... it wouldn't be something that you'd use all the time it would be more as a teaching tool." (HCW08 pharmacist)

"Again like as in do I see the relevance of that? Of course... because often people don't consider the hidden costs associated with... IV therapy. They often see it as like... a more comprehensive treatment for an infection when it's really not necessary." (HCW14 pharmacist)

"The fact sheet I think would be good for education purposes... when you're trying to introduce something new to staff..." (HCW09 paediatric nurse)

One participant advised that the utility of the sheet would be increased if it were available in electronic format with reference links to support easy further reading around the topic.

#### Recommended location:

 Locate strategically in ward to encourage staff and student education (HCW03 paediatric nurse; HCW14 pharmacist)

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	CONTENT	DESIGN
Flow chart and table of suitable antibiotic agents (flow	<ul> <li>Simplify the content in the table of suitable antibiotic agents: describe the content in fewer words and consider reducing the amount of antibiotic options listed.</li> </ul>	<ul> <li>Change the use of yellow in the flow chart (for the 'no' boxes) to a colour that has greater impact/stands out more.</li> </ul>
chart)	<ul> <li>Provide more information in the exclusion criteria: are there alternative names for the conditions listed and/or others to consider?</li> </ul>	<ul> <li>Split the content of the box that describes 'signs and symptoms for improving' in the flow chart into two boxes</li> </ul>
	<ul> <li>Indicate the appropriateness of each oral antibiotic for paediatrics: tablet or liquid dosing, and appropriateness of taste.</li> </ul>	

# ?STOP guideline chart and lanyards

- Consider ways of reducing reliance on consulting infectious diseases to aid in healthcare worker's decision-making.
- Indicate appropriate oral antibiotic agents for making the switch, along with how to navigate the timing of oral doses in supplementary information to the guideline.
- Change the title of the guideline to more directly reflect who it is intended for (the user).
- Address common barriers for taking antibiotics orally among paediatrics (tablet or liquid dosing, and appropriateness of taste).
- Improve the readability of the chart by creating a clearer alignment between the key questions asked and their corresponding information boxes (1 and 2).
- While several participants indicated their satisfaction with the colours used, two recommended either: avoiding the 'alarming' use of red, or utilising a traffic light system of colouring (red, amber, green).
- Consider ways to improve the readability of the small print in boxes one to three on the lanyard.

## Patient chart labels

 Consider ways to improve the readability of the black text on the red chart label.

#### Fact sheet

 Provide an electronic version of the sheet with reference links.

#### Potential barriers for uptake

Several potential barriers to the uptake of the intervention materials were identified by participants. First, it was suggested that the authority of the intervention materials could be undermined unless they are officially endorsed as practice protocol:

"There may be on the occasion some practitioners who may have their own ideas and won't follow a guideline or a poster unless it's actually like an official, that's what we're going to do guideline. As opposed to suggestive guideline." (HCW11 paediatric nurse)

Second, and as previously noted, paediatric nurses HCW03 and HCW08 indicated that one challenge to realising successful outcomes for the intervention will be ensuring oral antibiotics are taken correctly at home, noting issues with taste, swallowing tablets, and/or a patient-guardian's misunderstanding or lack of attention of dosing requirements.

Third, as noted previously in regards to the ?STOP guideline, some participants felt that the guideline's advice to contact an Infectious Diseases (ID) consultant to aid in decision-making risked delaying important decisions, and therefore, undermining efforts to achieve timely IV to oral antibiotic conversion. This concern was seen to be compounded by the challenge of regional hospitals not having paediatric infectious disease teams to fall back on.

"my biggest concerns with it would be the fact that we are a regional hospital. And we don't have paediatric infectious disease team... So there can be a lag time with that which I think could potentially slow up the whole process. And just the guidance, so if you don't have access to ID or ID aren't going to get back to you until the afternoon what are you going to do before

then? ...a lot of it does rely on infectious diseases and without having that person in our hospital [it] could be an issue." (HCW08 pharmacist)

Finally, pharmacist HCW08 raised concern about the short-term nature of the intervention in relation to the long-term efforts usually required to ensure sustainable behavioural change in medical practice.

"...we're a teaching hospital... we always have new doctors coming. So I guess when this study is going it will be intensive, everyone will know about it. But in a year's time when it's not going anymore if we've just got this to refer to I think it could fall over yeah." (HCW08 pharmacist)

#### **SUMMARY: POTENTIAL BARRIERS FOR HEALTHCARE WORKER MATERIALS**

- The authority of the intervention materials could be undermined if they are suggested guidelines, as opposed to endorsed practice protocol.
- Outcomes of the intervention could be thwarted by common challenges in ensuring oral antibiotics are taken correctly at home.
- Relying on contacting an infectious diseases consultant to aid in decision-making could risk delaying efforts to achieve timely IV to oral conversion.
- The short-term nature of the intervention may be limited in its capacity to foster sustainable behavioural changes among healthcare workers.

#### Part 1 Summary

Overall, the intervention materials received positive endorsements from participants, who indicated their relevance and utility with only minor structural changes recommended. There are, however, further suggestions for optimising its uptake that can be drawn from the findings. Considering participants diverse material preferences, it is advantageous to encourage study sites to tailor the intervention to local needs by selecting those materials they find most appealing, rather than offering a standardised package for all locations. Anticipating potential barriers to the intervention's uptake, as noted by participants, offers further opportunities for supporting the intervention. Among these, ensuring the intervention receives strong endorsement and promotion from study sites, having strategies to address paediatric specific challenges to taking oral antibiotics, and identifying further avenues to aid practitioner decision-making will be important. Finally, considering strategies that support sustainable behavioural change will be important, especially given the short-term nature of the intervention and the reality of high staff turn-over in regional and rural hospitals.

