CONSULTATION RESPONSE

Senate Community Affairs References Committee Inquiry into the My Health Record system

September 2018

Allied Health Professions Australia (AHPA) welcomes the opportunity to provide feedback to the Senate Community Affairs References Committee Inquiry into the My Health Record system. AHPA is the national peak body representing allied health professions. We have 20 individual member associations, and a further six organisational friends who represent allied health professions or professions closely aligned with the allied health sector. The AHPA membership represents some 93,000 allied health professionals working across a range of settings. Our friend organisations represent a further 5,400 professionals.

Those allied health professionals work across not only the health sector but also across education, social services, disability and aged care. AHPA and its member associations are committed to ensuring that all Australians, regardless of their background, socioeconomic status or individual abilities, can access safe, evidence-based services to support them to realise their potential for physical, social, emotional and intellectual development to participate in life fully.

This submission has been developed in consultation with AHPA's allied health association members.

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Audiology Australia, Australian Podiatry Association, Australasian Society of Genetic Counsellors, Australian Association of Social Workers, Australian Society of Medical Imaging and Radiation Therapy, Australian Music Therapy Association, Australian Orthotic Prosthetic Association, Australian Physiotherapy Association, Australian Psychological Society, Australian and New Zealand Arts Therapy Association, Australian and New Zealand College of Perfusionists, Chiropractor's Association of Australia, Dietitians Association of Australia, Exercise and Sports Science Australia, Occupational Therapy Australia, Optometry Australia, Orthoptics Australia, Osteopathy Australia, Rehabilitation Counselling Association of Australasia, Speech Pathology Australia.

Introduction

The introduction of the Personally Controlled Electronic Health Record (PCEHR) in 2012, now known as My Health Record, was welcomed by Allied Health Professions Australia (AHPA) and its member associations. AHPA recognised that allied health practitioners often work in relative isolation from other health professionals and we believed then, and still do, that the system promised significant opportunities for improved access to important health information and an ability to communicate more effectively with other health professionals. Despite the allied health sector's interest in the system, the initial rollout of the PCEHR did not actively engage the allied health sector or seek to facilitate access to conformant allied health software options. As a result, use of the system by the sector was hampered by a number of structural and systemic issues resulting in very limited take up.

Since then, AHPA has advocated with the Australian government on behalf of its members, arguing for increased access and support through engagement with the National Electronic Health Transition Authority (NEHTA) and the Department of Health. An approach to the Health Minister in 2016 and follow up engagement with the Department of Health resulted in a small grant that supported AHPA to undertake activities to support allied health providers involved in the various Department of Health My Health Record participation trials in Far North Queensland and the Nepean Blue Mountains region. That work showed many structural and systemic barriers to registration for, and use of, My Health Record by allied health providers. It also showed the need to support increased digitisation of the allied health sector as a key enabler for use of My Health Record.

In response, AHPA and its member associations initiated a number of activities to support improved digitisation in the allied health workforce. AHPA ran a number of digital health workshops with its members, as well as with the Australian Digital Health Agency (ADHA) and software vendors to identify ways to support increased use of digital products by allied health practices. A range of approaches have been made to the software industry in the hope of finding solutions to the lack of conformant software for allied health practitioners. Despite positive engagement, no solutions have yet been identified and software vendors remain unwilling or unable to fund the development of My Health Record conformance. AHPA also funded and delivered a series of five webinars for the allied health sector focused on supporting practitioners to understand the role of technology in their practices and supporting decision-making about clinical information systems for allied health. In addition to AHPA work, some of our individual member associations are undertaking ongoing work to support their membership in the digital health space.

