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FUTURE OF SHOUT

There has been substantial coverage in the past fortnight on the potential closure of SHOUT. Media coverage includes:

- [SHOUT deserves ACT government support, 22 March 2017, *The Canberra Times*](#)
- [Friends of Brain Injured Children may reduce therapies if SHOUT closes, 22 March 2017, *The Canberra Times*](#)
- [Bosom Buddies counts cost of SHOUT closure, 23 March 2017, *The Canberra Times*](#)
- [Stanhope/ Minister's blunt cuts hurt vulnerable people, 21 March 2017, *CityNews*](#)
- [*The Canberra Times Editorial, 22 March 2017*](#)

You can read more about SHOUT's decision to close in their media release (dated 27/03/2017) which is attached.

On 16 March we were advised that the SHOUT Board had met with the Minister for Disability, Rachel Stephen-Smith MLA the week before and based on this discussion as well as advice from their auditor and funding body they took the decision to wind down the operations of SHOUT. This will be effective from the end of May 2017.

There will be a Special General Meeting on Wednesday 26 April 2017 at 12pm at SHOUT to ratify this decision. If the members support the Board's decision then SHOUT will close, ending over 35 years of service to the Canberra Community. We will then need to transfer this function to another organisation, so that these small organisations can continue to receive centralised administrative support.

Last week in the Legislative Assembly there was debate and comment from all members and further media coverage. It is clear that there is recognition from all members of the Legislative Assembly that self-help groups are valuable in our community for the peer support they provide and the services they offer to their members.

HCCA has been a long term member of SHOUT and over time members, including members of our Executive Committee, have contributed to the work of SHOUT through membership of the Board. HCCA recognises the value of self-help groups in peer support, in providing information, participating in policy development and advocacy as well as opportunity to build the skills that are so important to self-management for those people living with chronic conditions.

HCCA has benefitted from our association with SHOUT. We have used a number of their services over the years, including access to photocopying, administration support, and room bookings. We still use a range of their services. SHPOUT processes credit card payments of HCCA membership and we continue to use their meeting rooms. Our Executive Committee met in the SHOUT small meeting room on 22 March and on 29 March the

ENDORSEMENTS

Consumer Representative Endorsements

Leia Earnshaw → WYC Maternity Quality and Safety Committee

HCCA Staff Endorsements

None.

HCCA Events

Consumer Representatives Forum

Please note: This meeting is for current consumer representatives endorsed by HCCA. If you have any questions about this, please contact Kate Gorman on kategorman@hcca.org.au.

Time: 11:00am to 2:00pm

Date: Wednesday 29 March 2017

Venue: SHOUT large meeting room, Building 1, Pearce Community Centre, Collet Place, Pearce.

HCCA Consumer Reps Forum will be held in the large meeting room at Pearce.

I have been providing support to SHOUT behind the scenes. The HCCA Executive Committee is committed to finding a sustainable solution to make sure the work

We encourage the ACT Government to work with SHOUT's member groups to find a solution to fund the central administrative support function.

Darlene Cox
Executive Director

COMMITTEE VACANCIES

Nominations for the committees below close on **Monday 17 April 2017**.

The Walk-in Centre

This committee provides strategic direction for the Walk-in Centres at the Belconnen Community Health Centre and the Tuggeranong Community Health Centre. It is responsible for reviewing and recommending changes to key performance indicators, risk management, adverse events, clinical policy, occupational health and safety, and quality assurance projects and accreditation. The successful nominee will have consumer experience using the services at any of the Walk-in Centres. Ideally, the committee are looking for a consumer between the ages of 20-25 and/or with children between 6-8 years old. If you are interested in applying but do not fall into these criteria, please submit a nomination form anyway.

This committee meets every two months on the third Thursday of the month, from 9.30-11am. The location alternates between the walk-in centres at Belconnen and Tuggeranong.

Health in Pregnancy Working Group (ACT Health)

The aim of this working group is to improve service delivery for larger women during and between pregnancies to support optimal outcomes for mother and baby. It looks at evidence-based services and programs, ACT Health policies, guidelines and resources and training opportunities to support staff to deliver services in a client-centred, non-judgemental and sensitive way.