# Part 2: Considerations for tailoring an information sheet to best meet the needs of patient-guardians

In this section, we present healthcare worker and patient-guardian views and recommendations for the tailoring of the information sheet: 'Making the switch: Changing from intravenous to oral antibiotics. Information for parents and carers' (see Appendix A). Specifically, participants were asked to reflect upon the ways in which the sheet's content and design could be best tailored to meet the needs of patient-guardians. Additionally, healthcare workers were asked to consider the material's relevance and utility within their personal practice and that of their colleagues, and patient-guardians were asked to reflect upon the sheets' relevance for informing them of their child's treatment, along with their likely engagement with it.

Fifteen healthcare workers situated in the paediatric departments of the two study sites consented to being interviewed, as well as eight patient-guardians at those sites whose children were receiving IV antibiotic therapy for an infection. In what follows, we provide an overview of healthcare worker and patient-guardian's general impressions of the material, followed by their personal preferences and recommendations for optimising the content and design of the information sheet. Next, the utility of the sheet is considered from both healthcare worker and patient-guardian perspectives. Finally, potential barriers identified by participants for the uptake of the information sheet are presented.

#### Overall impressions of the information sheet

In general, healthcare workers and patient-guardians shared positive views about the information sheet, noting its usefulness and appropriateness for informing parents and carers.

"I think the information for parents was well written and suitable guidelines for parents." (HCW01 paediatric resident)

"[It is] certainly a useful piece of information to give to parents if they're wanting more information about antibiotics and... why we need to consider going onto an oral form of antibiotics..." (HCW11 paediatric nurse"

"I thought it was fine, um, it was very easy to read and well written... I thought it was a good information sheet" (PG04).

"No, I actually, it's one of the better ones that I have read actually, um, so I mean there's nothing there that I can think that youse didn't cover..." (PG05)

#### Personal preferences and recommendations for optimising the content and design

#### Content

#### Healthcare workers

While few healthcare workers commented on the information sheet, most who did expressed their satisfaction with the sheet's content, noting its appropriateness for informing patient-guardians about treatment options, in what was described as an often overwhelming environment. Adding to this, one healthcare worker felt the sheet was an important educational resource for patient-guardians, dispelling misconceptions about IV versus oral antibiotic use.

"The information sheet for the parents, Making the Switch is fabulous actually... And it does give you... [information about the] side effects and all... it's really cool." (HCW09 paediatric nurse)

"Making the Switch I think that's really handy for parents because hospitals can just be information overload and once people have something tangible or something they can take with them they can soak it up in their own time and read through it." (HCW10 paediatric nurse)

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"There is a certain stigma in hospital especially like some parents believe that the IV therapy will be more effective than oral therapy. That's not always the case and this is a great fact sheet to help dispel that..." (HCW14 pharmacist)

Importantly, one healthcare worker highlighted the importance of the sheet for empowering patient-guardians to make informed decisions about their child's care.

"...it [is] empowering the patients and... Well in this case the carers take control of the child's care... (HCW14 pharmacist)

While most healthcare workers felt the volume of information presented in the sheet was appropriate, one suggested it was lengthy for patient-guardians. To address this concern, they recommended providing a quick summary of the sheet's main messages for those guardians who may feel overwhelmed by the volume of information presented.

"With the one for the parents I can see the message that it's giving the parents but I do think it's a lot of information to take on... they need that much information but they also need just a quick area that they can get the main points out of it." (HCW08 paediatric pharmacist)

Furthermore, one pharmacist (HCW14) felt the language used is inappropriate for those patient-guardians with low literacy levels. They recommended the sheet be reduced to one page with simplified language to accommodate such needs.

"Out here obviously we've got issues with like literacy and healthcare literacy... which I could see something like this not being utilised as much as like in a metropolitan area... not to dumb it down too much but I think it could be simplified for [rural] residents here just to use a bit more... simplistic language. You know shorten it up to one page... I think would be highly beneficial... [For example] just things like you know probiotics for some children probiotics may help restore... good gut bacteria... oftentimes we simplify that down into like you know there's normally good bugs in like in our tummies, like literally to that level. Which can be quite helpful and I think for out here like might be beneficial." (HCW14 pharmacist)

## Patient-guardians

Nearly all patient-guardians shared their satisfaction with the content of the information sheet, emphasising its relevance for informing them about their child's treatment options, with one patient-guardian also describing the 'peace of mind' and 'reassurance' that such information can provide.

"I think it's good to have it all kind of laid out... a lot of people wouldn't really understand a lot about antibiotics and IV and oral... like you kind of just do what the doctors tell you to do." (PG06)

"So, yeah, I think that that explains it quite well, when, [you are] in that point where you're trying to decide. It gives you enough information as a parent to make the decision and ultimately everyone wants to get home from hospital." (PG08)

"...it just made me understand what's going to happen and the reasons for switching to oral and the difference and it just was informative... [it provides] more peace of mind... And [is] reassuring... It's good to know what's going on, especially when it's your child." (PG04)

Patient-guardians discussed how the clarification they gained through the information enabled them to better communicate treatment plans to their child and was empowering because it equipped them with the information to more confidently ask healthcare workers questions and participate in the decision-making concerning their child's treatment.

"Yeah it does make me feel... alright and [to know] how to communicate with my son at home [about his treatment]." (PG07)

"...it actually gives you the idea of what to look for... sometimes you do feel sort of out of place if you were to ask questions [feeling] well we didn't go to medical school, we don't know, so you shouldn't, you shouldn't challenge. Some days you just don't, whereas if you had that information like that, you know where you are, so you know that you don't a) sound stupid, or b) sound forceful." (PG08)

Most patient-guardians indicated that the use of language in the sheet was at an appropriate level to enable comprehension. One patient-guardian, however, briefly touched upon their difficulty reading and understanding parts of the sheet, illuminating the diversity of patient-guardian's literacy levels.