While My Health Record has continued to develop and improve, AHPA and its members remain acutely conscious that there remain ongoing barriers to use of My Health Record by the allied health sector. AHPA has continued to work to address these barriers, developing a strong working relationship with the ADHA. We very much acknowledges ADHA CEO Tim Kelsey and CMIO Monica Trujillo, as well as other key agency staff, who worked with AHPA to map out opportunities and challenges for the sector and to establish an ADHA/AHPA allied health working group focused on progressing some areas of work. That group met throughout 2017 and into 2018 and focused on increased use of My Health Record by the allied health sector, primarily through a digital health champion initiative, and addressing structural issues limiting access to the system. It also resulted in funding for a number of awareness activities earlier this year, aligned with the My Health Record Expansion Project and the broader provider awareness campaign being undertaken by the Agency. AHPA worked closely with the Agency to deliver communications information through its members, participate in the training of allied health champions, and to deliver a digital health showcase event for the sector.

Despite our positive engagement with the Agency, some of the key barriers limiting access for the allied health sector remain and will require a more serious commitment of time and resources to address. The registration process for any health practitioner not covered by the National Registration and Accreditation Scheme (NRAS) continues to be far more onerous than that for those that are registered with the Australian Health Practitioner Regulation Authority (AHPRA) and includes a need to renew registration yearly. This is perceived by the significant workforce not covered by the NRAS that the Australian government does not seek their involvement.

Even more frustratingly, AHPA notes the ongoing lack of viable conformant software options for the sector. We note that the Australian government has financially supported a large number of software vendors in other sectors including general practice, pharmacy, pathology and diagnostic imaging to make the necessary changes to ensure their software is My Health Record conformant. Other governments have funded access to My Health Record in hospitals. That funding has been critical to providing access for those health professionals and in the absence of similar funding initiatives for the allied health sector, will mean that the allied health sector continues to be only peripherally engaged in the system. While we acknowledge the greater fragmentation of the software market for allied health, we also note that government support has been provided to vendors with a smaller market share than some of the allied health software providers.

The allied health sector sees the benefit of and is eager to play a role in My Health Record but needs a realistic commitment of funding and resources for that to be achieved. We hope this submission will help highlight the needs and opportunities that exist in the engagement of the allied health sector in My Health Record.

Responses to the terms of inquiry

The AHPA response addresses all areas of focus and have been structured to follow the individual points of inquiry. We encourage the Committee to contact us if additional clarification is sought on any point.

A. The expected benefits of the My Health Record system

AHPA takes the position that the My Health Record system has the potential to significantly improve the accessibility of patient health information for health professionals and health consumers. This carries clear benefits in a range of scenarios, from increased accuracy of medications information for older people, to access to important health and allergy information in situations of trauma. Many of these benefits have been documented in a range of submissions to other inquiries into My Health Record and its precursor, the Personally Controlled Electronic Health Record as well as in reviews of similar systems internationally. The benefits of My Health Record for the allied health sector are also significant, though not necessarily as obvious as some of those in the medications and medical space. Use of My Health Record will improve the efficiency of patient care and allow practitioners to more effectively understand their patient's health with clear benefits to patient care. This is also relevant where allied health professionals play a role in helping support the overall health and wellbeing of a person beyond their own clinical interventions.

The key current challenge for many allied health professionals is that they are most likely to work without significant health information about a patient. Allied health professionals work across a broad range of settings including hospitals, rehabilitation facilities, within schools and other education providers, in community health services and an ever increasing number now work in private practice. Access pathways for allied health services vary significantly. As primary contact providers, many allied health services are the first point of contact with a health consumer experiencing a particular health issue. This might include anything from a musculoskeletal sports injury, to speech and language difficulties for a child, to ongoing issues arising from a traumatic injury or surgery. Many consumers of course are referred by other health professionals including general practitioners and specialists or even within a hospital network but there is little consistency in the quality of the information provided in those referrals.

This means that that allied health practitioners often operate without access to detailed health information for the consumer. Referrals may lack sufficient detail, consumers may see a practitioner directly, discharge summaries may not be provided to a practitioner. As such practitioners are heavily dependent on the information they can solicit during initial assessment sessions. However, this process is time-consuming, may be inaccurate and consumers may unknowingly not share information that may impact on the quality of care that the practitioner can provide. A functioning, effective My Health Record system will address these issues, provided allied health practitioners are able to access it. The benefits are also likely to go well beyond the health system and include disability, education, social services and other areas allied health practitioners provide.

