AN ASSESSMENT OF THE ADVANTAGES AND DISADVANTAGES OF MULTIDISCIPLINARY MODELS OF CARE DELIVERY IN RENAL GENETICS CLINICS

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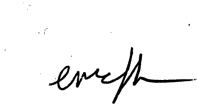
ABSTRACT

The use of genetic testing in clinical practice has the potential to change the diagnostic landscape for patients with rare and inherited forms of kidney disease; multidisciplinary clinical models are proposed to support its adoption in clinical practice. However, there has been little investigation into the advantages and disadvantages of multidisciplinary models in renal genetics services. Additionally, the literature lacks information on the structures and workflows of renal multidisciplinary services which support the use of genetic medicine. Therefore, the aims of this thesis were: 1) to model the structure and workflows of multidisciplinary renal genetics clinics and 2) to investigate their advantages and disadvantages according to clinic team members. The research was conducted with clinical members of the renal genetics consortium, KidGen Collaborative. A literature review and an exploratory two-stage mixed methods design were employed, consisting of semi-structured interviews and an online survey. Process maps were used to define the clinical models and thematic coding and descriptive statistics were used to analyse the advantages and disadvantages. The most important advantages of the model to clinic team members were shared expertise, professional development and education and accurate communication across specialties. The perceived financial unsustainability of the model was the most prevalent concern to team members. The findings of this study are directly relevant to the KidGen Collaborative and other specialist clinical services seeking to implement genetic testing for the diagnosis of rare and inherited conditions.

STATEMENT OF ORIGINALITY

I hereby declare that this submission is my own work and to the best of my knowledge it contains no materials previously published or written by another person, or substantial proportions of material which have been accepted for the award of any other degree or diploma at Macquarie University or any other educational institution, except where due acknowledgement is made in this thesis. Any contribution made to the research by others, with whom I have worked with at Macquarie University or elsewhere, is explicitly acknowledged in the thesis.

I also declare that the intellectual content of this thesis is the product of my own work, except to the extent that the assistance from others in the project's design and conception or in style, presentation and linguistic expression is acknowledged.



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CHAPTER 1. INTRODUCTION

1.1.The prevalence of kidney disease

Chronic kidney disease (CKD) affects approximately 200 million people worldwide (Ojo, 2014) and is a rising global concern (El Nahas & Bello, 2005; Jager & Fraser, 2017). Its incidence in the Australian adult population is estimated to be 11.5% (White, Polkinghorne, Atkins, & Chadban, 2010) and approximately 16% of the Australian adult population has at least one indicator of kidney damage (Chadban et al., 2003). The incidence of treated end-stage kidney disease (ESKD), the most severe form of CKD, is projected to increase by 45% over the next decade (2011-2020) (Australian Institute of Health and Welfare, 2014), requiring an estimated cumulative cost of between $11.3 billion and $12.3 billion (Cass et al., 2010). Inherited renal diseases are a significant cause of CKD and ESKD in both adult and paediatric populations (Alkanderi, Yates, Johnson, & Sayer, 2017). It is estimated that 10% of CKD cases in the Australian adult population are due to genetic renal disease (Mallett et al., 2014). The prevalence of genetic kidney disease in children in Australia and New Zealand is 70.6 children per million age-representative population (Fletcher, McDonald, & Alexander, 2013).

Most genetic disorders are clinically and genetically heterogeneous (Bergmann, 2017). Advances in technologies such as next-generation sequencing (NGS) have increased understanding of the genetic aetiologies of many renal diseases, and are opening up clinical applications, such as diagnostic utility, choice of therapy and family counselling (Groopman, Rasouly, & Gharavi, 2018). However, technological developments are disproportionately in advance of their translational clinical application (Mallett, Fowles, mcgaughran, Healy, & Patel, 2016). New clinical models are needed to support and sustain the integration of genetic and genomic medicine into clinical care in order to maximise benefits to the patients and their families and to meet the challenges inherent to genetic and genomic medicine. Multidisciplinary (MDT) care is purported to improve patient diagnosis and management while facilitating the translation of genetics and genomics into clinical practice (Mallett et al., 2016).

1.2.The rise of genetics and genomics and their translation into clinical practice

The second half of the 20th century heralded landmarks such as the discovery of DNA (Watson & Crick, 1953), the development of DNA sequencing techniques (Saiki et al., 1985; Sanger, Brownlee, & Barrell, 1965) and the identification of disease causing genetic mutations. The

sequencing of the human genome as part of the Human Genome Project (Venter et al., 2001), a 13-year endeavour completed in 2003, ushered in a new era of medicine sometimes referred to as the Genomic Era (Guttmacher & Collins, 2003).

Genetic and genomic technologies are becoming increasingly sophisticated. Up until recently, diagnostic genetic testing in a symptomatic individual was performed on one or a few predictive loci. Today, whole-exome sequencing (WES) and whole-genome sequencing (WGS) enable interrogation of a patient's entire genome to single-nucleotide resolution (Katsanis & Katsanis, 2013). These technologies offer increased diagnostic sensitivity and the tantalising possibility of a quick end to the "diagnostic odyssey" for patients and their families (S. Bowdin, Ray, Cohn, & Meyn, 2014). Rare and complex disorders, often associated with complex or variable genetic polymorphisms and an interplay of environmental factors, are well suited for diagnostic investigation with WES, WGS or gene panel sequencing (Mayeux, 2005). Descriptions of these tests is provided in Table 1.1. Genetic disorders often aggregate in families due to heritability, and the application of genetic and genomic technologies has expanded from diagnostic services to include predictive and pre-symptomatic testing, which is useful for families with a member with a genetic disorder.

Table 1.1: A description of various types of genetic tests used in the diagnosis of rare and complex disorders

Type of test	**Description**
Gene panel sequencing	Covers the protein coding regions of multiple genes that have a known disease-related function
Whole exome sequencing	Covers the protein coding regions of all known genes in the DNA sequence
Whole genome sequencing	Covers the entire DNA sequence

To support genetic and genomic medicine in clinical practice, clinical genetics has emerged as a medical speciality. Clinical geneticists receive specialist training in genetic counselling, the provision of genetic testing and interpretation of test results (Haan, 2003). Vast amounts of data are generated by gene panel sequencing, WES and WGS, which require interpretation in order to provide a clinically useful diagnosis for patients and their families. Aside from some monogenic and well-defined genetic disorders, the interpretation of results is a highly complex and time-consuming task. It requires an understanding of clinically relevant genes, the limitations of the test ordered and the curation of genetic variations (Pandey, Maden, Poudel, Pradhananga, & Sharma, 2012). Curation is often done manually by examining relevant literature (den Dunnen &

Antonarakis, 2000) and variant databases which are being established to facilitate storage and sharing of disease-associated variants (Johnston & Biesecker, 2013). For clinical geneticists working in a general genetics service, test ordering and result interpretation is further complicated in instances of rare or complex disease. The generalist nature of these genetics services and the absence of ready access to specialist knowledge of a patient's phenotype makes decision-making and diagnosis more time-consuming and difficult.

In addition to the need for specialist training in genetic testing and result interpretation, challenges exist in communicating the complexities, psychosocial risks and ethical issues associated with genetic and genomic testing with patients and their families. Interpretation of genetic and genomic results, particularly for rare and complex diseases, may be complicated by the return of incidental and secondary findings. These findings are unrelated to the reason the test was ordered and present ethical questions about whether and how to disclose these findings. This is further complicated when secondary findings have low clinical actionability. Different laboratories and clinical settings vary widely in their secondary findings reporting practices (Ackerman & Koenig, 2018). The return of secondary results also carries with it possible ethical implications for health insurance, as well as the risk of burdening patients with the unsettling news of a disease-risk in the absence of available clinical interventions. The role of the genetic counsellor has emerged to help patients and their families understand and navigate these complexities and make informed decisions about their healthcare. Genetic counsellors may often work with clinical geneticists to provide genetic services.

The increasing utility and affordability of genetics and genomics is creating pressure for its wider adoption by non-genetic specialists in clinical practice. Yet this is impeded by the readiness of the clinical workforce (Korf et al., 2014). Many medical practitioners report that they do not feel adequately trained in genetic and genomic test ordering, result interpretation and subsequent decision-making in their medical field. A survey of 220 internists from two US academic medical centres found that 73.7% rated their knowledge of genetics as very/somewhat poor and most felt they needed more training on when to order tests (79%), how to counsel patients (82%) and interpret results (77.3%) (Klitzman et al., 2013). A survey of paediatric oncologists found that only a minority were confidence in incorporating genomic testing into their clinical practice. Those who were confidence in interpreting test results, were significantly more likely to discuss and utilise results as part of clinical care (L. M. Johnson et al., 2017). Therefore, in order facilitate the integration of genetic and genomic technologies into non-genetic clinical practice, adequate workforce training is necessitated.

1.3.The role of multidisciplinary teams in medical genetics and genomics

One of the key questions of the Genomic Era is how to organise the healthcare system to facilitate the implementation of medical genetics. While genetic and genomic technologies rapidly develop and offer transformative change to disease anticipation, diagnosis and management, new clinical models are needed to implement and manage genetic and genomic tools, the genetic discoveries emerging from clinical and research data, patient preferences and ethical concerns. A MDT model has been advocated for translating genetics and genomics research into international best-practice care.

MDT care refers to when professionals from a range of disciplines work together to deliver comprehensive care that addresses as many of the patient's needs as possible (NSW Government, 2014). The value of MDT care has been explored in a variety of clinical settings, particularly oncology, with advantages and disadvantages associated with its use. Examples of suggested advantages and disadvantages of MDT models reported in healthcare research literature are provided in Table 1.2.

Table 1.2: Examples of advantages and disadvantages of MDT care in clinical settings reported in healthcare research literature. Sources: Carter, Garside, and Black (2003); Rosell, Alexandersson, Hagberg, and Nilbert (2018); Pillay et al. (2016); January et al. (2016); Epstein (2014); Morley and Cashell (2017)

Advantages of MDT care in clinical settings
Provides support for further patient management
Develops competence of junior colleagues
Develops individual clinician competence
More accurate treatment recommendations
Improved communication between team members
Team working provides a sense of partnership and friendship
Improves diagnostic outcomes
Sharing of information
Strengths professional relationships across disciplines
Disadvantages of MDT care in clinical settings
Time consuming
Resource intensive
Difficulty balancing the contribution of team members

Difficulty attending MDT meetings due to travel distance or scheduling
Difficulty aligning roles and practices of multiple professional disciplines

Research into the structure, benefits and limitations of MDT models in clinical genetics and genomics is now underway, with findings suggesting improvements in diagnostic outcomes and care recommendations, and team members' professional development through education and oversight (S. Bowdin et al., 2014; McGowan, Ponsaran, Silverman, Harris, & Marshall, 2016; Ormondroyd et al., 2017). MDT models offer a promising avenue for the uptake of genetic and genomic technologies as the co-location of genetic and non-genetic specialties may help to overcome some of the current barriers to its adoption among non-clinical specialists, such as lack of education about genetic testing and interpretation of results. For rare and complex diseases, a MDT model may also be of benefit to clinical geneticists by giving them ready access to specialist information about the patient phenotype.

Investigations into the value of MDT models for use of genetic testing have emerged from oncology, and particularly, multidisciplinary tumour boards (Parker et al., 2015; van der Velden et al., 2017). McGowan et al. (2016) conducted a qualitative case study of a genomic tumour board for breast cancer patients with advanced disease. A tumour board traditionally incorporates clinicians from multiple professional disciplines; the genomic tumour board diverged from a traditional tumour board by including professionals with expertise in clinical or basic sciences relevant to genetics and genomics, bioinformatics and bioethics. Interviews with team members revealed that members believed that more precise patient care recommendations and physician professional development had been achieved and that this could be largely attributed to the MDT model. Teamwork was cited as being important to interpreting genomic data and making recommendations; the team setting also served as an educational forum to increase genomic understanding for all clinicians.

The use of genetic and genomic medicine in a MDT model has also been reported in cardiology services. A report by Zentner et al. (2015) outlined the model and outcomes of a MDT cardiac genetics clinic established at the Royal Melbourne Hospital in 2007. The clinic aim is to confirm or negate a suspected diagnosis of an inherited cardiac condition to allow implementation of a personalised management plan. Team members attending the MDT clinic include cardiologists, clinical geneticists, genetic counsellors, as well as fellows and trainees in each field. MDT aspects of the model include a pre-clinic whole team planning meeting to discuss and make decisions about patient access to genetic testing and evidence-based care management and planning, followed by consultations and post-clinic review meetings with relevant team members. Of the

1170 individuals seen over a 6-year period, 381 underwent genetic testing (32.6%) and a pathogenic mutation was identified in 47.6% of tests. The authors suggest that the high yield of diagnostic outcomes can be attributed, at least in part, to the simultaneous review of patients by multiple team members, including cardiologists and clinical geneticists. The study was not able to provide longitudinal data on the impact of MDT models on patient outcomes.

A survey of cardiologists and genetic counsellors working in multidisciplinary clinics for inherited heart rhythm disorders uncovered a number of advantages and disadvantages associated with the model of care (Roston et al., 2018). It was found that expert-led MDT clinics, which incorporated physicians, genetic counsellors and nurses, were an ideal setting for communicating the complexities and implications of genetic testing with patients and their families. The genetic counsellor played a key role in this. Physicians and genetic counsellors were reported to work closely together. However, a majority of genetic counsellors reported dissatisfaction in their relationships with physicians. While further research into this is called for, one plausible explanation for the dissatisfaction may be found in a study by McGowan et al. (2016). In this research, it was observed that within a MDT genomics tumour board it was primarily the treating physicians who conferred consensus on the group's recommendation; this dynamic was stable across a 13 month time frame. It was suggested a lack of engagement from other health professionals might be the results of traditional power-dynamics which may need to be broken down for effective multidisciplinary collaboration.

1.4. Summary

Multidisciplinary models have been advocated to facilitate the adoption of genetic medicine into clinical practice. Reports of multidisciplinary models in fields such as oncology and cardiology, which are early adopters of genetic technologies, are promising. Investigation into the value of MDT models in renal genetics is warranted.

CHAPTER 2. SCOPING REVIEW OF MULTIDISCIPLINARY RENAL GENETICS CLINICS

2.1. Overview of Chapter 2

This chapter describes the methods and results of a scoping review of the types and outcomes of MDT renal genetics clinics in health services research literature

2.2. Introduction

Genetic and genomic technologies offer new clinical approaches to genetic renal disease and require new models of care delivery in order to maximise individual and health-system utility. The implementation of genetic and genomic medicine in nephrology requires the close involvement of clinical geneticists and genetic counsellors in addition to nephrologists and allied health members. The multidisciplinary delivery of care calls for a MDT model of care delivery (Mallett et al., 2015). However, there is little data on the specific models of MDT care employed in renal genetics clinics or on the outcomes for patients and clinicians. Therefore, a scoping review of the literature was performed in order to identify literature describing and reporting on structures and outcomes of MDT models in renal genetics clinics or teams.

2.3. Methods

2.3.1. Search Strategy

A search for peer reviewed, English language publications using Medline and Embase was conducted between 24 and 28 May, 2018, following consultation with a university librarian with database and search strategy expertise. Keywords and subject headings were selected to identify articles which related to the use of MDT team models to support genetics or genomics in nephrology (see Table 2.1). The search was filtered to exclude conference abstracts. Boolean operators and truncated terms were used to maximise the sensitivity and efficiency of the search strategy. The sensitivity of the search strategy was tested by confirming it was sensitive enough to recognise three key papers meeting the inclusion criteria which were identified during the conceptual stage of the review.

Table 2.1: The search strategy used to conduct the scoping literature review

Database	**Subject headings**	**Keywords**
Embase	Kidney Disease OR Nephrology Nursing OR Nephrology	Kidney disease* OR renal OR nephrology*
	AND	
	Team Nursing OR Interdisciplinary Communication	multidisciplin* OR multi-disciplin* OR MDT OR interdisciplin* OR inter-disciplin* OR multiprofession* OR multimodal* OR patient care team OR medical care team OR healthcare team OR case review OR case discussion OR case conference OR transdisciplin* OR trans-disciplin*
	AND	
	Genetic Screening OR Genetic Counselling OR Genetic disorder OR Genomics	genetic test* OR genetic screen* OR genetic OR genetic counsel* OR genom*
Medline	Kidney Diseases OR Nephrology Nursing OR Nephrology	Kidney disease* OR renal OR nephrology*
	AND	
	Patient Care Team OR Patient Care Management OR Nursing, Team OR Interprofessional Relations	multidisciplin* OR multi-disciplin* OR MDT OR interdisciplin* OR inter-disciplin* OR multiprofession* OR multimodal* OR patient care team OR medical care team OR healthcare team OR case review OR case discussion OR case conference OR transdisciplin* OR trans-disciplin*
	AND	
	Genetic Testing OR Genetic Counseling OR Genetic Services	genetic test* OR genetic screen* OR genetic OR genetic counsel* OR genom*

	OR Genetics, Medical OR Genomics	

2.3.2. Study Selection

Search results were combined in Endnote X7 and duplicates were deleted. The remaining articles were subject to title and abstract screening against the inclusion criteria in the web application, Rayyan QCRI. A full text review of retained articles was performed using the inclusion criteria. Review articles were used to snowball additional articles but were excluded from full text analysis and data extraction.

2.3.3. Inclusion Criteria

The following criteria were operationalised: (1) English language, (2) full text for the article was available, (3) empirical research and (4) the study reported on patient and/or clinician outcomes in MDT renal genetics clinics or teams.

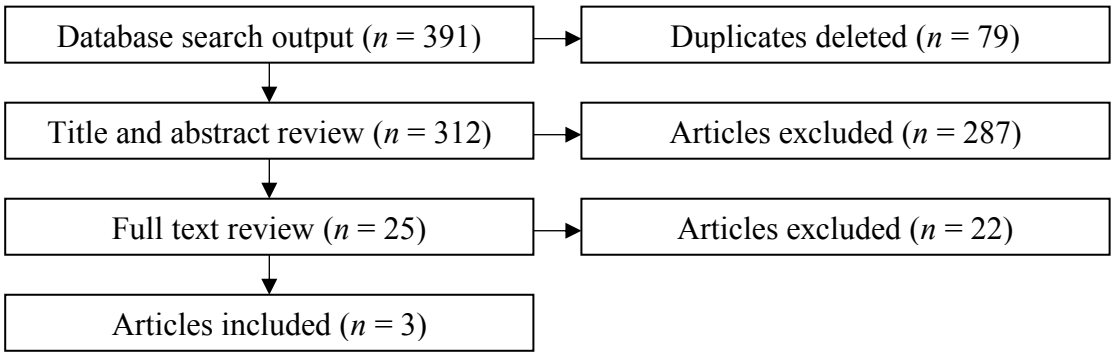
2.3.4. Data Extraction

Data from the included articles were extracted, including: the location of the clinic or genetic service being reported on, a description and characteristics of the MDT model, provision of genetic services, patient and/or clinician outcomes and the perspective of the study on the benefits and limitations of the MDT model employed.

2.4. Results

391 records were identified through initial database searches. This number was reduced to 312 after duplicates were removed. After title and abstract screening, 25 articles underwent full-text screening against the inclusion criteria. The final dataset consisted of 3 empirical articles. The data screening process is presented in Figure 2.1.

Figure 2.1: Article screening process



2.4.1. Clinic or genetic service location

Two studies described the use of a MDT model in renal genetics clinics; the first located within Freeman Hospital, Newcastle upon Tyne, UK (Alkanderi, Yates, Johnson, & Sayer, 2017), and the second at Royal Brisbane and Women's Hospital, Brisbane, Australia (Mallett et al., 2016). The third study described the use of a MDT model in a national accredited diagnostic genetic service for renal disease, the Australian Renal Gene Panels service at the Children's Hospital in Westmead, Australia (Mallett et al., 2017).

2.4.2. Descriptions and characteristics of the MDT models reported on

Both renal genetics clinics reported a MDT model which included clinical geneticists and nephrologists (adult and paediatric in the UK). The Australian clinic also employed a genetic counsellor. The Australian genetic service was comprised of nephrologists, clinical geneticists and molecular geneticists.

MDT activities were described in all three studies. In the UK renal genetics clinic, the MDT model allowed families to see the clinical geneticist, adult and paediatric nephrologist in the same clinic room on their first clinic visit. This was typically the only MDT meeting with patients; follow up meetings were arranged with individual clinicians on subsequent visits. In the Australian renal genetics clinic, the clinical geneticist and nephrologist saw families in the same room upon referral to the clinic. Subsequent MDT meetings were not explicitly reported on but were implied for the review of the results of clinical investigations. The Australian genetic service developed its targeted exomic sequencing approach using an expert MDT. A MDT committee review with clinical renal and genetic specialists was reportedly used for clinical assessment and gene verification.

2.4.3. Provision of genetic services

At the UK renal genetics clinic, single gene tests and small panels were used for diagnostic services. The Australian renal genetics clinic did not report the type of genetic testing provided to patients. The Australian genetics service employed a targeted exomic sequencing approach with ten curated multigene panels.

2.4.4. Reported outcomes

The UK renal genetics clinic reviewed 244 individuals who attended the clinic over a 5-year period (2010-2015), comprising 80 probands, 50 affected relatives and 114 unaffected relatives. Patients with a known genetic diagnosis with pathogenic or likely pathogenic mutations were referred with their families for genetic counselling and genetic screening with prognosis in light of genetic results. 62 cases were referred for more precise molecular genetic diagnosis which was provided in 42% of cases. Nine probands remained without a molecular diagnosis.

The Australian renal genetics clinic reported outcomes and changes in clinical diagnosis for 108 patients from 100 families seen over a 2-year period (2013-2015). Of 108 patients, 75 (69%) of patients underwent genetic testing. As a result, a previous diagnosis was confirmed for about half the cohort and a quarter of referred cases received a change in diagnosis.

The outcomes of 135 unrelated families referred to the Australian genetics services over two years were reported on. A genetic diagnosis was identified in 58 of the 135 families (43%). The rate was 46.3% in children and 39.7% in adults, but the difference was not statistically significant.

2.4.5. Benefits and limitations of the MDT model

All three studies reflected to some extent on the usefulness of a MDT model. The authors of UK renal genetics clinic study believed the model provide an "environment of excellence to allow rare renal diseases to be managed appropriately" (p. 456). This was attributed in part to the bringing together of genetics experts and clinicians, which purportedly facilitated the diagnosis and management of inherited disease. The study from the Australian renal genetics clinic argued that its model improved patient diagnosis and care, and represented a clinical template which was "viable, translational and patient-focused" (p. 59). According to the Australian genetics service

study, the use of a MDT model for clinical assessment and gene verification increased the validity and utility of their diagnostic model.

2.5. Discussion

All three studies reported genetic diagnoses and changes in diagnosis for a percentage of referred patients. While the involvement of a MDT reportedly increased team members' confidence in patient diagnosis and care and facilitated clinical management, comparative data on patient diagnostic and care outcomes from different clinical models would be useful to more clearly delineate to what extent outcomes are attributable to a MDT model. This could be achieved through a longitudinal study design which compared outcomes in a setting before and after the implementation of a MDT model, or through the comparison of similar renal genetics clinics operating with and without MDT models. As genetic and genomic technologies rapidly develop and are implemented in healthcare, it is difficult to capture the impact of clinical models alone on outcomes. Instead, outcomes, such as those reflected in the reported studies, are likely to be attributed to advancements in genetics technologies as well as updated clinical models.

