HEALTH MATTERS

Health Consumers’ Council (WA) Inc. Magazine
Issue 2 2016

My Health Record

Choosing Wisely Australia & Advance Care Planning

Aboriginal Advocacy: Tania’s patient & carer experience...

My Health Record: Electronic patient records system, worth getting right

Involvement in the arts helps prevent mental illness

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Welcome to
My Health Record

My Health Record is a secure online summary of your health information. You can control what goes into it, and who is allowed to access it. You can choose to share your health information with your doctors, hospitals and other healthcare providers.

Other questions you might have:

- Find out about the benefits of having a record
- Visit our frequently asked questions
- Learn more about privacy and security
- Find out what's new

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Cover: Stock vector

Foreword

Welcome to the 2nd edition of Health Matters for 2016, in this issue we focus on 'Your Health Information.' We feature two articles on My Health Record, one from the perspective of WA Health, and from the perspective of a non-English speaking health consumer.

The Patient will see you now - Thinking beyond accreditation to focus on the Patient Experience Clinical Senate Debate December 2015

In the last issue of Health Matters we outlined the December Clinical Senate Debate presentations. The Recommendations have now been publically released and are available in full on page *. There are some very positive initiatives that have been endorsed for action. The Patient First program will recieve some much-needed attention to revitalise this valuable resource, with the help of a small amount of funding. The initative to develop a definition and agreed measurement tools for patient experience are also encouraging. These levers for cultural change offer opportunities to make our very good health system even better through a stronger patient-centred focus.

Most Clinical Senate debates include a Recommendation in relation to IT, and this was no exception, calling for the "prioritisation of a single electronic platform accessible by all area health services that is able to provide information on patient care providers, appointments and clinics, discharge summaries and resources available in the community." IT improvements could facilitate significant positive change for the health consumer, as we flag in this edition of Health Matters.

Patient Experience Week, Consumer Awards 2016

As the clock winds down to Patient Experience Week, HCC is very excited to be able to present for the first time, a series of events to mark Patient Experience Week. Over two days local, national and international leaders will showcase Patient Experience excellence in practice.

Speakers include: Professor Michael Greco, Patient Opinion Australia CEO; Dr Karen Luxford, Clinical Excellence Commission of New South Wales, Director of Patient Based Care; Professor Anne Williams, Murdoch University, Chair of Health Research and Helen Fernando, Consumer Advocate and 'Patients for Patient Safety' champion, will present on the latest and best patient experience tools. New author Kate Ryder will talk about her book, 'An Insider's Guide to Getting the Best out of the Health System'. Kate will have signed copies of her book available for purchase.

Patient Experience Week will close with the annual Health Consumers' Council Health Consumer Excellence Awards. Since 1997 the Health Consumers' Council has been celebrating the achievements of the unsung heroes in WA Health, from the administrator to the clinician and to recognise health consumers that go out of their way to make a difference.

The theme of the next edition of Health Matters is 'Cancer Survivorship'. If you would like to submit an article, please contact us on info@hconc.org.au so we can provide submission guidelines.

Pip Brennan
Executive Director
Health Consumers' Council

Letters to the Editor...

Letters to the Editor aims to capture your feedback. We welcome your letters & messages. You can leave messages on Twitter and Facebook using hashtag #hconcwa_editor, email info@hconc.org.au or post GPO Box C134, PERTH WA 6839, please include your name, suburb and phone number. Letters may be edited for legal issues, space or clarity.

Message from the Health Matters Editor

Dear Members,

After the announcement in our last edition that we would be producing a digital edition, with a limited print run we recieved an overwhelmingly positive response. The phone was ringing with members checking that they would still recieve Health Matters by post. Others were concerned about rising costs and even though they loved reading Health Matters they didn't want to be costing the HCC money. It was fantastic to hear how much members value Health Matters. We love to hear from you.

We want to know if you find the information provided valuable, if there is something that you would like explained.

Lucy Palermo

Lucy Palermo Marketing & Communications Coordinator / Health Matters Editor | HCC

Love Frank's Articles

Dear Editor,

I love reading the articles by Frank Smith, it is great that consumers are able to contribute articles to Health Matters.

Anonymous Female

Editor: Thank you, we love receiving articles from Frank. You can read more of his articles on the Health Consumers' Council Blog available at www.hconc.org.au

Our Advocacy Service

Assists you when making a complaint about you, your family or community's health services. This free service is available to anyone in WA.

We can help you by:
- Talking through your complaint
- Contacting the service to try and resolve the problem
- Helping you to make a formal complaint about a doctor, hospital, psychiatrist, allied health professional or any health service

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Sharing your patient experience, helps the Health Consumers' Council to advocate for better health services in WA.

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My Health Record

Frank Paterson | Department of Health WA

On March 4, 2016 the Commonwealth Government officially launched My Health Record, formerly known as the Personally Controlled Electronic Health Record (PCEHR)

My Health Record provides a secure online summary of an individual's health information. The individual record holder controls not only what goes into his or her health record, but who can access it.

With a My Health Record an individual can view and share health information with his or her doctors, hospitals and other healthcare providers, enabling the best possible care. The record is also accessible nationally.

A number of enhancements are being made to the My Health Record system including improvements to the record holder's first-access experience. These changes should make it easier for the holder to:

- set up the record at the first login
- control who has access to the record
- upload Advance Care planning documents to the record.

Further modifications to the system will simplify processes while preserving clinical safety and providing appropriate guidance to consumers on privacy and security.

These improvements will be effective from the first week of April. Other improvements planned for later in the year will enable the system to interact securely with mobile devices.

To increase GP participation in the My Health Record system, incentives are being offered to practices that upload shared health summaries. On-line training is also available for clinical and non-clinical staff working in community pharmacy, hospitals, specialist medical practices, allied health and aged-care facilities.

Greater clinical content is available under the revised record system which enables the uploading of pathology and imaging reports.

"Opt out" trials

My Health Record is currently an opt in system nationally with over 2.6 million people registered. In April however, opt-out participation trials will begin in Northern Queensland and the Nepean Blue Mountains region of New South Wales. All consumers in these areas will have a My Health Record unless they choose not to. This will see a further 1 million people registered. An evaluation of these trials will guide the Commonwealth on decisions about moving to an opt out model nationally.

WA Health's connection to My Health Record

Through the Notifications and Clinical Summaries (NaCS) system, WA Health has the capability to upload discharge summaries to an individual's record as well as view content in the individual's My Health Record. The NaCS system is live at Fiona Stanley, Royal Perth and Princess Margaret hospitals in the metropolitan area and has been implemented at all hospitals throughout the Great Southern region.
Rollout is underway throughout the South West and plans are being finalised for rollout to further metropolitan sites and country regions over the next 12 months.

Work in the Great Southern region has been very successful and well received with hospitals, general practices, community pharmacies, aged care, allied health and Aboriginal health services working collaboratively to create a "connected community" where all can access and contribute to the My Health Record system. This has been supported and coordinated through the National eHealth Transition Authority (NEHTA).

Hospitals and general practices can also help consumers register for a My Health Record through an automated assisted registration process.

Advisory groups have been established in each of the Great Southern and South West regions. These include representatives from all stakeholders including the WA Primary Health Alliance and consumers.

WA Health looks forward to working with all stakeholders – particularly the WA Primary Health Alliance and Health Consumers' Council – to encourage participation in the My Health Record system.

For the latest updated information on My Health Record this link is provided https://myhealthrecord.gov.au/internet/mhr/publishing.nsf/content/home

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Under the *Freedom of Information Act 1992* you can access your WA Health medical records. Unfortunately this only applies to health records from a public health service. If you are having problems accessing your medical records contact Health Consumers' Council (WA)

CCE Program: 'Your Health Record'

Louise Ford Consumer & Community Engagement Manager | HCC

Universal sign for medical records Image Source: http://www.hablamosjuntos.org/signage/PDF/SymbolPoster_Sep10.pdf

Electronic technology is now used in all facets of life. The recording of patient information is the next logical step. In practical terms there are great advantages to utilising electronic records, these include reduction in paper use, easy access to records (as long as there is an internet connection), no loss of records in the mail or via administrative mistakes, instant access to records and being able to access your own records. A further advantage in terms of 'My Health Record' (about to be trialed in Queensland on an 'opt-out' basis) is that it would "develop an effective, national shared electronic health record system." There is currently an 'opt-in' mechanism for those who wish to use it. (Source: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/eHealth/Report/c02)

My concerns regarding 'My Health Record' are based on the possible and potential increase in inequities in health care via the use of electronic recording method. How do you explain this recording method to people with low health literacy and/or low literacy in English? Will the use of 'My Health Record' contribute to the 'human touch' so many would like as part of their patient journey? Will it contribute to the development of trust between provider and patient? Will the 'My Health Record' website provide information in languages other than English? (Currently it doesn't.) And will health care professionals utilise interpreter services to explain to patients what it is all about?