"...it has a lot of, like important information and it seems, it's written in a way that a parent can understand." (PG06)

"it's not so simple that you feel like an idiot for reading it, but there's no terminology in there that I think that people, like my husband, ex-husband, would have any problems understanding." (PG05)

"Some things I couldn't read like I couldn't understand." (PG07)

Two patient-guardians highlighted the side-effects section of the sheet to be lacking clarity; not providing enough details concerning the side effect of vomiting, and not presenting this information in a user-friendly format.

"The only part that's confusing is the vomiting. It says you give an IV antibiotic for vomiting and then allergic reaction might be vomiting..." (PG02)

"I thought there could be a bit more emphasis... on the side effects area. Because you know if your child did have a reaction... you would be looking through this to figure out which one, what type of reaction they're having and that's not very [clear], that's on the back of the sheet... if this had dot points or something to make it a bit more [evident because] if I was reading through this and in a hurry I probably would have passed over it several times... That would be a bit more helpful I think. Because you've got your checklist here which is great but maybe a checklist for the side effects of you know just a bit easier to read would be good." (PG01)

#### Design

While little feedback was received about the design of the information sheet, both healthcare workers and patient-guardians shared positive views, noting the effectiveness of the sheet's layout, use of colours, bullet points and checklist. Furthermore, a few participants valued the sheet for being 'straightforward', 'not cluttered'.

"So I think it's a good design because it's, I mean it's just easy to read. And laid out you know there's a few, each one has a few dot points. And so they're not trying to memorise everything but it's fairly straightforward I think." (HCW10 paediatric nurse)

"...[there is] good information there. Colours are good." (HCW11 paediatric nurse)

"Um, looks pretty standard to a lot of information sheets I've seen... the picture's nice to break up, um, all the words... It seems to be a good amount of bullet points and short paragraphs and not just a lot of, you know, medical language... font size is nice." (PG06)

"It's pretty straightforward, it's easy to read." (PG02)

"...it's not cluttered, it's just all there and you can see it quite well." (PG08)

Only minor feedback was provided by one healthcare worker who felt local photos might be appropriate.

"We could probably find our own child that we could put a photo of, does it matter?" (HCW09 paediatric nurse)

#### Useability

#### Healthcare workers

The information sheet was valued among healthcare workers as an aid for answering patient-guardian questions and communicating more effectively about a child's antibiotic treatment plan and options. The sheet was also considered important for informing patient-guardians to be on the same page with healthcare workers regarding their child's treatment. Similarly, the importance of an information sheet for backing up healthcare worker treatment decisions was stressed.

"And any questions that families might have. And then and knowing what to say to parents and families if they ask any questions... I have a lot of blank looks... And the more information I'm able to give them makes sense to get them more comfortable." (HCW10 paediatric nurse)

"Good communication tool with the parents so that we are on the same page when we are treating a child..." (HCW02 paediatric registrar)

"And I can show them [patient-guardians] this and say according to this guideline I think we have to put in another IV cannula and I think everyone will be happier if there's a clear guideline. As opposed to "Oh the doctor is just doing it on a whim, maybe she just wants practice to stab a kid" which is sometimes true. No it's nicer if I've got something to back myself up." (HCW04 paediatric intern)

#### Patient-guardians

While most patient-guardians stated that they would read the information sheet, a range of views were shared concerning their preferences for receiving it. Half of patient-guardians valued having a healthcare worker talk them through the sheet and answer their questions, while others preferred to be handed the information to read in their own time.

"...it's always nice to have someone to go through and point out some of the dot points and then give you the chance to read it later on." (PG03)

"...yeah go through and explain stuff with me at the same time [as receiving the sheet]." (PG07)

"I don't like people going through things, because I sometimes feel like you have to feign interest or ask questions, even though you understand it, just to make them feel useful... Not to be rude, but yeah, I don't like that at all, I'd rather go through it at my own time and then be able to ask questions, if and when they come up, I guess." (PGO5)

Half of patient-guardians felt they would only read the information if it were given when their child was likely to be switched from IV to oral antibiotics.

"...if he wasn't already on anything I wouldn't be looking for a sheet that says switching from IV to oral. So not really until he was on an IV and progressing." (PG01)

"And I think that's probably where I would find it most beneficial, or obviously if she was in hospital on the IV and we were discussing stepping her down to orals, then before we step down, having this to read then." (PG05)

Furthermore, some patient-guardians stressed their preference for receiving the information sheet once their child was out of emergency and settled in the paediatric ward.

"But not as like I said before not when you first come in [in emergency] and they say "Oh by the way". I'd be like why are we even talking about this right now. I don't think that that's appropriate at all." (PG01)

"...basically when you're in Emergency... your main focus is on your child getting better... Whereas once you get up here [the paediatric ward] and they're in bed, they're asleep, and you get that time where you think, where do we go to from here? That would probably be the better time to do it." (PG08)

Two participants stated they were unlikely to read the sheet, yet for different reasons; one had a medical background and already felt sufficiently informed, while another preferred to hear from a doctor.

"I wouldn't because of my background [as a nurse], but I could see, for example, my ex-husband would find that very helpful, [having] no medical background and I think he would keep it." (PG05)

"Yeah I probably wouldn't have read it because you're mainly just relying on the doctor's opinion. Because yeah if they tell you one thing I mean I guess you trust them. And if it works that's good." (PGO2)

#### SUMMARY: RECOMMENDATIONS FROM HEALTHCARE WORKERS AND PATIENT-GUARDIANS

#### Content

- Provide a quick summary of the sheet's main messages for those guardians feeling overwhelmed by the volume of information being presented.
- Consider reducing the sheet to one page with simplified language to accommodate low literacy needs.
- Create a dot-point breakdown of possible side-effects to help the information be identified more easily.

