



Health Care Consumers' Association ACT INC
100 Maitland Street, HACKETT ACT 2602
Phone: 02 6230 7800 Fax: 02 6230 7833
Email: adminofficer@hcca.org.au
ABN: 59 698 548 902
hcca.org.au | hcca-act.blogspot.com |
[@HealthCanberra](https://facebook.com/HCCA.ACT)

28 April 2015

Ms Sharon Chambers
CNC Gastroenterology & Hepatology Unit
The Canberra Hospital
Email: Sharon.chambers@act.gov.au

Dear Ms Chambers,

RE: HCCA Feedback on Patient information from the Gastroenterology Unit

I am writing to provide feedback on patient information from the Gastroenterology Unit.

The Health Care Consumers' Association (HCCA) of the ACT was formed over 30 years ago to provide a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT 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 gastroenterology, 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 these resources to increase understanding of how the Gastroenterology and Hepatology Unit is run and what patients, families and carers can reasonably expect from their experience and treatment team when attending the unit for a procedure. 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 blue ink, appearing to read 'Darlene Cox', written in a cursive style.

Darlene Cox
Executive Director

28 April 2015



Health Care Consumers' Association ACT INC
100 Maitland Street, HACKETT ACT 2602
Phone: 02 6230 7800 Fax: 02 6230 7833
Email: adminofficer@hcca.org.au
ABN: 59 698 548 902
hcca.org.au | hcca-act.blogspot.com |
facebook.com/HCCA.ACT | [@HealthCanberra](https://twitter.com/HealthCanberra)

HCCA FEEDBACK ON PATIENT INFORMATION FROM GASTROENTEROLOGY UNIT APRIL 2015

Submitted 28 April 2015

Author: Eleanor Kerdo

Policy Officer

Contact: eleanorkerdo@hcca.org.au

02 6230 7800

Background

HCCA welcomes the opportunity to provide feedback on the patient information from the gastroenterology unit at the Canberra Hospital. HCCA recognises the importance of documents like these in developing the expertise of health consumers to actively engage with 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 essential right of a health care consumer as addressed in the Australian Charter of Healthcare Rights, particularly the charter rights of access, communication and participation.

General Comments

In preparation for this feedback we circulated these documents to our members who have had a recent experience with gastroenterology, 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.

Possible Additional Sections

There were several suggestions from consumers on information that could be added to the patient information sheets that would help inform those who attend your service. One such suggestion was the addition of version control and dates to all footers of the documents along with page numbers. This is useful for consumers to keep track of the possible multiple pieces of information given to them in one session and check the relevance and currency of the information provided.

Way finding to the Gastroenterology and Hepatology Unit could also be included in the forms and patient information. For many people navigating the hospital campus poses serious challenges, particularly given the changes due to the Health Infrastructure Program. We suggest the inclusion of a map pointing out the location of the unit and parking. If this is not possible, due to space limitations or changing locations, we suggest at a minimum, including information suggesting people ask at main reception should you have trouble locating the unit.

In all of the brochures provided it is essential that the section *Useful Websites* or *Further Information*. These could provide links other patient information sheets or reputable websites. These could include the following which our members have found useful:

- Better Health Channel Victorian Department of Health
http://www.betterhealth.vic.gov.au/bhcv2/bhcmcd.nsf/pages/E03lite_en
- NHS Patient Information
<http://www.nhs.uk/conditions/bowel-cancer-screening/Documents/Having-a-colonoscopy.pdf>
<http://www.nhs.uk/Conditions/gastroscopy/Pages/Introduction.aspx>

- Patient UK
<http://www.patient.co.uk/health/gastroscopy-endoscopy>
<http://www.patient.co.uk/health/colonoscopy>
<http://www.patient.co.uk/health/sigmoidoscopy>
- Choosing Wisely
<http://www.choosingwisely.org/doctor-patient-lists/colonoscopy/>

Using patient information fact sheets, developed by other hospitals could be used to help develop your patient information sheets.

“Can the documents recommend websites for further reading? I would think that the Dept of Health, GESA, and Bowel Cancer Australia would offer useful additional information. Crohns and Colitis Australia might be another site to include, as the patient may be suffering from IBD, and about to undergo their first of many colonoscopies.” – HCCA Member

There are several clear resources that have been developed both in Australia and overseas that we think are valuable to improving consumer knowledge about these procedures. We suggest that you use a number of other clearly developed patient information documents to inform your documents, after all there is no reason for you to have to reinvent the wheel.

How to contact your doctor

Throughout all of the information sheets provided consumers are directed to ask further questions of their doctor if they have any concerns. It would be useful to include a section in the patient information sheets on how to contact your doctor, phone numbers, emails or pagers.

Interpreter Services

Information on how to access interpreter services both during consultations and if help is required to read the patient information or sign consent forms would be useful to include. HCCA understands that the ACT Health Multicultural Health Policy Unit can provide consistent language and symbols to be included. You can contact them on: (02) 6205 1011.

Information about Billing and Medicare Rebates

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? Is there an extra cost for my sedation?