The Health Legislation Amendment (eHealth) Bill 2015 received submissions of support but also those which expressed concern about electronic recording mechanisms. For example:

"Impact on vulnerable groups

2.20 As noted in Chapter 1, the Parliamentary Joint Committee on Human Rights (PJCHR) raised a number of concerns about the impact of an opt-out model on the right to privacy and rights of vulnerable groups, including children and people with disability. [26]

2.21 The Consumers eHealth Alliance recommended that the trials be delayed until the issues raised by the PJCHR are addressed and suggested 'reflection on the critical points raised by the PJCHR in respect of the nature and scale of vulnerable people - and the practical and legal difficulties of obtaining proper, informed, consent from an unengaged populace'. [27]

2.22 The EM noted that the anticipated benefits in health outcomes as a result of the Bill would be:
...skewed towards vulnerable families as they currently face more challenges in accessing timely and appropriate healthcare and will have more to benefit from improved health outcomes. These people are also less likely to participate in an opt-in model as they are more likely to be challenged by the registration process. [28]

2.23 This statement was supported by Carers Australia's submission which noted that 'carers are less likely to participate in an opt-in model and are more likely to be challenged by the registration process'. [29]

2.24 The department submitted that the current Pesonally Controlled Electronic Health Record (PCEHR) system provides special arrangements to support children and vulnerable people to participate in the system by allowing authorised representatives to act on their behalf. The department noted that the Bill provides additional arrangements to ensure:
...that people providing decision-making support will...need to give effect to the will and preference of the person to whom they provide decision-making support. Ensuring that representatives can continue to act on behalf of individuals (including children and persons with a disability) to help them to manage their

record as part of opt-out is a privacy positive under the eHealth Bill. Authorised representatives will be able, for example, to opt-out the individual for whom they have responsibility from having an electronic health record, if this meets the will and preference of the person they are representing. [30]

2.25 The department further noted that the process has been designed to:

...cater for those people who have difficulties in coping with bureaucratic processes to ensure it is highly accessible and easy to understand so that they are able to exercise their right to opt-out without unnecessary complexity. While phone and online channels are expected to cater for the majority of individuals, the Department of Health is working to ensure that alternative processes will be available to all individuals including those needing additional support or with limited documentation. [31]"
(Source: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/eHealth/Report/

Image Source: https://www.law.ox.ac.uk/research-subject-groups/centre-criminology/centreborder-criminologies/blog/2015/05/gender-class-and

c02)
While conducting research for this article, I came across the Blog 'Mission: Health Equity, A blog about health issues affecting vulnerable populations'. The post, 'How Can Non-English Speaking Patients 'Meaningfully Use' Patient Portals?' by American based doctor Neda Ratanawongsa, written in 2014 remains current and is equally valid in an Australian context and reflects my own concerns on the matter. The follow is an excerpt from this post:

"We are rolling out our patient portal – MYSFHEALTH – to all of SFHN's primary care, specialty care, and hospital patients. Patient portals offer tremendous benefits to patients, improving access to their own health information, promoting engagement in their health, and facilitating adherence to medications. Diverse patients want to use health information technology to access their health records and communicate with their health care teams. However, multiple studies have found disparities in portal enrollment or use by race/ethnicity, age, gender, educational attainment, and health literacy. (Many thanks to GIM colleagues Urmimala Sarkar and Courtney Lyles for their work in this area!)

Surprisingly, there is a dearth of resources or research about how to make portals more accessible to non-English speaking patients. In San Francisco, 45% of households speak a primary language other than English: 19% Cantonese or Mandarin, 12% Spanish, 3% Tagalog, and the remainder a mix of Russian, French, Vietnamese, Korean, and other languages. Because it is so crucial to offer health care in a patients' preferred language, SFHN prioritizes providing both health care and health education across our populations' key languages.

Unfortunately, across the U.S, patient portals are not available to most patients who are non-English speaking; to my knowledge, there are only a handful of patient portals in Spanish and only one offering Chinese languages. This will prove an enormous barrier to engaging a large proportion of SFHN patients, even though many of these patients do use the Internet via computers and/or mobile devices."
The author continues "But most importantly, I want to reduce disparities in patient portal access and engagement for our patients. When health information technology is designed to be linguistically and culturally concordant, it has tremendous potential to engage non-English speaking patients to promote self-care and quality of life. Patient portals could be powerful tools to improve the health and health care of all safety net patients.

Given the realities of the English-language portal we now have, we are working to allow patients to designate proxies to help access their patient portal records. This requires detailed education and consent to ensure that patients truly understand what sensitive information may be contained in their online health records." (Source: http://mission-healthequity.blogspot.com.au/2014/12/how-can-non-english-speaking-patients.html)

I have looked for evidence of research undertaken in Australia on this issue but have not been able to locate anything of substance (if anyone can enlighten me I would love to know about it.) I am left wondering if Australia took note of the lessons learnt in the US or if we are going to have to travel the same paths rather than build on what has been identified already.

National News

Pip Brennan Executive Director | HCC

"In 1990, 15c of every dollar collected through tax went to health – now it's 24. Medicare is being billed more than one million times a day. We currently spend $154 billion across all parts of the health system."

"The best measure of quality is whether a patient recommends a product, a service, a provider or a facility to another."

The Honourable Sussan Ley, Federal Health Minister, addressing the Committee for the Economic Development of Australia (CEDA), 31st March 2016. Her full speech to CEDA can be viewed online here: https://www.health.gov.au/internet/ministers/publishing.nsf/Content/health-mediarel-yr2016-ley160331.htm

Contact the Health Consumers' Council if you would like more information or a copy.

Reform Updates

The Honourable Sussan Ley is overseeing no less than six major reforms in the health sector. Key updates in the reform are noted below.

The Primary Care Review

As was anticipated, the reform of primary care has centred on the treatment of people with chronic conditions. In order to create a more joined up system for people with chronic conditions, there will now be the option of consumers choosing a GP to manage their care co-ordinated from one place. The initiative is known as Health Care Homes and will bring together medical, allied and community support services under one co-ordinator, no matter who will actually fund the service. Currently the consumer has to try navigate a fragmented patchwork of services that may be funded by Medicare, state and local governments or the community. A two year trial with up to 65,000 consumers and 200 medical practices will commence in July 2017. The Primary Health Networks will facilitate this reform's implementation.

It would be interesting to see whether over time the co-ordinator could be an allied health practitioner, a nurse practitioner, midwife or similar, but at present the co-ordinator of care will be a GP.

The full media release is on the federal Health website at this location: http://www.health.gov.au/internet/ministers/publishing.nsf/Content/health-mediarel-yr2016-ley024.htm
Please contact us on 9221 3422 if you would like more information or a copy.

The Medicare Benefits Schedule Review

The review into the Medicare Benefit Schedule has supported the Health Care Homes initiative by providing a more flexible approach to funding chronic care rather than the fee for service model which does not support co-ordinated, effective care for the consumer. The fee for service model will still apply throughout much of the health system, but specifically to support consumers with chronic conditions, more flexible Medicare billing will apply. This is anticipated to provide better care for rural and regional consumers, and will be tested during the two year Health Care Homes trial. (http://www.health.gov.au/internet/main/publishing.nsf/content/mbsreviewtaskforce)

My Health Record

A big part of the missing puzzle in coordinated care is the sharing of information across primary care and hospitals. The federal government is part way through a trial of My Health Record where consumers are automatically signed up to My Health Record and can then nominate to opt out. When My Health Record was initially launched some years ago as The Patient Controlled Electronic Health Record, consumers could opt in, and so few did it made the roll out of the record difficult.