If you are interested please contact Kate Gorman at the office – kategorman@hcca.org.au

“These are all very good suggestions..... the end product is going to be vastly superior”

A year ago some of our members were involved in a focus group facilitated by the ACT School Health Team. Kate Gorman organised the focus group and prepared a summary which was sent to ACT Health. Often the story of consumer input ends here, but not this time!

The School Health Team came back to us to ask for our input into letters that will be sent home if a student misses any of the vaccinations. The letter explains where and when they can arrange a free vaccination for their child. It also flags the potential cost of a GP consultation. It will include the contact details of the Translator and Interpreter Service. It also includes a short summary of the costs of catching the disease. We hope this will highlight the importance of getting children vaccinated.

We believe it is important to celebrate the wins made by HCCA and its members, as they all contribute to a better functioning health system. Let us know if you've had a win – no matter how small – so we can share the news and keep the enthusiasm going.

Consumer Health Forum – Consumer and Carer Leadership Colloquium 20-21 March 2017

On 21 March 2017 HCCA supported Kathryn Briant and Yelin Hung to attend the Consumer and Carer Leadership Colloquium in Canberra. The event was hosted by Consumer Health Forum Australia, National Rural Health Alliance Inc and Mental Health Australia. It was held at the Vibe Hotel at Canberra Airport. Sue Andrews (HCCA President) is a member of the CHF Board and facilitated some of the discussion.

Yelin provided a few comments on the event:

“The purpose of the Colloquium was to work with consumers/carers to find different avenues to advocating for a better Australian health system and to have a uniform people-centred approach to raise quality, reduce waste and improve our health and well-being. There were participants from all over Australia including our sister

organisations Health Consumers NSW, Health Consumer Alliance of South Australia and Health Consumers Queensland; also a myriad of interstate community organisations and government representatives such as Martin Bowles and Andrew Stuart from the Department of Health and other government sectors.

The model of engaging with consumers needs to be changed to be able to hear the voices that haven't had the opportunity to have a say. Health care is about consumer choice and what is appropriate for consumers, there needs to be more data transparency so that consumers can make a better informed decision. Lucy Thompson from the Australia Digital Health agency stated that set standards on digital health produce services that are meaningful to the consumer and clinical staff. Also, telling the stories and lived experiences of consumers is a powerful tool used for mind transformation.

A note that was prominent in this discussion was that developing services without consumers in the room, you might be as well developing half of the service or the service is not relevant to the consumer. So, it was interesting to hear in the room that there is nothing about without us.

Kathryn also recorded a few thoughts:

“The Consumer and Carer Leadership Colloquium, , was a great opportunity to get to meet other consumers and carers working in health advocacy. An introductory dinner on Monday 20 March was great for networking with other attendees. Then on Tuesday 21 March, we looked at being informed and influential in health reform, how to be strategic and effective as consumer leaders, and how to better collaborate with other consumers and consumer groups in the future. Some key learnings were that:

- Consumer input adds great value - health services should see us as an advantage, not a hindrance!
- Underpinning our advocacy with data/evidence can help support our case as consumers.
- Partnership with consumers needs to keep being encouraged at all levels – this leads to better health outcomes for everyone.”



1 Yelin, Kathryn and Sue at the CHF Colloquium

HEALTH POLICY UPDATE

HCCA are working on a wide variety of exciting policy issues on which we would appreciate your input:

- The Australian Government's Department of Health consultation on a [Single Aged Care Quality Framework](#) (Consultation 1) and [Options for Assessing Service Provider Performance Against the New Standards](#) (Consultation 2) . Input is due to HCCA by **Friday 7 April 2017**, we will collate your comments and complete the consultation survey.
- Draft National Maternity Services Framework - [click here to access all the info on the COAG website](#). Input is due to HCCA by **Tuesday 11 April 2017**.
- Wounds Australia Consultation on the Pan-Pacific Clinical Practice Guideline for Prevention and Management of Venous Leg Ulcers - if you would like a copy of the guideline to comment on, please call or email HCCA. Input is due to HCCA by **Thursday 13 April 2017**.