The limited number of included studies reflects the infancy of this model in renal genetics at this point in time. It also limits the value and validity of comparisons and generalisations about MDT models in renal genetics clinics arising from this review. It may be useful to broaden the inclusion criteria to capture conference proceedings, abstracts and posters in order to identify more relevant data.

Missing from the data set were studies including clinicians' views on the value of MDT models in renal genetics services. In clinics which have previously operated without a MDT model, clinicians exposed to both operating procedures have valuable insights into the benefits and limitations of MDT models. Future studies would benefit from data capture and analysis of clinician perspectives.

2.6. Conclusion

Genetic and genomic technologies offer new diagnostic and patient-tailored care opportunities which are set to transform healthcare. For patients with genetic renal disease, the emergence and clinical implementation of genetic services is improving diagnostic outcomes and treatment therapies. In order to maximise patient and service outcomes, MDT models of care delivery are being implemented in various renal genetics clinics and services around the world and early data

on patient outcomes looks promising. Further investigation into long-term patient outcomes as well as clinicians' perspectives on the value of MDT models. Structuring the healthcare system to support the use of genetic services is pivotal to its ongoing success.

CHAPTER 3. METHODS: STUDY ONE

3.1. Overview of Chapter 3

This chapter provides a detailed description of the methods used in Study One; the first of two sequential studies. It includes an overview of the project design, the study setting and participants, recruitment, procedures, data gathering instruments, data analysis and limitations.

3.2. Overall research project design

This research project employed an exploratory sequential mixed-methods design consisting of an initial qualitative study which informed a subsequent, primarily quantitative study. The data collected and analysed in Study One was used to inform the design and analysis of Study 2. Study One primarily sought to address Research Aim One (RA1), *to model the structure and workflows of selected KidGen clinics and the renal genetics services which existed prior to KidGen*. The data required to model these services was collected through semi-structured key informant interviews with selected KidGen clinical team members. The interviews also gathered information on key informants' perspectives of the advantages and disadvantages of the MDT models employed in their respective KidGen clinics. This information was then used in the design of Study Two. Study Two was designed to address Research Aim 2 (RA2): *to investigate the advantages and disadvantages of multidisciplinary teams in renal genetics clinics from multidisciplinary team members' perspectives*. This study took the form of an online survey which was primarily quantitative in its design. The present chapter will focus on the design and methods employed in Study One.

3.3. Study setting and participants

The overall research project was conducted with clinical team members of the KidGen Collaborative, a consortium of multidisciplinary renal genetics clinics established within 14 adult and paediatric hospitals Australia-wide. The KidGen Collaborative is closely affiliated with the Australian Genomics Health Alliance (Australian Genomics), a national research collaboration working to facilitate the integration of genomic medicine into healthcare (Australian Genomics Health Alliance, n. d.). The aim of the KidGen Collaborative is to establish novel diagnostic pathways for inherited kidney diseases and to provide an Australian Genomics funded research-genomics arm to undertake functional analysis for patients for whom a diagnosis is not available (Pearce, 2016). Clinical, diagnostic and research teams collaborate to advance clinical and

diagnostic renal care and scientific understanding of the causes of inherited kidney disease. Families and individuals at KidGen clinics are seen by multidisciplinary teams which include renal physicians (adult and/or paediatric), clinical geneticists and genetic counsellors.

15 KidGen clinics across every Australian state and territory were in operation at the time of this research project. Five of these clinics, one from each Australian states, were selected, in consultation with members of the KidGen Governance Committee, for investigation in Study One. Representation of every Australian state in the project design was intentionally pursued to facilitate the comparison of clinic models by state. A senior clinical team member from each of the five selected KidGen clinics acted as a key informant in Study One.

3.4. Recruitment

Participants for the semi-structured interviews were identified through a purposive sampling technique (Palinkas, et al., 2016). The key criteria for eligible participants were active involvement in a KidGen clinic, and depth of knowledge of clinic structure and workflows. Prior to the project's commencement, five KidGen clinical team members from NSW, QLD, VIC, WA and SA participated in key informant interviews with project co-supervisor, Stephanie Best, from which, preliminary high-level process maps of the five clinics'[1] structures and workflows were produced (see Appendix B). In order to build on the relationships formed in this preliminary research, the same KidGen members were targeted for recruitment, following consultation with members of the KidGen Governance Committee, who confirmed their eligibility. Once ethical approval was attained, recruitment commenced. Initial contact took place via email by the KidGen Collaborative Program Manager, who provided an overview of the project and directed willing participants to contact the researcher via email. Participant information and consent forms (see Appendix C) were provided to participants by the researcher either at the commencement of interviews held in person or via email for participants requiring a phone interview.

3.5. Procedure

Interviews were held in-person at hospital locations where travel arrangements permitted and via telephone in instances where travel was not feasible. Informed consent was obtained prior to interview commencement for face-to-face interviews and via email for telephone interviews. Participants were informed that the interview would take approximately 30 minutes and would be audio recorded. The interviews were semi-structured with both open and closed-ended questions.

[1] Names of KidGen clinics withheld to preserve the anonymity of the participants and the facilities where research was conducted.

The semi-structured interview is a common qualitative tool used in health care research, especially that which involves social and cultural dimensions; the semi-structured format allows for flexibility in the interview, and consequently, may generate richer data than a structured interview (Al-Busaidi, 2008). Interviews were transcribed by the researcher at an intelligent verbatim level, in which pauses and meaningless filler words such as, "um" and "like", were omitted and sentences were lightly edited to correct grammar. The transcripts were then checked against the recording by the researcher to ensure accuracy. Following transcription, data was analysed to address the research aims and to inform the design of Study Two.

3.6. Data gathering instruments

3.6.1. Semi-structured interviews

The pre-developed interview guide was broken into three sections. The first section included a mixture of closed- and open-ended questions regarding the structure and workflows of the key informants' KidGen clinics. These questions were developed from and designed to extend the high-level process maps of the key informants' clinics constructed prior to the commencement of the research project (see Appendix B), and as such were tailored to each clinic. Questions sought to identify changes in the clinics' structures and workflows since the time of the preliminary interviews, fill gaps evident from the high-level process maps, and to uncover more details about processes and pathways. The questions in this section were asked in an order which reflected typical clinic workflow: patient referral, patient intake and triage, clinic preparation, patient clinic, genetic testing, return of results and patient discharge. The final question in this section of the interview asked the key informant to identify any bottlenecks in their clinics' existing workflows.

The second section focused on renal genetics services which were available for renal patients with a condition of suspected genetic origin prior to the commencement of a KidGen clinic in the hospital setting. Questions were open-ended and sought to gain insight into the types of services which existed, their structures, workflows and clinician/clinician and clinician/patient communication channels. The final section asked key informants for their perspectives on the advantages and disadvantages of multidisciplinary models as used in their KidGen clinics.

3.7. Data analysis

3.7.1. Process mapping

The first research aim (RA1) - *to model the structure and workflows of selected KidGen clinics and the renal genetics services which existed prior to KidGen* – was addressed by process mapping KidGen clinics' and other renal genetics services' structures and workflows based on the data collected in the key informant interviews. A process map is a diagram or illustration of the steps and decisions which comprise an activity (J. K. Johnson & Debono, 2016). It is intended to show the boundaries of a process—that is, where the process begins and ends—and the steps of the process in their correct sequence. Process mapping was selected to address RA1 in this research project as it enables the structures and workflows within KidGen clinics and other renal genetics services to be visually defined, and subsequently compared and contrasted. Defining models of care is essential prior to evaluating care models in terms of their advantages and disadvantages.

Process mapping has found broad applications in healthcare where it is commonly used to assist in identifying areas for improvement and to create a shared understanding of processes for future quality improvement exercises (Jun, Ward, Morris, & Clarkson, 2009). Types of process maps used in healthcare research include spaghetti diagrams which represent the physical flow of an object or person through spaces or systems and are used to expose inefficient layouts, and swim lane activity diagrams which can represent non-linear processes and assign activities to the roles or persons who perform them (Jun et al., 2009). A high-level process map is designed to give a holistic overview of the essential processes of an organisation. Given that RA1 was to define the models in use, rather than uncover the details in clinic processes, it was determined that high-level process mapping would be the most appropriate tool for data analysis. The pre-existing high-level process maps provided the preliminary data which was clarified and extended upon in the key informant interviews, in order to produce updated and re-formatted high-level process maps.

The updated process maps were created in Microsoft PowerPoint, Version 16.2. A symbol set representing processes and key roles was created using icons available from the website, Noun Project (Noun Project, n. d.) and Microsoft PowerPoint (see Table 3.1). Process maps of KidGen clinics were created to represent clinic workflows prior to the patient clinic, during the patient clinic, throughout genetic testing and the interpretation of test results and for the return of test results to patients. Multidisciplinary meetings or activities within these workflows were visually represented within a rectangular background, coloured according to various stages of KidGen clinic workflow (see Figure 3.1). A process map representing a generic overview of renal genetics services prior to the establishment of KidGen clinics was created using the same symbol set. Process maps were shown to key informants upon completion for confirmation of accuracy and editing as required.

Table 3.1: Process mapping symbols

Symbol	Description
	Indicates the beginning of clinic workflow
	Indicates the end of clinic workflow
	Patient with a renal condition
	Nephrologist
	Clinical geneticist
	Genetic counsellor
	Registrar in nephrology or clinical genetics
	Laboratory services
	Referral base
	Patient’s family
	Blood sample

	Forward information
	Letter
	Emailed information
	Mailed information
	Conversation held in person
	Conversation held via phone call
	Research project

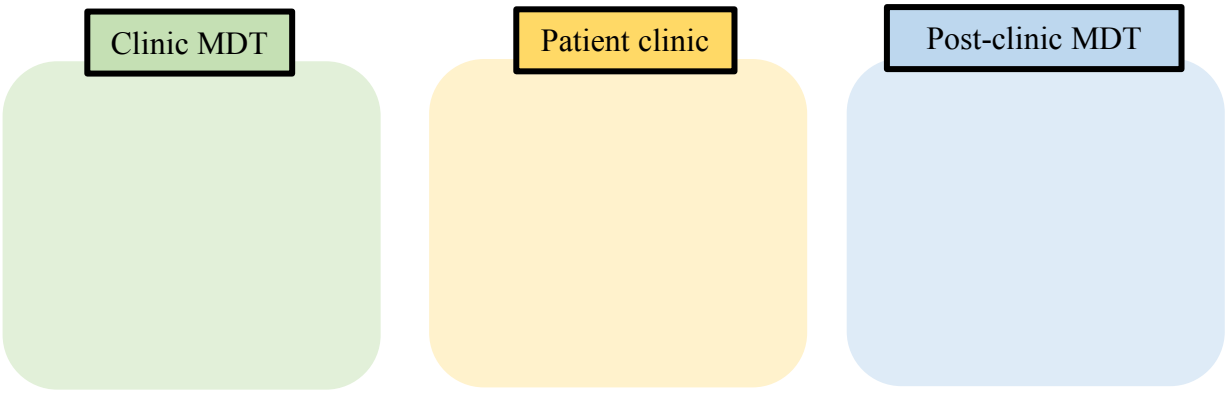


Figure 3.1: Rectangular backgrounds used in process maps of KidGen clinics to represent multidisciplinary (MDT) meetings and activities and colour-coded according to the following stages of clinic workflow: prior to the initial patient clinic appointment (green), a patient clinic appointment (orange) and following the initial patient clinic appointment (blue).

3.7.2. Coding analysis

The second research aim (RA2) – *to investigate the advantages and disadvantages of multidisciplinary models in renal genetics* clinics – was addressed by coding analysis of the

interview transcripts. Transcripts were imported into NVivo software, Version 12.1, for coding. A hybrid approach of qualitative methods of thematic analysis was used to develop the code structure (Fereday & Muir-Cochrane, 2006), in which, a deductive organising framework was applied as a start list of codes, and themes were inductively coded within the organising coding framework (Bradley, Curry, & Devers, 2007). Deductive coding involves the application of pre-determined codes in the analysis, in this particular instance, advantages and disadvantages of multidisciplinary models for team members and patients in renal genetics clinics. Inductive coding emerges from the data through close-reading and inter-textual comparison; codes are developed to reflect themes and concepts which are present in the interviews (Vaismoradi, Turunen, & Bondas, 2013). Inductive coding was used to specify the types of advantages and disadvantages of multidisciplinary models for team members and patients in renal genetics clinics which were discussed in the interviews. The inductive codes were developed iteratively, with trial and refinement of codes and through discussion with multiple coders.

Applying an integrated approach enabled the analysis to focus on the pre-determined themes of advantages and disadvantages of the model without limiting the types of advantages and disadvantages which might be reported in the results of this research to that which had been previously identified and discussed in theoretical work. The final coding frame, which consisted of a list the types of advantages and disadvantages of multidisciplinary models for team members and patients in renal genetics clinics, was used to inform the design of the online survey in Study Two.

3.8. Limitations

Creating a process map to capture any organisation's structure and workflows is limited by the knowledge and accuracy of the information obtained by the key informants. Given that the time restraints of the project necessarily limited interviews to one key informant per clinic, and not multiple informants per clinic, there is the potential for aspects of the clinic processes to be inaccurately described and depicted, particularly those in which the key informant was not actively involved. This risk was addressed by creating high-level process maps which were designed to capture a broad overview of clinic workflows rather than a detailed summary of individual processes. Additionally, the key informants who were purposively recruited were known, through previous research and consultation with members of the KidGen Governance Committee, to have a good understanding of clinic workflows.

Qualitative data analysis has been criticised as lacking rigour in its methodology due to a reliance on the researcher's subjective interpretation of the data (Anderson, 2010). The small scale on which qualitative research is often carried out, as in this research project, may challenge the reliability, or reproducibility, of the findings. The interpretative nature of data analysis is also criticised as potentially being less valid, or accurate in its representation of phenomena, than quantitative research. Coding in discussion with a second coder was undertaken to increase the reliability of the findings.

Data triangulation was used to ensure the reliability and validity of findings addressing RA2. The advantages and disadvantages coded in Study One from the interviews were used in conjunction with key findings from the literature review to design an online survey in Study Two which investigated the advantages and disadvantages of multidisciplinary models in renal genetics clinics in a larger and broader sample than Study One. The results of Study One and Two were then compared against each other to interpret and contextualise the findings. Member checking was employed to validate the process maps (Creswell & Miller, 2000). Key informants were asked to reflect on the accuracy of the process maps once they were completed and minor changes were made as suggested.

3.9. Summary

In summary, Study One consisted of in-depth, semi-structured interviews with five key informants from KidGen clinics across Australian states. Each interview was transcribed and analysed to address RA1 by creating process maps of the clinics' structures and workflows as well as of renal genetics services as were in use prior to the establishment of KidGen clinics in their respective hospital settings. Interviews were also coded using an integrated coding method for the advantages and disadvantages of multidisciplinary models in renal genetics clinics. The findings were used to answer RA2 and to inform the design of Study Two. The results of Study One are presented in Chapters 4 and 6.

CHAPTER 4. RESULTS: STUDY ONE – RA1

4.1. Overview of chapter

This chapter presents the results of Study One which address RA1 – *to model the structure and workflows of selected KidGen clinics and the renal genetics services which existed prior to KidGen* – through key informant interviews with KidGen team members. High-level process maps of clinical workflows prior to the establishment of KidGen renal genetics clinics and of structures and workflows of KidGen clinics are shown and described. Study One results which address RA2 through coding of the advantages and disadvantages of MDT models in renal genetics clinics are discussed in Chapter 6.

4.2. Participants

All eligible participants (N = 6) agreed to participate, however, one member was unavailable within the Study Two timeframe and so the total number of participants was five. All five participants were actively involved in KidGen clinics located in public hospitals in different Australian states at the time of the research project (see Table 4.1). The sixth participant, who was not available to participate in the interviews, was recruited from a state with two eligible participants. Therefore, coverage of all five Australian states was not affected by his/her inability to participate in a key informant interview. Participants all held senior roles within the KidGen Collaborative and were specialists in one, or more, of the following fields: adult nephrology, paediatric nephrology and clinical genetics (see Table 4.1). Interview lengths ranged from 26 minutes to 34 minutes; the average interview length was 30 minutes. Participants in Study One were also eligible for participation in Study Two.

Table 4.1: Summary of interview participant demographic characteristics (N = 5).

Characteristic	**Item**	**Frequency**
State	QLD	1
	NSW	1
	VIC	1
	SA	1
	WA	1
Gender	Female	2
	Male	3

Professional Group[2]	Adult Nephrologist	4
	Paediatric Nephrologist	1
	Clinical Geneticist	1

4.3. Renal genetics services prior to the establishment of a multidisciplinary operating paradigm

During the interviews, key informants were asked to describe the types of genetics services which existed for patients with a renal condition of suspected genetic aetiology prior to the establishment of KidGen clinics with their MDT operating paradigm. In their responses to interview questions, participants detailed which medical specialties were involved and how services were coordinated from the time of referral for genetic testing or counselling to the return of genetic test results. Four of the five key informants responded to questions on this topic from their personal experience of working in these services. One key informant had not worked in his/her current role prior to the establishment of KidGen clinics and consequently acknowledged that it was difficult to accurately answer this question from personal experience. Anecdotal descriptions were provided briefly instead. Two main models (referred to as Model A and Model B) of care delivery and management for renal patients with a genetic condition of suspected genetic aetiology were described by key informants.

4.3.1. Model A

Four of the five key informants discussed a model of care represented as a high-level process map in Figure 4.1 and described here. Renal patients, managed by a nephrologist within a hospital nephrology department, were referred to a hospital general genetics service for genetic testing and/or genetic counselling. The referral to the general genetics service was executed by a referral letter from the patient's managing nephrologist. The patient would be triaged by the

[2] The total frequency for Professional Group exceeds the number of key informants as one key informant was an adult nephrologist and clinical geneticist.

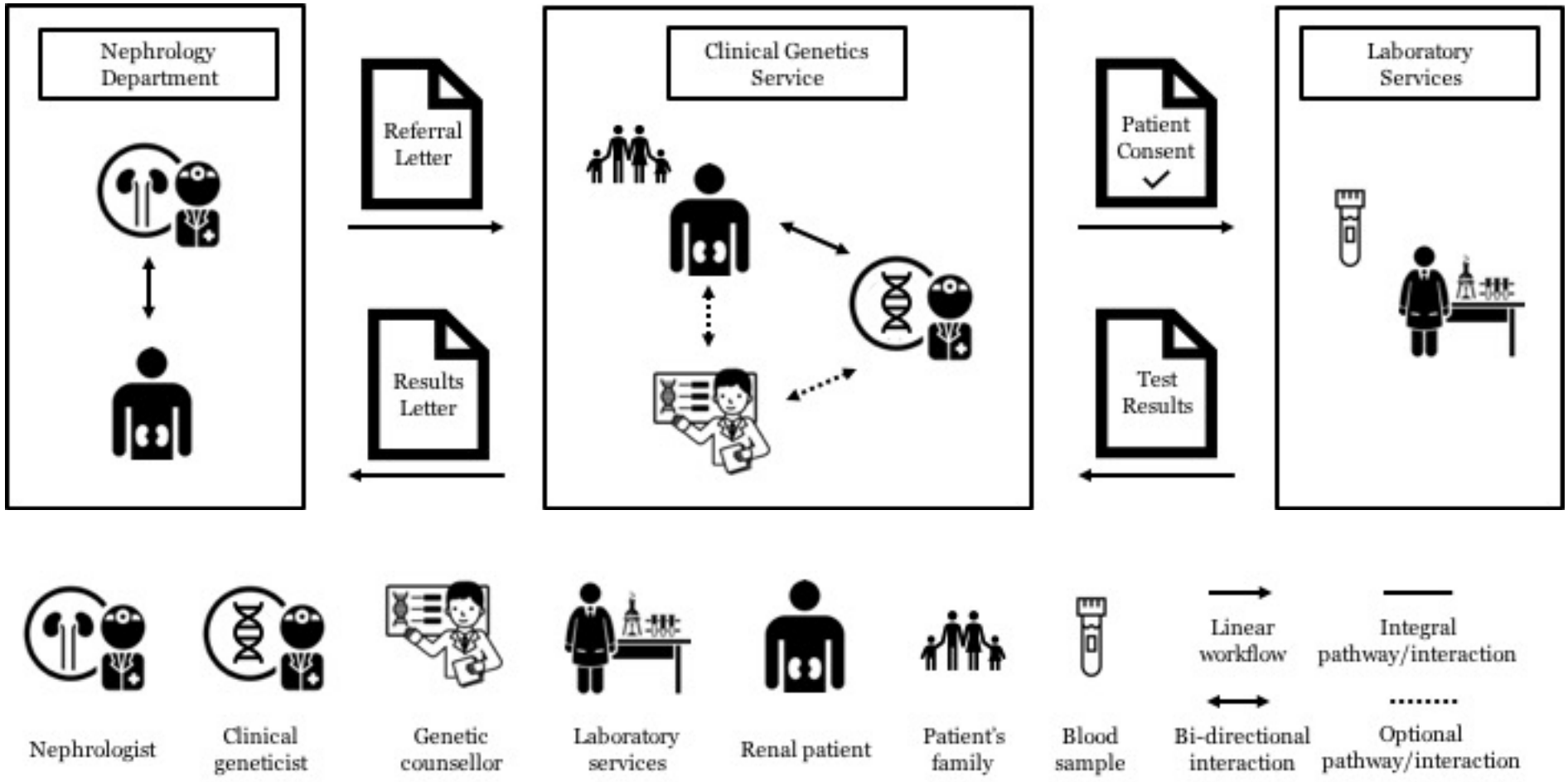


Figure 4.1: A high-level process map of Model A, depicting the typical structure and workflows of renal genetics services for patients with a renal disease of suspected genetic aetiology prior to the establishment of multidisciplinary KidGen clinics in public hospitals around Australia. Some variations in this model were described, including whether or not the family and/or genetic counsellor, would be present during the clinical genetics service appointment.

general genetics service and placed on a wait list of 6-12 months for an appointment. During the appointment, the patients, and possibly their family, were seen by a clinical geneticist with or without a genetic counsellor present. Given that in a general clinical genetics service, the clinical geneticist is not an expert in renal phenotypes, he/she may have needed to consult with an expert and/or review the literature after the patient appointment and prior to deciding whether to offer a genetic test. If genetic testing was deemed appropriate by the clinical geneticist and testing was available, patient consent was obtained and a blood sample was sent to a laboratory service for genetic testing. Laboratory services performed the genetic test and returned the results by letter to the clinical genetics service. The clinical geneticist interpreted the results and sent the results by letter to the referring nephrologist, who provided ongoing care and management of the patient.