This is a difficult area as IT is changing so rapidly, however the Health Consumers' Council supports the new attempts to make this technology work. This is because the lack of a co-ordinated flow of information between primary and hospital sectors is a constant stumbling block to safer, more connected care, and better planning of health services. We often simply do not know enough about a person's journey through the health system to understand how best to deliver effective health care. An article on My Health Record has been provided by WA Health's Frank Patterson, who has worked on this project for more than a decade. See page # for this article.

Mental Health and Alcohol and Other Drugs

In Western Australia, the WA Primary Health Alliance and the Mental Health Commission will be co-commissioning both community mental health as well as alcohol and other drug services in our state. The amount of alcohol and other drug funding from federal health will be announced imminently.
http://www.health.gov.au/internet/ministers/publishing.nsf/Content/the-hon-sussan-ley-mp-latest-news

Private Health

In late 2015, the federal Health department undertook a consumer survey on the subject of private health insurance, which more than 40,000 people responded to. More than 90% of respondents said they found it difficult to determine which was the best health insurance policy for their circumstances. Our national Consumers Health Forum is advocating for the introduction of a MyCover plan which proposes "that the health insurance rebate should be withdrawn from those policies which fail to meet set consumer-friendly standards of simplicity and comparability. These standards should be designed by industry, government, clinician and consumer groups."

Leanne Wells from the Consumer Health Forum notes, "The intricacy of varying benefit levels offered by health funds, the confusing 75 per cent Medicare benefit rate and the uncertainty about whether the patient will pay a gap, no gap or a "known" gap, make for a maze of knowns and unknowns. And that's before widely varying doctors' fees are accounted for.

"The result can mean differences in the order of more than a thousand dollars in what insured patients may have to pay out of pocket for the same operation."
In order to understand what the total costs will be for an operation requires significant work from consumers to contact their clinical specialist, anaesthetist, hospital and health insurance fund. Ms Wells notes "That places unreasonable demands on consumers to deal with such complicated matters at a time of high anxiety about a forthcoming operation, if indeed they have the time and ability to do so."
If you want to find out more about the proposal for a MyCover plan, keep an eye on the Consumers Health Forum website www.chf.org.au

Update from Choosing Wisely Campaign

The National Prescribing Service (NPS) is overseeing the national Choosing Wisely campaign. This campaign is running in parallel to the Medicare Benefit Schedule review and co-ordinates clinical specialists reviewing treatment and tests that they routinely offer. Specialists include emergency medicine, intensive care, infectious diseases, allergy and immunology, palliative care, nursing, GPs, pathology, pharmacology, radiology, ophthalmology, physiotherapy, endocrinology and dermatology. Each group of specialists have reviewed test and treatments relevant to their speciality and nominated five items which are at best unnecessary and at worst actually harmful. The 61 tests and treatment (Emergency Medicine highlighted 6 treatments and tests) are as various as end of life care to the prescription of medication to children. Some recommendations seem frighteningly obvious, such one as the palliative care group of specialists note- "To avoid adverse medication interactions and adverse drug events in the case of polypharmacy, do not prescribe medication without undertaking a drug regime review".

Interestingly some recommendations also call for a more consumer centred approach with clearer communication between health care provider and consumer. The importance of discussing goals of care – what is important to the consumer are mentioned by several specialists. While the 61 Recommendations are not in particularly consumer friendly language, at least they are available in the public domain. For more information, visit their website http://www.choosingwisely.org.au/home or contact us on 9221 3422.

Also from the Choosing Wisely Campaign website

5 questions to ask your doctor or other healthcare provider

Some tests, treatments and procedures provide little benefit. And in some cases, they may even cause harm. Use the 5 questions to make sure you end up with the right amount of care — not too much and not too little.

1. Do I really need this test or procedure?
Tests may help you and your doctor or other healthcare provider determine the problem. Procedures may help to treat it.
2. What are the risks?
Will there be side effects? What are the chances of getting results that aren't accurate? Could that lead to more testing or another procedure?
3. Are there simpler, safer options?
Sometimes all you need to do is make lifestyle changes, such as eating healthier foods or exercising more.
4. What happens if I don't do anything?
Ask if your condition might get worse — or better — if you don't have the test or procedure right away.
5. What are the costs?
Costs can be financial, emotional or a cost of your time. Where there is a cost to the community, is the cost reasonable or is there a cheaper alternative?

http://www.choosingwisely.org.au/resources/consumers/5-questions-to-ask-your-doctor

Statewide News

Pip Brennan Executive Director | HCC

Image Source: http://robdose.com.au/wp-content/uploads/2013/04/L1001174.jpg

Health Service Reform

In the last week of March, the new state Ministers for Health and Mental Health were announced. The Honourable John Day will once again take up the health portfolio, while the Honourable Andrea Mitchell will take on the mental health portfolio. She was formerly the Parliamentary Secretary for outgoing Mental Health Minister Helen Morton.

Meanwhile, it has been an interesting time in health, with the impending devolution of the Director General of WA Health's responsibilities to the Area Health Services. As noted in the last Health Matters, the Area Health Services are respectively North Metropolitan, South Metropolitan and the newly formed East Metropolitan, Country Health and Child and Adolescent Health Services. The new Health Services Bill 2016 went to Parliament on 23 February 2016. It names the Director General as the System Manager, while the Area Health Services will be known as Health Service Providers and will be accountable for the delivery of safe, high quality health care in their respective areas. The Area Health Services will have Boards, and the Board members are being recruited currently. The new Boards will come into effect on 1 July 2016, as Interim Boards.

Maternity Services at Bentley Hospital

After hard work from the Bentley Community Advisory Council, Maternity Choices WA and with a little help from the HCC, the previous Minister for Health reversed his decision to close Bentley Maternity services which will remain open for at least the next 2 years.

Clinical Senate Debate – Patient Experience – the Recommendations are in!

In March 2016 the first Clinical Senate debate was on Superbugs. Of keen interest to HCC was finding out which Recommendations from the December 2016 Clinical Senate debate on Patient Experience would be endorsed. The final verdict is as follows:

4 recommendations endorsed

- WA Health should introduce a system-wide, consistently branded 'Patient First' program that drives the patient experience agenda and under which all key patient experience improvement programs are measured, with results publically

available.
- The Senate recommends Chief Executive Officers visibly and actively lead consumer partnership programs and have related Key Performance Indicators (KPIs) in their performance agreement with their boards
- In consultation with consumer and carer peak bodies:
    - A statewide definition of a great patient experience is developed that incorporates a value-based, patient-centered approach. WA Health, as system manager, is to ensure this is adopted by the whole of Health.
    - Patient experience tools are developed or selected for use that reflect the indicators that matter to patients.
- The Senate recommends that a consumer is appointed as a member of the State Health Executive Forum - SHEF (or its equivalent post legislative amendments to create Health Service boards).

5 recommendations endorsed in principle

- The principles of customer service (including empathy and communication) are integrated into mandatory training modules for employees who have direct patient contact. Where possible, this would be embedded into existing training. Consumers and carers are central in the development and delivery of the added elements of the modules.
- WA Health - as system manager - adopts one tool to rate patient experience that is common system-wide to monitor and benchmark for patient experience. The results from the one common tool must be fed back to SHEF, AHS Exec/Boards, individual wards within healthcare facilities and consumers. Feedback should include results from all sites. Consideration should also be given to adopting additional tools for particular subgroups of patients and carers, e.g. CaLD, Aboriginal etc.
- The trial of Patient Opinion be expanded across WA Health (beyond WACHS) to provide a constructive platform for the public and health services to connect to improve quality. In the process: The capacity to collect data into the DATIX Consumer Feedback Module should be explored. Data should be reported at all system levels
- The Clinical Senate recommends prioritisation of a single electronic platform accessible by all area health services that is able to provide information on patient care providers, appointments and clinics, discharge summaries and resources available in the community.
- WA Health explores how to support staff in caring for patients with behaviours that are challenging for healthcare providers and who may be our most vulnerable patients. http://ww2.health.wa.gov.au/Improving-WA-Health/Clinical-Senate-of-Western-Australia/Clinical-Senate-debates-and-publications/2015-Clinical-Senate-debates

March 2016 Clinical Senate Debate – Superbugs

The March Clinical Senate debate had two streams of discussion – over-use of antibiotics and the containment of superbugs. The two issues are inter-connected as the over-use of antibiotics diminishes their effectiveness and is one of the drivers for resistant superbugs. Speakers included WA Health's Dr Paul Armstrong, Dr David Speers from QEII Medical Centre and Dr Owen Robinson from Fiona Stanley Hospital. Visiting from Victoria was Professor Lindsay Grayson, the Director of Infectious Diseases and Microbiology Department at Austin Health. He presented on – "New initiatives that seem to work." His presentation is available as a video on this link: https://www.youtube.com/watch?v=zS9YiYtKlaw

The outcomes of the Recommendations will be presented at the next Clinical Senate Debate, due on 3rd June 2016 on the topic of Research Training and Research.