We recently made a submission to the Australian Medical Council (AMC) review of the training, education and professional development programs of the Royal Australasian College of Surgeons. This is a part of the AMC's periodic assessment of specialist medical programs against approved accreditation standards. Our submission raised a number of consumer issues relating to the specialist medical training of surgeons including post-operative pain management, communication and the monitoring of patient outcomes. Thanks to everyone who provided input!

Kathryn Briant
Policy Team Member

NEWS FROM CONSUMER ORGANISATIONS

[Health Consumers NSW](#) have recently released a report titled 'Involving Health Consumers in Health and Medical Research: Enablers and Challenges from a Consumer Perspective', a collaborated project with Research4Me. This report is the result of a consumer workshop held in October 2016 and outlines the types of research consumers are involved in, key enablers that would help support consumer involvement in research and how consumers can add value to clinical trials.

[If you would like to read this report, you can find it here.](#)

Doctors poor at estimating benefits and harms

"Most doctors tended to overestimate the benefits of treatments and underestimate their harms. ... it may reflect not being taught, recalling or keeping up to date with relevant evidence."

Doctors are not much better than their patients when it comes to estimating the benefits and harms of treatment, screening and tests, say Australian researchers.

Their systematic review of 48 studies with over 13,000 (mostly) doctors found most participants could only correctly estimate benefits for three of 28 outcomes assessed. It was a similar story for harms, with the majority of doctors correctly estimating harm for 9 of the 69 outcomes.

And just like their patients, most doctors tended to overestimate the benefits of treatments and underestimate their harms. The researchers from Bond University in Queensland say there are many possible explanations for the mismatch. But whatever the reasons for these distorted perceptions so common in the profession, the problem needs to be addressed, the researchers say. [Click here to read more about this interesting study.](#)

LOCAL EVENTS

Living a Healthy Life with Long Term Conditions

SHOUT Inc. in partnership with ACT Health are providing a free six-week course for people who have been living with a chronic health condition for six months or longer. The course includes topics such as symptom management, including pain, fatigue, anxiety, depression, shortness of breath and dealing with negative emotions. Other sessions include communicating with health providers, physical activity, healthy eating, action planning, problem solving and peer support. Below is a table of the next sessions:

Location	Dates and Times
Gungahlin Community Health Centre	Tuesdays from 10:00am – 12:30pm May 2, 9, 16, 23, 30 and June 6
Phillip Community Health Centre	Thursdays 10:00am – 12:30pm May 4, 11, 18, 25, June 1 and 8

If you would like to register for the course, please contact Community Health Intake on 02 6207 9977.

ITEMS OF INTEREST

Primary Care

ACT Health Nurse Practitioner Review: online survey now open!

ACT Health are currently undergoing a review of their governance arrangements for nurse practitioners and have developed a survey for health consumers, employers and nurse practitioners to partake in. The survey aims to address consumer views and concerns on existing governance requirements and matters of primary health care services sustainability and succession of the nurse practitioner program. More information is attached. [If you would like to participate in the ACT Health Nurse Practitioner Review Survey, click here.](#)

Online Tool Helps Patients Comprehend their eHealth Notes

Hong Yu, PhD, professor at the Department of Quantitative Health Sciences at the University of Massachusetts has designed an online tool for consumers to simplify their eHealth records into language that is easy to understand. The tool, called [Clinical NotesAid](#), works by copying and pasting the text you don't understand into a textbox where it will automatically link the clinical jargon to a corresponding simplified definition. Yu says with the ongoing focus on patient-centered care, it is important that patients be able to comprehend their eHealth record notes and that enhancing medical understanding and improving healthcare management is particularly important for patients with chronic conditions. [To read more about Dr Yu's Clinical NotesAid tool, click here.](#)

Online portal for complaints and concerns launches

The [Australian Health Practitioners Regulation Agency \(AHPRA\)](#) has recently launched a new public online portal offering individuals a clearer and simpler process when making a complaint or raising a concern about registered health practitioners and students.

The portal is an additional channel available through the [AHPRA website](#). Alternatively, individuals can still call 1300 419 495 to make a complaint or raise a concern, and there is a simplified PDF form available for those wanting to make a complaint or raise a concern that way.

