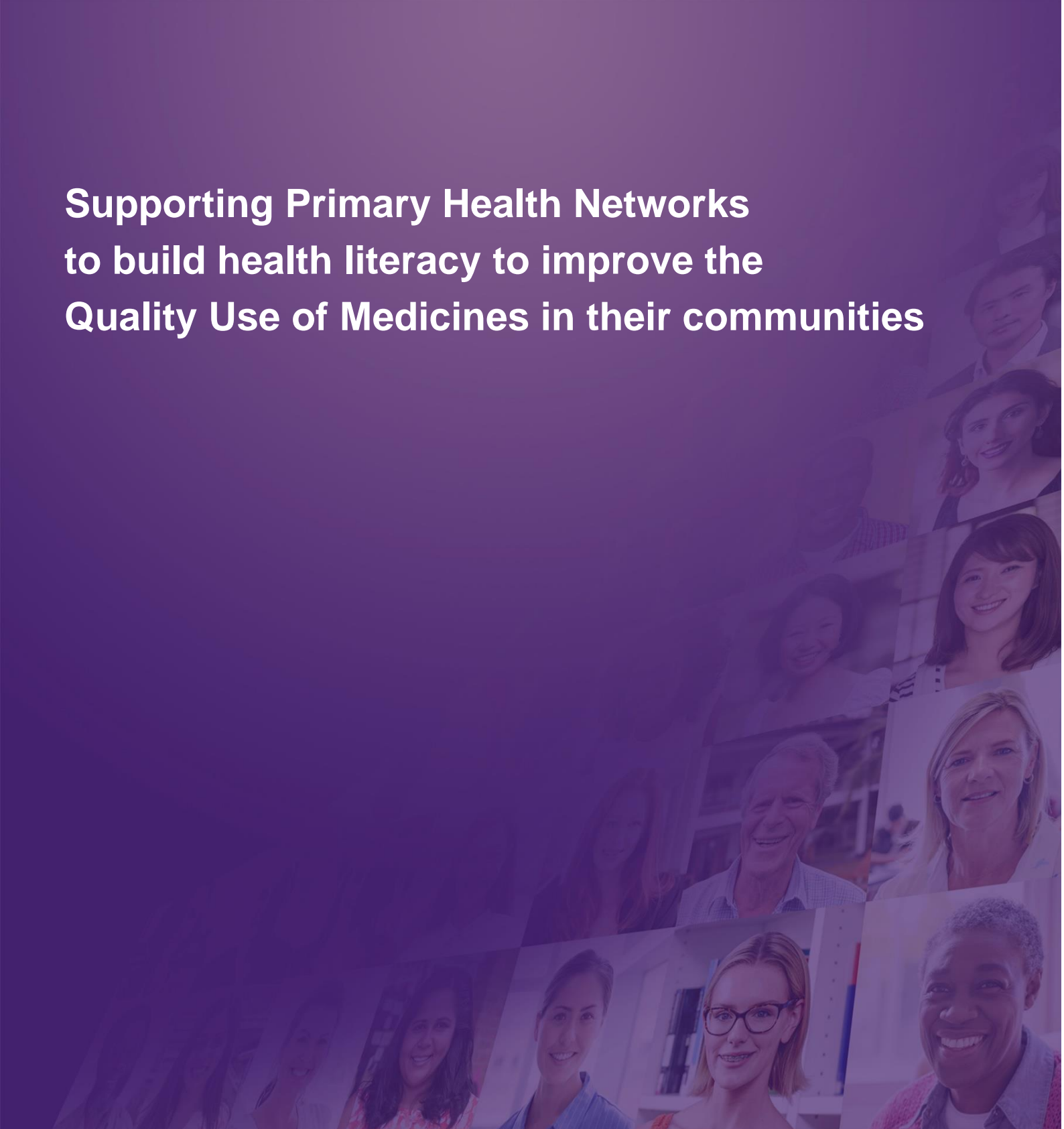


Supporting Primary Health Networks to build health literacy to improve the Quality Use of Medicines in their communities



RESEARCH REPORT
DR PENELOPE BERGEN

Contents

Research summary	4
Key recommendations	4
Practical next steps for PHNs	5
Short-term	7
Medium-term	8
Longer-term.....	8
Introduction.....	8
What is health literacy?	9
What is QUM?	9
Roles and responsibilities	9
Consumer responsibility	10
Health provider responsibility	10
Methodology	11
Research limitations	11
PHN Staff Feedback	12
Consumer Feedback.....	12
Clinician Feedback.....	13
Findings.....	13
PHN Staff Feedback	13
Existing Tools for PHNs	14
QUM	15
Pathways of care.....	17
Collaborations	18
Funding and priorities.....	19
Summary	20
1 <i>Policy/strategic</i>	20
2 <i>Practice: The everyday tools and culture of primary care;</i>	20
3 <i>QUM</i>	20
Consumer Feedback.....	20
The barriers to improving health literacy around medicines	20
 RESEARCH REPORT	
DR PENELOPE BERGEN	
The overall culture needs to change	21
Overcoming barriers to improving QUM literacy in communities	22
Summary	23
1 <i>Models of care:</i>	23
2 <i>Culture shift:</i>	24

3	Tools:.....	24
	Clinician Feedback.....	24
	People don't want to look like bad patients (in front of the doctor)	24
	There's only so much we can do.....	25
	Systems can fail us	25
	Solutions.....	26
	Summary	28
	1) People don't want to look like bad patients (in front of the doctor)	28
	2) There's only so much we can do.....	28
	3) Systems can fail us (clinicians and patients)	28
	4) Solutions.....	28
	Recommendations	29
	What does government and/or the health sector need to do?	29
	How can PHNs be supported?	30
	How can PHNs support GPs and other health professionals?	30
	How can PHNs, GPs and other health professionals support consumers?.....	30
	Rural and remote needs.....	30
	Next Steps.....	31
	Conclusion.....	33
	Appendix 1 <i>Rapid desktop review</i>	35
	Appendix 2 <i>Findings—complete data</i>	38
	Presentation of comments	38
	PHN Staff Feedback	38
	Existing Tools for PHNs	39
	QUM	40
	Collaborations	41
	Funding and priorities.....	41
	Consumer Feedback.....	42
	Barriers to improving health literacy around medicines	42
	Current service models are not working.....	42
	The overall culture needs to change	43
	Overcoming barriers to improving QUM literacy in communities	45
	Basic information must be easily accessible.....	45
	Clinician Feedback.....	47
	People don't want to look like bad patients (in front of the doctor)	47
	There's only so much we can do.....	49
	Systems can fail us	51
	Solutions.....	54

Research summary

The aim of this research was to outline a set of agreed responses to facilitate the sharing of information and further improvements for PHNs to deliver against their health literacy objectives.

This project explores the responses of nominated staff at Primary Health Networks (PHNs), consumers and clinicians across Australia between June and September 2021, to identify gaps and recommend strategies to improve health literacy generally, and health literacy as it relates to the quality use of medicines (QUM). It does this by analysing interviews with PHN staff, consumers and clinicians and by framing those responses within the broader context of the work of PHNs.

While this project aimed to focus on health literacy as it relates to QUM, three distinct levels of action were identified that reflected all the participant comments and analysis of the data. The three levels include the development of a practical national health literacy framework, which aligns with the recommendations in the Draft National Preventive Health Strategy¹ and the Mitchell Institute's Self-care for health: a national policy blueprint². The ultimate focus is around instigating a cultural change by developing health literacy in the environment and increasing individual health literacy for consumers.

The work undertaken by PHNs around health literacy and QUM literacy is varied, multi-level and contextual and yet the findings are clear: Some PHNs see health literacy as integral to everything they do; some see it as separate to the core work that they prioritise in their region, which for some, involves dealing with responses to natural disasters; all recognise the complexity of health literacy and QUM literacy delivery in varied forms and in varied and complex communities. There is also recognition across the board that there are "never enough" resources to be able to take all the actions they would like to be able to take.

The core aim of this research was to support PHNs to build health literacy to improve the quality use of medicines in their communities. The following recommendations incorporate that aim, the findings of this research, and as many varied options as the findings of this research could accommodate for all PHNs to be able to find something that they could immediately adapt or utilise where needs apply, aligning with two core levels of individual and environmental health literacy, and:

- the National Safety and Quality Health Service (NSQHS) standards and the Australian Commission on Safety and Quality in Health Care (ACSQHC) guidelines and their definition of health literacy
- environmental health literacy including system-based policies and processes as described in the findings by PHN staff and clinicians to cover their existing needs and their desires for change
- individual health literacy: the needs of consumers as individuals, navigating a complex system that is difficult to understand.

Key recommendations

To set a strong foundation for ongoing work, and to support and enable PHNs to develop health literacy to improve QUM in their communities, the 'Practical next steps for PHNs' section lays out what could be achievable in the short, medium and long-term according to the data in this research. These practical strategies are aimed to strengthen health literacy at the organisation level and the consumer level by developing communication between health providers and consumers, reiterated in the systems-based approaches outlined in the National Strategy for Quality Use of Medicines,³ and support providers who work in the general practice setting to adopt a greater focus on health literacy as it relates to QUM.⁴ Lastly, these steps include the development practical tools as a part of that strategy, to increase and improve individual health literacy and health literacy as it relates to QUM.⁵

One underlying message is that all communications in health, from the policy level to the relationships between primary health clinicians and patients, to the daily needs of people as consumers, is that written health information must meet health literacy standards and guidelines re readability and actionability. Still far too much information is written beyond the capability of most consumers, whether it be Consumer Medicine Information leaflets, the language used by GPs or pharmacists, understanding a prescription, a policy, a medicine label or a press release: health communication must be strengthened and improved.

The following recommendations are further explained and outlined in the 'Practical next steps for PHNs' section below.

What does government and/or the health sector need to do?

- Develop, implement, and mandate a set of national indicators for QUM for care outside Australian Hospitals, in the community. This includes continuity of care when patients are discharged from hospital, and community care and aged care; integrate these indicators into other existing data sets, for example, the Australian Government's Practice Incentives Program (PIP) Quality Improvement (QI) Incentive
- development of a national, coordinated health literacy framework and strategy (in line with the recommendation in the draft [National Preventive Health Strategy](#)) that adheres to NSQHS standards and ACSQHC guidelines. This could be done by ACSQHC in conjunction with NPS MedicineWise, CHF and consumers
- support and invest in bolstering the health workforce in regional, rural, and remote areas. Suggestions include developing frameworks for providing social support in rural and remote areas for clinicians on placements; increase rural doctor, nurse practitioner and other health support worker placements; streamline the process for providing opportunities for overseas-trained doctors in rural and remote.
- health education modules to be developed and included in curricula for primary and secondary schools across states and territories (with NPS MedicineWise and appropriate state and national health and education agencies)
- aligning with the key recommendations of the foundations for primary health care reform in the Department of Health's Primary Health Care 10-year plan 2022-2023,⁶ support the development of voluntary patient registration with a general practice for people with complex medications and/or complex conditions to develop and invest in continuity of care, minimise medicine misadventure and increase QUM and develop a communication strategy for patients regarding the benefits of voluntary patient registration for QUM and health outcomes.

How can PHNs be supported?

- Develop a strategy for implementation: policy/executive level, dedicated long-term funding for PHNs to work in the general practice and pharmacy spaces; and specific QUM inclusions within that health literacy space
- to adhere to NSQHS standards and ACSQHC guidelines, the easiest and most accessible way to increase health literacy in health consumers is for health literacy to underpin every program. Key purpose funding is a determining factor for the work that many PHNs do in relation to health literacy and health literacy as it relates to QUM. General Practices, practice nurses, pharmacists, allied health, and other health professionals working in the community require dedicated health literacy resources at their fingertips to build health literacy and health literacy as it relates to QUM. This cannot be supported by short-term solutions. PHNs must be supported and rewarded for improving health literacy responsiveness of their services and health literacy as it relates to QUM with dedicated, long-term funding, investment and measurables (this includes practical support for PHNs to define health literacy; provide QUM toolkits; national QUM community care indicators; practical tools for general practice, and evaluation options for shorter-term and longitudinal projects.

¹ Australian Government, Department of Health, *Consultation paper: Development of the National Preventive Health Strategy*.

² Nichols, T., Calder, R., Morgan, M., Lawn, S., Beauchamp, A., Trezona, A., Byambasuren, O., Bowman, J., Clinton-McHarg, T., Willis, K. and Kearns, R., 2020. *Self-care for health: a national policy blueprint*: Policy paper 2020-01.

³ Commonwealth of Australia, Department of Health, 2002, *National Strategy for Quality Use of Medicines*.

⁴ Commonwealth of Australia, Australian Institute of Health and Welfare, 2020, *Australia's Health 2020: Health Literacy* <https://bit.ly/3Dg00YE> viewed 11 August, 2021.

⁵ Consumers Health Forum of Australia for NPS MedicineWise, 2020, *Consumer Health Literacy segmentation and activation research project*, pp32-34.

⁶ Australian Government, Department of Health, *Consultation Draft, Future focused primary health care: Australia's primary health care 10 Year Plan 2022-2023*. <https://bit.ly/3AQjhcJ> viewed 10 August 2021.

How can PHNs support GPs and other health professionals?

- Within a practical-level health literacy framework, embed health literacy and health literacy as it relates to QUM as a core function of general practice and pharmacy. This may be through models of care such as non-dispensing pharmacists working with patients and advising GPs on QUM in the general practice setting, noting that some PHNs have already seen the benefit of investing in this
- further development of practical and adaptable packages or toolkits for QUM that could be used with or within existing PHN tools (*Sharepoint, HealthPathways, GoShare/Healthily* and/or other community directories) and/or can be adapted to other online software used by individual PHNs as they provide practice support services to GPs in their clinical work settings including desk-top tools and resources. Starting with *HealthPathways* is suggested given it is widespread in PHNs.
- dedicated QUM training via Continuing Professional Development (CPD) for primary health clinicians more generally
- develop, promote and deliver CPD education and training for GPs and other members of the primary care team in QUM ensuring they are linked to current CPD requirements. Clinical audit and PDSA tools could be included
- clinician feedback showed that they are keen for more small-scale funding to be available for individual practices to run localised projects for health literacy as it relates to QUM. As well as continued support for these programs there needs to be more data and evaluation of these projects to be able to push for long-term funding to be made available to integrate the projects that work for positive change.

How can PHNs, GPs and other health professionals support consumers?

- Both clinicians and consumers are keen to see the development of education packages starting with children learning to understand communication about their health and medicines in primary school, following on to taking more responsibility and understanding the healthcare system in high school.
- there were also suggestions for practical tools, electronic systems and training for clinicians that can change the culture of primary health care and the relationship between consumers and primary health clinicians
- create structured, localised pathways of care within *HealthPathways*, aiming for that information to be accessible to patients/consumers. This is critical for consumers' involvement and informed consent.
- develop and introduce consumer peer education modules in QUM that local consumer educators could be trained to deliver.

Rural and remote needs

- More support workers are needed: Aboriginal Health Workers and Health Practitioners, nurse practitioners, nurses, rural and remote pharmacists
- Support and training for Aboriginal Health Practitioners, Aboriginal Health Workers and Remote Area Nurses regarding communications about QUM in remote Aboriginal and Torres Strait Islander communities
- Decrease the barriers to hiring overseas-trained doctors specifically for rural and remote area
- Pharmacists could also play a bigger role in providing information about services and care pathways; provide place-appropriate training for pharmacists to take on a broader role
- Develop the role of pharmacy and other support workers as adjuncts in general practice in rural and remote areas. This could decrease the number of people ending up in crisis care including hospitals in cities
- expand embedded pharmacists in primary health care services to Aboriginal Community Controlled Health Services (ACCHS) to assist in addressing issues in remote areas
- consider other access options tele-pharmacy services for remote health services- though only when supported by on the ground staff, including Aboriginal Health Practitioners

- Increase localised pathways to care in rural and remote areas; interconnected services by including or increasing social prescribing and awareness of services in specific catchment areas via *HealthPathways*
- funding needs to be equitably applied, recognising that it costs more to deliver services in remote areas
- reconsider funding models for remote area dialysis units: recent changes to pharmacy support staff have resulted in some remote dialysis units being without pharmacy support for patients taking multiple medicines daily. Remote communities already have extremely low numbers of pharmacists. If pharmacists cannot be hired, investing in Aboriginal health workers, and providing QUM training must be considered as an alternative. While funding for more on-community pharmacists in remote Aboriginal and Torres Strait Islander communities would be ideal, any resources that can support the development of the capacity of nurses in remote communities regarding health literacy as it relates to the QUM could be useful.

Practical next steps for PHNs

The following is a summary of some practical steps that can be taken by PHNs with the support of NPS MedicineWise, in line with the overall research recommendations. These suggestions are examples of PHN and community-level steps that emerged from all the discussions and feedback provided to this research.

These suggestions align with, and will drive the uptake of, the ACSQHC National Safety and Quality Primary and Community Healthcare Standards. The following shorter-term activities contribute to the three core standards: Partnering with Consumers; Clinical Safety, and Clinical Governance.

Short-term

.Partnering with Consumers Standard

- To benefit cultural change and the development of tools and resources from direct community feedback: Identify and develop consumer engagement champions who can serve as role models and mentors for health literacy and QUM literacy in your communities, particularly looking at diversity and patient segments most in need. Consumer champions contribute to individual health literacy by having direct contact and engagement with their networks and communities. They also contribute to the health literacy environment by nature of their inclusion in organisational feedback and strategic planning
- to expand the health literacy environment, develop orientation packs for PHN consumer advisory groups to support them to work effectively with their PHN and for their communities. Again, this could be a collaboration with NPS Medicine Wise and/or the Consumers Health Forum (CHF), utilising existing tools adapted for region-specific use
- Taking advantage of opportunities created by this research report and the development of relationships with contributing PHNs, to link with one or more PHNs on small, short projects on topics of local importance, as instructed by individual PHN needs. Begin embedding the call to reduce the on-size-fits-all approach, contribute to local, short projects, and develop QUM and health literacy tools that are needed in specific PHN catchment areas. Depending on the needs of the community, this is an open invitation to increase individual and/or environmental health literacy.

Clinical Safety Standard

- Run webinars on building health literacy to improve the quality use of medicines in communities, for PHNs, designed for collaboration and showcasing successes and/or looking for solutions to challenges in health literacy. This would encourage collaboration with other PHNs; or it could be aimed at the level of bringing GPs and pharmacists together, depending on local needs. Collaboration of this nature will benefit PHNs by: sharing successes in QUM tool development; cultural change between clinicians; and potential change in sharing successes at the strategic level. Overall, it will contribute to the health literacy environment.

Clinical Governance Standard

- Contribute to the health literacy environment providing staff with training (that may not be in the scope of regularly-funded staff training) in how to work with consumer advisory groups and/or other consumer feedback channels. This could be done in collaboration with CHF and NPS MedicineWise. Re-packaging

existing resources can be done relatively easily and quickly to provide immediate cultural within PHNs, and for clinicians who rely on consumer advisory groups for general practice feedback.

Medium-term

Clinical Safety Standard and Partnering with Consumers Standard

- Develop individual health literacy with the development of locally adapted resources according to local needs: for example, developing webster packs with symbols and language relevant to the dominant language and/or ethnic groups in your area; printing notepads, business cards, fridge magnets with links to reliable websites for medicine information such as the Health Direct website, NPS MedicineWise *MedicinesLine* or *5 Questions to ask your Doctor/5 Questions to ask about your medicines* etc.; short, plain English Consumer Medicines Information sheets (CMIs) for the area's most commonly prescribed medicines. This will benefit QUM tool development, and a cultural change between consumer and clinician. In the longer-term, this could benefit the general improvement in health literacy and medicine-related harm
- more specific work on reviewing what QUM content and prompts could be integrated into *HealthPathways* (which is in common use across most PHNs) as recommended in the draft 10-year Primary Health Care plan regarding the implementation of consumer-facing regional health literacy approaches.⁷

Clinical Safety Standard

- Develop short online learning modules for PHN staff in health literacy and QUM literacy. This could be done in collaboration with NPS MedicineWise, and/or local primary care clinicians. The benefit in doing this is in cultural change in parallel with policy change at the PHN level. It will help build an awareness of health literacy at the PHN staff level and aligns with a health literacy inclusion in a PHN charter.