4.3.2. Limitations of Model A

Referral of renal patients to general genetics services in Model A was described as infrequent due to the cost and availability of testing. In comparison with KidGen clinic referral rates, referrals were *"rare"*, *"spectacularly low"* (KIA) and *"not very common"* (KIC). The *"incredibly expensive"* (KIC) cost of genetic testing was cited as a deterrent to referring patients to genetics services (KIC) and as a preventative from having the test funded even after referral (CIB). The absence of local supportive laboratory services in some hospitals also inhibited referral. Places which did have supportive laboratory services *"were doing a bit of genetic testing"* (KIA). However, even in such instances, testing was available for only *"one or two phenotypes"* and the testing was *"for two genes"* (KIA).

Furthermore, the *"silo"* model of care in Model A made it difficult for clinical geneticists to discuss the interpretation of variants with laboratories or the patient's phenotype with nephrologists (KID). The lack of integration between clinical departments and laboratory services meant that there was also much less information available to clinical geneticists about *"the testing that's being done"* and the genes that were covered (KID). Errors in test ordering, such as ordering the wrong test, also came as a result of miscommunication between clinical departments (KIB).

4.3.3. Model B

A second model of care by which patients with a renal disease of suspected genetic aetiology might receive genetic testing was described in brief by four of the five key informants. In this model, the nephrologist took responsibility for ordering a genetic test for his/her patient. Approval from the

clinical genetics service was obtained prior to test ordering. The nephrologist who ordered the test would also receive the results from the laboratory.

4.3.4. Limitations of Model B

Genetic test ordering in this model was limited by many of the same factors as discussed in relation to Model A. These include the small number of renal phenotypes for which a genetic test existed, a lack of funding for genetic tests and the availability of laboratory services (KIA). Some hospitals did not have access to local laboratory services equipped to provide genetic testing and nephrologists were required to seek out appropriate testing services elsewhere, whether nationally or internationally (KIE).

4.4. Multidisciplinary models of care in renal genetics clinics

In order to address RA1 – *to model the structure and workflows of selected KidGen clinics and the renal genetics services which existed prior to KidGen* – key informants answered questions about the structure and workflows of their respective KidGen clinic. The clinics were either adult ($N = 3$) or paediatric ($N = 2$) renal genetics clinics. Each clinic employed a genetic counsellor, a clinical geneticist and one, or two, nephrologist(s). Four of the five clinics offered primarily exome panel sequencing and one clinic offered whole exome sequencing (WES). The length of clinic operation ranged from 1.5 years to 6 years. Table 4.1 provides an overview of the clinics' characteristics.

Table 4.1: Characteristics of the five KidGen clinics

	Clinic A	**Clinic B**	**Clinic C**	**Clinic D**	**Clinic E**
Length of operation (years)	6	3	1	2.5	1.5
Type of clinic	Adult	Paediatric	Adult	Paediatric	Adult
Type of testing offered	Exome panel	Whole exome sequencing	Exome panel	Exome panel	Exome panel

The key informants responded to questions which elicited a broad overview of the following stages of clinic workflow: patient referral and clinic intake, preparation for patient clinic appointments, the patient clinic appointment, genetic testing and the interpretation of test results and finally, the return of test results to patients. A description of these stages and the similarities and variations in

workflow between clinics is provided below. High-level process maps which depict these workflows for each clinic which are provided in Figures 4.2 – 4.6 at the end of the chapter.

4.4.1. Clinic workflow prior to KidGen patient clinic

Patient referral

Referral into KidGen clinics was executed by referral letter for all five clinics, and with an additional standard referral form for two clinics. The referral base across all five clinics consisted of primarily adult and/or paediatric nephrologists with a small number of referrals coming from other professional disciplines (see Table 4.3).

Table 4.3: Referral base of KidGen clinics

Clinic	Referral base
Clinic A	Primarily adult nephrologists and general practitioners
Clinic B	Primarily paediatric nephrologists and a small number of general paediatricians, urologists, oncologists and general practitioners
Clinic C	Primarily adult nephrologists from across the state
Clinic D	Primarily paediatric nephrologists, clinical geneticists and a small number of general practitioners
Clinic E	Primarily adult and paediatric nephrologists from across the state

Clinic intake and triage

Upon receival of referral documentation, each clinic had established workflows for deciding upon patient intake into the clinic and for triaging the patient. Intake across all five clinics was dependent on whether or not the patient was considered an appropriate candidate for genetic testing and/or counselling given their medical condition and history. The patient's condition and other factors, for example, pregnancy, were taken into account in order to triage the patient for an initial clinic appointment. In three of the clinics, patient intake and triaging was jointly decided upon in a MDT meeting. Clinic A managed intake and triaging between the nephrologist and clinical geneticist and in Clinic C, the clinical geneticist handled these responsibilities (see Table 4.4)

Table 4.4: Management of patient intake and triage by professional role(s) or setting in KidGen clinics

Clinic	Clinic intake and triage

Clinic A	Nephrologist and Clinical Geneticist
Clinic B	MDT meeting
Clinic C	Clinical Geneticist
Clinic D	MDT meeting
Clinic E	MDT meeting

Role of the genetic counsellor

The genetic counsellor took responsibility for the coordination of the patient clinic appointments in each KidGen clinic. Prior to the patient clinic appointment, the genetic counsellor would also contact the patient and their families by phone and in writing, to provide them with an overview of the clinic and its services, and to obtain pedigree information. This information would then be brought to a MDT clinic meeting prior to the patient appointment. If further information was required, the genetic counsellor would contact the patient again after the MDT meeting and prior to the patient clinic appointment.

Multidisciplinary meetings

As part of each clinic's workflow, MDT meetings were held with the nephrologist(s), clinical geneticist, genetic counsellor, as well as a number of other professional groups in some clinics (see Table 4.5), prior to the patient clinic appointment. In Clinic E, laboratory scientists were in attendance to offer advice on the limitations of genetic tests for upcoming clinic patients and to assist in the interpretation of test results for patients who had received a genetic test. Clinic E also invited referrers to attend the MDT meeting in order that they might contribute their knowledge of the patient's medical history. Clinic A structured their KidGen clinic to include advanced medical trainees in nephrology and clinical genetics. Therefore, advanced medical trainees were also in attendance at MDT meetings.

Clinics D and E held their MDT meetings by virtual teleconference. This was to allow members who were off-site or referrers to call in and participate. Clinics A, B and C held their MDT meetings on-site and in person.

Patient intake and triage were discussed within these MDT meetings at certain clinics (see Table 4.4). As part of the MDT meetings in all clinics, clinic members would discuss potential diagnoses and whether or not a patient would be likely to benefit from a genetic test. Clinic members would

present to the MDT from their area of expertise; the genetic counsellor would present the patient pedigree if available.

Table 4.5: Attendance at KidGen multidisciplinary (MDT) meetings by professional groups across clinics

	Team members in attendance at KidGen MDT meetings					
	Nephrologist	**Clinical Geneticist**	**Genetic Counsellor**	**Advanced Medical Trainees**	**Laboratory Scientists**	**Referrers**
Clinic A	✓	✓	✓	✓		
Clinic B	✓	✓	✓			
Clinic C	✓	✓	✓			
Clinic D	✓	✓	✓			
Clinic E	✓	✓	✓		✓	Optional

4.4.2. KidGen patient clinic

On the day of the patient clinic, Clinics A, D and E hold a MDT immediately prior to the patient appointments. For Clinics A and E, this is an additional MDT meeting and allows team members to collectively review the cases briefly before the patient appointment. For Clinic D, this meeting is the primary MDT meeting for team members of the clinic. Clinic D also held a brief MDT meeting at the conclusion of the patient clinic appointments to debrief and discuss any issues that arose during the course of the appointments.

The patient's initial clinic appointment was attended by the patient with or without members of the patient's family. The purpose of this clinic appointment was to discuss the patient's condition, the value and implications of a genetic test if testing was determined to be appropriate, or the implications of a previous test result if the patient had undergone a genetic test prior to referral to the clinic, as was the case in some clinics.

In Clinics A, B and D, patients were seen by the nephrologist, clinical geneticist and genetic counsellor in the clinic appointment. Clinic B intentionally staggered the entry of team members to the clinic appointment so as to not overwhelm the patient. In Clinics E, patients were seen by all three professional groups if time permitted. However, when the clinic was busy two patient clinic appointments were run concurrently and patients were seen by a nephrologist and clinical

geneticist or a nephrologist and genetic counsellor. In Clinic C, patients were seen by any combination of the three professional groups, as the particular case required.

Patients who were offered genetic testing were counselled by the clinical geneticist and/or genetic counsellor as to the limitations and implications of the genetic test. Patient consent was obtained in order to proceed with the genetic test. This process took place as part of the clinic appointment workflow in all clinics except Clinic C, where patients were consented for genetic testing by the genetic counsellor in a separate room at the conclusion of the clinic appointment.

4.4.3. Genetic testing and the interpretation of test results following the KidGen patient clinic

Four of the five clinics utilised local supportive laboratory services for genetic testing; Clinic A sent patient blood samples to inter-state laboratory services for testing due to the absence of local supportive laboratory services. A number of clinics reported occasionally ordering genetic tests from overseas laboratory services when the appropriate test was unavailable in Australia or was offered for free or with a faster turnaround time through an overseas service. The workflow for the interpretation of genetic test results was different between clinics and depended on the type of genetic test, the complexity of the patient's phenotype, relationships with members of laboratory services and established clinic workflows.

Four of the five clinics described the importance of communication with laboratory services in the interpretation of test results. The exception to this, Clinic C, reported that, in most cases, the test result matched the patient's phenotype as predicted and interaction with laboratory services had been minimum at the time of the interviews. Clinics B and E incorporated MDT meetings with laboratory scientists as part of their clinic workflow. As discussed earlier, Clinic E conducted their clinic MDT meetings with laboratory scientists in attendance; this facilitated cross-disciplinary discussions about the interpretation of the test results and limitations of the test in light of phenotypic information.

Clinic B offered WES testing to patients; WES is known to generate a large degree of variants of uncertain significance (VUS) which are time-consuming to curate. The interpretation of VUS is further complicated by rare phenotypes, such as those seen in KidGen clinics. Therefore, to decrease the time required to manually curate WES test results, state-wide MDT 'Variant Prioritisation Clinics' (VPCs) were held between KidGen clinic team members and laboratory scientists in order to prioritise which VUS should be prioritised for curation. Positive test results

were discussed at a subsequent VPC and then brought to the local KidGen MDT with clinic team members.

Clinics A and D both discussed the value of communication with laboratory services in the interpretation of test results, although formal meetings were not part of regular clinic workflows. Instead, discussions with laboratory services would usually take place via phone or email with the nephrologist and/or clinical geneticist. Clinic A described the frequency of these interactions as comparatively low to the initial years of clinic operation, when a greater degree of interaction was required to enable laboratory scientists to gain the necessary expertise in genetic variants associated with kidney disease. Clinic D reported a high degree of communication with the laboratory services. Much of this was initiated by the laboratory services and was focused on enabling the scientists to make sense of the genetic variants by providing phenotypic expertise. Clinic D also reported a laboratory run variant interpretation MDT meeting which was attended by members from any clinic utilising the laboratory service for the genetic testing of renal disease; however, this meeting was described as ancillary to the KidGen workflow.

4.4.4. Return of genetic tests results to patients

Genetic test results were returned to patients either in a clinic appointment, or, in Clinics A, C and E, via mail or phone call when the results were straightforward. Patients who received their results via mail or phone call were invited to attend a follow-up clinic appointment to discuss their results. In Clinic A, appointments scheduled for the return of test results – referred to as 'review clinics' – were run by advanced trainees in nephrology and clinical genetics concurrently with other clinic appointments. The KidGen clinic nephrologist and/or clinical geneticist would make themselves available during the review clinics as required, however, it was primarily facilitated jointly by the advanced trainees.

As the KidGen clinics were not designed to provide ongoing care management, patients who did not require further testing were generally referred back to their referring physician. Patients who did not receive a conclusive diagnostic result may have been enrolled, by their consent, into a research project funded by Australian Genomics, in order to better understand the genetic causes of rare and inherited kidney diseases.

4.5. Summary

This chapter presented the results of Study One which addressed RA1 – *to model the structure and workflows of selected KidGen clinics and the renal genetics services which existed prior to KidGen* – through key informant interviews with KidGen team members. It provided a descriptive overview of services prior to the establishment of MDT KidGen clinics as well as the typical operating procedures of selected KidGen clinics. High-level process maps of the clinic operating models are provided at the conclusion of this chapter to summarise the models and for visual reference. The results of this chapter are discussed in Chapter 5. The following chapter provides an overview of the results of Study One as they relate to the second research aim: *to investigate the advantages and disadvantages of multidisciplinary teams in renal genetics clinics from multidisciplinary team members' perspectives*.

Figure 4.2: High-level process map depicting the structure and workflows of Clinic A.

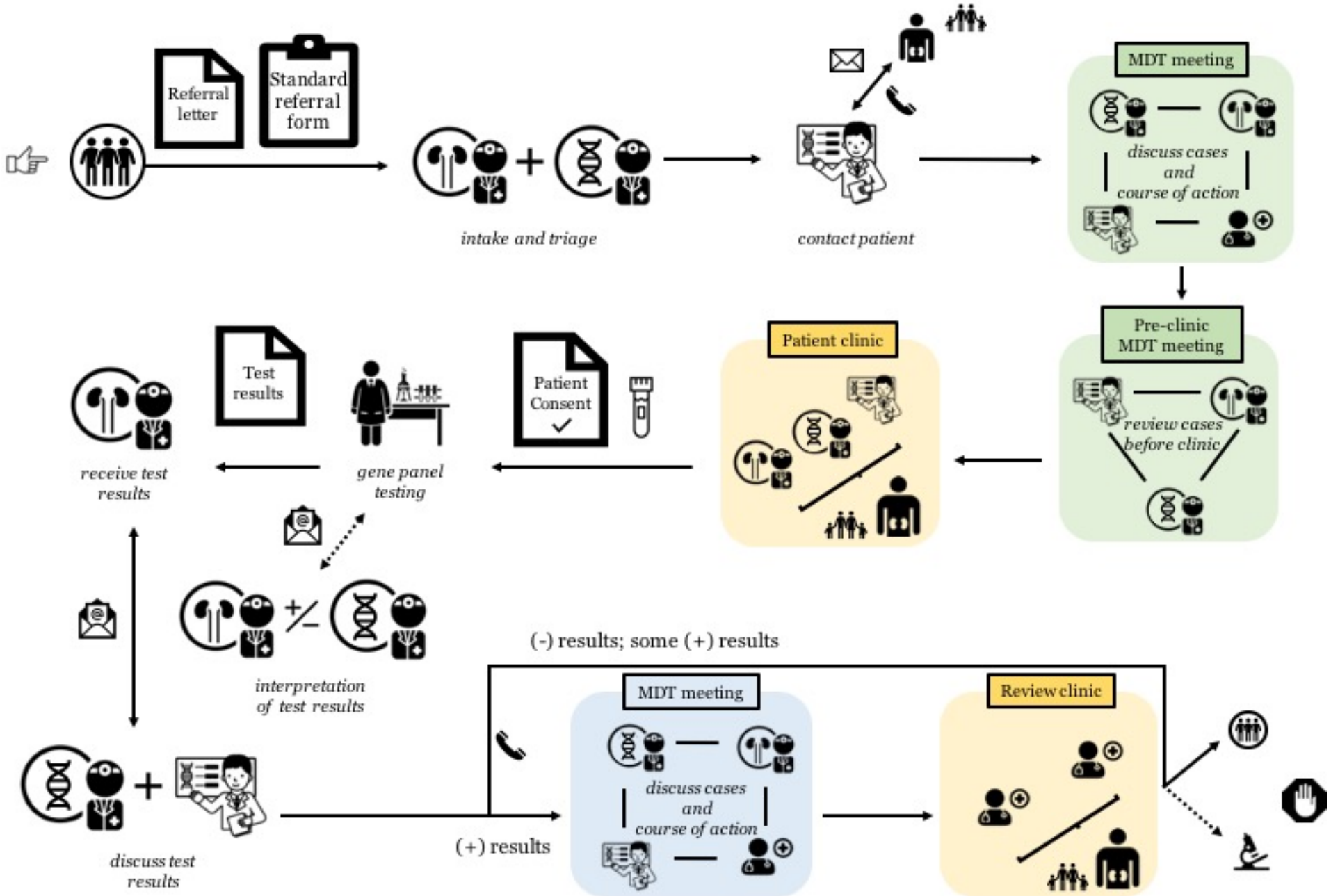


Figure 4.3: High-level process map depicting the structure and workflows of Clinic B.

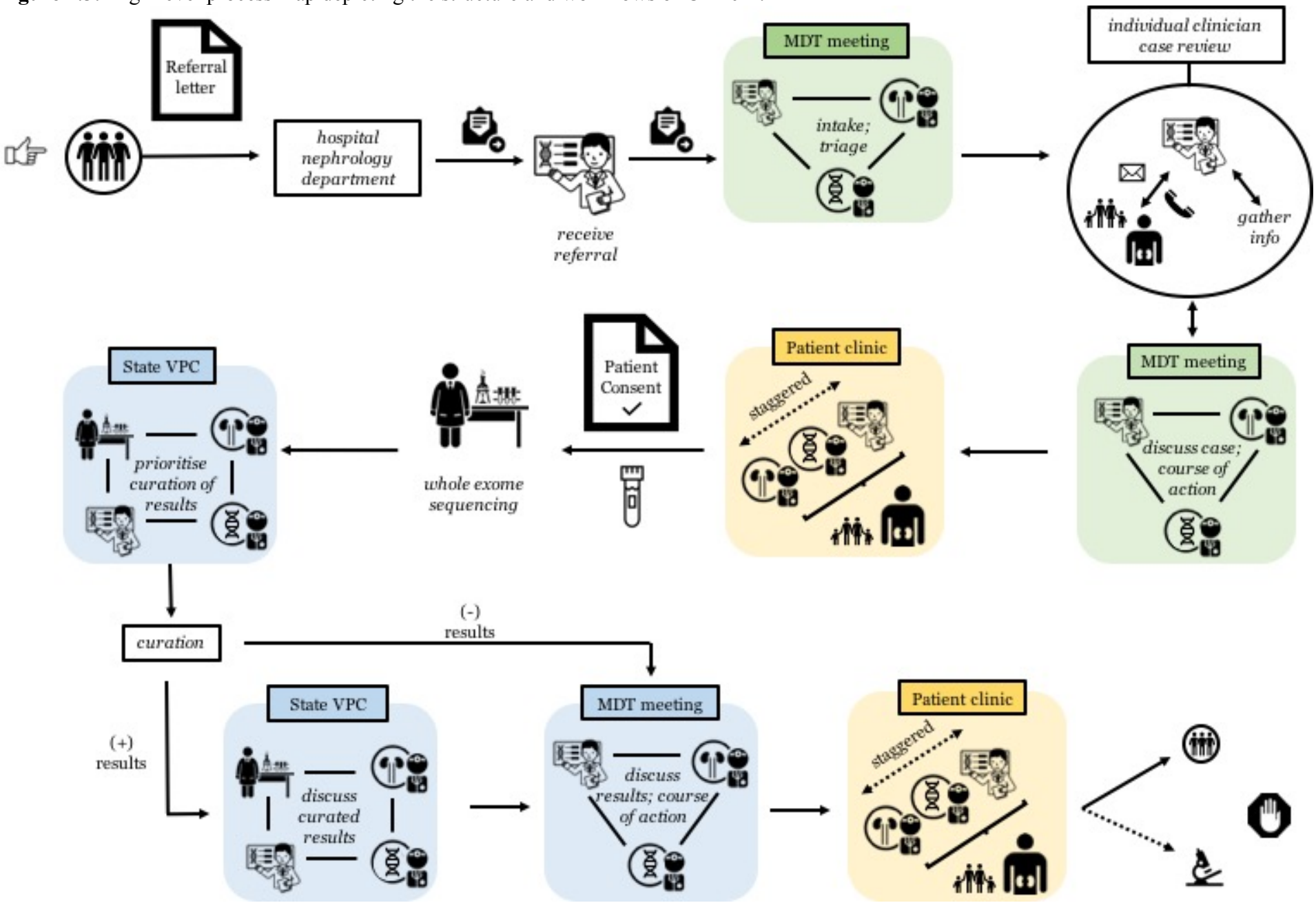


Figure 4.4: High-level process map depicting the structure and workflows of Clinic C.

