A TAXONOMY OF CASE MANAGEMENT

Development, dissemination and impact

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Candidate’s statement

This is to certify that to the best of my knowledge, the content of this thesis is my own work. This thesis has not been submitted for any degree or other purposes. The intellectual content of this thesis is the product of my own work and all assistance received in preparing this thesis and sources have been acknowledged.

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Signed:

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In accordance with the University of Sydney policy on thesis editing, editorial assistance was sought in the final production of this thesis.

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Abstract

Background

Case management is a widely-accepted care coordination strategy used in diverse contexts. for people with complicated health conditions. Case management is complex and variable due to the interaction of its components: model (theory); context (service); population and health condition; case manager's actions. This complexity impedes practice, quality analysis, policy and planning. The aim was to develop a case management taxonomy for a common understanding and language and assess the impact of national and international dissemination.

Method

Using mixed methods, Phase 1 was a scoping and mapping review to examine the key components of case management described in the literature, critical review of international frames on potential conceptual and technical frameworks, nominal group of experts and feasibility analysis to finalise the taxonomy. During development, brain injury was used as an example of a common multi-dimensional and disabling health condition. Phase 2 involved the taxonomy dissemination to diverse groups concerned with different health conditions in Australia, other country and international organisations, scientific community, service providers and users. Impact assessment of dissemination followed to examine the impact level from ‘no impact’ to translation of the new knowledge into practice.

Results

The taxonomy identifies the components and their relationship (two taxonomy trees), provides a glossary. The service tree comprises acute, mobility and intensity

characteristics. The intervention tree comprises nine main actions, 17 actions, 8 related actions of case manager interventions. There were 51 personalised taxonomy presentations to audiences across 11 countries. Non-personalised presentations via conferences, publications and social media exposed the taxonomy further. After dissemination data was collected from two questionnaires and opportunistic information. All questionnaire respondents perceived the taxonomy to be highly acceptable and practical. Of these respondents, forty-three impact ratings showed higher level taxonomy impacts and use from personalised approaches.The taxonomy was translated into meso organisation policy, concepts and language in international frameworks and embedded in tertiary education. There are emerging uses in research and over 15 case managers and services use the taxonomy.

Conclusion

The taxonomy provides a framework to manage case management complexity. It identifies and defines the components and their relationships. Impact ratings show the case management taxonomy is a useful tool in different sectors and fit for purpose across different health conditions, hereafter called the '*case management taxonomy'*.

Contents

Candidate's statement ..... **i**
Acknowledgements ..... **iii**
Abstract ..... **iv**
List of tables ..... **ix**
List of figures ..... **x**
Abbreviations used in this thesis ..... **xi**
Related publications and presentations ..... **xii**
CHAPTER 1 INTRODUCTION **1**
1.1 Case management terms 1
1.2 Impetus for the research 3
1.3 Case management context 5
1.3.1 History of case management 5
1.3.2 Case management today 8
1.4 Statement and significance of the problem 9
1.4.1 Significance of the problem 9
1.4.2 Potential contribution of the research 11
1.5 Research program 11
1.6 Thesis outline 13
1.7 References 15
CHAPTER 2 GENERAL METHODS **21**
2.1 Introduction to chapter 21
2.2 Ethics and industry partner agreement 21
2.3 Research methods 23
2.4 Qualitative research 26
2.4.1 Scoping review 27
2.4.2 Nominal group technique 35
2.4.3 Framing and framework methods 37
2.4.4 The taxonomy 39
2.4.5 Feasibility assessment 40
2.5 Dissemination and implementation research 43
2.5.1 Dissemination 44
2.5.2 Impact analysis of dissemination 49
2.6 Research protocol 52
2.7 Context 54

2.8 Time frames 54
2.9 Funding 54
2.10 References 54
CHAPTER 3 SCOPING AND MAPPING REVIEW 65
CHAPTER 4 CRITICAL REVIEW OF INTERNATIONAL FRAMEWORKS . 89
4.1 Introduction 89
4.2 Methods 92
4.3 Results Stage 1 – conceptual and theoretical meta-framework 94
4.4 Results Stage 2 – technical framework(s) 126
4.5 Discussion 141
4.6 References 143
CHAPTER 5 DEVELOPMENT OF THE TAXONOMY and FEASIBILITY ANALYSIS 157
5.1 Introduction 157
5.2 Intervention tree publication 158
5.3 Service tree 176
5.4 The complete taxonomy 183
5.4.1 Intervention tree and table 183
5.4.2 Service tree and table 191
5.4.3 Glossary for the case management taxonomy 193
5.5 References 200
CHAPTER 6 DISSEMINATION OF THE CASE MANAGEMENT TAXONOMY AND THE IMPACT OF DISSEMINATION 201
6.1 Introduction 201
6.2 Theory and method 201
6.2.1 Dissemination method and plan 202
CHAPTER 7 Introductory and first contact resources adapted to each target audience context 204
7.1.2 Methods for the impact assessment and analysis 213
7.2 Results 220
7.2.1 Dissemination 220
7.2.2 Impact assessment 228
7.3 Discussion 238
7.3.1 Dissemination 238
7.3.2 International frameworks 241
7.3.3 Policy and legislation 242
7.3.4 Research 245
7.3.5 Education and training 247

7.3.6 Clinical practice – service delivery 248
7.3.7 Summary and conclusion 249
7.3.8 Limitations 251
7.4 Appendix 6.1 REDCap survey questionnaire 253
7.5 Appendix 6.2 Personalised dissemination audiences 256
7.6 Appendix 6.3 Conference paper and poster presentations 260
7.7 Appendix 6.4 Group 2 Comments and explanation 267
7.8 Appendix 6.5 Impact scale raters and ratings 272
7.9 References 273
CHAPTER 8 SUMMARY AND CONCLUSION 275
8.1 Overview 275
8.2 Discussion of outcomes and contribution 279
8.3 Limitations 281
8.4 Future directions 285
8.5 References 285

List of tables

Table 1.1 Overview of research program 13

Table 2.1 Framework for conducting a scoping review..... 31

Table 2.2 Implementation research outcomes and definitions (Proctor et al. 2011)..... 50

Table 4.1 Preliminary list of technical frameworks..... 129

Table 4.2 Short-listed frameworks and results of critical review against specified criteria 138

Table 5.1 DESDE-LTC Service Inventory results for nominal group case management organisations and including Main Types of Care..... 179

Table 5.2 Taxonomy of community-based case management in brain injury (BICM-T) – interventions (actions) table (Appendix 2 from published article in Section 5.2)..... 184

Table 5.3 Taxonomy of community-based case management services table – care coordination and case management..... 192

Table 6.1 Proposed timetable for dissemination and assessment of impact of dissemination 213

Table 6.2 Impact assessment scale 218

Table 6.3 Potential audiences for whom personalised dissemination did not proceed..... 223

Table 6.4 Presentation questionnaire (Group 1) responses 229

Table 6.5 Mean impact rating for each audience..... 236

Table 6.6 Data for web-based dissemination activities..... 237

Table 6.7 Personalised dissemination audiences..... 256

List of figures

Figure 2.1 Impact of research 48

Figure 2.2 Outline of the research program phases and steps 53

Figure 5.1 Intervention tree (throughputs) of the community-based case management taxonomy (Figure 3 from published article in Section 5.2) 183

Figure 5.2 Service tree (inputs) of the community-based case management taxonomy 191

Figure 6.1 Health condition focus of personalised presentation audiences..... 225

Figure 6.2 Location of audience and sector..... 226

Figure 6.3 Ratings for questions related to awareness and acceptability of the taxonomy, percentage of total responses 231

Figure 6.4 Ratings for questions related to assimilation and practicality of the taxonomy, percentage of total responses 233

Abbreviations used in this thesis

BIRD	Brain Injury Rehabilitation Directorate
CANS	Care and Needs Assessment Scale
DESDE-LTC	Description, Evaluation and Classification of Services for Long Term Care
icare	Insurance and Care, NSW
ICHI	International Classification of Health Interventions
ICC	Intraclass correlation
ICF	International Classification of Functioning, Disability and Health
LTC	Lifetime Care and Support Authority
NSW	New South Wales
PPCHC	Person- and people-centred health care
WHO	World Health Organization
WHO-FIC	World Health Organization Family of International Classifications

Related publications and presentations (but not forming part of this thesis)

Peer-reviewed publications

Young, J., Lukersmith, S., Salvador-Carulla, L., & Stancliffe, R. (2017). Case management for children and adolescents with acquired brain injury in community settings: A scoping review. *Brain Impairment*. doi:10.1017/BrImp.2017.3 (in press)

Salvador-Carulla, L., Lukersmith, S., & Sullivan, W. (2017) From the EBM pyramid to the Greek temple: A new conceptual approach to guidelines as implementation tools in mental health. *Epidemiology and Psychiatric Sciences*, *26*(2), 105-114. doi:10.1017/S2045796016000767

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Lukersmith, S., Scarf, C., & Millington, M. (2015). Rehabilitation counseling in the context of family capital. In M. J. Millington, & I. Marini (Eds.), *Families in rehabilitation counseling: A community-based rehabilitation approach*, (pp. 67-85). New York: Springer Publishing Company

Conference presentations

Lukersmith, S., Croker, D., Maclean, L., & Gleeson, R. (2017). *My Plan – a new meso to micro level building block to promote person-centred care planning*. 17th International Conference on Integrated Care, Dublin, Ireland.

Lukersmith, S., Valentijn, P., & Salvador-Carulla, L. (2017). *A meta-framework and conceptualisation of person and people-centred integrated health care.* 17th International Conference on Integrated Care, Dublin, Ireland.

Lukersmith, S., Valentijn, P., & Salvador-Carulla, L. (2017). Workshop: *A participatory evaluation of the validity and feasibility of the Meta-framework of Person and People-centred Integrated Health Care (PPCIHC) as a tool.* 17th International Conference on Integrated Care, Dublin, Ireland.

Lukersmith, S., & Salvador-Carulla, L. (2014) *What are clinical practice guidelines? A typology analysis within the context of a new taxonomy of scientific knowledge*. Conference of the Guideline International Network, Melbourne, Australia.

Lukersmith, S., & Salvador-Carulla, L. (2014). *Are clinical guidelines a type of applied scientific framing study? An analysis of the interaction between guideline recommendations and using different sources of knowledge in clinical reasoning.* Conference of the Guideline International Network, Melbourne, Australia.

CHAPTER 1 INTRODUCTION

The research program for this thesis concerned the development and dissemination of a taxonomy of case management to support policy, planning, quality analysis and practice of community-based case management. It also included an impact analysis of the dissemination. In the first chapter of this thesis, I start by briefly explaining the various case management terms. This is followed by reflections on my professional experiences and curiosity that provided the impetus for the research program. I introduce case management past and present, discuss the complex factors related to case management and the associated problems, followed by an overview of the research program and thesis outline.

1.1 Case management terms

The terms case management, care management and care coordination are often used interchangeably (Ahmed, 2016; Madden, Fortune, Collings, & Madden, 2014; McDonald et al., 2014; Prokop, 2016). Care coordination is the umbrella term used to incorporate health service elements and resources, and other concepts such as quality, delivery and organisation to integrate (health) care (McDonald et al., 2014; Van Houdt, Heyrman, Vanhaecht, Sermeus, & De Lepeleire, 2013). Care coordination is defined as

> *the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities and is often management by the exchange of information among*

> *participants responsible for different aspects of care. (McDonald et al., 2014, p. 5).*

Coordination, on the other hand, is a noun and refers to the actions or activities involved in the process. The dictionary definition of coordination is ‘the process of organizing people or groups, so that they work together properly and well’ (Merriam-Webster Dictionary, 2017).

Case management could be considered a special case of care coordination. The critical difference between care coordination and community-based case management is that the latter always involves a partnership and collaboration between the case manager and the client (Case Management Society of America (CMSA), 2016; Case Management Society UK (CMSUK), 2009; Marfleet, Trueman, & Barber, 2013; National Case Management Network of Canada (NCMN), 2009). Case management is broadly considered within care coordination but goes beyond the coordination of health and medical care related services to involve setting personal activity and participation goals, and developing a plan for how to meet the client’s needs for cross-sector care and support (including education, work, and social and community services).

In this research program the term ‘person-centred’ community-based case management is used to refer to a complex intervention for a person with a health condition. The term case management itself does not reflect person-centredness. Most people prefer not to be considered a ‘case’ nor seek to be ‘managed’ (as an adult). Yet the term case management, with all its variations in approach and context, remains the most frequently used, even if poorly understood, term in the international literature and practice. Over time that may change, but for pragmatic

reasons and the purposes of this research program, we have used the term case management.

1.2 Impetus for the research

Over many years, amongst other roles, I have worked as an occupational therapist and case manager. In these roles I have supervised, trained, mentored, managed and employed other case managers in various work contexts. Case management clients, the service users, were people from across the age range, from children through to working adults, with different health conditions from mental health, neurological conditions and intellectual disability to complex work or vehicle crash-related injuries such as traumatic brain injury, severe orthopaedic injuries and spinal cord injury. Each person had barriers and facilitators in their unique situation at home, work, education and community settings. Sometimes the role was called case management and other times by another name, but usually it was mobile and community-based with the client contact in their home, work, school or a community facility. I, and other case managers, sometimes assumed a dual role as therapist and case manager for the same client. On some occasions the work was office-based with minimal client contact and involved a more administrative and desk-based role of coordination for health-related treatment and rehabilitation. The mix of people and variation in my work activities provided opportunities, but also frustrations due to the lack of a common understanding of case management.

To many health professionals, researchers, funders of services and policy makers, case management can appear to be a simple role of service coordination. For some, the case manager is considered a type of administrator. In the experience of many community-based case managers, it involves much more than administration or

service coordination, and involves interventions which potentially benefit and enable the client's recovery and facilitate their community participation. Case managers plan with the person/their family; explain the role, benefits and anticipated outcomes of case management; estimate costs and justify interventions and actions to ensure client needs are met. Case managers in the healthcare sector have many different job titles, come from a diverse range of professions, and have different skills and experience.

The quality of case management varies, but defining good case management for different health conditions and contexts is difficult. As an employer of case managers, I had questions around work role, case manager skills, practice quality, expectations and measuring case management outcomes. Later I moved into research and various projects within the area of best practice and health services research. Many of these projects involved using different sources of knowledge and understanding the influences of the client situation, service and community context. The work required the use and management of different sources of information on complex interventions – whether it was developing clinical guidelines or practice tools for integrated care; planning, monitoring and evaluation; or advising on case management.

This combination of practice and research experience maintained my interest and questions on case management, complexity and health services research. My reflections on case management as a complex health and social care intervention led to a desire to better understand case management and best practice, and the related policy, services and systems issues, and provided the impetus to undertake the research program described in this thesis. The research program was informed by my own experiences and the international experiences of both my supervisors,

and was challenged by the evolving world of person-centred integrated health and social care.

1.3 Case management context

1.3.1 History of case management

Case management emerged in the 1960s in response to the de-institutionalisation of large numbers of people with severe mental health conditions (Dieterich, Irving, Park, & Marshall, 2010; Mas-Exposito, Amador-Campos, Gomez-Benito, & Lalucat-Jo, 2013). As the alternative solution to out-of-hospital care, case management involved assessment, planning and referral of people with mental health conditions to outpatient mental health and health-related services. The client was a recipient of case management rather than a partner in this model. The client typically did not have the internal or external resources to proactively set their goals and determine their own support needs as a person emerging from long-term institutional care. Decisions were made on the client's behalf about what was required and where they should go. This model focused on the coordination of health services and is referred to as a broker model.

In the decades since the 1980s, the increasing cost of health care and decentralisation of health services influenced the role of case managers, particularly in the USA (Kersbergen, 1996). The case manager was typically a nurse or social worker and usually employed by the health insurer or funder (Health Maintenance Organization – HMO) or the hospital. Their role was to manage and coordinate the inpatient and outpatient services according to a pre-determined pathway. The client's diagnosis and treatment were guided by an algorithm which aimed to meet both client healthcare needs and service and funder requirements. The algorithm typically

included cost-saving strategies such as early discharge, pre-determined treatment needs and selected medical practitioners. This managed care or medical case management approach meant that case managers were simultaneously assuming a case management and gatekeeper role to control costs (Blakely & Dziadosz, 2008; Casarin et al., 2002; Fraser & Strang, 2004; Kersbergen, 1996).

In some countries with universal healthcare policies (e.g. Australia, France, Finland, United Kingdom, Israel), in the inpatient acute and post-acute rehabilitation hospital settings the case manager is known as a discharge planner (Fox et al., 2013). Policy differences associated with universal health care tend to lead to a focus on client context and less on the gatekeeper role. This expanded perspective of case management emerged with a level of clinical input and judgement from the case manager (discharge planner) and healthcare team, leading to an individualised case management response. It is sometimes referred to as clinical case management (Creed et al., 1999; Wulff, 1991).

The broker, medical and clinical models of case management in the health sector continued to focus on the disease and coordination of health services. Concepts of client strengths or capacity building, self-management and determination, or setting goals for resuming life roles and community participation were absent in these approaches to case management. In time, and particularly in the mental health service setting, the limitations of the broker, medical and clinical case management models for improving clinical and social outcomes were recognised (Blakely & Dziadosz, 2008; Killaspy & Rosen, 2011; Schaefer & Davis, 2004).

Case management then moved beyond an exclusive medical and health service focus towards a hybrid model, particularly in the mental health sector. This hybrid

model is referred to as ‘assertive community treatment’, or ‘intensive case management’ (Baier, Favrod, Ferrari, Koch, & Holzer, 2013; Blakely & Dziadosz, 2003). Additional case management activities included targeted social participation outcomes, monitoring and adjustments to services and supports, as well as the usual tasks of coordination and referral (Blakely & Dziadosz, 2003). Case managers had the relevant health professional training and experience to be able to provide both the clinical support and the case management (Killaspy & Rosen, 2011). As such, case management started to look towards client goals for health and social outcomes that included purposeful roles within their community, as well as individual outcomes such as fewer hospitalisations. In this way, the focus moved from the illness and service systems towards recognising the client as a person.

Case management was also more recently applied to a range of different settings including vocational rehabilitation and return to work following injury (Selander & Marnetoft, 2005). In non-health oriented settings, different activities have been woven into the meaning and scope of case management. A model of case management emerged in the legal system which involved assessment, better exchange of information, problem solving, management, advocacy and building consensus to achieve an outcome (Schepard, 2000), with the case management role sometimes shared across a team of people (Higgins, 2007). Case management was used to identify and build a consensus, and define the issues in dispute, to reduce time delays and achieve better outcomes and costs.

Running parallel to the changes in case management over 20 years has been a broadening of health concepts. There have been significant changes in the perception of health and disability towards the holistic conceptualisation of health and functioning espoused in the biopsychosocial model. The model incorporates

three domains of health – impairments of body functions and structures, activity limitations, and participation restrictions. The interaction of context (environment and personal factors) determines the person's functioning in the three domains. The International Classification of Functioning, Disability and Health (ICF) defines and shows the relationship between these domains and the contextual factors (World Health Organization, 2001). Recognition of these domains of health and the contextual factors means the focus of community-based case managers for people with complex health conditions includes all domains of health, and involves linking and facilitating cross-sector care and support services including health, education, work, community and social services.

1.3.2 Case management today

Case management has evolved and is now used in different settings with clients of different ages and with different health conditions. Today there are numerous approaches and models of case management referred to in the literature. Case management models include: clinical; therapy or rehabilitation; medical; strengths-based; nursing case management; rehabilitation; assertive community treatment; intensive case management; care coordination; generalist, traditional or standard; discharge planning; peer assisted; advocacy; managerial; and a mixture of approaches or hybrid models (Bedell, Cohen, & Sullivan, 2000; Bjorkman, Hansson, & Sandlund, 2002; Chamberlain & Rapp, 1991; Fraser & Strang, 2004; MacNeil Vroomen et al., 2012; Petersen, 2004; Rosen & Teesson, 2001). Each has benefits, disadvantages, variations and adaptations to the setting and structures in which they operate.

Case management is responsive to the individual and their context and makes a unique contribution towards the integrated long-term care, community participation

and support of the person with a chronic or complex health condition (Fitzsimmons, 2003; Joo & Huber, 2012; N. Lannin, Henry, Turnbull, Elder, & Campisi, 2012; Rapp & Goscha, 2004). To achieve this, case management involves independent and interdependent components, and a range of interventions (actions) which are influenced by temporal factors and service context including mobility, intensity and geography (Dellemain & Warburton, 2013; Killaspy & Rosen, 2011; Medical Research Council (MRC), 2008; Shepperd et al., 2009; Wade, 2005). Case management has now emerged to be, by definition, a complex intervention (Medical Research Council (MRC), 2008), which is not fixed, linear, nor a ‘one size fits all’ approach.

1.4 Statement and significance of the problem

1.4.1 Significance of the problem

Case management is at the same time a ‘healthcare service’ and a ‘complex intervention’. Internationally it is commonly used for a range of key health conditions. In Australia, case management is provided and funded in a range of statutory personal injury schemes, and public health and rehabilitation services. It is one of the services and interventions provided under the roll-out of the National Disability Insurance Scheme for people with disability. Under this scheme a local area coordinator undertakes case management interventions to provide information, plan for supports, and link, facilitate and coordinate community supports. For a person with a more complex health condition, an external case manager is employed. There is significant expenditure on case management in the health sector. As an example, the Insurance and Care NSW agency (icare) funds the treatment, rehabilitation and care of people severely injured in motor vehicle crashes. In the last financial year,

5% of the agency's total multi-million dollar expenditure was on community-based case management services (Insurance and Care NSW (icare), 2017).

Over decades many researchers have attempted to assess case management and tackle the problems of describing and assessing the quality and benefits of case management. Several systematic reviews and many literature reviews describe this heterogeneity and the lack of a common language to describe the components, similarities and differences in case management (Kopke & McCleery, 2015; N. A. Lannin et al., 2014; Rapp & Goscha, 2004; Reilly et al., 2015; Smith & Newton, 2007). Variability, complexity and poor descriptions are overwhelmingly recognised in the literature as the fundamental issues that have limited the ability to identify what is case management, make comparisons to undertake quality analysis, assess the impact of case management on health outcomes, develop policy, plan services and analyse cost-effectiveness (Glasziou, Meats, Heneghan, & Shepperd, 2008; Gray & White, 2012; Haslanger, 1995; Huber, 2002; Jacobson Vann, 2006; Kopke & McCleery, 2015; N. Lannin et al., 2012; N. A. Lannin et al., 2014; Parry & Stevens, 2001; Reilly et al., 2015; Smith & Newton, 2007). However, there is a lack of consensus on how to analyse this complexity (Cochrane Collaboration, 2011; Craig et al., 2008; Fernandez et al., 2015; Kannampallil, Schauer, Cohen, & Patel, 2011).

The issues for case management are similar to issues around analysing the quality of other complex interventions, integrated health care and healthcare programs, and health services research where analysis is not well developed (Howarth, Devers, Moore, O'Cathain, & Dixon-Woods, 2016; Petticrew, 2011; Reynolds & Sutherland, 2013; Salvador-Carulla, Garcia-Alonso, Gibert, & Vazquez-Bourgon, 2013). Researchers have highlighted the need to include other sources of knowledge and evidence for the analysis of complex interventions, including expert knowledge,

client-reported outcome measures and grey literature, and adopt different approaches (Hopewell, McDonald, Clarke, & Egger, 2007; Raine et al., 2016; Salvador-Carulla et al., 2014; Shepperd et al., 2009). The use of a range of methods and different sources of knowledge is particularly relevant to case management given the contextual complexities involved. The fundamental issue of the lack of a common understanding and agreed language of case management remains.

1.4.2 Potential contribution of the research

The research program described in this thesis involves the development of a formal knowledge map for case management. A taxonomy identifies the components of case management, their relationship to each other, and definitions for a common understanding and agreed language. Potentially, the taxonomy we have developed during this research will be a useful tool and structure which, when combined with other health service research methods and tools, supports the assessment of case management to enable quality analysis, policy and planning. The dissemination of the taxonomy and analysis of the impact of dissemination will determine its acceptability and applicability to different sectors involved in case management, and provide general learnings for other implementation researchers.

1.5 Research program

The research program used mixed methods. There were two phases to the research program with multiple steps in each phase. Phase 1 involved the development of the taxonomy using mixed qualitative research methods. Phase 2 involved the dissemination and impact analysis of the dissemination using health services research methods.

The research questions were:

1. How can the knowledge around case management in brain injury be framed through the development of a preliminary taxonomy?
2. What is the impact of the dissemination of the taxonomy in various contexts?
3. What is the feasibility of using the case management taxonomy in different sectors such as policy, research, education and clinical practice?

There were three steps in Phase 1 and two steps in Phase 2. Each step was an individual study within the research program. Refer to Table 1.1 for an overview of the phases, steps, research methods and outputs. In Chapter 2, Figure 2.2 provides an outline of the phases, steps and outputs in the research program. Reference will be made to Figure 2.2 at the beginning of each subsequent chapter to orient the reader.

Table 1.1 Overview of research program

Phase 1		**Development of the taxonomy**	
Step	**Description**	**Method**	**Outputs**
1.1	Scoping and mapping study	• Literature review • Identification of studies • Mapping of data	Identification of components described in the literature
1.2	Critical review and selection of international frameworks	• Literature review • Thematic analysis and critical review • Development of conceptual and theoretical meta-framework on person-centred integrated health care • Identification of technical frameworks	Determination of • Conceptual and theoretical meta-framework • Technical frameworks
1.3	Iterative development of the taxonomy and feasibility analysis	• Development of Beta 1 version using results from steps 1 and 2 • Development of Beta 2 version by nominal group • Feasibility assessment and review of alignment with frames for final version	Development of Beta versions (2) and final taxonomy
Phase 2		**Dissemination and impact analysis of dissemination**	
2.1.	Dissemination	• Dissemination planning • National and international dissemination activities	Completion of personalised presentations and non-personalised presentations
2.2	Impact analysis of dissemination	• Survey and opportunistic data collection • Impact of dissemination assessment and analysis	Assessment of feasibility (acceptability and practicality) of the taxonomy in different sectors

1.6 Thesis outline

Chapter 1 describes the personal impetus for the research and outlines the purpose and design of the research program. The chapter also introduces case management terms and describes the context for case management – the history, current situation, complexity and associated problems.

Chapter 2 provides the conceptual background and rationale to the research program's mixed qualitative and health services research methods. The specific methods used for each step in the program are outlined. The subsequent chapters (Chapters 3–6) provide the details of the relevant methods used in each step of the research program, and the results.

Chapter 3 contains the publication of Step 1.1 – the scoping and mapping review of case management.

> Lukersmith, S., Millington, M., & Salvador-Carulla, L. (2016). What is case management? A scoping and mapping review. *International Journal of Integrated Care*, *16*(4), 2. doi:10.5334/ijic.2477

Chapter 4 documents the methods and results for Step 1.2, the critical review of international frameworks. The chapter details the two stages to identify the conceptual and theoretical meta-framework, and technical frameworks. We developed the conceptual and theoretical meta-framework for a person- and people-centred integrated healthcare system. The section on the meta-framework includes an excerpt from an expert commentary publication (in press) associated with person- and people-centred integrated health care:

> Lukersmith, S., Huckel Schneider, C., Salvador-Carulla, L., Sturmberg, J., Wilson, A., & Gillespie, J. (2016). *An expert commentary on the state of the art in person-centred care*.

Chapter 5 contains a preface and the publication arising from the final step in the development of the taxonomy (Step 1.3) in two parts.

> Part 1 contains the publication and associated appendices:

Lukersmith, S., Fernandez, A., Millington, M., & Salvador-Carulla, L. (2015). The brain injury case management taxonomy (BICM-T); a classification of community-based case management interventions for a common language. *Disability and Health Journal*, 9(2), 272-280. doi:10.1016/j.dhjo.2015.09.006

Part 2 provides supplementary information on the methods and results of the service tree, service table and DESDE-LTC (Description, Evaluation and Classification of Services for Long Term Care) service classification questionnaire which was not included in the publication due to size restrictions.

The Appendices in Chapter 5 include three case studies and the case study questionnaire that were also not included in the publication.

Chapter 6 describes Phase 2 of the research program, the dissemination and impact analysis of dissemination. This includes Step 2.1 – the dissemination plan, methods for dissemination within Australia and internationally, and results – and Step 2.2 – the analysis of the impact of the dissemination in various sectors. The appendices for this chapter include the impact questionnaire and the details of the personalised dissemination results.

Chapter 7 provides a brief summary of the overall research program, the results and limitations. The contributions made by the research program, the implications and future directions for case management research are discussed.

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CHAPTER 2 GENERAL METHODS

2.1 Introduction to chapter

The research program involved the development of a taxonomy for community-based, person-centred case management, dissemination of the taxonomy, and analysis of the impact of dissemination. The mixed qualitative methods used included scoping and mapping, taxonomy, nominal group technique, feasibility analysis, dissemination strategies, and impact analysis of the dissemination. This general methods chapter provides the conceptual background to the research methods and an overview of the research program protocol. Details of the method for each step are provided in the relevant chapter.

2.2 Ethics and industry partner agreement

Ethics approval for the research program was obtained from the University of Sydney's Human Research Ethics Committee (HREC). There were two applications for different phases of the project. Ethical approval obtained (no: 2013/1027) in 2014 related to Phase 1 and the involvement of case management experts as participants in a nominal group. Ethical approval obtained (no: 2015/782) in 2015 related to the dissemination in Phase 2 and the involvement of individuals representing the target organisations.

The research program involved an industry partner – the Lifetime Care and Support Authority (hereafter referred to as LTC). At the time of planning and commencing the research in 2013, LTC was a statutory authority of the New South Wales (NSW) state government. In 2015, with government sector restructuring, LTC became part of Insurance & Care NSW (icare). Icare is a public financial enterprise governed by an independent board of directors that delivers insurance and care services in NSW

(https://www.icare.nsw.gov.au/). LTC is the section of icare that supports the long-term care needs of persons injured in motor vehicle crashes. LTC funds the assessment of reasonable and necessary treatment, rehabilitation, attendant care and other services such as case management to people severely injured in motor vehicle crashes in NSW. People are eligible if they have sustained a catastrophic injury, specifically either a spinal cord injury, moderate to severe brain injury, amputations, severe burns, blindness or a combination of these health conditions.

There was a written agreement between LTC and the researchers. This was in addition to an existing part-time work contract held by the doctoral candidate as a part-time evidence-based practice advisor for LTC. The agreement was an adapted version of the research funding agreement LTC uses for research grant recipients. As support was in-kind and no funding was provided, the funding sections were removed from the agreement prior to signing. The agreement outlined the common understanding on the use of the taxonomy within the business practices of LTC, the in-kind support to host the nominal group meetings, agreement on consultation regarding nominal group membership, conflict of interest statement and intellectual property rights where the rights to new material were granted to the University of Sydney, and the doctoral candidate. The LTC General Manager, doctoral candidate and primary supervisor signed the agreement on 14 November 2013.

For this project, LTC provided limited in-kind support for the nominal group engaged in the development phase (Phase 1). The in-kind support involved:

- LTC staff time to participate in the nominal group. Three members of the nominal group were employees of LTC but were involved because of their

expertise in case management, and in policy and planning of case management, and represented different professions.

- Ten days of the doctoral candidate's time within the terms of the pre-existing work contract as evidence-based practice advisor over a period of 6 months.
- A room in which to hold the seven nominal group meetings.

The development of a conceptual and theoretical framework for person- and people-centred health care involved research on person-centred health care completed by the doctoral candidate and primary supervisor occurring throughout 2014–2015. However, the meta-framework was presented in a report brokered by the Sax Institute, Sydney – a research organisation for health policy (https://www.saxinstitute.org.au/). Two expert commentaries were commissioned by a government policy agency. The Sax Institute contracted the doctoral candidate and supervisor as part of a five-person team from the Menzies Centre for Health Policy, University of Sydney. The meta-framework was included in the expert commentary on person- and people-centred health care. A section of the expert commentary is included in Chapter 4 of this thesis with permissions granted. The doctoral candidate was funded to write the expert commentary by the Sax Institute.

2.3 Research methods

This research program lies within the broad groupings of framework analysis, qualitative research, and health systems and implementation research methods. In order to manage complexity, and be sensitive to and consider contextual issues inherent in health research, it is essential to use mixed research methods and by so doing provide opportunities to use broader sources of knowledge (Colditz, 2012; Howarth, Devers, Moore, O'Cathain, & Dixon-Woods, 2016; Medical Research

Council (MRC), 2008; Salvador-Carulla et al., 2014). As outlined in Table 1.1 (Chapter 1), the project involved two phases:

Phase 1: Development of a type of classification (taxonomy) for a complex intervention in community-based case management involving three steps: 1.1) scoping and mapping; 1.2) critical review and selection of international frameworks; and 1.3) iterative development of the taxonomy and feasibility analysis.

Phase 2: Involved two steps: 2.1) dissemination of the taxonomy; and 2.2) impact analysis of the dissemination.

The differences between scientific knowledge and scientific method are often blurred, particularly distinctions between ‘evidence-based scientific knowledge’ (based in quantitative and mixed methods using data) and ‘experience-based scientific knowledge’ (either expert or experiential, using qualitative methods). The emergence of health system and implementation research (including research on quality) has highlighted the need to better understand the different contributions of discovery, corroboration and implementation research methods. It is also important to understand the knowledge derived from each method as well as the interplay and synthesis of the information (Colditz, 2012; A. Fernandez et al., 2015; Nilsen, 2015; Salvador-Carulla et al., 2014). A preliminary typology of scientific framing studies was developed in response to the need for classifying scientific knowledge and methods (Salvador-Carulla et al., 2014). There have also been increasing calls for broadening the use of different sources of knowledge in both clinical research (Colditz, 2012; Petticrew, 2011) and health services and implementation research (Bate, Robert, Fulop, Ovretveit, & Dixon-Woods, 2014; Howarth et al., 2016; Powell

et al., 2015). Scientific knowledge develops through different approaches to reasoning: deductive reasoning (the general to the specific) as occurs in randomised controlled trials where a hypothesis is assessed by observing and collecting data (e.g. effectiveness of clinical interventions); and inductive reasoning (the specific to the general) as occurs in qualitative research where concepts and insights are gained and theory developed through understanding patterns in data (Pope & Mays, 2007; Taylor, Bogdon, & DeVault, 2016).

Another type of 'elicited scientific knowledge' develops through abductive reasoning, which is used to identify and explain the best or most plausible pattern, associations or interactions in the context. An additional aspect of knowledge developed from experience and context is described as 'conjectural knowledge', which refers to the 'feel' about a situation, the ruses and shortcuts considered to achieve results. It is a kind of ad hoc and expedient reasoning used particularly when there are many uncertainties (Bate et al., 2014). The type of reasoning comprises both prior expert knowledge (e.g. clinicians) and users' experience (e.g. patients/clients) (Salvador-Carulla et al., 2014). Scientific expert knowledge is defined as:

> *A set of formalized know-how, understanding, experience and insight in a defined area of knowledge, which is informed, contextualized, stable, consistent and connected. It is elicited using qualitative approaches alone or combined with quantitative methods to generate means-end inferences and non-inferential knowledge to complement evidence (Salvador-Carulla et al., 2014, p. 3)*.

Elicited expert knowledge has also been referred to as 'expert practice knowledge' gained through experience (Lukersmith, Hopman, Vine, Krahe, & McColl, 2016) or

practical wisdom, social practice knowledge or ‘knowledge-in-practice-in-context’ (Bate et al., 2014). The term expert practice knowledge is used in this research program. In this research program expert practice knowledge is considered a critical component to inform and develop the taxonomy. Expert knowledge was specifically sought during Step 1.3 of Phase 1 through the nominal group and feasibility assessments. Quality research methods highlight the need to better understand context, both external context (political and regulatory environments) and the internal context (culture, leadership, size, scope, staff satisfaction, etc.).

The research program drew on different sources of knowledge, and thereby reasoning, by using mixed qualitative methods in the first development phase and implementation research methods in the second phase. In the second phase, methods included dissemination and impact analysis techniques to corroborate the taxonomy in real-life practice. These methods provided further insights into the acceptability and applicability of the taxonomy and its generalisation to different health conditions and contexts. The following sections outline the concepts behind these methods.

2.4 Qualitative research

Qualitative research was first developed in the social sciences but has been used in health sciences for more than 20 years (Pope & Mays, 2007). In qualitative research, there is a wide range of different research approaches and methods. In this research program various qualitative methods were used including scoping and mapping review, critical analysis (of international frames), using expert practice knowledge and group consensus building techniques (nominal group), and feasibility assessment.

2.4.1 Scoping review

It was important to clarify whether there was an existing taxonomy for case management, and for disability and health, as well as to identify, characterise and map how case management had been described in the literature. The heterogeneity, complexity and inadequate descriptions of the components of case management, as discussed in Chapter 1, demanded a flexible exploratory approach with breadth in the range of literature, rather than a focused and narrower systematic review. The scoping review did not seek to assess case management quality, nor synthesise the evidence on effectiveness of case management interventions. The focus in this research program was on the components and definitions.

A review of peer-reviewed literature provides information from observational and experimental studies. However, there is also a body of information within the grey literature which includes practice and expert knowledge from, for example, case management societies, professional associations and organisations that develop case management standards or describe services. The literature review therefore needed to incorporate both peer-reviewed and grey literature. The scoping review method was appropriate. A scoping review is exploratory research, and has been used where the research topic is broad, heterogeneous or complex (Arksey & O'Malley, 2005; Kastner et al., 2012; Levac, Colquhoun, & O'Brien, 2010; Pham et al., 2014), uses a breadth of literature and different study designs (Arksey & O'Malley, 2005; Levac et al., 2010; M. D. Peters et al., 2015), and where the topic is indicative and suggestive, rather than definitive or descriptive (Anderson, Allen, Peckham, & Goodwin, 2008).

There have been few definitions of scoping reviews. The terms scoping, mapping review and study have variously been used to describe a literature search that uses

quantitative and qualitative research literature, and grey literature. In 2001, the first definition suggested scoping reviews

> *aim to map rapidly the key concepts underpinning a research area and the main sources and types of evidence available, and can be undertaken as stand-alone projects in their own right, especially where an area is complex or has not been reviewed comprehensively before (Mays, Roberts, & Popay, 2001, p. 94)*.

Arksey et al. (2005) extended the aim of mapping key concepts to include four common reasons to undertake a scoping review:

1. To examine the extent, range and nature of research activity
2. To determine the value of undertaking a full systematic review
3. To summarise and disseminate research findings
4. To identify research gaps in the existing literature (Arksey & O'Malley, 2005, p. 21).

More recently, Daudt et al. (2013) refined the definition to

> *scoping studies aim to map the literature on a particular topic or research area and provide an opportunity to identify key concepts; gaps in the research; and types and sources of evidence to inform practice, policymaking, and research (Daudt, van Mossel, & Scott, 2013, p. 8).*

Two reviews of scoping studies have been identified (Anderson et al., 2008; Pham et al., 2014). Anderson et al. (2008) sought to describe the nature of scoping reviews undertaken by a specific program in the United Kingdom (UK). The authors

concluded that although scoping reviews are not well defined, there are discrete components. More recently, Pham et al. (2014) undertook a scoping review of scoping reviews published in peer-reviewed and grey literature. The authors identified 344 scoping reviews published over 13 years to 2012, the majority of which addressed a health topic. They noted the heterogeneity of scoping reviews and high variability in terms of their purpose, methodological process, terminology and reporting. The term ‘scoping review’ was most commonly used in the literature, rather than ‘study’ and the authors advocate for the term ‘review’. As the scoping review for this research program was not to be confused with a clinical or primary research study, the term scoping review has been adopted.

The scoping review method is broadly described as mapping key concepts in order to examine the extent and range of a topic, such as theory and components, but also other important contextual information (e.g. health system, location, time) including purposively looking at other countries (Anderson et al., 2008; Clapton, Rutter, & Sharif, 2009; Grant & Booth, 2009; M. D. Peters et al., 2015; Pham et al., 2014). It is an iterative rather than a linear process (Arksey & O'Malley, 2005). The scoping review (including mapping) provides a descriptive account. As a result, there needs to be a trade-off between the scope and what is manageable to map in terms of time and resources (Levac et al., 2010; Pham et al., 2014).

The need for standardisation of terminology and methods for scoping reviews has been highlighted by a number of researchers (Daudt et al., 2013; Gough, Thomas, & Oliver, 2012; Levac et al., 2010; M. D. Peters et al., 2015; Pham et al., 2014; The Joanna Briggs Institute, 2015). The framework for conducting a scoping review was first articulated by Arksey (2005) and has since been expanded by Levac (2010) and

others. A summary of the framework and key recommendations for methods as discussed in the literature are provided in Table 2.1 below.

Table 2.1 Framework for conducting a scoping review

	Framework stages (Arksey & O'Malley, 2005)	**Additional steps recommended** (Levac et al., 2010)	**Strategies and tools** (Armstrong, Hall, Doyle, & Waters, 2011; Clapton et al., 2009; Gough et al., 2012; Hidalgo Landa et al., 2011; M. D. Peters et al., 2015; The Joanna Briggs Institute, 2015)
1	Identifying the research question	Clarifying and linking the purpose and research question • clearly articulate the research question • consider purpose • consider rationale	• develop and document protocol – need for explicit and accountable methods including plan for presenting results (recognising that these may be changed and refined as the review progresses) • identify the key question which articulates the scope, and also a series of sub-questions so that potentially broad research is combined with a clearly articulated scope of enquiry • clearly articulate the core concept examined
2	Identifying relevant studies	Balancing feasibility with breadth and comprehensiveness in the scoping process • use question and purpose to guide scope • assemble a team (content and method experts) • justify decisions and acknowledge potential limitations	• employ rigorous, replicable search strategy, define and refine search terms – document justification and changes • identify databases and search engines • create and apply inclusion and exclusion criteria filters • can be broad or narrow in scope, deep or not so deep in detail • search should include grey literature, include hand searching of reference lists • report search results including flow chart review decision processes for inclusion of studies, reference list and grey literature searching, removal of duplicates • team may include project lead, information scientist/officer, subject matter expert, senior analyst/quality assurance input

	Framework stages (Arksey & O'Malley, 2005)	**Additional steps recommended** (Levac et al., 2010)	**Strategies and tools** (Armstrong, Hall, Doyle, & Waters, 2011; Clapton et al., 2009; Gough et al., 2012; Hidalgo Landa et al., 2011; M. D. Peters et al., 2015; The Joanna Briggs Institute, 2015)
3	Selecting studies	Using an iterative and team approach to selecting studies and extracting data • team should decide on inclusion and exclusion criteria • reviewers meet and refine search strategy if needed • reviewers independently review articles and another reviewer decides where there are disagreements	• define context of studies (e.g. geographical or cultural factors, specific racial or gender-based interests) • manage storing and sorting of literature, lists and documents, enable queries through use of a bibliographic manager database e.g. Endnote, Reference Manager • requires representative samples to enable new conceptual understandings to be generated
4	Charting the data	Incorporating a numerical summary and qualitative thematic analysis • team develop data charting form and variables to extract • team iteratively charts with form updates • sample and check consistency of extraction between reviewers	• structured approach to charting • use of a spreadsheet to chart data • peer review process of the final product to minimise bias • data to include authors, year of publication, study location, study population, intervention type/study type, study aims, methods, outcome measures, results • there is a saturation point reached where no new studies are identified
5	Collating, summarising and reporting the results	Identifying the implications of the study findings for policy, practice or research • analyse findings • report results • consider meaning of findings	

	Framework stages (Arksey & O'Malley, 2005)	**Additional steps recommended** (Levac et al., 2010)	**Strategies and tools** (Armstrong, Hall, Doyle, & Waters, 2011; Clapton et al., 2009; Gough et al., 2012; Hidalgo Landa et al., 2011; M. D. Peters et al., 2015; The Joanna Briggs Institute, 2015)
6	Consultation (optional)	Adopting consultation as a required component of scoping study methodology • establish purpose of consultation • use preliminary findings to inform consultation • articulate stakeholders to consult • incorporate opportunities for exchange with stakeholders	

There are concerns about potential bias in scoping reviews related to the reviewers' own interests, lack of training, and limitations in their perspective due to discipline or language (Hidalgo Landa et al., 2011). Others suggest that a reviewer's background creates a 'trade-off" between potential bias in perception and the interpretation of a subject (Anderson et al., 2008; Davis, Drey, & Gould, 2009; Hidalgo Landa et al., 2011). Others have suggested that subject matter experts are necessary team members (Clapton et al., 2009). A reviewer's background and expert knowledge on the subject can be an advantage to the conceptual mapping, as well as a potential source of bias.

The possible quality appraisal of the studies included in scoping reviews has been discussed in the literature (Armstrong et al., 2011; Clapton et al., 2009; Daudt et al., 2013; Levac et al., 2010). However, few scoping reviews (22.4%) undertake a critical appraisal step (Pham et al., 2014). Although quality appraisal is possible for clinical studies, such studies are only one type of the literature and information used in scoping studies. While quality appraisal of studies may be possible for some scoping reviews depending on the purpose and resources, the complexity around the review question, and breadth of studies including grey literature, mean that there is often no quality appraisal performed. At present, there is no consensus on whether it is necessary, possible or realistic, nor is there a proposal for how to manage quality appraisal of each type of literature. In this research program, study quality and study design were not considered, as the focus was on concepts (description of components, definitions, etc.) rather than the outcomes and efficacy of case management. Furthermore, quality appraisal of practice and expert knowledge information from grey literature is contradictory to the paradigm of expert and practice knowledge.

2.4.2 Nominal group technique

The aim of this research was to develop a common understanding of ‘what is case management’. In so doing it was important to identify ‘what is not’ case management and consider the contextual factors. Critically, we needed to elicit expert practice knowledge from case management experts through discussion and consensus as part of the mixed methods to iteratively develop the taxonomy. The use of expert practice knowledge was also essential for the contextual relevance and potential application of the taxonomy in real-life practice.

There are numerous approaches and techniques for seeking expert knowledge and structuring communication, including Delphi techniques, and focus group and nominal group techniques. There has been substantial use of Delphi techniques in information, health and social sciences research since the 1970s (Rowe & Wright, 2011). The technique uses a group structure to manage a complex problem and assess, distil and combine judgements of experts. The Delphi technique uses multiple rounds of independent ratings, such as through questionnaire or survey. The ratings are compiled, summarised and then distributed to the group before another round of ratings. There is a degree of anonymity of the responses and the feedback is controlled (Okoli & Pawlowski, 2004; Rowe & Wright, 2011). Although the Delphi technique does not require face-to-face meetings, there have been modifications to the technique to include face-to-face discussions with independent ratings (Rowe & Wright, 2011; Skulmoski, Hartman, & Krahn, 2007).

A focus group is another technique for seeking expert knowledge. Focus groups are group discussions organised to explore specific issues or focus on some common frame of reference or topic (Bender & Ewbank, 1994; Kitzinger, 1994). The format of a focus group is less structured, which allows interaction between participants to

relate their experiences and reactions. The discussion, potential for conflict, peer pressure or development of consensus between participants often relies on the skill of the moderator/facilitator, and may lead to some participants modifying their opinion. There is no specific mechanism to conclude what the group has to say on a given topic (Kidd & Parshall, 2000; Kitzinger, 1994).

Similar to the Delphi technique, the nominal group technique uses a structured approach to develop consensus between participants, but through face-to-face discussion. The nominal group technique has been used for developing taxonomies in health sciences research (Kitson, Price, Lau, & Showler, 2013; Lewin et al., 2011; Lowe, Ryan, Santesso, & Hill, 2011; Michie et al., 2011). The technique allows the use of prior information and expert knowledge (Horton, 1980; Ruiz et al., 2011). The approach uses a group judgement technique to make decisions.

After formulating the preliminary ideas and related questions relevant to the problem, the nominal group facilitator poses the questions to the nominal group members. In a nominal group, responses and ideas related to a given question or problem are discussed and openly clarified. Following discussion in the group, further iterations are developed and the final solution to the problem is established through consensus (Horton, 1980; INAHTA & HTAi, 2014; Jones & Hunter, 1995). All group members are encouraged to participate in the discussion and contribute. The facilitator may ask members in sequential order in a round robin type of format. A nominal group must therefore be of a manageable size to allow for member participation (Horton, 1980; Jones & Hunter, 1995).

2.4.3 Framing and framework methods

Developed from framing theory, framework methods and frame analysis in the social sciences refer to the use of frameworks to manage, analyse, understand and interpret information around communication and perceptions (Goffman, 1986). In the health and research sciences, framing is used to develop frameworks which contribute to the understanding and analysis of complex phenomena, and guide decision making, particularly in situations of uncertainty and insufficient evidence (Salvador-Carulla et al., 2014). In the UK, frame analysis has been used to study the implementation of translational research and gaps in policy (Caldwell & Mays, 2012). For this research program, we used scientific framing as one of the methods to develop a derived framework, a taxonomy of community-based case management.

Social science framing in social and organisational research has been used for decades to manage complex issues and to make sense of societal and contextual communication issues, evaluation and meaning around information, and the influence on opinion (Chong & Druckman, 2007; Creed, Langstraat, & Scully, 2002; Creswell, 2013; Dewilf, Francois, Pahl-Wostl, & Taillieu, 2007; Goffman, 1986; McGettigan, Sly, O'Connell, & Hill, 1999). Framing in the context of the social sciences is seen as

> *underlying structures or organizing principles that hold together and give coherence to a diverse array of symbols and idea elements…which are relevant for our understanding of an issue or situation…and like a window we see the world through frames that determine our perspective while limiting our view to only a part of a complex world around us (Creed et al., 2002, p. 36).*

Social framing is not standardised nor typically explicit.

Scientific framing methods in health sciences are different, because they are explicit and use standardised techniques. A framework in health sciences refers to a structure, a system or plan which has categories, constructs and variables, and outlines relations between them but not typically explanations nor a process (C. C. Lewis et al., 2015). Qualitative research methods use inductive reasoning within a framework to manage data, analyse and interpret. The frameworks and related codes may be conceptual or theoretical, and concern relationships, perspective or characteristics. This method of analysis in medical and health research is often referred to as thematic analysis or qualitative content analysis (Creswell, 2013; Gale, Heath, Cameron, Rashid, & Redwood, 2013).

In other areas of health sciences research, framing is used to manage complexity, broader sources of knowledge and uncertainty. Examples are found in very different areas of health research. For example, in epidemiology and health management systems research, scientific frames include international classifications such as the International Classification of Diseases (ICD) (World Health Organization (WHO), 2016), and in implementation research, there are determinant frameworks which concern the relationships between contextual factors and outcome (C. C. Lewis et al., 2015). A recent systematic review of implementation frameworks for healthcare innovations concluded that frameworks should include generic concepts such as setting (Moullin, Sabater-Hernandez, Fernandez-Llimos, & Benrimoj, 2015). A scoping review determined research dissemination frameworks (Wilson, Petticrew, Calnan, & Nazareth, 2010). Recently a typology of scientific frames was developed which includes, among others, clinical guidelines, health atlases, health classification

systems, position papers, declarations and related scientific documents (Salvador-Carulla et al., 2014). Frames of scientific knowledge are

> *a group of studies of prior expert knowledge specifically aimed at generating formal scientific frames…and must be explicit, standardized, based on the available evidence, agreed by a group of experts and subdued to the principles of commensurability, transparency for corroboration and transferability that characterize scientific research (Salvador-Carulla et al., 2014, p. 1045).*

In this research program, we used existing scientific frameworks (international classifications) and framing methods to inform the structure, organisation and language of the community-based case management taxonomy. Using a single framework was not possible because of the concepts and complexity of case management. The 'organising' frameworks needed to concern 1) the key conceptual and theoretical concepts, and 2) the technical concepts in community-based case management. The conceptual and theoretical framework needed to incorporate a biopsychosocial model of health together with the principles of person-centred integrated health and social care. The technical frameworks needed structures which accommodated context, as well as the service variables in case management (e.g. inpatient versus community-based case management). A critical review of international frameworks was conducted to identify those most appropriate.