What is the Clinical Senate?

The Clinical Senate is a forum established in 2003 where collective knowledge on clinical issues can be shared and provided to the Director General and State Health Executive Forum (SHEF). SHEF is a key body, promoting action within WA Health.

The debate involves presentations on the topic of the day, including a consumer presentation, a general discussion of the issues raised, ending with resolutions.

The resolutions from the Clinical Senate Debate are presented to the DG and SHEF for formal adoption and ultimately actioning.

The website notes; "Matters discussed will include the coordination and development of clinical planning clinical and resource decision making; other relevant clinical issues in health service delivery in Western Australia; and issues of key concern to the Director General".

For more information visit:
www.clinicalsenate.health.wa.gov.au/about/index.cfm

Consumer Approach Vs Tuberculosis Control in WA

Majok Wutchok | Consumer Representative | ANUTR | MPH Student

Tuberculosis (TB) is considered the second most killer disease after HIV/AIDS in developing countries. Every year there is a mass movement of Australian's travelling overseas on holiday and returning home. A major concern is there isn't proper health promotion and public health education to protect consumers when they and their relatives return from overseas. Due to the lack of public health education they and their family may not be aware they are coming home infected with a tropical or communicable disease.

I recommend that the WA Health Department set up a consumer overseas travellers screening taskforce, in order to avoid a future catastrophic spread of disease across the state. There is also a need to engage with health care providers to empower consumers who are infected with Tuberculosis and other communicable diseases and to support and empower their community.

The current program, 'Western Australia Tuberculosis Control Program' is administered by the North Metropolitan Area Health Service (NMAHS). However, the program only endeavours to screen and treat the disease once it has been acquired, it does nothing to educate those at risk on prevention methods. 'Western Australia Tuberculosis Control Program' detailed as follows:

'The program manages Tuberculosis in Western Australia and offers a state-wide public health service that operates as a resource centre and clinic. Aspects of the service include:

- *Treatment of Active TB: Diagnosis, treatment and case management*
- *Surveillance and prevention of TB*
  - *Active screening of high risk groups*
  - *Contact tracing*
  - *Diagnosis and treatment of latent TB infection (preventative therapy)*
  - *Tuberculin Skin Test (TST), also known as Mantoux testing and BCG vaccinations to selected populations. Training and accreditation can be provided for relevant health professionals.*
- *Free Health Service: All services related to the diagnosis, treatment of TB and relevant medications are provided at no charge. (See "Fees and charges related to the diagnosis and management of tuberculosis and leprosy" (Operational Directive OD 0229/09))*
- *TB Infection Control*
  - *Advice on pre-employment screening of Health Care Workers and Tertiary Students*
  - *Advice on Management of TB risk in health care settings*
  - *Assistance with contact tracing in health care settings*
- *Hansen's Disease (Leprosy): Outpatient clinic service and consultative advice*
- *Consultation: Specialist advice from medical and nursing staff is readily available, including preventative advice, health service education and access to information programs.*
- *Policy and Operational Directives: Develop, implement and review policy relevant to TB management and control*
- *TB Notification and Enhanced Surveillance data base: Maintenance and reporting on TB epidemiology'*

(http://www.health.wa.gov.au/acc/tb/)

Even in 1918 as far as Tuberculosis was concerned 'Prevention is better than a cure' (Louis Cobbett, British Journal of Tuberculosis, Volume 12, Issue 1, January 1918, Pages 16-19). According to the World Health Organisation (WHO 2014), prevention strategies involve encouraging and conducting research. It has been suggested that integrated intervention programs with consumers and their communities' involved can be very beneficial. As opposed to Vertical programs which are considered limited, integrated programs are considered far more effective for prevention. However, integrated programs need established communication and consistent health education together with consumers' participation across all aspects.

In regard to primary health care and consumers, the involvement of a population group from high-risk consumers is paramount. At the same time public health education and community health promotion are also considered as components, which are associated with continuous use of those preventive measures by the consumer's communities. It is important that sustainable prevention measures are taken to educate those at risk to prevent catching Tuberculosis and other communicable diseases when travelling, rather than simply screening and treating the disease when it has already been contracted.

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>
> Meegan Taylor | Operations Manager, Health Consumers Council ”

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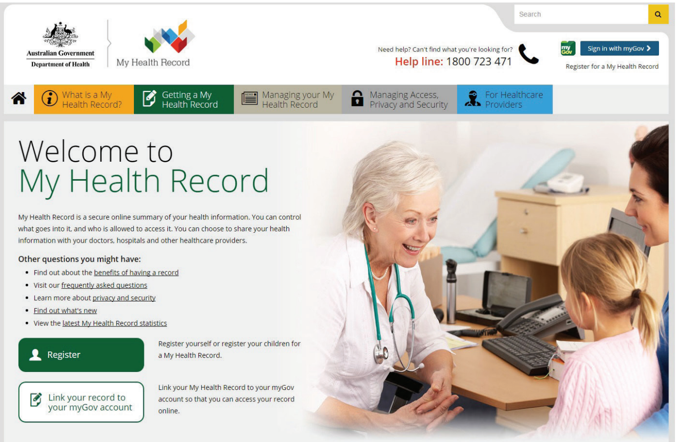
My Health Record: Electronic patient records system, worth getting right

Dr Martin Whitely Advocacy, Policy & Research Manager | HCC



Need help? Can't find what you're looking for?
Help line: 1800 723 471

Register for a My Health Record

Welcome to
My Health Record

My Health Record is a secure online summary of your health information. You can control what goes into it, and who is allowed to access it. You can choose to share your health information with your doctors, hospitals and other healthcare providers.

Other questions you might have:

- Find out about the benefits of having a record
- Visit our frequently asked questions
- Learn more about privacy and security
- Find out what's new
- View the latest My Health Record statistics

Register yourself or register your children for a My Health Record.

Link your My Health Record to your myGov account so that you can access your record online.

Pictured: My Health Record Home Page

Health consumers need their medical history to help them and their treating doctors make better decisions based on the knowledge of what has worked, and what hasn't in the past. They may also need them for a variety of reasons, including making sense of what happened in a critical incident, making complaints, and on very rare occasions to support legal action.

When consumers approach the Health Consumers' Council for assistance, advocates spend a considerable amount of time and energy trying to establish a consumer's medical history. To do this advocates typically assist consumers to access their own patient records via Freedom of Information processes. At least six weeks later the records arrive, and the laborious work of ploughing through piles of documents, with often barely legible handwritten notes, begins. Usually this happens too late to influence treatment.

Without easy access to patient records even conscientious, competent doctors are through no fault of their own are blind to this valuable information. When doctors aren't able to get the full picture consumers often express frustration to HCC advocates that doctors are suggesting the same treatment that failed or caused harm in the past. This can have particularly serious consequences for patients who are temporarily or permanently incapable of expressing their wishes.

It is of particular concern for involuntary mental health patients whose unique knowledge of their own history is too often ignored. Numerous, mental health consumers have complained to HCC advocates that their treating psychiatrist has insisted on them taking a particular antipsychotic or antidepressant when the patient knows there are alternatives they tolerate better.