#### Design

• Consider using local photos.

#### Potential barriers for uptake

The reality of diverse literacy levels among patient-guardians (as noted by HCW14 and indicated by PG07 earlier) presents a challenge for tailoring the information sheet. As such, the role of healthcare workers in gauging the individual needs of patient-guardians when delivering the sheet will be important for ensuring inaccessible information is adequately explained. However, if patient-guardians lack the confidence to request help, it may be difficult for healthcare workers to be responsive to their needs. As two patient-guardians reflected, not feeling comfortable to speak-up can leave them uninformed.

"I'm comfortable asking questions because I've sort of got experience with him being sick and whatnot. But initially as a new parent, not so much. You sort of just feel like you've got to let the doctors make the choices and it's usually the afterthought when something goes wrong that... you realise you should be asking questions." (PG01)

"Yeah, I think maybe it's also a confidence thing in myself... so it took a little while for me to realise... if I want the proper information or information that I feel like I need... then I really need to ask." (PG06)

#### SUMMARY: BARRIERS FROM HEALTHCARE WORKERS AND PATIENT-GUARDIANS

- Accommodating diverse literacy needs in a single information sheet presents a barrier to ensuring the information presented is accessible to all patient-guardians.
- Low patient-guardian confidence and comfortableness to ask questions can be a barrier to increasing their health literacy and may hinder healthcare worker efforts to assist in their understanding.

#### Part 2 Summary

Overall, healthcare workers and patient-guardians provided positive feedback and endorsement for the information sheet, with few recommendations being made. Healthcare workers tended to value the utility of the sheet as a communication aide when discussing child treatment plans, while most patient-guardians felt it was informative and empowering for understanding and participating in their child's care. Of greatest concern, however, was the challenge of designing an information sheet that can meet the diverse literacy needs of patient-guardians. While some would benefit from simplified and condensed information, others could find this presentation condescending. In responding to patient-guardian needs, it is evident that healthcare workers will play an important role in gauging patient-guardian needs and preferences when delivering the sheet. Even so, it is possible that some patient-guardian needs will be difficult to recognise and therefore meet, due to their lack of confidence or comfortableness to speak up and ask questions.

# Part 3: Towards a culturally appropriate patient-guardian information sheet for Aboriginal and Torres Strait Islander peoples

In this section, we present Aboriginal and Torres Strait Islander healthcare workers', herein respectfully referred to as Indigenous healthcare workers, views and recommendations concerning the adaptation of the information sheet: 'Making the switch: Changing from intravenous to oral antibiotics. Information for parents and carers to meet the needs of Indigenous patient-guardians (Indigenous patient-guardians; see Appendix A for a copy of the sheet). Specifically, Indigenous healthcare workers were asked to consider the ways in which the content and design could be most appropriately adapted, along with how Indigenous patient-guardian uptake of the material could be best supported. Five Indigenous healthcare workers from two study sites consented to being interviewed. Here, we provide an overview of participant reflections on the social and cultural contexts which can shape the ways Indigenous patient-guardians engage with medical information in regional and rural Queensland. Next, Indigenous healthcare worker perspectives and recommendations for optimising the content and design of the sheet to meet the needs of Indigenous users are presented. The utility of the sheet by Indigenous patient-guardians is then considered, along with recommendations for supporting their uptake of the material. Finally, potential barriers identified by participants for the uptake of the information sheet are presented.

#### Acknowledging the social and cultural determinants of Indigenous health

Indigenous peoples represent a significant number of patients who are treated in rural and regional hospitals in Queensland. The cultural and social contexts of their engagement with medical information materials are critical for understanding key factors that may impact upon their uptake of such information, and critically, the ways in which materials can be adapted and shared to optimise their accessibility and appropriateness for Indigenous peoples. While Indigenous healthcare workers shared much about these contexts throughout their interviews, Aboriginal and Torres Strait Islander social and cultural determinants of health provide an important orientation for situating their perspectives and recommendations.<sup>1</sup>

# Considering the whole picture: the cultural and social context of Indigenous patientguardians engagement with medical information in rural and regional Queensland

Consistent throughout all interviews, Indigenous healthcare workers spoke of the contextual realities in which Indigenous patient-guardian engagement with the information sheet would occur.

"...you know, over 50 per cent of our patients are Aboriginal... And then I think the patients here... may have more complex needs... because of the special context in which we exist, and I do think it's an under resourced area here [for Indigenous people]... there's all of those things that come with being remote... if you've got poor literacy, poor education... economic problems as well..." (IHW02)

Challenging circumstances noted, for example, by one Indigenous healthcare worker included the reality of housing insecurity and crowded living conditions experienced by many remote Indigenous patient-guardians. They highlighted how these dynamics can impact upon how medication is taken out of hospital.

<sup>&</sup>lt;sup>1</sup> It is beyond the scope of this report to summarise Indigenous social and cultural determinants of health. For an overview of these please visit, <u>Australian Indigenous Health Info Net</u>.

"...[the sheet] has a checklist of... what time to give the kids the antibiotics... A lot of our Indigenous people don't have their own home, they're living from place to place... so, things like keeping medication cool in the fridge is not always a possibility. And even... [having a] stable home life [to support medication being taken correctly]... Medication might say give it at a certain time... [but] they could have meals late in the evening because that's just when everything's settled down for the family... it's hard when I talk to mums and... they've always got family over..." (IWH01)

Indigenous healthcare workers noted the challenge of designing a 'one-size fits all' information sheet for Indigenous patient-guardians, acknowledging the inherent diversity among Aboriginal and Torres Strait Islander peoples, both culturally and socially. In particular, varying English literacy levels were considered a significant factor to accommodate when adapting the sheet.