2.4.4 The taxonomy

A taxonomy is a scientific framework within the category of classifications. It is a type of knowledge map with a classification structure used to organise knowledge around concepts and components (Lambe, 2007; Salvador-Carulla et al., 2014). The

taxonomy is different from other classifications as it shows the relationship between concepts and components, and provides definitions (Lambe, 2007; Salvador-Carulla et al., 2014). Research taxonomies have been used in health as a knowledge map to describe, understand and explain complex real-world concepts in health services research (Bradley, Curry, & Devers, 2007). Taxonomies have been used to develop consensus and a common language in very different areas such as patient safety and reporting of adverse events (Larizgoitia, Bouesseau, & Kelley, 2013), rehabilitation interventions (Dijkers, 2014; Sykes, 2014), health-related behaviours (Salvador-Carulla et al., 2013), and complex psychological behavioural interventions (Abraham & Michie, 2008). Taxonomies have been developed using mixed methods but typically use both expert knowledge (obtained through working groups or more formalised structures) and research evidence, and involve iterative development. This research program used mixed methods of a scoping review, nominal group and framing with international frameworks to develop the taxonomy.

2.4.5 Feasibility assessment

Substantial importance has been placed on the concept of feasibility, feasibility assessment and analysis with regard to pilot or feasibility studies in preparation for large-scale randomised controlled trials (Arain, Campbell, Cooper, & Lancaster, 2010; Lancaster, 2015), and on properties (metrics) such as reliability and validity of assessment scales and outcome measures (Burholt et al., 2007; Colquhoun, Letts, Law, MacDermid, & Edwards, 2010; Lobban et al., 2007). In this research program, we were concerned about feasibility as a concept but also in terms of characteristics and properties, as it relates to health service planning, policy, quality analysis tools or instruments, and implementation research.

There appears to be no consensus on the definition of feasibility, nor is there one method for measuring it. However, there is consensus on the context-dependent nature of feasibility, that is, the variations in usability and applicability of a tool between contexts such as different countries (Salvador-Carulla & Gonzalez-Caballero, 2010; Slade, Thornicroft, & Glover, 1999). In this program, feasibility refers to the extent to which a tool (in this case the taxonomy) is appropriate and suitable for health services research (including policy, planning and quality assessment), when used in a specific way for a specific purpose.

Slade et al. (1999) identified six characteristics of feasibility outcome measures: brevity, simplicity, relevance (also described as applicability), acceptability, availability and value (Slade et al., 1999). Andrews et al. (Andrews, Peters, & Teeson, 1994) identified three dimensions of feasibility: applicability, acceptability and practicality. Applicability refers to the usability of the tool and the tool's importance to the user (whether the taxonomy is useful in a particular context in terms of its dimensions and its application). Acceptability refers to the ease with which a user can use the instrument, in this case the 'user-friendliness' of the taxonomy. Practicality relates to the implementation, training requirements and complexity around interpreting and reporting the information gained through the use of the tool (which includes, for example, the cost of implementation of the taxonomy, and the training required (Salvador-Carulla & Gonzalez-Caballero, 2010; Zeilinger et al., 2011; Zeilinger, Nader, Brehmer-Rinderer, Koller, & Weber, 2003).

In this research program, feasibility assessment was performed using developmental evaluation methods. There are several different types of evaluation methods that can be used to assess feasibility. Some of the are briefly mentioned below. Summative evaluation provides information on the tool's efficacy, and measures outcomes

against pre-determined goals and a framework (Scriven, 1996). Formative evaluation is often used to manage complexity, to improve on an existing model and make continuous improvements (Quinn Patton, 2009). It is defined as

> *a rigorous assessment process designed to identify potential and actual influences on the progress and effectiveness of implementation efforts (Stetler et al., 2006, p. S1).*

Participatory evaluation refers to engaging current or potential users and experts in the formative evaluation (Stetler et al., 2006).

Developmental evaluation is a type of formative evaluation but it occurs during the development of a tool or the first stages of a new initiative. In a sense, it provides a 'diagnostic analysis' of the feasibility and focuses on enhancing the likelihood of the tool or initiative being a success (Geonnotti, Peikes, Wang, & Smith, 2013 ; Stetler et al., 2006). It is particularly used in the situation where there is a limited knowledge base to deal with the complexity (Quinn Patton, 2009). Developmental evaluation provides valuable information on feasibility as the tool is developed, particularly if potential users (e.g. case managers and policy makers) are involved in the evaluation (participatory evaluation). For this reason, developmental evaluation was used in this project to assess feasibility. Two developmental evaluations were undertaken in the project: mapping of case management interventions and service components to international frameworks and a questionnaire to expert case managers involving reporting time spent on specific interventions across case studies. These are described in detail in Chapter 5.

2.5 Dissemination and implementation research

Implementation research is the 'how to' component of changing health care practice (Proctor, Powell, & McMillen, 2013). It has been defined as '*the scientific study of the processes used in the implementation of initiatives as well as the contextual factors that affect these processes*' (D. Peters, Adam, Alonge, Akua Agyepong, & Tran, 2013, p. 27) and as *'the study of theories, process, models and methods of implementing evidence-based practice'* (Raine et al., 2016, p. 122). Implementation research is sometimes referred to as knowledge translation research, because it is aimed at understanding and applying approaches and methods to close the gap between what is considered effective (evidence) and the best approach for policy and practice. Knowledge translation research includes activities or processes that aim to facilitate change and the uptake of research outcomes into health policy, practice or products. It potentially combines elements of research, education and quality improvement to create links into practice (Graham et al., 2006; Lang, Wyer, & Haynes, 2007). As applied research it assumes a critical role in bridging a gap between invention and diffusion (Caldwell & Mays, 2012).

Knowledge translation research is divided into two groups. Type 1 *translational* research is sometimes called 'bench to bedside' research, moving a laboratory discovery to testing for efficacy (more good than harm) in patients. Type II *translational* research includes effectiveness research in terms of impact in real-world contexts, diffusion of research, health systems research, dissemination and implementation research (Rabin, Brownson, Haire-Joshu, Kreuter, & Weaver, 2008). Only dissemination and implementation research is relevant to this research program.

Implementation research specifically concerns the study of determinants, processes and outcomes of research in terms of how it is used in practice and policy, quality assessment and service or system improvements. It is the factual application of scientific knowledge to real-life practice and policy, particularly in situations of complex interventions (D. H. Peters, Tran, & Adam, 2013). Generally, health systems and implementation research aim to not only monitor implementation but also evaluate what works and how. In order to evaluate, the components of the change need to be understood. These include the context, processes, practices, outcomes (Turner, Goulding, Denis, McDonald, & Fulop, 2016), and other factors associated with successful integration of the research into a particular setting. Other factors that need to be included in an evaluation are how to enhance capabilities of government, improve performance of implementing and provider organisations, and strengthen capabilities and performance of providers (D. Peters et al., 2013; Rabin et al., 2008). Implementation research can address issues around complexity of health interventions in different contexts and variations across health conditions, as occurs in case management. This research program focused on the processes of dissemination.

2.5.1 Dissemination

Nilsen (2015) has drawn on and combined earlier explanations and defined dissemination in this way:

> *Implementation is part of a diffusion-dissemination-implementation continuum: diffusion is the passive untargeted and unplanned spread of new practices; dissemination is the active spread of new practices to the target audience using planning strategies; and*

> *implementation is the process of putting to use or integrating new practices within a setting (Nilsen, 2015, p. 2).*

Dissemination of research findings into practice is necessary to achieve a return on investment and to apply research findings to improve outcomes in a broader community (Colditz, 2012; Wilson et al., 2010). The need to routinely incorporate dissemination activities into project design has been highlighted (Collins, 2011), such that dissemination is now considered to be an integral part of project design and is reported as a requirement in implementation research (Wilson et al., 2010; World Health Organization (WHO), 2014). For example, a dissemination plan is a standard section of every project for the European Horizon 2020 program (http://ec.europa.eu/programmes/horizon2020/) and also for the Economic and Social Research Council in the UK (http://www.esrc.ac.uk/). In 2014, the National Health and Medical Research Council (NHMRC) in Australia established a policy which required any NHMRC-supported research to be publicly available through an open access institutional repository or publication (National Health and Medical Research Council (NHMRC), 2014).

The aim of a dissemination plan may involve increasing awareness, disseminating research findings (in this project the taxonomy) (Shidhaye & Ayuso-Mateos, 2013), and engaging and supporting stakeholders to identify potential uses in their context (i.e. persuasive communication theory) (Wilson et al., 2010). Some of the tasks for the development of a dissemination plan include:

5. Identification of target audiences – the stakeholder categories, groups and individuals to target

6. Dissemination channels and approaches – the appropriate communication channels and methods (e.g. email, face-to-face presentation, social media)
7. Development of tools and aids for communication – for example, PowerPoint presentation, leaflet, website, and uses of social media such as YouTube, Twitter
8. Mechanisms for the dissemination process – the protocol for communication and follow-up for each target audience (e.g. who would lead the communication, when and how) (Amaddeo, 2010).

For this program, the aim of dissemination was to use proactive approaches to spread the information rather than rely on diffusion. The target audience was organisations and individuals involved or likely to be interested in case management. Information was disseminated via pre-determined channels, using planned strategies and potentially resulting in the uptake of the taxonomy for different applications. For example, the target audiences may use the taxonomy to support communication and articulation of case management; to provide a framework for developing policy, or planning and managing resources for case management; or as a tool to describe case managers' interventions, and undertake quality analysis and best practice.

During the development of the dissemination plan, different sectors where dissemination and implementation of research findings may have an impact or influence outcomes were discussed and identified. Figure 1 articulates the impact pathways and sectors and sub-sectors identified for this research program, but which are also relevant to other research (refer to Figure 2.1). These are:

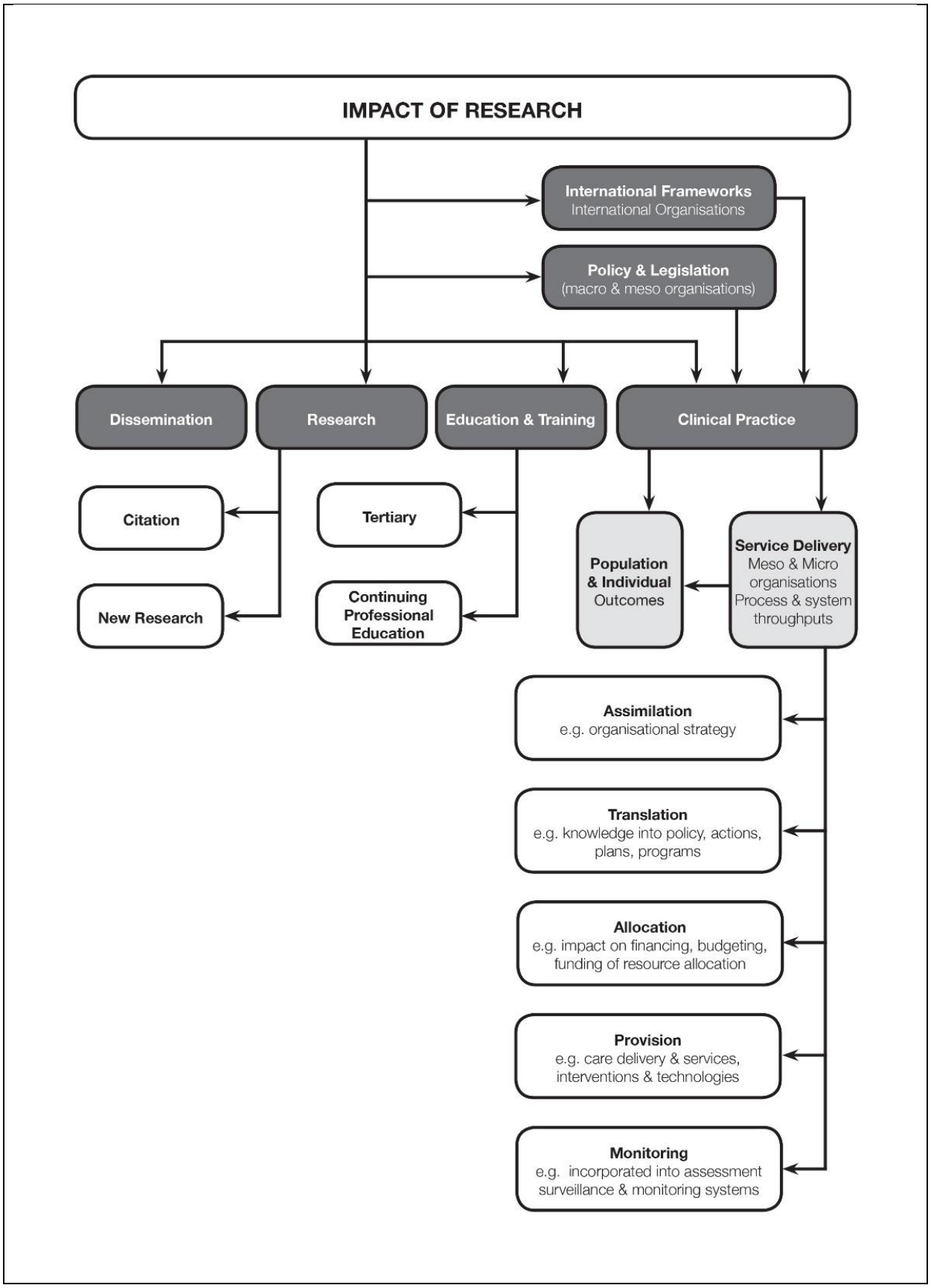
1. International frameworks
2. Policy and legislation

3. Dissemination
4. Research
5. Education and training
6. Clinical practice, in which research findings may impact
    a) Service delivery (the process and system throughputs)
    b) Population or individual outcomes.

In Figure 1, the arrows indicate pathways of influence of the research. For example, there is a second arrow indicating international frameworks and policy influence on clinical practice. If the research has an impact on policy (for example, adopting the taxonomy as a common language), there will be a secondary influence in clinical practice (service delivery) where the taxonomy may be used as a common language and inform service structures. In this research program, the taxonomy would not directly influence population and individual outcomes, but may indirectly through service delivery. This pathway is articulated in Figure 1.

There is an analysis of the impact of dissemination after a period of time to allow organisations and individuals to consider implementation.

Figure 2.1 Impact of research



2.5.2 Impact analysis of dissemination

Impact analysis refers to the measurement and assessment of the outcomes of research findings. There is increasing importance placed on the need to establish the research outcomes, benefits and impact, to reduce waste (Cohen et al., 2014; Macleod et al., 2014; Parry & Stevens, 2001; Raine et al., 2016). However, determining research outcomes and the impact of research is complex. Describing interventions and context, the relationship between them, and the influence of context is particularly difficult for complex interventions (Raftery, Hanney, Greenhalgh, Glover, & Blatch-Jones, 2016), such as case management. In 2009, the health service and treatment implementation research community developed the Consolidated Framework for Implementation Research (CFIR) which has five domains: intervention characteristics, outer setting, inner setting, characteristics of the individuals involved, and the process of implementation (Damschroder et al., 2009). However, these domains concern ‘drivers’ of implementation research rather than outcomes (C. Lewis et al., 2015). They are relevant to the impact of the intervention on population and individual outcomes, but do not accommodate the parameters of health services and implementation research. The domains are not relevant to assessing the impact of dissemination of a classification. A classification such as the case management taxonomy may have impact on practice, but also international organisations, policy, education and training and service delivery.

Different tools are needed for impact analysis at different points on the diffusion-dissemination-implementation continuum. This project involved active dissemination of the taxonomy to the target audiences (Leeman, Baernholdt, & Sandelowski, 2007) but also some incidental diffusion (passive unplanned spread of the information). The research activities did not directly contribute to implementation of the taxonomy,

in terms of either its uses or its integration within specific settings. Although the taxonomy was implemented in a number of settings, the target organisation or individuals within each setting were responsible for implementation. In this project, the impact analysis examined the impact of dissemination only, not the effectiveness of implementation methods.

Proctor et al. (2011) articulated a preliminary taxonomy of implementation research outcomes and definitions. The taxonomy includes eight outcomes and definitions as shown in Table 2.2.

Table 2.2 Implementation research outcomes and definitions (Proctor et al. 2011)

	Implementation research outcome	**Definition**
1	Acceptability	The perception among implementation stakeholders that a given treatment, service, practice or innovation is agreeable, palatable or satisfactory.
2	Adoption	The intention, initial decision or action to try or employ an innovation or evidence-based practice.
3	Appropriateness	The perceived fit, relevance or compatibility of the innovation or evidence-based practice for a given practice setting, provider or consumer; and/or perceived fit of the innovation to address a particular issue or problem.
4	Feasibility	The extent to which a new treatment, or an innovation, can be successfully used or carried out within a given agency or setting.
5	Fidelity	The degree to which an intervention was implemented as it was prescribed in the original protocol or as it was intended by the program developers.
6	Implementation cost	The cost impact of an implementation effort.
7	Penetration	The integration of a practice within a service setting and its subsystems.
8	Sustainability	The extent to which a newly implemented treatment is maintained or institutionalised within a service setting's ongoing, stable operations.

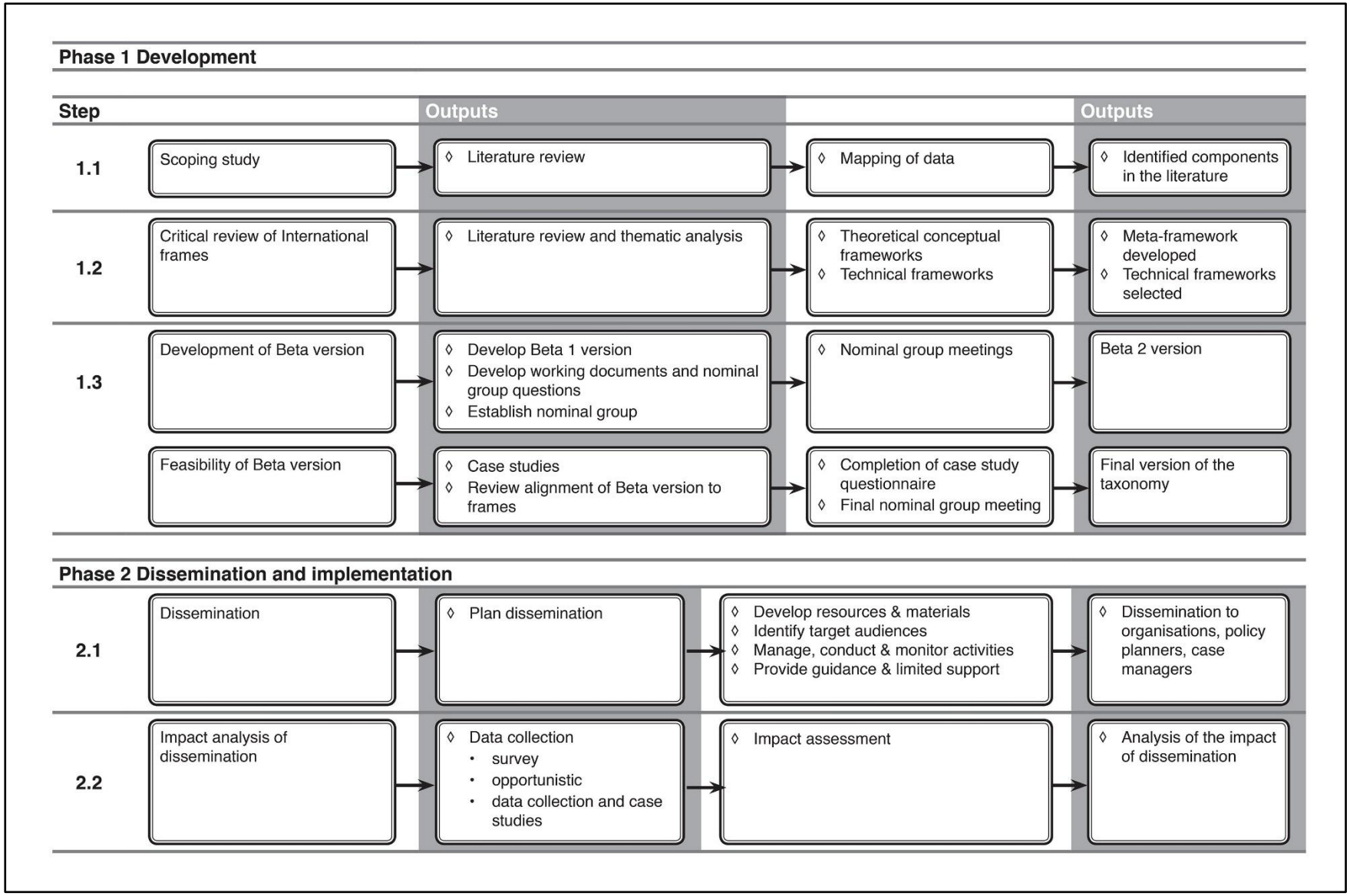
The availability of quality tools to measure all or any of the eight outcomes, and thereby analyse the impact of implementation research, is limited. Lewis et al. (2015) analysed the psychometric properties of 104 instruments which measured implementation outcomes for mental health or behavioural implementation research. They used the eight domains identified by Proctor et al. (2011). The results suggested that only 50 of the tools met the *acceptability* criteria, 19 met the *adoption* criteria and only 10 instruments met one of the other 6 criteria (C. C. Lewis et al., 2015). Quality measurement tools are needed to measure the impact of implementation research.

The dissemination in this research program was limited to the diffusion and active dissemination of a taxonomy. It differs from the implementation research for a health treatment or public health service where the treatment or health service commences. The impact analysis in this research program was a hybrid model using qualitative methods; a survey supplemented with an interpretative analysis case study model; and an adapted rating checklist informed by the eight domains of implementation research outcomes. The original rating checklist has been piloted in two previous implementation research studies (the impact analysis of the use of Integrated Atlases of Mental Health in Spain and the EdLinkQ Initiative in Queensland, Australia) (A Fernandez, Maas, Mendoza, Wand, & Savlador-Carulla, 2016; Gandre et al., 2017), and was further revised for this research program. In this research program the impact analysis included all sectors except clinical practice (population and individual outcomes), refer to Figure 2.1 above. The impact analysis did include the impact on clinical practice context (service delivery).

2.6 Research protocol

The research program occurred over two phases and involved five steps using mixed methods as outlined in Figure 2.2. Phase 1, the development of the taxonomy, involved two groups of people and three steps: Step 1.1 involved a scoping review and mapping of case management components identified in the literature; Step 1.2 was a critical review of international frameworks, thematic analysis, development of a conceptual and theoretical meta-framework, and identification of technical frameworks; Step 1.3 involved the iterative development of the Beta 1 version of the taxonomy using the information from the previous two steps, a nominal group to develop the Beta 2 version, a feasibility assessment using case studies and review of the alignment to the international frameworks, and development of the final taxonomy. In Phase 2, the dissemination and impact analysis of dissemination, involved two steps: Step 2.1 involved the development of a dissemination plan and the tools and dissemination activities to reach international organisations, policy and legislation organisations, researchers, education and training organisations, and clinical practitioners (service delivery); Step 2.2 involved survey and opportunistic data collection, development of case studies, impact ratings and then impact analysis.

Figure 2.2 Outline of the research program phases and steps



2.7 Context

The research program was conducted in Sydney, Australia. The development phase of the program occurred in Sydney, Australia. The dissemination phase involved contact with target organisations and individuals in Australia and 11 other countries.

2.8 Time frames

Phase 1 of the project (taxonomy development) occurred between July 2013 and February 2015. In Phase 2, dissemination occurred between February 2015 and July 2016, with the impact analysis between May and August 2016.

2.9 Funding

The project received no direct funding. There was limited in-kind support provided by LTC as outlined in Section 1.2 'Ethics and industry partner agreement'. Step 1.2 of Phase 1 included the development of a conceptual and theoretical meta-framework. The meta-framework was part of a larger piece of work, an expert commentary report on person- and people-centred integrated health care. (An excerpt of the expert commentary relating to the meta-framework is provided in Chapter 4.) While the meta-framework was developed prior to this larger work, the expert commentary was funded by the Sax Institute (policy research institute).

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CHAPTER 3 SCOPING AND MAPPING REVIEW

This chapter is Step 1.1 of Phase 1, the scoping and mapping review (refer to Figure 2.2 in Chapter 2 General Methods). The chapter is an open access publication with appendices.

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RESEARCH AND THEORY

What is Case Management? A Scoping and Mapping Review

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The description of case management in research and clinical practice is highly variable which impedes quality analysis, policy and planning. Case management makes a unique contribution towards the integration of health care, social services and other sector services and supports for people with complex health conditions. There are multiple components and variations of case management depending on the context and client population. This paper aims to scope and map case management in the literature to identify how case management is described in the literature for key complex health conditions (e.g., brain injury, diabetes, mental health, spinal cord injury). Following literature searches in multiple databases, grey literature and exclusion by health condition, community-based and adequate description, there were 661 potential papers for data extraction. Data from 79 papers (1988–2013) were analysed to the point of saturation (no new information) and mapped to the model, components and activities. The results included 22 definitions, five models, with 69 activities or tasks of case managers mapped to 17 key components (interventions). The results confirm the significant terminological variance in case management which produces role confusion, ambiguity and hinders comparability across different health conditions and contexts. There is an urgent need for an internationally agreed taxonomy for the coordination, navigation and management of care.

Keywords: case management; complexity; care coordination; integrated care; taxonomy; scoping

Introduction

Case management, also known as care coordination is a complex integrated health and social care intervention and makes a unique contribution to the health, social care and participation of people with complex health conditions.[1–4]. In the 1960's case management emerged in response to the de-institutionalisation of large numbers of people with severe mental health conditions who required referral to outpatient health and other community services. During the 1970's and 1980's, the increasing cost of health care and de-centralisation of health services influenced the role of case managers [5, 6]. Since the 1990's, case management has existed in a range of settings including acute, post-acute hospital, rehabilitation, long term care and community-based settings. Case management tasks are now performed by people from various disciplines, for people with different problems in diverse contexts and communities. These multiple interdependent and interacting parameters of case management produce variability in the description of case management [5, 7–9]. The significant terminological variance, lack of understanding and a common language for case management and care coordination has impeded quality analysis, policy and planning [4, 10–12]. There is an urgent need for a common international language, but which first requires an understanding of the terms used to describe case management in the literature.

There are multiple parameters that influence case management. Case management operates in very different service sectors (health, social, correctional, work/vocational, veterans, legal sectors) and different settings (public sector, private and non-government organisations) and with different community and support resources (high and low resource settings). Its presence in diverse contexts demonstrates the importance of case management in the horizontal integration of care across health services, social services and other sectors as well as the vertical integration across primary, community, hospital and tertiary health care services [13].

In the health sector, case management and care coordination occurs within an inpatient setting, or mobile and community-based. In this scoping review we only considered community-based case management. Community-based case management is a mobile rather than office based health service. Case manager contact with the client (and/or their family) may occur in a different setting such as the client's home, workplace or other community

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venue as considered appropriate by the case manager and client. Community-based case management is the most holistic and person-centred of the approaches (model) as it meets at the junction of the client in their own context. Due to its holistic and comprehensive approach, community-based case management is also likely to involve most of the components of case management of other models that have a narrower focus.

Health sector case managers are from different disciplines (e.g. nursing, occupational therapy, physiotherapy, psychology, rehabilitation counselling, social work, speech pathology) and different practice areas (social and welfare, primary care). Further, there are a number of case management models and theories underpinning practice approaches, due in part to the different sectors where case management operates, the age and health conditions of the client [9]. Hence, both in practice and the literature, a range of names are applied to the role and tasks of a case manager such as: community/care coordinator, support facilitator or broker, case monitor, discharge planner, planning facilitator, case worker, clinical/rehabilitation case manager. Other client characteristics and temporal factors (e.g. whether the client's problem is new, acute or chronic) also affect the tasks and actions of the case manager. All these different factors related to the case manager, client and context influence what case managers do (i.e. case management tasks as interventions). Whilst there are differences between case management tasks and context, there are also similarities, yet there is no common language to describe these variations.

In spite of the abundance of literature on case management in all its forms, case management descriptors are often non-existent or poorly described with mixed concepts and constructs. There appears to be no consensus on what is, and importantly what is not case management. The heterogeneity, complexity and inadequate descriptions of the components of case management demands a flexible exploratory approach and consideration of a breadth of literature compared to the methods of a focused and narrower systematic review. This review aims to characterise and map how case management has been described in the literature. The review did not seek to assess the quality, nor synthesise the evidence on effectiveness of case management interventions. The focus in this research programme was on the components and definitions. It is the first step of a larger study to develop a taxonomy, a knowledge map and common language for community-based case management. Community-based case management was the focus because it is likely to contain elements of other approaches. People with key complex and chronic health conditions were selected, as case management is frequently used to support their management and the integration of their care.

Aim of the research

The objective of this study was to scope and map '*How case management is described in the literature*' in particular the definition, the theoretical basis, the components and activities (interventions) performed by the case manager.

Theory and Methods

Study design

The study design was a scoping and mapping review. As exploratory research, scoping reviews are particularly appropriate when the area is complex, and used to map the key concepts underpinning a research area [14]. A scoping study aims '*to map the literature on a particular topic or research area and provide an opportunity to identify key concepts; gaps in the research; and types and sources of evidence to inform practice, policymaking, and research*' (p. 8) [15]. A scoping review balances the feasibility of the literature search with the breadth and comprehensiveness in the scoping process [16].

The scoping review used five of the six steps in the framework articulated by Arskey et al [17] and extended by Levac [16] which are: 1) identifying the research question; 2) identifying relevant studies; 3) study selection; 4) charting (mapping) the data; 5) collating, summarizing and reporting the results. Consistent with many scoping reviews, quality appraisal was not undertaken as the focus was on language and descriptions of the concepts and components of case management rather than the methodology, outcomes and efficacy of the included studies [15, 16, 18–20].

Scoping and mapping methodology

We used an iterative process in the scoping review that allowed for flexibility in the search, reviewing and mapping steps. A flexible approach was necessary due to the diversity in the terms around case management, the model or approach taken, the contexts in which it operates and the health conditions of the recipients of case management. The steps taken for the scoping review are outlined below:

1. The research question

The main research question was 'How was case management described in the literature'. The sub-questions were:

I. How was case management for complex and chronic health conditions, described in the literature (brain injury, diabetes, mental health, spinal cord injury)?
II. What was the theoretical basis (the model) (if any) linked to the case management approach?
III. What were the components, and activities performed in case management; and how are they described?

2. Identify relevant studies

This scoping study used quantitative, qualitative research literature as well as the grey literature. Peer reviewed papers provide information from observational and experimental research. Grey literature provides information from expert practice knowledge and expert experience knowledge [21] . In this study we consider grey literature to be literature '*produced at all levels of government, academics, business, industry in print and electronic formats, but which is not controlled by commercial publishers*' [22]. It includes papers, reports, technical notes or other documents produced and published by governmental

agencies, academic institutions, professional associations such as case management societies, and other case management organisations and groups that develop standards or describe services and the activities of case managers.

The search terms and strategy were developed, trialled and discussed then refined with the co-authors and an information specialist. Over three meetings, the co-author team reviewed examples of the literature and refined the selection of studies. This refinement involved combining key words for case management and key words for definition in the final search strategy with limits to specific health conditions. Our decisions on key words and limits are outlined below:

- The variation in names, and complexities of contexts and health conditions posed challenges to systematic searching across multiple databases. We collectively identified the relevant descriptors of case management for the key word search terms based on our familiarity with the literature and community-based case management context.
- There were no limits on the type of study as the range of literature of interest included qualitative, quantitative intervention and non-intervention studies for key health conditions, reports on case management standards, service descriptions, literature reviews and theoretical papers.
- Literature on case management not provided in the community was excluded. However, research papers and grey literature that referred to general case management activities and actions were included.
- The number of descriptions for case management required limits established for the range of health conditions. Five complex or chronic health conditions were included: brain injury, diabetes, mental health conditions and spinal cord injury. Brain injury was included as it is complex health condition and potentially impacts multiple domains of health. It was also of interest to the industry partner (Lifetime Care) involved in the larger study [23]. Mental health conditions were included because of the complex impact of the conditions but also because of its history in case management. Diabetes was included as it is a common chronic health condition. Although less common, spinal cord injury was included as it provides its own set of unique challenges around long term community-based and integrated supports.

Multiple databases were searched for published literature, complemented by searches on key organisation websites and snowballing with hand searching of references lists. The database search was carried out in Week 3 July 2013. The databases were Medline, Cochrane, OTseeker, and PsycBITE. The grey literature key websites searches were conducted in August 2013 and February 2014. The organisational websites were: *Australia*: Case Management Society of Australian and New Zealand (CMSA); Transport Accident Commission (TAC); Lifetime Care and Support Authority (LTC); National Disability Insurance Agency (NDIA); WorkCover Authority (NSW), Brain Injury Rehabilitation Directorate (New South Wales – NSW); Department of Health NSW; *Canada*- National Case Management Network; *United Kingdom* (UK) – Case Management Society of the United Kingdom (CMSUK); British Association of Brain Injury Case Managers (BABICM); National Health Service (NHS); *United States of America* (USA) Agency for Healthcare Research and Quality; Commission for Case Manager Certification; Case Management Health System; Case Management Society of America; American Case Management Association.

The limits were English language, humans with no limits on study type. The inclusion criteria were:

- No limits on publication dates (Medline 1946- Week 2 July 2013)
- Community-based case management
- Case management related to health conditions of brain injury, diabetes, mental health conditions, spinal cord injury
- A definition of the case management and description of the actions, activities, interventions.

3. Study selection

The authors agreed that an iterative process to the exclusion, selection of studies and data extractions was appropriate. In order to manage the copious amounts of literature located, a hierarchy of steps for the exclusion of literature was developed in consultation with co-authors. A bibliographic manager database (EndNote X7) supported the management of the body of literature and exclusion process. The steps for exclusion after the removal of duplicated papers were:

i. Exclusion by health conditions, social issues (e.g. ex-prisoners or offenders, homeless persons), single health conditions in low health service resource settings (e.g. Malaria in a developing country),
ii. Exclusion by case management setting (inpatient, acute care or residential settings such as nursing home, correctional institution), telehealth (no face to face).
iii. Exclusion because of inadequate (or absence) of a description of case management, the case manager actions or interventions.

4. Mapping the data (charting)

The scoping review involved conceptual mapping to the point of saturation when no new descriptions, concepts or components were identified [17, 24]. The focus was on the components and definitions of case management interventions. The information was extracted and stored on an Excel spreadsheet for data management and to enable numerical summation and qualitative analysis. SL extracted data from a sample of 6 papers, which was then reviewed and checked by LSC and MM. The information variables to be extracted were then revised and reduced in agreement with all authors. SL continued with the data extraction and mapping. The final extraction table was reviewed by all authors. Obvious inconsistencies noted were discussed and revisions made.

Extraction and mapping of the case management information began at a global level of the country and type of paper, followed by high level information on the model or approach, theoretical basis, then more detailed components and then finally the description of these components. The final variables mapped were: paper author, year of publication, title, type of study where relevant (or paper), health condition of population, country of study, name of case management model, linked theoretical basis, case management definition, components of case management, descriptors, actions/activities described (sometimes called steps, activities, actions or interventions in the literature) and additional comments. The mapping of information was done to the point of saturation, where no new information (concepts, descriptions, components) were identified. Once it was apparent that no new information was extracted, a further six papers were reviewed and data extracted and mapped, to ensure that the point of saturation had been reached.

5. Collating, summarizing and reporting the results

The information and mapping results from the studies were collated, analysed, summarised and reported. The results were also used as one step in a larger study to develop a taxonomy on case management [23].

Results

Our search yielded a total of 6,847 peer reviewed research study papers and 22 grey literature papers, a total of 6,869 references. This was reduced to 6,314 after duplicates were removed (see **Figure 1** for a summary of the screening and eligibility process). After reviewing the titles and abstracts from the search results for health condition (excluded n = 3,600), and removing practice context other

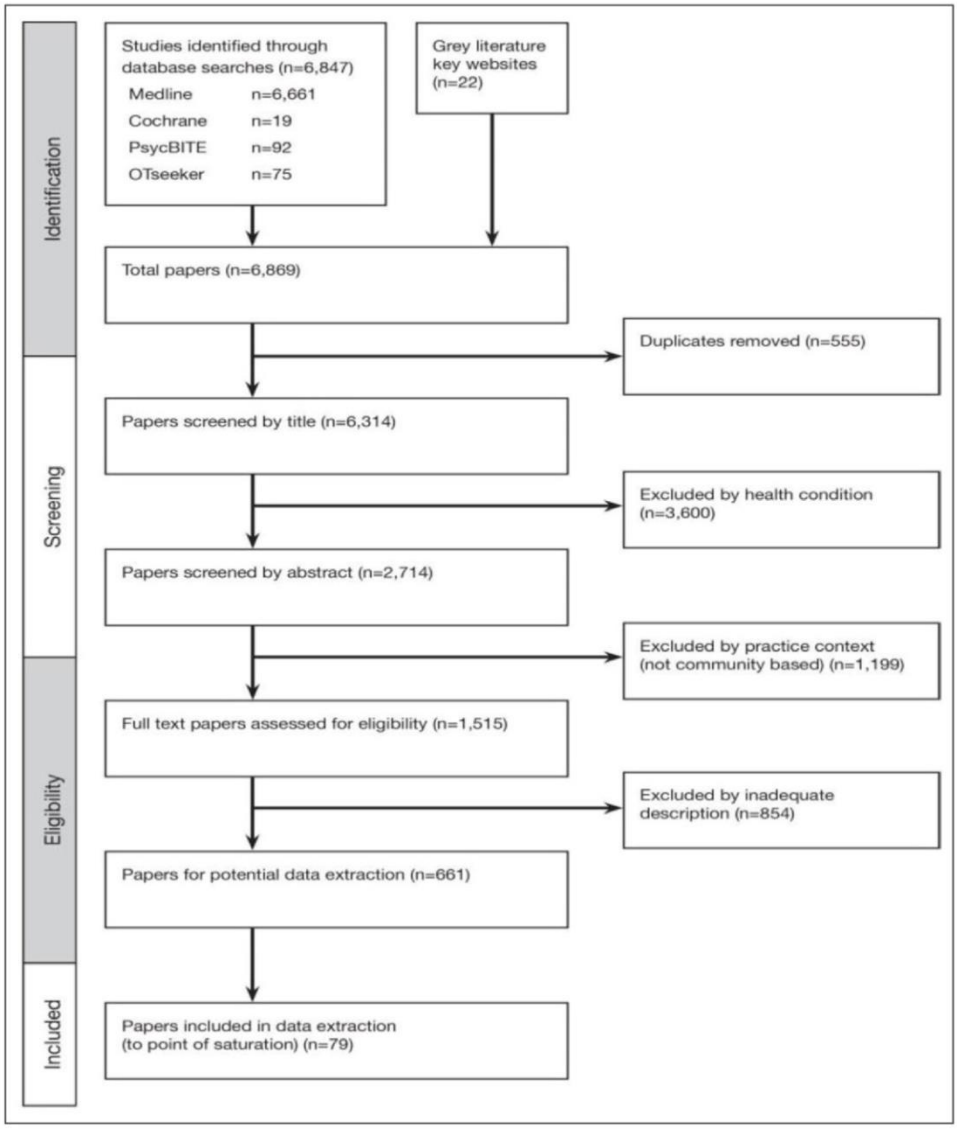

Figure 1: Flow of Study Selection.

than community-based (excluded n = 1,199), and finally removing those with inadequate description in the paper (excluded n = 854), we had 661 potential references for data extraction and mapping. A total of 12 grey literature papers and 61 randomly selected research papers were included in the data extraction and mapping to the point of saturation, when no new information was provided. We selected the grey literature papers because of their focus and the content related to the components to be mapped (model, definition, description of activities or interventions by case managers), such as model descriptions or statements from professional case management associations. To ensure the point of saturation was reached, the data from a further 6 research papers was extracted and mapped making a total of 79 papers.

The papers analysed included 65 papers from peer reviewed journals published 1988–2013 and 14 papers from the grey literature. Appendix 2 provides the details of the 79 included papers. **Table 1** describes the global analysis of the papers. In 63 papers there was 10 different countries of focus and 14 there was an international perspective (e.g. literature review). There were 26 papers on mental health, eight on diabetes or chronic/long term health conditions, 12 brain injury, two on spinal cord injury and 31 were not related to specific health conditions. There was one systematic review, 42 qualitative research methods papers, 7 intervention studies, 11 theoretical papers, 5 editorial perspectives or expert opinion, 11 papers were practice guidance and professional association standards and two conference papers.

The next layer of data extraction resulted in an increasing level of detail on case management as described in the literature. Twenty-three specifically identified definitions of case management, (rather than general statements) are provided in Appendix 3. Some definitions were repeated

	Source of the paper	
Characteristic	**Published papers (n = 65)**	**Grey Literature (n = 14)**
Country of focus		
Australia	7	9
Canada	1	1
Germany	1	0
Hong Kong	1	0
Japan	1	0
New Zealand	0	1
Spain	1	0
Sweden	1	0
United Kingdom	5	1
United States America	33	2
International	14	0
Health Condition		
Mental Health	26	0
Diabetes/chronic or long term health condition	8	0
Brain injury	8	4
Spinal Cord Injury	2	0
Not specific	21	10
Type of paper/study		
Systematic review	1	n/a
Qualitative study (includes literature review)	40	2
Intervention study (includes study protocols)	7	n/a
Theoretical paper	11	n/a
Editorial/perspective/ expert opinion	5	0
Practice guidance/standards	1	10
Conference paper	0	2

Table 1: Description of the mapped papers.

in a number of papers, for example a case management society definition was used in a number of papers.

We found descriptions of different models and theoretical descriptions of the case management approaches in 23 papers. These were mapped to five different models. Exploration on the most common or frequently adopted model was not in the study scope. In some instances, there was a specific model or theoretical basis. For other papers, the approach was broadly described. On this basis, we could map the approach to a model. In other papers several models were discussed (e.g. systematic review). There was a total of 57 papers which did not identify the theoretical basis of the case management approach nor refer to a model. The mapped models of case management, related terms, theoretical description and case management features are provided in **Table 2**. In this table, we have not provided examples of papers providing a description as many papers such as literature reviews, opinion or theoretical papers and systematic reviews referred to a number of these models or their variations.

The key components of case management described in the papers were extracted. Terms used for these components include activities, functions, tasks, responsibilities, duties, steps and interventions, standards. Across the 79 papers, we mapped 69 of the various terms used in the literature to 17 component headings, which were broadly defined. Only examples of the terms extracted from the literature and mapped to the component are provided in **Table 3**.

Discussion

The results of the scoping and mapping review confirms that there is a huge body of peer reviewed and grey literature on case management, yet there is significant terminological variance. Following literature searches, exclusions by health conditions, case management context (community-based) and papers with inadequate descriptions we extracted data and mapped the components of case management from papers (n = 79) to the point of saturation. There was a broad range of literature included in the study (quantitative, qualitative, theoretical and practice guidance papers) and from 11 countries and international perspectives (n = 14).

The mapping of extracted data was complicated because of the variability in the language to describe case management. There was heterogeneity in the descriptions, terms and phrases to describe the models, which reflects the difficulties in the articulation of the differences and similarities between the models and the interventions provided by case managers. For the purposes of this scoping review, we mapped the models described to five key models of case management based on a theoretical description of each. Whilst there are more than five case management models, many are variations, adaptations and interpretations of a model to the specific context.

We extracted 69 components in the literature to describe what case managers do (the interventions/activities). We identified 17 key components and mapped the 69 descriptions to these. Each key component had multiple different but related terms to describe the intervention. There was also complexities mapping of the components (activities and interventions) performed by the case manager. In the literature, there was semantic confusion between the components (interventions) of case managers with skills, standards, aims and objectives. For example, 'stable person- invested but not involved' [54] is a description of a standard or skill of the case manager (the 'how') rather than a component of case management (the 'what' is done). The component descriptions were also variously defined from different perspectives of the client, case manager, project or team organisation, program, service or organisation. For example, the description of 'gatekeeper' (clinical and financial) [9, 55, 56] listed as a case manager activity, is aimed at the sustainability of the service or system, at most is an (administrative) responsibility of the case manager to the service or organisation rather than an intervention directed at the client. These difficulties confirm the complexity around case management resulting in terminological variance used. The literature in this scoping study spanned a 25 year period (1988 to 2013). While case management to coordinate services has been used since the late 19th century and contemporary case management emerging since the 1960's [57], this scoping review confirms that over time the description and terminological variance remains.

The terminological variance reflects the ambiguity and confusion about roles and the interventions performed by case managers. Specificity and replicability of case management are essential to evaluation of effectiveness [58]. There are complex interdependent and dependent factors influencing what case management interventions are done, when, with whom and in what context. A clear understanding and consensus on the components and a common language to describe these factors will provide the tool for measuring outcomes, and making comparisons for effectiveness and quality evaluations.

Limitations

The study was limited to the descriptions and terms used in the literature to refer to the same or similar concept including the model, theory and components. A limitation in the search strategy was not including all possible databases. Databases such as EMBASE were not searched as it is primarily a biomedical and pharmacological database and considered unlikely to host a significant body of community-based case management literature. Search of the database CINAHL may have revealed additional relevant literature. Whilst other databases could have been considered, the volume of literature from the four databases provided more than sufficient material to use for data extraction to the point of saturation. The extensive search for grey literature added to the volume of peer reviewed literature. However, the point of saturation was reached after the data extraction from 79 articles retrieved through the four databases and multiple grey literature websites.

The search restricted to only four health conditions is a study limitation. The trial of searches without health

Model and mapped terms	Theoretical description	Case management features
1. Broker **– Service broker** **– Managed care** **– Medical case management** **– Generalist** **– Gatekeeper** **[9, 25–29]***	An impartial organizational or service focused approach to connect a patient to needed services and to coordinate between different service providers, with an emphasis on a network of providers thereby containing costs by preventing inappropriate access and use of services	Case managers attempt to assist clients to identify their needs and broker services and supports. Contact is limited.
2. Clinical **– Rehabilitation** **– Direct care** **[28, 30–42]**	Involves clinical, collaborative, strategic and communication roles with patient and key stakeholders (e.g. providers, payers, employers): establishes comprehensive case management goals and objectives, interventions, and outcomes including specified timeframes; provides clinical interventions and brokers other clinical services; aims to assist, facilitate, monitor and resolve client issues using clinical skills, clinical services and community resources; may involve adjusting the therapeutic regimen or communicate the need for adjustment to other providers. The individual goals and needs of the client dictate the response and services. In the rehabilitation model this aim is to restore functional ability prior to the injury or illness; case management is extended to include identifying and assessing client skill deficits, barriers to achievement of personal goals, teach skills, provide support and responsibility for the continuity of care and coordinating services including in times of crisis.	Contact can be brief, or an episode of planned activity over 2–3 years.
3. Chronic care **– Long term** **– Integrated care** **– Standard** **[9, 43–47]**	More system wide integrated care but tailored to the individual e.g. in primary practice working with a multidisciplinary team and utilizing system supports. Provides proactive support by the team; and recognizes that quality care is predicated on productive interactions between clients, families and caregivers, providers ; case managers are providers with specific system supports (e.g., protocols), structured relationships with specialist expertise for consultation, support and integration; typically have strong links to the primary care provider to support ongoing coordinated and integrated care with follow-up; condition neutral and is applicable across conditions and risk factors	Longer term involvement with a focus on the integration of care and supports
4. Strengths based **[9, 27, 28, 30, 38, 39, 41, 48–53]**	Based on the premise of the client using their own strengths, resilience, interests, potentials, abilities and knowledge to lead to recovery rather than on their limits (deficits); adopts an ecological perspective that recognizes the importance of people's environments (context), the individual's resilience; emphasises the importance of the relationship with the case manager, to support and enable clients to develop skills	
5. Assertive **– Intensive case management** **– Recovery** **– Intensive comprehensive care** **[5, 29, 53]**	Assertive case management focuses on recovery rather than cure of the health condition (e.g., mental health). It involves; a team providing all necessary treatment and care (at home or work) in their natural environment rather than involving other services; aims to reduce hospitalizations: and purposively outreaches to clients to support their opportunities for choice and living a meaningful and satisfying life as a member of a community. Intensive case management addresses the social and health needs of people, is intensive and long term with an individual case manager.	*Assertive*: Clients are shared by a team to provide services including outreach, direct services such as counselling, skill development, family consultation and support, crisis intervention. Time of involvement is unlimited *Intensive*: small case load which are not shared across the team. *Intensive comprehensive care*: combination of assertive and intensive

Table 2: Mapped models of case management, and related names, theoretical description and case management features.

*refer to Appendix 2 for details of the articles in scoping study.