The potential benefits to consumers, doctors and government of individual electronic patient records are considerable. Immediate access to a patient's full history would allow doctors and patients in collaboration to make better treatment decisions. This can lead to improved health outcomes and reduces the burden on the health system in the long run.

The benefits of real time access to accurate information about a patient's medical history are understood by both sides of politics. Since 2012 the Commonwealth Government's, both Labor and Liberal, have spent approximately $1billion to introduce the Personally Controlled Electronic Health Record (PCEHR), a shared electronic health summary. Initially this pilot program was an opt-in system and take up rates were disappointingly low.

In 2015 PCEHRs were renamed as myHealth records. A more significant change to the pilot program was that it was shifted from an opt-in to an opt-out system. Inevitably this will improve the disappointingly low take up rate, while still respecting the rights of the small number of consumers' likely object to being involved in the system.

The pilot scheme has attracted more than its fair share of criticisms. The Australian Medical Association complained the system was slow and needed modification and there have been isolated privacy breaches. These problems must be fixed before the system is rolled out nationally. Privacy must be 100% secure and if the system isn't easy to use for doctors it won't work for patients. These concerns aside all parties, including the AMA, government and consumer groups, acknowledge the potential for immediate access to suitably protected patient records to be a win-win-win innovation.

If you need to speak to an Advocate, call Health Consumers' Council on (08) 9221 3422 or 1800 620 780 (Freecall country only).

Illuminance Solutions Pty Ltd
Unit 10, Level 3, 440 William St
Perth WA 6000
Ph: (08) 6102 7284
www.illuminancesolutions.com.au

PATIENT EXPERIENCE WEEK EVENT

Illuminance is proud to partner with the Health Consumer Council for Patient Experience Week. This annual event that celebrate accomplishments, honours those who impact patients daily, and reenergises efforts to make the patient experience the best it can be.

We believe Patient Experience is important for the healthcare industry, which is why we – along with our partner, Empower ICT – have chosen to sponsor the event. The event brings the focus back to why patient experience is an important part of patient – and industry professionals – wellbeing, and patient healthcare. The ultimate goal is to improve the health consumer experience, and to continue working together to enhance health services in WA. The event recognises the spectrum of professions that impact patient experience, from nurses and physicians, to admin and government departments. All groups have the opportunity to enhance the patient experience.

ILLUMINANCE SOLUTIONS

Technology is at the heart of every business, in every industry. Illuminance not only develops tailored solutions to fit your business and your industry, but we guide you through the project stages. We are working with companies to change the way we do business, to make them more efficient and productive. As a Microsoft Gold Midmarket Solution Provider, we use the latest technologies to deliver holistic project management.

Since our foundation in 2009, we have established a strong track record of service delivery across a range of industries, including non-profit organizations, mining, finance and investment, and government agencies. Our skills include Project Management, Business Process Mapping, IT Blueprint, Solution Architecture, Cloud Readiness, Cloud Migration, and System Integration.

INTEGRITY

Success will come and go, but integrity is forever. We value your reputation as much as we value our own. Working with respect, honesty and transparency every day ensures we deliver on our promises. We believe that the only way to build a productive, long-term relationship with you is by doing the right thing without compromise.

EXPERTISE

With countless options and solutions in the marketplace, it’s often difficult to determine the best pathway – that’s where we can help. Owned and managed by a technically-astute and certified solutions architect, all members of our team are very talented developers, not accountants nor salespeople. We work with you to define your organisational requirements to meet your business outcomes and then overlay our technical know-how.

PROFESSIONALISM

Recognised and accredited by the Australian Computer Society (ACS), we are committed to stringent ethical standards. We adhere to the professional code of conduct and apply our specialised knowledge for the public good. Our professionalism anchors our commitment to integrity. We are extremely professional and always keep your best interest in mind.

The path to equity in Health Care

Louise Ford Consumer & Community Engagement Manager | HCC

Image Source: http://howarddentalcenter.com/the-path-to-health/

I have taken the liberty of borrowing the title of this article from a recently released report, 'The Path to Justice: Migrant and Refugee Women's Experience of the Courts' (2016) undertaken for the Judicial Council on Cultural Diversity. Within the sixty pages is an in-depth look at the experiences of women from diverse cultural backgrounds when accessing the court system in Australia. The Report is available here: http://www.jccd.org.au/

I wrote this article as I found many aspects of the Report relevant to the same group of people accessing health care in WA and thought it would be useful to identify some of these barriers in Health Matters. Like the courts, health care finds an increasing cultural diversity in the people using its services; this reflects the demographics of WA today. To paraphrase from the Report's Forward, written by The Hon Wayne Martin AC, Chief Justice of Western Australia, "Courts (health services) need to be responsive to these changes. This involves acknowledging and accommodating the different starting places and needs of court (health service) users in order to make the system more accessible and equitable. It is a fundamental principle in Australia that no individual should be disadvantaged in the justice (health) system by reason of their sex, race, religion, language, or national or ethnic origin." The report identifies pre-court barriers on page 7, these have several in common with access to health care e.g.

- *Lack of knowledge of legal rights (health rights)*
- *The importance of integrated support services*
- *The impact of pre-arrival experiences and traumatic backgrounds*
- *Lack of financial independence*
- *The potential cost of some forms of healthcare*
- *I would add that people may also be unfamiliar with the way in which healthcare is provided here e.g. appointment keeping*

Language/communication barriers are also identified in the Report which states *"Language is one of the greatest barriers faced by migrant and refugee women using the court system. Limited English skills impact upon women's ability to engage with the legal system at every stage—dealing with police, engaging support services, completing forms and understanding paperwork, communicating with court staff, participating in court proceedings and understanding court orders. The provision of professional, appropriate and skilled interpreters is crucial if the legal system is to respond to the needs of migrant and refugee women and ensure that they can fully participate in court processes. Despite this, there is serious concern about the provision of interpreters in courts across*

Australia.

The major issues raised were:

- *Lack of clarity about who is responsible for engaging an interpreter;*
- *Failure to assess the need for an interpreter, or incorrectly assessing need;*
- *The skill of interpreters being engaged;*
- *Lack of awareness amongst judicial officers and lawyers about how to work with interpreters;*
- *Engaging interpreters who are inappropriate in the circumstances; and*
- *Unethical and poor professional conduct by interpreters."* (2006, p7)

Similar comments and issues can be made and raised regarding people accessing health care. Some ways of addressing the above were identified as:

- *"Creating procedures and protocols that provide robust guidance to judicial officers and administrative staff;*
- *Building accountability into the system;*
- *Improving data collection and IT systems;*
- *Undertaking regular court user satisfaction surveys – establishing complaints mechanisms;*

The need for a more uniform and systemic approach to the complexity of cultural and linguistic issues in managing access to justice was the strongest theme to emerge from the consultations. A piecemeal approach that neglected the intersection of issues was a particular concern." I consider that most of these issues and comments can be applied quite literally to healthcare.

Recommendations about how to address these areas of concern included:
"The need for a more uniform and systemic approach to the complexity of cultural and linguistic issues in managing access to justice was the strongest theme to emerge from the consultations. A piecemeal approach that neglected the intersection of issues was a particular concern." Furthermore, the Report added that:

- *"All courts should introduce Court Cultural Liaison Officers.*
- *Courts should invest in comprehensive cultural competency training for all court staff.*
- *All judicial officers should receive cultural competency training*
- *Courts should improve signage and information available upon arrival at court.*
- *All courts should have court interpreter policies that are publicly available and easily accessible*
- *Courts should run training sessions on court values and expectations for interpreters.*
- *They should establish a court interpreter's code of conduct and processes to address instances of unprofessional conduct by interpreters.*
- *Judicial officers and lawyers should receive training and guidance about how to work with interpreters."*

Regarding continuing barriers to communication the Report comments that it is imperative to "ensure that interpreters are appropriate for the individual woman, having particular regard to:

- The gender of the interpreter;
- The importance of maintaining confidentiality" (p29)

The use of interpreters in service delivery cannot be underrated yet unfortunately is an often neglected service. Recently, whilst running an information session, I met a young Afghani woman. At the end of the session she spoke with me via an interpreter; she related that she had taken her baby (at the time, 2-3-months old) to her local hospital as the child had a consistently high temperature she could not bring down. She attended the hospital ED three times, each time no interpreter service was used although she requested it; each time she left not knowing what was wrong with her baby or if there was anything more she could do. Luckily the baby recovered, but the young woman asked me if she needed to take her husband to the hospital with her before they would provide interpreter services…my questions are, how would anyone feel if that was their baby? What would have happened if the child had had a seizure or died?

