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21 September 2015

Erin Cronin
Acting Manager Division of Women, Youth & Children
Community Health Programs
School Youth Health Nurses
Email: erin.cronin@act.gov.au

Dear Ms Cronin,

RE: HCCA Feedback on Patient Information for ACT School Immunisation Program and Kindergarten Health Check

Thank you for providing opportunity for consumer feedback on patient information for ACT School Immunisation Program and Kindergarten Health Check. The Health Care Consumers' Association (HCCA) is a health promotion organisation that provides a voice for consumers on local health issues and supports consumers to participate in all levels of health service planning, policy development and decision making.

In preparation for this feedback we circulated these documents to our members who have had a recent experience with child and youth health care, have an interest in this area or have an interest in health literacy and patient information. The feedback provided is the collated responses to each document. We would like to commend your team for developing this resource to increase understanding of vaccination and early health checks and the importance of children and youth health. The fact sheets also inform families and carers of what they can reasonably expect from their child's participation in this program. Our feedback is attached.

Thank you for seeking consumer input on these documents. We are pleased to provide feedback on this patient information. We look forward to seeing how our comments can help shape the further development of these valuable resources. If any aspect of this response requires clarification please contact Eleanor Kerdo by email eleanorkerdo@hcca.org.au or by phoning the HCCA office on 6230 7800.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Darlene Cox', written in a cursive style.

Darlene Cox



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Background

HCCA welcomes the opportunity to provide feedback on the patient information for ACT School Immunisation Program and Kindergarten Health Check. HCCA recognises the importance of documents like these in developing the knowledge, skills and confidence of health consumers to actively engage in our own health care, understand the health system and to be able to participate as equal partners with health professionals to make informed decisions about our own and our family's health. Health literacy is an important element of our health system and reflects the rights of access, communication and participation set out in the Australian Charter of Healthcare Rights.

General Comments

In preparation for this feedback we circulated these documents to our members who have had a recent experience with child and youth health care have an interest in this area or have an interest in health literacy and patient information. The feedback provided is the collated responses to each document. Most of the feedback received was positive. One consumer wrote: *"This information is so much better than what we got when our children were immunised."*

All four documents provided are clearly written to allow parents and guardians to make informed choices about their child's health care. The documents contain little jargon, are brief and to the point. With this in mind there are a few minor suggestions from our members on how to improve the information.

Interpreter Services

There is inconsistent information about interpreter and translation services on the four documents provided. Information on how to access interpreter services both during further communication with the Health Protection team or ACT Health services referred to in these forms such as GPs, Community Health Intake Line, orthoptists and audiologists and if help is required to read the patient information or sign consent forms could be included. HCCA understands that the ACT Health Multicultural Health Policy Unit can provide consistent language and symbols to be included on ACT Health Patient information.

We would also like to know if this information is available in common community languages. We urge you to develop various language brochures for your website or database to be printed on demand. Providing access to health literacy is outlined as part of the ACT Health Multicultural Coordinating Framework as a key action area to increase health literacy.

‘Establish and maintain a register of materials available in languages other than English.’- Key Action Areas (Section 6.42) Internal Draft of ACT Health Multicultural Coordinating Framework 2014

If these brochures are developed, HCCA would be willing to provide community feedback on these documents.

More Resources and Information

We understand that these fact sheets are the main source of written information provided to parents and guardians around child and youth health. We wondered if these are available on your website?

We also suggest including a section on *Useful Websites* or *Further Information*. These could provide links other patient information sheets or reputable websites.

Kindergarten Health Check Form and Letter

One of our members question the use of the Body Mass Index (BMI) as a measure of weight adjusted for height, particularly in children, as it is not always an accurate measure of healthy weight. Attachment One contains a detailed exploration their concerns regarding the use of BMI in children and adolescents. We are aware that it is difficult to provide healthy weight ranges for children and teens because the interpretation of BMI depends on weight, height, age, and sex. There is a reference to the Centre for Disease Control age and gender growth chart, it would be of value to explain this in more detail. We are pleased that there is an explanation of the differences between adult and children BMI measurement.

We also know that General Practitioners (GPs) find it difficult to discuss overweight and obesity with patients, particularly parents with children in unhealthy weight ranges¹. We are aware of the Capital Health Network (CHN) Connect up for Kids Program², aimed at halting the growth of childhood overweight and obesity rates in the ACT. The CHN are working closely with Canberra GPs to try to increase knowledge and confidence in the GP workforce around overweight and obesity management in children. It would be useful to know how you are working with the CHN to ensure that our GP workforce can adequately address our health needs around childhood obesity management, particularly given that you are referring parents and guardians to GPs. This is particularly important as the GP is the point of referral.

In terms of the vision and audiology referrals it is also not clear if there is an out-of-pocket cost in seeking follow ups and treatment. It is often difficult for consumers and carers to navigate the Medicare rebate system or understand how a procedure like the ones explained in these forms are billed. For instance do I have any out-of-pocket costs? How do I claim a rebate? What about Private Health Insurance?

¹ King L, Loss J, Wilkenfeld R, Pagnini D, Booth M, Booth S. (2007) The Weight of Opinion: General Practitioners' perceptions about child and adolescent overweight and obesity. Sydney: NSW Centre for Overweight and Obesity.