"...not everyone has the same reading and writing abilities... I noticed when it comes to filling out forms [it can be] laboured and it's hard for them to even write their name... reading information will be the same, too overwhelming." (IHW01)

To this point, one Indigenous healthcare worker provided an overview of some of the target groups within the community that the sheet would need to be adapted for.

"Every community is different, every tribe is different, every individual is different with the Aboriginal people... you've got to work on your target group too because there's different kind of indigenous people... in this city... three stages or three different levels. [This sheet] would be okay for, what do we call them... uptown black fellas. For those that can read and write and went to school... and then... half of this would be okay for our suburban [black fellas] but, you know, you've got to put things in that the people identify with. And for our grass roots [black fellas]... you need to use words that they use and more pictures. So I don't know how you're going... to target three different indigenous groups." (IHW04)

In accommodating this diversity, two Indigenous healthcare workers stated the importance of locally adapted information sheets, designed in consultation with local Aboriginal community representatives.

"...if you're basically rolling something out that's targeting our people, our people should be involved in the development of it..." (IHW02)

"...I would really like indigenous... people from this area involved in this. Like the healthcare workers, you know... [for] this the document that, you know, they're putting forth, we still need to have that consultation with the community... one elder or just [Aboriginal] people in general... that has an invested interest... in indigenous health." (IWH04)

Given the various social stressors that may be impacting Indigenous patient-guardian engagement with the sheet, one Indigenous healthcare worker stressed the importance of ensuring the sheet is easy to 'consume' for Indigenous patient-guardians.

"...and if they've got other kids at home, if they've got other social things going on... we need to make it [is] as easy as possible... for people to consume it, make them want to consume it and make it quick to consume..." (IHW02)

Adapting the content and design for Indigenous patient-guardian users

#### Content considerations

While nearly all Indigenous healthcare workers felt that major content changes were needed to increase the information sheet's appropriateness and accessibility for Indigenous patient-guardians, all

agreed that the messages conveyed in the sheet were highly relevant for informing Indigenous patient-guardians about their child's treatment.

"I think that there is a need for – to expand people's health literacy and when people are in hospital if they're here for a period of time, that's an opportunity to expand people's understanding... so I think it's really quite good to have information like this... and I think it could be a very useful tool... not necessarily this sheet but the information on it I think is very useful and very relevant and I think it will better inform people..." (IHWO2)

"it would be... useful information to know the side effects... like, why... it's [antibiotics are] not agreeing with them, like, what's happening, is it because he's not well or is it because of the drugs... it would be helpful for them [Indigenous guardians] to know that..." (IHW01)

#### Information heavy

An opening comment made by most Indigenous healthcare workers concerned what they saw was too much information presented in the sheet.

"I just thought it was just too much information, overwhelmingly so." (IHW01)

"I think that this might look a bit overwhelming and that [it] might be off putting because there's... four columns of text and... that's too much, and even if someone might understand it if they actually read it, they might not even get to that stage because they just go, no, this is too much information..." (IHW02)

"That's a lot of information on there... to take in... it's just too much information for me to read that" (IHW05)

## Reducing to one page

Most Indigenous healthcare workers felt strongly that the sheet would be more agreeable with Indigenous patient-guardians if it were reduced to one page instead of two. One Indigenous healthcare worker, however, felt that while one page would be ideal, it was not feasible to reduce the content without losing its integrity.

"One page for sure." (IHW01)

"Yeah, one page... with-with your... core information on it. Make it more compact..." (IHW05)

"I suspect a lot of patients with low literacy and numeracy are not going to be able to compute it and make the connections between one page to another... I think that a single sheet [is ideal as]... anyone is going to prefer to just read one sheet. [However] I think it probably needs to be two pages as much as one page would be nice... just to get the volume of information across." (IHWO2)

#### Information to retain, exclude or add

When asked what information was most important to include, one Indigenous healthcare worker stated the importance of including a general 'what, why and how' explanation of antibiotic use. As part of this, another stressed the importance of retaining information that educated about antibiotics and bacterial infections, along with why switching from IV to oral antibiotics occurred.

"They want to know what the antibiotic is going to do. Um, why they need to come in hospital, why they need to have it, what it's going to do to them and how it's going to fix them." (IHWO4)

"...I think the most important things to convey is that antibiotics are for bacterial infections and that when a child is well enough you switch them from IV to oral as appropriate." (IHW02)

On the topic of side-effects, one Indigenous healthcare worker spoke of the importance of the

information on side effects for clarifying why it is advantageous to make the switch, if appropriate.

"I've had parents be like... can we give it through the drip? ...because in their minds, that's a better thing for their child is to have a needle as opposed to not having one, and that oral antibiotics might not be good enough... it highlights the [importance of including]... the more serious.... [side]effects, such as allergically or anaphylactic reactions... I don't know that there's necessarily anything more that needs to be put on here...." (IHWO2)

Another Indigenous healthcare worker, however, shared several concerns about the side-effects information. On the one hand, they felt there was a need for greater clarification when distinguishing between oral and IV antibiotic side effects, yet they also felt the sheets statement that information about side-effects would be provided by hospital staff was sufficient alone. Furthermore, they stressed the distrust in Western medicine that some Indigenous peoples have, and cautioned that side-effects information could make Indigenous patient-guardians reluctant to give their child antibiotics at all.