Clinical Governance Standard

- Work towards developing the health literacy environment with structures and systems to support a health literacy framework beginning with embedding health literacy and/or QUM literacy strategies in core activities, ensuring that services that are commissioned build the health literacy of consumers. This will benefit policy level, PHN level, clinician level and consumer-level needs around increasing QUM and health literacy.
- develop evaluation tools for PHNs to gauge health literacy and QUM in communities. This could also be done in collaboration with NPS MedicineWise, utilising and adapting existing tools for region-specific use. This will help to clarify the goals of health literacy inclusion at the strategic level. This in turn will benefit staff, clinicians and consumers by setting clear aims, goals and standards at every level.

Longer-term

Clinical Safety Standard and Partnering with Consumers Standard

- Education program development in collaboration with national and state-based health and education agencies. For example, a pilot school-term project for age-based curricula development, in collaboration with NPS MedicineWise, CHF consumers, and a school in your area, incorporating specific health literacy and QUM literacy-related components to existing curricula.
 - primary school and/secondary school curricula
 - encouraging collaboration and communication via professional communications training for GPs, pharmacists and other primary health carers. Bringing GPs and pharmacists together for relationships building was a key suggestion by clinicians.

School education programs will benefit consumers by contributing to improvements in individual health literacy and QUM literacy; clinicians and their relationships with each other which in turn will also benefit consumers and the ultimate goal, which is quality care; Education programs must include evaluation which will also strengthen the aims and goals of health literacy education.

Introduction

The context for this research takes into account existing strategies, programs and research on health literacy, including the National Strategy for the Quality Use of Medicines, the National Medicines Policy, the National Strategy for Quality Use of Medicines, the Draft Preventive Health Strategy, the Australian Commission on Safety and Quality in Health Care (ACSQHC) *National Statement on Health Literacy*, Australia's Primary Health Care 10 Year Plan 2022-2023, the Australian Institute of Health and Welfare (AIHW) *Australia's Health: Health Literacy 2020*, and the Royal Australian College of General Practitioners' (RACGP) Quality Improvement and Continuing Professional Development (QI&CPD) Program.

The aim of this research is to explore the role of PHNs in supporting improvements in health literacy and the Quality Use of Medicines (QUM) as it relates to health literacy: identifying existing work, gaps, and opportunities; and to deliver a set of health literacy and QUM goals and/or strategies.

What is health literacy?

Health literacy relates to how people access, understand, and use health information in ways that benefit their health. People with low health literacy are at higher risk of worse health outcomes and poorer health behaviours.⁸

Health literacy has two main components:

- Individual health literacy—these are individual skills, such as the ability to find, understand and use health information; for example, to complete health care forms or understand and use the health care system.
- The health literacy environment—these are the health system-based elements, such as policies, processes, and materials, which affect the way the individual engages with the health system.⁹



Figure 1: The two components of health literacy¹

What is QUM?

QUM sits within the health literacy sphere. Ultimately, it is about selecting and using the right medicines in the right doses at the right times. It is about recognising that there may be better ways than medicines to manage health problems; choosing medicine to suit the individual, taking into account their condition, risks and benefits, dosage, length of treatment, out of pocket cost, other existing conditions; using medicines safely and effectively by monitoring side effects, usage, outcomes and how they work with other medicines.¹⁰ QUM is a central objective of the National Medicines Policy.

Roles and responsibilities

According to the Australian Commission on Safety and Quality in Health Care (ACSQHC) those responsible for addressing health literacy are:

- consumers

⁸ Commonwealth of Australia, Australian Institute of Health and Welfare, 2020, *Australia's Health 2020: Health Literacy* <https://bit.ly/3Dg0OYE> viewed 11 August, 2021.

⁹ Australian Commission on Safety and Quality in Healthcare, 2014, *National Statement on health literacy: Taking action to improve safety and quality*, p. 1, <https://bit.ly/2UaJR0V> viewed 11 August, 2021.

¹⁰ Commonwealth of Australia, Department of Health, 2002, *National Strategy for the Quality Use of Medicines* <https://bit.ly/2Yvps8U>, Viewed 11 August 2021.

- consumer organisations and other support services
- healthcare providers
- organisations that provide or support healthcare services at a local level
- organisations that support healthcare providers and workers
- government organisations
- regulators and bodies that advise on or set health and education policy
- private organisations that provide health-based goods and services.

Healthcare organisations and support services can:

- develop and implement health literacy policies and processes that aim to reduce the health literacy demands of information materials, the physical environment and local care pathways
- provide and support access to health literacy and interpersonal communication training for healthcare providers, including training in communicating risk
- provide education programs for consumers aimed at developing health knowledge and skills.¹¹

Consumer responsibility

Health provider responsibility

<ul style="list-style-type: none"> ■ discuss any difficulties they might have in understanding health and information with healthcare providers ■ ask for further information about any aspect of their care 	<ul style="list-style-type: none"> ■ assume that most people will have difficulty understanding and applying complex health information and concepts ■ encourage people to speak up if they have difficulty understanding the information provided
<ul style="list-style-type: none"> ■ discuss difficulties in communicating with healthcare providers, ask family to help, or request support services such as qualified interpreters or consumer advocates ■ be open and honest with staff and provide details of medical history and medicines that they are taking 	<ul style="list-style-type: none"> ■ recognise the needs and preferences of individual consumers and tailor their communication style to the person's situation ■ use a range of interpersonal communication strategies to confirm information has been delivered and received effectively ■ use ways of communicating risk information about treatment options to people that are known to be effective
<ul style="list-style-type: none"> ■ improve their individual knowledge and skills by participating in education 	<ul style="list-style-type: none"> ■ participate in improvement projects aimed at reducing barriers to health literacy within the healthcare organisation's physical environment.¹²
<ul style="list-style-type: none"> ■ raise awareness in their community about the importance of health literacy ■ be involved in the development and review of consumer information and resources ■ be involved in the planning, design and delivery of policies, strategies and projects to reduce barriers to health literacy.¹³ 	

¹¹ ACSQHC, 2014, p.62, <https://bit.ly/3m0qPpA> viewed 13 August 2021

¹² Australian Commission on Safety and Quality in Health Care, 2014, *Health Literacy: Taking action to improve safety and quality*, p. 61, <https://bit.ly/3m0qPpA> viewed 12 August 2021

¹³ ACSQHC, 2014, p.58, <https://bit.ly/3m0qPpA> viewed 13 August 2021

Methodology

The basic tenets of the methodology used for this project are based on Constructivist Grounded Theory (CGT) Methodology¹⁴ which sits in the qualitative interpretivist paradigm¹⁵. The methods of Constructivist Grounded Theory were chosen as the interpretivist axiology is designed for small-scale studies and fits perfectly with small, in-depth qualitative studies, to allow for theories to arise after engaging with the data. While this research does not need to go to the theoretical level, the methodology allows for in vivo coding of data such as transcribed interviews and other written responses, sorted into categories which form key themes. Each stage of the data gathering (interviews, written responses, and feedback forums) was conducted to build on gaps or explore themes in the previously collected data; and each sector interviewed (PHN staff, consumers, and clinicians) followed the basic tenets of CGT, building a rich description from which a set of core themes emerged.

The research was overseen by a steering group selected from PHN staff and clinicians who accepted nomination by the PHN Cooperative Executive Office and a consumer representative from the CHF Safety and Quality Special Interest Group. The group met in May 2021 prior to the start of the research. The first stage of data collection was a rapid desktop review of PHNs and their work supporting health literacy and QUM literacy (see Appendix). The desktop review also looked at the best ways in which data could be collected for this research. The steering group met for a second time in June to discuss the desktop review and the next steps for the research. The response from the steering group was to focus the research strategy on what PHNs and communities needed rather than conducting a uniform survey.

The second stage of the research then involved interviews with PHN staff, as nominated by their CEOs. These interviews were drafted as a report which was sent to all participants for their feedback and/or clarification. Two participants responded. One had no comments and was happy with the representation of the responses in the report. The other had some minor feedback, which was incorporated. The draft report of the PHN staff interviews was tabled with the steering group. The group met again in August 2021 to discuss this first draft. The steering group's advice was to then get feedback from consumer and clinician groups. Four consumer groups and two clinicians' groups provided feedback which was incorporated into the first draft of the research report. This draft was tabled with the steering group in early October 2021, with the next meeting in October.

Research limitations

Initially, the 31 PHNs were contacted directly by the PHNs' Executive Officer regarding a request for a 45-minute-to-one-hour interview. The timing of the research was such that a lot of PHN CEOs or other representatives were not available and the response was slow due to a number of factors such as COVID-19 vaccine rollouts; end of financial year and ongoing disaster responses (drought, bushfire, floods).

On the advice of the PHN Cooperative Executive Office, a sample of 15 (almost half) of the total number of PHNs were selected to cover each state and territory, and a cross-section of metropolitan, provincial, rural, and remote populations. Of the 15 selected, a total of six PHNs responded. Of those six, two provided two staff members together in the same interview resulting in a total of eight individuals taking part in six interviews. They each fulfill various roles (see above), forming a broad picture of PHN needs and activities.

¹⁴ Bryant, A & Charmaz, K 2007, 'Grounded Theory in historical perspective: an epistemological account' in Bryant, A & Charmaz, K (eds.), *The Sage handbook of grounded theory*, Sage Publications.

¹⁵ Denzin, NK & Lincoln, YS 2011, *The Sage handbook of qualitative research*, Sage Publications.

PHN Staff Feedback

From the initial review, four key questions emerged to be put to PHN staff. Semi-structured interviews explored four key questions. Those questions were recommendations from the report that came from the initial rapid desktop review:

- What are you doing regarding health literacy and the quality use of medicines?
- What difficulties/gaps have you found?
- What do you need to move forward in this space?
- How do you share positive results/findings with other PHNs?

The interviews were with a diverse set of participants from various roles across the PHNs, allowing for a broad range of issues and themes to be discussed within those four basic questions. Questions were posed around health literacy and health literacy as it relates to QUM, giving the participants the option to frame their understanding of either or both according to their existing organisation operations.

The research design was based on examining and analysing the narratives of eight PHN members of staff from the six PHNs willing and available to take part. They represented the following PHNs:

- Primary Health Tasmania – Manager for Sector Improvement and Innovation
- North Queensland Primary Health Network - Executive Director
- Darling Downs and West Moreton PHN - GP Liaison Officer
- Northern Territory PHN - Chief Executive Officer and Manager for System Integration
- Coordinare: South Eastern NSW PHN – Director of Consumer Participation
- Capital Health Network – Senior Manager for Primary Care Programs and Senior Manager for Health System Improvement

This list covers the full diverse range of demographics in Australia. The regions covered include the following number of Australian Electoral Commission's demographic electoral boundaries:

- 10 rural
- 5 provincial
- 4 remote
- 3 inner metropolitan
- 1 outer metropolitan

Consumer Feedback

Several consumer groups were consulted:

- Community Advisory Group for the NT PHN
- ACT PHN Consumer Advisory Council.
- NPS MedicineWise Consumer Advisory Group (CAG)
- CHF Safety and Quality Special Interest Group (SIG)

The groups featured consumers from around the country, from varied cultural backgrounds and professions. The length of the meetings and the manner in which the responses were recorded were left to the meeting facilitators according to their needs.

The groups were sent the draft report following the PHN staff interviews and presented with a PowerPoint outlining the research aims and why we were seeking feedback for this project. Two core questions were asked:

- What do you think are the barriers to improving health literacy around medicines?
- How do you think we can overcome those barriers?

One group provided summarised notes, another was recorded and transcribed; the two other groups involved note taking and recording for transcription where possible.

Clinician Feedback

Due to the ongoing time constraints and pressures faced by clinicians, and that of PHN staff in organising out-of-session feedback forums, a two-pronged approach was taken to organise clinician feedback:

- An expression of Interest was sent to all 31 PHN CEOs, seeking clinicians from a variety of professions and geographical locations including rural and remote
- To broaden the scope of the focus group, clinicians from the Royal Australian College of General Practitioners (RACGP) were contacted via the chair of the RACGP quality committee.

A total of 10 clinicians sent in expressions of interest to attend the meeting. They included the following professions: GP, clinical pharmacist, community pharmacist, nurse practitioners, nurse, geriatrician, and primary carers with other specialties such as practice manager, social worker.

Of the ten, four clinicians attended the focus group: two pharmacists, a nurse, and a GP. Feedback was also provided in a separate one-on-one meeting with a GP, and written feedback was provided by three other clinicians: a nurse practitioner and two pharmacists.

Findings

PHN Staff Feedback

The responses in the findings are organised according to the groups providing feedback. This first set of findings is from the interviews conducted with PHN staff. They show that health literacy and health literacy as it relates to QUM are generally considered as separate from each other, and/or that QUM is considered a specific subset of health literacy. They are therefore presented in the findings as such, as two separate themes. The complete data set can be found in Appendix 2.

“We need a national framework for health literacy delivery”

The first and most striking response from the PHN staff interviewed was that they all spoke about the lack of a health literacy definition, the lack of a workable national framework (which may include adaptable tools for general practice delivery) and the resulting difficulty in evaluating any programs or changes in consumer or general practice behaviours. This set of concerns was succinctly summarised in the following comment:

“Unless there’s a national coordination strategy—and maybe this is the opportunity around this—because I think there needs to be a national project coordination strategy...And then from that, we nuance it to each of the specific regions that may have specific requirements.”

The responses described having a health literacy framework as something would provide consistency in a common approach. It would help guide standards, good governance, and evaluation.

The call for a national framework for health literacy aligns with existing recommendations in the Draft National Preventive Health Strategy,¹⁶ the Mitchell Institute's *Self-care for health: a national policy blueprint*¹⁷, and recommendations emerging in the government's 10-year Primary Health Care Reform.¹⁸

Existing Tools for PHNs

Within the unanimous call for a national framework around the delivery of health literacy-related programs, was a subset category about the tools currently being used by the participating PHNs. The participants for this research were asked about tools they needed and given examples of existing and suggested tools in the question list sent to them prior to the interviews. Their responses overwhelmingly focused on existing tools already in use.

HealthPathways

There is "a major focus on *HealthPathways*". *HealthPathways* is a free, web-based portal with evidence-based information on the assessment and management of common clinical conditions, including referral guidance. The pathways are written by general practitioners with support from local GPs, hospital-based specialists, and other subject matter experts. The portal provides access to pathways for clinical management and referral advice into local health services. By using this information, clinicians are equipped to make informed decisions about patient treatment. *HealthPathways* are designed to be quick and simple to use including information on: management and treatment options for clinical conditions; educational resources for patients; referral information for local services and specialists. *HealthPathways* was mentioned by all participants.

Considering that most PHNs already use *HealthPathways*, it can be utilised further as a unified approach to developing health literacy and QUM:

"We have HealthPathways...and while HealthPathways is a clinician decision tool, within HealthPathways you can access health literacy tools, you can then print and give to your patient. But again, you've got 31 PHNs individually funding all of this. And I think we need to have some collective approach so that we're, you know, all like-for-like across the nation..."

GoShare

Half the participants mentioned using or wanting to use *Healthily* [GoShare]. *GoShare* is a customisable content distribution platform, which enables the efficient and measurable sharing of health resources, tailored to patients' information needs. Based on current evidence, *GoShare*'s digital content bundles aim to improve patient self-efficacy and self-management behaviours, and empower people to play a more active role in their healthcare. *GoShare* is used to complement telephone and face-to-face interactions. Scheduling functionality enables tailored content to be sent automatically over a defined period of time, providing a highly scalable approach to patient education. *GoShare* Healthcare includes access to thousands of information sheets maintained by industry partners, access to videos and links to credible websites, apps, and other tools.

Trialling "off-the-shelf digital solutions" such as *Healthily*'s *GoShare* is one way that curated information is helping GPs have conversations with their patients about the quality use of medicines. None of the participants spoke of needing more such software. They did, however, speak about curated pathways of care that can already be added to *HealthPathways* and *GoShare*. [See the *Pathways of Care* section in this document.]

¹⁶ Department of Health. Consultation paper: Development of the National Preventive Health Strategy. Australian Government

¹⁷ Nichols, T., Calder, R., Morgan, M., Lawn, S., Beauchamp, A., Trezona, A., Byambasuren, O., Bowman, J., Clinton-McHarg, T., Willis, K. and Kearns, R., 2020. *Self-care for health: a national policy blueprint*: Policy paper 2020-01.

¹⁸ Commonwealth of Australia, Department of Health, 2021, Primary Health Care Reform, [Draft recommendations from the Primary Health Reform Steering Group](#)

Other digital solutions

PHNs will also use other software that fits within the scope of that used by their partners and collaborations. This includes state or territory health departments, the Commonwealth Government, and local general practices.

The general consensus about the PHN *Sharepoint* site was that it is useful for some working groups and that it was used more when the PHNs were first being set up. But for general sharing of information, there was no great desire or urgent need in any of the interviews for this to change.

QUM

Discussions around QUM resulted in the emergence of two key themes that were separate to the overarching notion of health literacy as it relates to QUM, but which would ultimately contribute to the development of health literacy as it relates to QUM:

- The lack of a framework for QUM outside Australian Hospitals. This includes community care, transitions between hospital and community or other care, and in aged care
- The under-utilisation of pharmacists in QUM. Embedding pharmacists in either general practice and/or within PHNs was mentioned by all participants as having been successful and something that should continue and/or be re-introduced.

QUM indicators

ACSQHC developed set of *National Indicators for Quality Use of Medicines (QUM) in Australian Hospitals 2014* which support the measurement of safety and quality of medicines use for quality improvement purposes, and to help health services to drive changes in healthcare practice. The indicators have been designed for local use in hospitals and on discharge from hospitals. PHN staff were unable to name a set of national indicators in place specifically for QUM in community care or, for QUM in aged care. There is a National Aged Care Mandatory Quality Indicator Program which collects data every three months but not specifically on medicines; and the Aged Care Quality Standards, which does not include QUM. Neither of these standards set professional indicators around the highest users of medicines in the general population in community care.

- In 2020, a set of indicators to measure health literacy and awareness of QUM in consumers was developed and published in the [Consumer Segmentation Research Report](#) in 2021 by CHF for NPS MedicineWise. These indicators could be utilised in a national quality improvement framework in line with the Australian Government's Practice Incentives Program (PIP) Quality Improvement (QI) Incentive.

Education programs for consumers

Keeping the focus on the consumer perspective is also a priority when considering QUM:

“When I hear the term quality use of medicines, it makes me think that there should be a packaged product, a program...Some kind of stepped education approach, and I know that that sort of is—NPS MedicineWise was well known for doing that for providers—but what I'm wondering is, where's the mirror image package for consumers that could help people step through their own understanding of their own medication? So the quality use of medicines from a consumer perspective, not from a provider [perspective]...I'd like to see that.”

All participants were also asked whether or not the development of a set of 5 *Questions to ask about medicines/your pharmacist*, specific to medicines, such as those developed by the Institute for Safe Medication Practices Canada,

and along the lines of the *Choosing Wisely 5 Questions to ask your doctor*, would be considered and/or would be a useful tool for PHNs. All agreed that the more practical tools that were available, the better.

Remote Indigenous communities dispense medicines directly from community health clinics, which have their own pharmacies. The dispensing is usually done by nurses. Of 80 remote communities, only three have a part-time, on-community pharmacist:

“Some of them get a visiting pharmacist, maybe once every three months and that's usually through a QUM-type program.”

While funding for more on-community pharmacists in remote Aboriginal and Torres Strait Islander communities would be ideal, any resources that can support the development of the capacity of nurses in remote communities regarding health literacy as it relates to the QUM could be useful.

