© 2019 The authors and IOS Press.

This article is published online with Open Access by IOS Press and distributed under the terms of the Creative Commons Attribution Non-Commercial License 4.0 (CC BY-NC 4.0). doi:10.3233/SHT1190780

# Mind the Gap: Information Sharing Between Health, Mental Health and Social Care Services

Timothy KARIOTIS <sup>a,1</sup>, Megan PRICTOR<sup>b</sup>, Kathleen GRAY<sup>c</sup> and Shanton CHANG<sup>a</sup>

<sup>a</sup> School of Computing and Information Systems, The University of Melbourne,

Victoria, Australia

<sup>b</sup> Melbourne Law School, The University of Melbourne

<sup>c</sup> Health and Biomedical Informatics Centre, The University of Melbourne

Abstract. Information sharing is key to integrated, collaborative, and continuous care. People with a lived experience of mental illness may access several services across the health, mental health and social care sectors, which creates challenges for information sharing. The health informatics community has traditionally not prioritised social care informatics. However, with the growing role of social care in the lives of people with complex health conditions, now is the time when we must consider the articulation between health informatics and social care informatics in Australia. This paper reports the results of a qualitative study to understand the current context of information sharing between health, mental health and social care services. Interviews and focus groups with nine clinicians, caseworkers and support workers were undertaken. Thematic analysis supported the development of several themes. These include the growing role of social care services, the importance of trust and the challenge created by the complexity of conditions people can present with when accessing social care services. To ensure the growing range of social care services do not get left behind with the increasing digitisation of the Australian health system, the health informatics community should prioritise the inclusion of social care informatics in its scope of practice.

Keywords. Mental Health, Social Care, Health Informatics, Social Care Informatics

## Introduction

Since the deinstitutionalisation of mental health care, there has been a growing range of services in the community targeted at providing recovery orientated support to people living with mental illness [1,2]. In addition, there are a number of services, such as housing and homelessness services, employment services, and welfare services that may play a key role in a person's health [3]. In this paper, we differentiate between health services (e.g. physical and mental health services) and social care services (e.g. disability support and homelessness services). People with a lived experience of complex mental illness may access a wide range of health and social care services [1]. It is well recognised

<sup>&</sup>lt;sup>1</sup> Corresponding Author: School of Computing and Information Systems, The University of Melbourne, Parkville, VIC, 3010, Australia; E-mail: timothy.kariotis@unimelb.edu.au

in Australia that the mental health system is highly fragmented, with one key issue being a poor level of information sharing between physical health and mental health services [4]. What is less well understood is how information sharing occurs between health services that provide treatment, and the large range of social care services that provide support in the community.

## 1. Mental Health Services in Australia

Australia's mental health system is complex and fragmented [5,6]. The Australian Institute of Health and Welfare [3] describes the mental health system as containing three spheres, as outlined in Table 1. There is limited evidence on the relationship between health services and social care services in Australia. However, 2002 [6] and 2014 [3] reports into mental health services provided anecdotal evidence of a lack of linkages between health and social care services, resulting in sub-optimal use of resources and poor experiences of care.

Type of Service	Examples
Medicare subsidies services	General Practitioners
	Psychiatrists
	Psychologists + allied health
Specialised Mental Health Care Settings	Public and private hospitals
•	Community mental health care
Support Services	Disability support services
**	Homelessness support services
	Community mental health programs

Table 1. Mental Health Services in Australia [3]

In the field of health informatics, it is well established that there is a gap in the knowledge base regarding social care services [7,8]. However, with the increasing role that social care services play in the lives of people with complex conditions, and the move towards more integrated services [1], it could make sense for the well-established health informatics community to consider integrating social care informatics into its scope of practice.

#### 2. Research Aims

This research aims to explore information sharing between health and social care services in Australia, specifically in the provision of care to people with a lived experience of mental illness, and to establish the key issues that will need to be considered when trying to improve information sharing between them. The key research question being answered is: how does information sharing currently occur between health and social care services in Australia? The answer may inform the Australian health informatics community of directions for future research and practice.

## 3. Method

Nine participants from across health and social care were recruited (Table 2). Participants were recruited through contacting services identified through government and service provider websites, and advertisements shared through key bodies (e.g. Primary Health Networks). All participants were interviewed either individually or in a focus group. Interviews were semi-structured based around themes of collaboration, information shared and needed, barriers and enablers, and privacy and consent. These themes have been developed by the first author in previous research [9]. All interviews were recorded, transcribed and thematically analysed by the first author within NVivo ver. 12 (QSR International, Melbourne, Victoria, Australia). The Braun and Clarke [10] thematic analysis method was used, which consists of six steps including familiarisation with data, initial code generation, searching for themes, reviewing themes, naming themes and reporting themes. Human research ethics approval was obtained from the University of Melbourne.

Participant Participant Type (Clinical/non-Clinical) State Number P1 Social Care (housing) VIC P2 Health + social care (homelessness) WA P3 NSW Social Care (disability support) P4 Social Care (disability support) VIC P5 Social Care (homelessness) WA P6 Health (mental health) VIC P7 Health (primary health care) TAS P8 Health (primary health care) TAS P9 Health (mental health) VIC

Table 2. Participant details

## 4. Results

Four main themes were developed during the thematic analysis; these are outlined in Table 3, with example quotes. Each theme is discussed in more detail below.