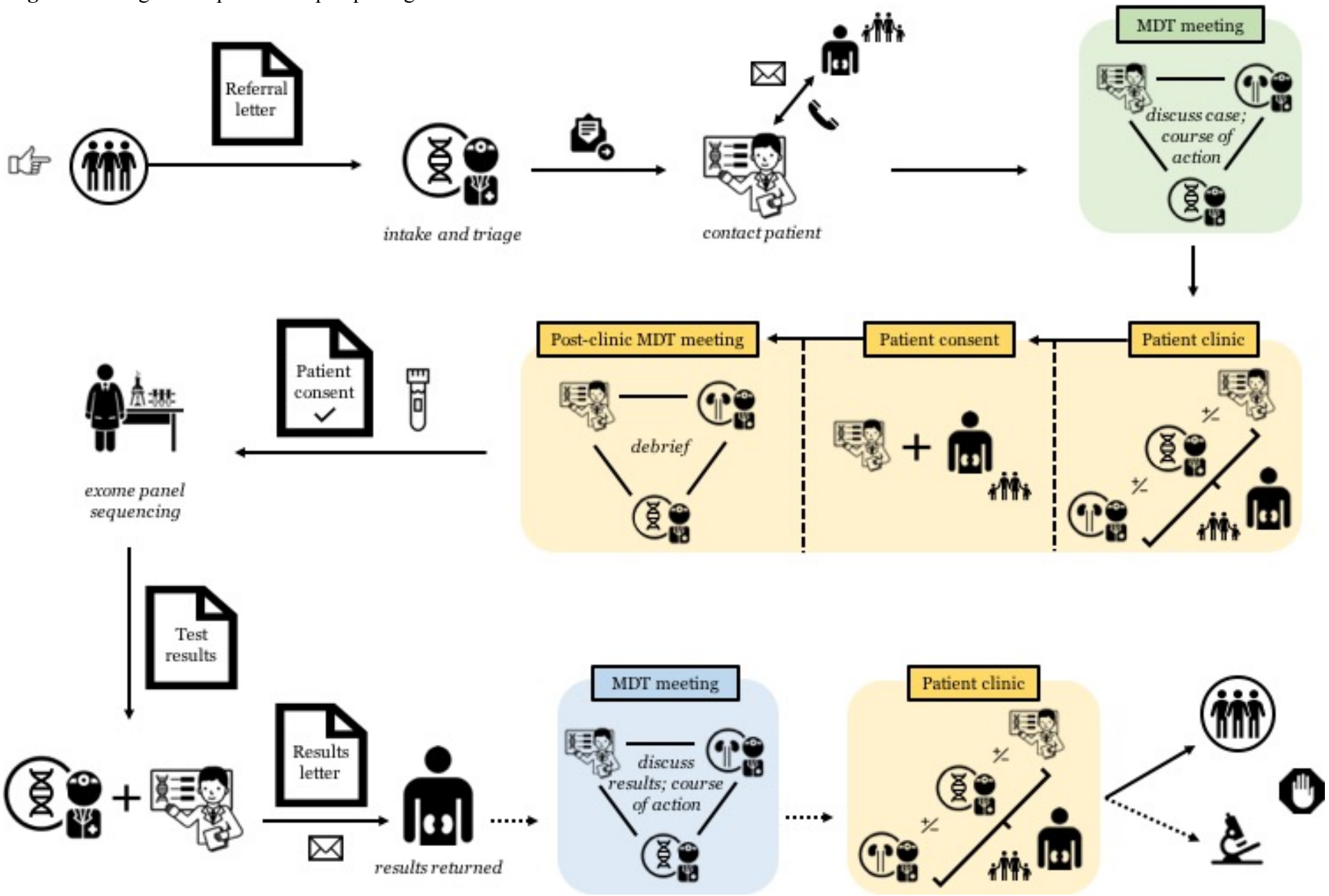


Figure 4.5: High-level process map depicting the structure and workflows of Clinic

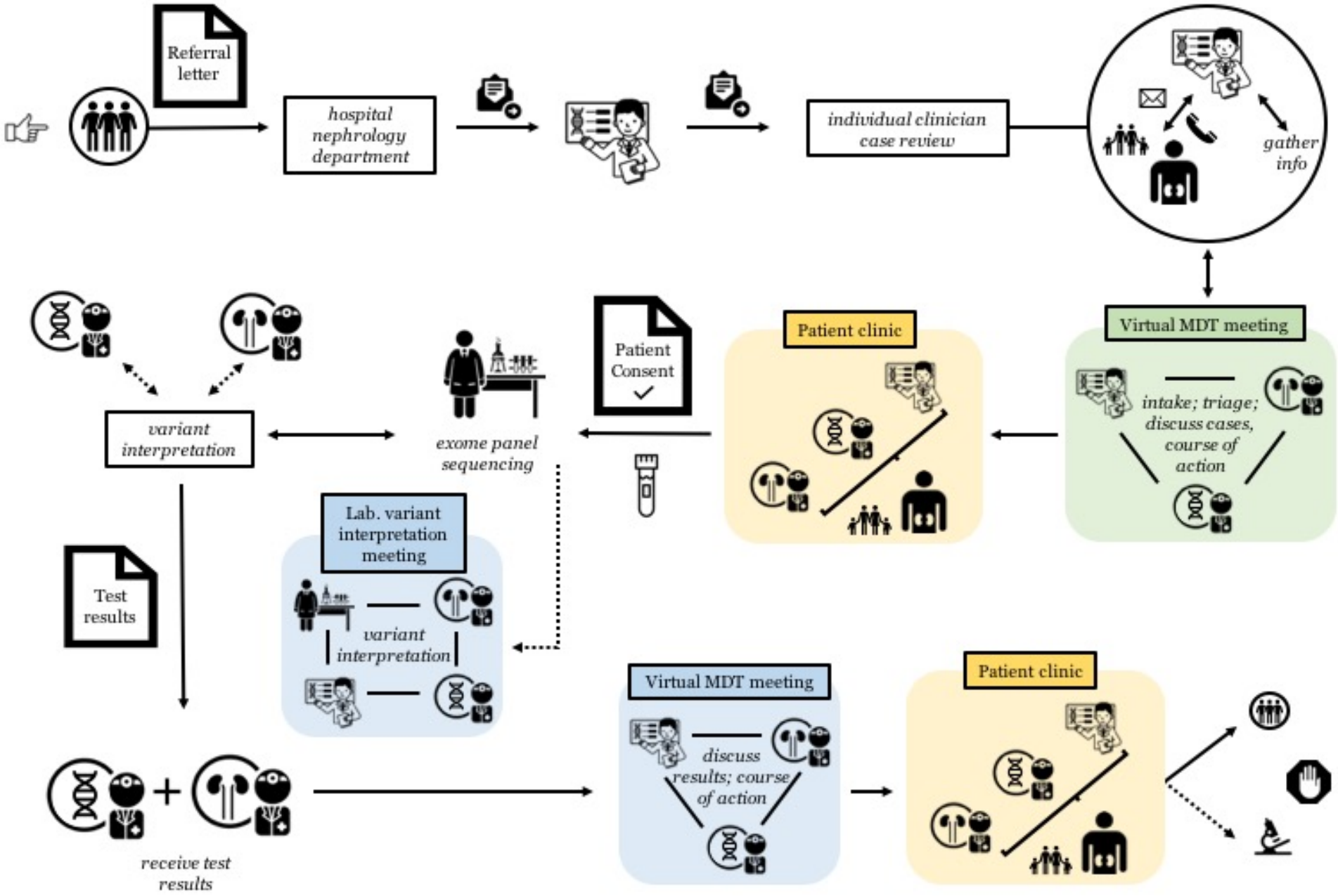
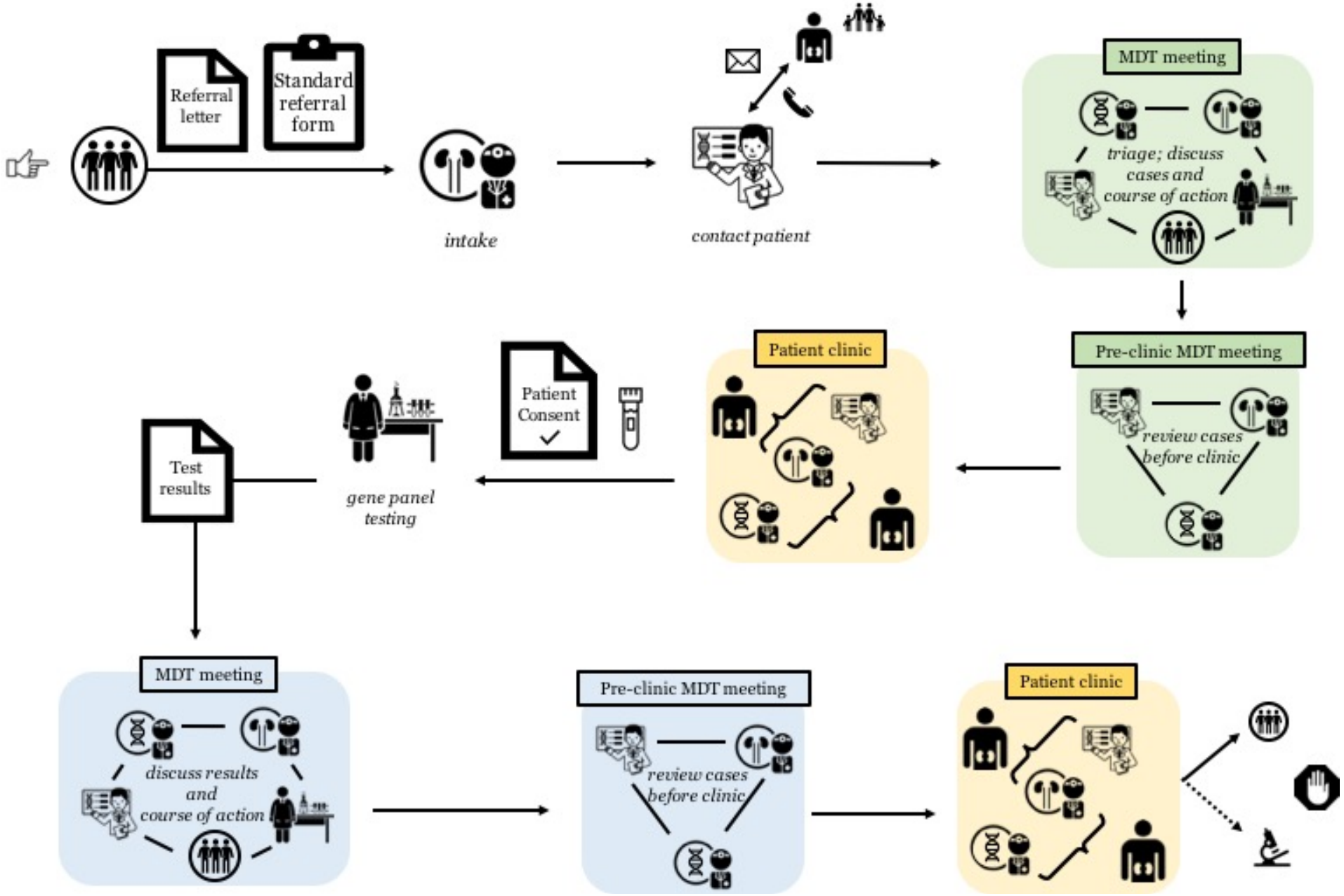


Figure 4.6: High-level process map depicting the structure and workflows of Clinic E.



CHAPTER 5. DISCUSSION: STUDY ONE – RA1

Process mapping was used to define the workflows in the provision of genetic services for renal patients in a general clinical genetics service and specialist MDT renal genetics clinics. This was in support of RA1: *to model the structure and workflows of selected KidGen clinics and the renal genetics services which existed prior to KidGen*. As the second aim of the research project was to the assess the advantages and disadvantages of a MDT model in renal genetics clinics, it was fundamental to first establish the operating procedures in both models in order to make meaningful associations between the way services are structured and provided, and the advantages and disadvantages described in Study One and Study Two. While the process maps of the MDT renal genetics clinics captured localised service models, the descriptions of genetic service provision prior to the establishment of the specialist MDT clinics were generalised. There is an existing body of literature on the operating models of general genetics services (Cooksey, Forte, Benkendorf, & Blitzer, 2005; McPherson et al., 2008; Pletcher et al., 2002). However, the operating procedures of specialist MDT genetics clinics are currently emerging and therefore greater attention was paid to the localised variations in these models.

In both the MDT and preceding operating model, the professional roles were reportedly the same, and consisted of adult or paediatric nephrologists, clinical geneticists and genetic counsellors. The main point of difference was the degree of integration and co-localisation of professional disciplines. The previous model could be described as a "silo" model of healthcare; renal departments and genetics services operated largely autonomously of each other with limited integration of services. Boundaries between professional disciplines were navigated by written documentation, such as referral and results letters. Silo models in healthcare have been criticised for inhibiting communication and information sharing between medical practitioners (Gittell, Godfrey, & Thistlethwaite, 2013). This is supported in the present study by the example of the wrong genetic tests being ordered for patients as the result of miscommunication between departments. Similarly, a clinical geneticist reported difficulty accessing expertise in renal conditions and communicating with laboratory services in a non-integrated model. For rare and complex conditions which require the input of multiple specialists, challenges in communication and accessing information pose clear barriers to timely and accurate diagnostic outcomes.

Within the renal genetics MDT operating paradigms, multiple professional disciplines were co-localised either physically or virtually in multidisciplinary meetings and physically in patient clinic appointments. Co-location is a key facilitator of effective MDT working (Doyle, 2008). However, attendance at MDT meetings is reportedly difficult for some due to travel distance (Rawlings,

2007). The capacity to attend meetings virtually enabled KidGen team members to attend who otherwise would have been prevented by travel distance. For Clinic E, a virtual MDT meeting also allowed referrers to take part in the discussion of their patient's condition and testing options. While having access to the referrer's knowledge of the patient's clinical history and condition is advantageous for clinic team members, it also offers the opportunity engage the referrer in the patient's care management. A study within palliative services found that general practitioners were deterred from referring their patient's to a specialist service due to a sense of loss of patient ownership and involvement (Yuen, Behrndt, Jacklyn, & Mitchell, 2003). Therefore, involving referrers in clinic MDT meetings may enable clinic referrals. While educating the referral base was not described as a reason for involving referrers, their attendance may have also provided an educational opportunity for learning about clinical genetics and its application to rare and complex renal disease.

A number of enabling factors for the provision of MDT care in renal genetics clinics were identifiable across the clinics. While the role of the genetic counsellor was present in both models of care delivery, its importance was particularly evident from process maps and emphasised by key informants in the MDT models. Within the workflow of each clinic, the genetic counsellor coordinated the patient clinics and spoke with patients and their families to obtain family history and any other information necessary. Given the logistical difficulty of coordinating a multidisciplinary clinic and obtaining detailed family histories, the inclusion of genetic counsellors in MDT renal genetics clinics may be critical to the model's implementation and sustainability.
Established networks with supportive laboratory services also emerged as an integral feature of establishing renal genetics clinics. The degree of communication with laboratory services appeared to change over time. The longest serving clinic, Clinic A, reported a high degree of interaction with laboratory services during the early stages of clinic operation with less frequent interaction in the present day. Other clinics, which were comparatively younger, were more engaged with laboratory services. Though Clinic A was functionally more independent of laboratory services, the relationships developed through collaboration were valued and still existent. Key informants reported these relationships as instrumental in building medical scientists knowledge of renal phenotypes. A high degree of collaboration between clinical team members and laboratory services was particularly evident in the workflows of Clinic B. State-wide MDT meetings were attended by scientists and clinical members from multiple clinics in addition to local MDT meetings. The additional processes in clinic workflow and regular, scheduled engagement with laboratory services is consistent with the additional complexity associated with the interpretation of whole exome sequencing compared with gene panels, as used by clinics in other states (Volk, Conboy, Wical, Patterson, & Kirmani, 2015). The necessity of strong

communication between laboratory and clinical services has been recognised and put forward as a recommendation strategy for the integration of genomics into clinical practice (Sarah Bowdin et al., 2016). A review of genetic testing in cardiovascular disease similarly emphasised the value of relationships between laboratory and clinical services in understanding disease causing genetic mutations and keeping up to date with rapid technological advancements (Arndt & MacRae, 2014). As the complexity of genetic testing evolves and is applied to rare and complex disease, strong relationships between clinical and laboratory services in MDT models may provide avenues for sharing of expertise across professional disciplines.

Though the clinics shared a common purpose – to provide a diagnostic and genetic counselling service for renal patients with rare and complex disease – variations in clinic workflow were apparent. Examples included the number of MDT meetings scheduled prior to a patient clinic appointment, attendance at MDT meetings, interaction with laboratory services in scheduled MDT meetings and the process of returning test results to patients. Analysis of the reasons behind these variations were beyond the scope and timeframe of this study. However, local variations likely reflected contextual differences such as the availability of resources, the types of genetic testing offered, the length of clinic operation and patient demographics. Models of MDT operating paradigms in renal genetics are emerging, and guidelines on clinical practice for renal genetics services were not available at the time of this research project. Reducing practice variation is a reported target for improving clinical systems according to a recent general survey of generalist and specialist physicians (Cook et al., 2018). Process maps of multiple clinics' workflows (see Figures 4.2 – 4.6) may provide useful resources in the establishment and development of operating procedures of MDT renal genetics clinics and fill a gap in the published literature.

CHAPTER 6. RESULTS: STUDY ONE – RA2

6.1. Overview of Chapter 6

This chapter presents the second part of results from Study One which address RA2 – *to investigate the advantages and disadvantages of multidisciplinary teams in renal genetics clinics from multidisciplinary team members' perspectives*. The advantages and disadvantages of MDT models in renal genetics clinics coded in the key informant interviews are presented, as well as bottlenecks which were identified in the clinic workflows.

6.2. Participants

Participants were the same key informants (KI) whose characteristics were outlined in Section 4.2. of Chapter 4.

6.3. Integrated coding of interview transcripts

The interview questions were used to create a deductive coding framework which served as a scaffold for the inductive coding of themes in the interviews. The deductive codes were pre-defined by the interview questions and included: bottlenecks in clinic processes, advantages of MDT models in renal genetics clinics and disadvantages of MDT models in renal genetics clinics. The key informants' responses to these questions were inductively coded for themes which are reported below. The advantages and disadvantages of the model were sub-classified as advantages and disadvantages for both clinic team members and patients. The themes of advantages and disadvantages for team members and patients are presented in Table 6.1 at the conclusion of the chapter.

6.4. Bottlenecks in the clinic processes

Key informants were asked if they could identify any bottlenecks in clinic processes. A bottleneck was defined as a point in clinic processes which was experiencing delays or inefficiency in some aspect of operation. Three key informants identified existing bottlenecks in clinic workflows and two key informants reported potential bottlenecks, which may present challenges in the future.

Clinic A reported a bottleneck in patient referrals into the clinic which was attributed to a lack of knowledge about the clinic's services within the potential referral base. Consequently, it was suspected that patients who were *"eligible and appropriate to* [be seen] *in this service model"*

were not always being referred to the clinic. It was suggested that one potential way to address this going forward was by educating the referral base as to what conditions would be eligible and appropriate to refer to the clinic. On the other hand, a high volume of patient referrals was described as a potential bottleneck in Clinic E. This risk was mitigated by the virtual MDT meeting, in which clinic intake was discussed and decided on. Therefore, the intake process was considered to provide an adequate level of control over the volume of referrals into the clinic, should they increase.

The time-scale on which the results of genetic tests were returned to patients was reported as a bottleneck in Clinic B. This was estimated to take six months. From the key informant's perspective, to wait that length of time after in-depth counselling in the clinic appointment was a *"horrible"* experience which needed to be shortened. Clinic C identified this as a potential bottleneck. However, the key informant saw the wait time as a fixed reality which did not present much of an issue as it was rare for the results to be needed urgently.

Clinic D identified a bottleneck in the administrative processes associated with test ordering. These processes, which involved gathering consent documentation, finding a supportive laboratory service and sending off the patient's DNA sample, were reported as not very straightforward and time-consuming.

6.5. Advantages of MDT models in renal genetics clinics for team members

The theme of *shared expertise* was a frequently reported advantage of a MDT model in renal genetics clinics for team members. This was attributed directly to the model, as the multidisciplinary structure meant *"having both specialities in the same room or in the same conversation about the patient"* (KID). This was advantageous as it brought together relevant elements of expertise from different professional disciplines, which had been previously separated in a non-integrated model, to inform decision-making and diagnosis and test results interpretation. An extended quote illustrates the theme of *shared expertise*.

"I think having both specialities in the same room or in the same conversation about the patient because as a geneticist you think of particular concerns, particularly we think about the implications for other family members, and you know, the extended testing, like, the extended implications and the implications of them having their own children and all of those things. And then the nephrologist is thinking a lot about the phenotype and so those things marrying together is really helpful. So often, you know, the geneticist might say, oh you know, what about thinking

about this and the nephrologist would say, well actually that could never happen because of XYZ and it works in both directions. So I think that is the biggest advantage of [the model]." (KID)

The value of sharing expertise was described as integral to a number of other advantages; this was particularly apparent in the theme of *collective learning and upskilling*. Collective learning and upskilling was facilitated by the *"closer collaboration between* [nephrologists] *and the genetic service"* (KIC). The interactions across professional disciplines was described from a nephrologist's perspective as a *"fantastic learning experience ... with the clinical geneticist there kind of educating us about clinical genetics"* (KIE). This was echoed by another key informant who believed that the collaboration would lead to *"upskilling on both sides* [with] *the geneticists more aware of renal conditions and vice versa"* (KIC). *Collective learning and upskilling* was also enabled by the collaboration of senior and junior team members from across professional disciplines. A number of clinics reported involving registrars in nephrology and clinical genetics for the purpose of *"training ... trainees a bit more"* (KIA). The MDT model facilitated this in Clinic A by structuring the review clinic, in which results were returned to patients, so that the genetics and nephrology registrar *"disclose the results together"* (KIA).

Having access to *shared expertise* in a MDT model in renal genetics clinics was also implied to be *time saving* in specific instances. This was reported by a clinical geneticist in comparison with the non-integrated model of care summarised by Model A in Chapter X. In a non-integrated model, it *"takes more time for someone who doesn't have expertise* [in renal conditions] *to decide on the testing and all of those things"* (KID). By implication, a MDT model which facilitates access to relevant phenotypic information, saved time for clinical geneticists who otherwise would have needed to contact experts and review the literature before ordering the appropriate genetic test.
Another advantage of a MDT model in renal genetics clinics was *confidence in the decision making process*. According to one key informant, having multiple people agreeing on something gave more surety in decision making. The analogy of the peer review process was used by way of explanation: *"There's something about ... multiple people agreeing on something – much like reviewers agreeing for a manuscript ... it gives more surety ... particularly if you're seeing patients with complicated and rare disease"* (KIA).

A *social environment* was also cited as an advantage of a MDT model in renal genetics clinics. Clinicians were described as one key informant as *"social creatures"* and the deconstruction of a MDT model to a non-integrated model could result in the loss of *"friends"* in professional settings. Therefore, a MDT model in renal genetics clinics carried personal advantages for clinicians.

Five advantages of MDT models in renal genetics clinics were coded for team members. These themes are displayed in Table 6.1 at the conclusion of the chapter.

6.6. Advantages of MDT models in renal genetics clinic for patients

In addition to advantages for team members, MDT models in renal genetics were described by key informants as having advantages for patients. Similar to the advantage of shared expertise for team members, patients were described as benefiting from the *access to expertise* which a MDT model facilitated in clinic appointments. As one key informant said, *"from the patient point of view it's ... nice because they get two sets of input"* (KIE).

This access to multiple areas of expertise in the one appointment had flow-on advantages for patients, such as a *streamlined service*. This meant that patients didn't *"didn't need to go to two separate specialists who ask them the same questions, and then have to communicate separately and then give them an answer. It kind of just happens in one go"* (KID). As a result, patients are able to *"get far more rapid access specifically to renal genetics information"* (KIC).

Another advantage for patients as a result of the MDT model in renal genetics clinics was *diagnostic outcomes*. It was reported by one key informant that in the renal genetics clinic, *"rates of diagnosis are so much higher"* and that they *"get more answers for patients"* (KIB). When asked about the underlying causes facilitating this, *shared expertise* amongst clinicians was cited as the reason, along with the increased sophistication of diagnostic testing.

A final advantage for patients discussed by team members was that of *personalised attention*. Within a MDT renal genetics clinic, patients were described as receiving *"more personal attention than they would have before ... in a general genetics clinic"* (KIC). One reason for this was the *"amount of counselling they're getting through the genetics counsellor"* which was attributed to a reduced time constraint in a dedicated renal genetics clinic compared to a general genetics service. The connection between *personalised attention* and time spent with patients was drawn by another key informant who said that *"...* [patients] *feel like they get their questions answered ... they feel we have the time – we take a long time, and I think they really feel listened to"* (KIB).

In summary, four themes emerged as advantages for patients of MDT models in renal genetics clinics for team members. These themes are listed in Table 6.1.

6.7. Disadvantages of MDT models in renal genetics clinics

The MDT model was described as *time consuming* by multiple key informants. Outside of the patient clinic appointment, *"a lot of the post-clinic administrative stuff is done in people's own time"* (KID). The administrative workload was described as substantive and involved collating consent documentation, selecting a laboratory service and organising the delivery of a DNA sample for the patient's genetic test. This took away from time needed to attend to routine work: *"I'm routinely here on a Saturday to catch upon my routine nephrology work because of all this"* (KIB). Within the patient clinic appointment, the presence of multiple specialists – each with a *"valid opinion"* – meant that it was *"difficult to stick to time"* (KID) and consequently clinic appointments would not uncommonly run over time.