However, as highlighted in the introduction, governments have not chosen to prioritise investment in access for the allied health sector. AHPA contends that one of the reasons is that the a key driver of government investment has been in achieving health system benefits relating to costs and system efficiencies with the intention that these will balance the cost of the system, e.g. reduced duplication of pathology or diagnostic imaging tests and reduced medications complications. The benefits to consumers of more targeted and effective allied health care may be less tangible and may be more of a consumer benefit and less likely to flow on to governments.

AHPA contends that the highly successful work done with the general practice sector provides a clear structure for enabling other sectors such as allied health. Between funding of peak bodies, ongoing in-practice PHN support, the practice incentives program and software vendor funding to offset any investment costs, the Australian government has a strong blueprint for how it could achieve far greater use of the system by allied health and specialist practitioners. Conversely, it is also clear that in the absence of similar subsidisation, the allied health sector will need to invest their own funds to purchase software and train themselves and their staff. Given the likely small financial benefit in use of My Health Record for allied health practices and the systemic barriers that remain as a result of the registration process for self-regulating (non-NRAS) professions and the lack of conformant software options, AHPA is concerned that the potential for strong allied health sector involvement will be missed.

B. The decision to shift from opt-in to opt-out

AHPA supports the move to opt-out, noting that there is clear evidence that the effectiveness of a shared record system significantly increases as a result of building a critical mass of consumers with records, provided a commensurate number of providers are using and adding information to the system. Our own involvement with practitioners involved in the 2016 opt-out participation trials and understanding about other similar international systems shows that the system becomes vastly more effective and the benefits far more significant as the volume of users grows. Conversely, our longer-term engagement with the system and its precursor show that without that volume of consumers, the benefit to engaging with the system isn’t there and practitioners may seek in vain to make use of the system, finding that their patients don’t have records or these don’t contain relevant health information.

We also note that there are situations in which providing consent under an opt-in system can be difficult despite support from the parties involved. We note this to be particularly the case where a person lacks capacity to make their own decisions due to disability or illness. There are significant logistical difficulties for those involved in supporting the person to consent on their behalf that are addressed under opt-out, particularly if the person lives in care while their family members are those with the ability to consent. We further note that the consumers impacted by this may be among those most likely to benefit from having a My Health Record.

We do note that it is essential that the opt-out process is supported by a rigorous information campaign to support consumers to make an informed and careful choice about whether to opt out. We believe that the introduction of legislation that allow the deletion of a record after a record has been created will address some of the challenges that may exist for some people in having a record created and subsequently determining that they would prefer not to have one.

C. Privacy and security, including concerns regarding:

i. The vulnerability of the system to unauthorised access

AHPA recognises the significant potential for unauthorised access to patient health information created by My Health Record. The design of the current system is such that access is via a large pool of health providers who differ in size, structure, and in the way that they are likely to access the system. While many health practitioners will use the National Provider Portal, a system that is likely to be highly secure due to the use of the Provider Digital Access (PRODA) gateway, many others will use a hospital-based portal or a range of different clinical information systems designed by commercial vendors for a range of organisations types.

The design of the My Health Record system means that many of the protections against authorised access are legislative rather than technological and are dependent on the processes and procedures implemented within a practice. For example, current implementations in general practice clinical information systems utilise whatever security protections are built into the local system rather than the two-factor authentication process and automatic timeout security system that underpins access to the Provider Portal. Yet the Portal is a read-only system whereas conformant clinical information systems can be used to add information to a record.