Component Heading	Broad description	Mapped terms
1. Case finding	To identify patients not in contact with services	– Assertive outreach – Detection of patients – Patient identification/outreach – Access – Outreach
2. Establishing rapport	Focusing on the connection developed between the case manager and client Establishing alliance and collaboration with the patient	– Establish and provide a one-to-one relationship – Initial phase – Engagement – Building on the relationship (including with other providers) – Establishing accountability – Establish responsibilities – Negotiate responsibility – Establish therapeutic alliance – Establish long term collaborative and human relationship
3. Assessment	Comprehensive understanding of the needs, capabilities and available resources and community services	– Need identification – Intake – Perform social diagnosis – Assess client and family – Interview – Assessment of needs (e.g. social support, levels of care, readiness and willingness for services, living situation, financial resources, access, barriers, home evaluation, need for referral – Community assessment – Gather information – Use comprehensive assessment instruments – Identify strengths and obstacles to attainment of goals – Cognitive and behavioural assessment – Identify present achievements, interests, resources, interests and aspirations – Document and communicate needs – Document aims and objectives – Estimate level of case management support required – Screening for co-morbid conditions – Determine decision making capacity
4. Planning	Development of plan with client input including setting goals, actions steps towards achievement of goals and selection of resources	– Gatekeeper of funds – Discharge planning – Decision making – Resource identification – Setting goals with client – Goal setting – Design and implementation of care packages – "Moving forward" – Design of an individualized care plan – Determine comparative costs of alternate plan options – Review relapse prevention options – Plan for disengagement of case management
5. Navigation	Facilitate safe and effective connections to services across settings	– Anticipate, identify barriers – Help remove barriers to holistic care
6. Provision of care	Supply care directly or be delegation (relevant to qualifications and experience of case manager)	– Crisis intervention – Patient interventions – Supportive and formal therapeutic interventions – Therapy – Skills training – Patient interventions – Group work – Medication management – Symptom monitoring

(Continued)

Component Heading	Broad description	Mapped terms
7. Implementation	Broker and implement the best package and arrange or purchase services on behalf of the client	– Care arranging – Service implementation – Clinical management – Communication – Arrange and activate services – Develop social networks – Locating and coordinating services – Perform a cost-benefit analysis – Identify formal and informal community resources and support programs – Collect and analyse data – Plan for clients transition along the continuum of care
8. Coordination	Navigating the system of providers and resources needed, referral, facilitate multi-disciplinary collaboration, to ensure and advocate with other agencies for the appropriate use of resources and supports to client, including their purchase of the services themselves.	– Continuity – Linking – Linking to needed services – agency liaison – Environmental interventions – Resource management – Liaison – Facilitation – Interagency coordination – Resource acquisition – Facilitate transitions – Educate and facilitate – Referral – Negotiate – Facilitate patient access – Advocate with providers – Consultation with stakeholders
9. Monitoring		– Proactive support – Monitoring service delivery – Monitor outcomes – Follow-up – Tracking clients – Maintain communication with stakeholders – Monitoring evaluation or reassessment – Maintenance/follow up – "Pushing/pulling and letting go" – Manage
10. Evaluation	Determine the clients progress toward established goals and outcomes and the effectiveness of care	Monitor outcomes and quality of care – Reassessment – Evaluate effectiveness including timeliness – Document client response – Evaluate availability of services needed – Determine. Prepare and communicate when case management services no longer required – Collect and analyse outcome data
11. Feedback		General – Case consultation – Reports to treating providers – Maintain privacy and confidentiality – Regular meetings with treatment team to review goals and progress – Listen to stakeholders, collect information objectively
12. Education/ information	Information and assistance to (e.g. client, family other service providers, workplace etc) to assist understanding of e.g. Health condition , Support services	– Providing information – Educate about early signs and symptoms – Assistance with applications, appropriate documents,

(Continued)

Component Heading	Broad description	Mapped terms
13. Advocacy	Advocate for the client, best practice and the payer in line with client's best interests	– Advocacy for social service programs, during hospitalisation etc – Advocate for more community-based services – Community advocacy – Obtaining financial assistance for the client – Intermittent function, affirmative, assertive approach to assisting client in receiving amenities or services that are being withheld unfairly. – Aiming to have gap/need filled – Assist clients to become autonomous and informed decision-makers
14. Supportive counselling	Provide practical and emotional support, encouragement to facilitate knowledge, coping, adjustment and functioning	– Encouragement/support – Provision of problem solving support – Confrontation – Counselling – Individual, family or social support – Provision of emotional support – Conflict resolution – Provide practical and emotional support
15. Administration	Complete administrative tasks	– Agency and other meetings – Complete paperwork – Treatment planning – Recording, report writing – Audits – Gathering statistics
16. Discharge/ Disengagement	Determining and planning for the appropriate time to discontinue case management including facilitating client independence and knowledge to self-manage condition and care needs	– Planning case closure – Case closure
17. Community service development	Support local community to take collective action to develop new, adapt or grow services or generate solutions to common local problems	– Identify gaps – Use of statistics – Prepare funding submission – Create options with generic services – Identify and act on service gaps and overlaps at the client, community and population levels.

Table 3: Examples of the terms in the literature mapped to component heading.

conditions limits produced in excess of 10,000 hits on Medline alone. For pragmatic reasons, the search strategy was subsequently limited to include four health conditions. Those selected by the authors were known to have community-based case managers involved in health, social care and education sectors.

The study did not undertake quality analysis of the research papers. It is recognised that this meant that equal weight was given to all papers and grey literature, which we consider was justified given the purpose of the scoping study to examine descriptors of case management components and context not efficacy of case management. There can also be concerns about potential bias in scoping reviews related to the reviewers own interests, lack of training and limited view due to discipline or language [59]. Others suggest that there is a 'trade off' of potential source of bias in perception and interpretation of a subject and conversely that subject matter experts are necessary [59–62]. In this instance, considering the complexity in case management, the three researchers background and expert knowledge was considered an advantage to the scoping and conceptual mapping.

The scoping review used five of the six steps in the framework articulated by Arskey et al [17] and extended by Levac [16]. The 6th step it the Arskey/Levac methodology is consultation with a broader group of experts and stakeholders to discuss the findings. This step was not performed as part of the scoping review but did occur in a subsequent step of the larger study to develop a taxonomy on case management. In the larger study, a nominal group of case management experts extensively discussed the results of the scoping review to develop the Beta 2 version of the case management taxonomy [23].

Conclusion

Case management with all its different names, variations and contexts continues to support the coordination, integration and management of health and social care in many different contexts for different health conditions. The results of this scoping and mapping study confirms the significant terminological variance which produces role confusion, ambiguity and hinders comparability across different health. There is an urgent need for an internationally agreed taxonomy for

the coordination, navigation and management of care. The result of this scoping and mapping review was the first of four steps to develop the case management taxonomy finalised in 2015. [23].

Future research

The results from this scoping and mapping study is part of a larger study to develop a knowledge map and common language, the case management taxonomy which has an intervention tree, service tree and glossary [23].

Supplementary Files

The supplementary files for this article can be found as follows:

- **Supplementary File 1: Appendix 1.** http://dx.doi.org/10.5334/ijic.2477.s1
- **Supplementary File 2: Appendix 2.** http://dx.doi.org/10.5334/ijic.2477.s2
- **Supplementary File 3: Appendix 3.** http://dx.doi.org/10.5334/ijic.2477.s3

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Competing Interests

The authors declare that they have no competing interests.

Author contribution

All authors contributed to the research and manuscript.

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Appendix 1 Search strategy key words

[‘support broker’ or ‘community care manag*’ or ‘case manag*’ or ‘care monitor*’ or ‘case monitor*’or ‘support coordinat*’ or ‘case coordinat*’ or ‘care coordinat*’ or ‘case management’] AND [definit* or model or Theor* or descript* or describe* or approach* or program evaluation or program develop* or taxonom*] AND [brain injury or head injury or brain trauma or head trauma or brain damage or ABI,mp or TBI.mp] OR [mental health or opioid related disroders or anxiety disorders or depressive disorder or schizophrenia or psychotic disorders or stress, psychological] OR [diabetes mellitus, Type 2 or Type 1, or diabet*] OR spinal cord injuries or spinal cord injury or SCI.mp or quadriplegia or tetraplegia].

Appendix 2 Studies included in the scoping review [1-79]

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Appendix 3 Definitions of Case Management

The following specific definitions were found in the published and grey literature.

Case management is:

1. An approach to service delivery that attempts to ensure that clients with complex, multiple problems and disabilities, receive all the services they need in a timely and appropriate fashion Rubin 1987 cited in [1].
2. A way of coordinating, integrating and allocating individualized care within limited resources through by means of continuous contact with one or more key professionals [2].
3. A comprehensive assessment and care planning process involving both the formal and informal system [3].
4. An approach which facilitates assessment and service provision to meet the client's treatment and support needs, and ensures continuity of care throughout the coordination of service delivery across time and setting (Commonwealth Department of Human Services and Health 1995 cited in [1].
5. A collaborative process that assesses, plans, implements, coordinates, and evaluates the options and services required to meet the client's health and human service needs. It is characterized by advocacy, communication, and resource management and promotes quality and cost-effective interventions and outcomes [4].
6. A client focused, collaborative, and educational practice which aims to assist clients to achieve a distinct set of goals within a specific and defined episode of their rehabilitation journey in conjunction with the treating team. This process is managed within a proactive, preventative and responsive problem solving approach [5].
7. A client centred approach involving coordination of multi-disciplinary services within a community that promotes more effective, positive and sustained outcomes for people with an ABI. Active participation and empowerment of the client or the client's designated representative (e.g. guardian) in all aspects of identifying and meeting client/ family needs. Collaborative process that holistically enhances the cognitive, physical, psychosocial, and vocational needs of individuals with acquired brain injury [6].
8. Is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patients care to facilitate the appropriate delivery of health care services. Organising care involves the marshalling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care [7].
9. Is service delivery that fosters client movement through a series of phased involvements within a community's health care systems - facilitate development of community/home base services, enhance efficiency in the delivery of care, ensure quality services, coordinate delivery of needed/appropriate services, target at-risk individuals, prevent admission to institutions and/or acute care facilities, contain costs by controlling access, improve quality of life for client , improve access of services for client, promote continuous participation by client and family, enhance clients health and level of functioning, achieve efficiency [8].
10. Is a collaborative effort which diagnosis, plans, implements, coordinates, supervises and evaluates different options of care according to the health needs of a person through the available resources and communication to promote quality and cost effective results [9].
11. The integration of services on the patient level … someone in the system is taking charge and seeing to it that all the little bits and pieces of the fragmented services system begin to come together in some coherent way. It embodies the concepts of continuity and comprehensiveness in a personalized manner [10].

12. A dynamic and systematic collaborative approach to providing and coordinating healthcare services to a defined population. It is a participative process to identify and facilitate options and services for meeting individual's health needs, while decreasing fragmentation and duplication of care and enhancing quality, cost-effective clinical outcomes. The primary goal of CM is to optimize client functioning by providing quality services in the most efficient and effective manner to individuals with multiple complex needs [11].
13. A collaborative client-driven strategy for the provision of quality health and support services through the effective and efficient use of available resources in order to support the client's achievement of goals [as] related to healthy life and living in the context of the person and their ability. (Canadian Home care association) Case Management is a strategy for maximizing client wellness and autonomy, within their context, through advocacy, communication, education, identification of service resources and service facilitation [12].
14. A comprehensive multi-dimensional assessment of medical, functional, and psychosocial needs; arrangement of community services; coordination across providers; intensive health education and support for lifestyle modifications; and, a methodical tracking of patients' progress between office visits for all recipients regardless of location of where services were provided [13].
15. A collaborative process which assesses, plans, implements, coordinates, monitors and evaluates the options and services required to meet an individual's health, care, educational and employment needs, using communication and available resources to promote quality cost effective outcomes [14].
16. Defined by the Transport Accident Commission as an episodic collaborative process to facilitate the client's achievement of a specified goal, or series of goals over an agreed period of time [15].
17. Often described in the literature as a strategy, a process, and a role. Health care and social service agencies view Case Management as a potential means for improving client care and support. Those who provide Case Management use a collaborative, client-driven process for the provision of quality health and support services promoting the effective and efficient use of resources. Case Management Providers support the clients' achievement of safe, realistic, and reasonable goals within a complex health, social and fiscal environment [16].
18. A collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality cost-effective outcomes [17].
19. Has clinical, strategic and communication roles, is to assist or facilitate resolution of the clients presenting issues, use clinical skills, community resources, client/family capacity to address the issues, it is goal focussed intervention and can be brief, or an episode of planned activity (2-3 years) [18].
20. Aims to ensure that the injured person obtains the services or entitlements that he or she needs. Wherever possible, the aim of providing these services and entitlements to the client is to develop self-sufficiency [19].
21. Is a model and set of technologies for the strategic management of cost and quality outcomes by the clinicians who give the care throughout an entire episode of illness (Zander 1988 cited in [1].
22. The case manager's main role in ABI is to encourage family involvement and participation in rehabilitation, ensure appropriate education about ABI, maximize benefit (insurance) coverage, align team expectations, attend case conferences and validate treatments that are functional and outcome-orientated. Assisting therapists with procuring equipment and anticipating long-term concerns and needs were additionally listed as important factors in the case manager's role (Hosack (1999) cited in [20].
23. A case manager serves as the human link between the client and the system. Its about problem solving. Case management aims to maximise effective use of services and the wellbeing of the

individual. Case management is a way of linking and coordinating services needed so that a client receives the best possible, comprehensive programme of care [21] (Westmead (children's) hospital).

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CHAPTER 4 CRITICAL REVIEW OF INTERNATIONAL FRAMEWORKS

4.1 Introduction

Chapter 4 concerns Step 1.2 of Phase 1 of the research program, the critical review of international frameworks (refer to Figure 2.2 in Chapter 2 General Methods).

As introduced in Chapter 1 and established in Chapter 3, there is a need for an internationally agreed taxonomy to provide a common understanding and language of case management. Conceptual and technical frameworks are required to advance a taxonomy that will fill this gap. Scientific framing methods and international frameworks (as introduced in Chapter 2 General Methods) were used in the research program to inform the theoretical concepts, structure, organisation and language of the community-based case management taxonomy. A framework is defined as a '*graphical or narrative representation of the key factors, concepts or variables to explain the phenomenon*' (Moullin, Sabater-Hernandez, Fernandez-Llimos, & Benrimoj, 2015, p. 3). Thus the next step in development of the taxonomy involved a critical review of international frameworks to identify cohesive frameworks fit for our purpose and which could underpin the taxonomy. As a taxonomy for case management has not been properly explored before, it was necessary to integrate a number of frameworks in order to incorporate all the key concepts, variables and technical aspects of case management. Our search included internationally relevant conceptual, theoretical, technical or operational frameworks, models, taxonomies, categorisations and classifications. This chapter describes the method used to review the international frameworks and the results.

The results of the scoping and mapping review in Chapter 3 provided a closer or micro perspective of the models, components and activities of case management. We needed knowledge of the factors of case management from a more distant or service perspective in terms of integrated health care, social systems and services parameters. We asked ourselves the 'how, why, where, what and when?' of case management to scaffold and begin the critical review of frames. The approach is similarly used for information-gathering, problem-solving experimental design, analysis, and clinical and system research (J. L. Miller, Eldadah, & Padgett, 2016; W. R. Miller, Zweben, & Johnson, 2005; Peck, 2016).

The first question, the 'how', refers to the approach, model and theoretical concepts. Globally, person- and people-centred integrated care is considered a vital strategy to reform the micro to macro level of health care (World Health Organization, 2015a). However, the terms person-centred and people-centred are used interchangeably, frequently linked together, and also discussed separately in practice and the literature. The case management approach for this research program is community-based person and people-centred integrated health and social care. Person refers to the patient or client. The community-based case management approach considers the person's goals and preferences, needs and functioning of the person, but also the determinants of health, their community and the influence of the person's individual context (barriers and facilitators) on disability, health and functioning. Critical to this case management approach and the 'how' question is a perception of 'health' as more than the absence of disease or impairments.

The 'why' of case management concerns the reason case management is used. Case management occurs within the broader concept of care coordination. Care coordination is within integrated care, a goal of many health systems. The distinction

between care coordination and case management is that the case manager always has a relationship with the client, and supports the client to manage, coordinate and integrate the individual care and support services needed using person-centred approaches. The key components of nano to macro levels of integrated and person-centred health care, the care cycle and health status help explain the variability that exists in case management across sectors. These answers to the 'how' and 'why' questions suggested the need for a comprehensive, conceptual and theoretical meta-model or meta-framework which incorporated and explained the cross-cutting concepts of integrated care, person-centred approaches, health and position case management. A meta-framework captures the complexity by building on and integrating individual models that capture different aspects and domains (Rabbi, Lamo, & MacCaull, 2014).

The next question, the 'where' of case management, related to the context of the case management service. We aimed for the case management taxonomy to be potentially relevant and feasible as a knowledge map, framework and common language across disciplines, in different health and social service contexts, in any country.

The 'what' of case management and care coordination concerned the technical components – inputs and throughputs. The inputs are the resources to provide case management services. The throughputs of case management are the process, what is done by the case manager, the actions, activities or interventions.

The 'when' or timing concepts of case management related to the service inputs in terms of the intensity or frequency of contact and actions by the case manager. These vary in different contexts and with people with different health conditions. The

answers to the ‘where’, ‘what’ and ‘when’ questions suggested that we needed technical frameworks to accommodate the service-related factors of case management.

Conceptual frameworks can be built on different sources of information such as previous research and existing models. Technical frameworks may not be sufficiently comprehensive, but provide a starting point for further development so that all concepts are accommodated.

Frameworks were developed in two stages: (1) conceptual and theoretical framework; and (2) technical framework(s).

4.2 Methods

We focused on frameworks already well-established in the scientific literature. The review was not intended to be exhaustive, nor to scope or review all potential frameworks. The mixed qualitative methods involved the following steps:

Stage 1. Conceptual and theoretical framework

1. A literature review on the theoretical and conceptual constructs of person- and people-centred integrated health care.
2. Thematic analysis of the advancement and change in the concepts and theory of person- and people-centred integrated care.
3. Drawing on the themes of existing frameworks, development of a practical and cross-cutting meta-framework to conceptually and visually represent the key factors, concepts and variables to explain the complex phenomenon of person-centred integrated care.

These steps were completed as part of the research program. Following the

completion of steps 1-3 a request by a commissioning agency (The Sax Institute) to write an expert commentary on person-centred health care. Steps 4-6 described below occurred as part of the development of the expert commentary.

4. Critical review of the meta-framework by a group of five *Sydney-based* subject matter experts and researchers. The meta-framework was included as part of a larger piece of work, an expert commentary on person- and people-centred integrated health care.
5. Critical review of the meta-framework by an *international expert consultant panel*, as part of a larger expert commentary paper.
6. Consideration and approval by an external research agency (the Sax Institute).

Stage 2. Technical framework(s)

1. Searches for technical frameworks to support the structure of the input and throughput components of case management. Only frameworks where there was evidence of international application, and testing, acceptance and operationalisation in different settings, were included in the critical review. The international application was determined by the presence of the framework on an organisation repository (e.g. the World Health Organization). For those that were not in such a repository, a Google Scholar search for each framework provided a list of citations. Review of the abstracts of several of the relevant citations confirmed whether the framework or model had been applied in different contexts and countries.

2. Review of the frameworks to determine if they were fit for purpose. The purpose for the framework was identified through the formative article or international organisation website, which described the model and provided a description of the framework. A preliminary list of potentially suitable frameworks was tabulated.
3. Critical review of short-listed frameworks according to the following criteria:
   a) An *ontological approach* rather than providing codes/categories or units only – the framework should provide a conceptual map with hierarchical relationships and definitions of the units to enable operationalisation.
   b) A relevant *unit of analysis* – relevant information coded or grouped in the framework.
   c) *Neutrality* – the extent to which the framework was neutral on service setting and provider discipline, as well as age, health condition(s) and needs of the client.
   d) *Interoperability and links* with other classifications or frameworks – this relates to the degree to which the frameworks aligned or linked to each other conceptually or structurally. It was inappropriate to consider using frameworks that potentially created more language and structural complexity. Rather, we sought frameworks which integrated and potentially simplified the case management concepts.

4.3 Results Stage 1 – conceptual and theoretical meta-framework

The literature review, thematic analysis and meta-framework were developed as part of the research program to inform the development of the taxonomy. The meta-framework provided the theoretical background to the case management taxonomy

and how case management is positioned within integrated care. The model of case management on which the taxonomy was based was person-centred community based case management. The meta-framework provided the theoretical constructs underpinning this model of case management in particular: person-centred health care (health determinants, experience and status), levels of service delivery in integrated care (nano, micro, meso and macro) and the care cycle. The meta-framework was included in the subsequently commissioned expert commentary on person- and people-centred health care. The expert commentary included additional topics, such as implementation approaches and impact measurement approaches of person- and people-centred health care (PPCHC) amongst others. The full expert commentary report and associated peer-reviewed publications arising will be published elsewhere. *Only the relevant section and meta-framework from the expert commentary (including appendices) is provided here.*

An expert commentary on the state of the art in person-centred care

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Executive summary of key points

- **Patient-centred, person-centred and people-centred care are all terms found in the literature and each relates to a different system level.**
- **Person- and people-centred health care (PPCHC) is a whole philosophy of care that considers health status, the person's experience, the environment, social determinants and personal factors.**
- **The Alma-Ata Declaration in 1978 provided the conceptual ground for the development of the public health approach to person-centred health care.**
- **Reactions to the Alma-Ata Declaration were mixed for a number of historical and political reasons and the concepts relevant to PPCHC have faced several barriers including: financial and governance structures favouring centralised health care, perceptions that community-based health was of second-rate quality, and reductionist approaches in evidence-based medicine (EBM).**
- **Three developments have been key to progress in adoption of PPCHC:**

  1. **There has been a growing international consensus on what constitutes PPCHC, and its benefits for whole populations.**
  2. **It has become increasingly clear that PPCHC requires a whole system perspective. The application of person-centred care in pockets of health care has not led to a substantive paradigm shift at the macro level.**
  3. **The conceptualisation of a holistic approach to health has advanced to include multiple components such as health status, experience of health, positive health, health and environmental determinants as contributory factors and personal characteristics among others.**

- **From these developments, we can now conceptualise PPCHC as comprising four key characteristics. At system level key characteristics of PPCHC are:**

  - **A holistic approach based on the biopsychosocial model, which finds structure in the WHO International Classification of Functioning, Disability and Health, is still being developed and supplemented by new taxonomies of health-related factors.**
  - **Empowerment of the person based on human rights. This characteristic of PPCHC emphasises equity, needs-based care, and the involvement of people in their own health care and decisions.**
  - **Complexity and context dependency – while there is no single model of PPCHC because each context is different, there is a common framework.**
  - **Integrated care and universal access – does not just refer to coordination between services but goes beyond this to refer to the person's inclusion, community care and their participation, engaging the person and assessing personal factors such as quality of life and planning for solutions at the patient and person level.**

Introduction and background

The terms patient-, person-, and people-centred are all found in the literature. In this commentary we have used the term person- and people-centred health care (PPCHC) as it is inclusive. PPCHC has been at the heart of recent attempts to improve the quality and responsiveness of the health system. It requires a major shift from established modes of clinical and administrative practice, making individuals, with their complex needs and preferences, the drivers of health care.

PPCHC is a whole philosophy and culture of care that drives a complex healthcare system. It includes a range of key characteristics including a holistic perspective of health, functioning and wellbeing, shared decision making, empowerment and co-production of care, integrated care, context and complexity. We can learn from countries and subsystems that have adopted a PPCHC approach. However, each country context is different. Australia will need to develop its own strategies and roadmap in moving towards person- and people-centred health care.

The expert commentary on the state of the art of person-centred health care (PCHC) was brokered by the Sax Institute in Sydney. It was an expert commentary, not a systematic review of literature.

There has been significant interest and development of person- and people-centred health care (PPCHC) concepts over the past 6–7 years. There is now a considerable body of broad reviews and consensus statements from global and other leading health organisations. These, as well as literature known to the authors, provided our starting point.

We began by capturing key messages in literature known to the authors. We then hand-searched references of this known literature using a snowballing method to expand the scope of references and search for specific exemplars of PPCHC. We also conducted a grey literature search of websites of national and international agencies, including WHO, International Foundation for Integrated Care (IFIC) and the Health Foundation. This collection of papers was supplemented by a targeted search of literature in the Medline database related specifically to the utility of information and communication technology to capture the most recent literature in this emerging subfield.

These papers were then drawn on to inform the following commentary.

1. Database searches served to complement review team knowledge of seminal papers.
2. Papers found were not appraised; rather expert knowledge was sought to appraise the evidence in relation to key questions which were:
    a. How had the concept of person-centred care changed?

b. What are the key characteristics of approaches to implement and advance person-centred care?

c. Has the experience of health care (as reported by healthcare consumers) become more person-centred?

d. Drawing on contexts comparative with the Australian healthcare system, which approaches to person-centred care have shown the strongest positive impact on consumer's experience of care?

A comprehensive list of websites searched for grey literature, as well as search terms for the Medline search, are listed below.

Method – literature capture and expert consultant panel

Websites searched for grey literature

- www.who.int
- www.wpro.who.int/en/
- http://integratedcarefoundation.org/
- www.health.org.uk/
- https://www.adhc.nsw.gov.au/
- www.euro.who.int/en/home
- www.apo.org.au
- websites of the organisations in the case examples e.g. the Southcentral Foundation www.southcentralfoundation.com/about-us/ for the Nuka system of health care example

Medline search terms

Person-centred*.tw OR people-centred*.tw AND

Ehealth.mp OR telehealth[MeSH] OR mhealth.mp OR Organizational Innovation[MeSH]. OR Medical Informatics[MeSH]. OR Information Systems[MeSH] OR Medical Records Systems, Computerized/ OR information technology[MeSH]. OR Electronic Health Records[MeSH]. OR Information Services[MeSH].mp

Search limited to 2000–2016.

Literature capture

There has been significant interest and development of person- and people-centred health care concepts over the past decade. The World Health Organization's 2008 World Health Report entitled 'Primary health care: Now more than ever' (World Health Organization (WHO), 2008) invigorated the broader person- and people-centred health care movement. There is now a considerable body of broad reviews and consensus statements from global and other leading health organisations. These provide our starting point.

- Consensus statements
  - Six international consensus declarations from the International College of Person-centred Medicine (ICPCM) particularly the 2014 Geneva Declaration on Person- and People-centred Integrated Health Care for All (International College of Person-centered Medicine, 2014)
  - The Salzburg statement on shared decision making which calls on healthcare practitioners to consider the role patients can and should play in their healthcare decisions (Salzburg Global Seminar, 2011)

- International organisation reports which reflect on the concepts of PPCHC, review and synthesise the evidence including:
  - The WHO people-centred and integrated health services overview of the evidence on the benefits that people-centred and integrated care can bring to people, communities and countries that presents a number of case studies (July 2015) (World Health Organization, 2015b)
  - The WHO 'Roadmap: Strengthening people-centred health systems in the WHO European Region: A framework for action' (2013) (World Health Organization – Regional Office for Europe, Health Services Delivery Programme, & Division of Health Systems and Public Health, 2013) and the recently launched online knowledge platform 'IntegratedCare4people' (World Health Organization, 2016b)
  - The Health Foundation/Health Policy Partnership Report provides an 'environment scan' in person-centred care (Harding et al., 'The state of play in person-centred care' report ; December 2015) (Harding, Wait, & Scrutton, 2015)
  - The WHO background briefing document to the executive board of WHO on the framework on integrated, people-centred health services (World Health Organization, 2015a)

  - 'Making progress in people-centred care: Country experiences and lessons learnt' (Montenegro et al., 2012)

- Systematic reviews
  - Mockford et al. (2012) (Mockford, Staniszewska, Griffiths, & Herron-Marx, 2012)
  - McMillan et al. (2013) (McMillan et al., 2013)
  - Rathert et al. (2013) (Rathert, Wyrwich, & Boren, 2013)
  - Dwamena et al. (2012)(Dwamena et al., 2012)
  - Milton et al. (2011) (Milton et al., 2011)

- Earlier reviews completed by Australian public agencies
  - Commission on Safety and Quality in Health Care (2011) (Australian Commission on Safety and Quality in Health Care, 2011)
  - New South Wales Ageing Disability and Home Care (ADAHC) (2008) (New South Wales Ageing Disability and Home Care (ADAHC), 2008).

- Recent policy papers by Australian agencies
  - Ernst and Young, Wentwest and Menzies Centre for Health Policy, model for person-centred home – December 2015 (Ernst and Young, WentWest Limited, & Menzies Centre for Health Policy, 2015)

Expert consultation

Eleven experts from the field of PPCHC accepted the invitation and provided comment and insights on an initial draft of the paper as a 'consultation group'. Invitations to participate in the consultation group were sent to leading scholars in the field, with both academic and policy backgrounds. Several invitees either did not respond, or did not have the time to review.

The consultation group was asked to respond to an earlier draft of this commentary, and was asked specific questions in relation to the commentary paper:

1. Bearing in mind the page limit, do you see any critical information gaps in what we have provided concerning the development and current perspective of person- and people-centred health care?

2. Are there characteristics or facilitators that we have not mentioned that, in your opinion, should be mentioned?

3. Do you know of any additional examples (or categories) of tools and methods to measure experience of person-centred care, at any level of the system?
4. Considering the key characteristics we have identified, do you have any case examples of approaches to advancing PPCHC that have shown a strong impact?

All responses were then gathered and considered in the final paper. The members of the expert consultant panel were:

- Robert Cloninger
- Jim Conway
- Catherine Cook
- Jocelyn Cornwell
- Diann Eley
- Eric Emerson
- Susan Frampton
- Karen Luxford
- Juan Enrique Mezzich
- Moira Stewart
- Christine Walker

Person- and people-centred health care (PPCHC) – definitions

The aim of PPCHC is to engage and empower persons in the management of their individual care; but also the promotion, prevention and planning at the system level as well as the equity, quality, efficiency and ethics of the care and health system. The anticipated benefits and outcomes of PPCHC are that all people are able to access high-quality health services that meet their needs and preferences for improved health of populations (International College of Person-centered Medicine, 2014; World Health Organization, 2015a, 2015c). The international development and progress towards PPCHC provide valuable information and lessons learnt, but confirm the benefits of PPCHC (Harding et al., 2015; Montenegro et al., 2012; World Health Organization, 2015b). Person- and people-centred health care (PPCHC) is an umbrella term that encompasses a whole philosophy or

culture of care, a way of thinking and understanding the experiences of people, and acting accordingly.

The development of a taxonomy of the terms in PPCHC would provide a common language and assist with policy and planning and analysis. In this commentary we adopt the following:

- **Patient-centred care** is generally applied at the level of the individual who is a service user and already within the healthcare system.
- **Person-centred health care** refers to both non-patients and patients or groups who have health-related needs in terms of being at risk, and require protective or preventative interventions as individuals or groups.

  Person-centred health care sees the person as a whole with many levels of needs and goals, with these needs coming from their own personal social determinants of health at the centre of care, rather than a set of conditions or diagnoses (World Health Organization, 2015c).

  It is guided by the ethical principle of respect for the autonomy, dignity and responsibility of each person. It considers the person (and their family) as the expert on their own context and situation. Accordingly, health care is organised on the basis of *need* rather than around disease-specific service silos.
- **People-centred** refers to the population and macro level of health services organised around health needs and expectations of people rather than diseases; and includes analysis of outcomes, policy development, planning and funding. People-centred care consciously adopts individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, trusted health systems that respond to their needs and preferences in humane and holistic ways. It also requires that people have the education and support they need to make decisions and participate in their own care (World Health Organization, 2015c).

As a core value of a health system and whole philosophy of care, PPCHC requires a commitment to measurable goals to improve equity for populations (particularly for vulnerable populations such as older persons, people with disabilities, or multi-morbidity). It is built on measurement and continuous improvement of the experience of health service users, to benefit the person, the community and the health services.

PPCHC considers health status, the person's experience, the environment, social determinants and personal factors. The whole person refers to the person, their health condition and his/her context (L Salvador-Carulla & Mezzich, 2012; World Health Organization, 2015c). In this sense, some authors prefer person-centred *health*care rather than person-centred care. 'Health' encompasses the whole system and the person's experience, not just the immediate care received (i.e. interventions). For the remainder of this commentary, we continue to use the term person- and people-centred health care.

In the literature there is also the term personalised medicine. Personalised medicine relates to the biomedical model of health care involving technologies tailored to every individual's genomic profile. Although recently expanded in precision medicine to the interactions of multiple genetically regulated processes for each person, it focuses on the body function, body structure and biological part of health only. As such, personalised medicine is not addressed in this paper.

Figure 1 shows the relationship between patient-, person- and people-centred health care at the levels of the system.

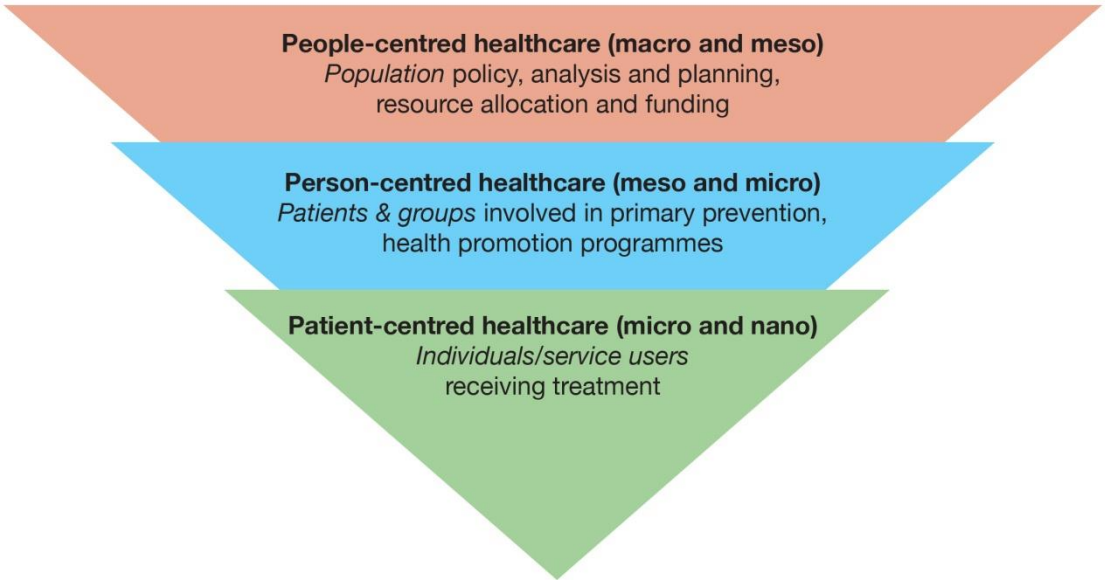

Figure 1: The relationship between people-, person- and patient-centred health care and system levels

The development of the concepts of PPCHC

Response to Alma-Ata

The Alma-Ata Declaration in 1978 provided the conceptual ground for the development of the public health approach to person-centred health care (PCHC). Recent reviews by authors of this commentary detail the Alma-Ata Declaration and the history of the formal adoption of the primary

healthcare model as the key means to provide comprehensive, equitable, and affordable healthcare services to all people in order to redress the existing inequalities in health within and among countries (C. R. Cloninger et al., 2014; L Salvador-Carulla & Mezzich, 2012).

The international response to the Alma-Ata Declaration throughout the 1980s and 1990s was mixed for a number of sometimes contradictory historical reasons (C. R. Cloninger et al., 2014) including:

1. Adoption of a 'selective' primary healthcare approach
2. Financial and governance structures favouring centralised health care
3. Marketisation – a fashion for market, or quasi-market, forms of healthcare provision
4. Reinvigoration of a disease-focused approach triggered by epidemics such as HIV
5. Surge in medical technology and a consequent reductionist disease focus
6. Cost containment and managerialism translating into too much reduction of variability in clinical management (recognising that in some developing countries, there has been a reduction in variability and a matrix of care resulted in healthcare improvements).

These historical barriers to the broader adoption of PPCHC elements as envisaged in the Alma-Ata Declaration are expanded upon in Appendix 1.

Several other parallel developments in clinical practice that spanned the period before and after the Alma-Ata Declaration acted as enablers and barriers to person-centred care. The notable movements toward person-centredness were:

- The design of a humanistic approach to medical practice and in psychotherapy (Harding et al., 2015; Leplege et al., 2007; MacLeod & McPherson, 2007; J. Mezzich, Snaedal, van Weel, & Heath, 2010; L Salvador-Carulla & Mezzich, 2012).
- The introduction of the concept of personhood and recovery to the psychosocial rehabilitation field and 'The Need-adaptive Assessment and Treatment' approach developed (L Salvador-Carulla & Mezzich, 2012).
- Development of person-centred models in other areas of health care such as family practice with the patient-centred clinical method (Levenstein, McCracken, McWhinney, & Stewart, 1986), the total person approach in

nursing (Nauman & Young, 1972) and the two-body practice in occupational therapy (Mattingly, 1998).

- The patients also responded to the disease-specific approaches by establishing a number of patient organisations to advocate for patient voices to be heard, involvement of patients in their own care, and equity in health care. Some of these organisations are Planetree and the Institute for Patient- and Family-centred Care (formerly Picker Institute) (United States), Patient's Association (United Kingdom), and the International Alliance of Patients' Organizations Institute (International) (Institute for Patient and Family-centered Care: IPFCC, 2016; International Alliance of Patients' Organizations (IAPO), 2006; Picker Institute, 2016; Stichler, 2011).
- The publicity and attention of the harm done to patients also gave rise to the safety and quality movement in health care. Internationally, governments responded with the establishment of organisations such as the Australian Commission for Safety and Quality Health Care (ACSQHC) (Australia), the National Institute for Health and Care Excellence (NICE) (United Kingdom), the Agency for Healthcare Research and Quality (AHRQ) (United States), and the Health Quality and Safety Commission (HQSC) (New Zealand). These organisations have helped to establish systems such as informed consent and reporting standards.

One of the most notable barriers to the broad adoption of PPCHC in clinical practice has been the reductionist approaches found in evidence-based medicine (EBM). While early in the evolution of EBM patient preferences and choices were included, the current interpretation has resulted in a steady decline in the status and use of key components of PPCHC, such as expert knowledge, observational data, and patient's narratives, experiences, choices and aspirations. PPCHC has built a philosophy of care and recognises the need for changes to practice to empower the person through engagement in decisions, building a broad understanding of health beyond the disease and impairment, and requiring a rigorous systematic understanding of the context and forms of integration of care.

Recent perspectives of PPCHC

Three developments, partly as lessons learnt from the mixed reactions to the Alma-Ata Declaration and other barriers listed above, have been key markers of more recent developments in PPCHC:

1. There has been a growing international consensus on what constitutes PPCHC, as well as its benefits for whole populations.
2. It has become increasingly clear that PPCHC requires a whole system perspective.
3. The conceptualisation of a holistic approach to health has advanced substantially to include multiple components such as health status, experience of health, positive health, health and environmental determinants as contributory factors, and personal characteristics.

Following these developments, we can say at the present point in time that PPCHC embodies four key characteristics described below. While we recognise that all characteristics of PPCHC are not included here we have maintained a policy and research perspective rather than operational. Necessarily it does not provide detail of operational characteristics such as responsiveness or cultural sensitivity of providers.

Even though person-centredness can be applied to specific aspects of an individual treatment or an organisation of care delivery, the four features described here provide a framework for its conceptualisation and analysis. The first three characteristics (holism, empowerment and complexity) can be regarded as attributes of PPCHC, that is, they are essential or inherent properties of a PPCHC system. The fourth characteristic (integrated care) can be regarded as an extrinsic property. It is possible that PPCHC can occur without integrated care, and integrated care can also be implemented without PPCHC (refer to Question 4 and Table 2). The major core driver for the development of an integrated PPCHC approach within the healthcare system is considered to be the shared values.

Key characteristics

1. Holistic approach based on the biopsychosocial model

The first key characteristic is that PPCHC follows a holistic perspective of health. The biomedical and social models are often presented as dichotomous, where the biomedical focuses on the disease, the diagnosis and impairments of the body, with the main concern being the medical treatment and professional help (Bircher, 2005; Engel, 1977). In contrast, the social model does not define people by the disease or diagnosis, rather the social outcomes of the individual, social integration and participation, human rights and empowerment (Bircher, 2005; Bircher & Kuruvilla, 2014; Shakespeare, 2006). Neither the biomedical nor the social model considers how the biological, physical, psychological, social, environmental, contextual, personal and cultural factors *interact* with each other to influence health and wellbeing.

Over the past 30 years a biopsychosocial perspective of health has been codified in the WHO International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001). The ICF biopsychosocial model perceives health as a function of the complex and dynamic interaction between all the domains of health which are body impairments, limitations of activity, the restriction in social participation and the interaction of these domains with the environment and a person's context (World Health Organization, 2002). It depicts a complex concept of health where the domains are relational, interactive and interdependent. Context also refers to environmental factors such as personal supports and relationships (including attitudes of others), products and technology, health systems and services, policies and the physical environment. Personal factors (mentioned but not developed in the ICF) include social and demographic indicators such as gender, age, race, education and profession; and lifestyles, habits and other personal characteristics which influence individual functioning (Simeonsson et al., 2014; WHO Collaborating Centre for the FIC in the Netherlands, 2013).

The ICF biopsychosocial model has been expanded to include subdomains such as health-related quality of life (Botbol, 2016; C. R. Cloninger, Salloum, & Mezzich, 2012; J. G. Huber, Sillick, & Skarakis-Doyle, 2010), spirituality (WHOQOL SRPB Group, 2006), the ability to adapt and self-manage challenges (M. Huber et al., 2011), bio-semiotics, referring to the person's ability to interpret and attach meaning to triggers in their environment (Sturmberg, 2016), meaning in life (Dezutter et al., 2013), and cultural interpretations (Ahmed & Bhugra, 2007; Harding et al., 2015). These subdomains have resulted in an expanded biopsychosocial model incorporating spiritual meaning and cultural health, among others.

The International College of Person-centred Medicine (ICPCM) has produced a matrix of the key *health components* of PPCHC that follow from this holistic approach (health status, experiences of health and contributory factors). The matrix incorporates the positive aspects of health, including wellbeing and recovery, good functioning, satisfaction with life and positive experiences of wellbeing, together with determinants or 'contributors' to health (J. Mezzich et al., 2010; L Salvador-Carulla & Mezzich, 2012). This conceptualisation captures core components of the broader person-centred health care concepts, including:

- Wellbeing and recovery/disease (L. Salvador-Carulla, Lucas, Ayuso-Mateos, & Miret, 2014);
- Functioning/disability (Leonardi, Bickenbach, Bedirhan Ustun, Kostanjsek, & Chatterju, 2006; L. Salvador-Carulla & Gasca, 2010);

- Personal experiences linked to both ill health (suffering, understanding and meaning of illness or satisfaction with the health services) and positive health (aspirations, life satisfaction) (JE. Mezzich et al., 2010);
- Personal determinants of health, including personal factors (demographic characteristics), lifestyle and general personality traits (e.g. extroversion, neuroticism, self-directedness, cooperativeness and self-transcendence) (R. C. Cloninger, 2013);
- Social determinants of health such as employment, education, violence and discrimination, food and transport, and including cultural factors (Bircher & Kuruvilla, 2014; Marmot & Wilkinson, 2007), social structures or constructs such as attitudes of others (barriers and facilitators) (Germov, 2009; Shakespeare, 2006).

2. Empowerment of the person based on human rights

The second characteristic of PPCHC is the empowerment of the person based on human rights. Underpinning the holistic perspective of health are the principles of human rights (Gruskin, Mills, & Tarantola, 2007; Harding et al., 2015; International College of Person-centered Medicine, 2014; London, 2008; World Health Organization, 2015b). Australia has ratified a number of Human Rights conventions that relate to health including the United Nations' Conventions on the Rights of Persons with Disabilities, Rights of the Child and the Elimination of all forms of Discrimination Against Women. In the 1960s a strong movement from persons with disability and later people living with diabetes and AIDS gave voice to human rights, empowerment and equity models. The phrase 'nothing about us without us', coined by disability activists in the 1990s (Charlton, 1998), is now adopted by many other interest and populist movements to proactively promote involvement of patients in decisions about their treatment and care and the engagement of people in health systems.

In healthcare practice, communication plays a central role in the empowerment and engagement of the patient, their family and people. Respectful and empathic communication supports engagement of the person as a partner in their care. At the people and population level empowerment means there is communication with people and families, and they are involved in the challenges of safety, quality and goals for better outcomes through co-design and co-production of health care. Patient or people engagement will vary across the healthcare system and levels, from the nano level of clinical setting/point of care through to the micro, meso and macro level with organisational design, governance and policy making (Carman et al., 2013). There is emerging evidence of the impact of

positive communications and empowering human interactions among providers (McClelland & Vogus, 2014); between health provider and the person (Haslam, 2007); and engagement with the patient, family and people. Recent studies identify a positive relationship between communication and engagement, with improvements in care coordination, goal setting, patient health outcomes, communication and outreach, a reduction in costs, improvements in safety and quality health care, enhanced leadership commitment and provider training (Greene, Hibbard, Sacks, Overton, & Parrotta, 2015; Hibbard & Greene, 2013; Rakel et al., 2011; Shortell et al., 2015).

Recently Greenhalgh and colleagues described the major aspects in classical evidence-based medicine that may inadvertently move away from a person-centred approach and devalue the patient and carer agenda (Greenhalgh, Snow, Ryan, Rees, & Salisbury, 2015). These are:

- Lack of patient input to the research process
- Low status given to experience ('anecdote') in the hierarchy of evidence
- Tendency of clinicians to conflate consulting a patient and use of decision-making tools with person-centred care, when it is only part of the communication
- Limited attention given to power imbalances that suppress the patient's voice
- Over-emphasis on the clinician–patient dyad (overlooking the ongoing work of self-management and the importance of the patient's wider social networks, both online and offline)
- Primary focus on people who seek and obtain care (rather than on the hidden denominator of those who do not seek or cannot access care).

The call for person-centred needs-based care, and the involvement of people in their own health care and decisions on services, was reinforced in the WHO 'World Report on Disability' (2011). WHO recommends engaging in shared decision making in matters that concern patients directly whether in health, education, rehabilitation or community living (World Health Organization (WHO) & World Bank, 2011). The recently published 'World Report on Ageing and Health' (2015) also reinforces the need to ensure person-centred case management and integrated care across the health and social care sectors (World Health Organization, 2015d).

3. Complexity and whole system perspective

The third characteristic at system level follows the paradigm shift embodied in systems thinking approaches and the recognition that change in health care requires a whole system perspective (De Savigny & Adam, 2009; Peters, 2014). There are examples of development of person-centred care in pockets of health care, some of which are presented as case studies in the WHO's 'Global strategy on integrated people-centred health services 2016–2026' (World Health Organization, 2015c). However, none of these demonstrate a substantive paradigm shift at the macro level. As each context is different, there can be no single model of PPCHC. There can be a common framework with different implementation strategies or adaptations at the local level.

PPCHC has to be achieved in health systems that are complex adaptive systems, with multiple interdependent components and relationships between agents, which are non-linear and context dependent. System approaches to implementing PPCHC should occur at both the individual practice level (nano, micro) and organisational and whole system levels (meso and macro). At the nano or person level, complexity arises from the interaction of the person's domains of health, and the context of the environmental and personal factors of the person's own context. At the micro, meso and macro system level, complexity arises from the relationships between various components of the healthcare system.

PPCHC can only develop with concurrent change from the bottom up (e.g. individuals' understanding of their health) and top-down system levels (e.g. reallocating resources to enable providers to deliver needs-based care). The key learning is that substantive change towards PPCHC will require whole systems and complex adaptive systems thinking to be fit for purpose in the Australian context.

4. Integrated care and universal access

The fourth key characteristic of integrated care and universal access emerged in the 1960s from the recognition of the connection between integrated and coordinated care and better outcomes. Developments in mental health led the way. The de-institutionalisation of large numbers of people with severe mental health conditions and/or intellectual disabilities (Beadle-Brown, Mansell, & Kozma, 2007; L. Salvador-Carulla, Costa-Font, Cabases, McDaid, & Alonso, 2010) posed new questions around the organisation of care. As the alternative solution to out-of-hospital care, day care and home support services emerged, as well as new integrated care programs (e.g. Assertive Community Treatment) and new health-related interventions such as case management. Case management involved the assessment, planning, coordination and referral of people with mental health conditions living in the community to outpatient mental health and other mainstream community services. However, the person was still seen as a passive (and disempowered) recipient

of case management rather than an active partner (Lukersmith, Scarf, & Millington, 2015; J. E. Mezzich, Botbol, & Salloum, 2015).

Integrated and coordinated care is now known to contribute to improved health outcomes and benefits for both the person and health system (World Health Organization, 2015b). The meaning of integration has developed beyond coordination and collaboration between services (vertical integration with primary, secondary and tertiary health care) to recognising and conceptualising inclusion, participation and community care, the need to engage the person, assessing personal factors such as quality of life, and planning for solutions (Harding et al., 2015). Integrated care needs to be accompanied by choice, shared decision making and community participation (Beadle-Brown et al., 2007; Lukersmith et al., 2015; Schalock et al., 2002).

PPCHC also emphasises horizontal integration of healthcare and inter-sector collaboration across multiple sectors of society through coordinated planning and community-based delivery of services. Primary and community-based care are necessarily critical components for the integration and accessibility of health care. The many sectors relevant to the inter-sector collaboration with health include education, social care, employment, housing, transportation, justice, finance, and ecological management (International College of Person-centered Medicine, 2014).

In 2013 Valentijn and colleagues developed the Rainbow framework of integrated primary care and it has since been used internationally (Valentijn, Ruwaard, et al., 2015; Valentijn, Schepman, Opheij, & Bruijnzeels, 2013). The Rainbow model identifies six domains of integrated care (clinical, professional, organisational, system, functional [technical] and normative [the cultural and context]) and two guiding principles (person-focused and population-focused) across the micro, meso and macro levels in a system. It articulates the horizontal and vertical integration of care across sectors. People-focused population-based care, such as preventive health programs, lie on the horizontal axis, whereas individual case management, which focuses on individuals and their immediate contexts, lies along the vertical axis.

WHO has accepted that ‘people-centred and integrated health services’ provide an essential basis for building equity and universal health coverage, and improving the health status and wellbeing of populations, with due respect for local contexts and specific attention to the social determinants of health (Milton et al., 2011; World Health Organization, 2011b). The first iteration of the WHO person- and people-centred health care concept was published in 2013 (World Health Organization – Regional Office for Europe et al., 2013). It provided a road map towards coordinated and integrated health services delivery and defined the key concepts and context for people-centred health systems. The road map also recognised the services necessary across the spectrum of care, settings

and people involved from primary care, secondary and specialist services, community, home and social care settings. The key concepts were processes, core services, intermediate and final outcomes. In 2015 a more detailed framework was published based on the previous work (World Health Organization, 2015c). Universal access is a corollary of PPCHC and particularly relevant for vulnerable and at-risk populations (World Health Organization, 2011b). Financial incentives and service reimbursement structures should enable universal access to care, and promote rather than inhibit organisations working together around the needs of the person (Ernst and Young et al., 2015; Goodwin, 2013; Goodwin et al., 2011; Salvador-Carulla et al., 2013).

The current conceptualisation of PPCHC

We have developed an expanded visualisation of PPCHC in a 'meta-framework of a person and people centred integrated health system (PPCIHC)' (refer to Figure 2) recognising that a system of PPCIHC should be people-centred and integrated. Figure 2 draws on the perspectives of health and models of care that inform the current conceptualisation of PPCIHC (J. Mezzich et al., 2010; Valentijn, Vrijhoef, et al., 2015; World Health Organization, 2001, 2015c). Integration and systems are depicted in the upper segment; the holistic biopsychosocial perspective and key components of health and the health cycle are in the lower segment. Our approach to case management in this study sits in the bottom sector of the model at the nano and micro level.