² <http://www.actml.com.au/programs/connect-up-4-kids>

We are pleased to see the link to Find a Health Services on the advice to parents and guardians on the outcome of the Health Check. On the information sheet there is reference to the Dietitians Association of Australia. We think it would be better to link to the Find a Health Service site here. Similarly, the Find a Health Service can be made for the private audiologist for the reference to the private audiologist.

The reference to the ACT Health Community Dietician service is not clear. The phone number provided is for the Community Intake Line. It may be better to tell people that they need to contact the Community Health Intake Line to make contact with the dietitian.

Formatting and typographic errors

As stated previously these resources are clear, and well laid out. In the *Information on Height and Weight Measurements*, in the third dot point the word **be** does not need to be italicised or bolded. There is also a space between web and site in the second last line.

In the *Kindergarten Health Check Results Form*, the word audiologist should be bolded to be consistent with formatting. It would also be of value to include a referral letter to an audiologist if necessary as with the vision referral.

ACT School Immunisation Program 2016, Vaccination Record, Consent and Health Information

Immunisation Student Vaccination Record Cover Sheet

There is a caution notice relating to aspirin and salicylate for the treatment of a fever. Two things; firstly, what is salicylate? Most people would not know that this is an active ingredient in medicines. In the past the NPS has maintained Active Ingredient Finder on their website and it was popular with consumers as it helped us to make sense of brand names and active ingredients. Secondly, why is it important to not use aspirin and salicylate?

The reference to giddiness and fainting: is it possible to include a sentence at the end such as: 'For most people this usually passes within 30 minutes'. It gives the parent or guardian an idea on what we could expect.

Vaccination Consent and Health Care Information

We think these information and consent forms are clear and provide quality information about vaccination to parent and guardians.

We note that gender in the form only contains options for male or female. We encourage you to include provision on the form for other gender identities. One of our membership organisations A Gender agenda have information about creating inclusive medical forms for gender diversity <http://genderrights.org.au/resources/medical-information>.

In the Office Use section on page two, we would like to know if there can be prompts here to encourage positive patient identification and procedure matching?

It would be useful to include a section in the patient information sheet on who to contact should your child have a reaction to a vaccine.

On page three of Immunisation Record Note, we acknowledge that parents and guardians have a responsibility to advise the provider of a change in health status but this is dependent on communication from the school about when this is going to occur. It is also not clear who we are meant to contact, the school? The Health Protection Unit?

On page three we also note that you ask the question *Are Vaccines Safe?* It is not clearly stated in the first paragraph following this question that for most people vaccines are safe and do not serious adverse reactions. We understand and appreciate the explanation of risks associated with vaccines but if you ask this questions we need to have this answered clearly, yes for the majority of children vaccines can be used safely before further explaining risk.

One of our members who had a bone marrow transplant while receiving treatment for cancer and had children who were receiving vaccinations, commented that there was no information that live vaccines like the Varicella vaccination is dangerous for any family member if they have severe immune suppression and that this vaccination must delayed. We suggest that, information regarding this should be included along with a tick box in the Pre-Vaccination Checklist in section B on this serious issue.

There were other questions raised by members that it would be useful to include on a Frequently Asked Questions Sheet or an online FAQ page. These include: You say most vaccinations cause reactions on page two, like what? What should I do if I am worried about my child's reaction to a vaccine? What if my child has a reaction after-hours when my GP is closed? My child has had a reaction to a vaccine before, does this mean it will happen again? If my child is distressed by needles can I attend to comfort them? Why doesn't it matter if my child gets vaccinated twice due to the Boostrex make up? I heard vaccines cause autism is this true? I do not have a current GP, who do we go to if my child misses a vaccination?

Formatting and typographic errors

It is difficult to read thin white font on the dark blue background. We have concerns this will make information difficult to read for those who are vision impaired. We suggest using Vision Australia's colour contrast analyser to ensure that your colour combinations provide good colour visibility, <https://www.visionaustralia.org/business-and-professionals/digital-accessibility-services/resources/tools-to-download/colour-contrast-analyser-2-2-for-web-pages>.

We also recommend bringing page three to the front of this pack and making this page one as it outlines what to do with each document in the pack, provides information about consent and contextualises the required documentation.

In the side-bar on the left of page three, we suggest putting paragraph three first as this describes the service and that this is provided for free. The current first paragraph could be

second followed by the current last paragraph, and then the current second section. This will provide clarity around the action required by parents and guardians receiving this information.

It does not say PTO to page four as it does with the other pages.

In section B on the current page one we suggest changing the word *consenting for vaccination*, to *consenting to vaccination*.

In section B it states should you have ticked something in the tick box *please describe*, it is not clear what information you need? When an event occurred? What the reaction was? This is confusing. There is also no space to include an answer.

It would be useful to include information as to how this checklist will affect the child's vaccination or if parents or guardians need to take specific action regarding this.

Concluding Remarks

We are pleased to provide feedback on these fact sheets and forms. Please feel free to contact us in regards to reviewing future drafts of these documents in both English and languages other than English.

We are happy to discuss our feedback further.