AHPA also notes the importance of education of practitioners and practice staff about appropriate security. We are aware that the Australian government has invested heavily in supporting practice security in general practices. Funding for both the Royal College of General Practitioners and the Australian Association of Practice Managers have resulted in training and resources such as the Computer Information Security Standards space to support understanding and appropriate processes in general practices. It is important to note that other parts of the health system, such as the specialist and allied health sectors, have not had the same funded activities undertaken which increases the risks that practices in this space do not have the same knowledge and understanding. This significantly increases the risk of incorrect or unauthorised use of the system and a risk to the practitioner. AHPA strongly argues that there is a significant requirement for investment of time and resources to address this knowledge gap through work with the allied health peak bodies and the sector.

AHPA also notes that more could be done by software vendors to reduce the capacity for local systems to remain unlocked and unprotected by passwords for extended periods of time, however this will depend on the willingness and capacity of those vendors to implement the changes that are required. Any government funding that supports software vendors to integrate My Health Record should focus on the local security aspects of systems in addition to current security requirements.

ii. The arrangements for third party access by law enforcement, government agencies, researchers and commercial interests, and arrangements to exclude third party access arrangements to include any other party, including health or life insurers

AHPA supports the passage of legislation that will further limit access to health information where it is not part of patient care. AHPA further contends that while it is necessary to ensure that potentially sensitive consumer health information is accessed appropriately, some of the key issues around access to information in My Health Record currently being debated in public relate only peripherally to the system itself and instead relate to broader issues about the negative impact for consumers related to certain health information becoming known.

AHPA notes that our members regularly receive reports about consumers experiencing genuine discrimination in relation to employment, access to insurance, particularly income and travel insurance, and access to services. As a result many practitioners that may deal with sensitive health information are highly concerned about the potential risks that arise from use of My Health Record and access to the information in a record by some third parties.

While these issues are not directly related to My Health Record, AHPA contends that the current discussions around access to health information could and should be addressed through targeted public consultation that seeks to identify the real issue areas and to drive broader reforms around discrimination on the basis of health conditions, particularly mental health conditions.

D. The Government’s administration of the My Health Record system roll-out, including:

i. The public information campaign

AHPA’s engagement with the Agency and awareness of the public information campaign suggests that there was extensive work done by the Agency to identify and reach a broad range of different target groups through its public information campaign. AHPA is not aware of any previous work around My Health Record awareness that was quite as comprehensive. AHPA also notes that the campaign made significant use of health practitioners, in particular general practices, to inform consumers. We understand that this is based on significant evidence about consumer trust and where they are likely to seek information. We note that this approach has resulted in significant inconsistency from one practice to another.

AHPA further contends that the campaign design, while seemingly sound, did not provide an effective means of competing with the negative campaign that played out in major media. From our perspective, certain interest groups were able to disproportionately direct the public discussion in the initial rollout period, often inaccurately.

AHPA also notes that there is a defacto endorsement role in any government campaign. By limiting the reach of this campaign, consumers and practitioners were presented with a contrast to other campaigns carried out by government which have been characterised by extensive television campaigns and much more obvious advertising. AHPA suggests that the impact of this has been the ability of some commentators to argue that government is surreptitiously carrying out its opt-out campaign, a perception that has fuelled the public dialogue around government control of personal information and concerns around the safety of health data.

AHPA believes that the key change required for the communications campaign is a means of providing consistent, national coverage that balances the previous negative campaign and is ready to react if privacy advocates and other interest groups again run a campaign during the closing weeks of the opt-out period. AHPA further argues that it will be essential to ensure that a refreshed campaign addresses the key concerns that have played out in media.

ii. The prevalence of ‘informed consent’ amongst users

AHPA contends that the issue of informed consent is one that is impacting heavily on the confidence of practitioners in relation to their use of the system. Our experience suggests that allied health practitioners are not currently using My Health Record in any significant way and the general awareness information has not yet sufficiently addressed this uncertainty among practitioners. This is leading a proportion of health professionals to defer to not using the system and to a position of overall concern about their patients using it.

One of the key challenges with the debate relates to what does and what does not constitute informed consent, where the question of informed consent is important and where not, and how this intersects with other issues around protection patient privacy.