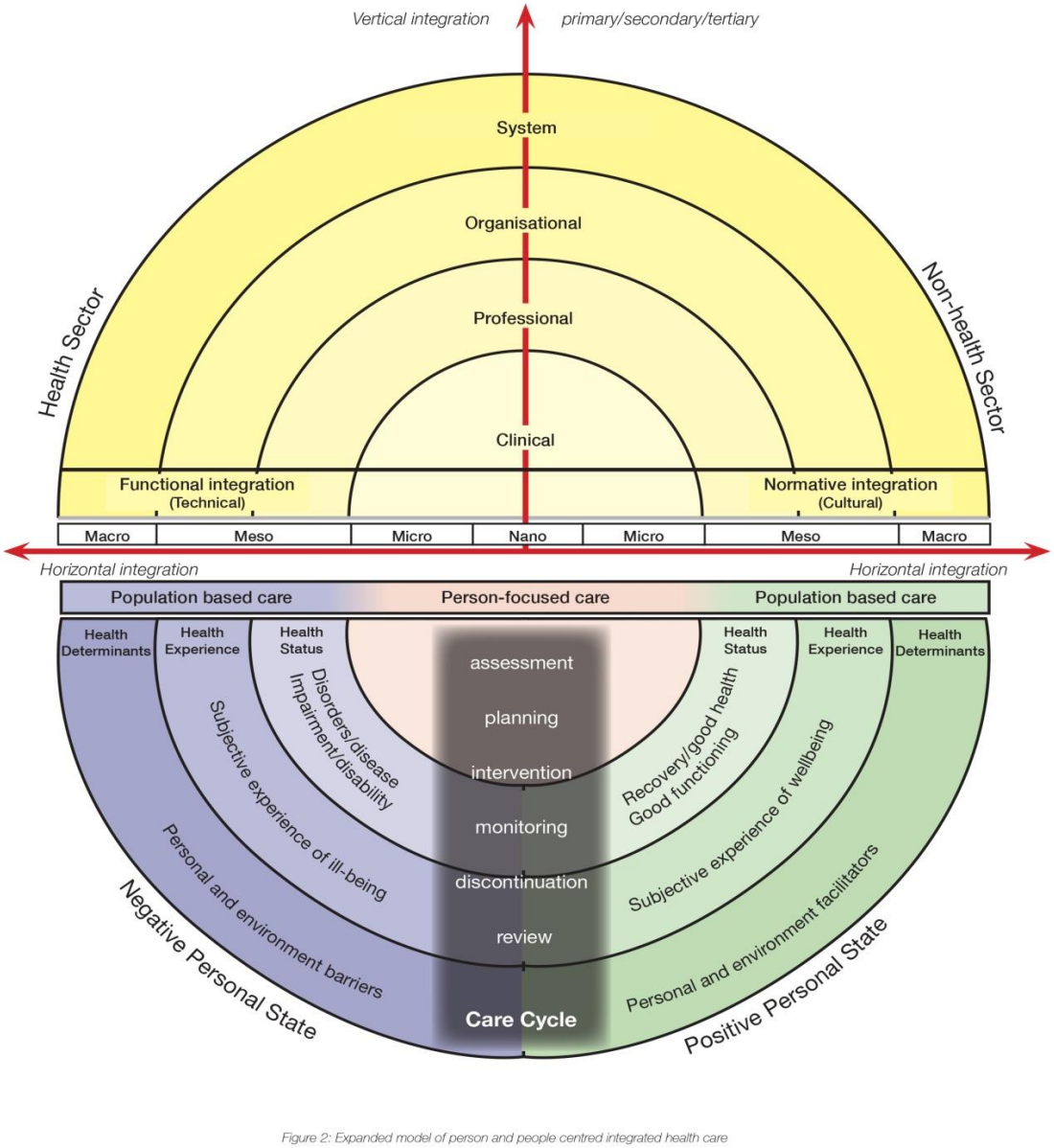

Figure 2: Meta-framework of person- and people-centred integrated healthcare system

In this next section we outline the key 'bottom-up' facilitators and enablers to advance change towards PPCIHC and remove barriers.

Co-production of care, shared knowledge and decision making

Co-production, shared knowledge and decision making form the cornerstone of facilitating PPCIHC. Co-production of health care refers to care that is delivered in an equal and reciprocal relationship between professionals and the patient/person, their families and the communities to which they belong (people and population). Co-production includes partnerships with patients, providers and the community and system to co-design changes to improve the safety, quality and outcomes of

health services at the people and population level. Co-production and co-design implies a long-term and meaningful relationship between the person, people, providers and health systems where information, decision making and service delivery become shared (World Health Organization, 2015c). Shared knowledge and decision making involves meaningfully engaging the person and, where relevant, their family (family-centred) in making decisions concerning their health and care (Barry & Edman-Levitan, 2012; Berwick, 2009; Lifetime Care Authority & Lukersmith, 2015; Tibaldi, Salvador-Carulla, & Garcia-Gutierrez, 2011; Victorian Department of Human Services). The evidence of the benefits of co-production and shared decision making is strong and is associated with more appropriate care, better match with patient needs and preferences, a reduction in misdiagnosis, and greater satisfaction and independence (Barry & Edman-Levitan, 2012; Dwamena et al., 2012; World Health Organization, 2015c).

PPCIHC requires a paradigmatic shift in thinking about health to a biopsychosocial perspective of health, a corresponding shift in the concept of knowledge and sharing of knowledge. Health systems that are disease-focused and arranged around specific diseases typically adopt a biomedical focus on health care that sees patients as passive recipients of health services. In contrast, PPCIHC empowers and engages individuals and families by recognising the value of their knowledge as the experts of their own context and the dynamic interaction of these factors in their health outcomes. PPCIHC depends on the person having the education and support they need to make decisions and to participate in their own care. This requires a paradigm shift for proactive sharing of knowledge and decisions between the patient and the health professional.

Table 1 shows the consequences of asymmetry of knowledge in the doctor/patient relationship with various healthcare approaches.

Table 1: Matrix of the doctor/patient relationship (adapted from Scambler (2001) and Habermas (1987))

Patient	**Health professional**	
Control	**Low**	**High**
Low	**External control** *Model* – Managerialism *Relationship* – Deficient *Dynamic* – Neither service user nor health provider has control	**Professional control** *Model* – Authoritarian (Biomedical) *Relationship* – Paternalistic *Dynamic* – Service provider has control
High	**Inverse control** *Model* – Consumeristic *Relationship* – Demand driven ('VIP syndrome')[1] *Dynamic* – Service user demands control and makes decisions irrespective of health professional recommendations	**Shared control** *Model* – Person-centred health care *Relationship* – Shared decision making *Dynamic* – Knowledge is shared and decisions made together. The service user has knowledge by experience of their own context (expert experience knowledge). Health professional has expert practice knowledge

The lower right cell shows how PPCIHC should operate with bilateral exchange of knowledge, information and decision making. An example of what this looks like in practice is provided in Appendix 2 in the planning phase of the healthcare cycle.

We identified four expressions of shared knowledge and decision making that contribute to this key facilitator for PPCIHC:

1. A sentinel approach to a lifelong healthcare cycle

Integrated PPCIHC also means that the *healthcare cycle* is provided by the community and in the person's community over the entre span of their life. We refer to this lifelong healthcare cycle perspective as a sentinel approach, where health care to address the immediate need is not perceived as the end. For example, a sentinel lifelong approach to attempted suicide would see acute treatment of the effects of attempted suicide as the beginning, not the end point, of health care. A healthcare cycle involves non-patients as well as patients, so the person remains engaged in the system of care (health and other sectors) beyond the acute health care.

[1] (Guzman, Sasidhar, & Stroller, 2011), (Klitzman & Chung, 2010)

The healthcare cycle involves:

For the non-patient or person not currently involved in health care

1. Maintaining health
2. Awareness of vulnerability to a health condition, e.g. self-examination for breast cancer

For the patient involved in health care

3. Initial contact
4. Diagnosis
5. Planning and management
6. Interventions
7. Monitoring
8. Discontinuation
9. Review

2. The expert patient, self-management and peer support programs

The expert patient involves shared decision making and empowerment of individuals and families and runs parallel to the need to engage people in their own health care, to promote choice, living healthy and fulfilling lives, and education for self-management. Patient organisations call for greater patient responsibility and advocate for greater involvement of patients in their own care which will lead to improved quality of life, and community and system benefits such as cost-effectiveness (International Alliance of Patients' Organizations (IAPO), 2006; Stichler, 2011). This is particularly relevant for people with complex or long-term healthcare needs, including those with chronic conditions, multi-morbidity, those living in disadvantaged communities and older populations. A focus on supporting, educating and enabling people to be partners and involved in the co-production of their own care should be from a lifelong perspective (World Health Organization – Regional Office for Europe et al., 2013).

Strategies for patient education, support and empowerment include peer support programs. Evaluation of the effectiveness of peer support programs suggests that there are consistent educational (information), emotional and instrumental benefits (Campbell, Phaneuf, & Deane, 2003; Dennis, Hodnett, Gallop, & Chalmers, 2002; Heisler, 2010). There are numerous examples of peer support programs that are a key or complementary healthcare service. A range of examples for different health include: in Australia, the LifeMoves program where peers Inspire peers for brain injury (BrainLink, 2015) and CHOICE, the youth mental health services (Howe & Dimopolous-Bick, 2014); in Canada, the peer support with breastfeeding (Dennis et al., 2002) and diabetes self-management (Heisler, 2010); and in Australia, the Chronic Illness Alliance which aims to build

capacity of health-based organisations to offer peer support programs to their clients and members (Chronic Illness Alliance, 2015).

3. Locally relevant person-centred primary and community care

Primary and community care are key components for universal and accessible care. *Person-centred* primary care is comprehensive care that integrates and coordinates care for all health problems and engages individuals, families and the community (De Maeseneer et al., 2012; World Health Organization (WHO), 2008). For the person, primary care involves horizontal and vertical integration of lifelong care (Valentijn et al., 2013) in their community. Acute services and secondary care need to be closely linked with the system of primary and community care with integration between them. Person-centred primary care has been shown to be the best solution to the major health challenges of case finding, managing and preventing infectious chronic diseases, and is seen to be essential for tackling non-communicable diseases (De Maeseneer et al., 2012; Salloum & Khazi, 2015). This change requires a shift from inpatient- and outpatient-based care to person-centred primary care strategies inclusive of ambulatory care (De Maeseneer et al., 2012; World Health Organization, 2015c), such as telehealth/eHealth, health promotion and ill-health prevention strategies. Pivotal to this concept is a single point of care access (including but not limited to the general practitioner as the point of access), empowerment of patients, reduction of barriers to healthy lifestyles, and care that reflects the values of the individual.

Implementing person-centred integrated care means being flexible in different contexts and evaluating impact (Goodwin et al., 2011; Harding et al., 2015; World Health Organization, 2015b, 2015c). Since 2013 there have been international and national efforts to develop a body of knowledge on best practices and frameworks or road maps to strengthen health systems towards PPCHC (CHRODIS, 2015; International Foundation for Integrated Care (IFIC), 2014; World Health Organization – Regional Office for Europe et al., 2013). The WHO has recently launched an online knowledge platform that aims to consolidate the lessons learnt and best practices on integrated people-centred health care, and provide platforms for sharing information on successful models of service delivery (World Health Organization, 2016b). Critical components in the design of context-specific strategies of person-centred care include: knowledge from mapping service availability and workforce capacity; an understanding of the local and country contextual barriers and facilitators; and finance analysis.

There are several successful examples of locally adopted approaches to PPCHC. In Cuba, a top-down development involves multispecialty community-based polyclinics, plus family doctor and nurse programs that operate countrywide. Approximately 80% of patient health problems and health

promotion are managed by the local clinics (Dresang, Brebick, Murray, Shallue, & Sullivan-Vedder, 2005; Reed, 2008). In Canada, the BETTER study developed prevention practitioner roles with existing team members in primary care settings. The study demonstrated that comprehensive assessment and planning for treatment was cost-effective and enhanced equity for vulnerable populations, specifically on the modifiable risk factors for patients with chronic diseases (Manca et al., 2014). In Scotland, a mixed top-down and bottom-up process has been adopted to develop a patient-focused system (Scottish Executive, 2006).

Knowledge of local priorities and care needs, what and where services exist, along with the gaps in services are key drivers to: planning for and providing services and supports; developing wider networks of providers; and inter-sector collaborations. In Spain and other countries in Europe, mapping to create an atlas of services for evidence-informed policy has been successfully done (Fernandez, Salinas-Perez, et al., 2015; L. Salvador-Carulla et al., 2015) and the process is currently underway in some health districts in mental health in NSW and Queensland (Fernandez & Salvador-Carulla, 2017). Mapping of other relevant sectors of community-based services is needed for integrated community-based care such as social sector (housing, employment, community programs) and education, to enable population-based health sector planning and inter-sectoral collaborations and partnerships.

Summary of key points

Three developments, partly as lessons learnt from the mixed reactions to the Alma-Ata Declaration and other barriers, have been key markers of more recent developments in PPCHC.

1. There has been a growing international consensus on what constitutes PPCIHC, as well as its benefits for whole populations.
2. It has become increasingly clear that PPCIHC requires a whole system perspective.
3. The conceptualisation of a holistic approach to health has advanced substantially, to include multiple components such as health status, experience of health, positive health, health and environmental determinants as contributory factors, and personal characteristics, among others.

On the basis of these developments, we can now conceptualise the PPCHC as being comprised of four key characteristics:

1. A holistic approach based on the internationally accepted biopsychosocial model. This model is now codified in the World Health Organization (WHO) International Classification of

Functioning, Disability and Health (ICF) but is still being developed and supplemented by new taxonomies of sets of health-related factors.

2. Empowerment of the person based on human rights. This attribute of PPCHC emphasises equality, needs-based care, and the involvement of people in their own health care and decisions.
3. Integrated care and universal access, whereby integration has developed beyond coordination and collaboration between services for the person (vertical integration) to inclusion, participation and community care, engaging the person and assessing personal factors such as quality of life and planning for solutions.
4. Complexity and context dependence. While there is no single model of PPCHC because each context is different, there can be a common framework.

The cornerstone for enabling PPCIHC groups together co-production of care, shared knowledge and decision making, and includes co-design of changes to improve the safety, quality and outcomes of health care. Expressions of shared knowledge and decision making that contribute to this key facilitator for PPCHC include:

- A sentinel approach to lifelong health care
- The expert patient, self-management and peer support
- Locally relevant person-centred primary and community care

Appendix 1: History of the development of PPCHC since Alma-Ata

The Alma-Ata Declaration took place at a time when it was the norm in both developing and developed countries for the central government to take the pre-eminent role in the provision of health, education and welfare services. The Alma-Ata Declaration provided a pivotal role in defining the core principles of primary health care – it should be fundamentally person-centred in that it affirms '*people have a right and duty to participate individually and collectively in the planning and implementation of their healthcare'* (World Health Organization (WHO), 1981). The Alma-Ata Declaration promoted a shift from vertical centralised health care in large hospitals in major cities, to a horizontal community-based and comprehensive healthcare system involving collaborations with sectors such as education, housing, food, and industry/the workplace.

The international response to the Alma-Ata was mixed, where some countries implemented comprehensive community-based primary health care (Heath, 2011), others pursued a 'selective primary health care' approach which involved narrowly targeted and vertically controlled, rather than community-based, health care. By and large, the impact of Alma-Ata on clinical practice in most countries is seen as being low. This is for a number of historical reasons (C. R. Cloninger et al., 2014):

1. The selective primary health care approach was favoured among key influence policy actors in global health including the Rockefeller Foundation, World Bank and USAID.
2. Financial and governance structures of health systems implicitly favoured top-down, centralised approaches to health care.
3. Perceptions of community-based healthcare services were that it was second-rate quality.
4. Notable large-scale health events, such as the HIV epidemic, reinvigorated a disease-focused approach to global health.
5. In the last century there was a surge in medical technology and capacity to diagnose and categorise disease, with accompanying treatment specialisation, and reimbursement and research funding (Gerber, Hentzelt, & Lauterbach, 2007; Heath, 2011; J. Mezzich et al., 2010; Turner-Stokes, 2007). Disease was viewed as a separate entity able to be perceived in objective terms (the diagnosis), and considered to be outside the unique characteristics and circumstances of the person (Engel, 1977; Rosenberg, 2002). This reductionist, disease-focused and increasingly objective approach was appealing to physicians in an increasingly technical healthcare environment. It included the use of an abridged set of symptoms and signs, objective measures for the diagnosis and categorisation of diseases which were consequently incorporated to operational diagnostic systems, prototypical clinical guidelines

of interventions, and training manuals. This trend was also accompanied by an increasing reliance on laboratory testing, biomarkers, imaging techniques and decision support systems (Fernandez, Sturmberg, et al., 2015; Moynihan, 2011; Rosenberg, 2002). The disease categories also became linked to the bureaucratic hospital systems and management, specialisations and other social structures such as insurance (Rosenberg, 2002).

6. A public policy focus on cost containment, health financing and economics, and managerialism in healthcare in the 1980s was accompanied by continuous standard monitoring of performance, inputs and outputs, measurable objectives and resource rationing to make the work of health practitioners more transparent through control and surveillance (Fernandez, Sturmberg, et al., 2015; Germov, 2005). Even though this approach has translated into reduction of variability in clinical management, it is also related to extreme specialisation and uncontrolled commoditisation and weakening of the doctor–patient relationship (Heath, 2005, 2011; J. Mezzich et al., 2010).

In clinical practice and possibly in response to emerging limitations in practice of the disease-specific and reductionist approaches, the concepts and development of person-centred health care (PCHC) started in the 1940s with the design of a humanism approach to medical practice in Europe (Paul Tournier's '*Medecine de la Personne*') and in psychotherapy within the USA (Carl Rogers' Client-centred Therapy) (Harding et al., 2015; Leplege et al., 2007; MacLeod & McPherson, 2007; J. Mezzich et al., 2010; L Salvador-Carulla & Mezzich, 2012). Two decades later W.A. Anthony introduced the concept of personhood and recovery to the psychosocial rehabilitation field, or 'The Need-adaptive Assessment and Treatment' approach developed by Y.O. Alanen in Finland, to encourage attention to the meaning of patients' experiences and to the nature of their needs (L Salvador-Carulla & Mezzich, 2012). Further changes in other areas of health care and clinical practice occurred: in the UK the patient-centred clinical method designed for family physicians to support a better understanding of the patient as well as the disease (Levenstein et al., 1986); in nursing the total person approach (Nauman & Young, 1972); and in occupational therapy the two-body practice and the use of narrative in practice reasoning (Mattingly, 1998).

The patients also responded to the disease-specific approaches with the establishment of a number of patient organisations. In the 1970s Planetree, a mission-based not-for-profit organisation, was established by Angelica Thierot, motivated by her own patient experience, to petition for greater recognition of patient rights, access to information and involvement in their own care (Stichler, 2011). This was followed by the Picker Institute which developed the principles and a framework of patient-centred care in 1987 (Institute for Patient and Family-centered Care: IPFCC, 2016; Picker

Institute, 2016). In 1994 the International Alliance of Patient's Organizations was established to advocate internationally for patient voices on healthcare policy and equity in health care. The organisation developed a patient declaration in 2006 (International Alliance of Patients' Organizations (IAPO), 2006).

While some of the clinical approaches mentioned above produced schools of clinical practice, and the Alma-Ata articulated the health system framework for PCHC through community-based primary health care, it was not universally accepted nor adopted in clinical practice. As a matter of fact, during the whole of the second half of the 20th century, instead of adopting a complex person-centred approach, clinical practice and health care has followed the opposite path (J. Mezzich et al., 2010). Although patient preferences and choices were included in the main components of evidence-based medicine in the early 1990s, the grading of the evidence left aside key components of PCHC, such as expert knowledge, observational data and patient's narratives, experiences, choices and aspirations, as 'colloquial evidence' and excluded them from the high-ranked knowledge base that guided evidence-based care, policy and practice (Fernandez, Sturmberg, et al., 2015).

The 21st century brought a new impulse for PCHC, including the development of country level and international collaborations and consensus to improve the conceptualisation, implementation and assessment of PCHC. A number of government and not-for-profit organisations focused on person-centred health and social care have emerged, as well as several international organisations established including the International Foundation of Integrated Care (IFIC), the International College of Person-centred Medicine (ICPCM), the European Society for Person Centred Healthcare (ESPCH) as well as the French speaking network (*1er Congrès francophone de la Médecine de la Personne*, Poitiers 28–29 March 2014).

ICPCM committed to developing a conceptual framework and knowledge base on PPCHC. In the past four years, the ICPCM has produced six declarations on person-centred care (http://www.personcenteredmedicine.org/) at the annual conferences on person-centred medicine in Geneva in collaboration with the World Health Organization (WHO) and the main international organisations in the health sector.

The development of the declarations involved a network organised by ICPCM and WHO and includes, among many other institutions, the World Medical Association (WMA), the World Organization of Family Doctors (WONCA), the International Network for Person-centred Medicine, and other organisations such as the Council for International Organizations of Medical Sciences (CIOMS), the World Federation for Mental Health (WFMH), the World Federation of Neurology

(WFN), the World Association for Sexual Health (WAS), the International Association of Medical Colleges (IAOMC), the World Federation for Medical Education (WFME), the International Federation of Social Workers (IFSW), the International Council of Nurses (ICN), the European Federation of Associations of Families of People with Mental Illness (EUFAMI), the International Alliance of Patients' Organizations (IAPO), the University of Geneva School of Medicine, and the Paul Tournier Association. The process of development of the declaration and their accompanying papers (e.g. Cloninger et al. 2014; Salvador-Carulla et al. 2013) constitutes a paramount example of framing of scientific knowledge in this new area of healthcare delivery (L. Salvador-Carulla et al., 2014). The cooperation between ICPCM and the International Foundation of Integrated Care (IFIC) since 2013 provides a valuable example of networking and cooperation across international organisations. There is now an international call for a fundamental paradigm shift in the way health services are funded, managed and delivered to be integrated and person-centred.

Appendix 2: What the *person-centred key messages* for planning do/do not look like (from Lifetime Care Authority and Lukersmith (2015))

DOES look like	DOES NOT look like
Hear, understand and respect the person and their context	
Do you think you need assistance to shower? If so, how would you like to be assisted, and what time is best for you?	You will need assistance in the morning to shower every day (*secondary message: I have professional experience and so know what is best for you*).
Assist the person to utilise their strengths and to build capacity with their supports and the community	
Let's look at your strengths....What do you think you are pretty good at? What are some of your qualities that you are proud of?	You might need help to understand it all, but you have to learn to accept that things are different now and you can't do a lot of things you used to do.
Assist the person to identify and aim for supports that are tailored to their individual needs	
There is a specialist computer skills class for people with disabilities at TAFE. Do you want to go to the specialist class or do you want to go to the mainstream computer class? What support do you think you might need to attend the mainstream class? You could find out from TAFE what support is available for the mainstream class, there may be peer support or a teacher's aide?	It will be better for you to go to the class at TAFE specifically for people with disabilities rather than the mainstream computer class.
Facilitate and promote participant opportunities, rights and responsibilities	
Do you want to return to work? Are there any risks to your return to work? How do you think your fatigue and memory will affect your work? What strategies can you think of that would support you?	You can't return to work now, it is too early and you might make a mistake because of your fatigue and memory problems. If you do, then it could jeopardise your job.
Facilitate and promote progress and review so that supports can be refined	
In six months' time, I will be checking in with you about how you are going with the steps towards your goals. After that we can see what changes to your supports you would like to make.	I will be reviewing your plan in six months. I will write you a letter to tell you what time the appointment will be.

4.4 Results Stage 2 – technical framework(s)

The WHO, a number of WHO Collaborating Centres and individual international collaborators have done extensive work over recent decades to develop international classifications for health care. Collectively the classifications are referred to as the WHO Family of International Classifications (WHO-FIC) (World Health Organization, 2016a). The classifications include: the International Classification of Diseases (ICD) which is currently undergoing its 11th revision; the International Classification of Functioning, Disability and Health (ICF); the International Classification of Health Interventions (ICHI) currently under development; and derived classifications such as the several international classifications for diseases such as oncology, behavioural disorders, neurology, dentistry and stomatology. There are also a number of related and relevant classifications including the International Classification for Nursing Practice. For the review of technical frameworks, we started with the WHO-FIC group of classifications, but also searched other classifications known to the researchers, and hand-searched references.

There have been previous reviews to identify frameworks to inform care coordination, although for different purposes. In 2007, the Agency for Healthcare Research and Quality (AHRQ) in the USA identified care coordination as cross-cutting and one of the national priorities. As such it was perceived as a key strategy that has the potential to improve effectiveness, safety and efficiency in the country's health system. The AHRQ commenced with a working definition in 2007 (McDonald et al., 2007, p. 5). The AHRQ's current definition of care coordination is:

> *Care coordination involves deliberately organizing patient care activities and sharing information among all of the participants*

> *concerned with a patient's care to achieve safer and more effective care. This means that the patient's needs and preferences are known ahead of time and communicated at the right time to the right people, and that this information is used to provide safe, appropriate, and effective care to the patient (Agency for Healthcare Research and Quality (AHRQ), 2016).*

Since 2007, the AHRQ has completed extensive work to develop measures and track the quality and equity of the American health system across inpatient and primary care. While the AHRQ definition concerns the broker or medical approach to case management (from the service perspective), which is not the approach to be used for the taxonomy, the first AHRQ report in 2007 involved an extensive review of care coordination (McDonald et al., 2007). One question for that review was '*What conceptual frameworks could be applied to support development and evaluation of strategies to improve care coordination?*' (McDonald et al., 2007, p. 9). The aim was to identify frameworks that predict or explain the factors in the healthcare setting which influence care coordination mechanisms and thereby patient outcomes and healthcare costs. A subsequent review by researchers in Belgium sought to update the theoretical frameworks for care coordination identified by the AHRQ (Van Houdt, Heyrman, Vanhaecht, Sermeus, & De Lepeleire, 2013). There have also been reviews of frameworks to inform integrated care (MacAdam, 2008; Minkman M, Ahaus K, Fabbricotti I, Nabitz U, & R., 2009).

Considering the relevant frameworks within WHO-FIC and the previous reviews that specifically focused on care coordination and integrated care (MacAdam, 2008; McDonald et al., 2007; Minkman, Ahaus, Fabbricotti, Nabitz, & Huijsman, 2009; Van

Houdt et al., 2013), we had a preliminary list of 24 frameworks. Several of these frameworks had already been included in our review, although others were discipline- or country-specific (e.g. Australian Classification of Health Interventions, International Classification of Mental Health Care) and others were not in English (Classification of Therapeutic Procedures in Medical Rehabilitation). Table 4.1 provides the preliminary list of technical frameworks and includes the name of the framework, authors, a brief description, a judgement on whether it was fit for our purpose (yes/no) and the reasons.

Table 4.1 Preliminary list of technical frameworks

	Framework	Purpose and brief description	Comments	
			Fit for purpose **Yes/No**	**Reason**
1	Activities of daily living (Katz, 1983)	This framework refers to the assessment and measurement of activities of a typical person in their everyday life. Activities considered include self-care (feeding, dressing, washing etc.), work, home and leisure. It is often used as a measure of functional status for people with disabilities, the elderly or children and is used in national surveys (e.g. in Australia, USA) and self-report measures of functioning. The model was subsequently expanded to include incidental activities of daily living (IADL) as is particularly professionally relevant to occupational therapists.	No	The focus of this model is for measuring the person's capacity and performance based on routine daily tasks. Our focus is on the activities of the case manager.
2	Cognitive workflow (Malhotra, Jordan, Shortliffe, & Patel; Van Houdt et al., 2013)	Provides a generalisable model of the cognitive processes and intricate workflow used to identify and categorise medical errors and predict same in practice. Although reported to be applicable to all healthcare settings, it is particularly relevant to emergency and intensive care settings.	No	The model is a framework of cognitive workflow and concerns operational processes.
3	Community-based rehabilitation (CBR) matrix (World Health Organization (WHO), United Nations Educational, International Labour Office (ILO), & International Disability Development Consortium, 2010)	CBR is a community development and inclusive development strategy to improve access of persons with disability to different sectors in low resource/developing countries. The matrix was developed to provide a common framework for CBR programs. The matrix has five key components (work streams) – health, education, livelihood, social, empowerment – and within each component there are five elements (groups of related activities).	Yes	The CBR matrix as a community development strategy is cross-cutting across sector support (horizontal integration of service).

	Framework	Purpose and brief description	Comments	
			Fit for purpose **Yes/No**	**Reason**
4	Description, Evaluation and Classification of Services for Long Term Care (DESDE-LTC) (L Salvador-Carulla, Dimitrov, et al., 2011; L Salvador-Carulla, Gonzales-Caballero, et al., 2011)	A classification system and common language for long-term care services, developed through a collaboration of six European countries. It provides common coding and standards for services in long-term care. DESDE-LTC allows for the collection of local information, mapping of services and data evidence to inform policy.	Yes	DESDE-LTC concerns long-term care services. Care coordination is coded in the classification.
5	Donabedian Quality Framework (Donabedian, 1966, 1982; McDonald et al., 2007)	This conceptual framework has been extensively used to evaluate quality of health care and the health services. The model's categories are structures and processes of care, and health outcomes.	No	The process category has potential relevance to the taxonomy. However, the categories are not sufficiently granular and some are irrelevant (e.g. diagnosis, treatment, preventive care, patient education and technical processes). The structure (service concepts) for our study were the inputs not the physical context such as buildings, services and structures (which are included in this model). The outcomes and effects of health care on individuals and populations was also not relevant for the taxonomy.
6	Mental health services matrix model (Tansella & Thornicroft, 1998)	The matrix model is a conceptual framework for mental health services. The model has two dimensions. One is geographical in terms of country, local and patient. The other is temporal which refers to phases of inputs, processes and outcomes. These dimensions form a 9-cell matrix to focus on critical issues for mental health services.	Yes	The matrix supports the management of two dimensions that vary in case management – the geographical (the patient micro level versus meso level) and the temporal level of inputs and outputs.

	Framework	Purpose and brief description	Comments	
			Fit for purpose **Yes/No**	**Reason**
7	Five phases of team coordination (Klein, 2001; Van Houdt et al., 2013)	This theoretical framework identifies and describes the phases of team efforts for coordination which include preparation, planning, direction, execution and assessment.	No	These phases refer to the characteristics and outcomes of team interactions, rather than intervention actions of coordination. Further, the teamwork interactions were developed considering situations that were less contextually complex (i.e. situations where there was a beginning and end point) than community-based case management.
8	Framework of team performance (Reader, Flin, Mearns, & Cuthbertson, 2009; Van Houdt et al., 2013)	The framework was developed to determine the relationship between teamwork and patient- or staff-related outcome in intensive care units, highlighting influential components such as team leader, team coordination.	No	The process-oriented model concerns team functioning within an inpatient unit. The focus is on the health professional rather than the components and actions performed.
9	Integrative model (Parker, Demiris, Wittenberg-Lyles, & Porock, 2010; Van Houdt et al., 2013)	The model concerns teams and provides a framework and strategies to enhance the success of interdisciplinary teams and collaboration, including the family of patients.	No	The model does not refer to coordination and collaboration for the individual patient.
10	Interaction model (Van Houdt et al., 2013; von Watzlawick, Beavin, & Jackson, 2000)	The framework concerns interpersonal communication as a system. It includes five axioms which are: one cannot not communicate, every communication has content and relationship, punctuation develops the relationships, communication can be digital and analogic, and communication is symmetric or complementary.	No	The model may be useful to explain aspects of communication. Although communication is highly relevant to case management, the framework does not provide structure to other case management intervention components.

	Framework	Purpose and brief description	Comments	
			Fit for purpose **Yes/No**	**Reason**
11	International Classification of Health Interventions (ICHI) (Alpha version 2013) (WHO ICHI Development Project, 2013)	ICHI has been in development since 2007 through the WHO Family of International Classifications (WHO-FIC). We reviewed the Alpha 2013 version. There is now a 2015 version. The classification of interventions has three axes (action, target and means) and is applicable to ambulatory as well as inpatient health interventions. The aim is for the classification to be used nationally and internationally for comparisons (without having to adapt it locally) to inform planning and policy.	Yes	Case management has been included in the ICHI definition. There are actions within the 2013 version that are potentially relevant to the proposed case management taxonomy.
12	International Classification of Diseases (ICD-10) (Vikstrom, Skaner, Strender, & Hilsson, 2007; World Health Organization (WHO), 2004)	This is an internationally developed and used classification to classify diseases and other health problems. It provides a standard for diagnostic classifications for epidemiological and health management purposes (e.g. hospital records). It considers aetiology, anatomical site, context for onset (e.g. infection).	No	Classification of disease is not a consideration as the proposed taxonomy will be neutral to health conditions.
13	International Classification of Mental Health Care (de Jong, 2000)	This classification was specifically developed through a WHO collaborating centre to describe interventions specific to mental health. The classification considers community-based as well as social service interventions. The classification is structured around a concept of modules of care which involves care delivered by groups of health professionals to groups of patients (rather than individual professional to individual patient). The second concept is modalities of care. There are 10 modalities of care in the classification, one of which is care coordination.	Yes	Care coordination is one of the modalities of care in the classification.

	Framework	Purpose and brief description	Comments	
			Fit for purpose Yes/No	Reason
14	International Classification for Nursing practice (Coenen, 2003; International Council of Nurses, 2008, updated 2015)	This framework provides a classification of nursing phenomena, actions, and outcomes involved in nursing practice. The classification includes multiple axes: e.g. phenomena (7 axes) and techniques (8 axes including target, action and means).	No	A number of the actions and axes were relevant to case managers who are nurses and related to clinical nursing practice. The purpose was for the clinical practice of one discipline rather than any health discipline and not community-based.
15	International Health Terminology Standards Development Organisation (IHTSDO) which incorporates the Systematized Nomenclature of Medicine, Clinical Terms (SNOMED CT) (Stearns, Price, Spackman, & Wang, 2001; Vikstrom et al., 2007)	This is an extensively used, clinical healthcare terminology reference, hierarchical classification system. It provides definitions of over 300,000 inter-related healthcare concepts, and even more relationships and definitions. The purpose is to provide a reference for the aggregation, collection and retrieval of healthcare data.	No	The purpose is primarily for classifying the clinical 'input' terminology and linking of terms that relate to each other so that aggregated data is consistent. Our interest for the case management taxonomy is on the throughputs, the activities and the relationship in community-based care rather than clinical interventions.
16	Interorganizational network theory (Alter & Hage, 1993; Van Houdt et al., 2013)	This framework focuses on networks between organisations and the development of interorganisational networks.	No	This model focuses on the organisation (the group) not individual actions or the service context.

	Framework	Purpose and brief description	Comments	
			Fit for purpose **Yes/No**	**Reason**
17	Management model for integrated care (Minkman et al., 2009)	This model was developed for the management of integrated care and identifies elements and nine clusters: quality care, performance management, inter-professional teamwork, delivery system, roles and tasks, patient centredness, commitment, transparent entrepreneurship, and result-focused learning. It encompasses multiple patient categories and emphasises collaboration characteristics.	No	While the clusters of roles and tasks are relevant to the case management taxonomy, the overall framework is operational and specifically focuses on the management and quality rather than the actions or service inputs.
18	OECD Health Care Qualities Indicators Project (Ara, Westert, Hurst, & Klazinga, 2006; Mattke, Epstein, & Leatherman, 2006)	The Organization for Economic Cooperation and Development (OECD) developed the indicators for health condition priority areas which are cardiac, diabetes, mental health, patient safety and primary care/prevention. The framework focuses on indicators for health performance and quality of health care, and a broader perspective of health (informed by a heath determinants model). The framework includes four tiers which denote causal pathways of health. The indicators focus on three dimensions of quality (effectiveness, safety and responsiveness) and two dimensions of access and cost expenditure.	No	The framework focuses on indicators which can be used to measure quality of health care with particular focus on priority health conditions. The focus is on indicators of quality rather than components of activities or service.
19	Organizational Design Framework (McDonald et al., 2007; Nadler & Tushman, 1988)	The AHRQ review presents key concepts from organisational design research. The concepts focus on organisations as information processing systems, where information flow between participants is a function of demands and capabilities with three concepts (information requirements, information processing capacity and the match between these). The framework considers the interdependence, uncertainty and complexity of information which is a function of the organisation's structure and structural linking.	No	This framework concerns information flow within an organisation as operational processes, e.g. multi-disciplinary clinic makes it easier for movement of information between specialist physicians. Operational processes are not relevant for the taxonomy.

	Framework	Purpose and brief description	Comments	
			Fit for purpose **Yes/No**	**Reason**
20	Relational coordination framework (Gitell, 2002; Gitell & Weiss, 2004; McDonald et al., 2007)	This model focuses on the relational aspects of coordination and the relationship between the participants. The parameters are: frequency, timeliness and problem solving aspects of communication among participants in care; helpfulness; shared goals and knowledge; mutual respect.	No	This is a process framework and concerns factors which potentially influence the quality of interactions between the provider and the person. Its focus is only the quality of coordination, which is only one action of case management.
21	System of Health Accounts (SHA2.0) (World Health Organization, 2011a)	A method and extended accounting framework to collect, track, measure and develop comprehensive data on healthcare spending. There are three axes and associated subsystems within it which include the functions of health care (ICHA-HC), healthcare provision (ICHA-HP) and financing schemes (ICHA-HF).	No	SHA2.0 concerns the financial aspect of services rather than the service inputs or components of the production of case management.
22	Time, interaction and performance theory (Mcgrath, 1991; Van Houdt et al., 2013)	The theory was about group interaction and task performance. There are four team activities (inception, technical problem solving, conflict resolution and execution).	No	The model focuses on the group rather than the activities of the individual. The theory appears to have been primarily used as a framework to evaluate group and team activities and effectiveness.
23	The social work/case management taxonomy (Abeyta et al., 2009)	This taxonomy of interventions was developed by and for social workers/case managers working with people with spinal cord injury (SCI). There are eight interventions (financial planning, discharge planning, discharge services, supportive counselling, information about and referral to peer/advocacy groups, education about SCI and other relevant topics, information about and referral to community/in-house services, and team conferences).	Yes	The interventions in the SCI taxonomy are potentially applicable to a case management taxonomy that is not specific to one health condition.

	Framework	Purpose and brief description	Comments	
			Fit for purpose **Yes/No**	**Reason**
24	Wagner chronic care model (Wagner et al., 2001)	This is a service and system framework that summarises the basic elements for improving chronic care at the community, organisation, practice and patient levels. The AHRQ review used the Wagner chronic care model as an example of organisational design (McDonald et al., 2007). The model adopts a system change strategy and perspective which focuses on chronic health conditions. It includes concepts around the health providers as well as the patient's role in longer term health management. The Wagner model proposes that evidence-based concepts and productive interactions should underpin the key elements of the community, health system, self-management support, delivery system design, decision support and clinical information systems. The model promotes collaboration and adjusting responses in each context to fit the partnership of patient and provider which in turn will result in healthier people and satisfied providers at reasonable cost.	Yes	The service delivery system design in the Wagner model specifically includes the actions of care planning and coordination.

The seven frameworks considered fit for purpose were critically reviewed against the criteria listed in Section 4.2 – ontological approach, unit of analysis, neutrality and interoperability. Table 4.2 shows the results of the critical review. Only three of the technical frameworks met all the criteria: Description, Evaluation and Classification of Services for Long Term Care (DESDE-LTC), the mental health services matrix model and the International Classification of Health Interventions (ICHI). The mental health services matrix model has been adapted and embedded in the structure of DESDE-LTC in terms of the inputs (3A) and throughputs (3B) at the micro service level. DESDE-LTC adapts and extends the matrix model to include the nano level of the individual. Consequently, only two technical frameworks were used in the development of the taxonomy: DESDE-LTC and ICHI.

Table 4.2 Short-listed frameworks and results of critical review against specified criteria

No	Framework	Ontological approach	Unit of analysis	Neutrality	Inter-operability	Comments
1	Community-based rehabilitation (CBR) matrix	No	No	Yes	Yes	The five elements (sectors) within the domains are not defined and do not describe service factors, nor inputs or throughputs of case management. For example, education refers to the sectors in education (early childhood, primary, secondary and higher, non-formal, lifelong learning). The elements are global terms for a group of activities. The CBR matrix can link to other frameworks such as the ICF.
2	Description, Evaluation and Classification of Services for Long Term Care (DESDE-LTC)	Yes	Yes	Yes	Yes	Originally for mental health but has since been applied to other sectors. DESDE-LTC defines long-term care service concepts in a hierarchical/tree structure, codes and a glossary. Relevant service categories include acute, non-acute, community concepts (e.g. mobile service/office-based) although the classification does not have the degree of granularity needed. Can link to other frameworks such as ICHI, and Rainbow model of integrated care.
3	Mental health services matrix model	Yes	Yes	Yes	Yes	In the matrix, the patient level of the **input** phase (3A) related to the service, and in the patient level process phase the **throughputs** (3B) related to the service activities are relevant to case management complexity components. The concepts of service geography influencing services at the macro (country), meso (local) and micro (patient) levels is also relevant to case management.

No	Framework	Ontological approach	Unit of analysis	Neutrality	Inter-operability	Comments
4	International Classification of Health Interventions (ICHI) Alpha version	Yes	Yes	Yes	Yes	ICHI specifically aims to cover health interventions, across the entire health system, relevant to different countries, across different levels of service and different populations. Three axes – target, action and means. We were only interested in the action axis (activities of CM). The framework built on previous specialist health intervention frameworks (e.g. European standard for surgical interventions, ICMHC). Links to ICF and can link to DESDE-LTC.
5	International Classification of Mental Health Care (ICMHC)	No	No	No	No	The unit of analysis is modalities of care. While care coordination is defined as a modality of care, the classification does not provide the level of granularity below this needed for the case management taxonomy. This classification focuses on mental health and pre-dates the inception of ICHI development in 2007.
6	Social work case management taxonomy	No	No	No	No	The taxonomy relates to one health condition – spinal cord injury – and one discipline – interventions provided by social workers in an inpatient setting. Although there is greater detail on the topic of interventions (the target), there was a lack of granularity in the interventions described. The taxonomy structure was grouped but did not consistently and succinctly define interventions nor demonstrate the inter-relationships between interventions.

No	Framework	Ontological approach	Unit of analysis	Neutrality	Inter-operability	Comments
7	Wagner chronic care model	No	No	No	Yes	Primarily developed as an organising framework for improving care for people with chronic illness rather than all health conditions. The model presents six concepts: organisational support, clinical information systems, delivery system design, decision support, self-management support, and community resources. These concepts are considered modifiable components. The model does stress the importance of self-management support, and patient-centred interventions (e.g. skills training) to establish goals which align with case management. The interventions are grouped (e.g. service delivery, management) but not coded, nor is the relationship between them identified. The model can be linked to the ICF, ICHI and meta-framework of PPCIHC.

4.5 Discussion

Healthcare systems are dynamic and complex. In health services and implementation research, complexity has been managed with methods using broader sources of knowledge, framing and frame analysis (Gale, Heath, Cameron, Rashid, & Redwood, 2013; Lagace, Nahon-Serfaty, & Laplante, 2015; Lewis et al., 2015; Moullin et al., 2015). A scientific frame is explicit, standardised, based on available evidence and agreed by a group of experts (L. Salvador-Carulla et al., 2014). Frame analysis is a method to enumerate and define ideas and themes within a broader topic to inform the definition of new concepts (Goffman, 1986; L. Salvador-Carulla et al., 2014). We used international frameworks to support the development of a new taxonomy for person-centred community-based case management. We undertook a critical review of international frameworks to inform the taxonomy in terms of the theoretical concepts and approach (including the concepts of health and disability); the technical concepts related to the service domain of case management (the inputs – the resources that are put into the case management service); and the factors related to the intervention domain of case management (the throughputs – the activities involved in case management).

We refer to the model and approach of case management for this research program as ‘person-centred and community-based case/care management’. Embodied in this case management approach are the characteristics of patient- and person-centredness; use of the person’s strengths; empowerment of the person based on human rights; a holistic approach based on the biopsychosocial model of health (ICF); co-production, shared knowledge and decision making around care; and integration of inter-sector care and support (e.g. health, social, education and employment). The rigorous and critical review of frameworks confirmed that there

was no existing framework that comprehensively accommodated the complexity of all these concepts and domains.

Following the review of related frameworks, we used different sources of information, existing frameworks and previous research to develop the meta-framework for PPCIHC. The meta-framework provided the conceptual framework for macro (national/state/regional) to nano (individual) levels of person- and people-centred integrated care. Our approach to case management is positioned in the bottom sector of the model at the nano and micro level. As a foundational conceptual framework and classification for the meta-framework, the ICF also provided the language for some of the component definitions in the taxonomy (e.g. health, disability).

The critical review of technical frameworks for the service and intervention components of case management identified two frameworks. These frameworks were not sufficiently comprehensive. The DESDE-LTC did not classify variations of mobile case management (care coordination) or intensity of the involvement with the person. The Alpha version of ICHI provided some activities consistent with case management, but there were many gaps. However, both of these frameworks provided a starting point for the development of the case management taxonomy intervention and service trees.

These four international frameworks (PPCIHC, ICF, ICHI and DESDE-LTC) were used to structure and inform the next step of the project which was the development of the Beta version (draft) of the case management taxonomy.

4.6 References

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CHAPTER 5 DEVELOPMENT OF THE TAXONOMY and FEASIBILITY ANALYSIS

5.1 Introduction

Chapter 5 concerns Step 1.3 of Phase 1 of the research program, the iterative development of the Beta 1 and 2 versions of the taxonomy, feasibility testing and revision for the final version of the taxonomy (refer to Figure 2.2 in Chapter 2 General Methods). The chapter includes a publication on the intervention tree and intervention table, which was used as part of the dissemination strategy. Due to the publisher's limits on manuscript word count, the published manuscript excluded the detail of the service tree and service table. They are provided separately in this chapter. The layout and explanation of the sections of this chapter are as follows:

Section 5.2 This section contains the published article on the method and results for the intervention tree and feasibility analysis. It includes Appendix 1 of the article which is one of four case studies included in the feasibility analysis. The other three case studies used in the feasibility analysis are appended to the article appendix for the purposes of this thesis.

Appendix 2 (the intervention table) and Appendix 3 (the glossary) of the published article are key taxonomy elements. Figure 3 in the published article is an image of the intervention tree. In order to provide the entire taxonomy in one section and avoid duplication, Appendix 2 (intervention table), Appendix 3 (glossary) and Figure 3 (intervention tree) from the article are provided in Section 5.4 of this chapter, along with the service tree and service table.

Section 5.3 This section provides additional information related to the method and development of the service tree and table of the taxonomy. It includes an excerpt of the DESDE-LTC Service Inventory, concerning care coordination, as a section appendix.

Section 5.4 The entire taxonomy toolkit is provided in this section. This includes the intervention tree, intervention table, service tree, service table and the glossary.

5.2 Intervention tree publication

Lukersmith, S., Fernandez, A., Millington, M., & Salvador-Carulla, L. (2016). The brain injury case management taxonomy (BICM-T); a classification of community-based case management interventions for a common language. *Disability and Health Journal*, *9*(2), 272-280. doi: 10.1016/j.dhjo.2015.09.006

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Research Paper

The brain injury case management taxonomy (BICM-T); a classification of community-based case management interventions for a common language

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Abstract

Background: Case management is a complex intervention. Complexity arises from the interaction of different components: the model (theoretical basis), implementation context (service), population and health condition, focus for the intervention (client and/or their family), case manager's actions (interventions) and the target of case management (integrated care and support, client's community participation). There is a lack of understanding and a common language. To our knowledge there is no classification (taxonomy) for community-based case management.

Objective: To develop a community-based case management in brain injury taxonomy (BICM-T), as a common language and understanding of case management for use in quality analysis, policy, planning and practice.

Methods: The mixed qualitative methods used multiple sources of knowledge including scoping, framing and a nominal group technique to iteratively develop the Beta version (draft) of the taxonomy. A two part developmental evaluation involving case studies and mapping to international frameworks assessed the applicability and acceptability (feasibility) before finalization of the BICM-T.

Results: The BICM-T includes a definition of community-based case management, taxonomy trees, tables and a glossary. The interventions domain tree has 9 main actions (parent category): engagement, holistic assessment, planning, education, training and skills development, emotional and motivational support, advising, coordination, monitoring; 17 linked actions (children category); 8 related actions; 63 relevant terms defined in the glossary.

Conclusions: The BICM-T provides a knowledge map with the definitions and relationships between the core actions (interventions domain). Use of the taxonomy as a common language will benefit practice, quality analysis, evaluation, policy, planning and resource allocation. © 2016 The Authors. Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

Keywords: Case management; Care coordination; Taxonomy; Intervention; Quality analysis

Case management (CM) is a complex intervention which makes a unique contribution toward the long term care, community participation and support of a person with a complicated health condition such as brain injury.[1–3] CM has multiple components, which interact with each other.[4–6] The components concern; the model or approach (theoretical background), implementation context (organization or service), case manager's actions

Abbreviations: (BICM-T), Brain injury case management taxonomy; (CM), Case management; (AUD), Australian dollars; (NSW), New South Wales; (LTCSA), Lifetime Care and Support Authority; (WHO), World Health Organization; (ICHI), International Classification of Health Interventions.

The method used for the development of the taxonomy was presented at the International Integrated Care Conference in November 2014, and the abstract of that conference presentation was published in IJIC. There was a poster presentation in 2014 at WHOFIC-Barcelona.

The authors have no conflicts of interest to declare.

There has been one paper presentation on the method at the International Integrated Care Conference in November 2014. There was a poster presentation on the ICHI component of the taxonomy in presentation in 2014 at WHOFIC-Barcelona and a poster presentation in July at the ASSBI conference in Sydney. These are not considered duplicate publication.

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(interventions), focus of the CM interventions (the person with the health condition, or their family/carers), the target of CM (e.g. activities and participation of the person with the health condition or environmental factors) and the time the case manager is engaged with the recipient (stage of recovery). The issues arising from the complexity in CM are similar to the evaluation of other complex interventions, integrated health care and health care programs.[7,8] The variability and lack of consensus on language poses challenges for quality analysis, evidence synthesis, policy development and planning for CM.[5,6,9–11]

Brain injury

In this research, there is a special focus on brain injury, which is an example of a common multi-dimensional and disabling health condition. As such, the taxonomy may be applicable to other multi-dimensional health conditions like dementia, chronic illness or mental health conditions or multi-morbidity.

The differences with definition and reporting of brain injury results in a range of incidence estimates based on hospital data from 91 to 377 per 100,000 population.[12,13] Brain injury potentially impacts on multiple domains of health and participation, the person's cognitive, physical, psychological, behavioral functioning and participation in life roles. In the USA, 2% of the population are reported to experience life-long disability as a result of traumatic brain injury.[14] In an Australian outcome study of various health domains for people with brain injury ($n = 198$) there were significant impairments of mobility (10%), use of the hands (14%), communication (4%), memory (61%), problem solving (52%), social interaction (20%), and at 3 years post injury less than a third of working age people were employed.[13]

Case management for person's with brain injury demands a complex response by services, programs and interventions.[1,15,16] In Australia, children and adults with brain injury were estimated to be 6% of users of Government funded specialist disability service[16] with the total life time cost per incidence case of traumatic brain injury estimated to be $2.5 and $4.8 million (AUD) for moderate and severe brain injury respectively.[15] People with moderate or severe brain injury require CM. In 2012, a local study at the Lifetime Care and Support Authority (LTCSA) in New South Wales (NSW), Australia; 89% of participants in LTCSA with brain injury received CM services.[17]

Taxonomy

In health services and implementation research, complexity has been managed with methods which use broader sources of knowledge, framing and frame analysis. Frame analysis is a method to enumerate and define ideas and themes within a broader topic to support defining new concepts.[18,19] One type of framing tool is classification, a taxonomy. The taxonomy organizes knowledge and articulates the relationship between concepts and components, and provides definitions.[18,20] In health services research taxonomies have been used as a knowledge map to develop consensus and develop a common language in very different areas such as patient safety and reporting of adverse events,[21] rehabilitation interventions[22,23] health-related behaviors[24] or complex psychological behavioral interventions.[25]

In studies on CM, either there is too little information to describe what is done (the interventions or activity) or there is significant variability in the terms and descriptions for the same activity.[11,26–31] For example, the range of terms used in the literature to describe the activity (intervention) of linking or referring the person to health or support services include *managed care*,[32] *brokering*,[33,34] *specialist case management*,[35] *systems coordinator*,[36] *coordinating*,[37] *service broker*[38] or *navigator*.[39]

Aim of the research

The research aims to develop a community-based case management in brain injury taxonomy (BICM-T), for use as a common language in case management quality analysis, policy, planning and practice.