"...it's got here, what are the side effects of antibiotics and it's quite a big... spiel around that... I don't know if that, all that's really relevant... I was a bit confused with that... are you implying that these side effects are only... with oral antibiotics... I would [they would] have thought that the same [as IV]... because it's the same antibiotics as such." (IHW03)

"...you've also got there that... the hospital will make you aware of potential side effects treatment plans, options and the like. So, I thought that probably covered it enough in regards to the side effects." (IHW03)

"...a lot of... our mob is still kind of reluctant or, or scared of... White man's medicine... so it will probably have an adverse effect, having all that outlined when... being an Indigenous parent myself... Straight away it's [the side effects are] making me think I don't even want my kid to have antibiotics at all... So, yeah... I'd look at either really dramatically shortening that or getting rid of that part altogether." (IHW03)

A few Indigenous healthcare workers highlighted some of the misconceptions held about how to take oral antibiotics and the need to finish a whole course, with one Indigenous healthcare worker sharing about her own experiences growing up. As such, they advised that information about antibiotic resistance and the need to complete a whole course be included.

"The nurse would tell [my mother], this is what you've got to do with [with the antibiotics], and then that was it... we never finished our antibiotics, we always had a stash of antibiotics in the cupboard that we never finished... [so] educating – people do the whole course, even when kids are better, finish it, they need it.... [because] as soon as we got better, [we thought] "I'm not taking it, I'm not sick." (IHW01)

"...something about antibiotic resistance might be useful because that's often the problem we have is that the child will complete half the course and the look better, so... the parents don't complete it... (IHW02)

Furthermore, one Indigenous healthcare worker stressed that it was important to acknowledge Indigenous peoples use of traditional medicines, yet to reinforce the importance of first trying Western medicine, along with how and why it will be helpful.

"Tell them how sick... they are themselves and [how antibiotics are]... going to help you. You can use... your cultural medicines but you need to work the white man way first and then... if you're not satisfied there then do... your cultural medicines." (IHW04)

#### Indigenous liaison officer's contact information

Some Indigenous healthcare workers felt it was appropriate to include Indigenous liaison officer's contact details on the information sheet, although one did note the challenge of officers being underresourced for providing appropriate support.

"For sure... we all have work phones... and we have certain hours, so it wouldn't encroach on our - it's part of our job." (IHW01)

"I think that would be a good idea because... even though you hand it [the information sheet] to them, sometimes they don't read it properly." (IHW05)

"...you can put us down [contact details]... because a lot of people look for liaison officers for help... it's just unfortunate we don't have an office space where we can take our people to sit down and yarn with them about things like this." (IHW04)

The Indigenous doctor (IHW02), however, raised a few concerns about including liaison officer's contact details, noting it could increase already over-stretched workloads, and cautioned that not all Indigenous healthcare workers were empowered to have the health literacy necessary to explain medical information.

"...it might increase their workload with a bunch of things that aren't actually their job... I think it also depends on... the person [liaison officer] as well... they might be not the greatest equipped to explain health information because... I don't think... we empower [them] to have great health literacy... [and therefore] they deskill and then that benefit is not passed on to the patient." (IHW02)

#### Adapting language

All Indigenous healthcare workers discussed the importance simplifying and adapting the language used in the information sheet to better accommodate the cultural and English literacy needs of Indigenous patient-guardians in order to increase the appropriateness and accessibility of the sheet.

"...you've also got to talk the way they talk... [do not use] words that they would never use, that they don't understand, so you have to put it in words that they know..." (IHW04)

Critically, Indigenous healthcare workers highlighted several examples of words that they felt were inaccessible to a lot of Indigenous patient-guardians, along with examples for how language could be simplified or culturally adapted to be more appropriate.

"And what's this word at the top here [intravenous]?... Some people mightn't know what that word means to start with." (IHW05)

"And like you've got 'infections', they don't know what infection means. It's a sickness... you're using big words, you know. Like you've got infection, absorbing medicines, antibiotics, you know, special criteria's, body temperatures... You've got to say... hot or cold... [For] medication... [you could say] tablets, capsules.... oral stuff, intravenous, you know. They don't know those words." (IHW04)

- "...some parents would be like, what's probiotics? So, [you need to explain what that is] yogurt drinks, Yakult, stuff like that, it would be handy that information because that's something they could just go to the store and get." (IHW01)
- "...[use culturally appropriate words] to make it more... relatable, most definitely in regards to, you know, a child is jarjum, and things like that, and mob instead of family... those little things will help make it a lot more relatable for our mob." (IHW03)

Furthermore, one Indigenous healthcare worker noted the importance of using terms consistently across the two pages.

"...where it said IV or intravenously and said through a drip and then later in the sheet it goes on to say give IV antibiotics. I suspect some of my patients don't really connect it later on when it says IV antibiotics even though earlier... it's stated that it's IV..." (IHW02)

#### Visual representation of the content

Finally, all Indigenous healthcare workers emphasised the need for visual representation of the sheet's content to make it more appealing and accessible to Indigenous patient-guardians.

"I think Aboriginal people are generally a lot more visual, ah, and I think the population I'm often dealing with are a lot more visual and fewer words. I think a lot of points could probably be illustrated, with pictures and captions, as opposed to paragraphs of words... and I think... that that is missing here" (IHW02)

"That way if their reading is not good at least they have a visual aid to help them remind them." (IHW01)

#### Design considerations

Closely connected to the call for visual representation of text, the most prominent feedback for the design of the information sheet was for visual representation of Aboriginal and Torres Strait Islander peoples through art, flags, use of colours, and images. In doing so, Indigenous healthcare workers felt the sheet would be identifiable and more appealing to Indigenous patient-guardians. Recommendations are summarised in the following:

- Incorporating Indigenous art:
  - "And obviously having some artwork across it... to make it identifiable... for our mob" (IHW03)
- Including both the Aboriginal and Torres Strait Islander flags:
  - "I just think that you need to just probably put the flags on and acknowledge... both cultures [Aboriginal and Torres Strait Islander peoples]." (IHW04)
  - "...you'd need the [Aboriginal and Torres Strait Islander] flags on there, you know what I mean?... to acknowledge that it's Indigenous." (IHW05)
- Using colours that Indigenous peoples can identify with:
  - "...looking at this green, this is very much a hospital kind of green... I think it's better to have [colours] that are more stimulating... I'm very biased towards oranges and yellows and reds... there is very much this idea of the Aboriginal colours and they are stereotypical Aboriginal colours but I think that might exist for a reason." (IHW02)
  - "What are the colours [to use]? Aboriginal people, red, black and yellow... You know we have islander people here as well, Torres Strait Islanders... I'm not sure how you're going to get around it putting both lots of, um, cultures in the one pamphlet." (IHW04)
- Including images that represent Indigenous peoples and their inherent diversity:
  - "I think it's really important to acknowledge that... the Aboriginal population has a wide variation in what people look like, and so there's people that look very Caucasian, people who look very Asian, I've got friends who look African Aboriginal... when choosing images and graphics, [ensure] you're choosing images that people can identify [with]... sometimes I think... [illustrations and/or cartoons] they're almost better than... real people... because if you look at a... photo [you might think] well I don't really identify with that... if you're choosing... skin tone...

choose multiple [tones] or you can choose someone who sits kind of in the middle who is kind of brown but not black and not white..." (IHW02)

Finally, to Indigenous healthcare workers recommended that the sheet's overall design be simple, refraining from clutter.

"...[design it so that] you look at it and it's not, like, a bunch of writing slapping you in the face, it's just simple." (IHW01)

"...just keep it... [so that] your eyes are visually drawn to one point and then the next point... without having too much artwork or anything like that, so maybe a picture, point, picture, point, picture, point... Whereas even looking at this now, it's just too full of words..." (IHW01)

#### Examples of appropriate Indigenous medical information sheets

Several examples of well-designed Indigenous patient medical information materials were noted by Indigenous healthcare workers as being appropriate for Indigenous patients.

- Aboriginal and Torres Strait Islander Asthma Action Plan materials
- Aboriginal and Torres Strait Islander antenatal materials
- Aboriginal immunisation information materials
- Closing The Gap health information templates

#### Considerations for supporting Indigenous patient-guardian uptake of the information sheet

When asked about the likelihood of Indigenous patient-guardians reading the information sheet, mixed responses were received. Some Indigenous healthcare workers felt it would be unlikely, noting a strong preference for the oral transfer of medical information through, for example, 'bedside yarning'. Others highlighted the sheets utility for reinforcing information, and stressed the benefit of repetition for instilling knowledge.

"...well if there's anything we go in and talk to them and ask them what they – do they understand. It's by word of mouth, like bedside yarning if you want to call it, um, and ask them do they understand. Um, and that's why they have liaison officers employed to translate all the stuff..." (IHWO4)

"They're better off just hearing it... Yeah, I think it will just get rolled up, put in the back pocket and then at a convenient time just chucked in the bin... because 'the doctor already told me, and I remembered that'." (IHW01)

"...[it is useful] as something to refer to and to give the patient afterwards so that they've got something to refer to after that conversation or to keep it in their brain..." (IHW02)

"I reckon all of it [using conversation and the information sheet], like, they say repetition for emphasis..." (IHW01)

Several recommendations were made for supporting Indigenous patient-guardians uptake of the sheet. As previously mentioned, IHW04 stressed the importance of accommodating the range of English literacy levels found among Indigenous patient-guardians. To this point, one Indigenous healthcare worker distinguished when it would be more appropriate to use a simplified and Indigenous specific sheet or the mainstream/general sheet.

"...I wouldn't necessarily give that to an Aboriginal patient just because they're Aboriginal but [rather] if... English is not their first language or... I think they're going to grasp things differently... [I would provide the Indigenous specific sheet]. [If] they're understanding everything I'm saying, which we have a wide variation in our community, I would probably give them... the mainstream [information]". (IHW02)

The prioritisation of conversation to aid in the delivery of the sheet was considered critical by all Indigenous healthcare workers for supporting Indigenous patient-guardian uptake.

"You need to explain things to our mob... show them that this is what's going to happen... Our mob won't walk around with paper... if you changed a lot of the information in here to suit your target, [then] I can assist by reading you know, when they come into hospital... a healthcare worker can do the same thing... because our mob won't sit there and read it, they'll throw it out." (IHW04)

"...if this sheet was just sitting on a wall and people were just to get it without any conversation I don't think it's useful but what I think is useful is if there's a conversation to explain why we do something..." (IHW02)

Finally, one Indigenous liaison officer felt that it could be appropriate to provide the sheet in the standard information pack that Indigenous patient-guardians would receive upon arrival to the hospital.

"...we generally give out to all new clients a... Aboriginal and Torres Strait Islander Hospital Liaison Officer resource pack... it could be something that we could... put into... that pack..." (IHW03)

# SUMMARY: RECOMMENDATIONS FOR CULTURALLY APPROPRIATE PATIENT-GUARDIAN INFORMATION **Indigenous** In creating a culturally appropriate information sheet, ensure that there has been consultation appropriate consultation with local Indigenous peoples who have a vested interest in Indigenous health Content Reduce the amount of text so it is less overwhelming Consider if the sheet can be reduced to one page without losing the integrity of the content Ensure that a general 'what, why and how' explanation of antibiotic use is covered • Retain information about when a switch from IV to oral antibiotics is appropriate and why it is beneficial Consider a different approach to the side effects section: provide greater clarification between IV and oral antibiotics or take out the section, leaving only the statement explaining how hospital staff will provide information about possible side-effects. • Provide information about antibiotic resistance and the need to complete a whole Acknowledge the place of traditional medicine, yet reinforce the importance of trying Western medicine first. • Try to include Indigenous liaison officer contact details. However, consider the local capacity of the officers before making this decision. Simplify and culturally adapt the language in the sheet to reflect the English literacy levels and language used by Indigenous patient-guardians. For example: o Consider finding alternative words for: intravenous, antibiotics, infections (to sickness), oral medicine (to tablets), absorbing medicines, temperatures (to hot or cold), o Explain what probiotics are and how they are found in products like: yogurt and Yakult. o Use culturally appropriate words to make the text more relatable, i.e. child to local words like jarjum (south-east Queensland), family to mob. Use terms for intravenous consistently across the two pages. Accommodate Indigenous peoples' preference for visual learning by visually representing text where possible.