Table 3. Themes and example quotes		
Theme		Quote Example
a.	Changing Landscape of Care	"I've sent through a request for information with consent, the legal team from the hospital has rung me and asked me what type of research I'm doing, and they refused to give it to meI think they saw that it wasn't health" P3
b.	Trust & Relationships	"if they're in the inpatient psych I would assess that the doctors are acting in their best interest and will try and cooperate with planning, giving information that would help plan a discharge" P1
c.	Complexity	"I sat down with her and showed her the form, and she was like 'why are all these things on here I don't remember doing this' and I was just like, you just did it yesterday, but she's on drugs and mental health andshe hadn't even really remembered that she'd done this form" P2
d.	Type of Information	"we will use GPsto supporthousing applicationsyou need to do a bit of coaching. I would actually dot point what we need in a letter" P4

Table 3. Themes and example quotes

"it's a pejorative description and say there are issues around the misinterpretation of something if it's read by a non-clinical person" P8

# 4.1. Changing Landscape of Care

The shift towards a greater role for social care services poses a challenge for 'traditional' health services in understanding the role of these services, and their information needs. Three of the four social care participants raised this theme in their interviews. This issue appeared especially pertinent for community managed organisations, many of which have names which do not always reflect the services they provide. Participants who were working in social care services tended to be clinicians, but they expressed that they were treated differently by health services when they sought information as a social care service, compared to if they were working in a health service. The concept of *power* is a meta-theme that crosses all themes, in that the medical model appears to take precedence over the recovery model that underpins support services.

"There's definitely a hierarchy in place that they'll use the medical model...above all else." P5

## 4.2. Trust and Relationships

Trust and interpersonal relationships are a major component of information sharing and were raised by eight of the participants. Service providers were more likely to share information with people in other services they knew. However, participants outlined that many services in the social care sector are under-resourced and have high turn-over of staff, which can impact the building of trusting relationships.

"...it comes down to who to trust, doesn't it? Trust...a mutual appreciation of each other's roles and to what extent can you share information." P6

## 4.3. Complexity

Social care services, such as homelessness services, tend to operate as open doors services, meaning people in a crisis with complex needs can walk in rather than needing an appointment or referral. These situations pose challenges for services to access information about people. The challenges are exacerbated because social care services tend to be excluded from the information sharing processes in health care, such as treatment plans. This issue was raised by two social care participants who work in high-profile services which people know they can access in a crisis. However, this issue was also acknowledged by three of the health service participants. There also appears to be a number of people within the social care sector, who may have no way to share information with the health sector, as the quote below outlines.

"So...the community driver might be worried about something, they don't necessarily have a way of feeding that back when they're worried." P8

## 4.4. Type of Information

The information collected and needed in health services may be different from the information collected and needed in social care services. This theme emerged from

discussions with all participants about their information needs. However, though the information collected on a day-to-day basis is different, there appears to be a shared need for information related to risk management, early warning signs and medication management.

"...there's information that could be shared...it might be helpful for a housing organisation to know...when the early warning signs are...so there's an opportunity for people to intervene early..." P6

## 5. Discussion and Conclusion

The results from this study point to a trust and understanding gap between health and social care services. These gaps have an impact on information sharing between services, which may impact the quality and experience of care [1]. These findings are reflective of evidence that collaboration and information sharing tend to be underpinned by established relationships between clinicians [11,12]. There have been efforts in Australia to improve relationships between different parts of the health system, one example being the Mental Health Professional Networks, which linked physical health and mental health clinicians [13]. These types of programs could also include opportunities for different service providers to develop a shared understanding of each other's information needs [8].

In addition to issues regarding trust and relationships, there are also issues around the type of information and culture towards information in health compared to social care services. Many support services do not provide health services or treatments, but rather recovery-orientated supports [14]. Information collected in a support service may relate more to the social, rather than the biomedical aspects of a person's life. However, it appears all services need information related to risk management, early warning signs, and medication management. With the digitisation of the health system, it will be critical to address how social care services will articulate with information sharing processes such as shared health summaries in My Health Record. Part of this understanding will involve mapping out the shared information needs and identifying ontologies and standards that can cross both health and social care services [8].

Health services in Australia, to some extent, have implemented information technology to improve information collection and sharing [15]. However, this does not extend to all health services, for example, allied health [16]. When it comes to the social care sector, it appears that though many have implemented information technology, it does not always meet the needs of staff [17]. A 2013 survey of community services found that the main area in which they needed support was information technology [18]. Technology is also one of several issues identified by Whiteford et al. [19] in a systematic qualitative review, as a barrier to system-level intersectoral linkages.

The findings of this study as they relate to the Australian context are limited by the breadth of jurisdictions, and types of service providers included. The findings do provide a unique insight into the growing role of social care services and should pave the way for future research into how information sharing could be facilitated to support the care of those with complex needs.