Lack of funding was also frequently mentioned as a disadvantage of the model for team members. Aside from the genetic counsellors, who were paid part-time through Australian Genomics, other team members were conducting work related to the renal genetics clinic in their own time which wasn't accounted for in their salary. This was common to the model across states. For example, *" ... everybody is doing it in addition to their job that they're actually paid to do"* (KID) and, *"it is very time consuming which is fine if the time is being paid for and set aside but it's not. And this is all squeezed in"* (KIB). The *lack of funding* also had flow-on effects for team members in relation to their ability to prioritise clinic administrative duties as *"if you're not funded to do something, it's pretty difficult to prioritise"* (KID).

Clinic capacity was described as a disadvantage of the MDT model. The time demands of a multi-specialist clinic offering a genetic service meant that it was difficult to see more than a few patients per clinic. Whereas, according to one nephrologist, in a *"typical renal clinic"* it would be possible to see *"a dozen patients in the morning or thereabouts"* (KIC). Therefore, the practical limitation of how many patients can be seen per clinic was a disadvantage of the model.

Three main disadvantages of a MDT model in renal genetics clinics were coded for team members. These themes are listed below in Table 6.1.

Table 6.1: Themes of advantages and disadvantages of MDT models in renal genetics clinics coded from the interviews

Advantages for team members	**Perceived advantages for patients**	**Disadvantages for team members**
Shared expertise	Access to expertise	Time consuming

Collective learning and upskilling	Streamlined service	Lack of funding
Time saving	Diagnostic outcomes	Clinic capacity
Confidence in the decision making process	Personalised attention	
Social environment		

6.8. Summary

This chapter presented the results of an integrated coding of interviews for themes related to bottlenecks in clinic processes and the advantages and disadvantages of MDT models in renal genetics clinics for team members and patients. The following themes of advantages for team members were identified: *shared expertise*, *collective learning and upskilling*, *time efficient*, *confidence in the decision making process* and *social environment.* For patients, perceived advantages included: *access to expertise*, *streamlined service*, *diagnostic outcomes* and *personalised attention*. The themes of disadvantages of a MDT model in renal genetics clinics for team members were: *time consuming*, *lack of funding* and *clinic capacity*. There were no coded disadvantages for patients. These themes were used in the design and analysis of Study Two, an online survey, which further investigated RA2. The following chapter details the methods used in the design and analysis of Study Two.

CHAPTER 7. METHODS: STUDY TWO

7.1. Overview of Chapter 7

This chapter provides a detailed description of the methods used in Study Two; the second of two studies in a sequential exploratory mixed-methods design. It includes an overview of the project design, the study setting and participants, recruitment, procedures, data gathering instruments, data analysis and limitations.

7.2. Research project design

This study was the second component of a sequential exploratory mixed-methods research project. It was designed to address the second research aim – *to investigate the advantages and disadvantages of multidisciplinary models in renal genetics clinics for team members* – through an online survey that was primarily quantitative in design. The survey questions were built using the advantages and disadvantages coded in the key informant interviews of Study One. Study Two was conducted online with clinical team members actively involved in KidGen Collaborative renal genetics clinics at the time of the research project. The location of team members' clinics was not a restriction to participation, and as such, the survey was national in its distribution, covering all five states and the Northern Territory (NT).

7.3. Recruitment

All KidGen Collaborative clinical team members across Australian states and the NT were invited to participate in Study Two. This included participants involved in Study One. Inclusion criteria for recruitment was involvement in a KidGen Collaborative clinic in the role of a clinical team member. Eligible participants were identified and invited via email to participate by the KidGen Collaborative Manager (see Appendix D). The number of eligible participants at the time of recruitment was 42. The breakdown of eligible participants per state can be seen in Table 7.1. KidGen clinical members from the NT were invited to participate. The NT KidGen clinic being in the early stages of operation had yet to commence patient clinics at the time of survey distribution. As such, NT participants' survey answers were intended to serve as baseline or control data. Participant information was provided on the landing page of the survey and participants were required to provide informed consent before participating in the survey.

Table 7.1: The number of KidGen clinical team members eligible to participate in the online survey by Australian state and territory.

Australian state/territory	Number of eligible participants
QLD	4
NSW	6
VIC	18
SA	6
WA	6
NT	2
Total	42

7.4. Procedure

An online survey was built using the online survey software management platform, Qualtrics. It was designed based on the advantages and disadvantages of multidisciplinary renal genetics clinics coded in Study One and reported in grey and peer-reviewed health services literature. The purpose of the survey was to validate the findings of Study One and to extend the findings by quantifying the perceived comparative importance of suggested advantages and disadvantages of multidisciplinary models, according to KidGen clinical team members. The survey was piloted by health service researchers (N = 6) with experience in survey methodology in order to test the quality of the survey design and flow. Minor editing was performed upon feedback.

Surveys with unique URLs were finalised and distributed to eligible participants by state and territory via email from the KidGen Collective Program Manager. Providing unique survey links by state and territory was designed to enable participants' answers to be correlated with clinic locations and the variations in clinic models where they existed between states. One follow-up reminder email was sent to eligible participants two weeks after the initial email invite was distributed. The survey began with participant information and patient consent and then proceeded in three main sections (see Figure 7.2): questionnaire on professional role and responsibilities in a KidGen clinic, qualitative reporting of the advantages and disadvantages of multidisciplinary models in renal genetics clinics and quantitative assessment of the importance of advantages and disadvantages of multidisciplinary models in renal genetics clinics. The survey was self-administered online and was estimated to take approximately 10-15 minutes to complete.

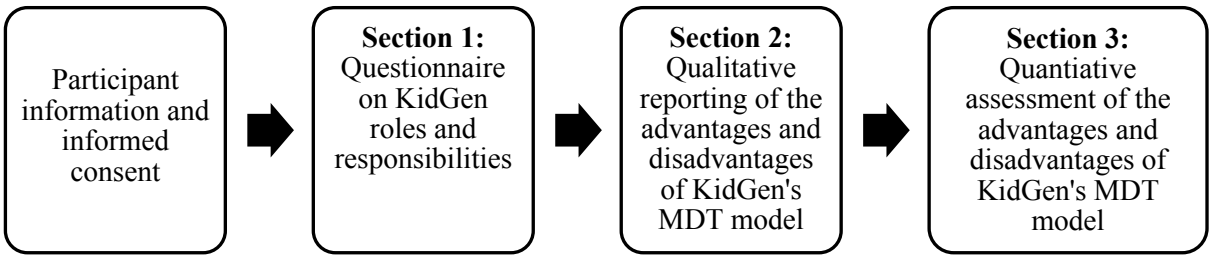


Figure 7.2: An overview of the progression and design of the online survey by survey sections.

7.5. Data gathering instruments

7.5.1. Questionnaire

Subsequent to providing informed consent, participants were asked to answer questions about their role and responsibilities in a KidGen clinic. The 9-item questionnaire (see Appendix E) employed single- and multiple-answer multiple choice questions, with an additional two open-text entry questions. The questions pertained to participants' roles and the length of time they had been working in their professional discipline and in a KidGen clinic, as well as their experience working in a MDT setting. Two open-text entry questions asked participants to describe their main responsibilities in a KidGen clinic, and, if they believed that the MDT model affected the way they performed and fulfilled their professional role and responsibilities, to provide examples of this. The questionnaire section of the survey was designed with skip-logic to only show questions relevant to each respondent.

7.5.2. Qualitative reporting of advantages and disadvantages

The second section of the survey (see Appendix E) consisted of two open-text entry questions which asked participants to list up to four advantages and up to four disadvantages of a MDT model in renal genetics clinics for team members. These questions were designed to extend the findings of RQ2 in Study One (see Chapter 6) using a larger and broader sample. To prevent participants from back-filling questions after being exposed to suggested advantages and disadvantages in section three, the backwards navigation feature was disabled between these two sections.

7.5.3. Quantitative assessment of advantages and disadvantages

The final section of the survey (see Appendix E) consisted of ranking and rating questions constructed using the types of advantages and disadvantages of MDT renal genetics clinics coded in Study One and identified in grey and peer-reviewed health services literature.

The first question asked participants to rank from a list of seven suggested advantages of a MDT model, the top four advantages by their importance to participants. The second question was identical in design but asked participants to rank four suggested disadvantages. Where participants did not believe that a suggested advantage or disadvantage was applicable to the model, they were instructed to number it as nine. In both ranking questions, the order of advantages and disadvantages was randomised for each participant. This was intended to obscure findings which may have arisen if participants were to simply rank the options in the order they were presented.

The final question employed a six-point Likert scale design (see Figure 7.3) and required participants to rate the extent to which they agreed or disagreed with suggested advantages and disadvantages of MDT models in renal genetics clinics. Participants were given the option to rate an advantage or disadvantage as 'not applicable' (N/A) if they did not believe it was of relevance to the model.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	N/A
A MDT model in renal genetics is not an efficient use of team members' time.	○	○	○	○	○	○

Figure 7.3: An example of the six-point Likert scale from the online survey used to assess the extent to which participants agreed or disagreed with suggested advantages and disadvantages of MDT models in renal genetics clinics.

The rating and ranking questions were employed in order to quantify the relative importance of and extent to which participants agreed or disagreed with the advantages and disadvantages coded in Study One and identified in the literature. Not only was this intended to increase the reliability and validity of previously identified findings, but it also enabled advantages and disadvantages of MDT models to be evaluated by their strength and relative importance to MDT team members.

7.6. Data analysis

7.6.1. Questionnaire

Questionnaire data was summarised by the frequency of responses and tabulated. Frequencies were also converted to percentages of the total sample responses and tabulated.

7.6.2. Qualitative reporting of advantages and disadvantages

Open-text entry responses for questions on the advantages and disadvantages of MDT models in renal genetics clinics for team members were grouped by themes and the frequencies of responses per theme were reported. Example quotes per theme were reported to illustrate the types of advantages and disadvantages listed by participants. Answers which could not be grouped were reported independently. The average number of advantages versus disadvantages listed per participant was compared by using a paired, two-tailed T-test to determine whether the means were statistically different. The purpose of this was to evaluate if participants associated the model with a greater number of advantages or disadvantages, or if no difference existed.

7.6.3. Quantitative assessment of the advantages and disadvantages

The analysis of advantages and disadvantages from ranking questions was conducted separately but in the same manner. The frequency that each advantage and disadvantage was ranked from one to four, and as nine for 'not applicable', was calculated across professional groups and displayed by histogram to visually compare responses. Due to the small sample sizes per professional group and per state, responses were not analysed across professional groups or states to determine if statistically significant differences existed. The weighted rank of responses was calculated to evaluate an overall ranking of advantages and disadvantages of MDT models in renal genetics clinics by importance to team members. Weighted rank was calculated by multiplying the frequency of a response by four if it was ranked first, three if it was ranked second, two if it was ranked third and one if it was ranked fourth (Tofallis, 2014). Weighted frequencies per advantage or disadvantage were then summated and divided by the total number of participants.

Results of the question in which participants rated the extent they agreed or disagreed with a suggested advantage or disadvantage were analysed by the frequency of ratings per response criteria (Allen & Seaman, 2007) and presented in a histogram as a percentage of overall responses. Descriptive statistics were applied to calculate the median in each advantage or disadvantage category, as a measure of central tendency, and the variability of responses was calculated by the range and inter-quartile range (IQR). The IQR is a measure of how spread out the middle values

are on either side of the median. Due to the small sample sizes per professional group and per state, responses were not analysed across professional groups or states to determine if statistically significant differences existed.

7.7. Limitations

Rating and ranking questions use an ordinal scale of measurement; that is, responses fall into discrete categories which possess an order of magnitude, however, the magnitude of the difference between data points is not known. Therefore, it not possible to quantify the difference between a ranking of one versus two or a "strongly agree" response and an "agree" response. It is simply possible to classify a response as greater or lesser than another response by a difference of unknown magnitude. Furthermore, parametric analyses, which are based on a normal distribution of interval data, are not applicable in the analysis of ordinal data unless a sufficiently large sample size is reached (Sullivan & Artino, 2013). This necessarily limits the types of analysis which can be performed on the rating and ranking questions to non-parametric descriptive types of analyses, such as the median as the measure of central tendency and frequencies.

7.8. Summary

The online survey was designed using the advantages and disadvantages of MDT models in renal genetics clinics coded in the key informant interviews and identified in the literature. It used primarily quantitative methods, such as ranking and rating questions, to validate and extend the findings of Study One and to address RA2. Qualitative responses were analysed by coding and qualitative findings were analysed by frequencies and T-tests. The results of Study Two are presented in Chapter 8.

CHAPTER 8. RESULTS: STUDY TWO

8.1. Overview of Chapter 8

This chapter presents the results of Study Two which address RA2 – *to investigate the advantages and disadvantages of multidisciplinary models in renal genetics clinics* – through an online survey of KidGen members from across Australia. It includes an overview of participant demographic characteristics and open-answer reporting of the advantages and disadvantages of a MDT model in renal genetics clinics. It also presents the results of quantitative ranking and rating questions, which were designed with the advantages and disadvantages coded in Study One.

8.2. Participants

A total of 42 KidGen clinical team members from across all five Australian states and the Northern Territory were identified by the KidGen Program Coordinator as eligible to participate in the online survey. Of these, 21 members participated in the survey, with 19 completing it and 2 partially completing it. The descriptive text answers of participants who partially completed the survey are included in the results of this study. However, they are excluded from the analysis of ranking and rating questions as they did not attempt these questions in the survey. The number of participants per state and territory is shown in Table 8.1.

Table 8.1: Summary of participants who were eligible to and who did complete the survey by Australian states and territories[3]

State/Territory	Number of eligible participants	Number of actual participants	Percentage of actual participants by total actual participants (%)
QLD	4	3	14.3
NSW	6	1	4.8
VIC	18	11	52.4
SA	6	3	14.3
WA	6	3	14.3
NT	2	0	0
Total	42	21	100.1

[3] Percentages do not add up to 100% due to rounding

The survey participants comprised four professional groups: genetic counsellors (33.3%), clinical geneticists (23.8%), adult nephrologists (33.3%) and paediatric nephrologists (9.5%). Registrars in nephrology and clinical genetics, as well as administrative staff also participate in some KidGen clinics, but none of the survey participants came from these professional groups. The length of time professionals had worked in their professional practice ranged from less than 12 months to greater than five years. The majority (71.4%) of participants had worked in their professional practice for greater than five years. The length of time professionals had worked in a KidGen clinic ranged from less than 12 months to 5-6 years. The majority of participants had worked in a KidGen clinic for either less than 12 months (38.1%) or 1-2 years (52.4%). Approximately half (52.4%) of participants had previously worked in a renal or genetics service which did not have a multidisciplinary structure whereas the other participants identified as having only worked in a renal and/or genetics service with a multidisciplinary structure (Figure 8.1).

Table 8.2: Summary of participant demographic characteristics[4]

Characteristic	Item	Frequency	Percentage (%)
Professional Group	Genetic Counsellor	7	33.3
	Clinical Geneticist	5	23.8
	Adult Nephroloigst	7	33.3
	Paediatric Nephrologist	2	9.5
Experience in professional role	<12 months	1	4.8
	1-2 years	3	14.4
	3-4 years	2	9.5
	5+ years	15	71.4
Experience in KidGen clinic	<12 months	8	38.1
	1-2 years	11	52.4
	3-4 years	0	0
	5-6 years	2	9.5
Experience in a renal and/or genetic service which does not have a MDT structure	Yes	11	52.4
	No	10	47.6

[4] Percentages may not add up to 100% due to rounding

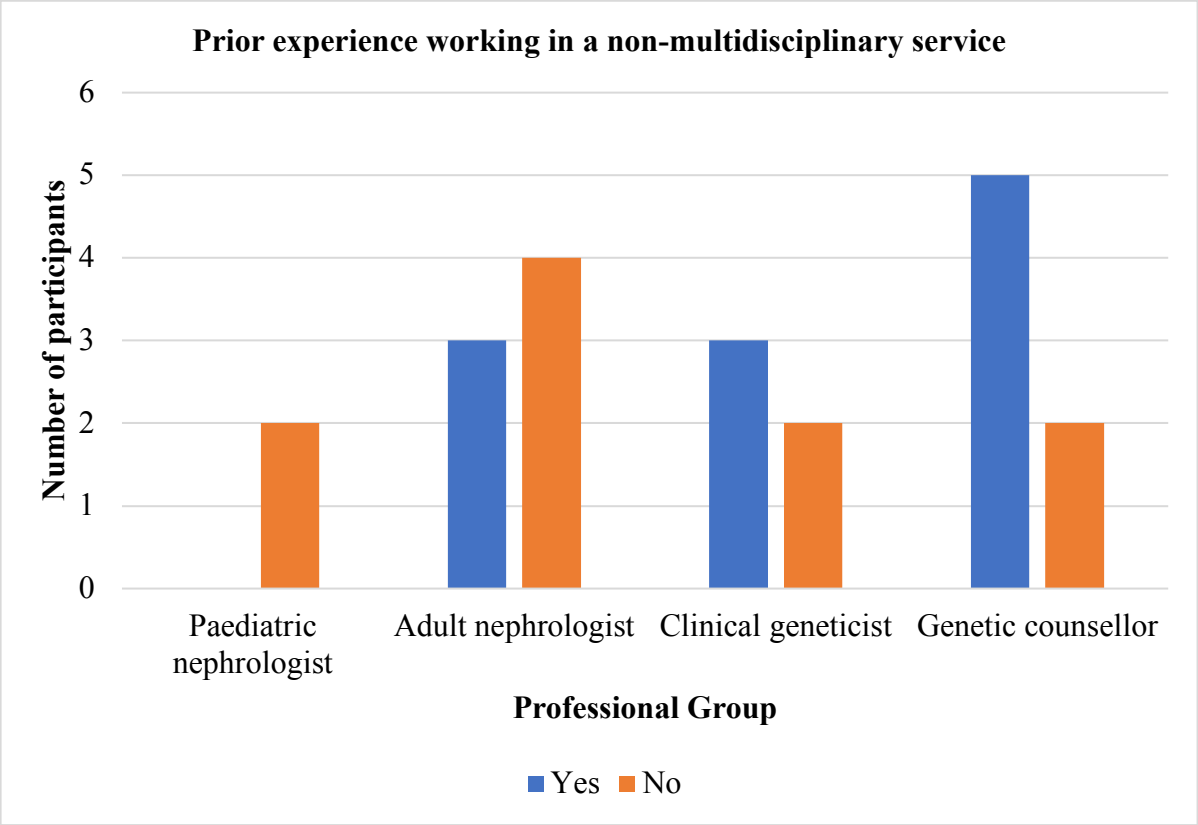


Figure 8.1: The frequency of participants who had versus had not worked in a renal and/or genetics service without a multidisciplinary structure prior to KidGen graphed by professional group.

8.3. Open-answer reporting of advantages and disadvantages according to participants

Participants reported a variety of advantages and disadvantages for team members which were, in their own views, outcomes of a multidisciplinary model in renal genetics clinics. The average number of advantages listed per participant was 2.7, with an average number of 1.6 disadvantages listed per participant. Participants were limited to providing between zero and four advantages and disadvantages by the survey questions and design. The difference between the average number of advantages and disadvantages listed by each participant was statistically significant according to a two-tailed, paired student's t test ($P < 0.05$).

8.3.1. Advantages of MDT models in renal genetics clinics

Many participants listed similar advantages of MDT models in renal genetics clinics, although some unique responses were also given. Advantages were sorted into broad categories in which similar concepts were grouped together. These categories included: collective learning and

upskilling, shared expertise, improved access to information, improved communication, building professional relationships and time efficiency. Although the questions asked participants to state advantages for multidisciplinary team members, a number of participants also listed advantages for patients. The frequency and examples of advantages in these categories are provided in Table X.3. Multiple examples are included where they convey different aspects of an advantage. The three most frequently cited advantages for team members are discussed in greater depth below.

Table 8.3: Frequency and examples of advantages of multidisciplinary models in renal genetics clinics for team members according to survey participants

Advantage	Frequency	Example(s)
Collective learning and upskilling	17	*"increased learning across disciplines"* (P15)
Shared expertise	10	*"information sharing that enhances knowledge and practice of all participants"* (P17)
Patient advantages	9	*"increased diagnostic yield"* (P1); *"more cohesive care delivered"* (P11); *"patients benefit from less appointments"* (P16); *"improved patient care"* (P19)
Improved access to information	4	*"easy access to specialists to answer questions"* (P2)
Improved communication	3	*"improved consistency in messaging with patients and referrers"* (P4); *"better explanations to patients and colleagues"* (P7)
Building professional relationships	2	*"building diverse professional relationships"* (P6)
Time efficiency	2	*"increased efficiency – saves time on follow up reading"* (P14)
Other	5	*"cost effective for healthcare and the patient" (P1)* *"best use of genomic testing*" (P1) *"opportunity to be recognised as the genetic counsellor with specialist knowledge in this area"* (P2)

		"crystallising shared goals for the clinic" (P4) *"clinical discussion of patient/family in terms of additional testing to clarify significance of variants or segregation analysis"* (P5)

Collective learning and upskilling

The most commonly purported advantage ($N = 17$) of multidisciplinary models in renal genetics clinics from participants is that of collectively learning from colleagues across professional disciplines. Not only was it the most commonly listed advantage but it was also frequently participants' first response, being listed first on 10 occasions with the remaining seven frequencies distributed across second, third and fourth responses. Examples of answers include, *"increased learning across disciplines"* (P15), *"upskilling across different specialities"* (P11) and *"builds expertise within a supported environment"* (P8). Answers also specified learning outcomes in other disciplines. One nephrologist answered that he/she had a *"better personal understanding of genetic testing and limitations"* (P20) as an outcome of the model. A genetic counsellor testified to an *"improved understanding of the renal condition"* (P19). Thus, working with other specialties in a multidisciplinary environment is purported to facilitate an increase in areas of skill and expertise outside of primary professional disciplines.

Shared expertise

The second most frequently listed advantage ($N = 10$) was that a multidisciplinary model in renal genetics clinics enabled the sharing of expertise. This was sometimes listed simply as an outcome of the model – for example, *"shared expertise"* (P16) and *"broader range of expertise in each condition"* (P7) – and sometimes also as a facilitator of other outcomes, such as collective learning and upskilling and improved decision-making. This is exemplified in a quote from Participant 17, who wrote, *"information sharing that enhances knowledge and practice of all participants",* thereby causally linking the exchange of specialist information as a product of the model with enhanced learning and practice for team members. Shared expertise in the form of 'collective experience' was also associated with improved decision making in the response, *"improved decision making: more likely to have all the pertinent pieces of information between us and draw on our collective experience"* (P8). Therefore, the sharing of expertise across multiple professional

groups, as an outcome of a multidisciplinary model in renal genetics, was listed as an advantage and a facilitator of other advantageous outcomes.

Improved access to information

A number of responses from participants ($N = 4$) claimed that an advantage of multidisciplinary models in renal genetics clinics was access to information. This included access to patient information, for example, *"obtaining first hand information about a patient; information isn't lost in the medical records"* (P9) and access to specialist knowledge, for example, *"easy access to specialists to answer questions"* (P2). Access to relevant information was also associated with improved decision making in the response, *"improved decision making: more likely to have all the pertinent pieces of information between us ... "* (P8). Improved access to patient information and specialist input are thus cited as advantages by survey participants.