The model and theoretical background for the taxonomy on CM is community-based and person-centered. The person-centered approach holistically considers the clients own context and situation, their strengths, the clients choice and goals for participation in life, their needs and preferences as well as actively supporting them to be involved in planning for supports.[40]

In this paper, we only report on the interventions domain performed by the case manager (throughputs domain). The case management service domain (inputs) is reported elsewhere.

Methods

The University of Sydney conducted the two phase study (Fig. 1). In December 2013, the University of Sydney granted ethics approval. Phase 1 involves the development of the taxonomy and Phase 2 the dissemination and implementation. The taxonomy on CM in brain injury involves two axis or domains of case management; 1) the service domain (inputs), the description of case management services provided by organizations and 2) the interventions domain (throughputs) which are the 'actions' performed by the case manager. Phase 2 has commenced but the methods and results are not reported here.

Phase 1, the development of the taxonomy involved two groups and four steps (refer to Fig. 1). The focus of this report is on Phase 1 and the case management interventions domain of the taxonomy. Step 1 the scoping study method and results are reported elsewhere. The next steps occurred over 14 months and involved two groups; a core group (SL,

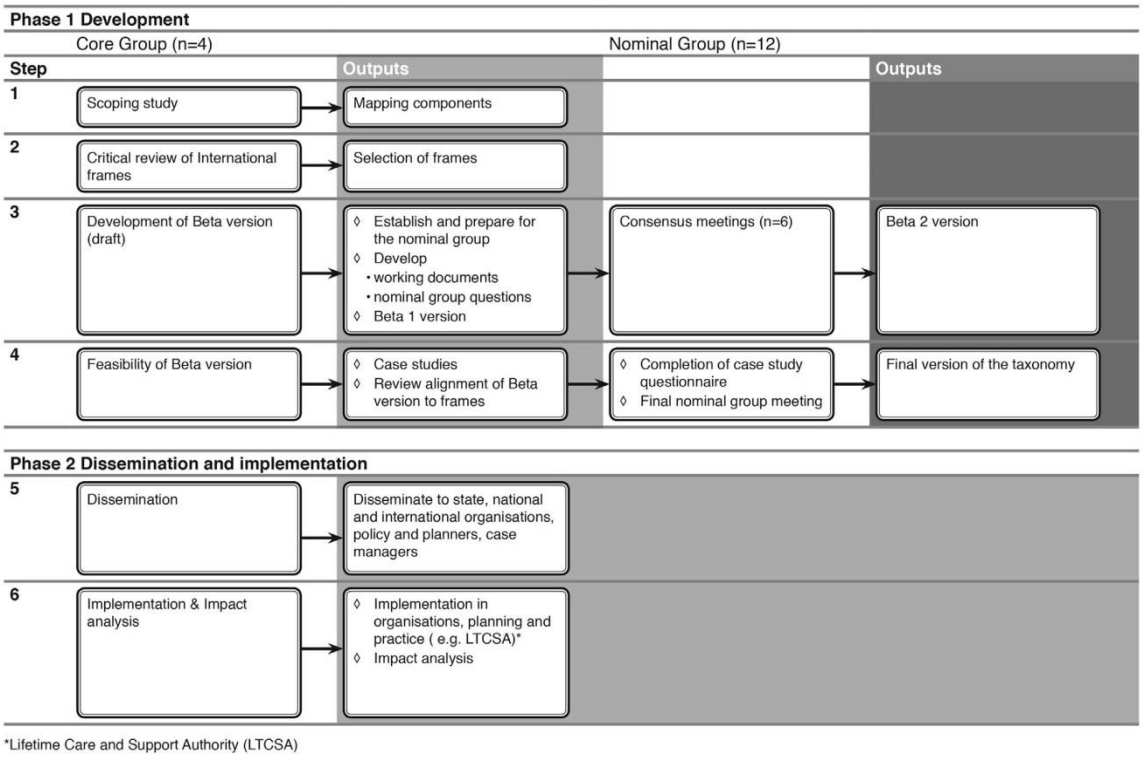

Fig. 1. The phases and steps for the development of the taxonomy of community-based case management in brain injury (BICM-T).

AF, MM, and LSC) and a nominal group of 11 CM experts. Steps 3 and 4 involved an industry partner, funder of community-based CM services for persons who have sustained a moderate or severe traumatic brain injury through a motor vehicle crash in New South Wales (NSW), the Lifetime Care & Support Authority (LTCSA).

Phase 1: Step 2 critical review of international frames

Step 2 used a frame analysis approach to identify the tools and international frameworks to support the key concepts that underpin community-based CM. In addition to the taxonomy, there was a need for frames to accommodate the complexity of the different domains in community-based CM (intervention and service). The core group completed a critical review of potential international frameworks to inform the theoretical background of the taxonomy including: the concepts of health and disability; factors related to the service domain of CM (the inputs); and the factors related to the focus of this report, the intervention domain of CM (the throughputs).

Phase 1: Step 3 development of Beta version (draft)

The core group members developed the Beta 1 version of the taxonomy using the knowledge from the scoping study and the international frames. The core group prepared the working documents and questions for the nominal group.

The final part of Step 3 was the iterative development of the Beta 2 version of the taxonomy with the nominal group. The nominal group technique allows a more structured approach than, for example, focus groups. The technique also allows the use of prior information and expert knowledge.[41] Expert knowledge is a type of scientific knowledge, which is critical to implementation research.[18,42]The expert knowledge from a multi-disciplinary group of people enhances the potential for, and use of the taxonomy. The nominal group technique uses an open group discussion and judgment technique to make consensus decisions.[43–45]

The members of the nominal group ($n = 12$) had expert knowledge of CM practice in brain injury (pediatric and adult), knowledge of different service contexts (public, private, non-government not for profit organizations), geographical context (urban and rural) and came from different professional backgrounds, and experience in policy and planning, funding, business and management.

Phase 1: Step 4 feasibility of the Beta version to develop the final BICM-T

A type of formative evaluation, the developmental evaluation, was undertaken to enhance the feasibility of the taxonomy.[46,47] Feasibility refers to the extent to which the use

of the taxonomy is appropriate in practice (including policy practice) and clinical situations, when used for a specific objective in a specific way. This analysis included applicability and acceptability. The applicability construct is defined as the usability of an instrument or in this case the taxonomy (or usefulness in terms of its dimensions, the application). Acceptability refers to the ease with which a user can use the instrument, the 'user-friendliness' of the taxonomy.[48–50]

The developmental evaluation activities involved mapping the alignment of the Beta version intervention domain to the international frames, and trialing acceptability of the actions and relevance to the expert case managers using case studies. The core group reviewed the Beta 2 alignment and consistency of the actions with the biopsychosocial concepts of functioning and language in the ICF and ICHI to identify inconsistencies and gaps, in language and relationships between components.

SL developed four case studies differentiated by injury type (three traumatic brain injury and one with spinal cord injury as a comparator), age (one child and three adults) and different stages post injury (stage one <2 years post injury, stage two >2 years post injury). The comparator case study on spinal cord injury (Case study 1) was included to trial whether there were major differences with another different, but severe and complex health condition. The case studies provided a synopsis of the client's context and functioning at two periods following injury (Refer to an example Appendix 1 Case study 4). The core group developed the case study questionnaire on the acceptability (relevance) and applicability (degree to which the action is important) of seven of the actions. At the time of the case studies the definition of two actions (advising and education) were not finalized with a consensus definition and excluded from the case studies questionnaire. On the Likert scale acceptability rating the end points were 1 (not relevant) and 4 (extremely relevant). Importance was rated as a percentage of time spent on each action per client per stage of recovery. Each nominal group member completed the case study questionnaire by week 6 (excluding the facilitator and one nominal group member but the inclusion of one observer (MM) $n = 11$).

Following the developmental evaluation, further revisions to the Beta version (definition, glossary and tree) were sent to the nominal group. The final meeting held four months later in Step 4 was to finalize the BICM-T with the nominal group.

Results

Phase 1, Step 2 critical review

The results of Phase 1, Step 1 the scoping study are not reported here. The results of Phase 1, Step 2 the critical review, identified three international frameworks which informed the taxonomy and assisted to develop the structure, the relationships and language of the taxonomy. The two frameworks discussed here relate to the intervention domain of the taxonomy.

i. The International Classification of Functioning, Disability and Health (ICF)[51] articulates the biopsychosocial model of health, the interaction of the person's impairments of body functions and structures, their activity limitations and restrictions for participation. As the ICF defines the domains of health including the influence of the contextual factors (environment and the person) on functioning, the concepts and language in the ICF aligns with the approach taken in community-based and person-centered CM.

ii. The World Health Organization (WHO) is developing a method of describing and classifying health interventions, the Alpha version of the International Classification of Health Interventions (ICHI).[52] The ICHI classification provides a standard definition of an intervention (an activity performed for, with or on behalf of a person or a population whose purpose is to improve, assess or modify health, functioning or health conditions). The ICHI defines three main axis for health interventions. These are the target of the intervention (the entities on which the action is carried out for example, the person's behavior, activities and participation), the action (a deed which is done by an actor to a target during a health care intervention such as therapeutic, managing), and the means (the entities describing the processes and methods by which the action is carried out such as the technique or approach, or method).[52] In addition to surgical and medical interventions, ICHI includes for the first time, a section on functioning interventions that target a body function, activities or participation, or an environmental factor that affects functioning.[51,52] As the taxonomy was to provide a description of the multiple interventions (components) performed by a case manager depending on the client and context, the ICHI classification actions was critical to the throughput (intervention) axis of the taxonomy.

Phase 1, Step 3 Beta version

Beta 1 version

In Phase 1, Step 3 there are four parts. The first, was to establish, recruit and prepare for the nominal group.

In the second part of Step 3, the core group developed other documents including the outline for the six nominal group meetings and questions to structure the discussion and systematically work through to consensus decisions. Examples of the questions are; *What is case management?*

*What is **not** case management? What is the relation between these components of CM? Have your specific suggestions been incorporated in an adequate way? If not, do you understand the reasons provided not to do so? Do you agree with the definition?*

The next part of Step three the Beta 1 version developed by the core group included groups of the key components described in the literature, and the description of the activities performed. In this first version of the taxonomy there were 17 components and 56 actions, definitions of the components and a draft definition of CM.

The final part of Step 3, the nominal group monthly half day meetings commenced in February 2014 facilitated by SL with LSC and MM (observers), and AF (rapporteur). Table 1 presents information on the nominal group members. Participants received the minutes to confirm group decisions and other relevant information prior to each meeting.

Over the next 10 months changes made to the taxonomy as a result of work with the nominal group: consensus on what is and what is not community-based CM (thereby deletion of some actions), changes in terms (such as changing component of the interventions domain to actions), grouping actions 'like with like,' establishing associations and relationships between the actions, removing repetition and further refining of definitions which in some instances led to redundant actions. The process was iterative not linear. The Beta 1 version of the taxonomy was refined to involve 13 main actions, 36 actions and 11 related actions.

Beta 2 version

The next and final part of Step 3, to develop Beta 2 version occurred after the 4th nominal group meeting. In between meetings 4 and 5 the core group undertook a review of the conceptual and language consistency across the taxonomy and alignment with the international frames of both the ICHI and ICF. Over meetings 5 and 6 of the nominal group, the Beta 2 version of the action relationships and definitions were refined, and the taxonomy interventions further reduced to 9 main actions, 22 actions and 8 related actions. The definition of community-based CM was finalized and a draft glossary of 60 terms. This version of the taxonomy (interventions and service trees) were first presented at the World Congress on Integrated Care in 2014.[53]

Phase 1, Step 4 feasibility of Beta version

In Step 4, and meeting six of the nominal group, the feasibility analysis through two developmental evaluation activities were completed. There was alignment with the ICHI on a number of titles for action and definitions including preparation, education, monitoring, advising and emotional support and gaps with respect to three main actions and eight main actions (in particular actions of engagement, coordination and planning).

The second evaluation activity, the case studies questionnaire confirmed the relevance of the taxonomy for CM experts. Table 2 provides the mean percentage of time, standard deviation and the mean relevance rating, standard deviations across the 11 case managers for the four case studies in Stages 1 and 2.

In Fig. 2 provides the average change from stage 1 to stage 2 of relevance rating by the case managers. A negative score indicates that the action is rated as less relevant at stage 2 of the case study than in stage 1, a positive score indicates the action is perceived to be more relevant in stage 2.

Table 1
Nominal group of case management experts

			Areas of expert knowledge						
				Case management					
	Name	Professional background	Client group[b]	Practice	Policy planning	Management	Funding	Service context[c]	Geographic[d]
1	Dianne Croker	Occupational therapy	A	x	x	x	x	Pub, Pr	U, R
2	Margaret Doyle	Speech pathology	A	x	x	x		Pub	U
3	Marion Fisher	Speech pathology	C	x	x	x		Pub, Pr	U
4.	Rebbekah Loukas	Psychology	A	x	x	x		NFP	U
5	Suzanne Lulham	Physiotherapy & law	B		x	x	x	Pub, Pr	U, R
6	Elizabeth Shannon	Physiotherapy	A	x				Pr	U
7	Jo Suhanic	Social work	B	x	x			Pub	U, R
8	Deb Toffolo	Speech pathology	B	x	x	x		Pr	U
9	Karen Williams	Nursing	B	x				Pr	R
10	Janine Wood	Speech pathology	B	x	x			Pub	U, R
11	Denise Young	Social work	B	x	x	x		Pub	R
12	Sue Lukersmith[a]	Occupational therapy	B	x	x	x	x	Pub, Pr	U

[a] Facilitator.
[b] Client group: Adult = A, Children = C, both adult and children = B.
[c] Service context: Public (Pub), Private (Pr), Not-for profit (NFP).
[d] Geographic; Urban (U) rural (R).

Table 2
Percentage of time and relevance of the actions in each case study per stage

Case study	1	2	3	4
Action	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
% of time				
Stage 1				
Engage	15.5 (6.1)	16.4 (6.0)	18.2 (9.00)	20.0 (9.2)
Assess	10.9 (6.3)	11.4 (4.5)	12.7 (4.7)	12.3 (5.6)
Plan	22.7 (6.1)	14.3 (7.6)	15.0 (6.3)	19.1 (5.8)
Train	9.5 (3.5)	8.9 (6.5)	13.9 (7.1)	14.1 (5.8)
Support	11.4 (3.9)	9.5 (4.7)	14.3 (4.2)	12.7 (5.2)
Coordinate	22.3 (10.1)	26.4 (11.2)	13.6 (3.9)	11.8 (7.8)
Monitor	8.6 (5.0)	13.2 (5.6)	12.3 (4.7)	10.9 (4.9)
Stage 2				
Engage	6.8 (3.4)	10 (6.3)	9.1 (6.3)	10.5 (8.2)
Assess	7.7 (6.1)	10.5 (5.7)	8.2 (4.0)	11.2 (6.6)
Plan	37.3 (25.2)	15.9 (6.6)	17.7 (5.2)	23.2 (6.4)
Train	8.6 (6.7)	15.9 (9.4)	15.0 (8.1)	10.6 (4.7)
Support	14.1 (8.0)	11.8 (4.6)	19.5 (4.2)	18.2 (7.2)
Coordinate	12.3 (9.3)	22.7 (13.7)	18.2 (7.2)	14.1 (5.8)
Monitor	12.4 (11.8)	14.1 (7.0)	12.6 (4.5)	12.3 (5.2)
Relevance rating				
Stage 1				
Engage	3.8 (0.4)	3.7 (0.5)	3.8 (0.4)	2.8 (0.8)
Assess	3.4 (0.9)	3.0 (0.6)	3.2 (0.6)	2.7 (0.6)
Plan	4.0 (0.0)	3.4 (0.7)	3.5 (0.5)	3.6 (0.5)
Train	2.8 (0.9)	2.6 (1.0)	3.4 (0.7)	3.4 (0.7)
Support	3.3 (0.6)	3.1 (0.8)	3.6 (0.5)	3.5 (0.5)
Coordinate	3.6 (0.5)	3.8 (0.4)	3.2 (0.6)	3.5 (0.7)
Monitor	3.3 (1.0)	3.5 (0.5)	3.3 (0.6)	3.4 (0.5)
Stage 2				
Engage	2.7 (0.9)	3.0 (0.8)	4.0 (0.5)	3.0 (0.5)
Assess	2.5 (1.2)	3.1 (0.7)	3.0 (0.9)	3.0 (0.8)
Plan	3.5 (0.7)	3.5 (0.5)	4.0 (0.4)	4.0 (0.0)
Train	2.5 (1.0)	3.3 (1.0)	3.0 (0.8)	3.0 (0.8)
Support	2.9 (0.9)	3.3 (0.8)	3.0 (0.5)	4.0 (0.7)
Coordinate	2.8 (1.2)	3.6 (0.7)	3.0 (0.9)	3.0 (0.6)
Monitor	2.6 (1.1)	3.6 (0.7)	3.0 (0.6)	3.0 (0.5)

Final version of the taxonomy

The information gained from these two evaluations in Step 4 resulted in further revisions to the Beta 2 version in the discussions at nominal group meetings five, six and seven. The delay for the 7th nominal group meeting held four months later, provided time for reflection by the group members and the opportunity to develop the final version of the taxonomy (BICM-T).

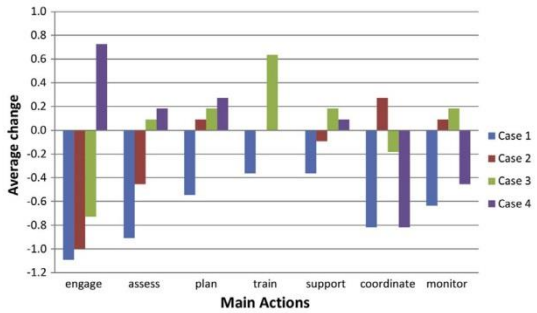

Fig. 2. Change in relevance between Stages 1 and 2 per case study.

The interventions domains of CM (throughputs) of the BICM-T contains 9 main actions (parent category), 17 actions (children category) and 8 related actions. Fig. 3 shows the intervention tree. The taxonomy interventions table (Appendix 2) provides the definitions of the key actions. The glossary (Appendix 3) provides 63 definitions of the actions, key concepts and terms in the taxonomy.

Discussion

The case studies evaluation confirmed the applicability and acceptability of the main actions in the taxonomy. As expected the percentage of time spent in each main action varied according to the case study context but was consistent across case managers. Variation only occurred in case manager estimates of time (SD > 10.0) with the actions of coordination (Case study 1 and 2 in stage 1, Case study 2 in stage 2), planning (Case study 1, stage 2) and monitoring (Case study 1, stage 2). Case study 1 was the spinal cord injury comparator of a 32 year old woman with spinal cord injury, a 3 year old daughter and in stage 2 (5 years after her injury), was considering having a second child. The variations in time may relate to the contextual complexities rather than her health condition.

The relevance results show a high level of acceptability (relevance − 3 relevant or 4 highly relevant) of the 7 main actions evaluated (engagement, holistic assessment, planning, training and skills development, coordination and monitoring) across all case studies in both stages. There was no main action that rated as irrelevant (mean rating <2) at any stage for any case study.

A high ranking of relevance does not necessarily mean a higher percentage of time. The percentage of time compared to relevance appears to vary depending on the case study and the client's situation. For example, the most time spent for Case study 4 in stage 2 was planning at mean of 23.2% (a time when this 15 year old boy was planning for post school activities). The main actions for Case study 2 in stage 2 coordinating and monitoring (both ranked mean = 3.6) had a difference in time spent (mean = 22.7 for coordinating and mean = 14.1 for monitoring). Case study 2 is a 56 year old man who lives in a group home with 24/7 formal care so whilst monitoring is important, there are others involved who assume some of this role.

There was higher consistency (SD < 1.0) in case managers relevance rating across the two stages in two case studies where there was significant support from family and friends (Case study 3 who is a 38 year old man and Case study 4 a 15 year old boy living with his supportive parents). It is possible that anticipating the role of the case manager may have been easier in these two case studies.

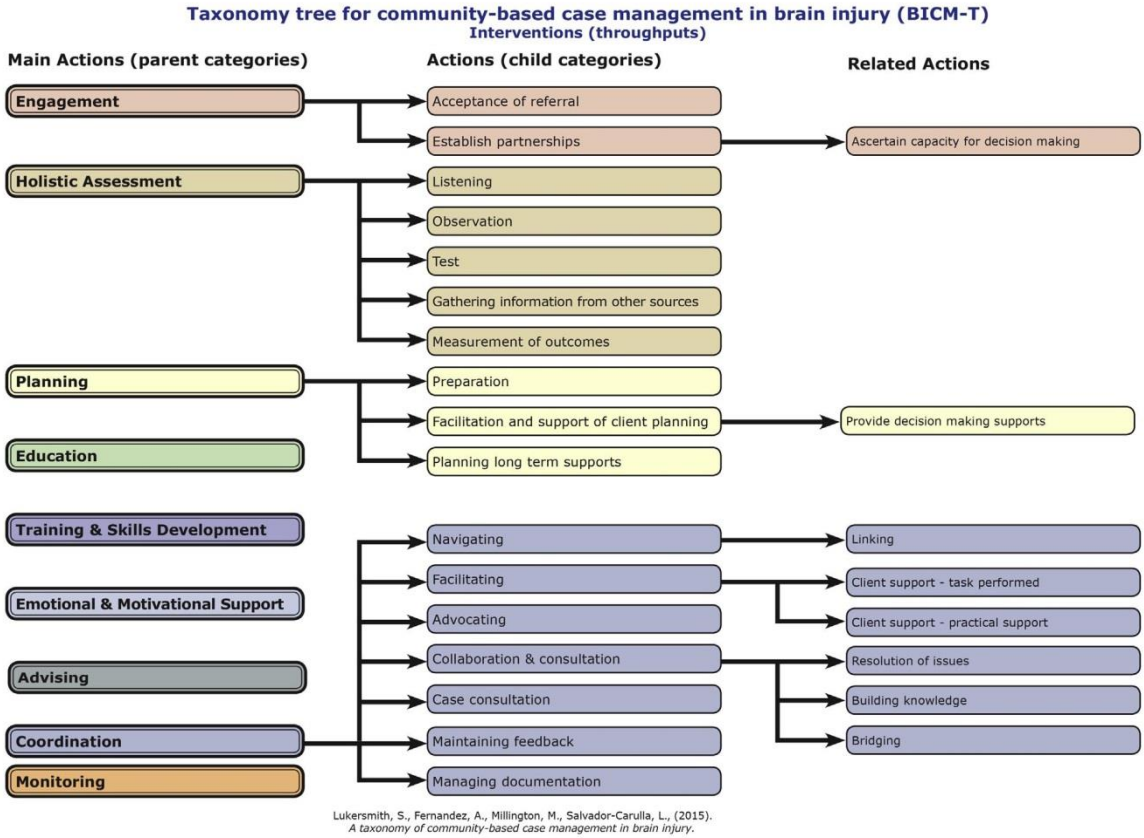

Fig. 3. Intervention tree.

The action engagement is less relevant in stage 2 for Case studies 1, 2 and 3 but more relevant for Case study 4. In Case study 4 stage 1, the client is at school, whereas in stage 2 he is a young adult and so the engagement has shifted focus from the parent to the client. The action training, in Stage 2, is more important for the case manager with Case study 2 as there were issues around poor carer training and transfer of skills with a communication device. In terms of changes between stages 1 and 2 for all cases, appear aligned to changes in the client circumstances.

We used rigorous mixed qualitative methodology using different sources of knowledge to iteratively develop the taxonomy. This included a scoping study of the literature (results not reported here), a critical review of international frames and expert knowledge and consensus decision-making through a nominal group technique. Implementation research and analysis of complex interventions should seek consideration of real world conditions including expert and practice knowledge, rather than removing their influence.[18,42] Our purposeful involvement of an industry partner organization (LTCSA) and experts in CM policy, planning and practice, to develop the taxonomy enhances the overall usability and practicality of the taxonomy in brain injury, and potentially other conditions and contexts.

In the development of the taxonomy, there was a focus on a common multi-dimensional health condition, brain injury in the development phase. While enhancing the potential for the taxonomy to be applicable and acceptable for other health conditions and contexts, the potential use of the taxonomy with other health conditions (e.g. mental health, severe physical impairment, long term chronic conditions including diabetes), contexts and different models of CM requires further analysis.

There are benefits of the BICM-T to CM practice, standards evaluation and quality analysis, policy and planning, economic evaluation, case mix typology and research. The taxonomy will support better understanding between stakeholders and organizations, models of CM, roles and responsibilities and the cycle of need for CM with respect to health condition, context and time. The taxonomy provides a common language and is a tool for CM best practice and quality analysis including establishing, professional standards, guidelines, outcome measurement and research. In terms of case mix, there are differences in CM actions with respect

to health condition, client context and environmental barriers. For example the CM interventions early post injury or diagnosis, compared to a time when the client's condition and participation is stable, compared to times of crisis or key life events. Similarly, the requirements for CM interventions for adults compared to a child living with their parent. Identifying skill requirements for specific actions assists appropriate training, competency requirements for case managers, and client referral to appropriate providers.

The benefit of the taxonomy is to provide clarity for practitioners and researchers in quality analysis. The taxonomy provides a common language around the intervention (actions), descriptions and their relationship, thereby outcome measurement and comparisons, research on effectiveness. As a number of researchers have identified, the poor description of complex interventions such as CM impedes quality analysis[9,23,27] and is particularly relevant for complex interventions such as CM.[4,26,54]

For policy makers and planners, the taxonomy is a tool to support resource allocation. The taxonomy provides a framework to enable differentiation and description of roles and responsibilities. For example, the difference in the role and responsibilities within a service funding organization undertaking CM actions (broker model; referring the client to services and outsourcing services), compared to a case manager employed by an organization, providing direct community-based CM services. The taxonomy enables articulation of responsibilities, expectations and potentially costs for different actions at a macro, meso and micro level. Whilst only the intervention (throughputs) domain is reported here, the use of the taxonomy throughputs (interventions) and inputs (service) domains also enables mapping of service and CM intervention capacity to identify gaps and support service planning at a macro level as has occurred in other areas of long term care.[41]

To our knowledge, this is the first taxonomy of community-based CM. While there are other descriptions of the components of CM and definitions,[30,31,55] our intervention domain tree of the taxonomy provides the definitions and relationships between the core interventions, the actions performed by case managers. These are the main actions (the parent categories), actions linked to these (the children categories), and related actions. Use of the taxonomy may benefit practice, quality analysis and evaluation, policy and planning, funding, business management and resource allocation.

Future research in Phase 2 of the study involves dissemination and analysis of the impact of dissemination of the taxonomy at state, national and international contexts and transfer to other health conditions and areas. The impact analysis includes assessment of how people in these different contexts may have incorporated the taxonomy in their 'new' knowledge (for example use in reports) or whether there has further levels of impact towards knowledge to action (for example application of the knowledge into programs or organizational structures, policy, planning).

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Supplementary data

Supplementary data related to this article can be found at http://dx.doi.org/10.1016/j.dhjo.2015.09.006.

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Appendix 1 from published article

Case study 4 – Client R

Stage 1 2 years after the injury

Client R is just referred to you for case management. Client R is a 15-year-old boy who sustained a traumatic brain injury (TBI) 2 years ago. As a result of the brain injury, he has ongoing impairments.

He lives with his mother, father and two younger sisters in a rented single storey home. The family receives a $255 subsidy rent from the Department of Housing. Both his parents lost their jobs prior to R's injury. The family migrated from India when Client R was 3 years old. Both his sisters were born in Australia.

Client R has a left hemiplegia with dystonia, and a hemianopia in his left eye, cognitive impairments. He is naturally left handed. He is learning to use his right hand for manipulation tasks e.g. buttons and zippers, with his left hand assisting.

Client R has no limitations with

- His communication (Hindi nor English)
- Moving around; he does not need support walking around in shoes with his orthotic device. When wearing bare feet, he walks with a limp. His balance is poor and he overbalances when he attempts to run or jog.
- Self-care; dressing, showering or personal hygiene

He has difficulties with

- Learning new information; once it is more familiar to him, he retains it and remembers things well.
- He becomes stressed when there are multiple tasks.

- In the morning before school, Client R finds it difficult working out and planning what he needs. His mother helps to organise him.

Client R does not do any domestic tasks except putting out the rubbish. This is consistent with his pre-injury domestic responsibilities. His two sisters were required to do more domestic tasks. His mother and two sisters share the domestic responsibilities – cooking, cleaning, washing and shopping. The family are Hindu and their diet is vegetarian. The language spoken at home is Hindi, although all the family are fluent in spoken and written English.

Prior to the injury Client R took the bus to school as both his parents worked. Both his mother and father drive. Prior to the injury he attended a local high school. He did not receive any learning support. His favourite subjects were the technical subjects. At school, he played football (soccer) in winter and cricket in summer. He was an average student. Before he was injured, he took the bus to school with his friends. This was important to him. Now he is driven to and from school by one of his parents.

Client R has a close network of a few friends at school whose friendship he continues to maintain. His family and particularly his mother are supportive, although sometimes she is overprotective and tends to ‘hover’ around if one of his friends visits him at home. He has extended family close by with two male cousins of similar age. Client R has good computer skills, plays computer games and enjoys woodwork.

Client R is developing some behaviour where he becomes annoyed at his mother and sisters. One day after his mother picked him up from school, he became angry and was verbally aggressive towards his mother. His father did not respond

or get involved. Client R went to his room and threw one of his sports trophies, which left a hole in the wall.

There is no paid attendant care or other formal supports.

Client R is very keen to take the bus to and from school, but his parents have concerns about his safety. He no longer plays with his football team on the weekend.

Stage 2 4–5 years after the injury

Client R continues to live in the family home. He has just turned 17 and recently finished school. He is due to complete Year 12 in 6 months. At school, he has achieved a reasonable pass in the subjects of Computer Science, General Maths, English, Information Processes and Technology. He did not do well in Society and Culture. He spends most of his spare time at home in his room playing games on his computer.

Client R does not know what he wants to do after school.

Additional case studies

The following three case studies were also used in the feasibility analysis but were not included in the published article above.

Case study 1 – Ms C

Stage 1 6 months after the injury

Ms C is a 32-year-old woman who sustained a spinal cord injury (SCI) Level T8 (ASIA A). Prior to the injury she lived with her partner and 3-year-old daughter. Her partner works full-time and is occasionally required to travel for work.

Whilst she also had some soft tissue injury to her right upper arm, this has resolved and she has full control and sensation of her upper limbs, shoulder, elbow wrist and hand. She has no movement or sensation in her lower trunk and lower limbs below the level of the SCI. She has a neurogenic bowel and bladder. She has a suprapubic catheter which she manages well with no urinary leakages or accidents. She undertakes a daily bowel regime with good effect and few accidents. Ms C is independent in transfers with only standby assistance for one transfer (bed to shower commode). Her spinal symmetry remains poor with significant scoliosis which to date has not been correctable despite numerous trials of backrest and wedge options. She reports increased back pain. She needs assistance to do routine skin integrity checks.

Ms C is a manual wheelchair user. She has a ‘smart drive’ on her wheelchair (a power assisted device she can switch on to go up hills, over thick carpet or grass). She will need assistance with shopping (push the trolley, reach to higher shelves, carry shopping to car, then transfer to house). Depending on the access in the laundry, she has the potential to be independent with laundry, but cannot put the clothes on the current outside clothes line. Ms C needs assistance with household tasks such as vacuuming, cleaning the bathroom, cleaning high areas, emptying bins. She can prepare and cook food if the kitchen is wheelchair accessible.

Prior to the injury, Ms C worked 3 days per week as a teacher’s aide in a public primary school. She used to drive to work and dropped off her daughter at a childcare centre on the way to work.

Ms C is due to leave hospital in 6 weeks. The family home needs major modifications and so the family is going to relocate and rent while the home modifications are completed. They will need to rent a home for 8 months. At this time, an accessible rental property has not been located.

Stage 2 5 years after the injury

Ms C has moved back into the modified family home. She is independent with self-care, some domestic duties. She has undergone driving assessment, resumed driving with a modified vehicle. Ms C receives 10 hours per week domestic assistance. Ms C has not returned to work as a teacher's aide and is on leave from her position with the Department of Education.

Ms C has indicated that she and her partner would like to have another child.

Case study 2 – Mr G

Mr G is a 38-year-old man who sustained a TBI, multiple fractures (pelvis and left humerus) 1 year ago in a motorcycle accident. Assessed as CANS level 5. His initial treatment and inpatient rehabilitation was in a metropolitan unit. He was discharged home 4 weeks ago. He lives with his partner, their two primary school-aged children (9 and 11 years) and a long-term family friend. Since the accident, they have moved. The current home is rented and has a swimming pool. His wife works full-time. The family friend works part-time, and returns from work each day at lunch time.

Mr G walks independently. He often walks up to 2 km per day as part of his exercise routine. He experiences stiffness, pain and reduced strength in his left hip and shoulder. He has difficulty with his shoulder range of motion above 90 degrees. He is independent with self-care tasks, although he has some difficulty

with shoes and socks because of hip pain and stiffness, dressing because of shoulder pain. He manages using adaptive techniques.

Mr G has impaired cognition including auditory memory, decreased perception, new learning and information processing speed. He has high level speech and language difficulties. He sometimes hesitates during conversations before responding, although this has improved over time.

He has difficulty remembering appointments, remembering his strategies (e.g. notebook, monthly planner and diary). His wife reports that initiating tasks is difficult. When he is sent to the corner store to purchase groceries, he has returned with an incorrect item. Mr G does not reliably use the strategies to improve functioning.

Mr G's behaviour has improved and he is generally socially appropriate. He is less distractible and now maintains eye contact during conversation although continues to exhibit lowered frustration tolerance with periodic episodes of frustration and anger. His wife describes periods where he seems depressed. At these times, he lies in bed and is unmotivated to engage in activities. There has been one recent occasion where he has become distressed during the night, crying for several hours and unable to be consoled. His sleep is erratic, where he does not go to bed until 2am and then sleeps in until midday. On other days he has a sleep during the day. His appetite has decreased.

Prior to the accident, his wife managed all the cooking, cleaning, shopping and bill payments and managed the household. Mr G was responsible for cleaning the pool, mowing and maintaining the garden. Prior to the accident Mr G was

unemployed but was completing a motorcycle instructor course. In the past, Mr G had worked as a storeman and interstate truck driver.

Case study 3 – Mr P

Stage 1 18 months after the injury

Mr P is a 54-year-old man. He sustained a traumatic brain injury 18 months ago – CANS level 7. He lives in a group home with access to 24-hour care.

Mr P has significant increased tone limiting active and passive movement in all joints. He has an intra-thecal baclofen pump and a daily regime of passive range of motion with his attendant care workers. Has recently developed type 2 diabetes and been diagnosed with osteoporosis.

He is regularly reviewed by three specialists at an outpatient clinic for ongoing medical management, and periodically requires other specialist consults.

Mr P has a percutaneous endoscopic gastrostomy (PEG) tube for nutrition and medication. His weight is reasonably stable, although there has been a slight increase in weight recently.

He has experienced significant dental hygiene issues and under regular dental consult with attendant care workers managing his hygiene regime.

Minimal active muscle control, poor posture. He uses an attendant controlled, tilt-in-space wheelchair. He has hoisted transfers with two people. There is a high risk for pressure, skin breakdown, UTIs, oral disease, aspiration, chest infections, nail injuries and joint injuries.

Mr P has no understandable verbal communication. He is able to communicate with consistent yes/no with eye gaze. He is now using an eye-transfer system (E-

Tran) alphabet board for spelling messages. He has only mildly impaired receptive language. Mr P enjoys jokes.

Mr P's reasoning is impaired with global cognitive deficits. He fatigues easily and there are significant behavioural outbursts when he becomes frustrated or fatigued.

Recently there has been a deterioration in mood noted.

Mr P was separated prior to the injury. He has five children. His father has recently passed away. He is very keen to see his children as much as possible and ex-wife does facilitate this to an extent.

Mr P is completely dependent with all self-care activities, participation, domestic life activities and mobility.

He enjoys watching his children at school/sporting activities or visiting their home, attending concerts, sporting events, movies, visits to parks and shopping centres.

Mr P's community participation goals are currently around maintaining stable medical condition; enhancing family relationships; maximising communication and environmental control possibilities through technology; and to trial more oral feeding. Oral feeding is for pleasure not for nutrition. His bed mattress needs replacement.

Service providers involved include a physiotherapist (oversees home exercise program, tilt-table use), occupational therapist, dietician, recreation officer, speech pathologist, case manager, several medical specialists and general practitioner, currently a psychologist, specialist communication devices service.

There is a recreation officer who is facilitating pet therapy, monthly Playhouse (adult entertainment venue) visits, at home rec/leisure options for attendant care workers to support his engagement.

Emerging issues

There are issues emerging between attendant care team and therapy team – there is no follow through of the recreation and leisure options at home, not using the communication boards. The attendant care team are feeling that the therapists are pushing for improvement that is not realistic.

There are issues around who gets to make decisions about day-to-day activity levels and scheduling.

The attendant care provider is unsure how to manage the visits to the adult entertainment venue.

There are aspiration risks in trialling oral intake/tasting, but this is an area that is very important to Mr P.

5.3 Service tree

The intervention tree provides the throughput components and their relationship throughputs, the actions (interventions) performed by the case managers. The service tree provides the components related to the inputs (the service).

Methods

The service tree was developed simultaneously and using the same methods as the intervention tree, which are outlined in the publication in Section 5.2 (Lukersmith, Fernandez, Millington, & Salvador-Carulla, 2015). These methods are briefly reviewed below, in relation to the service tree.

- The critical review of international frameworks (refer to Chapter 4) identified that the most appropriate framework to underpin the service tree was DESDE-LTC.
- The next step involved the nominal group. Key elements or components of case management service were presented to, and discussed with, the group. Key components identified were: the status of the user (acute or non-acute case management) and the type of care (mobile or non-mobile). These characteristics were included as a characteristic in DESDE-LTC (2011) but not coded with care coordination. Case management components omitted in DESDE-LTC were periodic, episodic or non-episodic case management, and low or high intensity of case management.
- Each member of the nominal group completed the *Evaluation and Classification of Services for Long Term Care (DESDE-LTC) – Service Inventory* available on the eDESDE-LTC website (Salvador-Carulla et al., 2011). The Service Inventory involves questions about the case management service.

  These are:

  i) identification of the service (name, address, legal status, funding source, details of the person completing the questionnaire;

  ii) identification of whether there is a 'Basic Stable Inputs of Care' (BSIC). A BSIC is the minimal set of inputs organised for care delivery, defined as follows:

  > *It is usually composed of an administrative unit with an organised set of structures and professionals that provided local care within a catchment area. BSIC is the minimal micro-level system of care*

provision. Within the production model (input-process-output), BSIC refers only to the provision of care and not to other inputs (products and devices) or procedures (intervention). The functions provided by the BSIC are described by a smaller unit of analysis called 'Main Types of Care' (MTC). (Salvador-Carulla et al., 2011).

The criteria for a BSIC include temporal and organisational stability.

iii) the description of the BSIC; and

iv) identifying the Main Types of Care. The service documents what main types of care are provided according to the following categories: guidance and assessment of needs; information; accessibility to care; outpatient care; day care; or residential care.

The Service Inventory was modified to include additional questions around descriptors of frequency of contact (intensity) and the extent to which the service user contact was away from the service premises (i.e. community-based and mobile). These additional questions are provided in the appendix to this section *Excerpt of the DESDE-LTC – Service Inventory*.

- The results of the DESDE-LTC Service Inventory for each organisation represented by the nominal group members were then discussed at the second last meeting.

Results

The results from the nominal group members' responses to the DESDE-LTC Service Inventory (Salvador-Carulla et al., 2011) are provided in Table 5.1.

Table 5.1 DESDE-LTC Service Inventory results for nominal group case management organisations and including Main Types of Care

	Organisation location	No. of BSIC in the organisation	Information codes	Accessibility to care codes			A4 intensity description	Self-help	Outpatient code	Day care	Residential	Comments
1	City	1	I2 1.2 I2.2	A1	A2	A4	Mobile >50% 1x weekly High (have support workers)	No	O5.1.1	No	No	
2	Regional	1	I1.5			A4	Mobile >50% 1x fortnightly Moderate	No	No	No	No	
3	Regional	1	No			A4	Mobile >50% <1 per fortnight Low	No	O6.1 Mobile >50%	No	R10	Transitional living program (TLU) – not 24-hour surveillance. Usually 2-week period and then negotiated. TLU not open permanently
4	City	1	I1.1			A4	Mobile >50% 1x fortnightly Moderate	No	No	No	No	
5	City	1	No			A4	Mobile >50% 3 days per week and 1x fortnightly Moderate	No	O5.1.1	No	No	
6	City	No	No			A4	Mobile <20% At least 3 days per week	No	O5.1.1	No	No	

	Organisation location	No. of BSIC in the organisation	Information codes	Accessibility to care codes			A4 intensity description	Self-help	Outpatient code	Day care	Residential	Comments
7	City	No	No			A4	Mobile Weekly up to <1 per fortnight depending on need	No	No	No	No	
8	City	1	I1.5			A4	As required	No	No	No	No	

Two organisations were not coded as having a BSIC because they lacked either organisational or temporal stability.

Results from the DESDE-LTC Service Inventory supported the discussions within the nominal group. The service tree for the taxonomy was iteratively developed through consensus, review of the alignment with DESDE-LTC, and then finalisation of the components, relationships and definitions for the service tree. The service tree and service table are provided in Section 5.4 of this chapter.

Section appendix

Excerpt from the Evaluation and Classification of Services for Long Term Care (DESDE-LTC) – Service Inventory

A. **ACCESSIBILITY TO CARE** (Facilities which main aim is to provide accessibility supports for users with long term needs)

- YES (if YES, may you please go to C1)
- NO (please go to D)

C1. Is this accessibility related to… (please tick the boxes that apply)

- **Communication**: Facilities which main aim is to facilitate the access to information.
- □ Yes □ No
- **Physical mobility:** Facilities which main aim is to facilitate the physical mobility of users with long term care needs.
  □ Yes □ No
- **Personal accompaniment**: Facilities which main aim is to facilitate the paid personal accompaniment by non-care professionals of users with long term care needs.
  □ Yes □ No
- **Case coordination:** Facilities which main aim is to facilitate the care coordination and the related accessibility to different types of services, professionals and tests by users with long term care needs. □ Yes □ No

  If YES, characteristics of the case coordination:

  - Does it provide acute/emergency care?
    □ Yes □ No
  - Which is the intensity of the contact?
    □ High, at least weekly; □ Moderate, at least once a fortnight;
    □ Low, less than once a fortnight
  - Which percentage of contacts with users occurs away from the premises (mobile care, e.g. users' home)?
    □ ≥50% □ 50%–20% □ <20% □ 0%
  - Is it health-related?
    □ Yes □ No
  - Is it provided face to face?
    □ Yes □ No

- **Other accessibility care**: Intended to facilitate the access to care which do not include any type of direct care provision.
  □ Yes □ No

5.4 The complete taxonomy

5.4.1 Intervention tree and table

Figure 5.1 Intervention tree (throughputs) of the community-based case management taxonomy (Figure 3 from published article in Section 5.2)

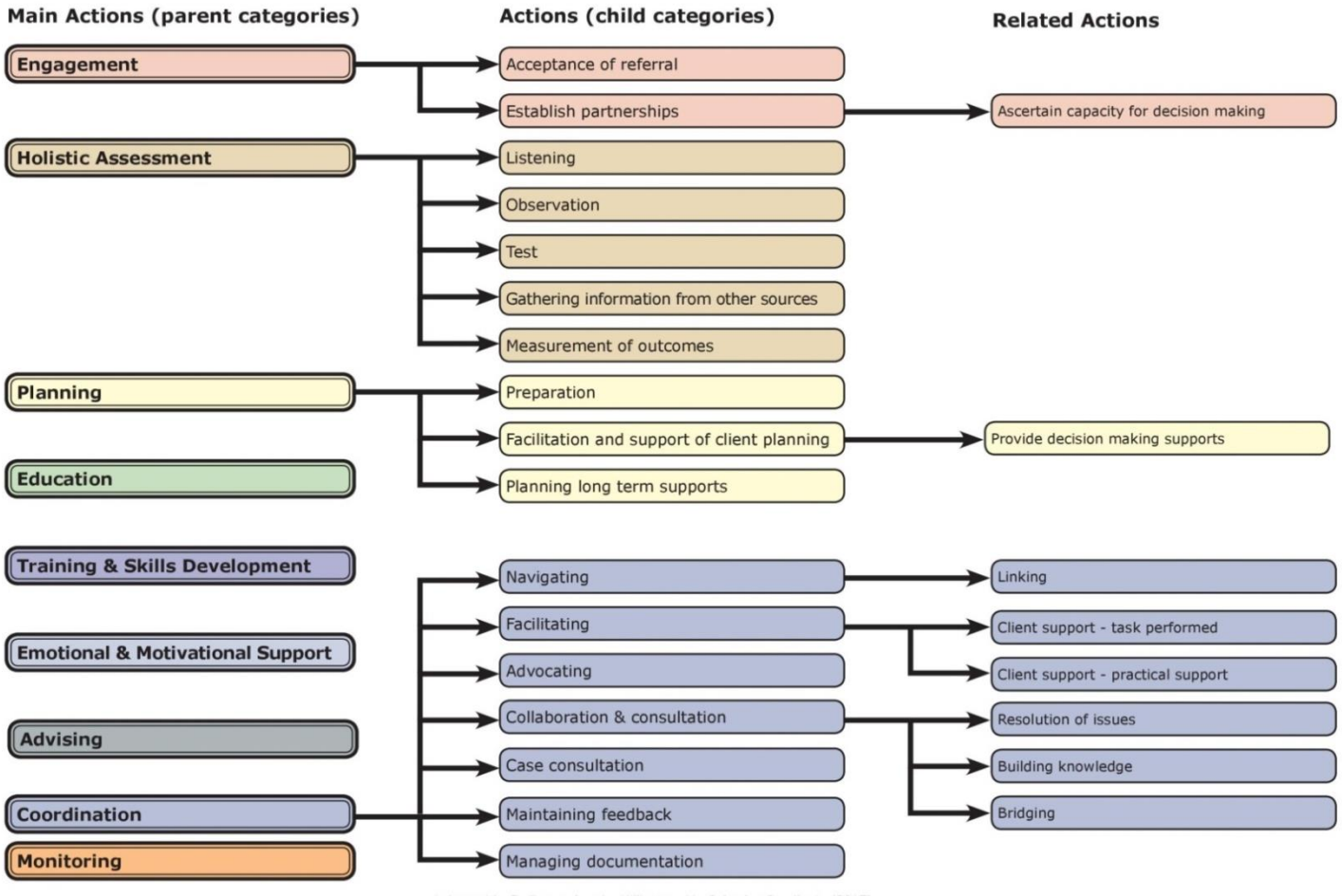

Table 5.2 Taxonomy of community-based case management in brain injury (BICM-T) – interventions (actions) table (Appendix 2 from published article in Section 5.2)

Definition of case management: Community-based case management is a multi-dimensional and collaborative process. It involves a set of interventions for assessment, planning, coordinating and review of the options and services required to meet the client's health-related needs, and support them to reach their goals related to participation in life roles.

Main actions (parent categories)	**Actions** (child categories)	**Related actions**
Engagement – Establish, develop and maintain a relationship with the client.	**Acceptance of referral** – Clarifying the match (or not) of the purpose of the client's referral, their context and the funding system with the case manager's expertise, capacity and availability; seeking an overview of the client, their location and possible needs including jurisdiction, related policies and systems e.g. Lifetime Care & Support Scheme, Workers Compensation, Transport Accident Commission, National Disability Insurance Scheme.	
	Establish partnerships – Collaborating with the client, family and other stakeholders to establish a relationship, and develop and maintain a partnership. Includes: • Obtaining consent • Identifying other key people to engage • Establishing and managing expectations of client and stakeholders • Education on the role of case manager	**Ascertain capacity for decision making** – capacity for decision making around issues such as finances, legal and quasi-legal matters.
Holistic assessment – Evaluating the client's health condition, functioning, environment, behaviour, situation or need for intervention in order to develop a comprehensive understanding	**Listen** – Listening to understand the person's perspective.	
	Observation – Observing the client's situation, functioning, environment and behaviour.	

Main actions (parent categories)	**Actions** (child categories)	**Related actions**
of them, their perspective, and what is important to them. Includes: their strengths, capacity, performance and needs across domains in relation to health, participation in key life areas (education, work, social, cultural and civic life), wellbeing and the contextual barriers and facilitators; assessment for the purpose of identifying appropriate intervention(s) and planning interventions. Excludes: monitoring.	**Test** – Evaluating the client's health condition, their functioning, environment, behaviour or situation using an assessment instrument (e.g. manual-based questionnaire, rating scale, semi-structured interview, standardised instrument) or screening tool.	
	Gathering information from other sources – Includes: • Other reports and assessments e.g. medical history • Past and current activities and participation • Identifying barriers and facilitators in the client's context e.g. client's, family and community strengths • Identifying areas of unmet need of client	
	Measurement of outcomes – Quantitative determination of characteristics of body parts, functioning or environmental factors which results in a continuous variable. Includes: Standardised assessment, observation and client self-evaluation.	
Planning – Supporting the client to develop their individualised plan including setting goals and priorities, actions, responsibilities to achieve the goals and identify the supports needed (services and resources).	**Preparation** – Performing initial work to promote good practice, management and success e.g. discuss options with service providers, or set up a trial for an upcoming plan.	

Main actions (parent categories)	**Actions** (child categories)	**Related actions**
	Facilitation and support of client planning to the extent possible or chosen by client. Includes: • Identifying their goals and priorities • Planning steps and actions • Identifying resources, supports and barriers • Identifying longer terms needs for support and resources (e.g. when case management needs to be re-instated, care, informal supports, network) • Formalising a process for monitoring maintenance of outcomes achieved • Reviewing for success, strategies and safeguards; weighing up the potential benefits, lessons learnt and what is important, the facilitators and barriers, while respecting and supporting client choice • Identifying client informed decisions, including plans for safeguards and responsibilities • Finalisation of plan: reconsidering and revising plan with client considering all information from client, scientific evidence and facts, professional experience, shared perspective and practical considerations. Includes: managing documentation – recording information about an individual, group or environment.	**Provide decision-making supports**

Main actions (parent categories)	**Actions** (child categories)	**Related actions**
	Planning long-term supports – Identifying, promoting and supporting the client's ownership and independence for management and coordination of their activities in key life areas, to resolve problems, thereby reduce or cease their need for paid case management (to the extent possible and including the family or significant others). Includes: • Identifying timing and manner for case management withdrawal • Supporting client to perform case management activities for themselves including self-advocacy	
Education – Providing structured information to client and stakeholders in a manner conducive to improve knowledge about matters relevant to the client's health condition, medical, or rehabilitation treatment, functioning, situation or strategies.		
Training and skills development – Teaching, enhancing or developing skills through context-specific practice to client and stakeholders. Includes: providing information or reinforcing training strategies developed by others for skill development e.g. memory or anger management strategies.		