In light of the growing role of the social care sector in the provision of care to those with complex conditions, health informatics in Australia should consider its role in contributing to the development of an Australian social care informatics movement. The

findings from this study outline several key themes that health informaticians looking to further this cause should consider in developing a way forward to improve information sharing across the broad range of services people access.

## References

- [1] S.J. Lee, E. Crowther, C. Keating, and J. Kulkarni, What is needed to deliver collaborative care to address comorbidity more effectively for adults with a severe mental illness?, *Australian and New Zealand Journal of Psychiatry*. **47** (2013) 333–346. doi: 10.1177/0004867412463975.
- [2] P. Bywood, L. Brown, and M. Raven, Improving the integration of mental health services in primary health care at the macro level, *Primary Health Care Research & Information Service*. (2015). http://www.phcris.org.au/phplib/filedownload.php?file=/elib/lib/downloaded\_files/publications/pdfs/phcris\_pub\_8443.pdf.
- [3] Australian Institute of Health and Welfare, Mental Health services In Brief 2017, (2017). https://www.aihw.gov.au/reports/mental-health-services
- [4] K.M. Griffiths, J. Mendoza, and B. Carron Arthur, Whereto mental health reform in Australia: is anyone listening to our independent auditors?, *Medical Journal of Australia*. **202** (2015) 172–174.
- [5] National Mental Health Commission, The National Review of Mental Health Programmes and Services, (2014). http://www.mentalhealthcommission.gov.au/our-reports/contributing-lives,-thriving-communities-review-of-mental-health-programmes-and-services.aspx.
- [7] M. Rigby, P. Hill, S. Koch, and J. Kärki, Social care informatics-the missing partner in ehealth, in: MIE, 2009: pp. 277–281. doi: 10.3233/978-1-60750-044-5-277
- [8] M. Rigby, P. Hill, S. Koch, and D. Keeling, Social care informatics as an essential part of holistic health care: a call for action, *International Journal of Medical Informatics*. 80 (2011) 544–554. doi: 10.1016/j.ijmedinf.2011.06.001
- [9] T.C. Kariotis, and K.M. Harris, Clinician perceptions of My Health Record in mental health care: medication management and sharing mental health information, *Australian Journal of Primary Health*. 25 (2019) 66–71. doi: 10.1071/PY17181
- [10] V. Braun, and V. Clarke, Using thematic analysis in psychology, *Qualitative Research in Psychology*. 3 (2006) 77–101. doi: 10.1191/1478088706qp063oa.
- [11] T. Fredheim, L.J. Danbolt, O.R. Haavet, K. Kjønsberg, and L. Lien, Collaboration between general practitioners and mental health care professionals: a qualitative study, *International Journal of Mental Health Systems*. 5 (2011) 13. doi: 10.1186/1752-4458-5-13
- [12] J.L. Zuchowski, D.E. Rose, A.B. Hamilton, S.E. Stockdale, L.S. Meredith, E.M. Yano, L. V Rubenstein, and K.M. Cordasco, Challenges in referral communication between VHA primary care and specialty care, *Journal of General Internal Medicine*. 30 (2015) 305–311. doi: 1007/s11606-014-3100-x.
- [13] J. Fletcher, K. King, J. Christo, A. Machlin, B. Bassilios, G. Blashki, C. Gibbs, A. Nicholas, and J. Pirkis, An evaluation of an Australian initiative designed to improve interdisciplinary collaboration in primary mental health care, *Evaluation and Program Planning*. 45 (2014) 29–41. doi: 10.1016/j.evalprogplan.2014.03.002
- [14] C. Harvey, L. Brophy, S. Parsons, K. Moeller-Saxone, M. Grigg, and D. Siskind, People living with psychosocial disability: Rehabilitation and recovery-informed service provision within the second Australian national survey of psychosis, *Australian & New Zealand Journal of Psychiatry*. 50 (2015) 534–547. doi:10.1177/0004867415610437.
- [15] Australian Digital Health Agency, Australia's National Digital Health Strategy, (2017). https://conversation.digitalhealth.gov.au/sites/default/files/adha-strategy-doc-2ndaug\_0\_1.pdf.
- [16] Department of Health and Ageing, The eHealth Readiness of Australia's Allied Health Sector, 2018 (2011). http://www.health.gov.au/internet/publications/publishing.nsf/Content/ehealth-readiness-allied-toc.
- [17] Infoxchange, Connecting Up, and TechSoup NZ, Digital Technology in the Not-For-Profit Sector, (2018). https://www.infoxchange.org/sites/default/files/it\_in\_the\_not-for-profit\_sector\_report\_for\_2018.pdf.

- [18] Australian Council of Social Services, Australian Community Sector Survey 2013, (n.d.). http://www.acoss.org.au/images/uploads/Australian\_Community\_Sector\_Survey\_2013\_acos.pdf.
- [19] H. Whiteford, G. McKeon, M. Harris, S. Diminic, D. Siskind, and R. Scheurer, System-level intersectoral linkages between the mental health and non-clinical support sectors: A qualitative systematic review, Australian and New Zealand Journal of Psychiatry. 48 (2014) 895–906. doi: 10.1177/0004867414541683.