8.3.2. Disadvantages of MDT models in renal genetics clinics

While fewer disadvantages were listed overall compared to advantages, patterns emerged which allowed some responses to be grouped into broad categories. The most frequently cited types of disadvantages which emerged from the data concerned an increase in required organisation, time inefficiency and different approaches and objectives. Two answers referred to clinic barriers rather than disadvantages. In these instances, barriers referred to a hospital environment which *"is not supportive of the model"* (P16) and financing which *"does not cover actual costs"* (P20) of the clinic. The frequency and examples of disadvantages are provided in Table 8.4. The three most frequently cited types of disadvantages for team members are discussed in greater depth below.

Table 8.4: Frequency and examples of disadvantages of multidisciplinary models in renal genetics clinics for team members according to survey participants

Disadvantage	**Frequency**	**Example(s)**
Time inefficiency	9	*"not very time-efficient"* (P11)
Organisation	8	*"additional organisation required"* (P8)
Different approaches and objectives	5	*"difficult to align very different clinical practices"* (P6)
Other	8	*"there is the risk that a team becomes too big and unwieldy"* (P3)

		"providing active supervision for junior team members can be a challenge" (P3) *"meeting occurs at an off-site location (need to travel/ teleconference)"* (P5) *"challenges limit professional ability because it is all new for everyone"* (P6) *"concern about clinical risk as what is each individuals' responsibility"* (P6) *"resource intensive"* (P17) *"need more space for extra clinicians/lab staff"* (P19) *"easy for miscommunication with extra people involved"* (P19)

Time inefficiency

A less efficient use of time for clinicians was the most frequently mentioned ($N = 9$) disadvantage of a multidisciplinary model in renal genetics clinics. It was also the disadvantage most frequently listed first by participants ($N = 7$). This disadvantage was perceived in multiple domains, including the length of time needed to explain genetics, for example, *"time is unequal in clinical setting genetics is slower to explain"* (P19), an increase in time spent on clinic and administrative tasks per individual patient, for example, *"more time consuming per patient (greater intake, out-take and administrative tasks)"* (P4) and challenges in limiting clinic appointments to their allotted times, as alluded to in the response, *"... patients sometimes do not appreciate their appointment running over an hour in total"* (P9). Furthermore, the need for multiple clinicians to see the same patient was also described and implied as a less efficient use of time, for example, *"multiple specialists seeing same person"* (P20) and *"a less efficient work model for the individual clinician"* (P18). Therefore, a multidisciplinary model in renal genetics clinics was perceived as being time inefficient in a number of aspects according to multiple participants.

Organisation

A number of participants cited that an increase and challenges in organisational requirements were a disadvantage of a multidisciplinary model in renal genetics clinics. This idea referred to the complexity of coordinating the schedules of multiple clinicians, for example, *"need for 3 specialists to coordinate a time"* (P14). It also included the difficulty of coordinating patient clinic

sessions with multiple specialists in attendance and needing to fulfil their requirements – an idea which was linked to clinic appointments running over their allotted time, for example, *"increased challenges of meeting requirements of all disciplines in the clinic"* (P4) and *"coordinating of sessions within the clinic, patients sometimes do not appreciate their appointment running over an hour in total"* (P9). Organisational challenges also clearly encompassed increased administrative duties in the opinion of a number of participants, such as, *"dealing with admin teams from two different clinical departments"* (P2) and *"greater intake, out-take and administrative tasks"* (P4) per patient.

Different approaches and objectives

The difficulty of aligning different approaches and objectives across clinical practices was also mentioned as a disadvantage of a multidisciplinary model in renal genetics clinics. This was mentioned quite explicitly in the response, "*difficulty to align very different clinical practices"* (P6) and implied by the response, *"sometimes agendas don't totally align"* (P13). The difficulty of aligning multiple approaches was also referred to in relation to its impact on patients. One participant reflected that there were *"differing opinions in approach to patient interactions"* (P7). The impact on the patient was also referred to by one participant, was said that *"different approaches can confuse and scare some patients"* (P13). Therefore, challenges in unifying approaches and objectives across professional groups was described as a disadvantage a multidisciplinary model in renal genetics clinics by some survey participants.

8.4. Ranked advantages and disadvantages of MDT models in renal genetics clinics

8.4.1 Ranked advantages of MDT models in renal genetics clinics

19 out of 21 survey participants ranked seven suggested advantages of multidisciplinary models in renal genetics clinics from one to four by their perceived importance to participants. If participants did not agree that a statement was an advantage of the model then they were asked to number it as nine to indicate that it was not an advantage in their own view. The frequency of responses across categories are presented, followed by an overall weighted rank of suggested advantages across participants.

Across all professional groups, the advantage most frequently ranked in first place, or as the most important advantage to participants, was 'promotes accurate communication across specialities' (8/19), followed by 'improves diagnostic outcomes' (5/19). In the second ranking, the most

frequent response was again, ‘promotes accurate communication across specialities’ (6/19) and then, ‘enhances team members’ professional learning and development’ (5/19). Of responses ranked as the third most important advantage to participants, ‘improves diagnostic outcomes’ was the most frequent response (5/19), followed by a tie between ‘enables timely access to relevant clinical and/or patient information for team members’ (4/19) and ‘enhances team members’ professional learning and development (4/19). In the fourth ranking, the most frequent response was ‘enhances team members’ professional learning and development’ (6/19), with a three-way tie for the second most frequent response between ‘improves diagnostic outcomes’ (4/19), ‘increases team members’ confidence in the decision-making process’ (4/19) and ‘enables timely access to relevant clinical and/or patient information for team members’ (4/19). The frequency of all responses in first to fourth places across all professional groups can be seen in Figure 8.2.

Three participants ranked ‘increases team members’ sense of well-being through social support’ as not an advantage of the model, and no participants included this suggested advantage in the ranking. ‘Enables team members to feel that their knowledge and contribution is valued by their peers’ was ranked as not an advantage of the model twice, and ‘improves diagnostic outcomes’ and ‘enables timely access to relevant and/or patient information for team members’ were each ranked once as not applicable (see Figure 8.2).

Responses per advantage were weighted by rank, summated and averaged to calculate a ranked order of advantages according to survey participants (Figure 8.3). ‘Promotes accurate communication across specialties’ was the highest ranking advantage. In second place was ‘enhances team members’ professional learning and development’ followed closely by ‘improves diagnostic outcomes’. In fourth place was ‘enables timely access to relevant clinical and/or patient information for team members’. ‘Increases team members’ confidence in the decision-making process’ was ranked fifth overall ahead of ‘enables team members to feel that their knowledge and contribution is valued by their peers’. The last category, ‘increases team members’ sense of well-being through social support’ received no votes by participants and was ranked seventh.

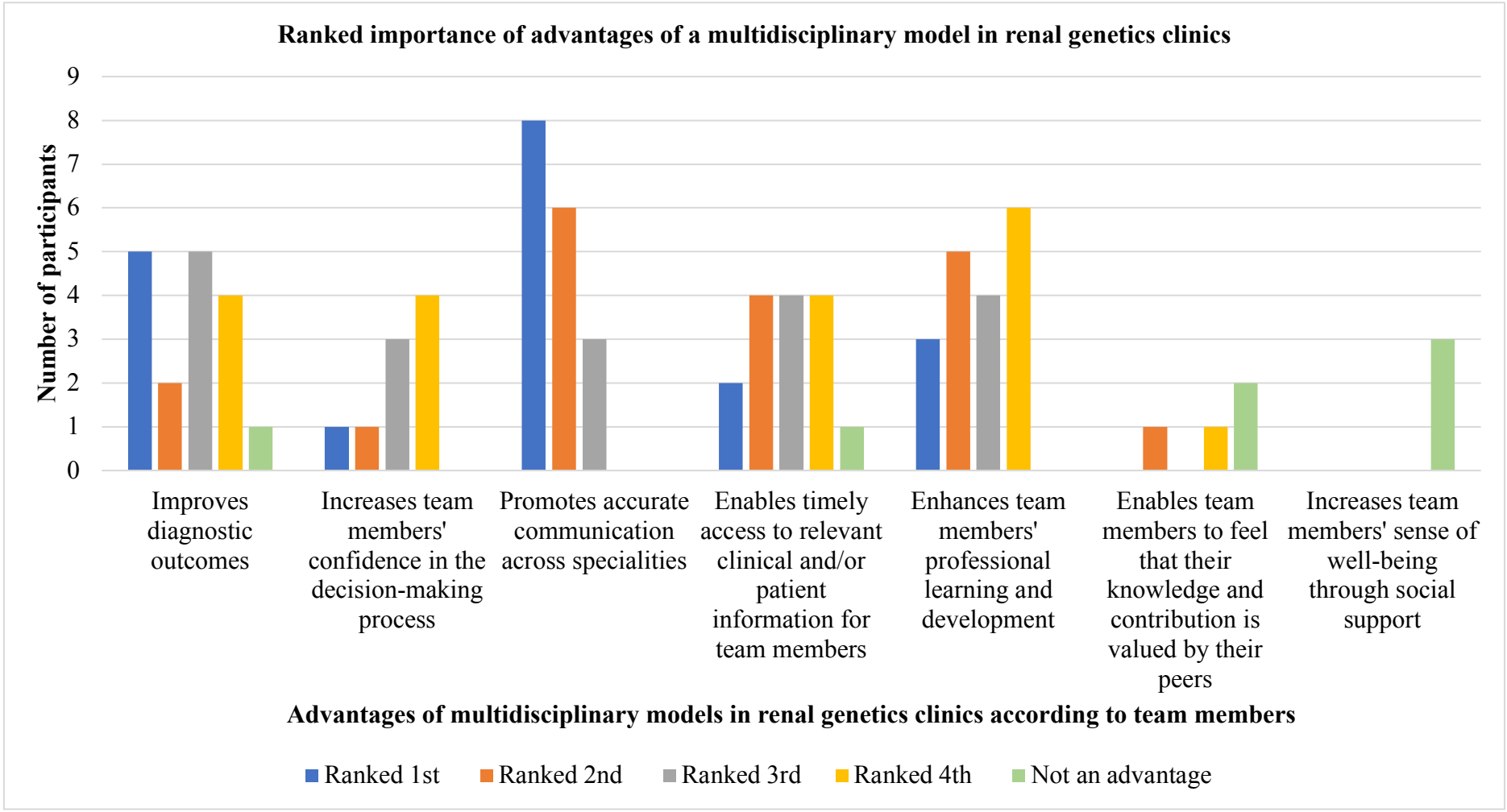


Figure 8.2: Frequency with which advantages of multidisciplinary models in renal genetics clinics were ranked from 1st to 4th – with 1st being the most important advantage – by participants across professional groups. Statements which participants did not believe were advantages of the model are indicated as 'Not an advantage'.

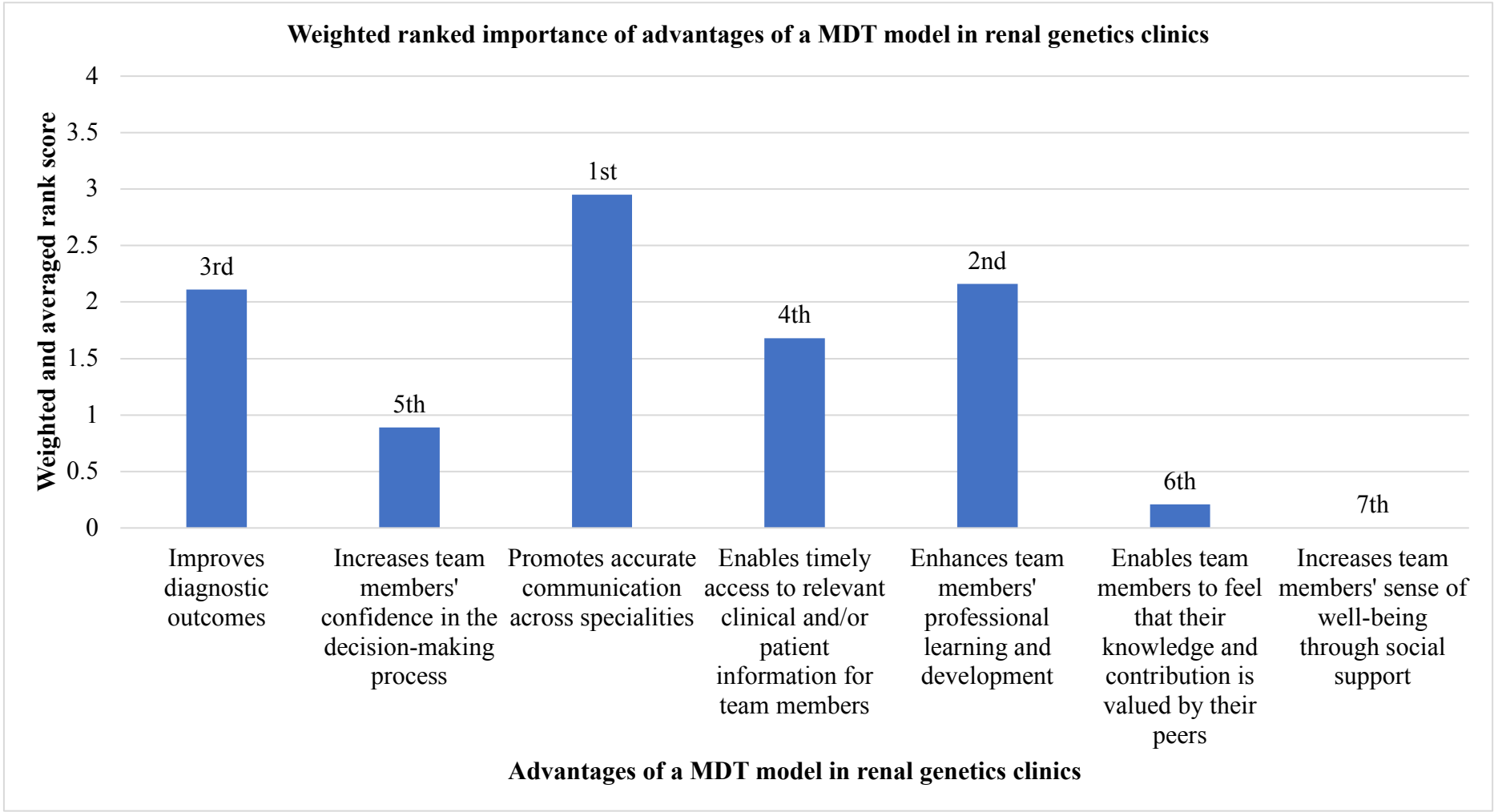


Figure 8.3: Advantages of a MDT model in renal genetics clinics ranked according to importance to participants across professional groups by the weighted average of participants' responses.

8.5.1. Ranked disadvantages of MDT models in renal genetics clinics

19 out of 21 survey participants ranked from one to four, four suggested disadvantages of multidisciplinary models in renal genetics clinics by their perceived importance to participants. If participants did not agree that a statement was a disadvantage of the model then they were asked to number it as nine to indicate that it was not applicable in their own views. The frequency of responses across categories are presented, followed by an overall weighted rank of suggested disadvantages across participants.

Across all professional groups, the disadvantage most frequently ranked in first place, or as the most important disadvantage to participants, was, 'creates challenges in unifying priorities and objectives across team members' (6/19), followed by, 'is not a financially sustainable model of care delivery' (4/19). The top second most important disadvantage was, 'is not an efficient use of team members' time' (5/19) and then, 'is difficult due to inherent differences in approaches and communication styles across team members' (4/19). Third place was equally divided between 'creates challenges in unifying priorities and objectives across team members' (3/19) and 'is not a financially sustainable model of care delivery' (3/19). In fourth place, 'is difficult due to inherent differences in approaches and communication styles across team members' was ranked the most frequently (3/19) with the remaining three disadvantages equally selected (2/19).

All four suggested disadvantages were rated as not applicable disadvantages of the model by multiple participants; the frequency of these ratings can be seen in Figure 8.4. Due to the comparatively high frequency of statements rated as not being a disadvantage of the model, the total ranked frequency for each disadvantage was calculated and compared with the frequency with which the statement was ranked as not being a disadvantage of the model (see Figure 8.5).

Responses per disadvantage were weighted by rank, summated and averaged to calculate a ranked order of disadvantages according to survey participants (Figure 8.6). The highest ranking disadvantage was, 'is not a financially sustainable model of care delivery' followed by, 'creates challenges in unifying priorities and objectives across team members'. The third ranked disadvantaged was, 'is not an efficient use of team members' time' and lastly, 'is difficult due to inherent differences in approaches and communication styles across team members'.

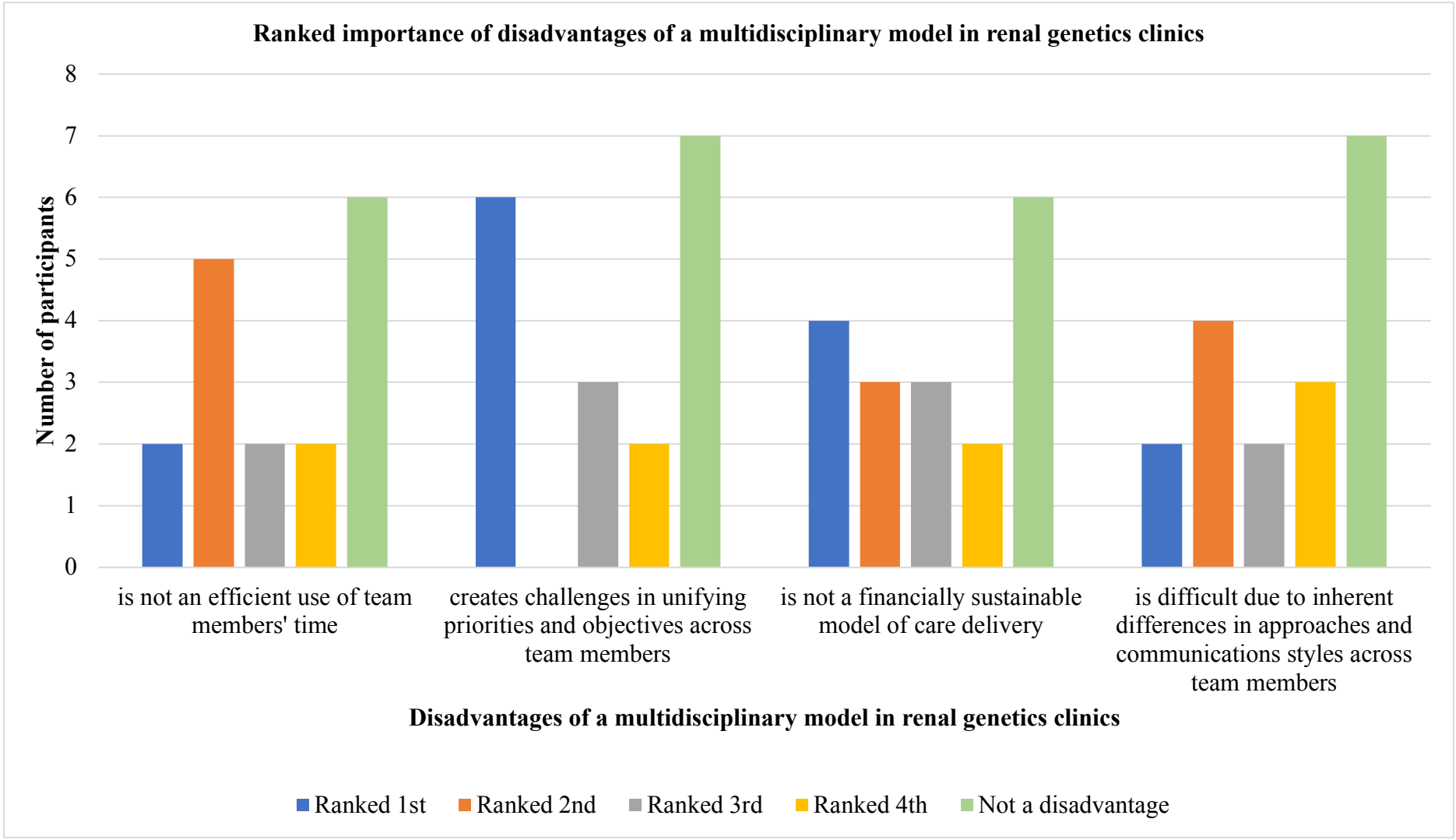


Figure 8.4: Frequency with which disadvantages of multidisciplinary models in renal genetics clinics were ranked from 1st to 4th – with 1st being the most important disadvantage – by participants across professional groups. Statements which participants did not believe were disadvantages of the model are indicated as 'Not a disadvantage'.

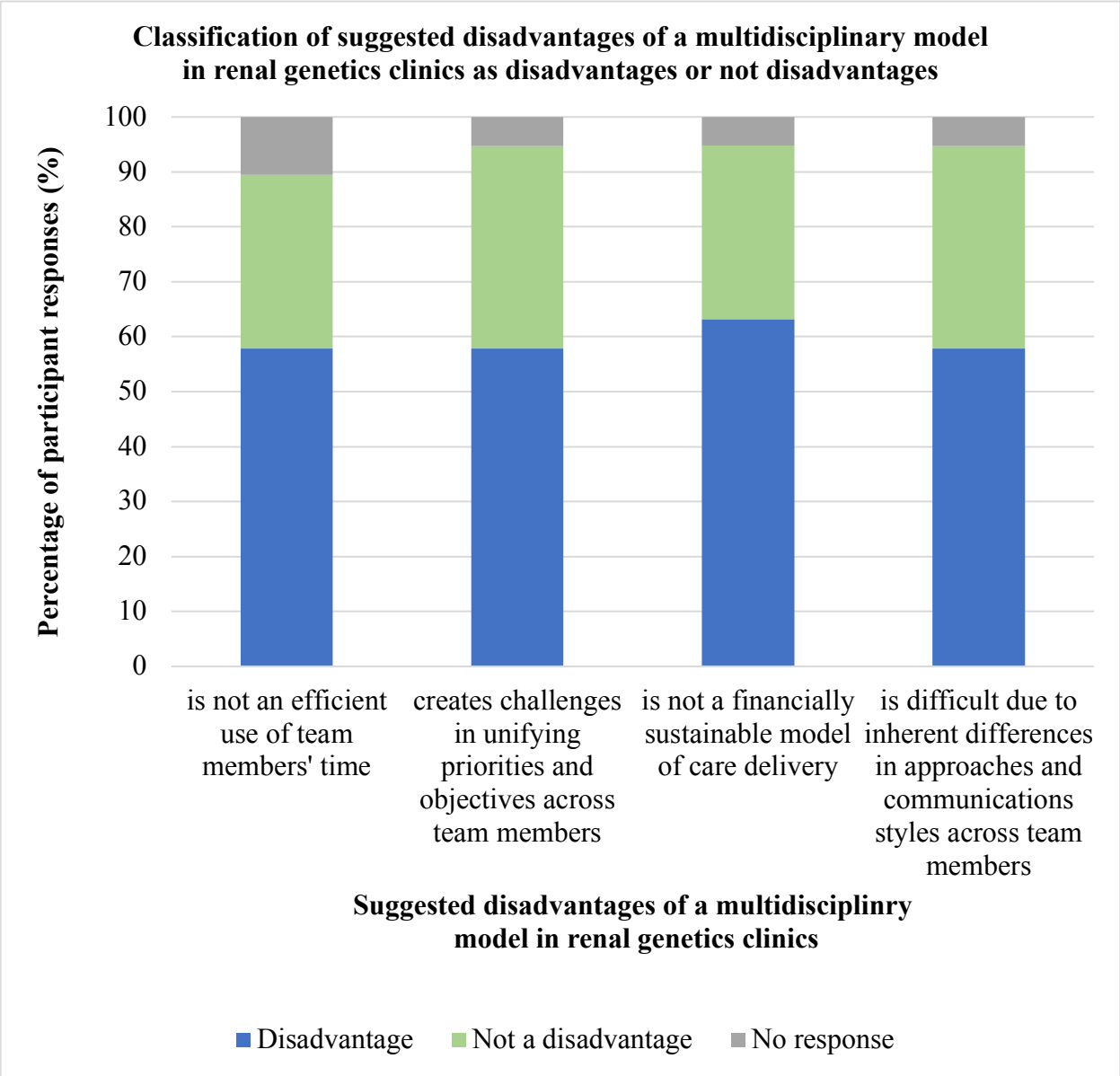


Figure 8.5: A stacked bar graph of suggested disadvantages of a multidisciplinary model in renal genetics clinics and the percentage of participants who indicated that the statements were disadvantages of the model or were not applicable. 'No response' is an outcome of incomplete ranking across disadvantage categories by some participants.