General practice constraints

Within these discussions around QUM was discussion about relationships with GPs. Responses were mixed. Three found the relationship with general practice challenging, although working online due to COVID-19 restrictions has opened other, less confrontational avenues, for relationship building:

“It's probably rather difficult at times to get more in the non-contractual services aka general practice, pharmacy etc. because they are driven by other incentives I guess than maybe our commissioned or commonwealth or state funded services that have a contract in place... So we try to drip feed information into that space rather than like a more methodologically sounds approach.”

“...and everyone's got to remember, these are small businesses. They are not public servants. They are not state-run. They are small businesses.”

“I think it is difficult to access GPs and especially I think COVID's added an extra little barrier. What we've done and I suppose the plus side of that is that we've done a lot of online education.”

A key problem for some general practices, particularly in rural and remote areas is, not having the workforce or, more specifically, difficulty in hiring overseas or overseas-trained doctors:

“Certainly in rural areas GPs are not short of patients. They're booked out for four to six weeks in advance. They've got real workforce issues. Time is critical. So even if they would spend more time with their patients to describe, you know, to really drill down into how to better manage your medication, or use their practice staff to do that, time is just such a priority for them. They don't have capacity is the issue, which is why we went to pharmacy in the practice as a an adjunct and a support structure which was embraced.”

“We've hit crisis point...one of our rural areas, and I'm out a lot, and...people are screaming. The practices are screaming, they're wanting us to help...an intern at the hospital gets a provider number and they might only work a couple of days in general practice and we're very concerned that gets counted but all of those interns doing registrar program and that different Fellowship Pathways, we've got Canadian students, quite a few here who are Australian-trained, Queensland-trained doctors, who are doing their registration internship. We can employ them because...they can...And overseas trained doctor...they're not these residents so we can't employ them...So they're trying to employ them, they want to stay and we need them, but because of the DPA classification, you can't employ them because they're considered a foreign person.”

Discussions around working for or with GPs was around existing programs that are currently being trialled or that are working well:

“...we really we have been looking at doing joint sessions for RACF clinicians and anyone and GPs working in that space and quality use of medicine has been part of that curriculum.”

Relationships with general practice are further complicated by GP relationships with, and attitudes towards, pharmacies:

“GPs and pharmacists adversarial all the time. Yep just absolutely does my head in. I just want them to all behave and do what they're really good at. And a general practice is really heartfelt when they say we really need them to be doing the quality use of medicines...and education and health literacy when we're prescribing because they're the experts...GPs, you know they can be quite nasty about each other and GPs call pharmacists pariahs...and that they'd upsell their mother for a dollar, and what they mean by upselling is you're getting your antibiotics and they're selling you probiotics at the same time. Okay, I'm on antibiotics...you need Vitamin C. You know, when a lot of what they're upselling doesn't have an evidence base to support it so and doctors get a little huffy about that.”

These relationships and limitations place a line down the middle of health literacy and QUM, with health literacy sitting with general practice and QUM with pharmacists. PHNs stated that embedding pharmacists within general practice has worked well and would continue to be of great benefit. Maintaining pharmacy roles within PHNs is also of great benefit, they said.

Pathways of care

The lack of service mapping, which would contribute to a much more effective set of *HealthPathways* for consumers was the third key theme of the interviews.

“The thing that we’ve had the most difficulty with is service mapping, understanding what is out there. And this is not a lack of services. So actually the service exists, you just don’t know about it. People think that there isn’t a GP or pharmacist or allied health or whatever but there is one, you just don’t know about it. People often work together or with the same person but don’t know each other exists.”

HealthPathways is a tool that all participants mentioned using and several suggested it would be useful for developing clear pathways of care by service mapping. It was suggested by several participants that *HealthPathways* could “pull all those bits and pieces together” and be used nationally as a repository of quality-assured health literacy tools that can be adapted to regional use. Ultimately this is “about pathways of care for people”.

The lack of local support and/or the lack of knowledge about local support in rural and remote areas means more people end up in crisis care, in hospitals, or having to travel to cities instead of getting the help they need locally.

“The vehicle that we use for health literacy predominantly to General Practitioners is HealthPathways. We actually invest quite a lot into HealthPathways as the PHN. And we certainly see value in using it with not just awareness about health, but awareness about interconnected services. We’re currently working on a social prescription health pathway, and that was based on a need”

For some areas, it was suggested that pharmacists could also play a bigger role in providing information about services and care pathways:

“Because they’re accessible, they are everywhere, they’re in rural and [some] remote communities and they don’t cost anything, so we have been doing some work around suicide prevention with pharmacists and making sure that they know how to ask the questions...So we see pharmacies more and more to play a role on the primary care space in the absence I guess of many services, especially in that space so again, anything that helps consumers to ask the right questions or pharmacists to ask the right questions, we would definitely be supporting.”

Collaborations

All the participants spoke of valuing relationships and partnerships with other PHNs, whether state-based or interstate. Exchanging and “bouncing ideas” and being part of a “broader network” provided support and solutions. One example is a health literacy collaboration using hospital data:

“There’s a really successful one that you probably do want to know about...in the [our] region...we developed a bit of a model of care...[it’s] called the Easy Model, it’s based on five Ps, we call it Public, Private, Primary Care, Patients and Peaks... So I’ll tell you about the asthma project...the Breathe Easy project—so they’re all got an ‘easy’ in them—so it’s

breathe easy. The point of intervention was an ED...We worked with the hospital data. What the brilliant young nurse navigator did: He got every asthma device...and [he got] every single one of them QR coded...and it would tell you all about what that was and how you used it and you could watch a short video on how to use it. Now, people have become very au fait with QR coding since covid. Why I say this [a short video] is so important...one lady...was pressing [her inhaler] in the air in her room at night, not in the mouth. Then one guy placed the whole thing [the inhaler]...in his mouth and pressed twice...And that is just really poor health literacy.”

These relationships are also either supported or facilitated by tools such as *HealthPathways*, the annual commissioning conference and other specialist group meetings that occur on a regular basis.

Each PHN also has various levels of collaborations with other organisations in their region, depending on what is available and what is needed. This includes historic relationships with each other from a time prior to PHNs, when they were called Medicare Locals. Some have relationships with the health department, hospitals, social services, local consumer groups, pharmacies and/or general practice.

“If we know somebody has commissioned a service or he's active in the space, then we will seek out, you know, support within the network. I think it's, it could be strengthened, but not without resourcing it. Okay. I mean, we're not in competition with each other we're supportive.”

While there is collaboration between PHNs where relevant and at various levels, most PHNs would be happy for more collaborations or discussions, but do not have the time or resources for more engagement beyond that in which they are already engaged.

“It would be nice to do more collaboration but more collaboration also asks you to do more time and there is often again, if you get other PHNs together, unless it's target conversation that has real purpose and real aim, it's often a waste of time.”

Funding and priorities

There were two key messages around funding that emerged in these interviews:

- The nature of funding for PHNs being tied to key purposes is a determining factor for many of the PHNs as to what can be done, by whom, and for how long when it comes to Health Literacy and QUM
- The capacity and resources to fund specific projects may well be there, but priorities for the PHNs lie with the more urgent needs of the communities they serve.
- These were grouped together because the majority of participants discussed the two as going hand-in-hand: we have the funding, but no drivers/we have the funding but it's not a priority, “piecemeal funding” is an issue—but there is always a disclaimer. The complexities around priorities for Commonwealth funding and its priorities, coupled with the broader context for each PHN and their individual priorities, makes the entire situation changeable and, to some extent, difficult to navigate.

- Some PHNs are making it their business to “develop the skills of health workers within our networks to improve communication with consumers” as well as “...ensuring the services we commission build the health literacy of consumers”.

“We’re working towards developing structures and systems to support a health literacy framework beginning with embedding health literacy in strategies in our core activities”

Summary

Three distinct levels of action were identified in the interviews with PHN staff, all of which would sit under the first of those identified actions: the development of a practical national health literacy framework, in line with the recommendation in the draft National Preventive Health Strategy. The three actions also include practical tools as a part of that strategy, to increase and improve health literacy and health literacy as it relates to QUM:

- 1 **Policy/strategic:** a national health literacy framework, in line with the recommendation in the draft National Preventive Health Strategy, to include dedicated funding for PHNs to support the development and delivery of: more developed pathways of care; national QUM community care indicators
- 2 **Practice: The everyday tools and culture of primary care;** practical tools for general practice to include health literacy tools; evaluation tools; QUM tools (such as 5 Questions to ask about your medicines); more and region-specific pathways of care
- 3 **QUM:** embedding pharmacists in general practice; provision of toolkits; training packages in health literacy as it relates to QUM.

Consumer Feedback

While all the consumer feedback agreed that consumers have to step up and be more responsible, it was also recognised that a lot of people do not know how, do not feel confident, or feel they do not have permission to do so.

Patients also sit within a cultural power structure that makes it uncomfortable for them to know how or what to ask in the space of a short consult with a clinician. Even for consumers who do not want to know more about their health or medical care, the option must be there for them to be part of the discussion and part of the decision making.

Consumers noted that without these discussions there can be no genuine consent on the part of patients. And those conversations start with the general practitioner.

The barriers to improving health literacy around medicines

“Sometimes the misuse of medicines is because people can't afford to buy medicine at the right time, like, people do not have money.”

Current service models are not working

According to the consumer discussions, the dissatisfaction with service models in general practice, pharmacy, and the funding model for PHNs, was described as preventing transparency, resulting in a culture that is mired in limitations and confusion for consumers, and lacking long-term vision. The comments from consumers listed below outline four key ways this plays out. This includes perceived complexities around MBS funding for GPs and preventing the inclusion of health literacy and QUM literacy due to limits on time and a perceived focus on business rather than patient care. While the message was that conversations around medicines must start with the doctor, there appears to be an overall preference, currently, to speak with pharmacists. The consumers also discussed gaps within these models that result in access difficulties for many consumers. Access in general is described as problematic for many consumers in many difficult situations and, ultimately, leaves health literacy and QUM.

“The free translator service is rarely utilised for those who do not speak English well enough to understand QUM: translator services are too limited (often too slow) and not utilised, leaving many without adequate information”

The four topics of discussion that the consumer groups highlighted are described here as:

- The overarching fee-for-service model is problematic
- The lack of visibility around GP funding, MBS numbers and how GP remuneration works, and privacy issues around personal details and personal medical histories worried consumers and leave them with a feeling of distrust of general practice
- The pharmacy model undermines QUM
- Community pharmacies selling ‘complementary therapies’, ‘alternative medicines’ and health supplements which can have contraindications for prescription medicines was the core of this message. It leads to a feeling of distrust of the motivations of pharmacists and a lack of clarity or oversight as to how and where pharmacists sit within the health system.
- The project-based funding model for PHNs prevents long-term investment
- Prescriptive funding limits long-term projects and evaluation of improvements in health literacy and QUM literacy outcomes. Funding for health literacy/QUM literacy should be part of a national framework for PHNs
- Access is an issue
- Access includes: the cost of medicines; the absence or lack of choice of pharmacists in rural and remote areas; telehealth is not available for all and can be unreliable and difficult to manage when it comes to e-scripts.

The overall culture needs to change

Every group had something to say about the overall culture of primary health care which results in a power imbalance between clinician and consumer/patient. The culture that sets up that power imbalance was described in four key ways: the relationship between primary health clinicians and patients/consumers; the relationships between GPs and pharmacists; the relationships between hospital and primary care, and lastly, the responsibility of the consumer to contribute to changing their own behaviours.

Where discussions around the relationship between GPs and pharmacists occurred, they were impassioned. There was a consensus across the consumer groups that the GP/pharmacist relationship is fraught. This prevents good, clear communication and therefore optimal care re QUM literacy and health literacy for the consumer. Also, the responsibilities after discharge from hospital are described as often not clear or transparent for the consumer which can hinder QUM. While there was discussion about consumers needing to ‘step up’ and be more active, the overall perception in the feedback was that the power—and therefore the responsibility and starting point for change—sits with the GPs and pharmacists.

“One of the challenges for consumers/carers is the assumption that care is integrated and most is not.”

“If we learned anything out of the royal commission into child sexual abuse is that we shouldn't put particular professions on pedestals. And we continue still with medical staff.”

- The power imbalance and information asymmetry between GPs and consumers/patients
- Conversations about health invariably start with a GP. However, people still put doctors on pedestals, and doctors are in a position of power, having medical knowledge that general consumers do not. This power imbalance means doctors need to be aware of that and must invite patients to feel confident enough to ask questions and expect to get answers and support. Doctors know how the health system works. Consumers do not
- The relationship between GPs and pharmacists is affecting patients and QUM
- The main message here was that pharmacists and GPs need to be providing consistent messages and working together for the benefit of patients. How many GPs have a personal relationship with the pharmacists in their area? Pharmacists are the more accessible to consumers so provide more advice to consumers. Doctors need to be more approachable
- Communication between hospitals and primary care
- The lack of coordination between hospitals/specialists and primary carers is troubling for consumers. There needs to be more clarity around who communicates what; who consumers can contact for information when in between hospital care and community care. The communication between primary health care and the hospital/acute care landscape is problematic for consumers who can end up with mixed messages, mixed medicines, no idea who to speak to, no idea who is right if all the clinicians involved are not providing the same message. Consumers don't know how the health system works. Clinicians do. They have the power in this relationship and they must provide clear instructions and clear communications
- Consumers need to step up
- The other extreme is that clinicians in the health service can't know what you needs and wants are if consumers are not telling them so. People must be encouraged to speak up and ask questions. The problem is that a lot of people are happy not to know, or don't want to know or don't care enough to ask or be involved in their own health care.

Overcoming barriers to improving QUM literacy in communities

Basic information must be easily accessible

While the responses to the two core questions asked of consumers were often conveyed within one answer, or within one discussion, a lot of the problems that may have been framed as a negative were in fact key pieces of information as to how to make improvements. Sometimes they were mentioned using turns of phrase such as “why don't they” or “they should”, and sometimes they were framed within personal stories of how things went wrong or right and what could have been done differently. Having considered the previous responses to the barriers to improving health literacy around QUM in communities, the following comments, and ideas about overcoming those barriers have been grouped into six core themes, under which those comments have been placed.

■ *Information on medicines and medicine safety*

Pharmacists were described as being “more valuable than doctors” in giving advice on medications, but a most consumers have no idea about the services that pharmacists can offer such as:

- Pharmacists can offer advice
 - Pharmacies can hold onto repeat scripts
 - Advice on safe storage of medicine
 - Offer safe disposal of medication
 - Impacts of sharing medications, particularly in families
 - The most common side-effects to look out for (and what to do about them)
 - Explaining trade names vs brand names vs generic brands and offer cheaper alternatives to those in need
- Pharmacy advice applies to over-the-counter medications as well as prescription medicine.

- Language and communications around medicines
- Everything conveyed to consumers, whether it is in discussion or on CMLs must be in plain, direct English. Information must be available in other languages; interpreter services must be made available; medicine packages must be labelled clearly; the more common side effects of all medications must be explained; how medications can be taken together must also be explain clearly and clearly laid out so that people are able to manage their medication without fear. Consumers must also be told that they can contact *Health Direct* if they have questions after hours or they have a simple question.
- Specific tools
- Consumers provided some examples of tools they thought would be useful for improving health literacy around medicines in daily lives:
 - a small card that can fit in a wallet or pocket, with questions to ask the doctor or pharmacists, reliable website addresses and import phone numbers on it
 - a small flyer or leaflet they can keep in a wallet or handbag
 - Fridge magnets with those same questions would normalise questioning health clinicians by being seen every single day by those in a household. The vast majority of homes in Australia will have a fridge.
 - The GP or pharmacist having small notepads with reliable website addresses for medicines information such as Health Direct or the NPS MedicineWise Medicines Line etc.
- The broader context: culture & influence of families and community leaders
- Engaging with the broader community and recognising the influence of family and broader cultures is vital for QUM. This can be done by working with community leaders and community workers on messaging and communications around QUM. Recognising that those such as peer workers, community workers, allied health works etc can be utilised and included in communications and spreading messages of medicines safety, and in directing consumers to appropriate advice
- Support, training, and incentives for GPs
- Consumers recognise that GPs need updated software and systems because it affects them, as the end user. *HealthPathways* can also be utilised to support consumers by including social prescribing. It has the potential to capture outcomes and guide future improvements to primary health care. Using the MBS and/or RACGP accreditation as incentives to prioritise health literacy, and strengthen requirements to include active listening or *Teach Back* for clinicians was suggested.

■ Education programs

A loud message that came through from all consumer groups was that education, starting in primary school, must be implemented in age-specific programs that can be included or an adjunct to existing school curricula. Teaching bodily autonomy to young people, normalising medicine and medicine-taking, normalising speaking about your body and your health to a professional and teaching critical thinking around your needs, your clinicians, and your overall experience within the health system must be prioritised.

Summary

The consumer feedback identified similar themes to those expressed by the PHN staff. Consumers tended to respond to both questions at the same time. As with the PHN staff interviews, the responses were organized first into in vivo topics and then into overarching themes. Three core themes were constructed from this organization of the consumers' discussions: Models of care; culture shift and tools.

- 1 **Models of care:** descriptions of the fee-for-service model with GPs, the pharmacy business model, and the lack of ongoing funding for PHNs were described as being detrimental to QUM for consumers due to obscuring clear communications, limiting access for several demographics, and preventing positive change

- 2 **Culture shift:** This focused on changing the power dynamic and behaviours of both consumers and primary health clinicians when it comes to QUM as well as calling for a change in the relationships between hospitals and primary health clinicians
- 3 **Tools:** Innovative ideas were put forward to improve the culture and the business models in primary health care by utilising existing tools, developing news tools and education packages, and developing clearer communication for a broader, multi-pronged approach.

Clinician Feedback

People don't want to look like bad patients (in front of the doctor)

It was unanimous that consumers, when in the position of patient in front of a doctor, see the doctor as an authority and therefore do not want to do the wrong thing, disappoint or otherwise “look bad” in front of the doctor. At the same time, when faced with a new or changing medication regime, there is only so much that can be absorbed, on the spot. For this reason, communication between patient and doctor tends to veer towards the superficial. It is only when a patient has had time to digest any changes suggested by the doctor that they may start to think of questions to ask. For these reasons, the discussions had by patients with pharmacists and/or nurses are more open and honest.

“I think one of the other issues that actually acts as a barrier to that idea of the ideal consultation is the capacity to absorb a lot of information. Imagine the quantum of information that needs to be absorbed to be told you have a chronic disease or to change the treatment of one.”

Comments from clinicians about people not wanting to look bad in front of their doctors were grouped in the following themes:

- **Doctor versus pharmacist conversations**
- **Not having a regular GP limits what people say to doctors**
- **People talk to pharmacists & nurses, not doctors**

The conversations the patients are having with their doctor are not the same conversations they are having with their pharmacist. The message was that people don't want to “look like you're being a bad patient” in front of the doctor.

As Australia does not have a patient registration system for all patients, and Australians are highly mobile, moving house, city or state with relative ease and frequency¹⁹, together with the choice of general practitioners in the capital cities, means there are a lot of people who don't have a regular GP. Also in rural and regional areas where there may be no GP, the irregularity of the relationship with general practitioners in Australia means that consumers are more likely to speak to a pharmacist, nurse or other primary health clinician before they speak to a GP.

- **People can only absorb so much information on the spot**
- **The emphasis is with the clinician [to start the conversations]**
- **The walk-in model of community pharmacists is good for patients**
- **Doctors can still be “empire builders”**

Consultations between doctors and patients present a situation in which it can be difficult for a patient to absorb information easily, particularly as information about medicines is invariably part of a discussion about life change,

¹⁹ Hassan, R., Zang, X. and McDonnell-Baum, S., 1996. Why families move: a study of residential mobility in Australia. *The Australian and New Zealand journal of sociology*, 32(1), pp.72-85.

health change or other potentially overwhelming diagnoses. Information won't be retained by the patient in this situation. Presenting patients with a short sheet of information about their condition, medicines, or other prescriptions, can be helpful to take home and consider. It can also encourage further discussion with the doctor, with a pharmacist or with a nurse or nurse practitioner (or in remote communities, an Aboriginal health worker), where a patient will feel more comfortable speaking openly, and with the doctor's prompt.