#### Design

- Provide visual representation of Aboriginal and Torres Strait Islander peoples
  through: art, Indigenous flags, Indigenous inspired colours that accommodate
  Aboriginal and Torres Strait Islander diversity, and ensure appropriately skin-toned
  drawings or cartoons of people that reflect the diversity of Indigenous peoples.
- Ensure that the design is simple and not cluttered
- Consider drawing inspiration from the Indigenous medical information materials

# Supporting Indigenous patient-guardian uptake

- Try to accommodate a range of English literacy levels (i.e. use the mainstream/general information sheet for those with high English literacy)
- Prioritise conversation when delivering the sheet to Indigenous patient-guardian to support understanding and allow for questions to be asked.

• Consider asking Indigenous liaison officers if they would include the sheet in their information packages for Indigenous patient and carer arrivals to the hospital

#### Barriers to uptake

As noted towards the beginning of this report, the cultural and social contexts within which Indigenous patient-guardian engagement with medical information occurs in regional and rural Queensland present significant complexities and barriers for information uptake. As Indigenous healthcare workers have indicated, these must be considered when determining how to best adapt and deliver the information sheet to Indigenous patient-guardians. Furthermore, throughout the report several barriers that touched upon socio-cultural, literacy, and Indigenous staff complexities were discussed, which may impact Indigenous patient-guardian uptake of the information sheet (see below for a summary of these).

In addition these, Indigenous healthcare workers noted further barriers to Indigenous patient-guardians uptake of the sheet. Specifically, one Indigenous healthcare worker highlighted the time-poor working conditions of healthcare workers as an impediment to ensuring adequate discussion about patient treatment plans.

"I think that dialogue between patient and health practitioner is really important... [However] as a health practitioner sometimes you just do not have time..." (IHW02)

Another Indigenous healthcare worker felt that healthcare workers did not always communicate in a way that Indigenous peoples could may understand.

"...when you ask them [Indigenous patients and carers], what they [understood], they just say no... Because it's not explained to them properly... [Not in] the way they talk... They [healthcare workers] use a lot of jargon, you know... sometimes we don't understand what they say... they don't really explain things clearly to us." (IHW05)

Finally, the reality of a fast-paced work environment with high staff turnover was considered a challenge for ensuring that staff remain aware of the information sheet.

"...things are pretty busy... so it's quite easy for something that we've put down two weeks ago to be covered and stuff, let alone 12 months ago..." (IHW01)

"if we're introducing a sheet like this to educate about antibiotics... who is going to deliver it?... staff get changed so often and things do move rapidly, and things can get lost." (IHW02)

#### **SUMMARY: BARRIERS TO UPTAKE**

- There is a reality of low English and Western health literacy held by many remote Indigenous patient guardians.
- A commonly held preference by Indigenous peoples is for the oral transfer of information as opposed to acquiring information through written text.
- The inherent diversity that exists between the many Indigenous nations and peoples across the state presents a challenge for designing an information sheet that could appropriately meet the diverse needs of Indigenous patient-guardians
- Indigenous patient-guardians may have misconceptions about how oral antibiotics need to be taken, leading to common occurrences of infection relapses and heightened risk of antibiotic resistance.

- Some Indigenous patient-guardians may lack trust in 'white man's medicine', with some preferring to utilise 'black fella medicine' before considering Western medicine.
- While Indigenous liaison officer's aide Indigenous patient-guardians in navigating their stay in hospital, they are often grossly under-resourced and overstretched in their work roles and therefore may not have adequate time to translate the sheet for Indigenous patient-guardians.
- Indigenous liaison officers are not always empowered with appropriate health literacy to translate medical information, which may impact on their capacity to aide Indigenous patient-guardians.
- The time-poor working conditions of healthcare workers can be an impediment for ensuring adequate discussion about patient treatment plans.
- Healthcare workers may not always communicate in a way that Indigenous peoples can understand.
- High staff turnover may be a challenge for ensuring staff remain aware of the information sheet.

#### Part 3 Summary

Significant changes to the content and design of the information sheet will be required to optimise the material's appropriateness and accessibility to Indigenous patient-guardians. Creating a sheet that is responsive to the cultural and social contexts within which Indigenous patient-guardians will engage with the information is an important starting point. Central to this will be designing with diversity in mind and accommodating Indigenous visual and oral learning preferences. In adapting the content, it is important that the text 'talks the talk' of its users, reflecting appropriate English literacy levels and incorporating Indigenous cultural terms. Ensuring that the design visually reflects Indigenous diversity through its use of colour, art and images will enable different Indigenous patient-guardians to identify with the sheet. Further to content and design changes, it was stressed that the way in the material is delivered to Indigenous patient-guardians will strongly influence its uptake. Here, the need to accommodate Indigenous oral learning through 'bedside yarning' was considered paramount.

While a series of practical recommendations were made to guide the material's adaption, Indigenous healthcare workers identified several barriers to its uptake resulting from: social inequities, cultural differences, Indigenous patient-guardian misinformation, the under-resourcing of Indigenous services, and the time-poor working conditions of healthcare workers to accommodate Indigenous patient-guardian needs.

Finally, to ensure the material is appropriate and responsive to the needs of local Indigenous patient-guardians it may be important that further consultation occurs with Indigenous peoples who have a vested interest in their people's health.