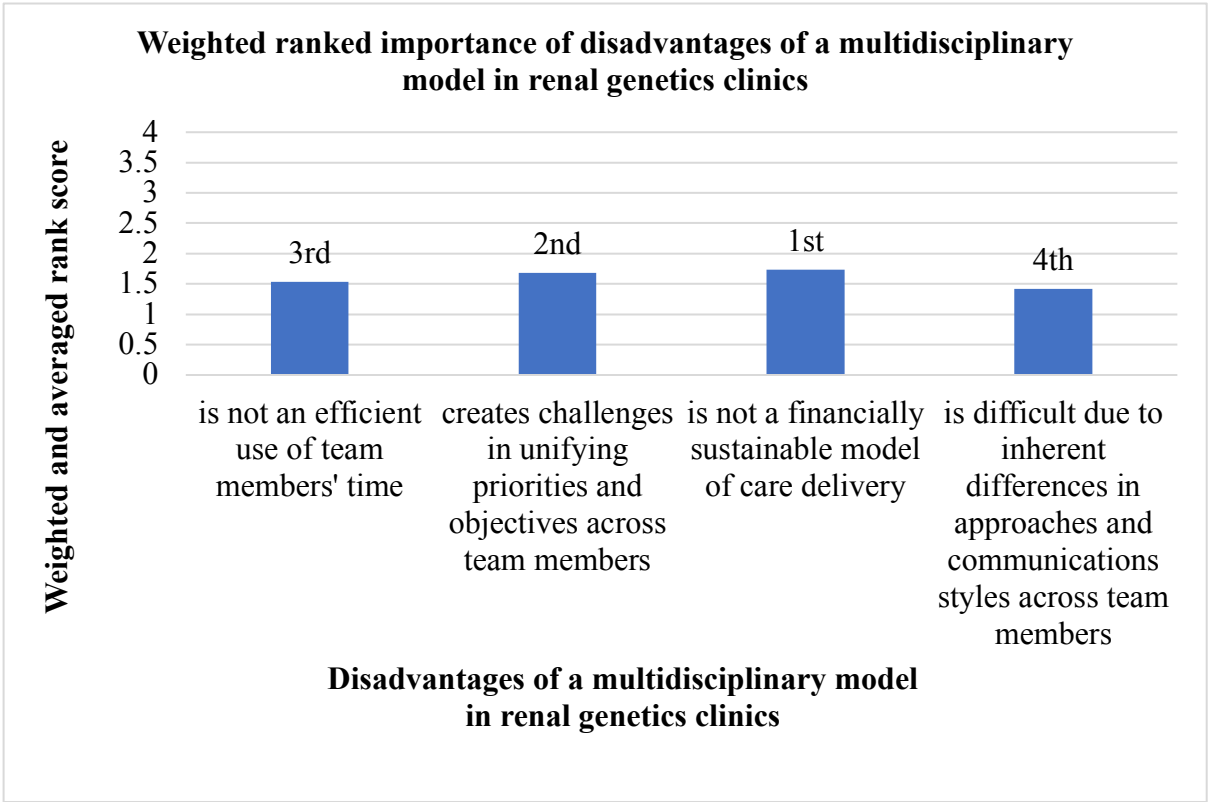


Figure 8.6: Disadvantages of a multidisciplinary model in renal genetics clinics ranked according to importance to participants across professional groups by the weighted average of participants' responses.

8.6. Agreement ratings of suggested advantages and disadvantages of a MDT model in renal genetics clinics

8.6.1. Agreement ratings of suggested advantages of a MDT model in renal genetics clinics

The frequencies of rating responses for suggested advantages are shown as percentages in Figure 8.7. The strongest agreement ratings were for 'enhances team members' professional learning and development' and 'promotes accurate communication across specialties'. For both of these advantages, responses ranged from Agree to Strongly Agree and Strongly Agree was the most frequent rating. 'Enhances team members' professional learning and development' was more frequently rated as Strongly Agree between the two statements. The advantage with the greatest variation in responses was 'reduces inefficiencies in administrative tasks (e.g., multiple emails or phone calls to contact health professionals or patients)'. Responses ranged from Strongly Disagree to Strongly Agree. The central tendency of the results and most frequent response was Agree. The frequency (Mode) and central tendency (Median) of the results for all suggested advantages is

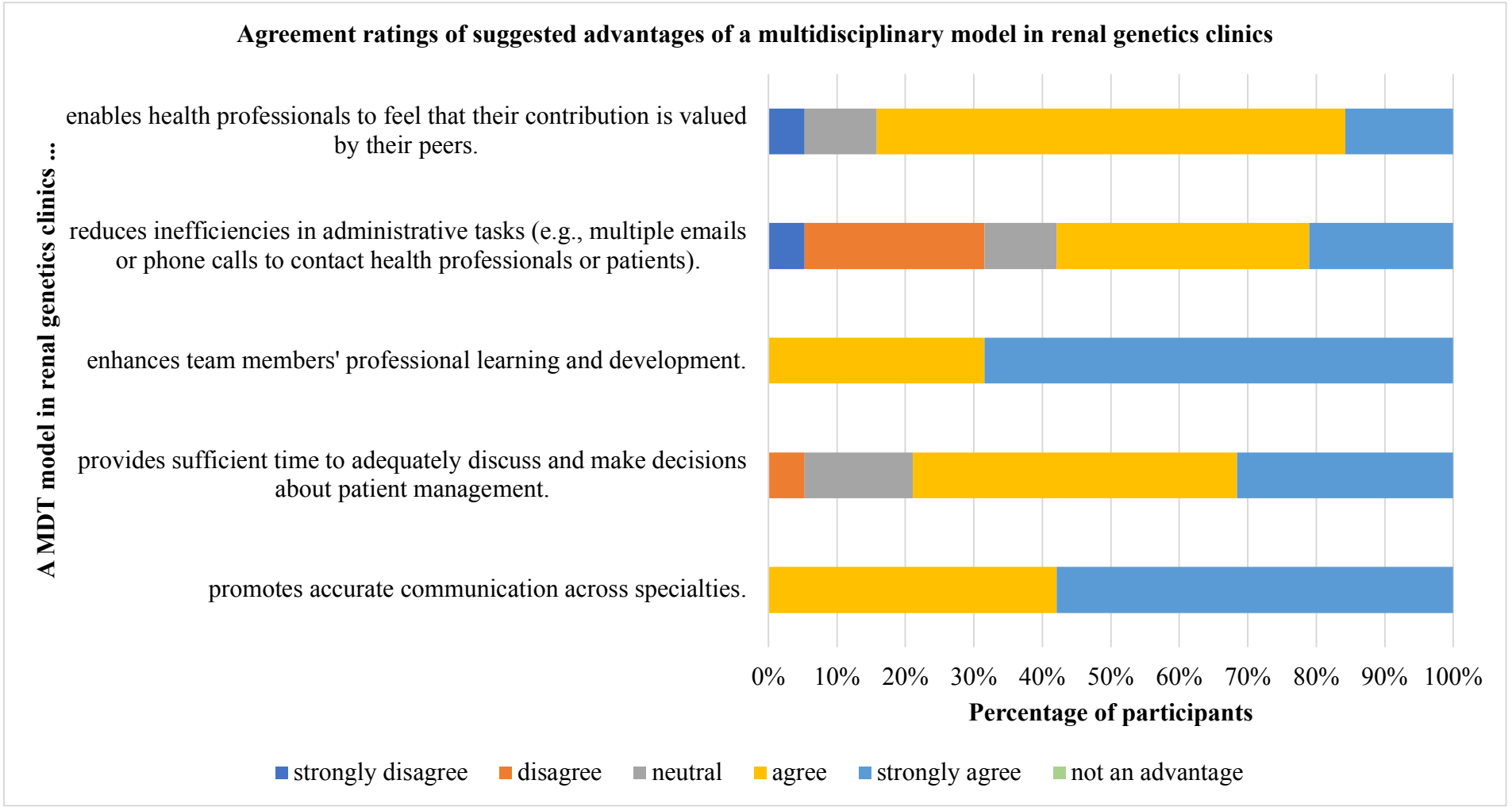


Figure 8.7: A stacked bar graph representing the strength of participants' agreement or disagreement with suggested advantages of a multidisciplinary model in renal genetics clinics.

shown in Table 8.5, along with the variability in responses, reflected by the Range and the Inter-Quartile Range (IQR).

Table 8.5: Descriptive statistics of Likert-scale data for suggested advantages of a MDT model in renal genetics clinics. For Median and Mode: 1 = Strongly Agree, 2 = Agree, 3 = Neutral, 4 = Disagree and 5 = Strongly Disagree.

A MDT model in renal genetics clinics …	Median	Mode	Range	IQR
promotes accurate communication across specialties.	1	1	1	1
provides sufficient time to adequately discuss and make decisions about patient management.	2	2	3	1
enhances team members' professional learning and development.	1	1	1	1
reduces inefficiencies in administrative tasks (e.g., multiple emails or phone calls to contact health professionals or patients).	2	2	4	2
enables health professionals to feel that their contribution is valued by their peers.	2	2	4	0

8.6.2. Agreement ratings of suggested disadvantages of a MDT model in renal genetics clinics

The frequencies of rating responses for suggested disadvantages are shown as percentages in Figure 8.8. The strongest disagreement rating was for ‘weakens professional relationships across disciplines’. For this suggested disadvantage, rating responses ranged from Disagree to Strongly Disagree with the most frequent response being Strongly Disagree. Substantial variation in ratings was observed across a number of suggested disadvantages. The greatest variation in ratings was for ‘carries inherent challenges in unifying priorities and objectives across team members’ which ranged from Strongly Disagree to Strongly Agree, with a median of Neutral and a mode of Agree. Descriptive statistics for all suggested disadvantages are shown in Table 8.6.

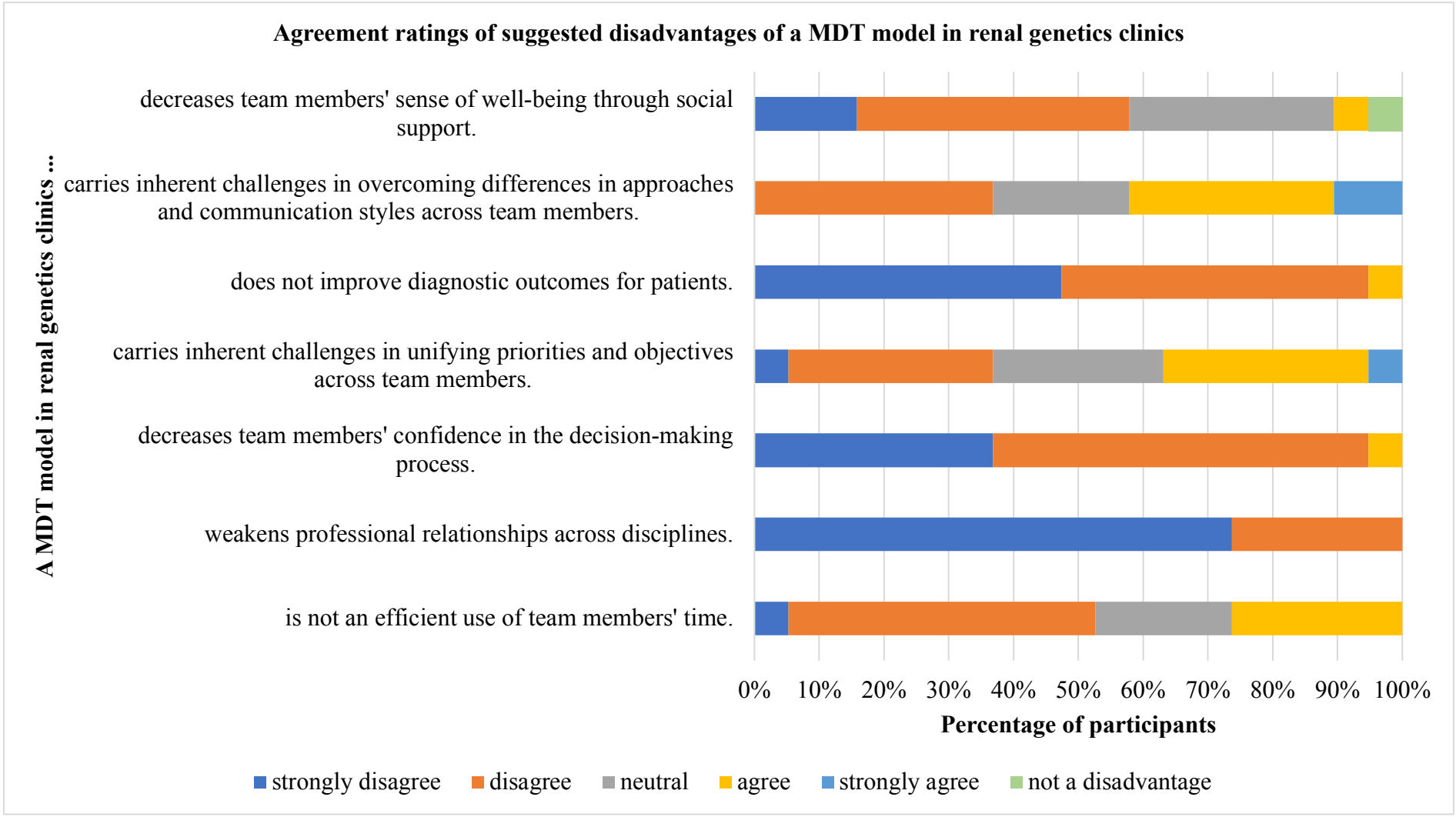


Figure 8.8: A stacked bar graph representing the strength of participants' agreement or disagreement with suggested disadvantages of a MDT model in renal genetics clinics

Table 8.6: Descriptive statistics of Likert-scale data for suggested disadvantages of a MDT model in renal genetics clinics. For Median and Mode: 1 = Strongly Agree, 2 = Agree, 3 = Neutral, 4 = Disagree and 5 = Strongly Disagree.

A MDT model in renal genetics clinics …	Median	Mode	Range	IQR
is not an efficient use of team members' time.	4	4	3	1.5
weakens professional relationships across disciplines.	5	5	1	0.5
decreases team members' confidence in the decision-making process.	4	4	3	1
carries inherent challenges in unifying priorities and objectives across team members.	3	4	4	2
does not improve diagnostic outcomes for patients.	4	5	3	1
carries inherent challenges in overcoming differences in approaches and communication styles across team members.	3	4	3	2
decreases team members' sense of well-being through social support.	4	4	3	1

8.7. Summary

In summary, a variety of advantages for team members and patients, and disadvantages for team members were described as an outcome of a MDT model in renal genetics clinics in the open-reporting survey questions. ‘Collective learning and upskilling’ was the most frequently suggested advantage and ‘time inefficiency’ was the most frequently reported disadvantage. There was a higher average number of advantages listed than disadvantages per participant. In the ranking questions, ‘promotes accurate communication across specialties’ was the highest ranked advantage overall, and ‘is not a financially sustainable model of care delivery’ was the highest ranked disadvantage overall. ‘Enhances team members’ professional learning and development’ and ‘promotes accurate communication across specialties’ had the highest agreement rating in the rating questions with substantial variation observed in the ratings of suggested disadvantages.

CHAPTER 9. DISCUSSION AND CONCLUSION

9.1. Overview of Chapter 9

Chapter 9 provides an overview and integration of the results of the research project as they relate to RA2: *to investigate the advantages and disadvantages of multidisciplinary teams in renal genetics clinics from multidisciplinary team members' perspectives*. A discussion of the results of RA1 can be found in Chapter 5. It concludes with an overarching summary of the findings of the overall study with implications for future research.

9.2. Discussion of findings

The research project was designed to assess the advantages and disadvantages of MDT models in renal genetics clinics using a sequential exploratory mixed-methods approach. Themes of advantages and disadvantages coded in the key informant interviews were used in the design of an online survey. The development of a quantitative survey tool from themes uncovered in an initial qualitative study is a common application of a sequential exploratory design in health services research (Tariq & Woodman, 2013). The survey, which had a larger and broader sample of respondents, also provided an opportunity to extend, validate and triangulate the findings of Study One. This was particularly important of the small sample size in the key informant interviews.

The response rate of 50% in the online survey was similar to estimated overall response rate of health professionals reported in the literature (Cho, Johnson, & VanGeest, 2013). Factors which may have contributed to nonresponses, in spite of reminder emails, include survey burden and lack of time, which are known barriers to survey participation amongst specialist physicians (Cunningham et al., 2015). A more equal representation of nephrologists, clinical geneticists and genetic counsellors was achieved in the survey participation than the key informant interviews, which was important in overcoming a selection bias in the assessment of the MDT model's value for team members (Pannucci & Wilkins, 2010). However, the relatively low number of survey respondents from each professional disciplines limited the types of analyses which could be performed on survey data.

Five advantages for team members were coded in the key informant interviews: shared expertise, collective learning and upskilling, time saving, confidence in the decision making process and a social environment. In the open-response survey questions of the survey, in which participants were asked to list advantages for team members, all of the same themes were mentioned, except

for social environment. In both studies, the themes of shared expertise and collective learning and upskilling were mentioned the most frequently. Responses across both studies reported these themes as causally linked; that is, team members' knowledge and practice was reportedly enhanced as a consequence of the sharing of expertise in a MDT model. In addition to the themes coded in the key informant interviews, survey responses included a number of additional types of advantages, including: improved access to information, improved communication (with both colleagues and patients) and building professional relationships. While these themes did not emerge from the interview codes, they were reported as advantages of MDT models in the literature and had therefore been incorporated into the design of the quantitative survey questions.

While the interview and survey questions asked participants about the advantages of MDT models for team members, in both studies, advantages for patients were also reported. The types of advantages includes diagnostic outcomes, a streamlined service in which patients are able to see multiple specialists at once, access to expertise as a consequence of seeing multiple specialists in the same appointment and personalised attention. While it was unclear whether key informants and survey participants provided examples of perceived advantages for patients due to misunderstanding of the research question, the frequency with which patient advantages were highlighted suggests it was a consequence of the importance placed on the provision of patient-centred care, or care that respects the patient's experience, values, needs and preferences in the planning, co-ordination and delivery of care (Gluyas, 2015). No disadvantages for patients were mentioned in either the interviews or the survey. This doesn't rule out the possibility of their existence and engaging directly with patients would provide an opportunity to understand the value of a MDT model from their perspectives. As this research project was primarily interested in the advantages and disadvantages of MDT model in renal genetics clinics for team members, advantages for patients which were coded in the interviews were not included in the design of the survey, with one exception. Diagnostic outcomes were included as it was aligned with the purpose of the clinic which was primarily to provide a diagnostic and counselling service for renal patients with rare and complex disease.

Of the three disadvantages coded in the key informant interviews – time consuming, lack of funding and clinic capacity – only the time intensive nature of the model was mentioned multiple times in the survey responses. Time inefficiency was the most frequently reported disadvantage for team members in open-text responses. Within the interviews, a clinical geneticist described the models as time inefficient because of the time required to organise a genetic test for patients. Within the survey, the majority of participants who described time inefficiency as a disadvantage of the model were clinical geneticists or genetic counsellors, with one exception. This may suggest

that time inefficiency was associated with the administrative workload required to organise genetic testing, as described in an interview. However, the time intensive nature of test result interpretation may have also been mind, as this is recognised as the most challenging and work-intensive aspect of analysis in renal genetic diagnoses (Bergmann, 2017). The second most frequently described type of disadvantage in the survey was to do with level of organisation required and included administrative tasks, coordinating multiple professional disciplines and aligning different schedules. Though organisation was not framed as a disadvantage in the interviews, these elements were apparent in key informants descriptions of clinic workflows. Another type of disadvantage, different approaches and objectives across professional disciplines emerged in the survey responses, but was not apparent in the key informant interviews. This may have been due to the small sample size in the interviews which inhibited data saturation in coding or this theme may not have been regarded as a prominent disadvantage by key informants. As this disadvantage was suggested in rating and ranking questions, it was possible to assess its importance to team members, as discussed below.

Despite participants being given the opportunity in the survey to list an equal number of advantages and disadvantages of MDT models in renal genetics clinics, there was a significantly greater number of advantages than disadvantages listed across participants. This may suggest that team members saw more benefits than limitations of the model. However, it doesn't indicate the relative importance of any reported outcome.

The quantitative ranking of the importance of suggested advantages and disadvantages to team members and rating of the extent team members' agreed with suggested advantages and disadvantages provided a means to assess the importance and relevance of the themes which were coded in the interviews and captured in the initial literature review. It also provided an opportunity to assess the validity of the themes using a broader sample of participants. Shared expertise was the most prominent theme coded in the interviews and listed in the open-response section of the survey; however, this advantage was not quantitatively assessed in so many words in the survey. The most similar advantage assessed in the rating and ranking questions was 'promotes accurate communication across specialties'.

Of the seven advantages available for participants to rank, 'promotes accurate communication across specialties' was ranked as the most important, followed by 'enhances team members' professional learning and development'. In the rating section of the survey, these advantages were also the most strongly rated by agreement with the least variability in participants' responses. Participants strongly agreed with 'enhances team members' professional learning and

development' more frequently than 'promotes accurate communication across specialties'. Interestingly, in the open-response survey questions, the idea of interprofessional learning was also the most frequently suggested advantage followed by the sharing of expertise. Therefore, both of these advantages emerged from the quantitative components of the study as the most important and strongly agreed upon advantages of MDT models in renal genetics clinics.

When the qualitative components of the research project are included, the theme of shared expertise is also amongst the most prominent advantages of MDT models in renal genetics identified in this research project. The key informant interviews, which contextualise the findings, point to the interrelatedness of the themes of shared expertise, accurate communication and interdisciplinary learning and development as outcomes of the MDT model. This was evident from the way key informants associated learning and upskilling with being "in the same room and the same conversation" with specialists from other disciplines (see Section 1.5 of Chapter 5). In other words, the multidisciplinary nature of the clinic was found to facilitate communication and sharing of expertise across professional disciplines which translated to interprofessional learning, amongst other outcomes.