Main actions (parent categories)	**Actions** (child categories)	**Related actions**
Emotional and motivational support – Providing client (family and others as appropriate) comfort, empathy or motivational support. Includes: supportive communication (without using theory based methods) to find strategies to solve or alleviate difficulties arising from their daily demands of life and situation, assisting, encouraging and reinforcing the client (and family as appropriate) to build independence, make decisions, exercise choice and responsibilities, take actions, and support the client's and family's adjustment to changed circumstances.		
Advising – Recommending a course of action to be followed to encourage a change of functioning, environment, attitude or behaviour in relation to health, goals or risks. Excludes: counselling and psychotherapy.		
Coordination – Navigating and facilitating the access, management and cohesion of services and supports for the client.	**Navigating** – Finding the most appropriate pathway through systems, services, resources and supports for the client given their context.	**Linking** – Linking client with appropriate supports and agencies e.g. referring – the action of sending the client to see another person or place for consultation, review or further action, help or advice.
	Facilitating – Making the process easier, identify gaps, anticipate problems, help remove or negotiate barriers, and promote safe and effective connections to services, and appropriate use of resources.	**Client support – Task performed by case manager** – Performing a task on behalf of the client e.g. making a medical appointment.

Main actions (parent categories)	**Actions** (child categories)	**Related actions**
		Client support – Practical support – Providing practice assistance or guidance to facilitate activities or participation e.g. attending a medical appointment with the client.
	Advocating – Mediation or pleading in favour of a client including lobbying to achieve access for the client to existing resources or services.	
	Collaboration and consultation to integrate services and supports – Includes: managing – delegating, managing or monitoring services or supports on behalf of client.	**Resolution of issues** arising with service provision.
		Building knowledge of local services and resources.
		Bridging – Building partnerships and coalitions between groups or organisations.
	Case consultation – Discussion with stakeholders to plan, improve and promote teamwork and achieve the agreed goals. Includes: meeting of multiple parties providing health service delivery or supports.	
	Maintaining feedback – Communicating, giving to and receiving information from stakeholders.	
	Managing documentation and information between stakeholders – recording information about an individual, group or environment e.g. case conference decisions, progress reports, concerns and barriers, request for services, referral, linkage and liaison with service providers, agencies and clients.	

Main actions (parent categories)	**Actions** (child categories)	**Related actions**
Monitoring – Continuous acquisition of information to evaluate the client's health condition, functioning, environment, behaviour or situation over a defined period in order to be able to determine their progress, anticipate or identify problems, additional goals or activities and modify plan and services as appropriate.		

5.4.2 Service tree and table

Figure 5.2 Service tree (inputs) of the community-based case management taxonomy

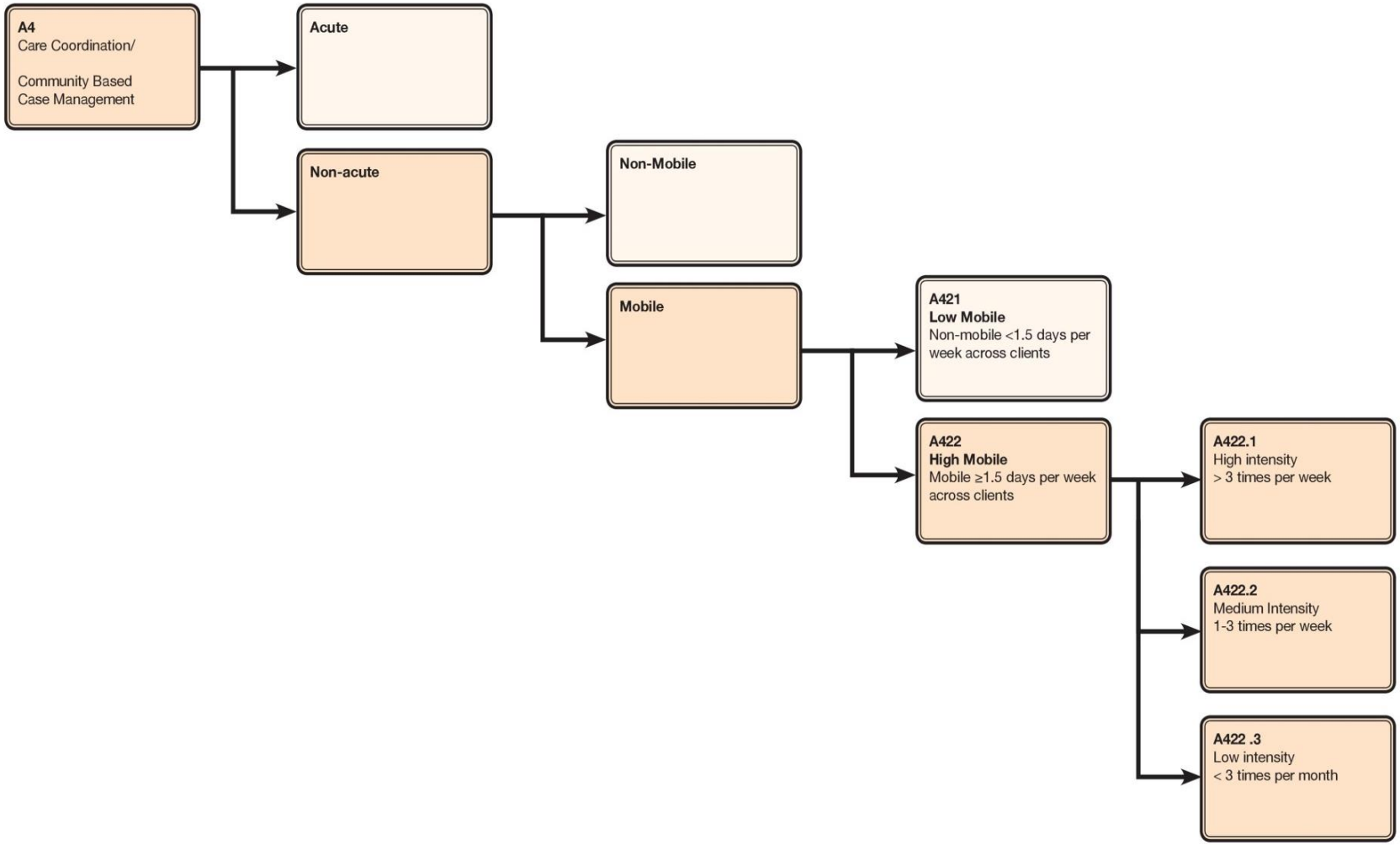

Table 5.3 Taxonomy of community-based case management services table – care coordination and case management

Acute			
Non-acute	Non-mobile		
	Mobile	**A421 Low mobile** Non-mobile <1.5 days per week across clients	
		A422 High mobile Mobile ≥1.5 days per week across clients	**A22.1 High intensity*** >3 times per week
			A422.2 Medium intensity 1–3 times per week
			A422.3 Low intensity <3 times per month

* Intensity refers to the capacity of the service to provide community-based case management interventions on different days, related to the same client.

5.4.3 Glossary for the case management taxonomy

(Taxonomy of community-based case management in brain injury (BICM-T) – published as Appendix 3 of published article in Section 5.2)

Acceptance of referral - Clarifying the match (or not) of the purpose of the client's referral, their context and the funding system with the case manager's expertise, capacity and availability; seeking an overview of the client, their location and possible needs including jurisdiction, related policies and systems e.g. Lifetime Care & Support Scheme, Workers Compensation, Transport Accident Commission, National Disability Insurance Scheme.

Action - A deed, which is done by an actor to a target during a healthcare intervention (WHO ICHI Development Project, 2013)

Acute – Refers to the service which provides care to clients who are experiencing a period of crisis or deterioration in physical, mental state, behaviour or social functioning related to their health condition and that the purpose of the service is to alleviate the deterioration (modified from (Salvador-Carulla et al., 2011)).

Advocating - Mediation or pleading in favour of a client including lobbying to achieve access for the client to existing resources or services. [modified (Fortune, Almborg, Cumeralato, & Best, 2014)

Advising - Recommending a course of action to be followed, to encourage a change of functioning, environment, attitude or behaviour in relation to health, goals or risks. (Fortune et al., 2014) Excludes: counselling and psychotherapy

Ascertain capacity for decision-making – capacity for decision making around issues such as finances, legal and quasi-legal matters

Bridging – Building partnerships and coalitions between groups or organisations

Care - The support, services and assistance provided to a client. Includes: formal and informal supports, aids and equipment, and care related products

Case Manager – A skilled person who provides the case management interventions to the client.

Client – A client is the individual person who is the user of the case management intervention.

Client support –

> **Task performed by case manager** - Performing a task on behalf of the client (Fortune et al., 2014) e.g. making a medical appointment
> **Practical support** - Providing practice assistance or guidance to facilitate activities or participation (Fortune et al., 2014) e.g. attending a medical appointment with the client

Collaboration - The action of working and cooperating with one another

Community-based case management - Community-based case management is a multidimensional and collaborative process. It involves a set of interventions for assessment, planning, coordinating and review of the options and services required to meet the client's health-related needs, and support them to reach their goals related to participation in life roles.

Consultation - Discussion with stakeholders to plan, improve and promote teamwork and achieve the agreed goals. Includes: meeting of multiple parties providing health service delivery or supports

Context - The factors that together constitute the complete circumstances of the person's life including the environmental factors that are external and extrinsic (e.g. products and technology, natural and human-made environment, support and relationships, attitudes, services, systems and policies) and the personal factors that relate to the individual' particular background and living (e.g. age, gender, motivation, habits, upbringing, coping styles, social background). (World Health Organization (WHO), 2001)

Coordination - Navigating and facilitating the access, management and cohesion of services and supports for the client**.**

Decision-making supports - Supports and ways used to enable the client to make their own decision. Some examples of supports to enhance access to information and understanding may be plain English explanations, communication aids, language translators. Examples of supports for decision making and choice may be the use of pictures, diagrams or demonstrations to better present options and anticipated outcomes(Lifetime Care & Support Authority (LTCSA), 2014).

Disability - Umbrella term for impairments, activity limitations and participation restrictions; it denotes the negative aspects of the interaction between and individual (with a health condition) and that individual's context (environmental and personal factors) (World Health Organization (WHO), 2001).

Education - Providing structured information to client and stakeholders in a manner conducive to improve knowledge about matters relevant to the client's health condition, medical, or rehabilitation treatment, functioning, situation or strategies (Fortune et al., 2014).

Emotional and motivational support - Providing the client (family and others as appropriate) with comfort, empathy or motivational support
Includes: supportive communication (without using theory based methods) to find strategies to solve or alleviate difficulties arising from their daily demands of life and situation (Fortune et al., 2014); assisting, encouraging and reinforcing the client (and family as appropriate) to build independence, make decisions, exercise choice and responsibilities, take actions, and support the client's and family's adjustment to changed circumstances

Engagement - Establish, develop and maintain a relationship with the client.

Establish partnerships - Collaborating with the client, family and other stakeholders to establish a relationship, and develop and maintain a partnership. Includes:

- Obtaining consent
- Identifying other key people to engage
- Establishing and managing expectations of client and stakeholders
- Education on the role of case manager

Expectations - A strong belief that something is true or will be the case

Facilitating - Making the process easier, identify gaps, anticipate problems, help remove or negotiate barriers, and promote safe and effective connections to services and appropriate use of resources.

Facilitation and support of client planning (to the extent possible or chosen by client) Includes:

- Identifying their goals and priorities
- Planning steps and actions
- Identifying resources, supports and barriers
- Identifying longer terms needs for support and resources (e.g. when case management needs to be re-instated, care, informal supports, network)
- Formalising a process for monitoring maintenance of outcomes achieved
- Reviewing for success, strategies and safeguards: weighing up the potential benefits, lessons learnt and what is important, the facilitators and barriers, while respecting and supporting client choice
- Identifying client informed decisions, including plans for safeguards and responsibilities
- Finalisation of plan: reconsidering and revising plan with client considering all information from client, scientific evidence and facts, professional experience, shared perspective and practical considerations.
  Includes: managing documentation and recording information about an individual, group or environment (WHO ICHI Development Project, 2013)

Family - A family is two or more persons, who are related by blood, marriage (registered or de facto), adoption, step or fostering, [modified (Australian Bureau of Statistics (ABS), 2011)

Formal supports - A task or work done by someone for another as a job or duty or task (paid). The support is usually organised or structured. Government, non-profit organisations and the for-profit sector usually provide the services. The term used to describe a person employed to perform the task may be support worker, attendant care worker, personal care assistant, domestic assistant, maintenance assistant or care worker. Includes:

- Community support and independent living support services to provide assistance with self-care, household duties, mobility and moving around the community
- residential and respite support services, classroom assistance in education or personal support in the workplace, communication supports, supported decision making, advocacy, peer support, assistance animals, or periodic

allied health services to maintain body function e.g. podiatrist (Lifetime Care & Support Authority (LTCSA), 2014).

Functioning - Is an umbrella term for body functions, body structures, activities and participation. It denotes the positive aspects of the interaction between the individual (with a health condition) and that individual's context (environmental and personal factors) (World Health Organization (WHO), 2001).

Gathering information from other sources – Includes:

- Other reports and assessments e.g. medical history
- Past and current activities and participation
- Identifying barriers and facilitators in the client's context e.g. client's, family and community strengths
- Identifying areas of unmet need of client.

Goal and goal setting - A goal is what the client aspires to achieve, the object of their ambition or effort: a desired end or result. Goal setting refers to the process of identifying the client's goals, establishing the action plan and then monitoring the progress towards achieving the goal (Brain Injury Rehabilitation Directorate (BIRD), 2014).

Health - Health refers to the level of functioning within a given health related domain (e.g. body structures, activities, participation) (World Health Organization (WHO), 2001).

Health condition – Umbrella term for a disease (acute or chronic), disorder, injury or trauma; a health condition may include other circumstances such as pregnancy, ageing, stress, congenital anomaly, or genetic predisposition (coded using the International Classification of Diseases - ICD)(World Health Organization (WHO), 2001).

Health related domains - Body functions, body structures, activities and participation, life areas, internal influences on functioning and disability (personal factors), external influences on functioning and disability (environmental factors)(World Health Organization (WHO), 2001).

Holistic assessment - Evaluating the client's health condition, functioning, environment, behaviour, situation or need for intervention(Fortune et al., 2014); in order to develop a comprehensive understanding of them, their perspective, and what is important to them. Includes: their strengths, capacity, performance and needs across domains in relation to health, participation in key life areas (education, work, social, cultural and civic life), well-being and the contextual barriers and facilitators (Lukersmith, Fernandez, Millington, & Salvador-Carulla, 2015) ; assessment for the purpose of identifying appropriate intervention(s) and planning interventions (Fortune et al., 2014).Excludes: monitoring

Informal supports - Resources (goods, services or a person who performs a task or work) that are inbuilt or purposively developed in the person's environment and enhance quality and security of life. Informal supports support the person when there is a need and may be reciprocated with different goods, services or tasks (unpaid).

Someone in the person's network including family member, friends (family or friend might be referred to as a carer) or members of a community (unpaid) often provide the informal supports. The support is typically "ordinary" and less formal and may be ad hoc. Participation and membership to clubs, interest groups, organisations, classes/education, volunteer work programs and other civic activities often result in a network and a range of supports that are informal. A person's network can provide the opportunity for support (Lifetime Care & Support Authority (LTCSA), 2014).

Intensity – The capacity of the service to provide community case management interventions on different days, related to the same client. (modified (Salvador-Carulla et al., 2011))

Intervention - An activity performed for, with or on behalf of a client or a population whose purpose is to improve, assess, or modify, health, functioning or health conditions (WHO ICHI Development Project, 2013).

Linking – Linking client with appropriate supports and agencies e.g. referring - the action of sending the client to see another person or place for consultation, review or further action, help or advice.

Listen - Listening to understand the person's perspective.

Maintaining feedback - Communicating, giving to and receiving information from stakeholders

Managing - Delegating, managing or monitoring services or supports on behalf of client (defined in the action Brokerage (Fortune et al., 2014) modified).

Managing documentation and information between stakeholders - Recording information about an individual, group or environment e.g. case conference decisions, progress reports, concerns and barriers, request for services, referral, linkage and liaison with service providers, agencies and clients.

Means – describes the processes and methods by which the action is carried out e.g. approach, technique, method or sample (WHO ICHI Development Project, 2013)

Measurement of outcomes - Quantitative determination of characteristics of body parts, functioning or environmental factors which results in a continuous variable (WHO ICHI Development Project, 2013). Includes: Standardised assessment, observation and client self-evaluation

Mobile – Contact with the client occurs in a range of settings including the client's home as judged appropriate by the case manager and client (Salvador-Carulla et al., 2011).

Monitoring - Continuous acquisition of information to evaluate the client's health condition, functioning, environment, behaviour or situation over a defined period (Fortune et al., 2014) in order to be able to determine their progress, anticipate or identify problems, additional goals or activities and modify plan and services as appropriate.

Non-acute – Refers to the service which provides clients with continuing care including regular contact with the case manager, which may be long term if required. Continuing care services may also provide acute care on a regular basis but this forms less than 20% of the usual activities of the service (modified (Salvador-Carulla et al., 2011)).

Navigating - Finding the most appropriate pathway through systems, services, resources and supports for the client given their context.

Observation – Watching and seeing to acquire information, and understand the client's situation, functioning, environment and behaviour (modified (WHO ICHI Development Project, 2013))

Person centred - A perspective and a way to discover and understand what people want and what they need. A person-centred approach in planning for community participation emphasises seeing the participant as himself or herself and adopting practices, which pro-actively considers the person's own context and situation. This means looking beyond the person's health condition or injury, and the services each organisation provides. Person-centred practitioners holistically look towards the person's aspirations and goals for participation in life, their needs and preferences as well as actively supporting them to be involved in planning for supports (Lifetime Care & Support Authority (LTCSA), 2014).

Personal factors - Factors that relate to the individual's particular background life and living and that are not part of the features of the health condition such as age, race, gender, social status, lifestyle, habits, upbringing, coping styles, social background, education, past and current life experiences (World Health Organization (WHO), 2001).

Planning - Supporting the client to develop their individualised plan including setting goals and priorities, actions, responsibilities to achieve the goals and identify the supports needed (services and resources).

Planning long term supports - Identifying, promoting and supporting the client's ownership and independence for management and coordination of their activities in key life areas, to resolve problems, in order to reduce or cease their need for paid case management (to the extent possible and including the family or significant others). Includes:

- Identifying timing and manner for case management withdrawal
- Supporting client to perform case management activities for themselves including self advocacy.

Preparation - Performing initial work to promote good practice, management and success e.g. discuss options with service providers, or set up a trial for an upcoming plan.

Referral - The action of sending someone to see another person or place for consultation, review or further action, help or advice.

Self-advocacy - Refers to the client being able to lobby or plead on their own behalf.

Service – A combination of inputs into a service production process, that delivers interventions to individuals or to the community.(Salvador-Carulla et al., 2013)

Stakeholders - Any person or organisation interested and/or involved in the client's circumstances. Includes: client, family, case manager, informal support persons, funder & service providers (e.g. therapists, teachers, attendant care workers, volunteers, unpaid carers, community support persons)

Support - A task, services, goods or work done by someone for another. Formal support is a paid job or duty or task, whereas informal support is unpaid (Lifetime Care & Support Authority (LTCSA), 2014).

Target – The entities on which the action is carried out e.g. human function, the person, their activities and participation, behaviour or environmental factors (WHO ICHI Development Project, 2013)

Test - Evaluating the client's health condition, their functioning, environment, behaviour or situation using an assessment instrument (e.g. manual-based questionnaire, rating scale, semi-structured interview, standardized instrument) or screening tool (Fortune et al., 2014).

Training and skills development - Teaching, enhancing or developing skills through context-specific practice (Fortune et al., 2014) to stakeholders. Includes: providing information or reinforcing training strategies developed by others for skill development e.g. memory or anger management strategies

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CHAPTER 6 DISSEMINATION OF THE CASE MANAGEMENT TAXONOMY AND THE IMPACT OF DISSEMINATION

6.1 Introduction

Chapter 6 concerns Steps 2.1 and 2.2 of Phase 2 of the research program, the dissemination of the taxonomy and impact analysis of the dissemination (refer to Figure 2.2. in Chapter 2 General Methods).

Implementation science involves methods based in the real world, frameworks and theories to identify, analyse and understand the dissemination, use and impacts of research in policy and practice (Papoutsi, Boaden, Foy, Grimshaw, & Rycroft-Malone, 2016). The general methods chapter (Chapter 2) provides an overview of the implementation research methods used in this second phase of the research program. The aim was to actively target stakeholders involved or interested in case management, ultimately resulting in their uptake of the taxonomy to support communication and articulation of case management; develop policy; plan and manage case management resources; and undertake quality analysis. This chapter details the methods of taxonomy dissemination, the analysis of dissemination's impact and the results.

6.2 Theory and method

Dissemination and implementation are described below:

- *Dissemination* is the systematic spread of information to target audiences via pre-determined channels and planned strategies. There is also unplanned

dissemination where information is passively diffused through unplanned channels, often by third parties (Nilsen, 2015).

- *Implementation* involves putting to use or integrating the research findings (i.e. the case management taxonomy) within a specific setting or structure over time.
- *Impact analysis of the dissemination* explores the extent to which the individual, group or organisation were cognisant of the taxonomy, adopted the language, incorporated it into their knowledge, assimilated the taxonomy into organisational plans and policy, or embedded it in their systems.

6.2.1 Dissemination method and plan

Introduction

A dissemination plan for the case management taxonomy was developed in February 2015 and revised in July 2015. The range of dissemination activities was established, the target groups or individuals identified, and the methods for communication decided. Six to 12 months after the dissemination activity, data was gathered on the uses of the taxonomy by each target audience.

The dissemination had to be flexible and responsive. There was a snowball effect with dissemination activities. Over time, there were other dissemination strategies, opportunities and target groups identified. The results report on all dissemination groups, activities and tools.

Dissemination plan

Aims and objectives

The aim of the dissemination plan was to:

1. Disseminate the taxonomy proactively to a wide range of audiences and potential users rather than rely on dissemination by passive diffusion
2. Increase the target individuals' and groups' awareness and relevance of the taxonomy to their context
3. Outline some of the potential uses of the taxonomy to target audiences relevant to their context
4. Inform potential users of the taxonomy's acceptability, application and use in other contexts and settings
5. Guide the use of the taxonomy where requested, as appropriate and possible

Specific tasks for the dissemination

1. Formulate the dissemination plan
2. Develop resources and materials to assist dissemination activities
3. Identify target audiences
4. Analyse the target group's or individual's context and activities related to case management
5. Select appropriate communication channels and tools
6. Undertake dissemination activities
7. Manage and monitor dissemination activities
8. Guide and support the target audiences if requested and appropriate

Dissemination resources and materials

The resources developed to assist with dissemination activities included:

1. The dissemination plan document in which target audiences were listed

CHAPTER 7 Introductory and first contact resources adapted to each target audience context

- Draft email
- PowerPoint presentation

2. Resources sent to the target audience to provide some background information
    - Two-page brief outline on potential uses to forward with introductory email
    - Published conference paper abstracts or posters as they arose
3. Excel spreadsheet to record communication and dissemination activities, and evidence of use of the taxonomy
4. Electronic filing system for all correspondence and documents
5. Resources for web-based channels
    - Introductory video for YouTube
    - Presentation, training material, policy paper or flyer for University of Sydney website (Centre for Disability Research and Policy [CDRP] and Brain and Mind Centre [BMC]) website

6. Social media – Twitter (account established) and ResearchGate (a social networking site for scientists and researchers to share papers; accounts for each of the researchers already existed).

Publications

Publications (articles and abstracts) concerning the taxonomy were both a resource for dissemination activities and a method of dissemination. The intervention tree of the taxonomy was seen as the most relevant to a broader range of audiences, from service providers to policy developers and planners. Consequently, the priorities were a publication related to the taxonomy intervention tree for a peer-reviewed journal article and the whole taxonomy toolkit for conference presentations.

Identification of target audience

Criteria

Target audiences were required to be organisations or individuals with a current involvement or key interest in case management in the health sector. Their role in the health sector may involve policy, service planning and health systems, funding, clinical practice, research, quality appraisal, professional association representation, or a more clinical focus such as employment of case managers and individual case managers. Other target audiences were continuing professional education trainers and educators of case managers at the undergraduate and postgraduate level, or health professionals who potentially work as case managers.

Potential audiences involved or interested in case management for people with health conditions other than brain injury were also targeted. Targeted audiences were those concerned with the following health conditions and sectors where case

management occurs: complex health conditions or disabilities, mental health, older persons or aged care, spinal cord injury, primary care and chronic illness.

Process

The researchers identified the following categories of key target groups:

- Australian national and state agencies (policy makers, funders and employers)
- Other country organisations (policy makers, funders and employers)
- International organisations
- Scientific community – researchers in implementation research, complexity and case management (universities and institutes)
- Service providers
- Case management service user and consumer organisations

Specific target audiences within each category were identified through:

- Discussion amongst the researchers using local and international knowledge and networks
- Establishing a Google Scholar database alert to identify current case management research. (Google Scholar was selected because the database includes broader sources of information and grey literature (e.g. online reports), compared to other databases such as PubMed which has peer-reviewed literature only. Relevant target organisations may produce reports on case management rather than publish in a peer-reviewed journal.

- Local knowledge of service systems (state and national) to identify Australian funders and service provider networks
- Professional work and business experience networks of the researchers to identify peak organisations (state, national and other countries, international), disabled persons' organisations (DPO)
- Other researchers, service providers, policy makers already known or met during the course of usual work or during taxonomy dissemination activities (e.g. at conferences)

Analysis of the context and relevance of the taxonomy

Once the target audience for personalised dissemination was identified, an analysis of the context and the relevance of the taxonomy to the audience was undertaken. The aim was three-fold: 1) For the doctoral candidate to familiarise herself with the context, and either prioritise or exclude the target audience in the dissemination plan timetable; 2) To explore the most appropriate communication channels (e.g. direct initial contact, bilateral direct contact), tools (e.g. face-to-face, Skype meeting, conference presentation) and resources for dissemination; and 3) To identify and discuss the potential uses of the taxonomy for the target audience, thereby enhancing the relevance of the taxonomy to them in their context and the potential for them to use it. Postulating on the audience's possible concerns and issues or gaps around case management, and potential uses of the taxonomy, allows interaction, discussion, and collaboration where appropriate and possible.

In the analysis of the target audience, information about the organisation or individual was sought on the internet or from publicly available documents. Relevant information included: an overview of an organisation's website to develop a broad

understanding of the organisation (e.g. mission statement, 'about us' information); the health condition(s) with which an organisation or individual was concerned; where relevant, high level information on the health system and structure in relation to case management (in Australia, at the state level if a state organisation; in other countries, high level information about the national health system and structures in which the organisation operates); the individual's and/or organisation's role related to case management (e.g. funder, employer); closer examination of statement or comments (if any) on the issues or concerns around case management; where relevant, the individual's position, responsibilities and their areas of interest in relation to case management; the relevant case management description (or lack of); documents which refer to case management; information or reports on any work the organisation or individual has previously undertaken on case management; and previous research or publications (if a researcher has other publications using ResearchGate, Google Scholar, PubMed). This information was considered in relation to each audience with respect to the dissemination goal, dissemination approach, method, resources, key messages, possible issues, and potential uses of the taxonomy.

Dissemination channels and tools

Dissemination channels and tools are the means through which the taxonomy was made known and available to the target audiences to facilitate its uptake and use. These are broadly classified as either personalised or non-personalised dissemination.

Personalised dissemination is where the researcher is proactive, tailors the dissemination approach to the target audience and presents the taxonomy in person, followed by communication regarding the audience's context and

potential uses of the taxonomy. Potential channels and tools for dissemination of the taxonomy included:

- Email – direct (to/from doctoral candidate), bilateral direct (target individual included in email communication or referred by candidate's supervisor), third party direct (introduction through a third party)
- Face-to-face meeting with organisational representatives and individuals
- Specifically arranged meeting online, with the opportunity for visual communication and screen-sharing through social media software (Skype or FaceTime)
- Written report to the individual or organisation to provide exemplars of use and/or recommendations (e.g. for researchers, Lifetime Care Support Authority)
- Routine organisational meetings where specific time is allocated to present the taxonomy (e.g. lunchtime education sessions, meetings such as discipline meetings, board meetings), special interest group meetings
- Contact initiated by referral from an existing target audience (i.e. snowball dissemination)

Non-personalised dissemination is where, even though particular aspects of the research program or taxonomy may be directed to the target audience, the disseminated information is not tailored to specific individuals or organisations. Dissemination may be direct, indirect, or occur by diffusion. Potential channels and tools for dissemination of the taxonomy included:

Direct

- Conferences – paper presentations and posters
- Peer-reviewed journal publications

Indirect

a) Web-based

- Develop and upload an introductory video on a video-sharing platform – YouTube (https://www.youtube.com/)
- Website: The University of Sydney website (CDRP and BMC) – presentations, training material, policy paper or flyer

b) Social media

- Twitter
- ResearchGate, including publications and a project abstract which people can follow

Diffusion

This occurs when one target audience will refer information to or educate others about the taxonomy and its potential uses, independently of, and usually unknown to, the researchers. Consequently, the researchers may not be aware of the use of the taxonomy in these cases.

Dissemination activities

The dissemination aim (refer to the section Aims and Objectives above) for each target audience differed according to the opportunities for communication and the method, and what appeared as realistic in the context. For example, with a personalised dissemination target audience, all of the aims may be relevant: provide

the information; increase awareness of the issues; provide some broad-based examples of its potential uses; describe uses in other contexts; promote uptake; and provide support and guidance on the uses of the taxonomy. However, for a non-personalised target audience, there is typically no opportunity to promote uptake of the taxonomy, nor discuss the audience's potential use of the taxonomy or provide support unless individuals specifically approach the researchers. Some examples of the latter are conference and lunchtime in-service presentations where there is limited opportunity to know the specific context of individuals in the audience.

The personalised dissemination activity to organisations and individuals involved the following steps:

1. Identify the target audience
2. Identify the specific goal of the dissemination activity
3. Identify the most appropriate communication channel and resources, and key messages
4. Establish the contact protocol to make the initial contact. If there is no response, undertake one follow-up contact only.
5. Present the taxonomy, and:
    c) Where possible, engage in discussion
    d) Following the dissemination presentation, and if appropriate, re-contact 2–4 months later by email or phone call to offer guidance if appropriate
    e) Respond to any contact initiated by the target audience
6. Maintain records of communication between the parties and evidence of any known use of the taxonomy

Management and monitoring of dissemination activities

Prior to each presentation and then again prior to the feedback survey, the targeted participants were provided with an ethics approved study participant information statement. The statement explained the study, who was carrying it out, what it involved, the time involved in the presentation and subsequent survey(s), management of results, information on potential benefits, harms, complaints or concerns, researcher contact details, and that consent would be acknowledged by attending a personalised dissemination activity (face-to-face or by electronic media) and completion of a web-based questionnaire.

The dissemination activities were recorded in an Excel spreadsheet. Recorded information related to the following parameters:

- Dissemination resources developed and descriptions
- For personalised dissemination, the details of the target audience (individual or organisation): location, description of the focus health condition for their work, sector, date of the presentation, method, by whom, and whether limited support was provided to the target audience following the dissemination activity.

Dissemination timetable

The proposed timetable for dissemination activities and the assessment of the impact of dissemination is provided in Table 6.1.

Table 6.1 Proposed timetable for dissemination and assessment of impact of dissemination

Activities	Timeline																				
	2014	2015												2016							
	Nov–Dec	Jan–June (6 months)							July–Dec (6 months)						Jan–July (7 months)						
Identify target audiences																					
Prepare and develop resources																					
Analysis of target audience																					
Select communication channels																					
Dissemination activities																					
Manage and monitor																					
Collect data on results of dissemination																					
Assessment and analysis of the impact of dissemination																					

7.1.2 Methods for the impact assessment and analysis

The method to analyse the impact of dissemination involved three steps: 1) data collection, 2) impact assessment, and 3) analysis of the impact.

Data collection

To answer the study questions, data was required to describe the impact of dissemination and the extent to which the taxonomy had been assimilated or used, as well as the sector of the individual or organisation. Data collection primarily

related to the personalised dissemination target audiences with only limited information possible for non-personalised dissemination activities.

Data collection commenced following the personalised dissemination to each target audience. Contact was maintained with the target audience as appropriate. This may have involved re-contacting the target audience following the dissemination activity, anything from 1 month up to 22 months later. If the researchers were involved in providing further guidance and support in the use of the taxonomy, the information on uses was likely to be known. It was only possible to collect data from non-personalised dissemination target audiences when dissemination was through a web-based strategy. There was no specific communication, nor potential for same, with some of the non-personalised target audiences (e.g. conference attendees, readers of peer-reviewed publications, visitors to a website) unless an individual initiated and approached one of the researchers (in which case they become a personalised dissemination target audience). For web-based dissemination strategies (e.g. Twitter, YouTube, University of Sydney website), there was some relevant electronic data available (see point 3 below).

A hybrid approach was adopted to gather data from a range of sources, and by so doing attempt to enhance reliability, and cross-check and corroborate with evidence on how audiences had used or not used the taxonomy. Data was collected through:

1. *Opportunistic collection*: This involved gathering information that became known to the researchers through their networks concerning emerging or potential uses of the taxonomy. Information and evidence on uses was also collected from the target audience via direct observation; face-to-face, phone or email discussions; informed third party observers; organisational, policy or

discussion papers or reports; citations; or through other publicly available sources (e.g. changes in information on an organisation's website). There were also purposeful approaches to individual presentation participants to confirm verbal feedback about uses. For example, if a case manager commented on their use of the language in the taxonomy, clarification was sought by email (excluding personal information of their client).

2. *Participant questionnaires*: Two questionnaires were undertaken among dissemination activity participants.

   a) *Presentation questionnaire*: A web-based audience response tool was used to gain real-time and immediate feedback on the taxonomy from participants at the end of a personalised presentation (before they left the room). The web-based tool was Mentimeter, a communication tool used to gain an audience's response on a topic (https://www.mentimeter.com/). The tool provided an opportunity for the audience to respond to two questions:

      i. Is the case management taxonomy relevant to your work?

      ii. Is the case management taxonomy practical?

   The responses involved rating their answer on a 5-point Likert scale ranging from 1 (Yes, a lot) to 5 (No, not at all). The respondents to this questionnaire are referred to as Group 1.

   b) *Progress questionnaire*: This was a survey with 24 questions that focused on eliciting information about the participant's awareness, and assimilation or uses, of the taxonomy. The questions related to the levels on an impact scale (described in 'Impact assessment' below). There were two junctions

in the questionnaire (Questions 8 and 17) where, if the respondent gave a 'no' response (e.g. Do you know of the community-based case management taxonomy (classification)?), they would be thanked for their time but not be required to proceed to further questions (refer to Appendix 6.1 for the questionnaire).

The questionnaire could only be sent to known participants of dissemination presentations, and when email addresses were made available. The respondents to this questionnaire are referred to as Group 2.

Sending out the questionnaire and data collection from the progress questionnaire was managed using the REDCap electronic tool hosted at the University of Sydney (Harris et al., 2009). REDCap (Research Electronic Data Capture) is a secure web-based application which supports data capture for research studies.

3. *Electronic data*: Relevant electronic data collected from web-based non-personalised dissemination strategies included YouTube views and likes, number of reads for publications, and number of publication citations.

Impact assessment

Personalised dissemination activities

The assessment of impact of personalised dissemination required the collection of data for each individual or organisational audience. Reliable assessment of impact was dependent on direct feedback from the audience. Thus, only those participants who responded to the presentation (Group 1) or progress (Group 2) questionnaires were included in the impact analysis for personalised dissemination.

Three researchers independently completed an impact rating for each progress questionnaire respondent (Group 2) only. Opportunistic data was collected where possible to supplement questionnaire responses, increase the range of data and corroborate information available. An illustrative or descriptive case study approach was used for rating the impact of the dissemination for the respondents in Group 2. A case study for each questionnaire respondent, which included a printout of responses to the progress questionnaire and a summary of the key points from the information collected opportunistically, was provided to each rater.

The impact of the dissemination for each progress questionnaire respondent was rated using one section of the adapted version of the Global Impact Scale of Research in Policy and Practice (Fernandez & Salvador-Carulla, 2014). The scale identifies the level of impact dissemination of the taxonomy had for each individual or organisation. The relevant section of the impact assessment scale is provided in Table 6.2 below. Questions in the progress questionnaire were developed to elicit responses linked to each impact level. The number of the questions which related to each impact level are listed underneath in italics.

Table 6.2 Impact assessment scale

Rated by

Name of person/organisation: **Date:**

Impact of the project in the target organisation on service delivery (process and systems outputs in policy or practice)

	Level of impact	Definition	Rating (tick cell)	Additional verifiable information
1	**Awareness** *(Q7–13)**	The target organisation and specific decision makers within the organisation are cognisant of the case management taxonomy, have taken action to improve its knowledge of the taxonomy and have received and provided feedback on the information delivered.		
2	**Assimilation** *(Q14–17)*	There is evidence that the target organisation and specific decision makers within the organisation have incorporated the case management taxonomy into their own existing knowledge-base and organisational strategy, or adopted the language in their work.		
3	**Translation** *(Q17–22)*	The target organisation has transferred the new knowledge from the case management taxonomy into policy action in legislation, plans, policy programs, regulatory norms, and/or official indicators, service or business structures.		
4	**Allocation** *(Q20–24)*	The translation of the new knowledge has had an impact on financing, budgeting, funding, and/or resource allocation in the target environment.		**Rater comments**
5	**Provision** *(Q22–24)*	Care delivery, including services, interventions and/or technologies directly related to the new knowledge of the case management taxonomy has been made available and it is used by the target population in the target environment.		
6	**Monitoring** *(Q24)*	The target organisation has incorporated the new knowledge into its own assessment, surveillance and monitoring systems.		

* Questions in the progress questionnaire that sought information for the impact level

Some organisations could never reach a level 4 (allocation), 5 (provision) or 6 (monitoring) because of the nature of their organisation and focus. These organisations do not typically provide or fund service delivery. These were international framework organisations (i.e. ICHI and DESDE-LTC), DPOs, policy organisations (e.g. National Institute for Health and Care Excellence (NICE)), professional associations and researchers. The options for rating these individuals or organisations could only be level 1, 2 or 3 on the scale.

Non-personalised dissemination activities: It is not possible to assess the impact of non-personalised dissemination activities beyond the incidence data obtained electronically.

Analysis of the impact of dissemination

The results of personalised and non-personalised dissemination were analysed in both qualitative and quantitative form using descriptive statistics. The qualitative information, case studies and examples were grouped to draw out patterns and gaps. The impact analysis also included analysis of the dissemination strategies, channels and tools (e.g. face-to-face and web-based), guidance and support activities, and the level of collaboration with target audiences.

Reliability of the impact assessment

Reliability of the impact assessment scale is critical to the assessment of impact. As with any scale, reliability assessment is essential to determine the extent to which the impact scale is measuring anything and how consistently. Reliability is broadly defined as the consistency of scores obtained from an administered instrument (Martinez, Lewis, & Weiner, 2014). The inter-rater reliability of the impact assessment scale was determined with an intraclass correlation coefficient (ICC)

analysis (Landers, 2011). The ICC is used when there are more than two raters and each rater completes a rating on all ‘rates’, in this instance the participants who responded to the REDCap survey. The raters are considered a sample of all possible raters. The statistical analysis to check inter-rater reliability was the ICC two-way random effects model. The latter means the intraclass correlation can be generalised to a more general population of raters. Furthermore, the specificity of the reliability assessment was on the mean assessment of raters rather than the reliability of individual raters, and consistency of raters rather than absolute agreement. There are no guidelines for interpreting the value of the ICC in terms of rater consistency in the range of values from 0 to 1. Some suggest it is desirable to achieve an ICC value of 0.70 or higher (Meyers, Gamst, & Guarino, 2013). Others report that a measure or scale may be considered reliable and therefore useful if the ICC value is 0.60 or higher (Bruton, Conway, & Holgate, 2000).

7.2 Results

7.2.1 Dissemination

The results of the dissemination Step 2.1 of Phase 2 involved data collection on the personalised and non-personalised dissemination activities including time frames, identification of audiences, developed resources, dissemination activities and, for non-personalised dissemination, the views or reader statistics.

Time frames

Personalised and non-personalised dissemination activities predominantly occurred between 9 March 2015 and 23 September 2016. Identification of target audiences, analysis of the target audience and determining the appropriate communication channels and methods commenced in December 2014 and continued until June

2016. The intensity of dissemination presentations varied. Some of the resources and materials to assist with dissemination activities were developed in February 2015. The dissemination activities continued beyond the planned timeline. Personalised dissemination in Australia commenced in March 2015 and continued periodically until September 2016. Personalised dissemination in the UK and Europe occurred between 3 October 2015 and 3 November 2015 except for a presentation via Skype on 23 July 2015 to a French researcher.

Identification of target audiences

Target audiences for personalised dissemination were identified via multiple means including professional networks, local service and organisational knowledge, referrals from other researchers, service providers and policy makers, and a Google Scholar search to identify other case management researchers. The Google Scholar alert commenced in September 2013 with weekly information requested. Initially the Google Scholar search terms included ‘case management’ or ‘case coordination’ or ‘community care management’ or ‘care coordination’ (up to 10 results). These search terms yielded significant numbers of irrelevant articles. After 1 month, the single search term was ‘case management’.

Resources developed for dissemination

The draft introductory email and a common PowerPoint presentation were developed. A two-page brief outline on potential uses was developed to accompany the introductory email. The published abstract from the World Congress on Integrated Care (WCIC) presentation in 2014 was also attached to the email (Lukersmith, Fernandez, Millington, & Salvador-Carulla, 2014). Prior to each presentation, the PowerPoint presentation was adapted to include possible examples of use or potential application relevant to the audience’s context. A second

conference poster presentation was attached to the email for some of the personalised dissemination activities after September 2015 (Lukersmith, Croker, & Salvador-Carulla, 2015).

Dissemination activities

Personalised dissemination

There were 60 groups and individuals identified as potential target audiences for personalised dissemination presentations. Individuals and groups of individuals from the same organisation (4 to approximately 20 people) were considered one audience.

Audiences: Of the targeted audiences, 51 audiences received a personalised presentation. Refer to Appendix 6.2 for the details of the audience: organisation, location, description of the sector they work in related to case management, health condition on which they focus, date dissemination commenced, method for dissemination, who performed the dissemination activity, and whether there was limited support provided to the individual or group in the potential use of the taxonomy. Names of individuals and organisational contacts are not provided. The reasons for the other nine identified audiences not receiving a personalised presentation were: five were not approached due to researcher time constraints; three were approached but chose not to proceed; and for one international audience, time and financial constraints prohibited the researcher from a face-to-face presentation, and the language barrier prevented a Skype presentation to the group. The details of the identified audiences for whom personalised dissemination did not proceed are provided in Table 6.3 below.

Table 6.3 Potential audiences for whom personalised dissemination did not proceed

	Name	Location	Description of sector related to case management	Dissem-ination complete	Outcome
1	Community-based case management for patients suffering from COPD	Denmark	Researcher – implementation (chronic illness)	N	no contact
2	University of Cadiz	Spain	Researcher – implementation (intellectual disability)	N	did not proceed
3	Motor Accidents Insurance Commission (MAIC)	Queensland	State policy maker, funder, employer	N	no contact
4	Quarterly Brain Injury Services Meeting (QBISM)	Queensland	State case management interest and support group	N	no contact
5	Redesigning Case Management – Living with Chronicity and Complexity	Spain	Researcher – implementation (chronic illness)	N	could not proceed
6	Redesigning Health Australia	NSW	State-based policy and service organisation	N	no contact
7	Trimbos Institute	Netherlands	Research institute	N	did not proceed
8	University of Sydney Social Work	NSW	Researchers, educators	N	no contact
9	Veterans Affairs	USA	Researcher, policy and planning	N	did not proceed

People exposed to the taxonomy: There was an estimated 398 people involved in the personal presentations across all audiences. The exact number of people cannot be calculated. An unknown number of people participated via teleconference or webinar, arranged by the organisation's liaison person.

Timing: Four audiences were reached with dissemination activities in 2014. The remaining 47 audiences were reached over 18 months from March 2015 to September 2016, with eight of these in 2016. The implications of timing and method of dissemination are discussed later in the results of the impact analysis.

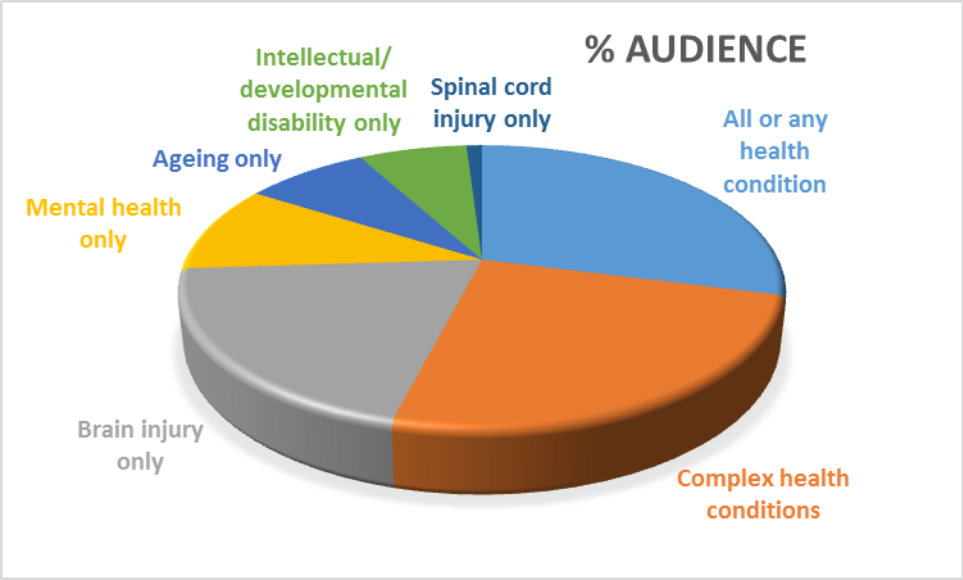
Procedure: The procedure for dissemination was limited to email only for 11 audiences, and face-to-face only for 20 audiences (including Skype visual). For 20 audiences, there were two or more incidences of communications involving a combination of face-to-face, email and Skype as there were requests for further information or questions about the taxonomy. There was a report with recommendations provided by the researcher on one occasion.

Support: Only eight audiences sought and were provided with support from the researchers in their application, or potential application, of the taxonomy within their context.

Who presented: The doctoral candidate (SL) completed 40 (78%) of the dissemination activities, 6 (12%) were completed by co-researchers (LSC or MM), and 5 (10%) were completed by a combination of two researchers (SL and LSC).

Health condition: Audiences were concerned with a range of health conditions. There were 15 (29%) focused on any/all health conditions; 13 (25%) on a range of complex health conditions such as spinal cord injury, intellectual disability, mental health, brain injury and chronic non-communicable diseases; 10 (20%) on brain injury; 5 (10%) on mental health; 4 (8%) on ageing and the health conditions associated with older populations; 3 (7%) on intellectual and developmental disabilities, and one group focused only on spinal cord injury (1%) (refer to Figure 6.1).

Figure 6.1 Health condition focus of personalised presentation audiences



Location of audience: The location of the dissemination audiences is provided in Figure 6.2 below. Countries include Australia, Canada, France, Germany, Netherlands, Spain, Sweden, UK, Switzerland, Taiwan and USA. The audiences per location are grouped into the sectors determined for the impact analysis. The total number of audiences within these sectors are: international frameworks (n=2), policy and legislation (n=7), research (n=23), education and training (n=3), and clinical practice (services delivery only) (n=16).

Figure 6.2 Location of audience and sector

Non-personalised dissemination

It is not possible to know exactly how many people were exposed to the taxonomy across all non-personalised dissemination activities. There were 986 people exposed to the taxonomy on the basis of the metrics retrieved for the web-based strategies alone (excludes conference presentation attendees). The details of non-personalised dissemination activities are provided below. Refer to Appendix 6.3 for the abstracts of paper presentations and PDF of poster presentations.

Scientific conferences

Paper presentations

- World Congress on Integrated Care in November 2014 in Sydney (Lukersmith, Fernandez, Millington, & Salvador-Carulla, 2014).

- World Health Organization Family of International Classifications (WHO-FIC) Annual Meetings – Two paper and poster presentations, one in October 2014 (Lukersmith, Fernandez, Millington, Brain Injury Case Management Nominal Group, & Salvador-Carulla, 2014) and the second in October 2015 (Lukersmith, Millington, Madden, & Salvador-Carulla, 2015). These meetings involve hundreds of people involved with the three key WHO classifications who potentially view the poster and a subset who attend the presentation.
- Guideline International Network (GIN) in Philadelphia in October 2016 (Lukersmith & Salvador-Carulla, 2016)

Poster presentations

- International Neuropsychological Society and the Australian Society for the Study of Brain Impairment (ASSBI) 5th Pacific Rim Conference in Sydney in July 2015 (S Lukersmith, D Croker, et al., 2015).
- International Conference on Evidence Based Health Care (EBHC) in Italy in August 2015 – an abstract was accepted but the invitation was declined due to the cost for travel.

Peer-reviewed publications

Two peer-reviewed journal publications, both open access (Lukersmith, Fernandez, Millington, & Salvador-Carulla, 2015; Lukersmith, Millington, & Salvador-Carulla, 2016).

YouTube

Two of three 10-minute videos were developed and then launched on YouTube on 6 April 2016 (https://www.youtube.com/watch?v=7apR5QX3mwo and https://www.youtube.com/watch?v=POv9WsIQxS0). The third video is scheduled for

development later in 2017 and will highlight the impacts of the dissemination of the taxonomy.

Website

To further promote access to the information on the taxonomy, an abstract and links to the YouTube videos and the taxonomy publication (S. Lukersmith et al., 2015) were placed on the University of Sydney Centre for Disability Research and Policy website on 6 May 2016 (http://sydney.edu.au/health-sciences/cdrp/projects/taxonomy.shtml.).

Information about the case management taxonomy research was launched on ResearchGate as a project on 2 December 2016 (https://www.researchgate.net/project/The-case-management-taxonomy-for-a-common-language-dissemination-and-analysis-of-the-impact-of-dissemination).

Twitter

A Twitter account with the handle name @CMTaxonomy was created on 5 October 2015.

7.2.2 Impact assessment

Collection of data to assess the impact of dissemination commenced at the time of dissemination activities and continued until November 2016. The assessment and analysis of impact occurred July–December 2016.

Impact of personalised dissemination activities

Group 1 – Presentation questionnaire

The two questions posed via the Mentimeter tool were only used with a limited number of audiences and only in Europe. The reasons for not using the tool with all

personalised audiences were: no prior knowledge of the tool prior to beginning the presentations in Australia; and limitations with the timing and internet access at individual presentations. In these circumstances at the presentations in Europe, the questions were posed to the participants using paper and pen, with responses collected anonymously. Responses were collected from 47 participants (Germany, n=4; Netherlands, n=1; Sweden, n=2; UK, n=16; Spain, n=4; World Health Organization, n=20). The results to the questions are provided in Table 6.4.