Why do I need a Colonoscopy/ Gastroscopy/ Flexible Sigmoidoscopy?

This section was suggested by several of our members. This section can explore the risk groups who will need these procedures and how often, and why these procedures are necessary? This information is crucial in ensuring that consumers and carers can make active decisions about our health care. The *Choosing Wisely Australia* also has some useful information about these procedures. This section could also include possible questions that consumers might want to ask before having the procedure, for example, what are the risks inherent in this procedure? What is the treatment in the unlikely event of a bowel perforation? Or are there alternative options to this procedure?

Structure of Patient Information and Forms

There are some areas of the information sheets that do not read as clearly due to wording and sentence structure. There is also differences in font size throughout all documents, including in the middle of paragraphs. Whilst some of this is addressed in this document we presume there is an internal ACT Health editing process to aid with this.

We understand that these brochures are the main source of written information provided to patients attending the Gastroenterology and Hepatology Unit, we wondered if this will be made available your website? Provision of this information on the website and in the clinic is excellent but many of those we consulted stated that the information in some cases seemed quite clinical and harsh and wanted to know the context in which this information is given, during a consultation? In the waiting room? After a consultation? Considering at what point a consumer takes in this quite detailed and complex information is essential to ensure good uptake of this patient information. Making sure that plain and welcoming language is used was also a common suggestion from our members on these documents. Many consumers we consulted suggested these documents could be used as part of wider information strategy using other platforms to increase health literacy around these common procedures.

We strongly encourage you to develop various language brochures for your website or database to be printed on demand. Providing access to patient information 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.

It was unclear to us why there were several different information sheets for different times of day or why the information in the information sheets with similar procedures and preparation requirements varied from sheet to sheet.

We suggest you amalgamate the forms and standardise all information where possible, so that each document presents the same level of information. This was by far the strongest suggestion made by those who read the information. For instance, can the Colonoscopy information be given all on one sheet?

Use of Clinical Language

We suggest removing some of the clinical language used throughout all of the patient information sheets provided. These forms need to be in plain language to help consumers make informed choices and feel secure with the quality of care they are being given. Words and phrases we suggest avoiding include but are not limited to; *air instilled, intravenous cannula, verifies consent and hazardous*. If there are words and phrases are required a plain language explanation is required.

Specific Comments

Specific comments will be given for the colonoscopy fact sheet under the headings within document. This information is applicable to ALL five fact sheets and provide comments on the associated forms and other patient information sheets provided.

Colonoscopy – Information for Patients

What is a colonoscopy?

Often we heard from consumers that they are apprehensive when it comes to bowel screening and colonoscopy due to fear or pain and discomfort during the procedure. We suggest starting this section stating colonoscopies are a very safe procedure, which you will be sedated for, so you will not feel pain or discomfort. We then suggest rewording this section as follows.;

‘A colonoscopy **is the** examination of the bowel **using** an endoscope to diagnose, and/or in some cases treat, **bowel conditions and diseases**. **This may be investigating pain you have been experiencing, or symptoms like** chronic diarrhoea and bleeding. An endoscope is a long, flexible tube with a tiny video camera and light at one end. The video image is shown on a monitor. Colonoscopy is also used to identify and remove polyps (polypectomy). Polyps are small abnormal growths on the lining of the colon **and vary in size and shape, and, while most are not cancerous, they may turn into cancer if left untreated.**’

What are the ~~possible complications of~~ risks associated with colonoscopy?

We suggest rewording the first sentence of this section to read,

Generally, colonoscopy is a very safe procedure. However, as with all surgical procedures, there are risk associated with colonoscopy. Please feel free to discuss any concerns you may have about this with your doctor or treatment team.

We suggest moving the most common and less concerning side effects to the top of this section, this means that consumers will understand what symptoms they can expect and what they may need to watch for if this indicates a serious complication. We suggest the second paragraph should read,

One side effect is abdominal bloating, pain and flatulence which will disappear within a couple of days. These symptoms are caused by the air that is pumped into the colon during the procedure.

As you discuss a range of complications and risks in this section ranging from minor to death we suggest the inclusion of a graphic that shows visually the likelihood of each risk to occur. This will aid consumers in making an informed choice about their care. This section should also include information about the need discuss with your doctor and sign a consent form in the unlikely event you will need a blood transfusion.

It is important to restate that complications from colonoscopy are very rare before listing these possible conditions.

Several of our members commented that perforation seemed to occur quite regularly, and that seeing this was worrying for them.

“What is the treatment for puncture of the colon? If it is a risk I would like to know the treatment options. Surgery? Transfusion? Where can I get further information about this? It would also be worth noting here this is more common in elderly patients.”—HCCA Member

We suggest including some brief information about how these complications are treated in the event they occur and move the sentence about these treatments to under the list of complications.

If a complication occurs there may be the need for hospitalisation, surgery, intravenous feeding or blood transfusion. Be sure to discuss any concerns you may have with your doctor.