This Report was commissioned by the Judicial Council on Cultural Diversity which "identified the need to develop a national framework aimed at strengthening the capacity of the Australian court system to provide access to justice for women from culturally and linguistically diverse backgrounds, including Aboriginal and Torres Strait Islander women." I believe that such a national framework is equally needed in the health sector.

Would you like to improve engagement with new and emerging communities in your workplace?

Health Consumers' Council's Cultural Competency for the Health Sector Workshop has been designed to assist health workers to gain knowledge and skills to work more effectivly with patients/clients from Culturally and Linguistcally Diverse (CaLD) new and emerging communities.

For more information or call (08) 9221 3422

Aboriginal Advocacy: Tania's patient & carer experience...

Tania Harris Aboriginal Advocate | HCC

Tania Harris joined the Health Consumers' Council in February of this year. Tania is an Aboriginal woman originally from Queensland. Prior to coming to the Health Consumers' Council Tania worked on various Aboriginal programs from ear health to parenting support. She has a special interest in the areas of disability and young people and how their engagement and empowerment in the health system can be supported and encouraged from an early age. Tania is hoping to complete her degree in Sociology next year, and incorporate that learning into new ways to help individual consumers get great outcomes.

You may have seen Tania with Pip Brennan on Channel 7 News on March 30, 2016 regarding the increase in parking costs for parents when Princess Margaret Hospital is moved to the new Perth Children's Hospital. In 2000 Tania's eldest daughter was born with Cerebral Palsy. The following is her patient experience:

Sixteen years ago today our first daughter was born amid a haze of doctors and nurses and neonatal specialists. Her birth day was the first time I had ever been into hospital, first time I had ever had any contact personally with the health system outside of regular GP and dentist visits. Her birth thrust us into a strange new world of hospitals and therapists and disability services, who spoke a language that seemed foreign and did it in places I didn't know existed.

It can be very overwhelming when your child is born with a disability and associated health problems. Often it is the last thing you are expecting when you are waiting for your bundle of joy, and not something anyone seems to raise the possibility of in a very meaningful way. Which is surprising seeing as disability is hardly uncommon. It is estimated that 1 in 5 Australians have a disability, a child is born every 15 hours with Cerebral Palsy and every 2 hours a child is diagnosed with Autism. (www.hwns.com.au/Resource-centre/disability-statistics)

I remember very clearly our daughters first ever outpatients clinic appointment at Princess Margaret Hospital. It was prior to her Cerebral Palsy diagnoses and we were still under a belief that she was just developing slowly but it wasn't really anything to worry about. It was for Neurology and the wait was so long I thought they must have lost our appointment or we had missed her name being called. I learnt fast this was how it was so better bring a book and something for the kid to both eat and do!

There is a lot of things I wish I had done differently, lots of things I wished I had asked, asked again and then asked again. But honestly, in those early years, much of my energy just went in to maintaining positivity, trying not to cry, comforting my distressed child. My saving grace was the wonderful allied health staff who would sometimes come to appointments with me, listened when I couldn't and asked the questions I couldn't get out. Sometimes just having someone there, who was there for me and only me, was enough to get me through another appointment.

In my work as an advocate, I am now in a position where I can be there for people when they feel they need it, just like so many have been there for me in the past. It is such a privilege that people allow me to be there and to be their voice should they be too overwhelmed at that time. There is nothing more personal and emotive than your own or your loved ones health, and I don't think there is a system more confusing for the newcomer. Luckily, we aren't in it alone, and I am very happy to be working for an organisation that seeks to empower and support people on their health journey.

Aboriginal Advocacy Program

Health Consumers' Council can help you navigate the system.

Assists you when making a complaint about your family and community's health services. This free service is available to anyone in WA.

We can help you by:

- Talking through your complaint
- Contacting the service to try and resolve the problem
- Helping you to write a complaint letter

Our Aboriginal staff travel the state to support you having a say about your health services, listen to your experiences and promote your health rights.

Call (08) 9221 3422 for further information.

Involvement in the arts helps prevent mental illness

Frank Smith | Health Matters Contributor

Pictured: Dr Christina Davies

A study at the University of WA has shown that exposure to the arts is good for your mental health. Dr Christina Davies, Research Fellow School of Population Health, found that once a person was involved in at least two hours of arts activity each week there was a clear correlation between time spent and wellbeing as measured by the Warwick-Edinburgh Mental Well-being Scale.

Dr Davies, who has a background in health promotion, said she had identified a gap in wellness research.
"The association between sports involvement and health has been known for 80 years. Now we know that there is also an association between arts involvement and mental health," she said. "There have been qualitative studies since the 1990s but there have been no population studies previously."

The first problem was to tie down the rather fuzzy concept of what is meant by arts involvement. "There was not even a definition of what is 'the arts'. We took the opinions for 280 experts and narrowed their responses down to 15 activities including attending, learning, participating or membership of arts related activities."

Next followed telephone interviews with 700 adults in Western Australia assessing both the time they spent involved in the arts and their mental wellbeing. Over 70 percent of those contacted agreed to participate in the survey, with arts engagements ranging from none to nearly 1600 hours per year.
Dr Davies said difference on the mental health scale between those who had a least two hours a week of arts activity and those who did not was much greater than that needed for statistical significance.

The study used statistical techniques to exclude a wide range of demographic and other variables including education, income, sports and religious activities, health and even whether the respondent had taken a holiday in the past year.

"There was still a relationship between arts involvement and mental well being however we looked at the results. "You get the doubters who say that the difference is because people who are engaged in the arts are richer or because people who are engaged in the arts also do sport, but we can now definitely say that excluding all those things people, who engage in the arts have higher mental well-being scores."

Dr Davies is now planning a larger study of the relationship between arts involvement and health over a long period utilising the Busselton healthy aging study from 1960 to 2020.

She said good mental health was the foundation for individual and community wellbeing, yet every year one in five Australians experience mental illness.

"People need a range of easy enjoyable options they can use to stay well. Depending on a person's interests, the arts can provide a range of health enhancing opportunities, activities and events."
This could include listening to music, reading, colouring, creative writing, watching movies or attending concerts.

"People need to give themselves permission to be creative and to make time for arts activities and events that they enjoy. It need not be expensive. There are free things, events, libraries and arts aps that can be downloaded."

The study was funded by a grant from Healthway and the WA Department of Health and published last month in BMC Public Health.

The Health Consumers' Council is a member of the WA Arts and Health Consortium Reference Group. This Group was created in 2015 to further the implementation of the National Arts and Health Framework to take it from national endorsement to practical action. The current focus of the project is to map what is already happening in arts and health in WA Hospitals and identify best practice as well as note barriers to incorporating the arts into WA Hospitals.

Choosing Wisely Australia & Advance Care Planning

Dr Matthew Anstey Intensive Care Specialist | Advisory Group Member, Choosing Wisely Australia

The second wave of Choosing Wisely Australia was launched last month, an initiative aimed at promoting discussions between patients and their healthcare providers about the treatments and procedures they are offered. 17 of Australia's peak medical colleges, societies and associations have each produced lists of tests, treatments and procedures that they believe are important for healthcare providers and consumers to question. In addition, there is an excellent "cheat sheet" for consumers entitled "Five questions to ask your doctor or healthcare provider", including with "do I really need this test?", "what are the risks?" and "what happens if I don't do anything?"[1]

One of the themes emerging across several of the lists of recommendations was around end of life care planning. The Australasian College of Emergency Medicine suggested that for "patients approaching end of life, ensure clinicians, patients and families have a common understanding of the goals of care". The Society of Palliative Medicine recommends "not (to) delay conversations around prognosis, wishes, values and end of life planning (including advance care planning) in patients with advanced disease". The College of Intensive Care Medicine stated that for patients with limited life expectancy, ensure that they "have a goals of care discussion at or prior to admission to the Intensive Care Unit".