Our position is that more clarity needs to be provided about how consent operates within the My Health Record framework and how this might compare to the way consent operates outside of My Health Record. For example, clarity around what patient health information can be accessed through the courts and through other means and in what situations, both within and outside My Health Record would benefit consumers and providers.

In addition, AHPA contends that some of the key current issues around informed consent relate not specifically to the notion of whether a practitioner has or requires patient consent to use and add information to My Health Record, which is addressed in the legislation, but rather to the risks associated with some health and other information being held in a person’s My Health Record. This is a significant issue for some parts of the allied health sector and reflects concern about a duty of care to consumers.

We contend that health practitioners have an important role in providing information and guidance to consumers to help ensure that they are aware of how their health information might expose them to unintended risks and to help consumers make decisions about whether should either not be uploaded in the first place, or be removed or protected through access controls. Because of their experience of the risks for consumers in some health information being discovered by others, whether through employment or insurance discrimination or because of the impact this may have on court cases the consumer is involved in, it is essential that consumers decide carefully before information is added to their record. For some areas of practice it may be that the default is for practitioners to suggest that consumers add access controls to any information they upload to ensure they can control access to sensitive information that might expose them to risk.

This is particularly true for mental health professionals but may well include other professions including those providing genetic counselling or other types of counselling. This role is one that has not been well considered and resourced—AHPA contends that those practitioners would benefit from access to targeted training and specific digital resource packs that they could provide their patients.

E. Measures that are necessary to address community privacy concerns in the My Health Record system

AHPA notes the sensitive nature of some health information that might result from consultations with allied health professionals. We have highlighted in the last point the role that allied health practitioners are likely to play in need to advise and guide patients so that they are aware of the potential risks associated with some health information being available in a person’s My Health Record. Consumers may not be aware of these risks and without guidance may expose information about their own health to their own detriment. This role must be supported and professionals, particularly those dealing with sensitive information, given the training and resources they need to perform this role. We contend that consumers are more likely to feel confident about that sensitive information if they have confidence that the health professionals they consult are both knowledgeable and confident in the system.

AHPA contends that this will require significant work and intensive engagement of some professions and their peak bodies with a focus on moving beyond awareness of My Health Record. It will require ensuring that the engagement role of individual providers is recognised and supported through training and resources, both for the health professional and to provide to consumers. We also reiterate our previous point about supporting better security in non-GP practices through initiatives like the RACGP CISS program.

We also reiterate our previous recommendation around addressing particular community concerns that have been raised in national media as part of an updated communications campaign. That includes the outcome of legislative changes currently before government.

We also argue that more education is required to ensure the public is aware of what changes and what doesn't in terms of health information security and access due to My Health Record. It is our contention is that many of the issues highlighted in relation to My Health Record and health information privacy are issues that already exist.

F. How My Health Record compares to alternative systems of digitising health records internationally

AHPA does not have specific expertise in other systems that are used internationally and does not seek to provide comment on this element of the inquiry. However, we note that a range of competing systems either exist or are being developed and implemented in Australia and elsewhere that provide the means to share health records and other patient information. AHPA contends that record sharing platforms must be nationally consistent, accessible to all health professionals where appropriate, and carefully regulated rather than relying on private interests. In the absence of full engagement of the health sector in use of My Health Record, we are concerned that the resulting vacuum may result in the uptake of varying systems in different parts of Australia with the result that the current fragmentation of health information continues.

G. Any other matters

AHPA has noted in its introduction that significant systemic barriers still exist to allied health use of the system, particularly around registration and software access to My Health Record. While we recognise that governments are constrained by budgets and existing work programs, we strongly argue for the need to set out and fund a program of work that will address these barriers for the allied health sector. This will need to occur within a reasonably short timeframe if the sector is to participate in realising the benefits of My Health Record for consumers once the opt out period has ended. Without this work program, and instead relying on the sector to self-fund access to conformant software, the allied health sector will continue to lack access and as a result remain unable to participate in key government digital health programs and reforms.