Doctors need to be willing to let pharmacists or other support workers fill those gaps in the health care process.

There's only so much we can do

One of the key messages under this theme is that we do not know enough about why patients make the decisions they do around medication use, stopping with medication, not getting scripts filled, getting them filled but not taking the medication, starting a medication, and then stopping, hanging on to a medication that's out of date, taking medication that's out of date, taking a family member's medication etc. It is easy to make assumptions but having some actual data on patient choices is vital to tackling the problem. What do patients tell their doctor about the medication they're prescribed? What don't they tell their doctor and why?

“Why patients decide not to take a medication as prescribed, really getting insights into what were the real reasons: Was it because their mate had taken it and got some side effects? Or was it because they had found some information on social media or the internet? Or was it simply they had a change of mind? Or was it too inconvenient? Was the regime that you were prescribing four times a day for an antibiotic for instance was that just not workable with their lifestyle?”

Primary health clinicians are in the position of seeing how little consumers know about their bodies, their health, their general literacy and how that affects the way their health issues including dealing with medicines. The below four themes made up the core of this overarching comment by one clinician: “There's only so much we can do.”

- **General literacy and health literacy, general knowledge is lacking**
- **Prescriptions and medications pile up**
- **We need to know more about the decisions consumers make around medicines**
- **Some people don't want to know**

“I know this is about quality use of medicines, but you've already missed the whole step about quality healthcare in general. And people have no health literacy: they don't know how many vegetables they should eat in a day. They don't know how much exercise they should do in a week, you know, we're struggling with that and you think that we're failing with medications? You know, there a way bigger issues at play.”

Systems can fail us

The lack of coordination, the lack of fundamental control over basic behaviours such as people having two doctors in different practices, and the lack of systems that link primary care clinicians with each other and with the hospital system is failing clinicians and consumers. There are successes in many general practices that could be replicated across whole systems; there are models of care .

“It would be really useful if we were confident that the same advice when giving [it] has been received if the patient asked the pharmacist, so having the same sort of medicines and advice from pharmacies, should be from the same sort of source, of truth, if you like, as providing us, GPs and patients can access themselves at home off the internet.”

“One of the issues with patients seeing multiple GPs is that they consider health to be simply a transactional experience. Patients are not customers (“the customer is always right!”). GPs have to have tough conversations and we aren't always there to tell them what they want to hear, give them what they want. Health literacy is poor, they don't realise that by fragmenting the care between multiple providers they are doing themselves a disservice.”

Solutions

Clinicians presented many and varied solutions to some of the myriad of challenges they face every day, particularly around health literacy and QUM literacy: linking systems, joint trainings with pharmacists and GPs; more patient prompts in plain English; funding for small projects rather than a one-size-fits-all approach for PHNs; encouraging more people to study to be a nurse practitioner; collecting more data to push for long-term funding for health literacy in line with the recommendation in the draft National Preventive Health Strategy; finding better ways to give patients better sources of information and education. Consumers and clinicians agree that school-based education about health, consumer health rights, responsibilities, practicalities, and health literacy as part of general life were all vital aspects of health care that must be addressed.

“Just adding the word evidence in the search bar, made a huge difference to the pickup rate [of reliable information]”

The following is a list of the core themes for which clinicians discussed specific solutions to systematic problems.

■ **Better promotion of existing resources**

Point people towards reliable sources: websites and phone lines; making sure the resources needed for social prescribing are also present in *HealthPathways* is a “useful resource”; having clinical decision software (such as a *Primary Sense*) that recognizes patients' conditions would support patient and clinician; understanding the importance of social media to consumers and how they're informing themselves.

■ **Needs a team approach, funding & training systems to support that**

Funding systems need to encourage the fostering of understanding and partnerships. As one clinician said: “It would be valuable to broaden the scope of activities to more than GP services, who are arguably already better resourced and have greater capacity to achieve these goals”.

Encouraging GPs and pharmacists to work more closely together, even changing the model so that pharmacists or pharmacologists are embedded in general practice is something to aim for.

“Wouldn't it be great if we could have a system like SafeScript that identified prescribing and dispensing of meds, for all meds, not just drugs or addiction”

■ **We need more support workers (nurses and peer/link workers)**

■ **People trust nurses: fund them**

Social prescribing, linking primary health clinicians and their patients with more social support; put money and effort into encouraging more specialist nurses around the country were discussed at length. That practice nurses do not have access to MBS item numbers was an agreed issue that should change. “People trust nurses” became a mantra for this discussion. Utilise what we have. If doctors are in short supply, nurse practitioners and specialist nurses the capacity to use MBS item numbers without the need to go through a GP. This would be extremely useful for rural and remote areas.

“Social prescribing: where doctors and nurses refer people, connect people more and help assist them to attend non-health services, so think men's shed, community choirs, things like that, and peer support groups and the missing ingredient to me, really make that happen. Other than us, a knowledge base of what's out, there is the link worker role.”

“...and the key thing is when they work, and when they're good things, we've going to make sure that they get out there, they become more normalized, and they get funded in the long-term rather than just seed funding.”

In remote Aboriginal communities, Aboriginal Health practitioners “are our saving grace in medication education, but they lack empowerment they lack support, and they lack consistent education around quality use of medicines”.

“Every single time a patient comes into a clinic to pick up medications, the doctor's not there, the nurse isn't there, the pharmacist isn't there. The local Aboriginal Health practitioner who is normally a family member is there every single time”.

■ **Ways to tackle misunderstanding**

Top of the wish list here was for more patient friendly resources from a consistent source of truth. To reduce harm and increase health literacy, the suggestions here was to give the Therapeutic Goods Administration (TGA) the capacity to set standards for all claims to health on any products in Australia to be evidence-based. Minimise any food, supplement or other product making dubious or unsubstantiated claims to health. Funding models must also include translation of consumer resources and other information into key Aboriginal and Torres Strait Islander languages.

■ **Health education must start at school**

This was a unanimous message from consumers and clinicians. Education program development must be developed in collaboration with national and state-based health and education agencies. Incorporate specific health literacy and QUM literacy-related components to existing curricula for different age groups.

■ **Useful data system for PHNs and prompts for GPs**

Embedding health literacy and QUM resources in all *HealthPathways*—an existing tool—or programs like *Primary Sense* was expressed repeatedly by the contributing clinicians. Specific examples of how they're being used are available in the data in Appendix 2.

■ **PHNs and NPS MedicineWise should fund small projects in small practices, not one-size-fits-all**

Giving PHNs the capacity to manage and instigate their own localised programs where specific needs exist was echoed repeatedly by clinicians. Fund local clinicians instead of “parachute in external clinicians” is vital.

■ Buy a national subscription for all doctors to the therapeutic guidelines

Australian medicines handbook was described as being difficult to navigate, and the therapeutic guidelines “still exist behind a pay wall”. Something helpful for doctors would be a universal subscription to be purchase by the Department of Health in the same way that there is access to the Cochrane Library database for Australia.

Summary

The clinician feedback was constructed into four overarching themes:

1) People don't want to look like bad patients (in front of the doctor)

This includes all the various ways and means that patients have of speaking with pharmacists or nurses rather than their doctor; that there is only so much somebody can absorb in a short consultation with a GP about a new health decision, a new medication, a new diagnosis etc. before they finally may have questions; many people don't have a regular doctor, especially either in rural and remote areas where there may not be a permanent doctor, or in very urbanized areas where people will go to the first doctor they can find if they have choices. Nurses and nurse practitioners are more trusted than doctors and should be utilized. One suggestion is that nurses be able to access MBS funding directly instead of being reliant on being paid via a GP could make an immediate difference re their availability to the general public.

2) There's only so much we can do

This is perhaps a truism in that clinicians can only do so much when the general health literacy of a population may be low, but as one nurse practitioner commented: “It is the health professional's responsibility” to know their community, understand what their region's PHN does, and to encourage patients to ask questions. General literacy and education levels in many areas may be low; general understanding of health, regardless of education levels and literacy levels can also still be very low; a lot of people do not have an interest in healthcare, their own healthcare, or in knowing anything about healthcare. And even those who are diligent and do try to do the right thing can still slip up. People can still accidentally take their partner's medicine, or an old medicine that should no longer be in the bathroom cabinet, or take two doses of something because they forgot they'd already taken it etc.

3) Systems can fail us (clinicians and patients)

'Systems and funding can fail us' highlights that there are gaps in the healthcare system in Australia that clinicians are not in a position to fix: that the Australian system allows people to have more than one GP, for example, and those GPs won't know about each other, is not a failing of general practice, it is a failing in the healthcare system. Registering with a GP and a pharmacist is common practice in countries in Europe, but Australia has only some areas where voluntary registration can occur, and then at this time it is for those with chronic illness. As well as this, there are electronic systems in place that can be unwieldy, or sometimes not work at all; relationships between clinicians and PHNs is patchy depending on the PHN, their KPIs and their funding. Again, this is a systematic part of the current model of care in Australia; and there are further difficulties for clinicians where funding is concerned. The realities of funding for certain things in certain areas can result in a complete failure to provide adequate care to some of the most disadvantaged patients. The realities on the ground can be far from whatever vision was expressed in a government policy.

4) Solutions

This provides some wonderful examples of successes and ideas that have resulted in positive change. The key messages here are that there is no one-size-fits-all; remote Aboriginal communities, for example, badly need funding for pharmacists and need funding to provide QUM training to Aboriginal Health practitioners, and to translate existing resources into relevant languages; PHNs and NPS MedicineWise should be funding small projects in individual practices; health education must begin in primary school and be part of the school curriculum throughout primary and secondary school; that there needs to be a team approach to having

pharmacists embedded in general practice; there are existing examples of improvements to IT systems for GPs that can improve patient outcomes. These can already be utilised and expanded. And lastly, there needs to be a national strategy to improve health literacy based on measurable outcomes leading to improvements, in order to seek and get long-term funding.

These themes aligned within the core three themes found in this research, namely: Policy, Culture and QUM tools.

Recommendations

The work undertaken by PHNs around health literacy and QUM literacy is varied, multi-level and contextual and yet the key recommendations are clear. Some PHNs see health literacy as integral to everything they do; some see it as separate to the core work that they prioritise in their region, which for some, involves dealing with responses to natural disasters; all recognise the complexity of health literacy and QUM literacy delivery in varied forms and in varied and complex communities. There is also recognition across the board that there are “never enough” resources to be able to take all the actions they would like to be able to take.

The recommendations and next steps of this research report try to incorporate as many varied options as the findings of this research could accommodate in order for all PHNs to be able to find something that they could immediately adapt or utilise where needs apply.

The core aim of this research was to support PHNs to build health literacy to improve the quality use of medicines in their communities. The following recommendations incorporate that aim, the findings of this research, and aligning the aim and the findings with three levels of health literacy:

- the National Safety and Quality Health Service (NSQHS) standards and the Australian Commission on Safety and Quality in Health Care (ACSQHC) guidelines and their definition of health literacy
- environmental health literacy including system-based policies and processes as described in the findings by PHN staff and clinicians to cover their existing needs and their desires for change
- individual health literacy: the needs of consumers as individuals, navigating a complex system that is difficult to understand.

What does government and/or the health sector need to do?

- Develop, implement, and mandate a set of national indicators for QUM for care outside Australian Hospitals, in the community. This includes continuity of care when patients are discharged from hospital, and community care and aged care; integrate these indicators into other existing data sets, for example, the Australian Government's Practice Incentives Program (PIP) Quality Improvement (QI) Incentive
- development of a national, coordinated health literacy framework and strategy (in line with the recommendation in the draft **National Preventive Health Strategy**) that adheres to NSQHS standards and ACSQHC guidelines. This could be done by ACSQHC in conjunction with NPS MedicineWise, CHF and consumers
- support and invest in bolstering the health workforce in regional, rural, and remote areas. Suggestions include developing frameworks for providing social support in rural and remote areas for clinicians on placements; increase rural doctor, nurse practitioner and other health support worker placements; streamline the process for providing opportunities for overseas-trained doctors in rural and remote.
- health education modules to be developed and included in curricula for primary and secondary schools across states and territories (with NPS MedicineWise and appropriate state and national health and education agencies)

How can PHNs be supported?

- Develop a strategy for implementation: policy/executive level, dedicated long-term funding for PHNs to work in the general practice and pharmacy spaces; and specific QUM inclusions within that health literacy space
- to adhere to NSQHS standards and ACSQHC guidelines, the easiest and most accessible way to increase health literacy in health consumers is for health literacy to underpin every program. Key purpose funding is a determining factor for the work that many PHNs do in relation to health literacy and health literacy as it relates to QUM. General Practices, practice nurses, pharmacists, allied health, and other health professionals working in the community require dedicated health literacy resources at their fingertips to build health literacy and health literacy as it relates to QUM. This cannot be supported by short-term solutions. PHNs must be supported and rewarded for improving health literacy responsiveness of their services and health literacy as it relates to QUM with dedicated, long-term funding, investment and measurables (this includes practical support for PHNs to define health literacy; provide QUM toolkits; national QUM community care indicators; practical tools for general practice, and evaluation options for shorter-term and longitudinal projects).

How can PHNs support GPs and other health professionals?

- Within a practical-level health literacy framework, embed health literacy and health literacy as it relates to QUM as a core function of general practice and pharmacy. This may be through models of care such as non-dispensing pharmacists working with patients and advising GPs on QUM in the general practice setting, noting that some PHNs have already seen the benefit of investing in this
- further development of practical and adaptable packages or toolkits for QUM that could be used with or within existing PHN tools (*Sharepoint*, *HealthPathways*, *GoShare/Healthily* and/or other community directories) and/or can be adapted to other online software used by individual PHNs
- dedicated QUM training via Continuing Professional Development (CPD) for primary health clinicians more generally
- develop, promote and deliver CPD education and training for GPs and other members of the primary care team in QUM ensuring they are linked to current CPD requirements. Clinical audit and PDSA tools could be included
- clinician feedback showed that they are keen for more small-scale funding to be available for individual practices to run localised projects for health literacy as it relates to QUM. As well as continued support for these programs there needs to be more data and evaluation of these projects to be able to push for long-term funding to be made available to integrate the projects that work for positive change.

How can PHNs, GPs and other health professionals support consumers?

- Both clinicians and consumers are keen to see the development of education packages starting with children learning to understand communication about their health and medicines in primary school, following on to taking more responsibility and understanding the healthcare system in high school.
- there were also suggestions for practical tools, electronic systems and training for clinicians that can change the culture of primary health care and the relationship between consumers and primary health clinicians
- create structured, localised pathways of care within *HealthPathways*, aiming for that information to be accessible to patients/consumers. This is critical for consumers' involvement and informed consent.
- develop and introduce consumer peer education modules in QUM that local consumer educators could be trained to deliver.

Rural and remote needs

- More support workers are needed: Aboriginal Health Workers and Health Practitioners, nurse practitioners, nurses, rural and remote pharmacists
- support and training for Aboriginal Health Practitioners, Aboriginal Health Workers and Remote Area Nurses regarding communications about QUM in remote Aboriginal and Torres Strait Islander communities

- decrease the barriers to hiring overseas-trained doctors specifically for rural and remote area
- pharmacists could also play a bigger role in providing information about services and care pathways; provide place-appropriate training for pharmacists to take on a broader role
- develop the role of pharmacy and other support workers as adjuncts in general practice in rural and remote areas. This could decrease the number of people ending up in crisis care including hospitals in cities
- expand embedded pharmacists in primary health care services to Aboriginal Community Controlled Health Services (ACCHS) to assist in addressing issues in remote areas
- consider other access options tele-pharmacy services for remote health services- though only when supported by on the ground staff, including Aboriginal Health Practitioners
- Increase localised pathways to care in rural and remote areas; interconnected services by including or increasing social prescribing and awareness of services in specific catchment areas via *HealthPathways*
- funding needs to be equitably applied, recognising that it costs more to deliver services in remote areas
- reconsider funding models for remote area dialysis units: recent changes to pharmacy support staff have resulted in some remote dialysis units being without pharmacy support for patients taking multiple medicines daily. Remote communities already have extremely low numbers of pharmacists. If pharmacists cannot be hired, investing in Aboriginal health workers, and providing QUM training must be considered as an alternative. While funding for more on-community pharmacists in remote Aboriginal and Torres Strait Islander communities would be ideal, any resources that can support the development of the capacity of nurses in remote communities regarding health literacy as it relates to the QUM could be useful.

Next Steps

The following is a summary of some practical steps that can be taken by PHNs with the support of NPS MedicineWise, in line with the overall research recommendations. These suggestions are examples of PHN and community-level steps that emerged from all the discussions and feedback provided to this research.

These suggestions align with, and will drive the uptake of, the ACSQHC National Safety and Quality Primary and Community Healthcare Standards. The following shorter-term activities contribute to the three core standards: Partnering with Consumers; Clinical Safety, and Clinical Governance.

Short-term

.Partnering with Consumers Standard

- To benefit cultural change and the development of tools and resources from direct community feedback: Identify and develop consumer engagement champions who can serve as role models and mentors for health literacy and QUM literacy in your communities, particularly looking at diversity and patient segments most in need. Consumer champions contribute to individual health literacy by having direct contact and engagement with their networks and communities. They also contribute to the health literacy environment by nature of their inclusion in organisational feedback and strategic planning
- to expand the health literacy environment, develop orientation packs for PHN consumer advisory groups to support them to work effectively with their PHN and for their communities. Again, this could be a collaboration with NPS Medicine Wise and/or the Consumers Health Forum (CHF), utilising existing tools adapted for region-specific use
- Taking advantage of opportunities created by this research report and the development of relationships with contributing PHNs, to link with one or more PHNs on small, short projects on topics of local importance, as instructed by individual PHN needs. Begin embedding the call to reduce the one-size-fits-all approach, contribute to local, short projects, and develop QUM and health literacy tools that are needed in specific PHN catchment areas. Depending on the needs of the community, this is an open invitation to increase individual and/or environmental health literacy.

Clinical Safety Standard

- Run webinars on building health literacy to improve the quality use of medicines in communities, for PHNs, designed for collaboration and showcasing successes and/or looking for solutions to challenges in health literacy. This would encourage collaboration with other PHNs; or it could be aimed at the level of bringing GPs and pharmacists together, depending on local needs. Collaboration of this nature will benefit PHNs by: sharing successes in QUM tool development; cultural change between clinicians; and potential change in sharing successes at the strategic level. Overall, it will contribute to the health literacy environment.

Clinical Governance Standard

- Contribute to the health literacy environment providing staff with training (that may not be in the scope of regularly-funded staff training) in how to work with consumer advisory groups and/or other consumer feedback channels. This could be done in collaboration with CHF and NPS MedicineWise. Re-packaging existing resources can be done relatively easily and quickly to provide immediate cultural within PHNs, and for clinicians who rely on consumer advisory groups for general practice feedback.

Medium-term

Clinical Safety Standard and Partnering with Consumers Standard

- Develop individual health literacy with the development of locally adapted resources according to local needs: for example, developing webster packs with symbols and language relevant to the dominant language and/or ethnic groups in your area; printing notepads, business cards, fridge magnets with links to reliable websites for medicine information such as the Health Direct website, NPS MedicineWise *MedicinesLine* or *5 Questions to ask your Doctor/5 Questions to ask about your medicines* etc.; short, plain English Consumer Medicines Information sheets (CMI) for the area's most commonly prescribed medicines. This will benefit QUM tool development, and a cultural change between consumer and clinician. In the longer-term, this could benefit the general improvement in health literacy and medicine-related harm
- more specific work on reviewing what QUM content and prompts could be integrated into *HealthPathways* (which is in common use across most PHNs) as recommended in the draft 10-year Primary Health Care plan regarding the implementation of consumer-facing regional health literacy approaches.²⁰

Clinical Safety Standard

- Develop short online learning modules for PHN staff in health literacy and QUM literacy. This could be done in collaboration with NPS MedicineWise, and/or local primary care clinicians. The benefit in doing this is in cultural change in parallel with policy change at the PHN level. It will help build an awareness of health literacy at the PHN staff level and aligns with a health literacy inclusion in a PHN charter.