These recommendations emerge from a concern from doctors and patients alike that there is a disconnect between what people say they want, and what they end up receiving at the end of their life. Surveys consistently show that most Australians, if given the choice, would prefer to die at home. However most die in hospital or in residential care (approximately only 14% die at home). I commonly see this paradox play out in my work in the Intensive Care Unit. There are two main types of patients who are admitted to the Intensive Care Unit. Some ICU admissions are unexpected, following accidents or sudden onset of illness. However there are also a significant number of patients for whom the exact timing of admission is unexpected, while the fact that they are eventually admitted is not. These people have significant underlying health issues, such as metastatic cancer, advanced heart, lung, kidney or liver failure. And unfortunately, when these people become so sick they are unable to express their wishes, we rely on their family members to guide us about those wishes. For those families who have had discussions with their loved one, and know what they would want, this is an easy discussion. When a family member says "my mum always wanted....", it becomes much easier for us to advise an appropriate medical course of action. Unfortunately, the majority have not had these conversations and then everyone involved has to guess. Furthermore, there are increasingly more and more "things" that medicine can do, but without a frank discussion of their benefits and risks, it can mean what is right for the patient can be forgotten.

One solution to these issues is advance care planning. Advance care planning is about having conversations between a person, their family members and their doctor(s), about what matters to them in the event that they are dying or incapacitated and unable to make decisions. Advance care planning starts with conversations, and in an ideal world, ends in a written document outlining these wishes (either an advance care directive, or nominating a person to act on their behalf through an enduring power of guardianship).[2] Recognising that the uptake of "advance care directives" has been slow, a new strategy is to initiate these discussions in patients that we would not be surprised if they had a significant deterioration in their health in the short-medium term (such as patients with metastatic cancer, advanced heart, lung, renal or liver failure). The "surprise" question is a direct but honest question that doctors use to identify patients appropriate for having an advance care planning discussion, "would you (the doctor) be surprised if this person died within the next 12 months?" In line with the Choosing Wisely campaign, patients themselves should feel empowered to have these conversations. At the other end of life, birth plans and discussions are commonplace. Conversations about death are just as important.

[1] For more information about Choosing Wisely and questions to ask your doctor, go to: www.choosingwisely.org.au

[2] For more information about Advance Care Planning in Western Australia, visit http://healthywa.wa.gov.au/Articles/A_E/Advance-care-planning

People don’t want the Australian way of death

Frank Smith | Health Matters Contributor

Pictured: Professor Hal Swerissen
Image Source: http://www.murrayphn.org.au/professor-hal-swerissen

We are all going to die, but not all deaths are equal. Most Australians with a terminal illness want to die at home, yet only 14 per cent do so, according to a new Grattan Institute report.

The report Dying Well shows that dying in Australia is more institutionalised than in most other countries in the world. In spite of their wishes, about half of Australians die in hospital and a third in residential care.

Medical and community attitudes plus a shortage of funds for home-based care mean that Australians die at home at half the rate that people do in New Zealand, the United States, Ireland and France.

The report, written by Professor Hal Swerissen and Stephen Duckett urges changes in health care policy and attitudes to enable more people to die comfortably at home and in home-like environments, surrounded by family, friends and effective services.
“More than at any time in history, most people die when they are old, and are more likely than past generations to know when in the near future they are going to die,” says report co-author, Professor Swerissen.

“That gives us a great opportunity to help people plan to die well – but we’re not taking it.”

Most people do not speak up about the way they would like to die. As a result they often experience a disconnected, confusing and distressing array of services, interventions and relationships with health professionals.

The report recommends more public discussion, including an education campaign, about the limits of health care as death approaches and the need to focus on end-of-life care.

It also calls for greater investment in community-based care to enable services for those dying of chronic illness to shift their focus from cures, that are unlikely to eventuate and institutional care to supporting people’s wishes to die at home.
It also proposes the widespread adoption of advance care plans. That allows people to choose what intervention is permitted when they are close to death.

About $5 billion is spent annually on the last year of life of older people, but only $100 million is spent on helping people die at home.

The reports claims that doubling the number of people who die at home will cost $237 million a year. But the cost to the taxpayer will be unchanged because it will release a similar amount of money by reducing the demand for aged care accommodation, hospices and hospitals.

Professor Swerissen says the issue is often clouded by the voluntary euthanasia debate. But even in countries where these are allowed voluntary euthanasia and assisted suicide are rare.

He said this report is about ensuring that when death inevitably comes for each of us, we die comfortably, in surroundings we would choose.

“The baby boomers are growing old and in the next 25 years the number of Australians who die each year will double.

“We need the courage to promote a national discussion about a subject that we might dislike but cannot avoid,” said Professor Swerissen.

Your medical records... Is there really Freedom of Information?

Lucy Palermo Marketing & Communications Coordinator / Health Matters Editor | HCC

Accessing your own health information should be relatively straight forward, but time and time again Health Consumers' Council receives calls from consumers who are having problems accessing their medical records or a deceased family members records. Under the *Freedom of Information Act 1992* you can access your WA Health medical records, but only if they are held by a public health service.

The following briefly outlines the current procedure for retrieving your health records:

What is Freedom of Information (FOI)?

The Freedom of Information (FOI) Act 1992 gives you the right to apply for access to documents held by a (WA) Health Service. Your right to apply is not affected by why you want to obtain access.

How do I request information?

In accordance with the Freedom of Information Act 1992, applications must:

- be in writing (email and facsimile are acceptable)
- give enough information to enable the requested documents to be identified (e.g. full patient name including previous names if applicable and date of birth; date of attendance and service unit)
- give an address in Australia where notices under this Act can be sent
- if possible, include a day-time telephone contact number
- give any other information or details required under the regulations
- be lodged at an office of the agency with any application fee payable under the regulations
- be accompanied by a consent form, if applicable, that is dated within 12 months of the request for information
- for personal applications, copies of two forms of proof of identification e.g. drivers' licence, Medicare card etc (one with a current signature).

How can I request information for someone else?

In addition to providing a valid application, additional consent and/or supporting documentation is required when requesting information on behalf of others, or about others. You will need to provide their written permission. However if the person is deceased, you must provide your identification, and supporting documentation that clearly shows you are the closest relative to that person e.g. birth certificate, marriage certificate or death certificate. If you are not the closest relative, you must provide written authorisation from the closest relative permitting you to access the information.

What information can't be released?

Some documents fall under exemptions and cannot be released, e.g. if they compromise someone else's privacy or commercial or business affairs. Access may be provided to an edited copy of the document if it contains information considered to be exempt.

When will I get a decision?

Upon receipt of a valid application the agency has a maximum of 45 calendar days to make a decision regarding access. The notice of decision will include details such as:

- the date when the decision was made
- the name and the title of the person who made the decision
- the reasons for claiming the document is exempt if access is refused
- information on the rights of review and the procedures to be followed to exercise those rights.

How do I amend my personal information?

If you believe your personal information held by the Health Service is inaccurate, incomplete, out-of-date or misleading, you may apply to have that information amended.

Your request must be in writing, and must provide as much information and supporting information as possible to demonstrate how or why the records are considered to be inaccurate, incomplete, out-of-date or misleading. The onus to prove this lies with the applicant, not the Health Service.

If your request for amendment is refused you will be informed of the reasons for the decision and also the process to request an internal review.

(Source: www.ahs.health.wa.gov.au/For-patients-and-visitors/Freedom-of-Information)

The introduction of My Health Record should alleviate some issues related to accessing your health records. If you are currently having issues accessing your patient records, contact Health Consumers' Council on (08) 9221 33422.

Finding new uses for old drugs

Frank Smith | Health Matters Contributor

Pictured: Dr Nikolajs Zeps

Drug discovery is a long and expensive process littered with failures. However, if a drug is already approved and in use for treating one condition and can be repurposed to treat another disease, much time and effort can be saved.