The portal brings with it an improved user experience, incorporating features such as information pop ups that aid users in completing required fields. Automated correspondence is issued to all notifiers who use the portal, including advice that they will be contacted by a member of the AHPRA team within four days of submitting their complaint or concern to make sure details are complete for assessment.

If you need more information, you can contact the National Notifications Program team who is leading the online portal project. Please contact National Program Manager, Notifications [Monica Lambley](#) on 03 8708 9061 if you have questions.

ITEMS OF INTEREST (CONT.)

Latest news from CHN

Read all the latest news from the [Capital Health Network](#):

- [Health InterACTion issue 39](#)
- [2/52 Health Care Bulletin](#)

Safety and Quality

Nurses and midwives ready to prescribe

A health professional's scope of practice should guide their rights to prescribe, otherwise we risk having health professionals fight over prescribing rights like seagulls over chips, according to Dr Lisa Nissan, a pharmacist and Head of Clinical Services, QUT.



On 22 March 2017 Kathryn Dwan, HCCA Policy and Research Manager, attended the Registered Nurse & Midwife Prescribing Symposium at the Hellenic Club in Woden. This was an invitation only event with over 100 participants from a range of sectors including nurses and midwives from clinical, management, policy, education, professional, workforce, regulatory, and research backgrounds as well as consumers. It was convened by the Chief Nursing and Midwifery Officer in the Commonwealth Department of Health with the aim to progress a nationally consistent way forward on prescribing for nurses and midwives in Australia.

The nursing and midwifery profession seemed confident and keen to incorporate prescribing into their scope of practice at the Symposium. HCCA raised the importance of systems to manage the less able and responsible among the profession, and those present strongly agreed.

Consumer Involvement in Health Research – Article

[The Consumer & Community Health Research Network](#) are a Western Australia based network established by the [University of Western Australia](#) and the [Telethon Kids Institute](#) that enables consumers to be more involved in health research and have been featured in the latest edition of INSPIRE Magazine. The article *Providing Consumers and Community the Opportunity to have a Voice in Health Research* showcases the program of work that this network aims to achieve and its goals for future expansion and consumer involvement in health research. [If you would like to read this article on page 26-27 of INSPIRE, please click here.](#)

Otitis Media: Clarifying the Antibiotic Prescribing Gap

The prescribing of antibiotics for middle ear infection in children was addressed in a recent recommendation from the health profession-led initiative [Choosing Wisely Australia](#), facilitated by [NPS MedicineWise](#). The [Royal Australian College of General Practitioners \(RACGP\)](#) recommended against routine use of antibiotics for children aged 2 to 12 years (who aren't of Aboriginal and Torres Strait Islander descent) where reassessment was a reasonable option.

In Australia, 84% of acute otitis media (AOM)/middle ear infection is treated with antibiotic therapy, contributing to increasing antibacterial resistance in *Streptococcus pneumoniae*, *Haemophilus influenzae* and *Moraxella catarrhalis*, the most common bacterial otitis media otopathogens. It is usually a short-term infection. Dr Andrew Boyden, NPS MedicineWise medical adviser says, "Increasingly, the limited role of antibiotics for the treatment of acute otitis media is being recognised, which is reflected in contemporary clinical guideline recommendations.

For more information about the case study, visit www.nps.org.au/casestudy.

Or [click here for more information about the Choosing Wisely Australia recommendation is available here.](#)

ITEMS OF INTEREST (CONT.)

Health of Older People

Positive Ageing Awards 2017

As a part of the Seniors Week celebrations, the COTA Positive Ageing Awards was held on Friday 24 March 2017. HCCA nominated one of our consumer representatives, Denise Mott, for the work she does with our eHealth and Health of Older People Consumer Reference Groups. Denise was short-listed for the award. Below is a photo from the event with other HCCA consumer representatives who also attended.



Figure 2 HCCA Members at the Positive Ageing Awards

Conversations at the end of life

[lifeCircle](#) is an organisation operating through philanthropy and strategic partnerships based in Sydney. They have produced a three part documentary series called *Conversations* based on the lived experiences of ACT-based people who cared for their dying loved ones. The organisation believes that talking about dying can also encourage rich and valuable discussion about what really matters in life. The films are available on YouTube. They are about 5 – 6 minutes long and the three films address [Honesty & Openness](#), [Care & Support](#), and [Planning & preparation](#).