Clinical Governance Standard

- Work towards developing the health literacy environment with structures and systems to support a health literacy framework beginning with embedding health literacy and/or QUM literacy strategies in core activities, ensuring that services that are commissioned build the health literacy of consumers. This will benefit policy level, PHN level, clinician level and consumer-level needs around increasing QUM and health literacy
- develop evaluation tools for PHNs to gauge health literacy and QUM in communities. This could also be done in collaboration with NPS MedicineWise, utilising and adapting existing tools for region-specific use. This will help to clarify the goals of health literacy inclusion at the strategic level. This in turn will benefit staff, clinicians and consumers by setting clear aims, goals and standards at every level.

²⁰ Australian Government, Department of Health, Consultation Draft, *Future focused primary health care: Australia's primary health care 10 Year Plan 2022-2023*. <https://bit.ly/3AQjhcJ>, p. 33, viewed 10 August 2021.

Longer-term

Clinical Safety Standard and Partnering with Consumers Standard

- Education program development in collaboration with national and state-based health and education agencies. For example, a pilot school-term project for age-based curricula development, in collaboration with NPS MedicineWise, CHF consumers, and a school in your area, incorporating specific health literacy and QUM literacy-related components to existing curricula:
 - primary school and/secondary school curricula
 - encouraging collaboration and communication via professional communications training for GPs, pharmacists and other primary health carers. Bringing GPs and pharmacists together for relationships building was a key suggestion by clinicians.

School education programs will benefit consumers by contributing to improvements in individual health literacy and QUM literacy; clinicians and their relationships with each other which in turn will also benefit consumers and the ultimate goal, which is quality care; Education programs must include evaluation which will also strengthen the aims and goals of health literacy education.

Conclusion

The draft National Preventative Health Strategy has highlighted the need for a coordinated, national health literacy strategy or framework.

The health literacy framework would need to consider three levels: national policy level which must include clear definitions for health literacy and QUM; a strategic level for the work of PHNs and their relationships with general practice and pharmacy; and the practical level for GPs, nurses, pharmacists and other primary health clinicians and their relationships with patients.

The practical level would include curated tools such as QUM literacy programs and programs around health literacy for consumers, for general practice staff and at the PHN organisation-level. These tools could collect or produce data to be evaluated either independently or by PHNs depending on staffing. More detailed pathways of care; toolkits and checklists for communications around health literacy could also be developed with in-built evaluation options for take-up and longitudinal results. Adding health literacy components to existing programs; and developing training packages for relevant workers in QUM would also be practical ways of developing communications and potential evaluation options for increasing both individual and organisational health literacy.

Feedback around general practice revealed real workforce stressors. Existing low numbers of GPs, pharmacists, nurses, and other support workers in rural and remote areas remain problematic and have been exacerbated during COVID-19 due to travel restrictions for overseas and overseas-trained doctors.

The time constraints on general practice have shown that adding expectations around delivery of health literacy or quality use of medicines communications and practical support for patients/consumers is moot as either the capacity is simply not there and/or the region in question has other priorities.

Having checklists and easy-to-use toolkits to reframe existing practice and the culture of communications between clinicians and patients/consumers with a health literacy/QUM literacy component (which, as an example, could include options such as lists of questions for both doctor and patient to ask; or a QR code associated with an e-script, technologies, or simpler, plain English Consumer Medicine Information), and by having more defined pathways of care that can be accessed by GPs and patient, will provide greater avenues for communication and evaluation.

Changing consumer and general practice behaviours, and creating pathways of care within a national, coordinated framework, in and of itself underscores the value of health literacy as a fundamental building block on which all community healthcare sits. The other core building block is in communications: Still far too much information is written beyond the capability of most consumers, whether it be Consumer Medicine Information leaflets, the language used by GPs or pharmacists, understanding a prescription, a policy, a medicine label, or a press release: health communication must be strengthened and improved.

One participant summarised the approach of her PHN to health literacy, which perfectly sums up these findings and recommendations:

“What we’re trying to communicate nowadays is that regardless what the topic is, whether it’s mental health, whether it’s alcohol and tobacco or other drugs, whether it’s medicines that you get prescribed, whether it is making sure that people know where to find help, where there is after hours pharmacy etc., everything is about health literacy because you need to make sure that whatever you do, you provide it in a way that is easily understood and can be acted upon. So that’s where I think some of the messaging gets lost, where people think, yeah, yeah, health literacy belongs to this little bucket over here...but understanding that, actually, we need to have these always present in our mind when we plan, when we execute and when we evaluate...The other point that we have, is a gap that making sure that health literacy is sold as something that is everyone’s concern and really influences everything we do.”

Appendix 1

Rapid desktop review

Supporting Primary Health Networks to build health literacy in their communities

The websites of seven PHNs (Western Australia, Eastern Melbourne, Northern Queensland, Hunter New England, and Central Coast, Central and Eastern Sydney, Murrumbidgee, and the ACT) have been assessed as a sample, looking at the broader context of PHNs, including collaborative work, taking on board the recommendations from the first Steering Group meeting.

A sweeping search of each website was conducted, looking for: 'health literacy', 'literacy', 'quality use of medicines' and 'medicine'.

The strategic plans, last annual report, other work plans and other publications such as evaluations, visions, missions and values, news, newsletters, and other documents were all searched for the same topics and for an overview of information relevant to doing a survey or interviews with each PHN.

At the same time, two potential survey methods were drawn up and considered.

- 1) One is a full fact-finding list of questions incorporating the national approach to addressing health literacy by the Australian Commission on Safety and Quality in Health Care *National statement on health literacy*; the *Ten attributes of a health literate healthcare organisation* provided by Prof Kirsten McCaffery, courtesy of the Tasmanian Public Health Services Department of Health, and the recommendations from the *Consumer Health Literacy Segmentation Research* conducted and published by the Consumers Health Forum and NPS MedicineWise. The list of questions includes six core themes:
 - a. Embedding health literacy into systems
 - b. Consumer co-design
 - c. Planning, measurement, and evaluation
 - d. Ensuring effective communication
 - e. Integrating health literacy into education
 - f. Developing a coordinated approach

The lists of questions under these themes are comprehensive, looking at seeking answers specific health literacy such as:

- Are you supporting healthcare providers to develop or implement initiatives to increase health literacy as it relates to the Quality Use of Medicines?
- If not, why not?
- If yes, what kind of support are you providing?
- If yes, what results/outcomes have been reported or measured?

- 2) The second potential survey method took the *Ten attributes of a health literate healthcare organisation* provided by Prof Kirsten McCaffery, plus two extra themes, one featuring any obvious partnerships mentioned on the websites and one section on searches conducted on the website for 'health literacy' and 'quality use of medicines' and 'medicines'.

Preliminary findings for survey design

The first and complete list of survey questions is not going to yield results that can be utilised or that will result in the desired the outcome of answers regarding what, how or with whom health literacy, as it relates to the quality use of medicines, is currently being implemented within and across PHNs. The reasons for this are:

- '*Health literacy as it relates to the quality use of medicines*' is so specific as a starting point for surveying partnerships, interventions, strategies etc. that the survey will yield little information of any value. Of the sample websites surveyed, only one website had a specific page dedicated to "Quality Use of Medicines". This, in and of itself is not useful.
- 'Health literacy' as a more general term includes such a broad and complex set of contributing efforts, themes, services, policies, strategies etc. that it can be considered to be a foundational element in every aspect of a PHN's work without being mentioned. For example: The Hunter New England and Central Coast annual report for 2020 includes a campaign titled *Don't Distance Yourself From Your Health* which is specifically aimed at improving health literacy and primary care support without once mentioning the term. While campaigns or statements may not mention health literacy, it would be a fair assumption that improving health literacy is a concept that underscores the goals or is considered a fundamental driver for the goals of such projects.
- To this end, questions in a survey that specify 'health literacy' or 'health literacy as it relates to the quality use of medicines' throughout will not yield useful results as the term will be implied rather than specified in a lot of, if not most of the work done by PHNs. Surveying 31 websites with the intention of interpreting those implications is not the aim of this survey.
 - o As an example, a specific question under the ACSQHC themes would be: *Is Health literacy (general) written into missions, policies, operations and/or strategic plans?* There are strategic plans and annual reports found on the sample PHN websites in which neither health literacy, nor the quality use of medicines is mentioned. Specific questions about health literacy as it relates to the quality use of medicines will not yield the desired outcome for this survey.
- Supporting this finding is that the definition of a health literate health organization includes elements such as '*Addresses health literacy in high-risk situations, including care transitions and communications about medicines*'. An element such as this can be gleaned from a website according to the services provided, for example, having a specific 'aged care' section would indicate high-risk members of the population who may be involved in more care transitions than perhaps other segments of the population. However, detail regarding care transitions and communications in high-risk situations, can only be provided by primary health carers. Statements (turned into questions) based on the *Ten attributes of a health literate healthcare organization (see below)* are designed for primary health carers, not PHNs. In ascertaining the extent to which these themes or goals may underscore the support they offer primary health carers within their catchment area, answers to the attributes posed as questions (see below) will need to come from those primary carers, not PHNs:
 - o How/Do you design and distribute print, audio-visual, and social media content that is easy to understand and act on?
 - o How/Do you address health literacy in high-risk situations, including care transitions and communications about medicines?
 - o How/Do you communicate clearly what health plans cover and what individuals will have to pay for services?
 - o How/Do you use health literacy strategies in interpersonal communication, and confirm understanding at all points of contact?
 - o How/Do you meet the needs of the population with a range of health literacy skills while avoiding stigmatisation?
 - o How/Do you prepare the workforce to be health literate, and do you monitor their progress?
- PHNs are not primary health carers so questions that focus on primary healthcare are moot. What PHNs do for primary health carers is a focus on provision of support services according to local need, local

demographics, funding, availability of resources etc. which, again, can be gleaned by implication which is not the purpose of this project.

- While some PHNs did have obvious elements that respond to these statements, they are not going to yield satisfactory responses for a survey because they are aimed at the wrong audience.
- Questions such as 'To what extent is Australian scholarship informing health literacy QUM initiatives? (Please include relevant links, citations, or other relevant documents if available)' which is included in the first set of questions, are more likely to be answered by primary health carers than PHNs.

Recommendations

The difficulty in getting all 31 PHNs to complete an online questionnaire given the limited ways in which an online survey could be useful, and given the questions over finding a suitable approach for a written survey or questionnaire within the allotted timeframe, and given the potential for reluctance as mentioned in the first steering group meeting, particularly the comments on the timeliness of this project, we suggest the following approach:

Rather than a survey of all 31 PHNs on health literacy as it relates to the quality use of medicines, we suggest conducting interviews with a chosen set of core samples of PHNs, asking four key questions:

- What are you doing regarding health literacy and the quality use of medicines?
- What difficulties/gaps have you found?
- What do you need to move forward in this space?
- How do you share positive results/findings with other PHNs?

The strategy here is to focus on what PHNs need, not what they are, or are not, doing. As every PHN is different, has different approaches, a different focus according to its demographics, funding, needs etc., a uniform written survey is not going to be useful for them.

If PHNs wish to examine more closely their inclusion of health literacy as it relates to the quality use of medicines as part of their organisational structure, there are existing self-assessment tools such as the Deakin University "*Organisational Health Literacy Responsiveness (Org-HLR) Self-Assessment Guide*" or the HealthWest Partnership *Handbook for becoming a health literate organisation* which includes a priority setting tool for self-assessment (provided by Prof Kirsten McCaffery). These tools exist. We do not need to reinvent the wheel.

A topic for discussion by the steering group may include considering if this project should include the sample interviews based on the four key questions, followed by the same PHNs conducting one of these self-assessment tools as part of this project. Asking the PHNs Interviews with select PHNs willing to complete such a self-assessment tool would be more likely to produce the focused data required for optimal results in this project.

Appendix 2

Findings—complete data

Presentation of comments

Comments from all participants are presented in dot points for ease of reading under the core themes that emerged from the data.

Some of the responses are summarised meeting notes (where multiple mentions of the same idea occurred), some are from verbatim face-to-face interviews and are presented in quotation marks, and some were from group feedback sessions.

Due to the thematic nature of the categorisation, they are mixed together.

PHN Staff Feedback

Comments from participants, categorised as “we need a national framework for health literacy delivery”

- “There's no unified package [that's] vetted for you. No clinical evidence, you know the good governance around these documents. It's all just, it's a bit like vendors of your clinical software, you know, we need to set standards”
- We need a set of standards and a framework for health literacy; around the tools used; need a unified package with good governance structures
- “In terms of tools and what you can use...it's difficult to define. So how do you actually define it? What do you want to aim for?”
- “I can see [having] a framework and a mechanism to build health literacy in [would be useful], but we haven't got the manpower or the resourcing to have done that yet...and it's not been the priority”
- “In terms of health literacy, I guess it's also having a common way [which we currently don't have] in which we engage our consumers and access their feedback”
- “...Having a health literacy framework...is about that consistent approach. A framework would help guide what an evaluation would look like”
- “In terms of health literacy, like, how do you measure something like that in a community?”
- “We want to know, has it [any initiative around health literacy] actually worked? And I think that's where it becomes so difficult to measure health literacy or awareness raising or changes in consumer behaviour because you can't attribute it to one interaction”
- “...encourage health consumer information that is easy to comprehend, to support people to understand more about their health conditions and the actions to manage them”
- “We can also not expect that after 12 months [of a health literacy initiative], which realistically boils down to 6 months activity, we can see drastic changes that are statistically significant in terms of them showing how something has changed over time.”

Existing Tools for PHNs

Comments from participants, categorised as “we’re finding our own digital solutions”

- “We do have the PHN exchange, which is a platform on the Sharepoint I guess which is a website where we can upload questions, but it is used in a way that sometimes you get a response and sometimes you don’t. I looked the other day when I asked a question, like, one and a half years ago. Not one person responded...in the past received quicker responses”
- “People do use it but, again it's about how about how valuable it is for...specific work and I think this was...that was very much used when the organization was being, you know, the concepts around PHNs were being set up and they were very disparate. What's happening though my observation of what's happening now, over the last sort of few years, is that the coordination of PHNs through the Department of Health is becoming much more integrated. So, the information...there’s a lot of information on Sharepoint, which is for all of us, but I'm not sure about the actual working groups that are taking place now”
- “The Commonwealth PHN Secretariat has set up, you know, some Sharepoint sites and has encouraged sharing. And what have you. It's all very well. But it's another thing. So, I think many of us will pick up the phone and it's not uncommon to get a call from a colleague somewhere who's seeing something on your website or as heard, that you're doing X or Y or Z, and similarly, we will do the same”
- “Yeah, look every now and then every now and again [we might look at the Sharepoint site], yeah not many people respond, to be honest. Now there's a problem with access with that. Yeah, it comes and goes. I'd say that's biggest barrier. It's administered by the department actually, but we have that previously, so where we find we have the best networking relationships where we've actually made them on our own volition sort of thing perhaps rather than using the Sharepoint site not, so that's not a great idea”
- “...we're looking at other ways to support general practices to have those conversations with patients and we're looking at some off-the-shelf digital solutions [GoShare]...There's a few out there at the moment that GPs, for example, can use to then pass on curated information to consumers, patients, around a particular issue...”
- “What we've been using and testing is *GoShare* [a *Healthily* product]. So, they're the education bundles”
- “It would be a great national initiative to have *GoShare* bundles available”
- “So, the quality use of medicines from a consumer perspective, not from a provider perspective...I'd like to see that. And that's where I think about the *Healthily*. You know that product I was telling you about, that's what I think their strength is, is they are a tool that can be used for providers to do x, y, and Zed. But there's a cost So how do we access [it]? An auspiced evidence-based, consumer endorsed, validated tool, that is about quality use of medicines and that's sort of context specific for the different consumers depending on what their need is. Because, you know, someone with cardiac information is perhaps not so interested in the renal stuff”
- “We tend to use the same tools as [our state/territory] health services because often if we put material together top and Health Services have a process of validating, anything we develop before, they'll use it in their clinics”
- “...The practice data that we get access to is part of some of our other arrangements, particular around them, practice incentive payment, quality improvement, indicator that the Commonwealth government runs. So, we are provided with practice data so that gives us a, it's obviously quantitative, but it gives us a real idea in terms of what our supports or interventions or whatever, the best word is what that effect has been on consumers but in terms of their in shaping, their design of the programs know, that might not have that sort of qualitative approach”
- “There’s an array of tools out there. We have yellow envelopes that help people, residential aged care staff to do a transfer into hospital and vice versa. We have *HealthPathways*. We have health directory, we have digital health tools, we do have health direct number, GP assist, we do have an array of care coordination training and tools and so on and so on...And we obviously always try to develop our project proposals and communication proposals around health literacy to make sure that we always communicate in a way that is easily understood. So, heaps of tools that are available internally and externally.”

QUM

Comments from participants, categorised as “there are gaps [in QUM] that can be filled”

- “There should be a packaged product, a program...some kind of stepped education approach, and I know that that sort of is—NPS MedicineWise was well known for doing that for providers”
- “Within the hospital system there’s definitely a lot of support, but it’s once you step outside that system, there’s not so much support [for QUM]. All the information that you are receiving is quite inconsistent”
- The link between the gap in medicines management in hospital and the discharge, and the lack of communication back to the prescribing GP, and the troubles that people get into in-between times
- Quality Use of Medicines in aged care is a big gap
- “Embedding QUM and health literacy people in PHNs worked really well. We need to return to that”
- “The more I think we can add [around the Quality Use of Medicines], we don’t want to make things confusing, but if we can get a few different options on how they [health service providers] can provide that type of information, I personally think, the better....The health professionals, to also, encourage people to ask questions and say it’s actually okay and give you permission to actually ask those questions because there’s a lot of consumers that were saying they just feel like there’s no time and they’re not really encouraged”
- “...a lot of GPs will say health literacy is what we do, but it’s not the message we’re getting necessarily from consumers. Our pharmacist in general practice program...there was a trial in between 2016-2018, it was all about getting a community-based pharmacist to be embedded in a general practice. So, to date, we’ve had 11 General practices involved”
- “We did have a pharmacist working with us for a while...but no more. We do fund, we do have some commissioned services that...is of medicine in practice. So, pharmacy and the practice that it’s a non-prescribing pharmacist embedded, into general practice...So, there was some really diverse but really important bodies of work going on there, that will be great to scale up”
- “Feedback from GPs says they want pharmacies to do medicine education: we don’t want them trying to be a quasi-GP clinic that we really need them to be doing health literacy and compliance around quality use of medicines in pharmacy”
- “The department’s got structured PHNs now, and you know, I can remember we used to have the pharmacist with us here, pharmacists or a pharmacology student would be embedded here with the PHNs. And they were, every point, they were working with us on program design. They were fantastic. NPS quality use of medicine isn’t filling [that role] anymore. I think a lot of things need to rethink. They don’t sit where we are now: everything’s changed. You know, nobody’s buying great big office blocks and filling them with people anymore. They’re going who wants to work Monday, Wednesday, Friday. And who wants to work from home, Tuesday. And, you know, and we’ll rotate desks. It’s, you know, what I’ve seen in changes in 17 years are significant.”