Dr Nikolajs Zeps of St John of God Subiaco hospital has been working with an international project to map the whole genome (all the DNA) of pancreatic and several other cancers in the hope of finding targets for better drug treatment.
The Garvin Institute in Sydney is the Australian participant in the International Cancer Genome Consortium (ICGC), which brings together the world's leading cancer scientists to identify the genetic drivers behind more than 50 different cancer types.

Australian scientists plan to map the genomes of cancers from over 10,000 patients. Dr Zeps' team has recruited 90 patients from WA and sent their cancers for sequencing of their cancer genome so far. The parent project has sequenced pancreatic cancers from 350 patients over the five years of the project.

"It is an exciting project. The ICGC have sequenced pancreas, colon, breast, lung and up to 30 different cancer types so far," he said. "Pancreatic cancer is one of the most difficult to treat as it often metastases (spreads) to other organs before it is diagnosed. "Once this happens surgery is impossible. It is also resistant to treatment and chemotherapy has had only slight success.

"Fewer then 10 per cent of patients survive more than two years." Moreover, it is one of the few cancers for which survival has not improved substantially over the past 40 years and it is the fourth-leading cause of cancer death. Research so far has shown that there are at least four subtypes of pancreatic cancer with different chromosome structures.

Together with their partners, the Institute of Molecular Bioscience in Queensland, the Garvin group has identified novel genes in pancreatic cancer that control growth factors, including one that is involved in nerve development. This is a possible drug target which if controlled would prevent spread of the cancer, he said.

In addition, Herceptin, a drug used to treat breast cancer may also be useful for a sub-set of pancreatic cancers as the over-expressed growth gene in targets is also seen in many cancers arising in the pancreas.

The altered genome of pancreatic cancer shares similarities with the genome of other cancers meaning that treatments may soon be directed by genetics and not by the organ of origin.
The ICGC in Australia also looked at ovarian cancer, another highly resistant disease. It is hoped that information from both studies may identify drugs that work in one that also have an effect on the other.

Dr Zeps said part of the project was to improve communication between researchers by publishing on-going information on a website. In that way other researchers can access it and conduct their own analysis. This will maximise the impact of research world wide, not only in Western Australia.

The ICGC members include Baylor College of Medicine and The Methodist Hospital Research Institute in Texas, the Ontario Institute for Cancer Research, Johns Hopkins University in Maryland, the University of California San Francisco, the University of Verona Italy, the Cambridge Research Institute and the Sanger Centre in the UK.

The Australian participation in the ICGC project is being funded through $27.5 million grant from the National Health and Medical Research Council of Australia (NH&MRC), its largest-ever single grant so far.

EMER: How consumers & clinicians can improve patient experiences in Hospital Emergency Departments

Lucy Palermo Marketing & Communications Coordinator / Health Matters Editor | HCC

Welcome to the Emergency Medicine Events Register (EMER)

EMER is an adverse event and near-miss reporting system that is peer-led, online, anonymous and confidential. It is a means of supporting improvement in safety and quality in emergency medicine by understanding of contributing factors and how the risk of harm to patients can be minimised or prevented.

For more information please click here to watch the EMER video "Learning from our errors - Emergency Medicine Events Register".

The EMER is supported by ACEM and managed by the **Australian Patient Safety Foundation (APSF)**. The College encourages members to enter incidents to the database. CPD points can be claimed for reports submitted.

Pictured: Emergency Medicines Events Register Home Page

'1 in 10 diagnoses made by a doctor, is thought to be incorrect. It is estimated that each year in Australia 8,000 patients die from medical error. 300,000 hospital admissions are associated with potentially preventable adverse events'. (www.emer.org.au) The Emergency Medicine Events Register otherwise known as EMER, was developed so that consumers and clinicians could report adverse incidents. To allow clinicians to learn from their mistakes and create an open culture of discussing patient safety.

Speaking at 'Organisational Approaches to Implementing Patient Experience: Lunch Box Session' from EMER are Anita Deakin and Dr Carmel Crock (Royal Victorian Eye and Ear Hospital & ACEM). 'EMER is an adverse event and near-miss reporting system that is peer-led, online, anonymous and confidential. It is a means of supporting improvement in safety and quality in emergency medicine by understanding of contributing factors and how the risk of harm to patients can be minimised or prevented.' (emer.org.au)

An important factor to practice improvement in the Emergency Department (ED) requires hearing about the care experiences of patients and their family member or carer. Their experience and perspective (whether it be good or bad) is a key aspect to ensuring patient safety and high quality care in all areas of health care. It is important that health care staff are able to learn from consumer's experiences to ensure they are providing the best quality of safe health care.

The Following Is An Interview With Anita Deakin And Dr Carmel Crock:

Why did EMER consider consumer reporting?

Patients have a very different perspective to medical professionals – they see things that we don't necessarily see and they are an essential part of the team. The patient voice is extremely important and has often been overlooked in patient safety endeavors.

What involvement did consumers have in developing EMER?

From the inception of EMER we have had a consumer advocate on the Steering Group. Every step of the way we have considered how EMER could benefit consumers and how best we could engage them in the process. When we decided to introduce a consumer portal into EMER we involved consumers in developing the content and in testing it.

How does EMER improve patient experiences?

We are hoping it will improve patient experience by changing the culture of emergency medicine to openly discuss patient safety concerns within the specialty. We want to hear the patient's voice.

Once the data has been collected, compiled and analysed, are the findings conveyed to the health services to facilitate system change in health care?

Once the data has been collected, compiled and analysed the findings are fed back to the specialty so that trainees and specialists get to hear about the types of incidents that are occurring in Emergency Departments. Some of the ways that we provide feedback is by writing patient safety alerts, journal articles and conference presentations both nationally and internationally.

If so what mechanism is used to facilitate system improvements?

We look for patterns or "common themes" within the incidents reported and feed this information back to the Australasian College for Emergency Medicine (ACEM) that is responsible for training emergency medicine specialists. In this way the college is able to address these themes in their education and training.

Why is it important that consumers report these adverse incidents and what benefit they get by reporting them? Why did EMER think it was important to include consumers in the reporting of incidents? I understand that this is revolutionary and that nothing similar is being conducted elsewhere.

It is important for consumers to report adverse events so that system changes can be made to make Emergency Departments safer for all involved. Often consumers see things that clinicians aren't aware of, or see it from a different perspective. The consumer and the clinicians are both essential team members in the patient safety quest.

The EMER model works in the following way:

Identify – Report – Improve

Identify Risks To Patient Safety

The types of errors that EMER want reported into the system are any incident in the emergency department that either did cause harm or could have caused harm to a patient. This would include things such as diagnostic error, errors around procedures, medication error, errors around clinical handover and safe transfer of patients from the emergency department.

EMER records the serious incidents, but also near misses, good saves, and adverse events. Collecting near misses is very important because for every adverse event there are 10 near misses.

EMER want Emergency doctors and nurses to discuss error openly, they want them to think about patient safety, to think about how things could be done better. To discuss incidents with their supervisors, with medical students, with nurses, to create an open culture of discussing patient safety and error.

Report – Report Adverse Events And Near Misses

The anonymous online system is easy to use and only requires five minutes to enter the incident. Everyone involved with the incident from the consumer to the clinician are able to enter the information required.

When the information is collected it is classified using the Advanced Incident Management System (AIMS), a tool that was used to develop the international classification for patient safety.

Improve – Inform Clinical Practice And System Change

EMER provide immediate feedback to those who report an incident. Once they have read the report it takes them to a thank you page which provide information about the incident which includes a simple graphical representation of the data. It also includes an incident of the month, which provides users an example of what other people are reporting and information that is of interest to the research team.

Once the incidents have been classified using the Advanced Incident Management System (AIMS), specialists from multi-disciplinary groups then review the incidents to determine how they could have been prevented.
Source: www.emer.org.au

At the time of publishing this article Anita Deakin and Dr Carmel Crock from EMER were due to present at the session 'Organisational Approaches to Implementing Patient Experience: Lunch Box Session' on Thursday April 28, 2016. Sponsored by Illuminance Solutions and Empower ICT.

This article first appears as a post on the Health Consumers' Council Blog.

HEALTH CONSUMERS'
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