How to prepare for a colonoscopy

This section was difficult to navigate and confusing. For many it was unclear why there was not at least some description of bowel preparation provided, particularly given that it is then referenced further down the page. If that information is not included, how can consumers make sense of the following instructions? We recommend a brief description of bowel preparation and some information what to do if you have lost the instructions or not received them, if you have questions about these instructions, or are having any difficulty with the preparation.

DIABETICS **If you have Diabetes**

We strongly urge you to reword this title as suggested above, as many people take offense at being labelled a diabetic or by any disease or condition, as they are more than their condition. We also note this sentence falls in the middle of the how to prepare for a colonoscopy section. Many people who read this then thought all instructions that followed only pertained to people with diabetics. We suggest moving this sentence to the end of this section. We are concerned that your instructions for people with diabetes varies across the patient information sheets we have been given. For example, it is not included in the *Gastroscopy* or *Flexible Sigmoidoscopy* sheet at all. It is included on the *Afternoon Colonoscopy Test, Morning and Afternoon Gastroscopy Procedure*. The information on these forms also seem to differ to the broader information sheets that states the need to speak to your diabetic educator or specialist before the procedure. The forms suggest this in point two and then in point three say to take all medication excluding diabetic medication. This reads like people with type one and two diabetes should cease medication before the procedure, including insulin which does not seem likely. This was very confusing for those reading. We suggest that uniform information about what people with diabetes should do before a gastroenterology procedure. We also raise the issue that many people with diabetes can only see their diabetes specialist or educator every 3-6 months due to waiting periods for community and outpatient clinics, making it difficult to seek advice at short notice, it would be useful to provide guidance as to who to speak to if they cannot get into see their diabetes educator or specialist.

Bowel Preparation

We like that this section clearly explains why bowel preparation is important for our safety. We suggest clearly defining if you are talking about Nil By Mouth (NBM) fasting – as you are in this form or Fasting – with clear liquids as you do in the Colonoscopy and Gastroscopy procedure morning and afternoon information sheets. We often hear that consumers are sent home from tests and procedure like this after not understanding the differences between NBM or fasting with fluids.

How to get to Hospital

We suggest using this heading to discuss, the importance of not driving to hospital. In this section you can expand on why sedation effects your ability to drive, how having a carer for this period is useful, the need for a taxi if a driver is not available. It may be useful to provide information about community transport in this section.

What can you expect when you come for a colonoscopy?

We suggest removing the first paragraph and replacing it with, **You will be given an appointment time to attend the Gastroscopy Unit where your procedure will be done, by your treating doctor and medical team. Please allow 4 hours for your hospital stay.**

We would like to see included in the list of things to notify staff about before the procedure a dot point around **allergies or problems with anaesthetic and pain medications.**

This would also be a good place to explain the need to sign a consent form for the unlikely use of a blood transfusion and the risks involved with blood transfusion should this occur.

In this section it is important to clearly explain what sedation means in this context. For example, will I be awake? In pain? Will I remember? We noticed that this information is included on some of the patient information sheets but not others. It would also be useful to include a description of which treating team member will be looking after the patient at each point. For example, who is responsible for monitoring my oxygen and vital signs? Which is described on the Flexible Sigmoidoscopy patient information sheet and not on the other sheets.

Many consumers who read this section stated that it felt very clinical and would have liked to see plain language. Particularly the use of the term *intravenous cannula* which could be replaced with **small needle with a tube for administration of the sedation for your procedure**.

Many people will be anxious about these procedures and it may be the first time they have been sedated. This information sheets could play a vital role in calming any fears if they are written to address the needs and concerns of consumers. We suggest including a frequently asked questions sections with further links and opportunities to ask further questions about their care.

Information about confirming appointments – point 9 on forms Our appointment times are precious, so it is vital that you confirm your appointment at least one week prior to your booking date. If you do not attend for your appointment and do not make contact with this Unit, you may be removed from the waiting list. Notification of your non-attendance will be sent to your treating Specialist and General Practitioner.

Whilst we recognise the increasing pressure on your unit to deliver these procedures, however we have very serious concerns about the punitive tone taken in these documents around accessing your service. We find the language around appointment times and missing appointments particularly confronting. It isn't clear from the message above if the Gastroenterology Department, like other outpatient appointments provide a reminder letter and text message to confirm an appointment a week before the appointment. Often outpatient appointments are made up to six to eight months in advance and often require considerable rearrangement of daily living and other commitments to attend in the extremely limited choices of times that are available to us. We see as part of the role of this service to help aid our access by working with us to ensure we can make our appointments. It is unclear to us the need to inform specialists or our GPs of our non-attendance, is it to ensure we receive essential screening and support? This sentence of the form reads like our actions will be noted negatively by our treatment team i.e. you will 'dob' on us. We caution against using this language, if only for the reason of not wanting to deter people from continuing to see their treatment team. We also note that the forms themselves do not clearly state what number should be called to confirm your appointment. We suggest reviewing the language used in this section and as suggested previously ensure that information provided in all of the sheets are consistent with each other and provide the same information.