Comments from participants, categorized as “we need to identify pathways of care”

- “There needs to be a pathway identified for service providers to be able to deliver services to their patients/consumers/participants across the service system...So you take the big package and then you make it applicable for your region but there’s a lot of funding in *HealthPathways*. So, there’s been a lot of commitment to that strategy and it’s almost like this is the other side of that strategy, which actually works with consumers”
- “We’re doing a lot of that work [mapping services] with *HealthPathways* so that the GPs will be aware, and I guess a lot of that is word of mouth. If you tell a patient about a food hamper service, the word spreads pretty quickly. You’re looking for a white fridge that’s, you know, one meter by one meter and has an ice maker, you could literally filter, and the answer would pop up. We need something like that across Australia, so that if somebody is homeless, they need emergency accommodation or rent assistance or whatever. That information is hard to find because you’ll become homeless once. Like—that’ll be the event. That’s when you need the help and it’s hard to find”

- “GPs need awareness of resources for consumers: around quality medicine use. It should be something we do automatically, but it tends to only happen when there's an adverse event”
- “The other thing that we probably leverage a lot is our relationship the hospital and health service and, looking at the patient journey, in and out of primary care and into the hospitals as well...That sometimes can provoke a thought as well”
- “I think there's also the other issue...You know they get bounced from service to service to service and service...people really don't know what's available and how to access [services] and what to access and then once they access, and, you know, we're going to refer your son or daughter for psychological therapies: What does that mean? And what's their expectation around that? What can they expect from that? Will they be included? Will they be advised of the outcome? You know all of those things are things that are...I guess that's delving into concern providers, then about the roles they have...that then comes back to what are the resources available to us to train and develop our health professionals.”

Collaborations

Comments from participants, categorised as “we love collaborations”

- “...we were reflecting on just how fantastic it is to have that interaction [with other PHNs]”
- “[Re collaborating with other PHNs] Oh absolutely [useful]. I just got off a meeting with somebody in South Australia. We're doing a project for children in care. We could really be learning from one another”
- “Exchanging ideas with other PHNs is great”
- “They have the CEO Network and, and there's the national, then there's the [PHN1] and then there's the [PHN2-PHN3] one. So, we've got quite a few [collaborations with other PHNs]”
- “We have a [PHN4-PHN5] alliance that we use. From a project point of view, the national psycho-social support project, for example, we have working groups and community of practices where...we have had other PHNs contacting us to ask us what we're doing in the health literacy space”
- “...we were reflecting on just how fantastic it is to have that interaction [with other PHNs]. We're all facing similar problems we've got to deal with in different ways because of what's happening in our own areas, but I'd like to think [we're] close for the most part. Now having said that there are some areas that we like to try and trailblaze and try our own things, but that's I guess pretty natural, and we see that across many sectors, but for the most part, we like love to bounce ideas...Get learnings from the broader Network.”

Funding and priorities

Comments from participants, categorized as “funding is a problem, and we have other priorities”

- “What I would like to get out of this is some advocacy for specific funding, to be able to make this work [health literacy] a priority”
- “I think there's scope for that kind of work [health literacy], but it requires work force to drive it because it's not going to be tacked onto everybody's everyday job and we don't have funding for the workforce and that's the issue because it requires concentrated implementation”
- “The way things are funded; the piecemeal sort of funding is an issue. Because look even as employees, there is a question around certainty of employment. We're all employed on contract so that brings with it its own challenges, but we're not the only people and definitely not complaining, but I guess, and the piecemeal nature of the funding at least from my perspective that's reflective on the Commonwealth's priorities at the time. I appreciate that they can chop and change on a dime sort of thing. In terms of responding to whatever the prevailing health situation is. No better example than response to covid-19”
- “Project funding is really hard because actually, when you do a project, you need to know why you're doing the project. Their part of the project is funding [so] you need to know okay, so who will fund it once? It's all pointless doing a project and the economics are really good, and everything's great but then you've got

nowhere to go to get the funding. One of the outcomes is recurrent funding or not recurrent funding. It's best practice funding. It's like how we should be doing things from now, on? How do we fund it?"

- "That is something we could do from a, you know, safe use of medicines point of view. There's no reason why we couldn't fund a project around that. And support that kind of modelling because that's completely within our scope...there has been a bit of work done on that model...They show really positive outcomes, but there's no consistent funding"
- "...we've got a certain mandate to do certain things, health literacy is not, it's not on our list of priorities. So, we, you know, we have to deal with all these other issues, first, before we can even ask for money for, you know, to do this that or the other and then how do we incorporate it?"
- "...we really we have been looking at doing joint sessions for RACF clinicians and anyone and GPs working in that space, and quality use of medicine has been part of that curriculum. You know, we've done that in collaboration with the health service as well, but I'd say probably we probably we have competing priorities. And so, the allocation of time and resources is, yeah, it's hard"
- "There's not enough focus on health literacy, there's not enough funding for health literacy ever. Since, in Queensland Campbell Newman sort of dismantled health promotion in Queensland we just have never got back. So, health literacy generally, there's just no drivers"
- "One of our major issues is that we have this 'stop and go' type of funding initiative and it's really disruptive to any improvement initiative that you launch. Like, if we only have funding for a year or maximum one and half to two years it's constantly, like, you start with planning, then half of the year's already gone. By the time you execute some initiatives you have two months time and you do a little report and evaluation and you start again. That continuity of funding would really add to the sustainability of any improvement initiative that we have"
- "We are significantly disaster-affected. So, all of 2020, we were coping with floods and droughts and bushfires. And so most of the work that we had our program, regular program of work, was put on hold to manage and respond to this tidal wave, tsunami of disasters so we're still just, I think, coming to terms coming out of that in many regards and covid of course is, you know, playing havoc on everyone. So, the thinking in the body of work that was on our radar in 2019 is has been put on pause to some extent"
- "We just want someone to do it for us. We just don't have the time, bandwidth, or framework. I mean we obviously have our own nuance that we need to apply to it for each of the region's the different regions and different cohorts and different consumer groups that we might be working with but it's just another layer on all the layers of things that we need to do around health literacy...We're not the experts and we don't have the capacity resourcing or bandwidth to be that voice. But somehow we're left trying to navigate that system if that makes sense."

Consumer Feedback

Barriers to improving health literacy around medicines

Current service models are not working

The overarching fee-for-service model is problematic

- "If you've got a 15-minute consult with your doctor, it's very hard to get through all those fabulous questions from (NPS) MedicineWise and a lot of doctors don't like answering them"
- GPs have other things to get their heads around—[they] don't have time.
- "Doctors try to push people through because the more people you get through the more you get paid, but you know that's not their job. Their job is to look after their patients"
- "There's no MBS number [for QUM/health literacy]. The pure barrier is that it's because there's all these granulated ways of getting a fee and calculating it"

- “I have a problem with the medical director that sells their information from their desktop to pharmaceutical companies, or it goes somewhere. And we don't know how that data is being used. And so it taints things.”

The pharmacy model undermines QUM

- Pharmacies sell ‘complementary therapies’, ‘alternative medicines’ and health supplements which can have contraindications for prescription medicines, undermining QUM
- Many pharmacies do not cater for people who use wheelchairs and other ambulatory aids thereby making access to QUM difficult or impossible
- The free translator service is rarely utilised for those who do not speak English well enough to understand QUM: translator services are too limited (often too slow) and not utilised, leaving many without adequate information
- The lack of private space for confidential discussions in pharmacies in many states/territories in Australia could be preventing discussion with pharmacists and undermining QUM. Western Australian pharmacies have private consult rooms, why not in every state and territory?

The project-based funding model for PHNs prevents long-term investment

- Short-term, prescriptive funding limits long-term projects and evaluation of improvements in health literacy and QUM literacy outcomes
- Health literacy and/or QUM literacy should be part of any funding agreements for state and federal funding for primary health care
- Funding for health literacy/QUM literacy should be part of a national framework for PHNs
- Prescriptive funding for PHNs is not fit for purpose

Access is an issue

- Internet is not always reliable or accessible for telehealth for people in rural and remote areas so getting reliable information online is even harder
- Access to a pharmacist can be problematic for people in regional, rural, and remote areas of Australia
- The cost of medicines can be prohibitive. Sometimes medicines are best accessed online, at other times they are best accessed from a pharmacist
- “It can be difficult to transfer repeat scripts if shifting between online and face-to-face environments”
- There are unique challenges for people suffering homelessness in accessing information about medicines, or being able to follow directions, refrigerating medicines [etc.]
- [Re whether or not QR codes would provide better access for those for whom English difficult] “No! [a QR code is] Not at all [useful] and it doesn't go for emergency... You're just going to deal with only one kind of population. There's these 250 languages that we need. People think it's five languages. It's not.”
- “Sometimes the misuse of medicines is because people can't afford to buy medicine at the right time, like, people do not have money.”

The overall culture needs to change

The power imbalance and information asymmetry between GPs and consumers/patients

- “The biggest challenge is people do not stand up to doctors, ask questions of doctors, feel confident enough to find out what they don't understand”
- “If we learned anything out of the royal commission into child sexual abuse is that we shouldn't put particular professions on pedestals. And we continue still with medical staff”

- “I think that GPs should take the initiative to make the patient comfortable to ask questions. If the GP doesn't have time [they] should say, ‘you know, this is what I'm giving you because of this. For more information you should go and ask your pharmacist’, so that the patient walks from there with the confidence that, you know, we have permission”
- “Doctors are often not willing to engage or don't recognize that the person is smart enough to understand some of the explanation and the docs, they're very busy”
- “When you do ask questions particularly about medicines of your GP, often they don't know you've got a real problem. So, there is a real problem. And the other thing is on top of that is that most of them will not admit that they don't know. They're like politicians. They go around in circles trying to obfuscate everything just so that they don't give the impression they don't know”
- “People will not speak up and say, well, hang on a minute, you know, I've got something to say about this [their needs/disagreeing with a GP] and it's just, it's stupid. It is ridiculous”
- “Doctors get a kick out of being able to speak to people in scientific terms and show you how clever they which doesn't resolve the problem and we live in a society where almost everybody, certainly of my acquaintances, is reluctant to speak up when they don't understand something”
- “One of the challenges for consumers or carers is the assumption that care is integrated, and most is not”
- [GPs don't tell us things] “Do people know about voluntary patient registration? It's a really positive initiative but how do patients find out about it?”

The relationship between GPs and pharmacists is affecting patients and QUM

- “You go to the pharmacy, and they give you this information, which the doctor didn't give you. And then there's this sort of tussle in a way of, how come my doctor didn't tell me about these side effects or whatever it is, and it puts the pharmacist almost in a very difficult position because they're providing advice on something that has been prescribed by your regular GP. And, you know, you weren't told, and it's sort of a really difficult journey. So, it's even more important in a way that the doctor starts the ball rolling by saying, look, these are the potential repercussions”
- “Quite a few pharmacies...get very frustrated with having to explain to consumers the risks and stuff and answer consumers questions about medicines they've been prescribed that that consumer doesn't feel confident or comfortable asking their doctor. The pharmacist gets frustrated because it takes quite a lot of time for them to do that, not that they mind but they see that as a doctor's job”
- “I think that we really can make that more harmonious push-pull. We can get the GPs and the pharmacist on side so that they realize how important and critical their part is in all of this.”

Communication between hospitals and primary care

- “A discharge plan should include a list of medications, what they are for and when I should take them, and why I should take them, in a clear, simple table”
- “I find that with the GP it's really tricky, especially if some of your medications you're put on by a specialist or something or a hospital because then some GPs are hesitant then to make any changes without you going back to that specialist or whatever, and I think it gets back to that time and communication skills, that are agreed, requires two.”
- After discharge it should be clear where patients go or who they call if they have questions, for how long the hospital is responsible, and how any hospital prescriptions can and should be filled once discharged
- [the] interface between primary health care and hospital/acute care landscape is problematic particularly transitioning between community and hospital medication regimes
- “We seem to be quite good with health literacy in hospitals. But I think that's when it fails, when you're trying to get people back into the community”

- “You’re meant to be able to ring the ward or a designated person and ask all those questions, [via the] numbers on the discharge form. Who’s ever done that? I’ve never done it”
- Communications between hospital and primary care – point of discharge can be a risky time particularly when a person lives alone. They may not have transport to get to the chemist, other challenges like mobility and sight issues – discharge is fraught if they don’t have ability to enact what has been prescribed.

Consumers need to step up

- [re supporting behaviour/cultural change around QUM] “When you go to a GP if they actually give you a new medication and they do the right thing and give you the handout. No one reads it. When you open up your medication. There’s a little instruction thing inside it, you don’t read it”
- GPs must encourage patients to ask questions and take the responsibility to step up
- The patient, if there’s something they don’t understand, [it] is their obligation to speak up
- Both parties involved have an obligation to do their bit
- “You can take a horse to water. You can’t make it drink. So, it’s up to patients if they’re going to read the posters in a GP surgery or not. And if there’s something on that poster, and they don’t understand, it’s their obligation speak up and say, I don’t understand this because you can’t resolve a problem for somebody if you don’t know about it. But that communication...it’s a two-way thing”
- “[we need] a change in our culture, change program, for people to get a bit of a backbone and speak up”

Overcoming barriers to improving QUM literacy in communities

Basic information must be easily accessible

Information on medicines and medicine safety

- Advertise what pharmacies can do to bridge the access gap. The following information would be useful:
 - Pharmacists can offer advice
 - Pharmacies can hold onto repeat scripts
 - Advice on safe storage of medicine
 - Offer safe disposal of medication
 - Impacts of sharing medications, particularly in families
 - The most common side-effects to look out for (and what to do about them)
 - Explaining trade names vs brand names vs generic brands and offer cheaper alternatives to those in need
- Applies to over-the-counter meds: when requesting cold and flu tablets the pharmacist asked if they had any existing conditions. The person had glaucoma and the pharmacist advised that they couldn’t take this medicine as pseudoephedrine is counteractive to any pressure conditions
- Pharmacists are more valuable than doctors in giving advice on what you are taking

Language and communications around medicines

- These conversations must start with clinicians. We’re asking so much of consumers, and there’s so little responsibility and little time on pharmaceutical and medical practices.
- They could all [primary health clinicians] be using ‘teach back’
- Medicine information/CMIs must be in plain English and must be offered to customers in pharmacies. The feedback is that this is currently not commonly happening
- “If a doctor gives you a new script as opposed to print out the information about the pros and cons of that medication and all the rest of it, you need a degree to understand what the thing says. Anyway, yeah, there is no simplified version”

- “A family member had cardiac issues and were prescribed a particular drug – when the script was renewed were asked do you know side effects? The drug had the potential to destroy function of thyroid so would mean you were on medication for rest of life”
- Medicine information must be available in languages other than English where populations require it
- Use only plain English and/or international symbols on printed tools so that everyone can understand them, whichever language they speak
- Provide more funding for interpreter services
- Improve packaging and labelling of medicines
- Be sure that prescription stickers on medicine boxes are not covering vital information on the box
- Improve government communication about trusted websites. There is too much information and too much conflicting information on the internet. [There must be more visible health department information about reliable sources to access on tv, radio, social media, GP waiting rooms, fridge magnets etc.]
- Connection with Indigenous patients: “They don’t understand purpose of particular medicines they are taking. If prescribed antibiotics they often stop taking them when they feel better. Better communication is needed as there is a lack of understanding of medication purposes and what is going on in their bodies.”

Specific tools

- As patients have an obligation to speak up if they don’t understand something, it would be helpful for consumers to have prompts with them to know what questions they can ask – a small card in a wallet or pocket, a QR code to access information easily; a small flyer or leaflet they can keep in a wallet or handbag. All such tools can be useful to different demographics
- “I mean, the magnet is visual, the fridge is something which is where the food is kept [so is accessible every day]”
- “Fridge magnets – we all have a fridge, most of us have fridge magnets, they can be posted, they can have plain English information or universal symbols to remind people what is available to them every day [medicine hotlines; reputable websites; places to go to ask information]”
- “The 5 questions [to ask about your medicines] would be great if you get home and have questions”
- “A site that explains common terminology on scripts/prescriptions/medicines. Doctors then can tell you to go to a specific website with the right information. how do I look that up until two in the morning? When I’ve got time.”

The broader context: culture & influence of families and community leaders

- Recognise and work with the multiple sources of information available to consumers and patients (and which can lead to misinformation)
- Friends and family as part of the healthcare plan, particularly where QUM is needed
- Recognising other primary health care roles such as Aboriginal Health Practitioners; Aboriginal Community Workers; Health Promotion Officers; Allied Health Assistants, nurse practitioners etc.
- Better government communication including regular advertising about reputable sources of information, medicines helplines, health direct etc.

Support, training, and incentives for GPs

- Provide GPs with other updated computer software and systems
- Utilise *HealthPathways* which has great potential for patients. It has the potential to be available for patients and to capture outcomes.
- Consider alternative workforce models, such as integrated pharmacy roles in primary health care teams to improve health messaging for medicines

- “Mostly people don't know or don't think to ask their GP very specifically ‘do you have any resources on this topic that you could share with me?’ I think patients need to be encouraged to do that”
- As 80% percent is forgotten in GP appointments and 50% is understood wrongly, active listening or Teach Back must be part of ongoing training for clinicians
- The RACGP Standards for general practices specify that GPs should be providing patients with appropriate-level written information, including visual media, or translators for those with low English literacy. There may be a possibility for strengthening this requirement as part of GP registration.
- Use the MBS and RACGP accreditation as tools as incentives to prioritise health literacy and QUM literacy.
- “Mandate the use of prompts” and tools by GPs for consumers such as Choosing Wisely's *5 Questions* and/or *5 Questions to ask about your medicines*

Education programs

- “Going back to education is the main thing not only for the consumer but also for the health providers and talking about the education in school”
- “We need to in our society, maybe [teach health education] in schools, teach people that you do need to speak up”
- Education packages to include health rights and health literacy/QUM literacy programs for use in primary and high school education as part of critical thinking/literacy/civics programs: “This would be helpful for adults whose children are their translators and interpreters”
- “Is there an opportunity to incorporate QUM into primary and secondary school health curricula, or embed [it] as part of critical literacy thinking in schools?”

Clinician Feedback

People don't want to look like bad patients (in front of the doctor)

Doctor versus pharmacist conversations

- “I think a lot of that comes down to that conversation between pharmacist versus doctors and patients often. Like what I found was a lot of my clients is they will have a completely different conversation with the doctor about what they're doing with their medicines to what they have with me literally, five minutes later outside of the doctor's office because no one wants to look bad in front of their GP. They're like, oh no, we can't tell the GP we're not doing the right thing with our medicines, but we're happily tell a pharmacist”
- “For a lot of patients when it comes to medicines there's this real the not wanting to look like you're being a bad patient [in front of the doctor]”

Not having a regular GP limits what people say to doctors

- “I think rural and remote sometimes compounds that [lack of communication between doctor and patient] by such a transient prescribing staff base...our patients who are the worst at telling their doctors are the ones who are in communities where we don't have permanent doctors and its always locums. No one's going to tell someone [their private health issues] they've never met before. Whereas they'll come and tell us [pharmacists] because they know us. I usually find a lot of my clients will have very honest conversations with me, but they won't have a doctor, I don't even know who that doctor is, [and the patient is thinking] I've never met them before, I'm not going to tell them my business, but you know, I'll tell you, so yes, I think what really has a has a place to play in it as well, with people, is not having regular GPs”

People can only absorb so much information on the spot

- “I think one of the other issues that actually acts as a barrier to that idea of the ideal consultation is the capacity to absorb a lot of information. Imagine the quantum of information that needs to be absorbed to be told you have a chronic disease or to change the treatment of one”
- “My mother would sit and tell her GP that whatever she says she totally agrees with, and she does totally agree with, but without asking a single question or take in 90% of it...”
- “If an elderly person or anyone walks into a doctor and gets a diagnosis, they are overwhelmed. So, they’ve immediately got this overwhelming diagnosis of diabetes and they walk out with a script and they don’t even think about what are the questions to ask”
- “I recognise that a lot of information that you give patients won’t be retained. So, what I encourage them to do is I tell them, there’s an information packet in the in the packet of tablets. I try to encourage them to read it once and just throw it away. Those information sheets again are incredibly small fonts, huge amounts of information, poor language, really difficult to get your head around. I try to be realistic. What I’m hoping is that they might remember headache, or, calf pain, because they’ve got a clot in the leg, you know, that they’ll just make them think ‘I need to ask somebody about this symptom because it be related to the pill’. That’s as much as I want them to do as long as they try to do that...I’m not going to quiz you on it. That’s another line I’ll use. I just want you to look at it once and hopefully it will trigger something.”
- “Some of the information that patients have to deal with from the pharmacist is very confusing”

People talk to pharmacists & nurses, not doctors

- “They will be like [to the pharmacists], well, by the way, what I did while I was in with the doctor was just rubbish, and this is what I do when I’m at home, which creates so much duplicated work”
- People are often honest with nurses and nurses are in a really good position to go over medication, discuss ways to assist people to remember and record their medication as they take it e.g. using apps, discuss side effects that may not otherwise be shared even in a pharmacy. I’m thinking, in particular, sexual side effects where people don’t say they just stop taking the medication.
- “People are complex with complex health problems however I don’t think we use the expertise of nurses near as much as we should be in general practice or primary care. Nurses are not funded through MBS (well they are as long as a doctor claims the Medicare money).”