The documentary was launched on 23 March 2017 at Brindabella. Kathryn Dwan, HCCA Policy and Research Manager, attended as she has a long standing interest in palliative care. HCCA members attended also including Fran Parker and Adele Stevens.

LOCAL EVENTS (CONT.)

Making Financial Decisions for Your Future

Considering your future financial wellbeing? Thinking about how superannuation might contribute to that?

Join ACTCOSS for a free one hour session facilitated by HESTA to gain a better understanding of:

- What is Super
- Topping Up
- Finding and consolidating lost Super
- Insurance options
- What does your retirement look like for you?

Date: Thursday 30 March 2017, 5.30pm - 6.30pm

Venue: ACTCOSS Meeting Room, 1/6 Gritten St, Weston ACT 2611

Cost: Free

RSVP: [Click here to RSVP for this event!](#)

Contact Us

Health Care Consumers' Association Inc

100 Maitland St

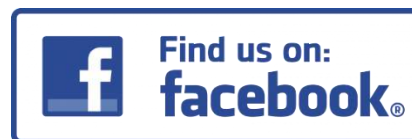
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Please note that Consumer Bites provides a small snippet of health related articles our members might find interesting to consider, ponder and analyse. The HCCA does not purport to endorse any opinions or the veracity of claims contained within the articles.

Consumer Bites is the fortnightly newsletter from **Health Care Consumers' Association ACT**

Editor: Khalia Lee

Late news from SHOUT – Email to members 27 March 2017

We received this email from Mandy and Phoebe, Business Managers at SHOUT.

SHOUT MEMBERS /TENANTS

Thank you so much for your support during this time. We are devastated that SHOUT has to close and that there will be little support for self help organisations in Canberra. This next couple of months is going to be extremely difficult for all of us and we are here to assist you with the transition. We will be organising a list of issues for each organisation separately.

If you wish to come and speak with us, please make contact, but understand that it could be up to 5 working days before we can see you depending upon the workload.

Some issues you will all need to be aware of:

Last day of SHOUT **services to members** will be 31 May. If you are moving out of the Pearce Community Centre (PCC), your organisation will need to have completely vacated PCC by this time.

If you would like to remain in your current space at Pearce then you will need to make contact with Gail, the PCC Manager ASAP to organise your own lease agreement with PCC. PCC will send you an EOI shortly.

Gail's contact details are:

Phone: 6290 1853

Email: pearcecentre@bigpond.com

We will provide Gail a list of SHOUT tenants, your email address, area in the building and rent that you currently pay and also your meeting room bookings for 2017. Your meeting room bookings will still be available to you for the rest of 2017 (at the same rate charged by SHOUT currently), but any new bookings will be charged at a new rate determined by the PCC committee.

As we see it, your organisation will need to acquire a phone, computer/IT services and a copier/printer of your own to continue to operate. (also depending upon where your new premises will be it would be a good idea to try and access some of the community organisations to be included in their email networks to make sure the community knows what is happening within your organisation).

We will look at the asset register to determine what equipment/assets are SHOUT's and what is owned by your organisation. If needed, we will clarify this with a person from your organisation.

If you have files on our computer (i.e. database etc) we can go through these with you, delete unnecessary ones, and **if you can please provide us with USB we can copy all files for you to take away. Please call ahead to arrange to do this, as we will need to allow time in our schedule.**

Any advertising material, letterheads, websites, brochures, membership forms, that have contacts of SHOUT on them will need to be deleted and changed by 31 May 2017.

Phoebe and I will also be sending you information on some space available at Woden Community Service at Callam **Offices** and also Endeavour House at Manuka. It will then be up to each organisation to decide where they will be moving to. There is no space available at MS in Deakin.

Any organisation with Volunteering Insurance with SHOUT will need to get their own insurance by 30 March 2017.

Any organisation using storage areas at SHOUT will need to have cleared this space by **COB Monday 29 May 2017 at the latest.**