Table 6.4 Presentation questionnaire (Group 1) responses

Questions	Score				
	1 **Yes, a lot**	**2**	**3**	**4**	**5** **No, not at all**
Question 1 Is the case management taxonomy relevant to your work?	25	17	5	0	0
Question 2 Is the case management taxonomy practical?*	21	21	3	0	0
Total rated at each level	46	38	8	0	0
Percentage of total respondents (n=47)	97%	80%	17%	0	0

* Two respondents did not complete question 2.

Group 2 – Progress questionnaire

The questionnaire was forwarded to 176 people identified from the 51 personalised presentation target audiences. It was sent on 15 May 2016 using the REDCap interface with a reminder after several weeks (on 9 June 2016) to those who did not respond to the survey. Only one reminder was sent. It was considered that after two email messages, respondents who were intending or willing to respond would have done so. Individuals exposed to personalised dissemination activities after May 2016

were not sent the survey, as there would have been insufficient time from dissemination to impact assessment for them to use the taxonomy. Some international organisations have a policy where staff cannot respond to questionnaires; this was the case for two personalised dissemination audiences (total of 21 people emailed but who could not respond). There were 43 respondents to the survey, which is a 24.4% response rate, with 34 completed and 9 incomplete surveys.

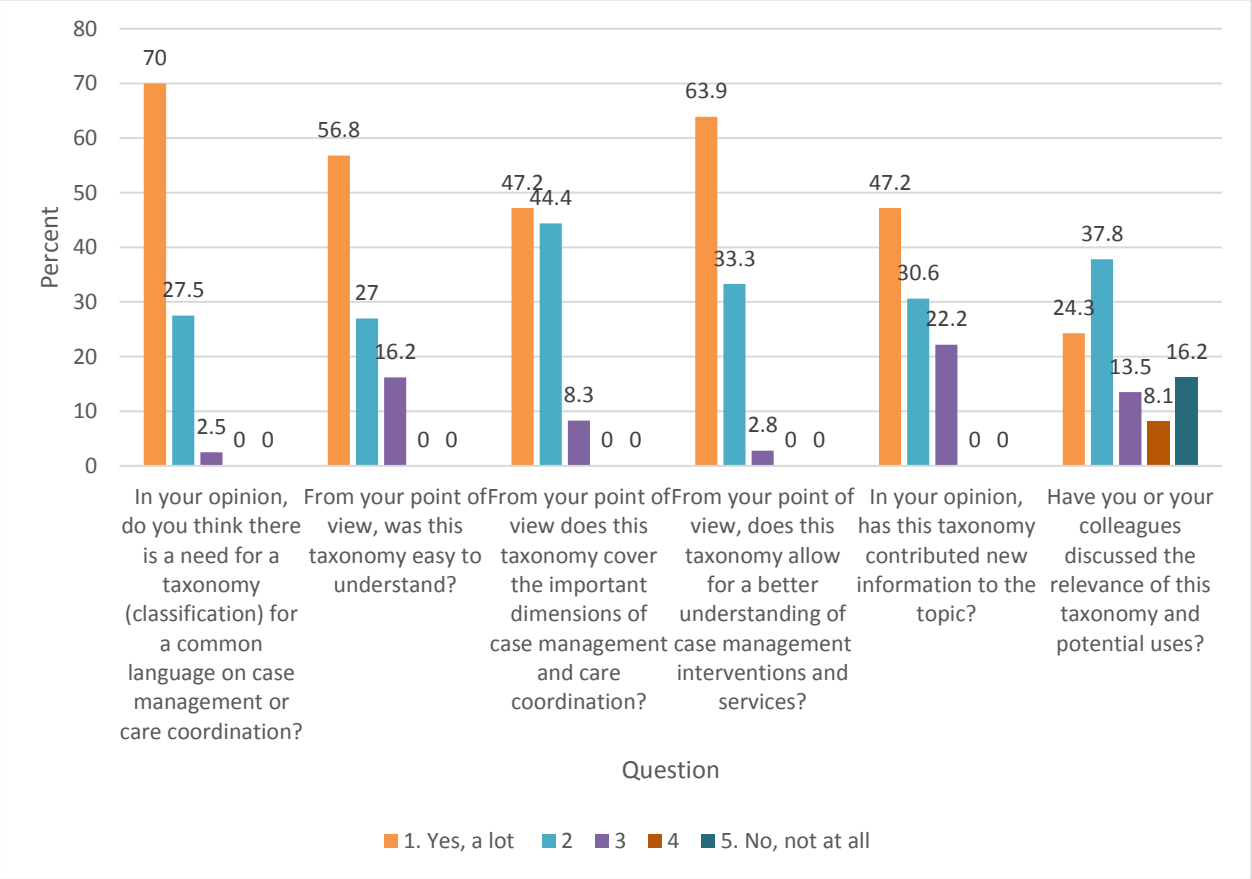
Forty respondents indicated their case management role. The roles of Group 2 respondents were: case manager/practitioner (16, 40.0%); researcher/academic (11, 27.5%); policy and planning (e.g. services, resources) (9, 22.5%); education of case managers (including potential case managers) (6, 15.0%); employer and manager of case managers (6, 15.0%); oversight of quality of case managers (5, 12.5%); professional association representative/executive (2, 5.0%); employed manager of case managers (2, 5.0%); consumer or care provider representative (1, 2.5%); and other (4, 10.0%). There were three respondents who did not complete this question. The categories of organisation were: state or provincial organisation – funder, policy maker, service provider (14, 35.0%); university (13, 32.5%); national organisation – funder, policy and planning, service provider (6, 15.0%); research institute (not part of a university) and professional associations (2, 5% each); consumer organisation (2.5%); and the three respondents who ticked ‘other’ did not provide an explanation.

In terms of health conditions, only three respondents did not state a health condition on which they focused. Most respondents focused on case management for people experiencing a range of health conditions (acquired and congenital), multi-morbidity, social concerns and across all ages (children to elderly living in the community). The broad range of health conditions reported included: mental health disorders;

intellectual disability including congenital conditions and genetic disorders such as Down syndrome; amputation; neurological and peripheral health conditions; orthopaedic condition; stroke; people presenting to primary care facilities with any health condition including chronic and long-term illness; dementia and cognitive decline; work-related injuries; spinal cord injuries; burns; and people with social care concerns. Only two respondents focused exclusively on mental health, five on brain injury, and two on spinal cord injury.

Figures 6.3 and 6.4 below provide summaries of respondents' ratings for questions related to the level of impact of the dissemination.

Figure 6.3 Ratings for questions related to awareness and acceptability of the taxonomy, percentage of total responses



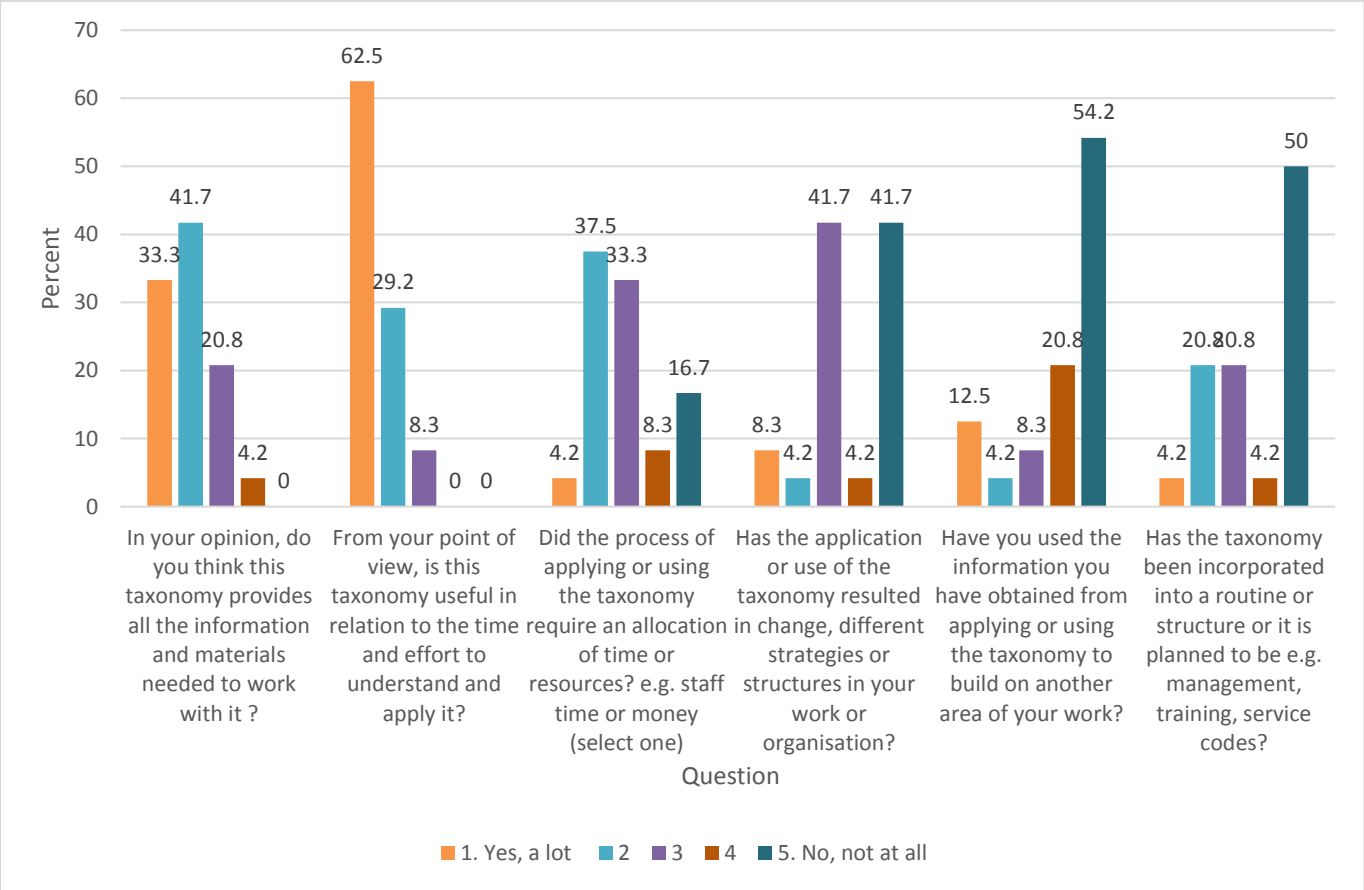
In Group 2 there was high agreement that the taxonomy was relevant (total rated 1 and 2 = 97.5%) and practical in terms of the ease of understanding (total rated 1 and 2 = 83.8%). Among respondents, 62.1% had discussed the taxonomy with colleagues, with 55.5% reporting they had sent information to a minimum of two or more people. Although the impact of diffusion dissemination is not known, these results confirm that diffusion has occurred. Results suggest that the taxonomy allows for a better understanding of case management (total rated 1 and 2 = 97.2%), contributes new information to the topic (total rated 1 and 2 = 77.8%), and covers all the dimensions that people consider important (total rated 1 and 2 = 91.6%); 72.2% of respondents had applied, or were planning to use, the taxonomy in their work or organisation.

Over half of the Group 2 respondents had forwarded information on the taxonomy to someone else or another organisation because they thought it was relevant to them (8.3% had sent it ‘to many’, 19.4% ‘to quite a few others’, and 27.8% ‘to one or two others’; 2.8% said they could not recall and 41.7% said they had not sent information to others). Responses to the question about whether respondents had referred to the taxonomy on internal documents or on their website were 13.9% rated 1 (yes, a lot), 16.7% rated 2, 8.3% rated 3, and 2.8% rated 4; the majority (58.3%) rated it 5 (no, not at all).

However, 72.2% of the respondents in Group 2 stated that they or their manager had applied or used the taxonomy in their work or organisation, or had made plans to do so. The majority had used all sections of the taxonomy (58.3% used the service tree, intervention tree and glossary, 33.3% the intervention tree only, 16.7% the service tree only, and 29.2% the glossary only). Those that had spent time and used the taxonomy found it had the information and materials needed to work with it (total

rated 1 and 2 = 75%) and that it was useful in relation to the time and effort involved (total rated 1 and 2 = 91.7%). Most of the respondents considered that the taxonomy had not resulted in change or they could not perceive a change (87.6% rated as 3, 4, or 5 No, not at all). Similarly, using the taxonomy to build on another area of work and incorporating it within routine or structure were rated low (total rating for 4 and 5 was 4.2% and 50%, respectively).

Figure 6.4 Ratings for questions related to assimilation and practicality of the taxonomy, percentage of total responses



The taxonomy is being incorporated (assimilated) into existing knowledge and is perceived as understandable, practical and useful. Respondents gave a range of responses to questions related to translation (using the taxonomy in policy, plans, service and business structures) and allocation (allocating resources or having an

impact on budgets, financing). Only some respondents had incorporated or planned to incorporate the taxonomy into their work or organisation (50%). The time frames for exposure to the taxonomy ranged from 1 to 18 months. It is anticipated that with the passage of time and as need arises (for which the taxonomy might be used), there will be an increase in the use of the taxonomy. The specific comments and explanations made by respondents in relation to survey questions are summarised in Appendix 6.4.

Evidence from opportunistic collection of information

A case study was developed for each of the 43 questionnaire respondents according to their sector and context/organisation using the responses from the questionnaires and evidence gathered from opportunistic information of application and use. Evidence of application and uses was collected from 2016 up until the time of impact ratings in 2016. Examples of the type of evidence are: changes in information on an organisation's website referring to the taxonomy being adopted as policy; minutes of organisational meetings where there is reference and agreement to use a definition from the taxonomy; email from case manager with de-identified excerpt from a medico-legal report which cites the taxonomy; clinical reports which use and acknowledge taxonomy definitions of interventions, tertiary course program document with taxonomy included as one of the foundational frameworks for practice.

Impact ratings

The impact of dissemination rating was on the 43 case studies based on the questionnaire responses and evidence from opportunistic collection of information. The rating was performed by the three independent raters. The rating for each case

study by each rater is presented in Appendix 6.5. It is noted that for some audiences, the rating scored by the three raters was the same, particularly towards the extremes of the scale (1 or highest level to 3 or 6 depending on the scale) and at the higher levels of implementation. Table 6.5 below provides only the mean rating for each audience. In the research column and clinical practice column, audiences are de-identified by initial or number respectively.

Table 6.5 Mean impact rating for each audience

International frameworks	Mean rating	**Research** (individuals and organisations)	Mean rating	**Clinical practice – service delivery** (individuals and organisations)	Mean rating
DESDE-LTC	3	Switzerland-G	1	Org1	3
ICHI	3	USA community	3	Org2	4
Policy and legislation		UNSW	2	Org3	3
BABICM/CMSUK	2	USydney-G	3	Indiv1	1
CMSA	2	USydney-Y	2	Indiv2	4
DPO	1	USydney-M	2	Indiv3	1
NICE	2	USydney-AM	1	Indiv4	4
BIRD-policy	5	UK-K	2	Indiv5	1
LTC-NSW	5	France-J	1	Indiv6	2
LTC-SA	4	UK-M	2	Indiv7	1
icare-w/c policy	4	BIRD-research	2	Indiv8	3
icare-w/c provider	2	Sweden-H	1	Indiv9	2
Mental Health-SP	1	Sweden-K	1	Indiv10	4
Education and training		UK-S	1	Indiv11	3
Berlin	4			Indiv12	2
USyd-M	5				

Audiences shaded in blue are those that were rated on the 3-level (not 6-level) impact scale.

The ICC for the ratings of the impact of dissemination of the case management taxonomy using the impact assessment scale is 0.84 (mean measures) which reflects high reliability of the scale.

Impact of non-personalised dissemination activities

There is no known feasible method for collecting data or determining the impact of conference presentations or visits to a page on the University of Sydney website, nor when dissemination by diffusion has occurred. The data for the impact of the web-based communication channels was collected on 15 January 2017 (Table 6.6).

Table 6.6 Data for web-based dissemination activities

Web-based channel	Launch or publication date	Views or reads	Likes/dislikes or comments	Time available to any audience
YouTube*				
Video 1	20/4/2016	88 views (70% viewing time)	3	34 weeks (average 2.6 views per week)
Video 2	20/4/2016	83 views (67% viewing time)	1	34 weeks (average 2.4 views per week)
Website				
CDRP website	3/5/2016	Not able to track	Not able to determine	32 weeks
Publications†				
The brain injury case management taxonomy (BICM-T); A classification of community-based case management interventions for a common language	Epub 23/10/2015	Mendeley:‡ 544 views 10 readers (the document was saved 6 times to a person's library)	4 citations	58 weeks
What is case management? A scoping review	Epub 19/10/2016	Journal metrics: 204 reads Twitter: 1 Twitter message sent, 8 retweets, 5 likes	1 citation	12 weeks
ResearchGate project – The case management taxonomy for a common language, dissemination and analysis of the impact of dissemination	Notified on ResearchGate on 2/12/2016	ResearchGate:‡ 55 reads	6 followers	6 weeks
Twitter				
@CMTaxonomy	Established 5/10/2015	12 followers 15 tweets 2 retweets		60 weeks

* All the YouTube views were from Australia.

† Citation in the scoping review is excluded

‡ Statistics were retrieved from Mendeley (https://www.mendeley.com) and ResearchGate profile of doctoral candidate (https://www.researchgate.net). Mendeley is a desktop and web-based program produced by the publisher Elsevier for managing and sharing research papers, promoting online collaborations and collecting research data on parameters associated with the impact of the researcher's publications. The country for most readers is not known. ResearchGate is a social networking site for researchers and scientists to share papers, correspond, ask questions and find collaborators.

7.3 Discussion

Discussion on impact of the research is grouped by the sector potentially influenced by the taxonomy: 1) Dissemination, 2) International frameworks, 3) Policy and legislation, 4) Research, 5) Education and training, and 6) Clinical practice – service delivery. It includes discussion on the results of the impact of personalised and non-personalised dissemination activities.

7.3.1 Dissemination

The aim of the dissemination of the taxonomy was to actively target organisations and individuals involved or interested in health sector case management who would potentially use the taxonomy. Sixty potential audiences were identified in 11 countries which were Australia, North America (Canada and USA), seven in Europe and one in Asia. The sectors represented were international frameworks, policy and legislation, research, education and training, and clinical practice (service delivery). Of these, 51 audiences received a personalised presentation of the taxonomy across 11 countries, involving an estimated 398 people whose focus was on either all health conditions or complex health conditions such as spinal cord injury, brain injury, intellectual disability, mental health and chronic diseases.

The majority of personalised dissemination activities occurred over an 18-month period to September 2016. Non-personalised activities included six paper or poster conference presentations between October 2014 and October 2016, two peer-reviewed journal publications, two YouTube videos, information on the University of Sydney website, and information disseminated through Twitter. Dissemination impact was determined through collection of data on the personalised and non-personalised dissemination activities.

For personalised dissemination, there were two questionnaires. The results of the questionnaires confirm that most people exposed to a personalised dissemination activity considered the taxonomy relevant and practical. The target audience's immediate and delayed responses have been exceptionally positive and reflect a high level of acceptance of the case management taxonomy across a range of countries, and people working with different populations (age and health condition). The immediate perception of the taxonomy being relevant and practical was noted in Group 1 (who completed the presentation questionnaire). There was also a high level of agreement with this positive perception in Group 2 (who completed the progress questionnaire), with responses to questions on the need for the taxonomy reaffirming its relevance and practical features. No one in the target audiences considered the taxonomy irrelevant or impractical; this was an interesting result given the range of audience sectors (from policy through to research and practice) and the structural levels within the system (from micro to meso and macro organisations) that the respondents represented (Fulop & Robert, 2015). The results from Group 2, which were collected any time between 1 and 14 months after the relevant dissemination activity, demonstrate that a positive perception of the taxonomy is sustained and so less likely to be as a result of momentary enthusiasm at the time of the dissemination activity. The limited time between the dissemination (and therefore the audience's awareness) of the taxonomy and opportunities to use and/or plan to make use of the taxonomy influenced the impact of the taxonomy. For some audiences the time was as short as 1 month; time frames to assimilate and fully use the taxonomy in some contexts may take years (e.g. education and training, research). Impact analysis of the dissemination over years is outside the scope of this research program.

With respect to the non-personalised dissemination activities, accessibility of the six publications and conference presentations would have been limited to only researchers and practitioners who either attended the conference or accessed the publication. The launch of the more accessible web-based dissemination channels was not until a few months prior to the collection of data on impact (Twitter October 2015, YouTube and University website page May 2016). The statistics on visits to the University web page are not available. Further, the web page has a download link for an embedded copy of the open access 2015 manuscript for reader ease. Downloads through the University web page are not tracked on the publisher's website. Copies of taxonomy information emailed between colleagues (diffusion dissemination) are also likely not included in publisher reader or download statistics. For these reasons, the publisher's electronic recording of views and readers of the publications are considered to be the minimum.

At the time of writing, the availability of the YouTube videos was limited to a small number of audiences within Australia. The view results of the two videos suggest that most people watch both videos, which is perceived as a positive outcome for a stronger understanding of both the problem, the taxonomy trees and potential uses. Viewers of the YouTube videos are likely to increase once target audiences in Australia and internationally are notified, and considering the taxonomy is now integrated into tertiary education in at least two university courses.

Overall, the dissemination results support the proposition that over time the taxonomy has the potential to provide a framework for a common understanding and language, which is fundamental to case management/care coordination analysis, policy development, planning and service management.

7.3.2 International frameworks

The taxonomy was disseminated to two targeted international frameworks linked to health systems – the ICHI and DESDE-LTC classifications. The mean impact rating for both frameworks was level 3 (translation), which is the highest possible impact level for this group. It was possible to track the impact of the taxonomy on these classifications. Since 2014, the taxonomy has had an impact on the revisions of both classifications with inclusions and amendments to earlier definitions taken directly from the taxonomy.

In the ICHI 2016 revision, the case management taxonomy actions (interventions) and definitions of coordination, planning, navigating and collaboration have been incorporated as new actions within the classification, or the previous ICHI definitions have been amended and aligned to the taxonomy (World Health Organization (WHO), 2016).

The 2011 version of the DESDE-LTC classification had one main type of care level code related to care coordination (code A4) and a characteristic ‘m’ related to case management (Salvador-Carulla et al., 2011). The classification listed characteristics related to the intensity of contact (high, moderate and low), and the percentage of user contacts away from the premises (mobile) associated with other main types of care (e.g. day care – code D) but not associated with the A4 care coordination code. Following the dissemination of the case management taxonomy to the DESDE-LTC revision group, the classification was changed. In the 2016 revision of the DESDE-LTC classification, the levels were extended to include two additional code levels incorporated from the taxonomy service tree (Salvador-Carulla & Fernandez, 2016). The levels incorporated were acute/non-acute, mobility (community-based

interventions), and the level of intensity (high, medium and low). Definitions were in line with, although not exactly, the definitions from the taxonomy.

These frameworks informed the development of the taxonomy (refer to Chapter 4 Critical Review of International Frameworks) and so had synergies with the taxonomy. Researchers provided support to each of the classification revision networks and further explanation on the potential relevance of the taxonomy. LSC and SL had limited face-to-face, email and phone contact with members from the ICHI revision network; LSC had contact with members of the DESDE-LTC revision network. The support provided may have assisted the two classification networks to translate the use of the taxonomy to their specific context. There were also two paper and poster presentations to the ICHI network at WHO-FIC meetings over 2 years, which provided opportunities for network members to become familiar with the taxonomy.

7.3.3 Policy and legislation

Tracking and assessing the impact of the taxonomy on policy and legislation is complex and particularly so because of organisational and temporal factors. The influence of research and frameworks on policy is typically less transparent and not specifically stated. Policy development also takes time such that any noticeable impact may not occur for 12 months or more. In this study, the time between dissemination activity and exposure to the taxonomy and impact assessment was as short as 2 months for one meso organisation and up to 14 months for one macro organisation. Mean impact ratings for the 10 targeted organisations in this sector ranged from 1 (awareness) to 5 (provision). There were contextual barriers and facilitators for each organisation. The key barriers identified were method of

presentation and time, and the facilitator for uptake and impact was having an immediate problem or issue with which the taxonomy may assist.

The mean rating for the two professional associations for case managers (CMSA, BABICM/CMSUK) was 2 (assimilation). It is known anecdotally that, after impact assessment, the association in the UK has progressed further and plans to incorporate the taxonomy into their structures in the future. The presentation by Skype to the Australian association was time-limited, which limited the discussion on the applicability of the taxonomy to their context. The UK organisation NICE (mean impact rating of 2) was interested in the taxonomy with respect to the commissioning and development of guidelines (e.g. in social care), understanding of case management, research and quality analysis. As development of a guideline or research takes time, sometimes years, it is possible (but not known) that the taxonomy has been incorporated as a framework or common language, or referenced, since the time of the impact analysis 7 months after the dissemination presentation.

The targeted DPO was exposed to the taxonomy via email only and the impact rating occurred 1 month later. The mean rating for this group was 1 (awareness). The method, timing and fact that there was no opportunity to discuss or contextualise the taxonomy, or highlight the potential relevance or use for the audience, are considered barriers to impact. In contrast, one organisation (Lifetime Care – South Australia [LTC-SA]) was rated impact level 4 (allocation). This organisation was exposed to the taxonomy with a face-to-face presentation 3 months prior to impact assessment. Despite the limited time frame, the organisation management and staff had already made use of and incorporated the taxonomy. One of the reasons appears to be the appropriate timing of exposure. At the time of the dissemination

presentation, the manager identified that roles were being reviewed at the time, and their organisational framework was being developed. All the staff were exposed to the taxonomy by the manager. Thus, the timely and tangible use of the taxonomy within their context was explored immediately.

The Brain Injury Rehabilitation Directorate policy group was also noted to have an immediate potential use for the taxonomy in reviewing the model, roles and responsibilities of case managers in the NSW regional network. The impact rating was 5 (provision). The policy directorate and members of the BIRD review committee undertaking this work used the taxonomy extensively as a framework and mapped their model to compare with the taxonomy, including the definitions.

The receptiveness and immediate problems or need (or not) of organisations at the time of the dissemination presentation appears to influence the level of impact, which is not unexpected. In the policy section of one meso organisation in Australia (icare – Workers Care), the people concerned had heard of the taxonomy through colleagues and requested a presentation, rather than an approach being initiated by the researchers. The overall impact rating was 4 (allocation) and for the provider management section 2 (assimilation). For this organisation, there was an immediate work plan with which the taxonomy subsequently assisted, a business case for severely injured workers, and an options and planning paper related to providers. The people concerned sensed that the taxonomy may be useful for their problem before the presentation, so discussion on its use was particularly targeted.

In another meso organisation (LTC), the impact rating was 5 (provision). LTC had already recognised the issues around terminology differences and understanding of case management interventions. Recognising the organisation’s concern around

these issues, SL had approached LTC to be an industry partner for this research program and contribute limited in-kind support for the development step of the nominal group. LTC has adopted the taxonomy definitions and framework publicly (stating same and placing links on their website) and recently has moved further on these plans to include the taxonomy in role assessment and operational plans for the organisation. In contrast, in a meso mental health organisation in Spain, the level of impact was 1 (awareness). The barrier was that, when approached by the researchers, the audiences could see no immediate issue relevant to the taxonomy. An additional barrier was that the taxonomy was not available in Spanish. This necessarily limited its immediate utility in that context.

Organisations that have an existing business, policy or practice need or concern with which the taxonomy may assist seem to incorporate the taxonomy in a short time frame.

7.3.4 Research

There are major barriers to tracking the incorporation of the taxonomy and impact of dissemination in research due to the time frames for research methods and publication. The reference or use of any framework or tool in research methods is significantly influenced by the process of scientific peer review and research funding rounds. Researchers are more likely to incorporate the taxonomy in their methodology once there are peer-reviewed papers published concerning the use of the taxonomy (and the problems it assisted with) and the practicality. If a research proposal incorporates the taxonomy, there will be a delay of 6 months or more from the opening of a funding round through to submission, funding approvals and commencement of the research. The impact of research on policy is also problematic. In research, the maximum level of possible impact is 3 (translation).

For this research program, information on the impact of dissemination was collected from researchers, citation data, and, when available, proposed research studies that have used, or plan to use, the taxonomy. At the time of the impact analysis, there was only one paper (November 2015) and one conference presentation (November 2014) published on the taxonomy. Data via the Group 2 progress questionnaire was collected from individuals across 10 different research institutions in six countries (three research centres and seven universities). The impact rating for these researchers ranged from 1 (awareness) to 3 (translation).

All those researchers rated level 1 had either recently completed a major research project (so were between projects) and/or had no relevant research project planned. In one research group, the early career researcher did not fully understand the potential uses of the taxonomy in the context of their research. There was a missed opportunity. Even though the group of researchers subsequently gained a better understanding and considered the taxonomy highly relevant and useful for their research, the time had elapsed and it was too late for the taxonomy to be used as an intervention analysis in their research project.

Five researchers were rated with an impact level of 2 (assimilation). One of these plans to incorporate the taxonomy in the methods for a proposed international study on complex mental health conditions pending finalisation of the funding application. Two researchers completed their research on case management/care coordination prior to the dissemination of the taxonomy, but subsequently referenced the taxonomy in publications on their research. The fourth researcher has since completed her research in which the taxonomy was used to map case management and has a publication in press. The fifth researcher rated level 2 was considering using the taxonomy in a UK based research project of multi-disciplinary case

management for frail older people with a range of long-term conditions. Two researchers (in USA and Australia) rated level 3 (translation) have integrated the taxonomy in their research methods for projects related to people with any health condition. There are four citations of the taxonomy in peer-reviewed research papers.

7.3.5 Education and training

It is not possible to track all uses of the taxonomy in the tertiary education and professional education and training sectors. Notifying the researchers is not a requirement for use of the taxonomy. Thus, an unknown number of course coordinators or individual educators may be using the taxonomy in tertiary training within Australia and overseas. Similarly, employers or supervisors may be including the taxonomy in their training of practitioners.

Two organisations (or departments within the organisations) were classified in the education and training sector. The mean impact ratings for these organisations were 4 (allocation) and 5 (provision). The researchers are aware that the taxonomy has been embedded in tertiary education courses and professional education and training programs, confirmed by responses to the Group 2 questionnaire and additional information obtained through email and verbal communications. At a minimum, the taxonomy has been incorporated in three tertiary and professional training courses, and in in-service training (professional education) for case management practitioners in two meso and one micro organisation. The taxonomy has been incorporated in the revised curriculum for the Master of Rehabilitation Counselling program at the University of Sydney; is used in graduate program (Masters) for occupational therapists at the University of Toronto, Canada; and in Berlin, Germany, a quality research and education institute is planning to incorporate

the taxonomy in their revised case management course curriculum. The meso organisations using the taxonomy are LTC-NSW, who has used it in case manager training and e-learning modules for planning facilitators, and the NSW Brain Injury Directorate who has used it in webinar training for rural case managers and has invited SL to present to program regional managers. The micro organisation employs 50 case managers and has used it in their in-service training. It is likely that the YouTube videos will be viewed more extensively once the links are disseminated through the various tertiary and training courses.

7.3.6 Clinical practice – service delivery

There was a wide range in the impact ratings for service delivery in clinical practice. Representatives from three micro organisations and 12 individual service providers responded to the progress survey. Four individuals were rated level 1; three individuals were rated level 2; two individuals and two organisations were rated level 3; and three individuals and one organisation were rated level 4. In their responses, individual practitioners described using the taxonomy as a common language to explain their role to clients and their families, employers and others; in client or medico-legal reports; to describe interventions and client needs; in relation to outcomes; and to justify costs or funding requests. One person commented that the taxonomy '*puts into words what we do, which is not an easy task*' (Individual 12) and '*it has given us a clear model or structure to clarify what we do and to guide our service development'* (Individual 9). Other comments refer to the taxonomy as a quality improvement framework; for example, '*It helps us to develop guidelines for service delivery…I have looked at the information [taxonomy] as a reflective activity – to guide me in thinking about what I do, how I do it and identify potential positive improvement*' (Individual 9). Observations of and anecdotal information from

practitioners suggest that as practitioners use the taxonomy language and definitions in their daily work, over time they are no longer cognisant of its use. It is adopted as their own language. The micro organisations described how the taxonomy is useful across their organisation and '*provides a differential description to case management across settings and caseloads…and in complex cases*' (Organisation 3). Another organisation, which had limited support from the researchers, is planning to '*have greater implementation [of the taxonomy] in our systems*' (report templates and codes) (Organisation 2).

7.3.7 Summary and conclusion

The taxonomy appears to be highly relevant and acceptable to people working in different sectors, across a range of countries, and where the focus is across the age spectrum and a range of health conditions. The results demonstrate a high level of assimilation of the taxonomy by all sectors to which the taxonomy was disseminated. There is evidence to confirm that there is considerable uptake occurring in the use and incorporation of the case management taxonomy as a common language. There are also several instances where the taxonomy has been translated and adopted into policy, organisation structures, and research and practice within a short period for implementation and service delivery research. Additional translations into use are emerging since the analysis of the impact of dissemination.

There is insufficient information to conclude the most appropriate methods, channels or tools for dissemination, nor methods for collecting data on impact. However, the results suggest that face-to-face personalised activities to targeted audiences has greater impact than non-personalised dissemination activities, at least for influencing uptake in the short term. Non-personalised dissemination methods will likely have

greater impact in the longer term, particularly within sectors such as research and policy.

The provision of some support appears to benefit an audiences' assimilation and translation of the taxonomy. The impact ratings for audiences that received some support from the researchers were higher than those where no support was provided. A contributing factor to the outcome for individuals and organisations is their location and access to the researchers to enhance communication after the dissemination activity. The presence of an immediate need in the audience's current or scheduled work program context at the time of the audience's introduction to the taxonomy is another factor contributing to the level of impact.

The measurement of the impact of dissemination in this project commenced with the questionnaire data and self-report by audiences. As contextual factors are critical, more information was needed than the questionnaire. The questionnaire data was supplemented by observation and other information (e.g. organisation websites). However, the feasibility of collecting more data on impact was limited by the diversity amongst the audiences in terms of their structural level within the system (macro, meso, micro level), context and responsiveness. Also, the person who responded to the questionnaire, or other requests for information on impact, may not be cognisant of the organisation's use of the taxonomy. This is known to have occurred in one meso organisation where the middle manager responded to the survey, but at the time did not know of other policy level organisational plans to use the taxonomy.

It is possible that the taxonomy has had a greater impact than has been reported. There are many complex and non-linear impacts in health system research that are difficult to track, particularly when health service research like the taxonomy provides

a common language and new meaning. For example, the word coordination was frequently used in case management before development of the taxonomy. In the taxonomy intervention tree, coordination is one of nine main actions, and has seven actions and six related actions, which provides a new meaning, distinction and relationship between actions. Thus, the intent of meaning has changed and bridges understanding between parties.

Opportunistic data collection through personal communications identified that some people had incorporated the taxonomy in their day-to-day work language (e.g. the new definition of coordination, and the actions and related actions), or used the framework but no longer recognised or recalled that this was the case. After becoming aware of the taxonomy and after 6 months of use, the taxonomy and current practice language had merged. This phenomenon was apparent with several practitioners and organisations, and highlights the difficulties in tracking impact working backwards.

Impact rating involves interpretive analysis of a complex range of factors which vary in each audience's context. There is the potential to improve the impact data using a more structured forward tracking case study approach over longer time frames. This would include more individualised self-report questions relevant to the system level context (micro to macro), report by an appropriate person(s) within the organisation, and data from independent observation. Further research is also needed to explore the barriers and facilitators for dissemination, implementation and impact analysis.

7.3.8 Limitations

Key limitations of the study were the time frames between the stage of dissemination activities, tracking the use of the taxonomy backwards, collecting impact data and

impact analysis. There needed to be time between the presentation and REDCap questionnaire to allow assimilation or use of the taxonomy in the audience's context. However, the research program timetable constraints meant that some people received the survey only 1 month after they were presented the taxonomy, while for others it was 14 months.

Contextual factors are critical to the impact of dissemination, not the least of which are the audience's system level, whether there was an immediate need, and the timeframe needed to use the taxonomy in the respective context. Typically, policy and practice people in micro and meso organisations would take a minimum of 18 months to move to the level of provision (level 5) or monitoring (level 6) on the impact rating scale, as would researchers translating the taxonomy into a common language or research method (level 3 on the impact rating scale).

There was no known systematic mechanism to track dissemination by diffusion or unplanned dissemination when the researchers were not involved. A further limitation for collecting impact data was the use of a voluntary self-report questionnaire as the initial trigger for impact rating. Although the response rate was good, it limited the number of audiences which underwent an impact rating. Non-response to the questionnaire is not a proxy for non-awareness; for example, only 45% of the people involved in the taxonomy development as nominal group members responded to the questionnaire.

7.4 Appendix 6.1 REDCap survey questionnaire

Confidential

Questionnaire on the case management taxonomy (classification)

The aim of the questionnaire is to find out how the taxonomy has been used and how practical it is. Most questions must be answered. However, if you have not used the taxonomy or there was limited application, the questionnaire will stop at the appropriate point.

The survey takes less than 10 minutes.

---

1 1. First Name _____

Last name _____

2 2. What country do you work in? _____

3 3. What is the name of your organisation? _____

4 4. What health condition/disease group do you/your organisation support or care for? (e.g. mental health, brain injury, older persons, any health condition etc)?

5 5. What is your role in relation to case management or care coordination? (select all that are appropriate)

- ☐ Policy and planning (e.g. services, resources)
- ☐ Education of case managers (including potential case managers)
- ☐ Professional association representative/executive
- ☐ Researcher/academic
- ☐ Case manager/practitioner
- ☐ Employed Manager of case managers
- ☐ Employer and manager of case managers
- ☐ Oversight of quality of case managers
- ☐ Consumer or care provider representative
- ☐ Other

6 6. In what category would you describe your organisation? (select from the drop down list)

☐ International organisation ☐ National organisation - funder, policy and planning, service provider
☐ State or provincial organisation - funder, policy maker, service provider ☐ University
☐ Research Institute (not part of a university) ☐ Professional association ☐ Consumer organisation
☐ Other

7. In your opinion, do you think there is a need for a taxonomy (classification) for a common language on case management or care coordination? (select one)

- ☐ 1. Yes (a lot)
- ☐ 2.
- ☐ 3.
- ☐ 4.
- ☐ 5. No (not at all)

8. Do you know of the community-based case management taxonomy (classification)?

- ☐ Yes
- ☐ No

www.project-redcap.org REDCap

Confidential

9. From your point of view, was this taxonomy easy to understand? (select one)

- ☐ 1. Yes (a lot)
- ☐ 2.
- ☐ 3.
- ☐ 4.
- ☐ 5. No (not at all)

10. From your point of view, does this taxonomy cover the important dimensions of case management and care coordination? (select one)

- ☐ 1. Yes (a lot)
- ☐ 2.
- ☐ 3.
- ☐ 4.
- ☐ 5. No (not at all)

Further comments _____

11. From your point of view, does this taxonomy allow for a better understanding of case management interventions and services? (select one)

- ☐ 1. Yes (a lot)
- ☐ 2.
- ☐ 3.
- ☐ 4.
- ☐ 5. No (not at all)

Further comments _____

12. In your opinion, has this taxonomy contributed new information to the topic? (select one)

- ☐ 1. Yes (a lot)
- ☐ 2.
- ☐ 3.
- ☐ 4.
- ☐ 5. No (not at all)

Further comments _____

13. Have you or your colleagues discussed the relevance of this taxonomy and potential uses? (select one)

- ☐ 1. Yes (a lot)
- ☐ 2.
- ☐ 3.
- ☐ 4.
- ☐ 5. No (not at all)

Further comment _____

14. Have you forwarded the information on this taxonomy to someone else or another organisation because you thought it was relevant to them? (select one)

- ☐ 1. Yes (to many)
- ☐ 2. Yes (to quite a few others)
- ☐ 3. Yes (one or two others)
- ☐ 4. Possibly - I cannot recall
- ☐ 5. No (never)

Further comment _____

15. Have you/your organisation referred to, or included any information on (or from) this taxonomy in your internal documents or website? (select one)

- ☐ 1. Yes (a lot)
- ☐ 2.
- ☐ 3.
- ☐ 4.
- ☐ 5. No (not at all)

Please provide a brief explanation _____

17. Have you/your manager applied or used this taxonomy in your work or organisation? OR you have made plans to do so?

- ☐ Yes
- ☐ No

Please briefly explain how you have used or applied the taxonomy? _____

Confidential

18. Which parts of this taxonomy did you use? (select all that are appropriate)

- ☐ All of it (service tree, intervention tree and glossary)
- ☐ Intervention tree
- ☐ Service tree
- ☐ Glossary

19. In your opinion, do you think that this taxonomy provides all the information and materials needed to work with it? (select one)

- ☐ 1. Yes (a lot)
- ☐ 2.
- ☐ 3.
- ☐ 4.
- ☐ 5. No (not at all)

Further comment _____

20. From your point of view, is this taxonomy useful in relation to the time and effort to understand and apply it? (select one)

- ☐ 1. Yes (a lot)
- ☐ 2.
- ☐ 3.
- ☐ 4.
- ☐ 5. No (not at all)

Further comment _____

21. Did the process of applying or using the taxonomy require an allocation of time or resources ? e.g. staff time or money (select one)

- ☐ 1. Yes (a lot)
- ☐ 2.
- ☐ 3.
- ☐ 4.
- ☐ 5. No (not at all)

Further comment _____

22. Has the application or use of the taxonomy resulted in change or different strategies or structures in your work or organisation? (select one)

- ☐ 1. Yes (a lot)
- ☐ 2.
- ☐ 3.
- ☐ 4.
- ☐ 5. No (not at all)

Please provide a brief explanation _____

23. Have you used the information you have obtained from applying or using the taxonomy to build on another area of your work? (select one)

- ☐ 1. Yes (a lot)
- ☐ 2.
- ☐ 3.
- ☐ 4.
- ☐ 5. No (not at all)

Please provide a brief explanation _____

24. Has the taxonomy been incorporated into a routine or structure or it is planned to be? e.g. management, training, service codes (select one)

- ☐ 1. Yes (a lot)
- ☐ 2.
- ☐ 3.
- ☐ 4.
- ☐ 5. No (not at all)

Please provide a brief explanation _____

7.5 Appendix 6.2 Personalised dissemination audiences

Table 6.7 Personalised dissemination audiences

	Name	Location	Description of sector related to CM	Health condition	Date commenced	Method	Who	Support
1	American Council Rehabilitation Medicine - community based treatment	United States America	Community of practice - interested in research	Complex health conditions	6/5/2016	SE	SL	Y
2	Brain injury association/Synapse (BIA)	NSW and Queensland	Two state brain injury association for persons with a brain injury	Brain injury	26/4/2016	E	SL	N
3	Brain Injury Australia	Australia	National disabled person's organisation for brain injury	Brain injury	26/4/2016	E	SL	N
4	Brain Injury Rehabilitation Directorate - unit managers	NSW	state policy maker, employer, educator of brain injury to wider health system providers	Brain injury	13/2/2015	F	SL	N
5	Brain Injury Rehabilitation Directorate -researchers	NSW	researchers, policy, planning	Brain injury	4/3/2015	F	SL	N
6	Bridging aging and disability international network (BADIN)	International	Research collaboration	All health conditions	28/11/2015	F E	LSC	N
7	British Association of Brain Injury Case Managers (BABICM)	United Kingdom	National peak professional body for CM specialising in brain injury	Brain injury	16/1/2015	F E	SL	N
8	Carer and advocate	NSW	service user and advocate	Intellectual and developmental disability	26/4/2016	E	SL	N
9	Case management activities and interventions in the NDIS	Australia	Researcher	Complex health conditions	1/5/2016	F E	LSC	Y
10	Case management for children and adolescents with acquired brain injury	Australia	Researcher	Brain injury	1/6/2015	F E	LSC	Y
11	Case Management Society of Australia (CMSA)	Australia	peak professional body for CM	All health conditions	18/12/2015	S	SL	N

12	Case Management Society of United Kingdom (CMSUK)	United Kingdom	National peak professional body for CM	complex health conditions	22/10/2015	F E	SL	N
13	Centre for Quality in Care – curriculum development for CM	Germany	Research, education	Ageing and older population	6/10/2015	F	SL	N
14	CM – qualitative researcher	United Kingdom	Researcher – qualitative research (CM)	All health conditions	22/10/2015	F	SL	N
15	CM and older persons	United Kingdom	Researcher – implementation (Older persons/aged care and cross cultural	Ageing and older population	19/8/2015	E	SL	N
16	CM for older persons	Sweden	Researcher – implementation (Older persons/aged care and multi-morbidity)	Ageing and older population	12/10/2015	F	SL	N
17	Cross sector service coordination for people with high and complex needs (Research project at the University of Sydney and Young people in nursing homes alliance)	Australia	Researcher - implementation research: Complex needs	Complex health conditions	30/7/2014	E	SL	N
18	Evaluation & Classification of services for long term care in Europe -DESDE	International	Classification revisions related to services	All health conditions	10/2/2015	F E S	LSC	Y
19	German Society for CM	Germany	National peak professional body for CM	All health	5/10/2015	F	SL	N
20	Griffith University	Queensland	Researcher - community support for people injured in motor vehicle crashes	Complex health conditions	26/6/2015	E	SL	N
21	Guttman Institute	Spain	Service provider and research institute – (brain injury and spinal cord injury)	Complex health conditions	26/10/2015	F E	SL LSC	N
22	Icare – Workers Care - provider management	NSW	state policy maker, funder, employer	Complex health conditions	28/11/2015	F E	SL	N
23	Icare- Lifetime Care & Support Authority (LTC)	NSW and ACT	state policy maker, funder, employer		7/10/2014	F E R	SL	Y
24	icare- workers care policy	NSW	state policy maker, funder, employer	Complex health conditions	21/9/2015	F E	SL	N
25	Integrated care – primary care	Netherlands	Netherlands - Researcher – implementation (primary care)	All health conditions	9/10/2015	F E	SL	N

26	Keystone Professionals	NSW	Sydney based service provider employer, trainerof CM	All health conditions	12/5/2015	F E	SL	Y
27	Kings College London - Mental health	United Kingdom	Research Institute – implementation science educators; mental health research; guideline methodology	Mental health	20/10/2015	F E	SL LSC	N
28	La Trobe University	Victoria	Researcher - neurological conditions	Complex health conditions	4/12/2015	E	SL	N
29	Lifetime Support Scheme	South Australia	state policy maker, funder, employer	Complex health conditions	11/3/2016	F	SL	N
30	March of Dimes	Canada	Service provider people with disabilities	Intellectual and developmental disability	15/12/2015	S	SL	N
31	Mental Health implementation research – University of Catalonia	Spain	Researcher – mental health	Mental health	26/10/2015	F	SL	N
32	Mental Health Research Partners in Recovery (PIR) –University of Sydney	Australia	Researcher - implementation research	Mental health	25/4/2015	E	SL	N
33	National Changhua University of Education	Taiwan	International research network rehabilitation counsellors	All health conditions	27/2/2015	F	MM	N
34	National Disability Insurance Agency	Australia	national policy maker, funder, employer	All health conditions	10/3/2015	S	SL	N
35	National Institute of Clinical Excellence	United Kingdom	national policy, research, guidance	All health conditions	15/10/2015	F	SL	N
36	Pharmacy Association	Australia	national professional body	All health	10/12/2015	E	LSC	N
37	Post-acute healthy care utilization after severe TBI	France	Researcher – implementation	Brain injury	25/8/2015	S E	SL	N
38	Rehabilitation Case Managers Network - Brain injury	NSW	service providers	Brain injury	4/5/2016	F	SL	N
39	Support Planning with people with complex support needs (UNSW)	Australia	Researcher - implementation research	Complex health conditions	30/4/2016	E	SL	N
40	Surry Place	Canada	Non-government organisation primary care, people with intellectual disability, research	Intellectual and developmental disability	20/11/2015	F E	LSC SL	N

41	Swiss Paraplegic Research	Switzerland	Research institute (Spinal Cord Injury)	Spinal cord injury	11/12/2015	E	SL	N
42	Transport Accident Commission	Victoria	state policy maker, funder, employer	Complex health conditions	10/3/2015	F E	SL	N
43	University College of London - mental health	United Kingdom	Researcher, clinical lead	Mental health	20/10/2015	F	SL	N
44	University of Sydney - Mental Health	NSW	Researchers	Mental health	16/12/2014	F	SL	N
45	University of Sydney Rehabilitation Counselling	NSW	Researchers, educators	All health conditions	11/6/2015	F	SL	N
46	University of Sydney Occupational therapy	NSW	Researchers, educators	All health conditions	10/6/2015	F	SL	N
47	University of Toronto	Canada	researcher, educator	Brain injury	20/11/2015	F E	SL LSC	Y
48	Vocational Traumatic brain injury project (VIP) BIRD and John Walsh Centre	Australia	Researcher - implementation research	Brain injury	13/2/2015	F E	SL	N
49	World Health Organization - International Classification of Health Interventions	International	Classifications related to health interventions	All health Services	10/10/2014	F E	SL LSC	Y
50	World Health Organization (WHO) – Ageing and Life course, Health systems	International	International policy development, research, guidelines	Ageing and older population	3/11/2015	F	SL	N
51	World Health Organization (WHO) – Disability, Rehabilitation	International	International policy development, research, guidelines	All health conditions	3/11/2015	F	SL	N

E = email; F = face-to-face; R = report; S = Skype

SL = doctoral candidate; LSC = co-researcher/supervisor; MM = co-researcher/supervisor

7.6 Appendix 6.3 Conference paper and poster presentations

WHO-FIC 2014 paper and poster presentation

WHO - FAMILY OF INTERNATIONAL CLASSIFICATIONS NETWORK ANNUAL MEETING 2014

WHO-FIC Network Barcelona ANNUAL MEETING 11-17 October

Mapping a preliminary taxonomy to ICHI

11-17 October 2014
Barcelona, Spain

Poster Number
WHO/CTS to insert

Lukersmith, S[1,2]., Fernandez, A[1], Millington, M[1.],Brain injury case management nominal group[2], Salvador-Carulla, L[1]

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Abstract Case management makes a unique contribution towards improved functioning and participation for persons with complex health conditions. The need for a common language and clarity about what is, and what is not case management was the impetus for the development of a preliminary taxonomy on case management in brain injury. The taxonomy was iteratively developed in four phases with mapping to ICHI in the final phase. There is alignment of the taxonomy with ICHI for some actions, but there are differences in the grouping of actions, as well as gaps in ICHI. Proposed inclusions to ICHI are identified.

Introduction

Case management makes a unique contribution towards the improved functioning and participation of a person with a complex health condition such as brain injury. Community-based case management has multiple components and variations, depending on the context in which it occurs and the client population. The description of case management and the components in the literature is highly variable. The need for language and clarity about what is, and is not case management was the impetus for the development of a preliminary taxonomy on case management for persons with brain injury and spinal cord injury. A component of the feasibility analysis of the beta version of the taxonomy is mapping to ICHI

Methods & Materials

The brain injury case management preliminary taxonomy (BICM-PT) developed in four phases.

Phase 1
A systematic search and review of the case management literature to extract information on the components, activities and descriptors of case management.

Phase 2
A critical review of appropriate frameworks to inform the structure of the taxonomy.

Phase 3
The iterative development and refinement of the draft taxonomy using consensus with a nominal group of experts in case management.