Doctors can still be “empire builders”

- “I’m not convinced that a lot of, particularly urban metro GPs, are completely comfortable with nurse pracs. I’ve worked in the country, and I think they’re amazing...I think their role could be invaluable, but I don’t know that a lot of my colleagues particularly in urban general practice would share that view. I think still a bit of empire building out there and ‘this is my space, and I don’t want other people doing what I should be doing. And it’s my role’ which I think is a shame, but I think we have to be realistic”
- “You’ve only got to look at some of the hesitations and, I suppose ill feeling, that has been around since pharmacies have been involved in giving vaccinations and some of the consequences that have sort of happened...I know the colleges had responses with the pharmacies giving vaccinations now. Covid-19 might actually help that because we all feel overwhelmed with the having to do vaccination clinics...it’s absolutely frantic at our practice at that the minute...and the waiting rooms are absolutely chockers because you’re trying to do normal general practice as well as the clinics.”

The emphasis is with the clinician [to start the conversations]

- “I’ve just Googled that [Choosing Wisely 5 questions] and looking at it, if you’re a good GP, you’re actually going to be covering, ‘Why do you need this? What are the risks? Are there simpler safer options?’ Sure. It is

about developing health literacy in patients and encouraging them to ask if you know, it's not being covered, yes”

- “I actually wonder if many GPs actually ask the question. Do you have any medications at home that you no longer take? Do you know those should be returned to the pharmacy for appropriate disposal? Provide reasons for this etc and have that conversation around safety”
- “If it's a new medication, I think personally, the emphasis should be with the clinician...The patient, they're going on to medication rather than using lifestyle measures to manage their condition. I think the emphasis has to come from the clinician, that you need to explain to them...I personally take the view that you need to reassure the patient there are no stupid questions. There are no silly questions, if you go home and you think about this and you look on the internet and you get a question, come back, and talk to me. That's often a line I'll use particularly with antidepressant drugs...there's a lot of resistance around medication.”

The walk-in model of community pharmacists is good for patients

- “They'll go to the pharmacist who will ask them questions...can you do this? Can you do that? Can you do this? And then they can walk back into that pharmacist tomorrow without making an appointment without going through any rigmarole and ask them more questions. So, they develop that relationship...My mother knows her GP exceptionally well and he's lovely. But she knows the pharmacist better and if she's in the shopping centre, she goes in, she talks to her. She gets, you know that advice...all the time, without any booking. It's just that walk-in model, which is, I think very conducive to getting the information and there's also directed a bit more by the pharmacist about making sure you're comfortable taking this medication”
 - “Yes, pharmacists are very accessible in the community. I agree”
- “A lot of pharmacies do have little consultation areas and we have a section where we can block off, and make it into a set, only a small pharmacy. So, it's not big enough to have a designated room as much, but we can block it off and, and have a little chat to them, like doing like a little meds check, just sort of go over all their medicines with them quickly. And usually, that will lead to a few questions.”

There's only so much we can do

General literacy and health literacy, general knowledge is lacking

- “I know this is about quality use of medicines, but you've already missed the whole step about quality healthcare in general. And people have no health literacy, they don't know how many vegetables they should eat in a day. They don't know how much exercise they should do in a week; you know, we're struggling with that and you think that we're failing with medications? You know, there a way bigger issues at play if we can't educate people on how [silent patch], how do you think we're going to educate them on having diabetes?”
 - “I had a lady this week. I've re-initiated medication for her diabetes. And...she has been non accepting of her diabetes diagnosis for years because she's just like, as you say, 'I can't have that. I don't do that because I'm too posh to have diabetes', you know, like it's more than just medicine, that's the problem”
- “And then you've got all the complexity of people who don't, you know, English as a second language...and I work in disability. So, it's got a really, you know, the added complexity of that. So, it's really hard. People are really complex, with really complex personal life other things”
- “And it's about what's their responsibility. And, you know, some like you said, we haven't got the diet and all the others, and certainly in the covid vaccination discussion that we're living with it at the moment you can see some people don't base their responses on science, rather, what Facebook or someone will tell them”
- “I remember having a girl, once who came in, she was very upset. She would have been about 15 or 16 and she said that she had a lump in her vagina and, you know, she was petrified because she knew someone that had leukemia or lymphoma or something and she just thought, well, I must have cancer and she was very distressed. I'm like, look, do you want me to have a look and see what this lump is in your vagina? And, you

know, it was her cervix...there is no concept of health at all. They don't know how they actually fell pregnant or how not to fall pregnant. You know, it's so bad. We can't fix it, or we don't have the time.:

Prescriptions and medications pile up

- “Then there are people that get the prescription every month but never take it, so the doctor thinks they're getting it every month. They just keep piling them up. I've come across that too, doing medication [reviews]”.
- “I would say my mother would keep (and she doesn't because I go in and take them off her) but she would keep them because, you know, you don't throw out something if you've paid good money for [it]. So, you know, her medicines could be expired, five, 10 years, but she still got them just in case”
 - “That's true! And the doctor thinks I'm still getting a prescription so it's all okay.”

We need to know more about the decisions consumers make around medicines

- We encourage people to go to the one GP and to develop that relationship. I don't know the answer. My have elderly parents, they go to the same GP and he's lovely and I've met with them, and they have an annual health check and they do visit that GP weekly just for a social reason if nothing else and so they have this relationship. Their pharmacist is on first name basis with them. But you know, they've also got me in the background checking their medications. They still do weird and wonderful things. My mother took my father's panadeine forte, you know, which he was prescribed years ago because you didn't throw medicines out. So, there is still...that's me keeping a tight control. So, you know, there's a lot of other people who are trying to do the right thing who are still slipping... And as the GP said, I never prescribed panadeine forte--because I bagged them all up and off we went to the GP and then I said no, you didn't but she's elderly, she didn't look they were in the wrong spot, and she took them so and that would be so common. I'm sure I'm sure every GP would see, they're probably on a daily basis where someone has taken [the wrong medication/their spouse's medication]
- Why patients decide not to take a medication as prescribed, really getting insights into what were the real reasons? Was it because their mate had taken it and got some side effects, or was it because they had found some information on social media or the internet, or was it simply they had a change of mind, or was it too inconvenient? Was the regime that you were prescribing four times a day for an antibiotic for instance was that just not workable with their lifestyle? Getting some real insights as to why patients make some of the decisions they make would be really interesting and helpful because obviously once you know, then you can make start to address the fundamental problem.

Some people don't want to know

- People who are newly diagnosed by a doctor are frightened to ask the doctor, like all the implications... they're always very reserved when they first diagnosed with something new and sometimes, they're just scared... I had one fellow had diagnosed as diabetic... and he said, oh no, I couldn't possibly be: I'm not fat; that's not in my family; I couldn't possibly be. And he was totally disbelieving...and he came, and he got his script, but he said, there's no way I can swallow a tablet that big I just can't do it. I said, well maybe go home and just, you know, sit down and, you know, just try with a glass of water. And he came back, probably half an hour later with his wife and said I just can't do it. So, it was metformin and 1 gram. So, I said look, I'll just give you the 500 milligram tablets only sort of half as big. I swapped the script over for him. He came back the next day. I just can't do it. I can't take it. So...it was the combination of 'I don't want to be diagnosed with diabetes and I don't want to take the tablet'.
- And so he wasn't able to talk to his GP about that at all?
- Not really. No, he didn't want to not really know...I don't know how much more you can support them than that, but I find that quite unusual.
- How many people just don't want to, or are only interested in engaging in terms of you know, consumers/patients?

- I'd say this is a significant percent.
- I think some just don't know, like, I had a fellow one night come in late, with him been discharged from hospital having had a heart attack and he had his four medicines, and I got them all for him, explained them all to him and why he was taking them and asked if he understood. He said, oh yes. I was given these six months ago, last time I had a heart attack and I said, so have you been taking them since then? He said, oh, no, they only gave me a script for one long...And then so, you can't blame the hospital because I'm sure someone would have told him that there needs to be an ongoing, do you know what I mean? It's how far do we nanny state it to help them, but we have to in certain communities. It's a really hard one, you know in disability we have people who've been on the same medication for 20 years and you when you say to them or the caregivers, you know, we need to really review these medications--like this has kept me on the straight and narrow. I'm going to stay on it. So, it is a bit of choice and control as well. So, this person leaving a hospital, took their one script and yeah, you know really as an adult, you would hope people put up his hand and said to his GP and a significant percent of people would have gone to their GP and said, you know, had this script...
- Oh, he didn't have a GP because the first time he had his heart attack, he had never been sick before. And the second time he had his heart attack he hadn't been sick since the first time.
- Behaviour change is a huge challenge particularly in general practice where so many other factors can have a bearing and influence on how you do something. It's a real challenge and people get you get entrenched and into a way of doing something

Systems can fail us

Systems fail patients

- We still have a medical model of care in Australia rather than a social model of care, so we still go to a doctor and are expected to do what we are told. When we don't, we are 'non-compliant' rather than have time discussing why we may not want to follow the health advice.
- While I certainly value and have a lot of regard for what pharmacists and of the advice pharmacists give to patients, I do get a little bit concerned about what sort of record keeping is going on, with regards to, you know, where you keeping a record that you've given this advice to this patient, you know, when you're giving clinical advice to somebody as a GP, we have to make medical records to record that, you know what I mean, and if you're involved with doing vaccinations, what sort of records you keeping about vaccinating the patient
- It would be really useful if we were confident that the same advice when giving [it] has been received if the patient asked the pharmacist, so having the same sort of medicines and advice from pharmacies, should be from the same sort of source, of truth, if you like, as providing us, GPs and patients can access themselves at home off the internet.
- Short consultation times and how GP practice is funded doesn't allow for an extended conversation
- I'm not sure if you're aware, but one of the other aspects of poor remuneration in general practice involves billing for longer consults actually loses you money, you are better off seeing patients for short consults and packing more into the hour. The perversity of the system means the longer you spend with someone re: education, health promotion / prevention etc, the less you will earn at the end of the day. E.G.
 - Standard consult <20 mins, Medicare rebate \$39.10
 - Long consult 20-30 mins, Medicare rebate \$75.75.
 - 4 patients an hour = $39.10 \times 4 = \$156.40$
 - 2 patients an hour = $75.75 \times 2 = \$151.50$
 - The longer the day goes on, the wider the gap gets.
- I had one medication I did with a lady and she had two doctors. She had the male doctor for most of her stuff, and the female doctor...but neither of them knew about each other and both of them were giving a blood pressure tablets...
 - And she was taking both of them?
 - She was taking both.

- How is it possible that someone can have two doctors in Australia and they don't know about each other?
 - Well, very easy, very easy.
 - That's madness
 - Complete madness
 - But I would say there's a lot of people who do that all the time, especially women, think they go and see a woman doctor for women things
 - That's right
 - And they see their normal Doctor for other things
 - They also see their Nurse Practitioner however we would usually be sending info to the GP. I rarely get info back though.
- I think one of the issues with patients seeing multiple GPs is that they consider health to be simply a transactional experience. Patients are not customers ("the customer is always right!"). GPs have to have tough conversations and we aren't always there to tell them what they want to hear, give them what they want. Health literacy is poor, they don't realise that by fragmenting the care between multiple providers they are doing themselves a disservice. (And they see different providers and tell different stories to increase the chances they will get what they want.)
 - Does anyone ever offer to inform the other doctor? I [nurse practitioner] put my info into MHR so everyone can see what I'm prescribing. I also send letters to GPs when I commence, stop, or change medications. Of course if you don't know they see someone else...but again worth asking them and communicating across services.
 - I've got very elderly parents, and they somehow mystically believe that the doctors would just know about each other
 - People do not understand. They truly believe we can see everything. And every pharmacy is linked. And primary care is linked to tertiary care etc. They worry about their information being everywhere but don't understand that health systems and services are not set up to communicate with each other. To their detriment often.
 - We did a study in [our area] just of the first six practices to sign up to an electronic database project. And we found in those first six practices 15 percent of the patients appeared in the records on both practices. So people were using GPs much like you'd use Woolworths, you know, you'd go to your favourite one. Usually, the one you're familiar with but you happen to go to another one when it's convenient. That's what you do. Not so when I worked in rural, but that's the situation in the urban environment.
 - Closer relationships with pharmacists would be helpful.
 - [*HealthPathways* is] for GPs to use. And no one else really. And it's so that when we refer people into the hospital system, we don't get our referrals rejected because we include every single thing that they tell us that they want. So in a world of limited public funding, if you forget to include the colonoscopy report from 2010, they'll reject your referral. So in that list, there's a reminder: don't forget to include that colonoscopy histology result that you never got in 2010. So it's a big list about what each outpatients department, like specialty, will want and what they would actually cover, you know, so for example, I do a lot of women's health and the public system will not pay for a tubal ligation in a female who no longer wants to have any more children. And so they actually list at the top of the Gynaecology Clinic referral criteria, that they won't see people for a tubal ligation unless they've had multiple children with congenital abnormalities.
 - The reason why you heard a lot from PHNs is that the PHNs, or not all of them, that most of the PHNs see that as one of their roles is to take these *HealthPathways* and almost kind of clinical protocol the *HealthPathways* and tailor them for the local environment and then send them out to all the GPs. And so I hear a mixture in my role of people that love them and people that think they're just pretty much how [the previous comment] described them really...They can be really useful especially, you know, like I really use it with my registrars to help them understand how much information they really need to collate before

referring off to the surgeons for the cholecystectomy that they want on a patient...because they've got recurrent gallstone symptoms...

- It would be lovely if they were reversed and the information came back to general practice in structured machine readable way with all the right information.
 - Instead we're treated like the community intern.
 - These conversations are currently underway between BH and primary care in Geelong at least.
- I find the *HealthPathways* really useful. Like I'm pleased that they've done that. They are a really clear guide as to you know, what we can expect and I use them sometimes when I have a woman with an abnormal cervical screening result, the clinical pathways will tell me when I do that referral, what category that should be allocated, so it's very clear and then I can say, well, you've allocated this a category 3 which is to be seen within a year and I've done a referral with all these criteria and it should have been a category 1. So I can then write back and say, why did you allocate it? [incoherent] I think you've made a mistake. This is what your *HealthPathways* criteria are in our district. So it's really quite useful. And I am pleased that we have it. It reduces the mystery in the system because the public system is quite mysterious how it works.
- When I worked in South Australia, which is didn't use the public system because it didn't work.
- There's information dumps for what's available in terms of community organizations. There are often run by local governments actually. So they could produce books and web pages of where to go for physical activity. That doesn't cost anything near where there's a walking group or Community Garden or community choir or whatever it happens to be which kind of tackles loneliness provides a network for people and opportunities for physical activity, which don't otherwise exist. But there's a big disconnect between local government, which is not Health PHNs, which are health and, in general practice. So, there's lots of things happening but not joined up.

PHN funding & KPIs can limit their capacity/usefulness

- The relationship between GP practices and PHNs is really patchy around the country. And some PHNs have a very good buy-in with their GP practices and they are working partnership to solve multi-health problems and others, you'd hardly know there was a PHN there, just a lot of email spam and not that much direct impact on day-to-day practice, or on patient care.
- I guess involving local pharmacists in some of those meetings [with PHNs], that would be interesting. And maybe promoting joint educational sessions between pharmacists and some of the locals GPs
- Having postgraduate education events, continuing, professional development events where pharmacists were involved and invited as well so they could give some of their insights, into feedback...you know, patients will often talk to their pharmacist rather than mentioned something to their GP something to that.
- PHNs are organizations that have certain KPIs and indexed funding and a lot of it short-term project funding and so they have a project worker and something happens [for] a couple of years and then it fizzles out.
- There's not been very much requirement to evaluate the impact of PHNs on patient outcomes at all. And there's virtually no evidence of what they do for patient outcomes, which is a problem when there's a need to advocate for increased funding for primary care sector via PHNs.
- I am astounded that I speak to GPs who do not know who the PHN is. I also think it is the health professional's responsibility to have an understanding of their community. You can't blame a PHN all the time if you haven't taken the time to find out the info yourself, become a member, get the newsletters etc. That comes back to how interested you are as a health professional to seek knowledge

Lack of QUM/Pharmacy resources, especially for remote communities

- Lack of appropriate and accessible medicines counselling resources, particularly for Aboriginal and Torres Strait Islander people.
- Because I think one of the biggest issues we were faced with this is confusion

- The need for the use of a QUM system is becoming a definite need particularly with the problem we have in this district with rotating GPs. Some system needs to be developed to assist in ensuring people easily understand the medicines they are prescribed. I did however have a query about a person who is not a pharmacist assisting in this type of work. Ideally, I feel that a pharmacist should be attached to the practice. This could be through technology or maybe a health assistant with a pharmacy qualification with direct access to a pharmacist or under their supervision.
- Lack of access to pharmacists especially HMR accredited/capable and particularly in remote and rural areas.
- Limited skills of health professionals in counselling on medicines.
- And then there was another point in there around, funding more on-community pharmacists. I don't know if you've heard yet. We've got our new funding structure, for S-100 [section 100 pharmacy support allowance] support services, which is what paid for pharmacists to work in Aboriginal communities. We've just taken a 30 to a 100 percent reduction. We've got a whole bunch of communities that now have no funding for pharmacy support at all. Even our big communities got a 30 to 50 percent reduction across the whole of Northern Australia. So Pilbara, Kimberley whole of NT, North Queensland, outback New South Wales. Forget your money for pharmacists basically, we have just had the most horrific funding cut I've ever same and it is just devastating...It's Federal. And it is just absolutely diabolical. Everything we've said around the funding model that's per-patient-base would decimate remote health where there is not a patient base that huge costs to this delivery because of travel...Our most vulnerable patients. And they've actually defunded all of our dialysis units. So if you're on dialysis and you're on medications, which all of our dialysis patients are 15-plus tablets... no support at all for quality use of medicines work anymore. I absolutely agree that Aboriginal health services need funding in metro services as well, need funding but they can walk out the door and walk into twenty pharmacies in their area and we've got here...not a GP, not a pharmacist and they've lost their funding. So yeah, it's just crazy.
 - And then the other flip side of it is we're a small pharmacy business supporting remote Health Services, and I'm now potentially going to have to lose a pharmacist because we don't have the funding for everybody's wages anymore.
 - I actually do a lot of work at a national level with the guild around Aboriginal and Torres Strait Islander programs. And we had so many discussions with the [Commonwealth] Department [of health] in the lead up and they made so many promises that the new funding structure, that no Aboriginal community that's in a remote area would be worse off under the new model, all of these promises and then they went oh, we didn't quite have enough money as we thought so everyone just gets less...but they're the same time they're being so cagey. They won't release the formula. They won't release the base funding. They won't tell us the calculations and how they came to these figures. That's through the guild and through NACCHO. So we do a lot of work with NACCHO as well. Even through NACCHO, we're not at a point where the department won't return our calls about this issue anymore. They're not replying to any emails about it. They've just gone to ground.
 - Maybe this needs to be on the news as we come towards a federal election!
 - This should be in the national press as a disaster.