Phase 4
Mapping the actions, main actions and related actions of the draft taxonomy to ICHI to identify the alignment and gaps and submission of proposed inclusions to ICHI

References

1. Salvador-Carulla L, Walsh CO, Alonso F, Gómez R, de Teresa C, Cabo-Soler JR, Cano A, Ruiz M. eVITAL: a preliminary taxonomy and electronic toolkit of health-related habits and lifestyle. Scientific World Journal. 2012;2012:379752.

2. ICHI Alpha 3 revised definitions (31 March -22 April 2014; Nicola Fortune and Ann-Helene Almborg, Megan Cumerlato, Lindy Best

Results

Following Phase 1 and 2 the BICM-PT beta 1 was developed which involved 12 actions and more than 50 components. The nominal group[1] formed to develop and refine the beta 1 version through iterative development and consensus. The group included multi-disciplinary expert case managers who work with children and adults in both urban and regional areas in different service contexts. The group refined the taxonomy which included 13 actions and 37 components.

Following the mapping to ICHI (Phase 4), the taxonomy was further refined (BICM-PT beta 2) as a derived classification from ICHI with 9 actions and 25 components (Table 1).

The proposed inclusions for ICHI outlined in Table 2 were forwarded in June 2014.

Table 1 The main actions in the BICM-PT taxonomy tree

1. Engage with the client	2. Holistic assessment	3. Planning
4. Education	5. Training & skills development	6. Emotional & motivational support
7. Advising	8. Coordination	9. Monitoring

There was alignment with the revised ICHI action definitions[2] and BICM-PT:

- *Preparation, Education and Monitoring* as separate actions
- The revised definition of *Training*
- Revised title from counselling to *Advising*
- Revised title from personal support to *Emotional support*
- The changes to Client support action
- *Task performed by another and practical support*

Table 2 Proposed inclusions to ICHI

Proposed new actions	
Coordination	*'Navigating and facilitating the access, management and cohesion of services and supports for the client'*
Planning	*'Support the client to develop their individualised plan including setting client goals and priorities, actions, responsibilities to achieve the goals and identify the supports needed (services and resources)'.* Includes*: Managing risks - (taken by the client) weighing up the potential benefits and likelihood of something happening, the impact or harms, respecting and supporting client choice and recognising acceptable risk is part of everyday life, for the development of strategies to manage unacceptable risks*
Inclusion to actions	
Emotional & motivational support	Inclusion*: engaging and building a partnership between the client and service provider*
Inclusions to titles	
Training	Training *and skill development*
Emotional support	Emotional *and motivational* support

Conclusions

It is not possible to map all actions and components of case management to ICHI Alpha 2 (including the February amendments). There is alignment of the BICM-PT beta 2 version with ICHI for some actions, but there are differences in the grouping of actions as well as gaps in ICHI.

Acknowledgments

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WHO-FIC 2015 paper and poster presentation

WHO - FAMILY OF INTERNATIONAL CLASSIFICATIONS NETWORK ANNUAL MEETING 2015

WHO-FIC NETWORK
ANNUAL MEETING
MANCHESTER UK
2015

Use of International Classifications (ICF, ICHI and DESDE-LTC) to develop a new taxonomy of Case Management

17-23 October 2015
Manchester, United Kingdom

Poster Number
WHO/CTS to insert

Authors: Sue Lukersmith[1], Michael Millington[1], Ros Madden[1], Luis Salvador-Carulla[1,2]
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Abstract

The ICF framework articulates the biopsychosocial model of health. The ICF was one of three international frameworks selected to underpin the development of a taxonomy of community-based case management interventions for brain injury. Use of an international frame such as the ICF resulted in efficiencies and strengthened the rigour of the taxonomy.

Introduction

Case management, care coordination, support planning are terms which represent the diversity in practice of case management (CM). CM has multiple components and variations differentiated by the theoretical approach or model, context, and the client population. The diverse expressions of CM have confounded professional consensus on a common framework and standard definition for CM. This has significant implications for clinical practice, monitoring, planning and semantic interoperability.

In this research case management practice was based on the theoretical background of the biopsychosocial model of health and disability, and two main care models (person-centred care and community care). In practice this means that case management is provided within a community context and adopts a human rights approach, which holistically considers the client's own context and situation, strengths, choice and goals for participation in key life areas, the barriers and facilitators to their participation, and promotes active involvement in planning.

A new taxonomy of case management was developed. It has been designed to allow for semantic interoperability and interconnectedness with three international classifications: functioning, disability and health (ICF), health interventions (ICHI) and services/care delivery (DESDE-LTC). The interconnection with the ICF is presented here.

Methods & Materials

Mixed qualitative methods were used to develop the taxonomy including scoping, framing and a nominal group technique of experts (n-12) to iteratively develop the Beta version of the taxonomy. The structure and concepts of the international frameworks was used in the development of the Beta version of the taxonomy. A two part developmental evaluation involved case studies and also mapping to the international frameworks to assess the applicability and acceptability (feasibility) of the Beta version, revision and then finalisation of the Brain injury case management taxonomy (BICM-T).

Results

The concepts and language in the ICF aligns with the approach taken in community-based and person-centred case management. The ICF identifies and defines the domains of health, their interaction and influence on functioning. At the onset of the nominal group, it was established that the ICF was to be adopted as a frame.

The framework and common language of the ICF facilitated discussions by providing a point of reference and clarity during nominal group discussions, supported the distinctions between concepts and enhances the consensus process for the definitions developed for the identified interventions. Examples are: the ICF concepts assisted with discussions around the differences between ability and capacity versus functioning; these discussions influenced the definition of the intervention (action)–*holistic assessment*; the ICF groups and definitions of contextual factors (environmental and personal) influenced the definitions of *formal and informal supports*. There were seven key definitions used in the taxonomy glossary taken directly from the ICF (context, disability, functioning, health condition, health, health related domains, personal factors).

As part of the feasibility analysis of the Beta version, developmental evaluations were undertaken. One of these involved using the ICF to review the conceptual and language consistency across the taxonomy. The taxonomy was reviewed for alignment with all three international frames (ICF, ICHI and DESDE-LTC)). This resulted in some refinement to the interventions and definitions.

Conclusions

The research used international frames to inform the concepts, development process, structure and review of the feasibility of the case management taxonomy. The ICF together with the other reference classifications (ICHI and DESDE-LTC) provided a conceptual knowledge map and a common language for the theoretical model of community based person-centred case management to underpin the taxonomy. Use of an international frame such as the ICF resulted in efficiencies and strengthened the rigour of the taxonomy.

Acknowledgments

We acknowledge the in-kind support of the Lifetime Care & Support Authority for 15 days of Sue Lukersmith's time during the development of the taxonomy and also hosting the nominal group meetings. We thank the nominal group members who so willingly contributed their expertise and time.

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GIN 2016 Paper presentation

The paradoxical challenge for guideline methods:

the person-centred health care clinical guideline

Sue Lukersmith, Luis Salvador-Carulla

Background: A key objective of clinical guidelines is consistency of practice. Arising from evidence-based medicine, current best practice guideline methodology uses clinical research as the main source of knowledge. There is terminological variance on person-centred, people-centred, patient-centred and personalised medicine. There is an obligation for clinicians to use a guideline yet a contradictory pull to be less flexible and responsive to the patient's context, individual preferences and needs. It leads to poor uptake and implementation of recommendations and presents a barrier to person-centred care. There is an urgent need and challenge to develop guideline methodologies which recognise and use both discovery research and implementation knowledge to promote person-centred health care.

Objectives: To clarify and identify the key characteristics of person-centred health care and sources of knowledge, to support the development of methods for person-centred guidelines; and to develop a preliminary method to assess for person-centredness.

Methods: An extensive literature review identified the key characteristics of person-centred health care. The characteristics were linked to a typology of scientific knowledge and a preliminary method for assessing guidelines 'person-centredness' was developed and piloted.

Results: Three guidelines which used standard and two emerging guideline methodologies (framing and logic modelling) were assessed. The results are presented.

Discussion: The key features and differences of person-centredness, advantages and disadvantages of each guideline development method are discussed. Further work is needed.

Implications: The contradictions in standard guideline methodology can be barriers to implementation. New methods that support person-centred care are needed.

ASSBI 2015 Poster presentation

The development and implementation of a taxonomy of case management in brain injury (BICM-T)
-providing the answers to the questions

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BACKGROUND AND AIM:

Community-based case management makes a unique contribution towards the improved functioning and community participation of people with complex health conditions such as brain injury [1-3].

How come there is no international consensus on what is, and what is not case management?

Case management necessarily involves complexities and variability associated with the services, interpretations of roles and responsibilities as well as client circumstances and context. There are multiple components to consider. Each country, organisation and service has their own 'model' of case management depending on the context and the client's health condition. Case management occurs in populations with such diverse health conditions as diabetes, malaria, dementia, HIV, stroke, mental health and brain injury. Case managers from different health disciplines bring slightly different approaches to their work.

Case managers performing one or a number of case management interventions are often called by many different names. To mention a few: Community care coordinator, care coordinator, case monitor, coordinator, local area planner, discharge planner, support broker, support facilitator and support navigator. Case management is not a discipline rather is set of interventions.

Further, not all case managers perform all of the same interventions. They do not work for the same types of organisations and services, nor within the same jurisdictions.

A quintessential Asian phrase used to explain similarities but differences "same same but different" is also true of case management.

Why is that a problem?

The variability of case management is a problem for research on case management effectiveness. There have been numerous systematic reviews [4, 5] and studies [6, 7] which highlight the difficulties with clinical trials, the heterogeneity between interventions, the range of outcomes measured and the association between case management components or interventions and client outcomes.

The lack of a common language on case management has a subsequent impact on quality analysis, policy development, planning and funding of services, as well as management of, and training for case managers.

What is the solution?

The aim was to develop a knowledge framework (the taxonomy) and common language for researchers and organisations like the Lifetime Care & Support Authority (LTCSA) and other stakeholders to support quality analysis, best practice, skill development and training.

METHODS

What is a taxonomy?

A taxonomy is a type of knowledge map and framing tool that uses a common language. As a classification structure, a taxonomy organises knowledge and articulates the relationship between concepts and components, and provides definitions [8, 9].

How did we develop the taxonomy?

The study used mixed qualitative research methods over 18 months to develop the taxonomy. The methods included a scoping study and critical review of international frames to develop the Beta 1 version. A nominal group technique used with a group of case management experts followed (refer to Table 1). The expert knowledge across the group included brain injury case management practice (adults and children), policy, planning, management and funding. It had representation from public, private and not for profit sectors, included different health disciplines and experts from both urban and rural settings. There were meetings over 6 months for refinement into the Beta 2 version. After a feasibility analysis using case studies and a review of the alignment to the international frames and a final nominal group meeting, the BICM-T was finalised in January 2015.

RESULTS:

What does the taxonomy involve?

The BICM-T is a multi-dimensional framework and considers factors related to the case management service domains and a taxonomy tree of key components (interventions or actions). It includes a consensus definition of case management and glossary of terms. The definition of case management in the BICM-T is

> **Community-based case management** - Community-based case management is a multidimensional and collaborative process. It involves a set of interventions for assessment, planning, coordinating and review of the options and services required to meet the client's health-related needs, and support them to reach their goals related to participation in life roles
>
> Lukersmith, S., Fernandez, A., Millington, M., CM Nominal Group, Salvador-Carulla, L. (2015) The Glossary: A preliminary taxonomy of community-based case management in brain injury (BICM-PT)

Only the intervention tree is presented here (Refer to Figure 1 below). Contact the first author for the glossary of terms, service tree and intervention and service tables.

How will it be used?

Organisations such as the Lifetime Care and Support Authority (LTCS) will be able to use the taxonomy to enhance communication, understanding and business practices over the coming years to:

- ✓ Promote better understanding between stakeholders including service providers, clients and organisations about what is and what is not case management. Enhanced language and understanding supports problem solving between stakeholders.
- ✓ Explore the different roles and the expectations for case management activities particularly with respect to clients in the post-acute phase following serious injury compared to clients who are many years post injury.
- ✓ Distinguish between different case management services and their strengths
- ✓ Strengthen training and mentoring opportunities including the development of training resources
- ✓ Link case management interventions with outcomes. If what is being done is better understood, then specific components of case management can be linked to improved outcomes.

As other organisations and researchers in Australia and other countries become aware of the taxonomy, additional applications of the taxonomy in different contexts are emerging.

Conclusions: The taxonomy is a knowledge to practice tool. It provides a common language for case management practitioners, services and funding organisations relevant for monitoring, comparisons, business planning and quality assessment.

Figure 1. Interventions (throughputs) tree

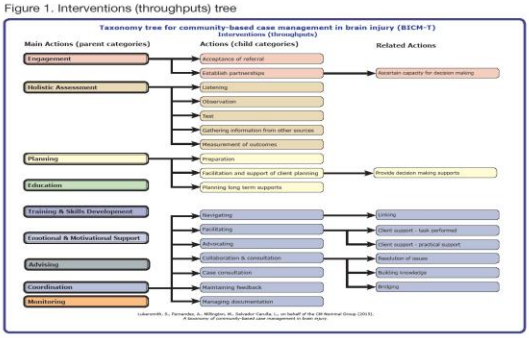

Table 1. Case management experts

	Name	Professional background	Areas of expert knowledge: Client group*	Case Management: Practice	Policy Planning	Management	Funding	Service Context +	Geographic ++
1	Di Croker	Occupational therapy	A	X	X	X	X	Pub, Pr	U,R
2	Margaret Doyle	Speech pathology	A	X	X	X		Pub	U
3	Marion Fisher	Speech pathology	C	X	X	X		Pub, Pr	U
4	Rebbekah Loukas	Psychology	A	X	X	X		NFP	U
5	Suzanne Lulham	Physiotherapy & law	B		X	X	X	Pub, Pr	U,R
6	Elizabeth Shannon	Physiotherapy	A	X				Pr	U
7	Jo Suhanic	Social work	B	X	X			Pub	U,R
8	Deb Toffolo	Speech pathology	B	X	X	X		Pr	U
9	Karen Williams	Nursing	B	X				Pr	R
10	Janine Wood	Speech pathology	B	X	X			Pub	U,R
11	Denise Young	Social work	B	X	X	X		Pub	R
12	Sue Lukersmith^	Occupational therapy	B	X	X	X	X	Pub, Pr	U

^ Facilitator
* Client Group: Adult=A, Children=C, Both Adult and Children=B
# CM practice: Practice, Policy and planning, Management, Funding
+ Service context: Public (Pub), Private (Pr), Not-for profit (NFP). ++ Geographic; Urban (U) rural (R)

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EBHC 2015 Abstract accepted but unable to present

How common taxonomies contribute to the reduction of evaluation bias in the analysis of variability and waste?

Sue Lukersmith, Michael Millington, Luis Salvador-Carulla

Background: Effectiveness analysis in systematic reviews and evidence synthesis of case management and care coordination is impeded by a lack of a common language to describe services and interventions. Research on health and community care has also reported on poorly integrated services, the duplication and waste. Some organisational health interventions potentially increase value and reduce waste, including those that target the integration of health care and community supports. In post-acute community-based settings case management and care coordination services are particularly important and make a unique contribution towards the improved management and integration of care with complicated health conditions such as mental health, dementia, stroke and brain injury. There are complexities and variability associated with factors of the organisations, interpretations of roles and responsibilities as well as patient circumstances and context. These systemic factors and the variability in care coordination interventions must be observed and appraised to minimise the potential for evaluation bias in quality analysis research. Common taxonomies provide an agreed language and can contribute to better understanding and observation of intervention variability to support quality analysis, health care policy, planning and service utilisation.

Aim: To analyse and map two very different cases of care coordination using a brain injury community-based case management taxonomy (BICM-T) and report on how variability may contribute to evaluation bias.

Methods: A case study on two care coordination services; an early high intensity community-based case management service and a longer term low intensity service for a brain injury population funded by one organisation and performed by providers from other organisations. The services were mapped to the intervention and service trees of the taxonomy. Further analysis demonstrated how these differences potentially influence observation of outcomes and observation of effectiveness in the integration of care.

Results: The mapping of the two case management services to the BICM-T highlighted the heterogeneity in case management and care coordination across the two axis of interventions and service. Some of the potential impacts on evaluation and service planning, utilisation and funding are described.

Limits: The documentation and descriptions available on the case management interventions and services. The documentation was supported by the researcher's contextual knowledge which enhanced mapping and analysis.

Conclusions: Brain injury impacts on multiple domains of health and participation, the person's cognitive, physical, psychological, behavioural functioning and participation in life roles. Case management for persons with brain injury demands a complex response by services, programs and interventions necessarily leading to variability in service and interventions. The case study in mapping case management for brain injury to the taxonomy identified differences between the two services. If not observed the variability could potentially result in evaluation bias. The case study exemplifies how mapping methods to a taxonomy of interventions and services can enable observation of differences, analysis of variability and contribute to reducing evaluation bias to increase value, reduce duplication and waste.

7.7 Appendix 6.4 Group 2 Comments and explanation

Comments and explanations Q.10 Covers the important dimensions of CM	Q.11 Allow better understanding	Q.12 Contributed new information	Q.13 Discussed the relevance with colleagues	Q.14 Forwarded information to others	Q. 15 Included information on or from documents, website	Q.17 Applications or use of the taxonomy	Q.19 Does it provide all materials needed	Q.20 Usefulness in relation to time and effort	Q.21 Require allocation of time or resources	Q.22. Resulted in change	Q. 23 Build on another area	Q.24 Incorporated (or planned to be) into routine structure or
Yes		Very useful	We would love for the it be expanded to include a quick reference guide with a 3 level rating system to help describe the intensity of services.	To other team members	Within community living plans to assist with funding request and explanation as to the services the case manager would provide.	Within community living plans	Further rating system would be useful or guidelines for the delivery of case management services in the community sector (would need to be population specific)....	Yes	Required explanation	Improved consistency with role of case manager	Not really	Work continues on making sure case managers fully understand the scope of their roles
I found the table offered from Sue most user friendly.	Puts into words what we do, which is not an easy task.	I can see it would be useful tool to explain to others re the diversity of the role.	I was involved in a CM network meeting which discussed this. This was soon after the roll out. Otherwise I have not discussed this since then.	I have not forwarded the full information package at all but have used some of the wording and descriptions in funding submissions.	I work for myself and do not have a website.	Have used this to explain my specific role with a client in my request for funding.			It took longer to draft a request for funding but I thought the end result was more comprehensive and professional. I had no feedback on whether this level of detail added to my submission or not, so I have 'slipped' back.	Nothing lasting.	I do not see what other use I would have for this.	No.
Yes	Yes, it clarifies tasks completed by case managers.	It has clarified information on the subject.	briefly during a case mangers meeting (internal).	No I have not forwarded this information to anyone	No, I have not referred to, or included any information on (or from) this taxonomy in my internal documents or website?	checked with the taxonomy that I had covered all services provided to my client (in a progress report on case management support).	Yes, it covers all case management tasks.	It is a good checklist to confirm all tasks are accounted for in case management reports	Time to read taxonomy then review the glossary for case management reports	the taxonomy has not been adopted by the case manager team. it is used by the individual as needed.	No, information from the taxonomy has not been used in other areas of my work or the work of the case management team.	No plans to use it systematically.
I find the Intervention Tree easier to understand and use than the Services Tree.	helps to articulate the breadth of what a CM does	has brought together lots of ideas of what CM is within the TBI service sector - common language, common understanding of what is therefore expected.	yes - but mostly those involved in the over-sight of the case manager service group	to all case managers that we work with, to other funders of similar services	it is now in the case management Expectations (our 'standards'), all training for new case managers,	determining when a professional CM is needed - as distinct from another purely coordination role; writing standards, defining/refining the role of a CM in planning,	sometimes I look for 'what CM is not', or - yes you do one or two of the main actions, but it is the breadth and combination of many of the actions that make you a case manager - so ?how many 'actions' make a CM, and if you only do one or two - then are you really something else?		it is easy to generalize and assume an understanding of what CM is - need to really understand via the glossary to fully apply the taxonomy	not yet - but I think it will as we refine our needs for CM for people across the rehab continuum	other than in defining what CM is NOT - so looking for cheaper alternatives to provide services that CM are not needed for.	standards, role of CM across rehab continuum.
Yes, however the taxonomy view case management as a profession. It is also possible to view it as a model or a function, thus adding important case management concepts such as case finding.	Yes, it helps to clarify the actions of case management.	Yes, it provides a useful taxonomy.	Yes, primarily within our research group working with case management. It is a needed initiative as case management is a broad and sometimes diffuse area in need of clarifying its actions.	Information has been forwarded to those researchers I collaborate with regarding case management.	No there has not been any need for that yet.	Currently, I have plans of utilizing the taxonomy as a way of describing case management and its actions in documents.			Not applicable since I have been involved from a researcher's perspective and have not applied or used the model.	No it has not.	The information found in the taxonomy will be of help for me in my future research regarding case management.	Not applicable.
None	This would be of great use in systematic reviews of case management as complex interventions. It would really help to unpick interventions with the potential to identify the real active components....	I am not an expert in this field, but an agreed taxonomy, if used widely, could be of real benefit - for example, improving consistency of language.	None	None	None	We may explore how this could be used in evidence synthesis to full understand what components are included in interventions and potentially which components are therefore driving any effect	None	None	Not used it in practice yet	Not relevant for our work - although as noted we may explore its use in evaluation of case management interventions	However, we may explore this if the taxonomy is useful for case management evidence synthesis	Not relevant for our work...

Q.10 Covers the important dimensions of CM	Q.11 Allow better understanding	Q.12 Contributed new information	Q.13 Discussed the relevance with colleagues	Q.14 Forwarded information to others	Q. 15 Included information on or from documents, website	Q.17 Applications or use of the taxonomy	Q.19 Does it provide all materials needed	Q.20 Usefulness in relation to time and effort	Q.21 Require allocation of time or resources	Q.22. Resulted in change	Q. 23 Build on another area	Q.24 Incorporated (or planned to be) into routine structure or
My own investigation into what informal learning influences the conduct of brain injury case manager's practice highlights the range of skill development from personal experience. I envisage that there may be room for some collaborative work on the part of the taxonomy regarding skills development and education.		Not new to me personally but makes great progress in providing an academic and theoretical framework for case management that has been sorely needed	Sue presented to CMSUK in 2015		I have referenced this in my Phd thesis. I will be incorporating this in documents in the future but as yet have given little thought to how this will sit within the body of the organisational framework							
	The importance of the taxonomy is that it delineates the elements of case management/coordination , makes it possible to assess their relative significance (for whom, under what circumstances) and progresses the case for consistent terminology. This all makes it more possible to demonstrate the impact of different case management interventions	Yes, see above. It fosters a common language and provides an evidence-base for the essential elements of this 'complex' intervention.	As researchers, we will be keeping updated on new research on the uses of the taxonomy. However, we expect it will be helpful in confirming the need for a clear approach to the purchase of case management for the NDIS	n/a	n/a	We cite this taxonomy in a journal article about planning in the NDIS which is currently under review.			It was used by the authors of a journal article for the purpose of explaining the elements and role of planning in the intervention tree	N/A	N/A	N/A
		It is a new tool, which is valuable to define what it is that case managers working with people with brain injuries do.	It is on the agenda to discuss at our next colleague meeting.	Haven't as yet.	Haven't as yet.							
As a contributor to the development, I may have had an advantage in the understanding..	The reason I do not say 'a lot' is because our Case Management group had already described and classified what we thought was case management, and although very compatible, there were some subtle differences.	see comment above	we have mapped the taxonomy to the work we had done earlier.	shared with other colleagues	see comment to 11 and 13.	tracking time and tasks against some of my current caseload	most, although not all. I can see that different work contexts can add to these dimensions.		have spent many hours working out how it fits in our context and how we could potentially use it.	not yet..but may over time.	not yet, but may over time	useful for training, and supervision/management
I do not know a lot about case management in practice, but the taxonomy is clear and seems to provide a sensible and logical breakdown of the types of actions that constitute case management			We have used the taxonomy as a basis for developing Action axis categories and intervention codes within the WHO's International Classification of Health Interventions (ICHI), to ensure that case management interventions are adequately covered	I have forwarded it to the ICHI development working group	We have prepared discussion documents in which Actions from the BICM-T are mapped to Action categories in ICHI							

Q.10 Covers the important dimensions of CM	Q.11 Allow better understanding	Q.12 Contributed new information	Q.13 Discussed the relevance with colleagues	Q.14 Forwarded information to others	Q. 15 Included information on or from documents, website	Q.17 Applications or use of the taxonomy	Q.19 Does it provide all materials needed	Q.20 Usefulness in relation to time and effort	Q.21 Require allocation of time or resources	Q.22. Resulted in change	Q. 23 Build on another area	Q.24 Incorporated (or planned to be) into routine structure or
	Excellent way to provide consistency of language around case management services and increased understanding of potential service provision	Yes - an excellent resource to allow for a greater understanding of the depth of case management services and allows a 'vehicle' to clearly articulate service provision in case management.	Team meeting and individual meeting with Sue Lukersmith Ongoing internal discussions within organisation Discussions with colleagues external to the organisation.	Insurers, in discussion with funders (LTCS) etc., and colleagues.	Trialled in some plans and in documentation - reference also provided. Awaiting update to templates to allow for easier use of CMT Website not updated as yet.	As above: Trialled in some plans and in documentation - reference also provided. Awaiting update to templates to allow for easier use of CMT Website not updated as yet.		For case managers who have to provide plans for approval of their 'time', it is a very useful tool to expedite descriptions of service and to emphasize particular needs of a case, in a consistent fashion and without having to duplicate the individual issues, which are often documented elsewhere.	Considered as ongoing CPD, however the efficiency of using the CMT will be worth this allocation of time and resources. It is thought that the greater the understanding of the CMT across industry etc., the easier it will be to use (i.e., if funders understand it, they can approve plans based on the taxonomy etc.) and hence create further efficiency...i.e, the more that use it, the more effective a communication tool it will be... Of note - we still have to prioritise the use of the CMT in all cases.	Not yet - but anticipated with greater implementation in our systems.	Across all jurisdictions and injury types (not just Brain Injury).	Planned
		Helps standardising the method	Still in process	Still in process	Not yet, plans to do so.	Plans to do so in the next revision of a case management curriculum that has been developed by our institute			No	Still in process	Still in process	Plans to use for the next revision of a case management curriculum by our organization
I suppose I had to look quite hard to see the communicative aspects of the activities associated with case management since 'communication' or 'knowledge exchange' both among professionals and between staff and patients/users is not an explicit descriptive category.		xxxx	We are thinking of using it in an adapted form to look at multi-disciplinary case management of frail older people with a range of long term conditions.	But it has been circulated to all members of my research team working on integrated care in England.	But we are highly likely to be referring to it in future in protocols for the next stage of our work on integrated care.	See comment above. We are using it to identify sites with similar MDT case management activities which then become candidates for comparative evaluation.			We are still in the process of using it so my answers are tentative.	Too soon to tell	I don't understand the question. Sorry.	xxx
		Provides a useful frame of reference by distilling existing information and CM practices	Has potential significance for future planning in relation to management CM	as above	in a draft options paper	answered above			As with any information or tool, time is required to understand and apply to a specific work setting	TBC		
		The subject is new to me	it is being discussed in connection with a business case for severely injured workers	My manager and a colleague	Business case	It is being incorporated in a business case for severely injured workers			Only the principle is currently being used - has not been applied in practice	It is influencing a strategy/business plan currently being written	Business option paper for severely injured workers	Same as above
		The online recordings that explain the taxonomy are excellent- well done Sue	I do not directly work in this area of practice/ research now.	This is the first time i have viewed/listened to information about the taxonomy (although I've heard about it from Sue over the past year), so have not yet forwarded the info to anyone else. The email also asked me NOT to forward the survey onto other people, so I have not.	I am not currently working for or as part of an organisation that provides case management							

Q.10 Covers the important dimensions of CM	Q.11 Allow better understanding	Q.12 Contributed new information	Q.13 Discussed the relevance with colleagues	Q.14 Forwarded information to others	Q. 15 Included information on or from documents, website	Q.17 Applications or use of the taxonomy	Q.19 Does it provide all materials needed	Q.20 Usefulness in relation to time and effort	Q.21 Require allocation of time or resources	Q.22. Resulted in change	Q. 23 Build on another area	Q.24 Incorporated (or planned to be) into routine structure or
	I believe it does. It provides a sense of the order of things.	There was no legitimate taxonomy prior to this.	I discuss this topic within my department and with members of the accrediting bodies for my profession in Australia	I have built it into documents, but less so direct conversations about it. I am building sefl-instruction training modules that will address it.	I have integrated the taxonomy into our course competency standards, and into the new curriculum design: generally referenced in tutorial strategy, structurally represented and directly taught in a case management unit of study.	The Taxonomy is an integrated feature of course design.	Its very intuitive and comprehensive. But it is the first iteration of a design that should be repeated within this specialisation and across case management models, in different countries and contexts. I believe it will likely sharpen in focus, become more universal in application, and start to develop innovative applications through this process over time.	It's intuitive. It makes practical sense out of complexity.	For my purposes, its part of my job. It requires investment from me to put it into practice, but not as an addition to my workload.	The case management nit of study will be framed by it, rather than the rather eclectic grab-bag of topics currently in use. It will also help in the design of case studies for the new tutorials.	The course review project is a black hole of attention and effort. I am contemplating how to use it for research purposes.	The taxonomy will also be used to redesign the training and monitoring of students on field placement.
NA	NA	NA	At the PSICOST core group and board	NA	NA	we have partly incorporated it into the DESDE-LTC classification	NA	NA	We have just incorporate parts of it into the DESDE-LTC systems This action did not required any additional funding	We have changed the original questionnaire	We will like to apply it to other areas apart from Brain Injury	NA
One of the components that we feel overlays our case management is our relationship approach. This is key for us.		I think it is consolidating known information	We have reviewed our role, what we consider important and whether the taxonomy includes all of these components.	Internal staff have reviewed the documents	In the process of drafting our own case management framework with reference to the taxonomy.	as detailed above	Further exploration of the stages of case management would be beneficial and definition of these	Was not time consuming to apply or interpret	Time for review by all staff to ensure buy in	The taxonomy itself has not elicited a change however has assisted a change already in progress	Early days however may be required, not yet known	Will assist in refining the case manager role and role division at different stages of injury/recovery and relationship with the client
		Very useful to have a common language	Potential for mapping services	Not yet but I plan to	N/A	Planning to possibly use it in an international study that will survey services for people with complex psychosis	Difficult to say as we haven't surveyed these services in depth previously		Not much - it is fairly straight forward	Not yet	N/A	Too soon to implement in this way - needs further trialling in different settings
The tree diagram with parent and child categories were helpful to understand the taxonomy as were the case mix examples in your manuscript	I think it will also allow for better evaluation-treatment definition to understand the mechanisms through which different types of case management interventions are needed	Yes I think it will help significantly to define concepts and contribute to a common language.	Luis Salvador-Carulla gave a presentation on the case-management taxonomy and on the DESDE mapping instrument for staff at March of Dimes Canada a not-for-profit organisation and we discussed the potential use of the tool for their organisation. I have also mentioned your work to the American Congress of Rehabilitation Medicine community based care task force.	ACRM task force members. I also referenced your work in a presentation I gave at a conference organised by March of Dimes Canada in March 2016- my presentation was on transitions from hospital to home.	We have not done this	Still quite preliminary but I am continuing discussions about using the taxonomy as part of program evaluation at March of Dimes Canada to evaluate their services where the goal is to support successful transition from hospital to home- I think this taxonomy will help them to better define the nature of the interventions they are providing in this transition.	I think having a copy of your manuscript which gives the case mix examples helps. The other thing that might be useful in terms of implementing it is some sort of data collection or data entry forms so that services can track which of the case-management interventions were delivered easily.		We have not actually implemented yet but I'd say it will require a time investment upfront but could quite easily in the long-run fall into usual routines of coding care provided provided appropriate tools are available to support coding of services/interventions.	Not yet implemented	Not yet been able to implement the taxonomy in my work but I think once implemented it would hopefully lead to change :) One thing that I am considering is including it in my course work (I teach a class on neurorehabilitation in the occupational therapy program) so that students graduate with an understanding of case-management and what it entails.	Not yet- The discussions we have had thus far with March of Dimes Canada is to pilot its use in one program and then talk about applicability and how to implement on a wider scale within the operations of that organisation.
This theoretical model that underpins our day to day working with clients is important because it helps us develop guidelines for service delivery. As a grass roots worker I would welcome further exposure to discussions and workshops about the taxonomy and how it can support the ongoing development of our services	We need to allocate more time to explore and understand the taxonomy, which will in turn help us improve our services	It has given us a clear model or structure to clarify what we do, and to guide our service development	Not enough! I would welcome more discussion and development of potential uses.	I think I have relied on the author to disseminate the information, and have not thought of passing it on myself - I could though!	Not that I know of	I have looked at the information as a reflective activity - to guide me in thinking about what I do, how I do it and identify potential for positive improvement.	I think I need to use it more before I could suggest changes or modifications. However, I think there could be an opportunity to use it more effectively if we were to have more workshopping opportunities to practise and get used to using it.	Reasonably easy to understand for an experienced case manager . it endorses what we do. For a newer worker, it may take some navigating and understanding.	I think we have been remiss in not allocating MORE time as a team. Busy day to day clinical work always seems to take precedence over time to step back and look at what and how we do things.	Not yet - but it has the potential to.	I have not taken it to this next step as yet.	I think the taxonomy reflects rather than sets the routines and structures we have already established for our service's functioning.

Q.10 Covers the important dimensions of CM	Q.11 Allow better understanding	Q.12 Contributed new information	Q.13 Discussed the relevance with colleagues	Q.14 Forwarded information to others	Q. 15 Included information on or from documents, website	Q.17 Applications or use of the taxonomy	Q.19 Does it provide all materials needed	Q.20 Usefulness in relation to time and effort	Q.21 Require allocation of time or resources	Q.22. Resulted in change	Q. 23 Build on another area	Q.24 Incorporated (or planned to be) into routine structure or
N/A	N/A	N/A	N/A	N/A	N/A	I used it to describe what I would do when applying for funding for case management to LTCS	N/A	N/A	Just learning to use it took a bit of added time	N/A	N/A	N/A
		I believe that the taxonomy has clearly described the case management role..	Have presented the BICM-T to managers and colleagues and encouraged it's use in describing the role of the case manager to funding bodies.	As above - have promoted use of the taxonomy to others within my organisation.	Website still awaiting review.	Using this language when describing case management. Comparison of the taxonomy to the BIRD Model of Case management.,			Time involved in the nominal group! ;) Some time in presenting/explaining and distributing the taxonomy to other CMs	Not as yet, but may contribute to team planning exercises in future.	As noted earlier, have compared the taxonomy to the BIRD model of care for case management as part of the case management steering committee.	Would like to see this happen - no immediate plans...
					I have just returned back to work after more than two years sabbatical to raise young children so this is a new development for me.							
		provides a differential description to CM across settings and caseloads	discussed importance of understanding the taxonomy as a tool for defining & quantifying CM hours	to the team	Introduced at Team Meeting	as a guide to defining/describing CM in complex cases			videos and discussion require time (therefore a dollar cost) but not onerous	current CM activities are consistent wiht the taxonomy	haven't used it in another area of work	not yet
						The taxonomy is under consideration for usage in the organisation						
NIL		NIL	BIRP CM meeting	Colleague working in similar role interstate	Discussed in relation to the BIRP model of case management which was also developed at the same time	I have briefly mentioned it in relation to services approved by LTCS and intend to discuss this further. As the taxonomy has been 'adopted' by LTCS I believe it will form a very useful basis and common language for discussing the model that LTCS adopts in relation to CM. Although I haven't looked at in this regard yet, I think it will also be very useful for discussing with funders and new clinicians 'what is NOT cm'			Very little	n/a	not yet but intend to	n/a
Very thoroughly	Breaks up the tasks in a logical manner	Assists to identify gaps in service delivery	I have applied this knowledge to my every day work environment	Relevant to speech pathologists working in any area of the profession	Referenced within masters dissertation	I plan to use the taxonomy in every day work to help build professional networks to assist in building capacity to address as much of the taxonomy as possible			Staff time	Need more time	Plan to in the future	Planned to be
The taxonomy is very practical and provides a good framework for practice and research.		The taxonomy offers a clear framework to analyse the topic and assists in identifying gaps in research in the area of case management. For example, areas of topic that has not been reported explicitly.	Discussion on the uses of the taxonomy for how research on case management for people with traumatic brain injury be conducted and reported for an universal understanding of case management and comparisons to be drawn from research papers.	I have not forwarded the taxonomy however it has been discussed with colleagues within my workplace.	Taxonomy used only within context of masters paper. Taxonomy has not been utilised within other documents as not directly within scope of documents completed within my day today work as physiotherapist.							

7.8 Appendix 6.5 Impact scale raters and ratings

Audience	Rater 1	Rater 2	Rater 3
International frameworks			
ICHI*	3	3	3
DESDE*	3	3	3
Policy and legislation			
CMSA*	1	2	3
BABICM/CMSUK*	2	2	2
DPO*	1	1	2
NICE*	1	2	2
LTC (SA)	2	6	3
BIRD	4	5	6
icare-w/c policy	3	3	5
icare-w/c provider	1	1	3
LTCNSW	4	6	6
Mental health -SP	1	1	1
Researchers and research organisations			
Switzerland	1	1	1
USA community	2	3	3
UNSW	2	2	2
Usyd -G	3	3	3
UCL	2	2	2
France	1	1	1
LSHTM	1	2	2
Usyd-Y	2	2	2
BIRD-research	2	2	2
Sweden-H	2	1	1
Usyd- M	2	2	2
UK-S	1	2	2
Sweden-K	1	1	2
Usyd-AM	1	1	1
Education and training			
Berlin	3	4	6
Usyd-M	4	6	6
Clinical Pratice - service delivery (invidiuals and orga			
Org1	3	3	4
Org2	1	5	6
Org3	2	2	4
Indiv1	1	1	2
Indiv2	2	5	5
Indiv3	1	1	1
Indiv4	2	5	5
Indiv5	1	2	1
Indiv6	2	2	2
Indiv7	1	1	2
Indiv8	2	2	5
Indiv9	2	2	2
Indiv10	2	5	5
Indiv11	2	2	6
Indiv12	2	1	2

*rating scale to 3 only

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CHAPTER 8 SUMMARY AND CONCLUSION

In this final chapter, Section 7.1 provides an overview of the problem, methods and results for each step of the research program. Section 7.2 discusses the research questions, outcomes and the contribution of the research. In Section 7.3, considers the limitations of the research program and Section 7.4 provides the directions for future research.

8.1 Overview

Case management sits broadly within care coordination services but is critically differentiated because it involves a partnership and collaboration between the client and case manager. Case management is a health service and a health intervention that makes a unique contribution towards the long-term care, participation and support of people with a health condition. Case management is used in diverse contexts, with different approaches, and goes by different names. The complexity of case management arises from the interaction of the different components: the model (conceptual and theoretical basis), implementation context (service), population and health condition, the case manager's actions, the method, and the focus or target for the intervention.

Since the emergence of case management in the 1960s, researchers have consistently highlighted issues with understanding, describing, measuring and undertaking quality assessment of case management interventions (Corvol et al., 2017; Hargreaves et al., 1984; Kopke & McCleery, 2015; Lannin et al., 2014; Norris et al., 2002; Perlman, Melnick, & Kentera, 1985; Reilly et al., 2015). A recent example is a systematic review of case management outcomes for caregivers of people with dementia. The case management service component of intensity was

managed by presuming that the case manager's case load determined intensity (the greater the case load, the lower the intensity), itself a rudimentary and possibly inaccurate assumption. The researchers supplemented this by also considering frequency of home visits, irrespective of what was done at the home visits (Corvol et al., 2017). Intensity is a defined component of the taxonomy service tree (inputs). The variability and poor understanding of case management lead to poor descriptions of case management, which in turn continues to hinder policy, planning, quality analysis and measuring the impact of case management on health outcomes.

The research program developed a taxonomy for case management – a framework to enable a better understanding and common language. The taxonomy identifies the components of community-based case management, defines them and articulates the relationship between components. There were two phases to the research: 1) development of the taxonomy; 2) dissemination and impact analysis of the dissemination. The methods to develop the taxonomy in Phase 1 involved: a scoping and mapping study; critical review of international frameworks; nominal group technique; and feasibility analysis. In Phase 2, personalised and non-personalised dissemination strategies were used for diverse target groups, which included national and state agencies in Australia, other country organisations, international organisations, the scientific community, service providers and service users.

Results of Phase 1

The results of Step 1.1, the scoping review, confirmed the immense body of peer-reviewed and grey literature on case management, and the heterogeneity of descriptions, terms and phrases to describe the models and case management interventions (Lukersmith, Millington, & Salvador-Carulla, 2016). The researchers

extracted and mapped 69 components to describe what case managers do (to the point of saturation when no new components were identified), which was reduced to 17 intervention headings. Five models and theoretical bases were identified. The terminological variance reflects the ambiguity and confusion about roles and the interventions performed by case managers.

In Step 1.2, the critical review of international frameworks advanced the development of the taxonomy in terms of the theoretical, conceptual and technical components. We developed a conceptual and theoretical framework – the meta-framework for person- and people-centred integrated health care. Two existing technical frameworks were appropriate to use – ICHI and DESDE-LTC. These three frameworks informed and supported the structure of the taxonomy.

The results of these first two steps enabled the development of a Beta 1 version of the taxonomy. The Beta version underwent extensive revision using a nominal technique to discuss and build consensus with a group of experts in case management. At this stage, the focus was on brain injury. Brain injury is an example of a common multi-dimensional and disabling health condition which demands a complex response from services, programs and interventions. The rationale was that if the taxonomy was ‘fit for purpose’ for brain injury, it would probably be appropriate for case management associated with other health conditions. The overall result from Phase 1 was the taxonomy. The final taxonomy incorporated three tools:

1. *Service tree and table*: The service parameters of acute/non-acute, mobile (low and high)/non-mobile, and intensity (low, medium and high) are defined in the service table and the relationships between components are set out in the service tree.

2. *Intervention tree and table*: The interventions, or case manager main actions (9), actions (17) and related actions (8), are defined in the intervention table and the relationships between the actions are set out in the intervention tree.
3. *Glossary* of all the terms in the two trees and tables and a definition of community-based case management.

Results of Phase 2

The dissemination of the taxonomy involved personalised presentations to 51 audiences in 11 countries over an 18-month period to September 2016. The audiences included organisations and individuals in different sectors including international frameworks, policy and legislation, education and training, and clinical practice (service delivery). Non-personalised presentations included conference paper and poster presentations, peer-reviewed publications and social media (ResearchGate, YouTube, website and Twitter). Forty-six people who attended personalised presentations, when questioned immediately following the presentation, rated the taxonomy to be very relevant to their work and very practical. Using a case study approach, information was collected (through survey and opportunistic data) from people representing 43 audiences exposed to the taxonomy through personalised presentations. Impact analysis involved three researchers rating the impact of the dissemination using either a three- or six-level impact scale, depending on the audience sector. The three-level impact scale was used on the international frameworks, policy and legislation, and research sectors. Inter-rater reliability assessment was good. This was followed by the analysis of the impact of the dissemination in the different sectors of international frameworks, policy makers, planners, educators, researchers and practitioners.

All audiences perceived the taxonomy to be highly acceptable and practical. Many have assimilated the taxonomy into their understanding and language for case management. There were higher level impacts and direct use of the taxonomy when there was a personalised approach and support from the researchers. Several meso organisations translated the taxonomy into policy, international frameworks incorporated taxonomy concepts and language, and clinicians and case management services have used the taxonomy in their work. The taxonomy is embedded in university undergraduate curricula and professional education, and there are current and emerging uses in research projects.

8.2 Discussion of outcomes and contribution

The research questions and outcomes are summarised below.

Research question 1. *How can the knowledge around case management in brain injury be framed through the development of a preliminary taxonomy?*

The results from Phase 1 of the program confirm that the taxonomy can frame knowledge around case management in brain injury, but also case management with other health conditions. The research methods facilitated managing the complexity of case management for a better understanding. The taxonomy frames the knowledge on case manager interventions, their relationship to each other, and definitions of both the intervention and service components of case management. The taxonomy provides a common understanding and language, which can enable and support the quality assessment of case management, policy development, planning and cost-effectiveness across contexts and health conditions.

Research question 2. *What is the impact of the dissemination of the taxonomy in various contexts?*

Research question 3. *What is the feasibility of the case management taxonomy in different sectors such as policy, research, education and clinical practice?*

The results of Phase 2 of the research answered these two questions. The impact analysis of the dissemination of the taxonomy showed that people working in different sectors, with people of different ages and health conditions, across a range of countries, and in different settings considered the taxonomy to be relevant and acceptable. There was a higher level of impact of the dissemination where the taxonomy had been assimilated into organisations and used as a common language. There are some incidences where the taxonomy has had higher impact, and has been translated and then adopted into policy, organisational structures, education, other research projects and case management practice. At this relatively early stage after dissemination activities, the impact analysis has confirmed the feasibility of the case management taxonomy.

The contribution of this research

The case management taxonomy is a useful tool and contributes to managing the complexity of case management in different sectors. The taxonomy provides a framework; it identifies and articulates the case manager's interventions (actions), the relationships between these actions (parent, child and related categories), service components, and defines all components. The taxonomy is shown to be a useful tool across sectors, including international frameworks, policy and legislation, education and training, and clinical practice (service delivery), and enables future

research on the quality, effectiveness, and population and individual outcomes from case management.

The level of impact of the dissemination is positive, particularly if the short time frame between exposure to the taxonomy and subsequent impact rating is considered. Based on the patterns of the initial impact evident following dissemination, it is anticipated that over time there will be further uses and a higher level impact of the taxonomy across sectors, particularly if the taxonomy becomes better known and applied and the feasibility is further tested.

The impact analysis and results confirm that the taxonomy is acceptable to case management services assisting people with a range of health conditions, including intellectual disability, mental health, neurological and orthopaedic health conditions, age related health conditions, dementia and others. Although originally developed with a focus on brain injury, the taxonomy should hereafter be simply called the '*case management taxonomy'*.

8.3 Limitations

The limitations are detailed according to the research phases.

Phase 1: In many situations, given the client context and temporal factors (e.g. early recovery period compared to 10 years after diagnosis), case managers do not always perform all actions in the intervention tree. Also, in some service contexts, case manager actions may be split between people. For example, the person who undertakes the assessment is not the same person who undertakes monitoring; or two people are involved in coordination interventions but the target is different (e.g. the actions may target the client, the family or the workplace).

While identifying and describing case manager actions is the critical first step, more granularity of the intervention characteristics may be useful in some sectors. In the ICHI, the target is defined as '*the entity on which the Action is carried out*' and the means as '*the processes and methods by which the Action is carried out'* (World Health Organization (WHO), 2016). The taxonomy intervention (throughputs) tree provides the interventions, or the actions of the case manager. However, the research program did not incorporate determination of the target or means of the action. More granularity in the taxonomy and the inclusion of additional characteristics of the two axes (target and means) could be useful in circumstances such as policy, planning and quality analysis.

During the development of the service tree, there was significant discussion of the parameters and definitions of mobile and intensity. The 2016 revision of DESDE-LTC adopted the mobility and intensity characteristics for case management, but did not include the exact definitions from the taxonomy. The impact analysis of dissemination did not differentiate between service and intervention trees. Further feasibility assessment is appropriate, as is review of the service tree definitions after translation of the taxonomy in different contexts.

Phase 2: A critical limitation perceived in the dissemination was the link to brain injury in the preliminary title of the taxonomy. Anecdotal evidence suggests that the connection to brain injury resulted in an assumption by some audiences that the taxonomy was irrelevant to case management for people with other health conditions. It would have been preferable to refer to it as a preliminary taxonomy during dissemination. Other limitations in the dissemination were delays in the availability of some of the resources to support the dissemination activities. There were unexpected delays in the first publication of the taxonomy, which could have

affected the perception of the taxonomy with some audiences (e.g. peer-reviewed publication is an important part of the scientific process for researchers). Also, social media resources would have supported the personalised dissemination activities. However, the YouTube videos were not available until the end of the dissemination activities (July 2016), and the delays in set-up of a Twitter account and the doctoral student's inexperience limited the number of tweets posted.

The time between audience exposure through a personalised presentation and data collection for the impact analysis was in some instances only 1 month. One month is insufficient time in any sector to move beyond the level of awareness and onto a higher level of impact.

There are issues around the most appropriate evaluation method for assessing and measuring impact. The research into policy pathway is not linear, but highly complex (Raftery, Hanney, Greenhalgh, Glover, & Blatch-Jones, 2016). As highlighted by Martinez et al. (2014), in implementation science there are numerous qualitative, quantitative and mixed methods which are appropriate to assess outcomes of an implementation initiative (such as the dissemination and impact analysis of the taxonomy) to gain comprehensive insights into the impact (Martinez, Lewis, & Weiner, 2014). As the results demonstrated, there is a diversity in how the taxonomy impacted different sectors. The impact rating can range from awareness at level 1 to monitoring at level 6 on the impact rating scale. In this research program, the data collection for the impact analysis was retrospective. The self-report questionnaire was the primary source of the data, supplemented where possible with opportunistic data collection. Consequently, respondents relied on their memory of any changes made over a period of up to 18 months. The problem of retrospectivity and time is

particularly relevant with some impact levels, for example, in the adoption of the taxonomy language or definitions in an individual's or organisation's work.

A recent update of a systematic review of the models and applications for measuring the impact of health research developed a broad taxonomy of five impact models, known as logic, constructivist, realist, participatory and co-production models. Of particular relevance to this research program is the constructivist model of impact (also referred to as interpretivist), which was developed in the social sciences (Raftery et al., 2016). This model focuses on people's interpretations of context and the interactional, incremental and non-linear mechanisms of impact. Exposure where there is repeated interaction over time between researcher and dissemination audience promotes a shared view and influences impact.

In implementation science, there is recognition of what are often slow and incremental impacts of research. More detailed assessment of impacts is recommended, particularly as knowledge of contextual issues is critical to describing impact (Raftery et al., 2016). The impact rating scale used in the research program for the impact analysis had high reliability. However, there were limits to the information collected for impact rating. Although, a case study approach was used, the approach combined the information from the questionnaire and opportunistic data, the researchers interpreted pieces of information and audience context. Future impact analysis will benefit from using a framework that traces forwards to establish impacts rather than working backwards (Raftery et al., 2016). While it was not possible in this research program, future methods to gain better insights into impacts of the research need to be within a framework that considers broader sources of information such as observation, administrative and documentary information, and

self-report case study. The self-report case study involves questions tailored to each sector and audience context as well as opportunities for discussion.

8.4 Future directions

The development of the case management taxonomy and the positive results of the dissemination are good first steps to support management of the complexity inherent in community-based case management. Future research which builds on these results will involve developing further resources to support the use of the taxonomy, including a guideline; a YouTube video which has practical examples of past and potential uses of the taxonomy; a coding structure for the taxonomy intervention trees; and implementation tools such as navigation tools and checklists. Future research should also consider extending the taxonomy to articulate the relevant target and means of the interventions. There is also a need to link case management skills and training to the interventions within the taxonomy.

There also needs to be further work on supporting known case management researchers on the use of the taxonomy as a tool in their research. Organisations such as icare require further support to adopt the taxonomy as a decision support tool. By mapping case management activities to the taxonomy, gaps in services and service availability can be mapped, and unique aspects of case management and interventions across sectors can be identified.

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