We need a national framework

- Agree lack of national standards/framework is barrier to consistent understanding and implementation of health literacy and QUM activities.

Solutions

Better promotion of existing resources

- Support and promote the utilisation of existing counselling resources. Underutilised resource is Medicines Book for Aboriginal and Torres Strait Islander Health Practitioners-
<https://www.remotephmanuals.com.au/home.html>

- Point people towards reliable sources. So I remember running a community event and was asked how do you search for health information? How do you Google health information without getting ads and people's opinions and just adding the word evidence in the search bar, made a huge difference to the pickup rate because then jump straight to mainstream effective sites.
- Role of consumers in determining gaps/preferences to inform improvements/strategies in health literacy (both individuals and health organisations)?
- NPS MedicineWise (NPS) would be a good example, where we know that if you want information about this medication, these are good sites. These are good resources. I would encourage you to use these websites rather than Google and maybe even if you prescribed a new medication, I think focusing on new medications if you had a, I don't know, like a business card with a couple of good website addresses on it that you handed out to people...you're giving them the option to get what we as a primary care provider decided as a reliable source of information. So off the top of my head NPS would be a good one
- People tend to go for what's top of the list. And probably it's unrealistic to think we can alter search engines to put what we see as medically related.
- I think the sort of danger with yet more and more and more resources is that it you get lost. As to what's the best and what's the most reliable source? I think I've always been a huge fan of *HealthPathways* and *HealthPathways* is making inroads...it's a really, really useful resource
- It would be really great if there we're sort of getting clinical decision tools and clinical support tools, decision-making tools...but to have that sort of succinct, patient friendly, easy language advice, that was applicable to you as the individual and that's a huge ask when I say that so that ideally you want the clinical decision software to be able to recognize what conditions the patient's got, what medications the patient's on and what the potential impact of the new medication might be. And then to come up with dot points that would be useful for both the clinician and the patient.
- There's new software...Primary Sense which my understanding is that Primary Sense is a sort of an add-on software package that's really sort of currently gathering steam if you like, in some of some areas of Queensland. And that has components of the same sort of thing as the medicine insight program, which can look at how you manage your diabetics and can do analysis and sort of audit search of your own personal software and it and it can just one of those decision support tools that might be able to help and influence some of the prescribing decisions that you make and some of the concerns that patients may have.
- I know my son who's obviously tech-savvy because he's younger than me, but he looks at Reddit and you know, and I'd never heard of Reddit before he started using it. But again, it's okay. It's one of those where you can just ask the question. You will get a response. You can ask a question...and you're getting completely unfiltered information

Needs a team approach, funding & training systems to support that

- I think it actually needs a team approach. It needs funding systems that encourage multiple bites of the cherry
- Courses & CPD for health professionals on how best to speak with people about their medicines to foster understanding and partnerships.
- It is about re visiting and re wording and encouraging and empowering people to take ownership of their health and we ae here to help guide. If we tell people what to do less likely they will follow instruction. If we invite people into their care more likely they will follow.
- It would be valuable to broaden the scope of activities to more than GP services, who are arguably already better resourced and have greater capacity to achieve these goals.
- Focus on supporting people in managing their health and working in partnership; enabling and empowering. Resist urge to 'put the onus' onto patients, as they are often the people with the least capacity and capabilities to manage this complex information. Recipe for disaster.

- I guess the scenario that you described where you pay a hundred dollars a year. I would look at that as a registration you're registering with a patient practice effectively or with it with a GPs. So that's a good. I like that as a concept because it means that there's a commitment from you as a patient to the practice... I'm a huge fan of registered lists... Apart from anything else. You can give Health advice that may not be what the patient wants to hear because, you know, the patient doesn't have the luxury of going to somebody else to hear what they want to hear... I think registered lists and registered connection, hadn't thought of it with a pharmacist, but I think that's a great idea as well means that you can get consistent advice as well. It's really really important. And obviously, there's that awareness and knowledge of the patient that is cradle to grave, which is always, there is the aim of what we really like to offer.
- As a clinician working at a practice, I'd be happy to take a number of phone calls, telehealth consults for that type of thing [short, quick answer sessions for patients]. And I get that sort of thing up. You tend to get the simple health concerns and health issues over the phone,
- Agree with highlighting role of pharmacists embedded in PHC services; need to expand to ACCHS and not just focus on mainstream GP services. Assist in addressing issues in remote areas. Funding needs to be equitably applied, recognising that it costs more to deliver services in remote areas. Support and training for RAN regarding communications about QUM in remote Aboriginal and Torres Strait Islander communities – also for AHP/AHW's (who are often local and bi/multi-lingual)?
- I think the idea of working closely with pharmacists, but preferably in practice, so optimum use of medication reviews and medication education where there can be that sort of interchange, an exchange of opinions between the GP and pharmacists to get the best practical solution. I think that makes a lot of sense.
 - Having a pharmacist in the GP practice?
 - Yes. So the model in my mind is to defund the community pharmacists as they currently exist, look for more efficient and cheaper ways of delivering medicines to people from warehouses...but have a very well-funded and well-supported use of pharmacists with all their training working within multidisciplinary teams, in the general practice, doing the medication education, the quality use of medicines, the audit and feedback sort of work with the systems. I'd like to be able to say, look, I want to start [you on] a new medicine. I can tell you all about it, but I'd really like you to spend a bit of time with my pharmacist in the practice about the practical implications of living with this medicine day by day and what you need to know about it and then we'll meet again and make sure that it's all going to work before you get started. And that's the sort of model that, you know, occasional I've managed to make happen, but it is not funded. It's not part of the design of our health system at the moment. So you'd actually have to take some of that 7.8 billion dollars that's currently used in dispensing and all those fees for the monthly pick-up of your regular pills and repurpose that money into something more valuable.
 - We are still ignoring how effective nurses could be in primary care.
- Wouldn't it be great if we could have a system like *Safescript* that identified prescribing and dispensing of meds for all meds not just drugs or addiction
- Some of the points made about patients having two or three GPs and not having a regular GP... I mean there's that's been a problem in the Australian system that number of people have tried to address and, my opinion at the end of the day, it really comes down to the individual GP... if the patient has a high level of trust from you, as their GP, not only will they trust your decision with regard to the medicines you prescribed but they'll feel comfortable asking about things... and that comes again, back to training programs for doctors in training.

We need more support workers (nurses and peer/link workers)

“Social prescribing: where doctors and nurses refer people, connect people more and help assist them to attend non-health services, so think men's shed, community choirs, things like that, and peer support groups and the missing ingredient to me, really make that happen. Other than us, a knowledge base of what's out, there is the link worker role.”

“...and the key thing is when they work, and when they're good things, we've going to make sure that they get out there, they become more normalized and they get funded in the long-term rather than just seed funding.”

- Consider other access options tele-pharmacy services for remote health services- though only when supported by on the ground staff, including Aboriginal Health Practitioners.
- I'd like to circle back to something that was mentioned earlier, which was about peer support and the barriers to peer support as a GP is, this all sense of confidentiality and how would you organize it plus, who's going to do the work and make it happen? So they've been a couple of submissions that have been pulled together to try and embed the concept of social prescribing, where doctors and nurses refer people, connect people more and help assist them to attend non-health services, so think men's shed, community choirs, things like that, and peer support groups and the missing ingredient to me, really make that happen. Other than us, a knowledge base of what's out, there is the link worker role. And so, there's the submission went in from the consumers Health form, and the RACGP, and mental health Australia to fund a demonstrator project through 10 PHNs of a Link Worker role to see how that would bring social prescribing to the fore and it make it more practical. And similarly, another project with equally well organization, and the Australian Health policy collaboration have been focusing on people with serious mental illness and the role models of peer lived experience and peer workers in people with mental illness. And so there's some there's certainly been a lot of thought and some policy documents to try and support these things to, to eventuate. Government does try and roll things out through PHNs, as its preferred way of doing things at the moment. So we might see little snippets improving the situation. And the key thing is when they work, and when they're good things, we've going to make sure that they get out there, they become more normalised and they get funded in the long-term rather than just seed funding.
- I agree peer workers and social inclusion [is] really important.
- So, I mean there were few and far between but the specialist nurses, especially dermatology nurse or community, mental health nurse or somebody, an arthritis, rheumatoid arthritis specialist nurses, we have a handful in the whole country. But where they exist they do this care coordination and answering questions, approachable, accessible, and informed, but not as scary or as always time poor as doctors. And so they, they're really part of the support network, the wraparound care for people with serious conditions, but they're just rare.
 - Maybe rare because we are not funded appropriately. Practice nurses do not have MBS item numbers. Nurses are not visible and so not counted in stats, data etc because doctors are claiming the MBS item numbers.
- I saw in your recommendations in there was discussions around Aboriginal and Torres Strait Islander communities and discussions about remote area nurses. I would probably substitute remote area nurses for Aboriginal Health practitioners. They really are our saving grace in medication education, but they lack empowerment they lack support and they lack consistent education around quality use of medicines. I've had discussions till I'm blue in the face with NPS about the need to support training for Aboriginal Health practitioners to empower them to do quality use of medicines education. Every single time a patient comes

into a clinic to pick up medications, the doctor's not there, the nurse isn't there, the pharmacist isn't there. The local Aboriginal Health practitioner who is normally a family member is there every single time. We want to talk about repetition and reinforcement around medication education. It's the health practitioners that do it. Parachuting in pharmacist like me despite whatever, you know, good I do when I'm in a community, doesn't solve the problem because I'm there one week of every six. What do you do the other five weeks when you go and pick up your medication? No one talk to you about your tablets. So that I would really kind of have a look at that.

“Every single time a patient comes into a clinic to pick up medications, the doctor's not there, the nurse isn't there, the pharmacist isn't there. The local Aboriginal Health practitioner who is normally a family member is there every single time”.

People trust nurses: fund them

- The system should include nurses being recognised for their skill set and utilized appropriately. Oh and also being able to be paid for the work they do not someone else being paid for the work they do. Never was this more obvious than at the beginning of a pandemic in Australia we saw practice nurses losing their jobs. Why? Because they were not able to earn money for the GP practice. Absurd!
- People trust nurses. In fact most trusted health profession for over 25 years. The government should use that! The community value us. The government doesn't sadly otherwise they would rectify what is a failed primary care funding model.
- Nurses whether it is in hospital after the specialist has done his /her round and explained something to the patient the nurses who are there 24hrs a day are the ones that reenforce the info. Using nurses in primary care to their full capacity could add great depth to patient understanding of medication safety.
- The nurses already have quite a lot of telephone time. And one of the problems with the vaccination clinics is that they getting behind even with those pathology follow-up periods.

Ways to tackle misunderstanding

“Misinformation could be tackled by actually saying that any product, food or supplement or anything else [that] has health claims on it, those claims require to be evidence-based claims. Otherwise, they can't be made. So that's a beefing up of what TGA have for their advertising of medicine standards, to extend them to all health claims and you would very rapidly change some of that deluge of information that people receive.”

- I think there's some low-hanging fruit that you could tackle around misinformation and around pointing people towards better sources of information. So the misinformation thing could be tackled by actually saying that any product, food or supplement or anything else [that] has health claims on it, those claims require to be evidence-based claims. Otherwise, they can't be made. So that's a beefing up of what TGA have for their advertising of medicine standards, to extend them to all health claims and you would very rapidly change some of that deluge of information that people receive about whether they should be eating probiotics or antioxidants or whatever else it is today. So that's one thing we [know that is] straightforward enough, but requires political support.
- Top of the wish list would be for more patient friendly resources from a consistent source of truth... patient-based language to the resources and information that's available. So having a greater emphasis on the information being provided in a way that the consumers wanted to be provided and that's not just printed or electronic. It's the individual language, layman's language. It may be for certain medications, if you have these conditions and you might be on drugs for those conditions.

- Funding models to include translation of consumer resources/information into key Aboriginal languages (and validation of translations)?
- If we can actually give patients a couple of links on a as you say tear off pad or a card and promote that that that would that would hopefully make a difference
- I don't think we write things enough for people in simple sentences and points. I don't think it's being a nanny state when I provide my patients with written instructions how to start or change medications over.
- A real challenge to GPs is the information that patients get from social media around why they should or shouldn't use certain medicines...social media seems to have an awful lot of sway...I do think we tend to still take it for granted that if we, prescribe something, the patients will take it. I don't think there's another realization that a lot of patients, not all patients, a lot of patients will question and do their own research, if we prescribe them a new medication and unfortunately the places they go to, to do that research are not the best, are not reliable and are often social media-driven...I think the first step is an awareness that that's what patients may do. And how can we address that is the sort of next step.

Health education must start at school

- So, some of that, how do you recognize information as good information needs to be a public campaign needs to be embedded in schools. It needs to be embedded in health worker curricula to be able to share that information and to help kind of coaching patients around better information.
- Yeah, all the consumer groups liked the idea of talking about having education campaigns starting in primary schools. Is that something that you think would...?
 - Yes, yep. It starts very early [unanimous agreement]
- I think this comes back to education in the beginning, you know, by the time they've had the heart attack in their diabetes diagnosis we've already lost so much time. We should have been talking to them years before they even had interface with the health system. They do need to get taught at school. Their parents need to teach them their parents probably, don't know. So that's why rely on their school
- Health literacy work needs to start before people get sick, so whilst anything PHNs could do to help is great, it then essentially becomes secondary prevention work because the initial problem has already happened
- You need to reinforce [primary school education] in high school because you know, it's high school students who are going to have contact with primary care that they're going to remember and learn from. So some education at that level and also because that's when the student starts to take some level of responsibility or interest in their own health. I mean, certainly at a primary school level, getting our kids to become comfortable talking to nursing staff GPs, pharmacist about health issues. So for junior younger age students to be aware that it's okay to talk about things and it's okay to bring these subjects up so that they have the opportunity to learn a little bit more about what their concern is about... even an awareness of that just knowing that that when you come into the doctor...that you come for certain issues. You may be offered treatment. You may be offered...very, very straightforward advice...I try to keep the focus with the high school student with a parent has come with them. So to try and encourage them that this is their responsibility as well to a degree. So yeah, I think it would be helpful. If it takes me two minutes because I'm an experienced GP. Well, that's great. But it doesn't mean it was a silly thing to ask. If it means that that thing that was worrying, you has been addressed, which is what we want. That's the bottom line. So, please ask.

Useful data system for PHNs and prompts for GPs

- Embedding health literacy and QUM resources etc. in all *HealthPathways*.
- A printed sheet like a prompt...So, if there's a prompt that the patient's got the...and if they bring up something because of that sort of resource, I think that's great...I certainly think it should be explored and it's a good head start if someone else has done a lot of the work and we can access that sort of resource. That would be great. Yeah, that'd be great...I think actually in a pharmacist would be better. Probably both [GP and pharmacists] but in a pharmacist...If they're dispensing medication or a new medication for that patient coming in...then they

give them the little list, the five questions if it's a new medication, or because it's a new patient. They still give it to them because effectively it's a new medication to that individual...I think that would be good but having it available in both is probably the way to go

- So myself and a colleague [name] and our PHN decided to work on an IT solution with a view to being able to electronically read, medical records, de-identified, so privacy was maintained, and to do that in real time. And the advantage of real-time is that then when there's an issue to do with prescribing, you can send a pop-up alert to the GP the moment of being about to press the print button. And so we designed the system to look for rare, but dangerous incidents that would not be picked up by the in-built software that the GPs are using to prescribe. And we got about a 40 percent change in behaviour on that alert. So it's having a significant impact. And we've recently added a further functionality where we can prompt for gaps in care which might be the monitoring of medicines, it might be the absence of a medicine that's indicated, or the presence of a medicine that perhaps is being overused. So working, the system will, for example, let's take diabetes, read the average blood sugar from the pathology file and go oh, this person's potentially being over-treated with medication and therefore prompt for de-prescribing and most prompts are there for prescribing. But this prompts for de-prescribing which I think is great. So that's a system called Primary Sense. And the good news is that about 19 PHNs around the country are considering adopting it, but it's it covers 90% of the population of [the region] and the GPs interact with it intensively and positively and they find that alerting and the care Gap prompts not too intrusive because we've tailored them not to be too intrusive and quite helpful. But at a PHN level it allows you to pull information to look under the bonnet of primary care and see what's happening. So you could see who's being prescribed, what for, what reason and in what numbers, and whether those people are having the requisite monitoring to provide safe care. So you can do a lot of the same things that the medicine insight data does but with the real-time option, you can actually intervene. And with the unique patient identifiers, you can follow-up to see what happened as a consequence of your intervention as well. So I think that's a practical way of in terms of influencing GP prescribing and quality use of medicines.
- And then there's a couple of other people completely unconnected with that, that are looking at computer decision support for the use of pathology and for the use of imaging because that came out of the medical benefit schedule review process that call for real-time computer decision, support that tries to I guess, a bit like *HealthPathways* to provide useful information to GPs (that you might see a person with a particular set of conditions only once a years to how you're going to be bang up-to-date and know what to do about that condition?)
- Just ask PHNs you mentioned short-term, you know, piecemeal funding, do you think it would make any difference if the funding model was different?
 - I actually think what would make a difference is some kind of national strategies of the outcomes you're looking for. So if it was seen as a priority to improve health literacy, then a short measure of health literacy and the requirement to see that improving and some opportunity to kind of show and tell about what's leading to Improvement and what's not leading to Improvement. And also, if you don't measure it, if you don't see any outcome, then it's really hard to seek long-term funding.
- I think very succinct information packs for patients in patient friendly language would be, would be really, really useful the CMI's, really good. It's just too much information. It's not very user-friendly.

PHNs and NPS MedicineWise should fund small projects in small practices, not one-size-fits-all

- We initially had quality use of medicine small project grants with our small project grants, but we applied for some under QUM that were actually exceptionally successful and still have continued to this day for what was less than 20,000 dollars in spending to do things like, let's go talk to every Aboriginal community in the Kimberley and find out their interpretation of the symbols on Webster packs, which then led to the result of 'nobody understood' the symbols on Webster packs because they're not culturally appropriate and therefore we have to change how we talk about medicines in the Kimberley we don't use times and symbols because people are not taking their medicines at the correct time of day. And I think that's where the PHNs have such a

role in funding grassroots, small projects that make a difference for individual communities. This one-size-fits-all--I know NPS do a great job, but they do a one size fits all which actually means not actually appropriate for most people not for my clients in Aboriginal communities that I'd never use NPS resources for that very reason they're not culturally appropriate, you know, and that's where the PHNs I think have such a role where they can fund small GP practices to run small projects with their patients around quality use of medicines and those sorts of things. So that's where I think the PHNs have a role to play.

- They should be more responsive to the community and what that community wants.
 - And they need to fund local clinicians instead of wanting to parachute in external clinicians (who's never lived and worked in the area, but has lots of opinions) to sort problems and then devaluing those that actually have local knowledge.
- I think a small practice or, you know, a group of patients within the same factors that have the same issues for like a diabetes, could meet together as a group of patients with somebody coordinating them to talk about their medicines....
 - Yeah, but who's going to facilitate that you know, like we're short on GPs. We're short on nurses. We don't have allied health professionals. The pharmacist too busy. Maybe in an urban environment, whether there's lots of work force or something. Is that a magical place? I don't know.
 - I think what's being said it's also too is that there's just not one approach. So really important for Rural really important for Aboriginal Community, certainly in disability or mental health despite the best people's work and intention towards it they still in these big slips and gaps and people who won't engaged or can't engage.

Buy a national subscription for all doctors to the therapeutic guidelines

- One of the thing that's, and the most effective national guideline, for most medicines is actually therapeutic guidelines are usually either the guidelines, the Australian medicines handbook is a pain to find a way through midst and buy medicine, but the therapeutic guidelines still exists behind a pay wall. So doctors can't access it without paying a subscription, patients can't access it. So I think that would make some sense for that to be purchased for the population of Australia. Pretty much like, we purchased the access to the Cochrane Library database for Australia.