Improved diagnostic outcomes was also highly ranked and strongly rated in the survey questions. Diagnostic outcomes also emerged from the interviews as a key advantage of MDT models in renal genetics clinics. The evidence for a positive impact of MDT models on genetic diagnoses is growing in the literature (Alkanderi et al., 2017; Bergmann, 2017; Mallett et al., 2016; Zentner et al., 2015). What is less clear, however, is the point at which multidisciplinary collaboration confers an advantage on diagnostic outcomes, particularly for rare and complex disease. The key informant interviews highlighted the role of both shared expertise and genetic testing technologies in rates of diagnosis. It is not known whether the MDT discussions prior to genetic testing conferred a diagnosis which was confirmed by genetic testing, or whether the involvement of multiple specialisations in the interpretation of test results was the key to diagnostic outcomes. Future research might examine patient diagnosis across different stages of clinic workflow and in comparison with the results of genetic testing to determine the point at which an advantage is conferred. However, even if genetic testing conferred less of an advantage than MDT collaboration, it likely played a crucial role in the validation of diagnoses, especially for rare and complex conditions which had remained undiagnosed for so long.

Despite the relative importance of the suggested advantages to team members, which emerged from the overall weighted ranks, participants mostly agreed in the rating section that each one statement was a true advantage of a MDT model in renal genetics. The lowest ranked suggested

advantage, ‘increases team members’ sense of well-being through social support’ had the highest proportion of neutral responses of all suggested advantages and disadvantages in the rating section and was not considered applicable to the model by one participant. However, the majority of participants indicated that they believe the model to increase team members’ sense of well-being through social support.

Whilst patterns emerged from the quantitative assessment of advantages, a greater degree of variability was observed in the assessment of disadvantages of MDT models of renal genetics clinics. Within the rating section, roughly one third of respondents rated each suggested disadvantage as not applicable, or not a disadvantage, of the model. From the remaining responses, ‘is not a financially sustainable model of care delivery’ was the most important disadvantage to team members. This disadvantage was not available for participants to rate in the survey. In the open-text response section of the survey, the financial unsustainability of the model was mentioned only once and was phrased as a barrier rather than an outcome of the model. In the interviews, the financial unsustainability of the model was mentioned by numerous key informants. With the exception of the genetic counsellors who were funded part-time by Australian Genomics, team members were funded by their hospital salary which did not take into account the renal genetics clinic workload. It was unclear whether the perceived unsustainability of funding was an outcome of the model or an external barrier. Financial challenges to genetic services have been documented in the literature and include inadequate funding for the time spent per patient and limited government funding for genetic tests (McPherson et al., 2008; Pletcher et al., 2002). Therefore, while the financial sustainability of the model is of concern to a majority of the participants, further research is needed to determine whether changes in hospital and government funding structures would overcome the issue.

Across the remaining suggested disadvantages ranked and rated in the online survey, variability in participants’ responses was observed. In the overall weighted ranking of disadvantages, all four were similarly weighted and in the rating section, participants’ agreement with suggested disadvantages was more variable than for suggested advantages. In the ranking section, two thirds of participants indicated that they agreed that time inefficiency was a disadvantage of the model. This was also the most frequently described type of disadvantage in the open-text responses of the survey. However, in the ranking section the majority of participants disagreed that the model is not an efficient use of team member’s time and agreed that the model provided sufficient time to adequately discuss and make decisions about patient management. A large degree of variability in agreement responses was also observed in the rating of statements concerning challenges due to differences in approaches and communication styles, and challenges in unifying priorities and

objectives across team members. For both statements, roughly equal numbers of participants agreed and disagreed that they were disadvantages of the model. The variability in responses may have been due to the particular models and team dynamics in respondents' clinics, or associated with professional discipline. However, the low number of participants per professional group and per state prevented responses for being analysed by either category.

9.3. Summary of key findings

The results of the research project as they relate to RA2 revealed that professional learning and development, accurate communication across specialties and shared expertise were the most important advantages of MDT models to team members of MDT renal genetics clinics. The perceived financial unsustainability of the model as it currently operates emerged as a significant concern in the interviews and survey. Time inefficiency was frequently reported as a disadvantage; however, across all disadvantage categories, there was considerable variation in responses. Due to the low survey response rates per state and territory and professional discipline, it was not possible to draw conclusions about the effect of local variations in MDT models or professional discipline on participants' responses.

9.4. Conclusion

Inherited renal diseases comprise a significant proportion of cases in both paediatric and adult nephrology services (Alkanderi et al., 2017; Mallett et al., 2016). Developments in genetic testing technologies are opening up new applications in the diagnosis of inherited renal diseases (Bergmann, 2017) yet challenges to its clinical adoption remain. MDT models have been advocated for overcoming barriers, which include a lack of knowledge amongst clinicians about the use and application of genetic medicine (Korf et al., 2014). Whilst MDT models are established in fields such as oncology, their recent emergence in renal genetics warrants research into their operating paradigms and associated advantages and disadvantages for clinicians. This thesis addressed both of these knowledge gaps by conducting a literature review to investigate what is known about the operating models and outcomes of multidisciplinary renal genetics clinics and by conducting an exploratory sequential mixed-methods design to investigate 1) the structures and workflows of multidisciplinary renal genetics clinics and renal genetics services which preceded them, and 2) to assess the advantages and disadvantages of multidisciplinary renal genetics clinics for clinical team members.

High-level process mapping of MDT renal genetics clinics in different Australian states revealed common elements in clinic structures and workflows. Clinics were composed of three core professional disciplines: adult or paediatric nephrologists, clinical geneticists and genetic counsellors. Common elements across all clinics included MDT meetings to discuss patient cases, potential diagnoses and the appropriateness or results of genetic testing; multidisciplinary attendance at patient clinic appointments was also common to all clinics, although variability was observed in the way this was structured. Interaction with laboratory services was also integral to most clinic models. Local variations in operating procedures were also observed across clinics which may be the result of contextual differences in resource availability, funding models and patient demographics. The results of this phase defined the MDT models used in renal genetics clinics prior to the assessment of their advantages and disadvantages. They are of direct relevance to the KidGen Collaborative and may assist in the development and standardisation of clinic operating procedures.

Thematic coding of interviews derived a number of different types of advantages and disadvantages of MDT models for team members. These, along with other advantages and disadvantages of multidisciplinary ways of working identified in the literature, were assessed for relevance and perceived importance across a wider and broader sample of KidGen team members in the survey. There was considerable variation in survey responses as to the applicability and importance of reported disadvantages of the model. This may have been due to variations in team dynamics and operating models in KidGen clinics. However, these differences could not be explored further in the results of this research project due to low response rates per state and professional groups, and provide an avenue of further research.

Overall, the key advantages of MDT models in renal genetics clinics were shared expertise, accurate communication across specialties and professional learning and development. Improved diagnostic outcomes was a key advantage reported for patients. Contextualisation of these findings in the key informant interviews indicated that the co-location of team members in MDT models was instrumental to the sharing of expertise and accurate communication across specialties, and these contributed to professional learning and development. Lack of clinical workflow training and education in genetic medicine is a recognised barrier to its adoption; therefore, MDT clinical practices offer a clinical model which enhance clinicians' learning and development while improving diagnostic outcomes for patients. Future research should investigate the rates of diagnostic outcomes across MDT renal genetics clinics and the advantages and disadvantages of these models for patients and their families.

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16 May 2018

Dear Professor Braithwaite

Reference No: 5201800281

Title: *Assessing the value of multidisciplinary team models in renal genetics clinics*

Thank you for submitting the above application for ethical and scientific review. Your application was considered by the Macquarie University Human Research Ethics Committee (HREC (Medical Sciences)).

I am pleased to advise that ethical and scientific approval has been granted for this project to be conducted at:

- Macquarie University

This research meets the requirements set out in the *National Statement on Ethical Conduct in Human Research* (2007 – Updated May 2015) (the *National Statement*).

Standard Conditions of Approval:

1. Approval is contingent on continuing compliance with the requirements of the *National Statement,* which is available at the following website:

http://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research

2. This approval is valid for five (5) years, subject to the submission of annual reports. Please submit your reports on the anniversary of the approval for this protocol.

3. Proposed changes to the protocol and associated documents must be submitted to the Committee for approval before implementation.

It is the responsibility of the Chief investigator to retain a copy of all documentation related to this project and to forward a copy of this approval letter to all personnel listed on the project.

Should you have any queries regarding your project, please contact the Ethics Secretariat on 9850 4194 or by email ethics.secretariat@mq.edu.au

The HREC (Medical Sciences) Terms of Reference and Standard Operating Procedures are available from the Research Office website at:

https://www.mq.edu.au/research/ethics-integrity-and-policies/ethics/human-ethics

The HREC (Medical Sciences) wishes you every success in your research.

Yours sincerely

Professor Tony Eyers
Chair, Macquarie University Human Research Ethics Committee (Medical Sciences)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

Details of this approval are as follows:

Approval Date: 15 May 2018

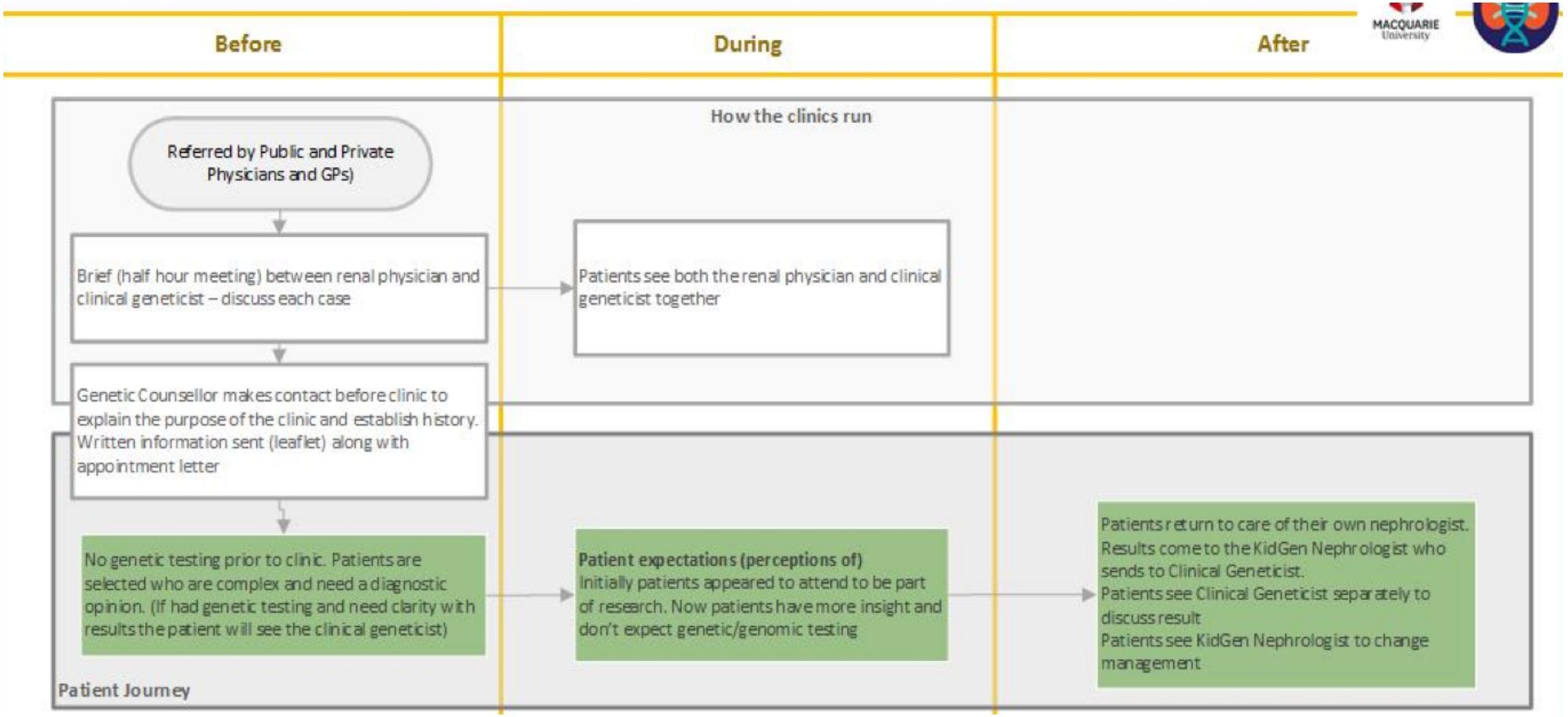
The following documentation has been reviewed and approved by the HREC (Medical Sciences):

Documents reviewed	Version no.	Date
Correspondence responding to the issues raised by the HREC (Medical Sciences)	1.0	Received 11 Apr 2018
Macquarie University Ethics Application Form	2.0*	Received 11 Apr 2018
Email Invitation (Clean & Tracked Changes)	2.0	11 Apr 2018
Macquarie Participant Information and Consent Form (PICF)	2.0	11 Apr 2018
Key Informant Interview Schedule	1.0	11 Apr 2018
Questionnaire and Survey Items	1.0	11 Apr 2018

Documents Noted	Version no.	Date
KidGen Letter of Support	N/A	04 Apr 2018

***If the document has no version date listed one will be created for you. Please ensure the footer of these documents are updated to include this version date to ensure ongoing version control.**

Appendix B: Example of a preliminary high-level process map showing the workflow of a KidGen renal genetics clinic



Source: Dr Stephanie Best, 2017

AUSTRALIAN INSTITUTE
OF HEALTH INNOVATION
Faculty of Medicine and Health Sciences

MACQUARIE University
SYDNEY·AUSTRALIA

ASSESSING THE VALUE OF MULTIDISCIPLINARY TEAM MODELS IN RENAL GENETICS CLINICS

Investigators' / Supervisors' Name & Title: Professor Jeffrey Braithwaite, Dr Janet Long and Dr Stephanie Best

Investigator's / Student's Name & Title: Ms Elise McPherson

Dear KidGen member

We would like to invite you to participate in a study of the value of multidisciplinary models, as used by KidGen Collaborative renal genetic clinics, to clinicians and patients. You are being invited to participate in this study because of your key role in a KidGen multidisciplinary clinic.

Who is carrying out the study?
The study is being conducted by Elise McPherson (elise.mcpherson@hdr.mq.edu.au) to meet the requirements of a Master of Research in Medicine and Health Science, under the supervision of Professor Jeffrey Braithwaite of the Australian Institute of Health Innovation, Macquarie University (jeffrey.braithwaite@mq.edu.au).

What does the study involve?
The project aims to evaluate the value of multidisciplinary models in KidGen clinics as compared with models used in pre-KidGen renal genetics clinics. Value will be assessed by creating and comparing site-specific process maps of current and pre-KidGen clinical workflows and surveying KidGen members about their experience with the multidisciplinary model.

The study is comprised of two activities. Participation in both activities is highly appreciated.

1. Audio recorded key informant interview **(15-30 minutes)** at a convenient time to create a process map of current and pre-KidGen renal genetics clinic models. The process maps will be emailed to the key informants for any revisions or comments after the phone interview.

2. Online survey **(15 minutes)** of KidGen members' roles and responsibilities and their perceptions of the value of multidisciplinary models in renal genetics clinics.

How will my data be used?
A summary of the results of the data will be made available to participating KidGen staff in the form of an executive summary. No individual will be identified in any publication of the results, though we may use some verbatim quotations in presentations of our findings. Findings from this study will form the basis of a Master of Research thesis and may be disseminated through peer-reviewed publications and at academic conferences.

Confidentiality and privacy

Any information or personal details gathered in the course of the study are confidential. Only aggregated, de-identified data rather than individual responses will be made available to KidGen Collaborative Governance. Therefore, participants should feel free to express their personal opinions in the online survey. Given the small number of participants involved in the study, it may not be possible to guarantee anonymity in the process maps. However, the researchers will not provide identifying details about individual participants or their workplaces in any presentations or reports about the study. Access to the data will be restricted to the chief and co-investigators of this study. Data will be stored in de-identified form and your personal details will not be kept with your survey/focus group/interview data. Data will be stored securely at the Australian Institute of Health Innovation and destroyed after 7 years.

Do I have to take part?

Participation in this study is entirely voluntary. You are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence.

I, *(participant's name)* have read and understand the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this research, knowing that I can withdraw from participation in the research at any time without consequence. I have been given a copy of this form to keep.

I agree to participate in the following study activities:

☐ Key informant interview

☐ Online survey

Participant's Name: _____
(Block letters)

Participant's Signature: _____ Date: _____

Investigator's Name: _____
(Block letters)

Investigator's Signature: _____ Date: _____

More information
The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics & Integrity (telephone (02) 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

Appendix D: Key informant interviews email invitation

Subject line: KidGen participation in Implementation Science Project

Dear all

Elise McPherson is undertaking her Masters in Implementation Science at Macquarie University. Our collaboration with this Implementation Science team, including assisting in this project, is an important component of KidGen and therefore [*name withheld to preserve anonymity*] and I would be most appreciative if you could find the time to assist her with her interviews.

Elise's study which aims to assess the value of multidisciplinary team models in KidGen renal genetics clinics is designed in two phases - a key informant interview and online survey - and Elise is currently recruiting for participation in the key informant interview. This is targeted towards [*group withheld to preserve anonymity*] and will build upon interviews conducted by Stephanie Best late last year.

KidGen clinics are likely to benefit from the work which will help us understand similarities and differences in structure and operating procedures across states. Participation is entirely voluntary but highly appreciated.

Could you kindly see the attached study invitation. If you're willing to participate please let Elise (elise.mcpherson@hdr.mq.edu) or myself know by return email.

Thank you

Appendix E: Online Survey

#[5] - Investigating the value of multidisciplinary team models in renal genetics clinics

Start of Block: Part A: Questionnaire

Q1

Dear KidGen member,

Welcome to a survey of KidGen members' roles and responsibilities and their perceptions of the value of multidisciplinary team models in renal genetics clinics. You are being invited to participate in this survey because of your key role in a KidGen multidisciplinary clinic.

The survey is part of a project being conducted by Elise McPherson (elise.mcpherson@hdr.mq.edu.au) to meet the requirements of a Master of Research in Medicine and Health Science, under the supervision of Professor Jeffrey Braithwaite of the Australian Institute of Health Innovation, Macquarie University (jeffrey.braithwaite@mq.edu.au). The project aims to evaluate the value of multidisciplinary team models in KidGen renal genetics clinics as compared with care delivery models in which renal and genetics services are not integrated. The survey is expected to take approximately 15 minutes to complete.

How will my survey data be used?
A summary of the results of the data will be made available to participating KidGen staff in the form of an executive summary. No individual will be identified in any publication of the results, though we may use some verbatim quotations in presentations of our findings. Findings from this study will form the basis of a Master of Research thesis and may be disseminated through peer-reviewed publications and at academic conferences.

Confidentiality and privacy

Participants should feel free to express their personal opinions in this online survey. Any information or personal details gathered during this study are confidential. Only aggregated, de-identified data will be made available to KidGen Collaborative Governance. No identifying details about individual participants or their workplaces will be included in any presentations or reports about this study. Access to the data will be restricted to the chief and co-investigators of this study. Data will be stored in de-identified form; this means your personal details will not be kept with your survey data. Data will be stored in secure servers at the Australian Institute of Health Innovation for up to 7 years.

Do I have to take part?

Participation in this survey is entirely voluntary. You are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence.

[5] Surveys were numbered from 1-6 to correspond with a state or territory

Q2
I have read and understood the information above.

I agree to participate in this survey, knowing that I can withdraw my participation in the survey at any time without consequence.

- ○ Yes (1)
- ○ No (3)

Skip To: End of Survey If I have read and understood the information above. I agree to participate in this survey, knowing... = No

Page Break

Q3 Do you currently work in a KidGen renal genetics clinic?

- ○ Yes (1)
- ○ No (2)

Skip To: End of Survey If Do you currently work in a KidGen renal genetics clinic? = No

Page Break

Q4 How long have you worked in a KidGen renal genetics clinic?

- ○ Les than 12 months (2)
- ○ 1-2 years (3)
- ○ 3-4 years (4)
- ○ 5-6 years (5)

Page Break

Q5 What is your role in the KidGen renal genetics clinic?

- [ ] Paediatric nephrologist (1)
- [ ] Adult nephrologist (2)
- [ ] Clinical geneticist (3)
- [ ] Genetic counsellor (4)
- [ ] Advanced trainee (7)
- [ ] Administrator (5)
- [ ] Other (Please specify): (8) _____

Page Break

Q6 What are your main responsibilities in the KidGen renal genetics clinic?

_____

_____

_____

_____

_____

Page Break

Q7 How long have you worked within your current role and field of practice (e.g. nephrology, genetic counselling)?

- ○ Less than 1 year (1)
- ○ 1-2 years (3)
- ○ 3-4 years (4)
- ○ 5+ years (5)

Page Break

Q8
A multidisciplinary team (MDT) can be defined as a group of health care professionals from a range of disciplines who work together to gain a collective understanding of complex patients' needs.

Does your role in a KidGen renal genetics clinic involve participation in MDT meetings or activities? This may include, but not be limited to, attending MDT patient intake meetings or variant interpretation meetings.

- ○ Yes (1)
- ○ No (2)

Skip To: Q14 If A multidisciplinary team (MDT) can be defined as a group of health care professionals from a rang... = No

Page Break

Q9 Please select from the list below all of the MDT meetings and activities that you participate in as part of your role in a KidGen clinic.

- ☐ Patient intake meetings (1)
- ☐ Pre-clinic patient discussion meetings (2)
- ☐ Patient clinic appointments (3)
- ☐ Post-clinic debriefing meetings (12)
- ☐ Results and variant interpretation meetings with clinical team (11)
- ☐ Results and variant interpretation meetings with laboratory team (14)
- ☐ Results and variant interpretation meeting with clinical AND laboratory teams (15)
- ☐ Other (Please specify): (13) _____

Page Break

Q10
Have you worked in a renal and/or genetics service **which does not have a MDT structure**?

- ○ Yes (1)
- ○ No (2)

Skip To: Q14 If Have you worked in a renal and/or genetics service which does not have a MDT structure? = No

Page Break

Q11 What was/is your role in a renal and/or genetics service **which does not have a MDT structure?**

- ☐ Paediatric nephrologist (4)
- ☐ Adult nephrologist (5)
- ☐ Clinical geneticist (6)
- ☐ Genetic counsellor (10)
- ☐ Advanced trainee (7)
- ☐ Administrator (8)
- ☐ Other (Please specify): (9) _____

Page Break

Q12 Does the MDT structure of the KidGen clinic affect the way you perform and fulfill your professional role and responsibilities?

- ○ Yes (1)
- ○ No (2)
- ○ Unsure (3)

Skip To: Q14 If Does the MDT structure of the KidGen clinic affect the way you perform and fulfill your professio... = No

Page Break

Q13
Provide up to four examples of ways in which you think a MDT structure affects the way you perform and fulfill your professional role and responsibilities?

- Example 1 (1) _____
- Example 2 (2) _____
- Example 3 (3) _____
- Example 4 (4) _____

Page Break

Q14
MDT models in health services are described as having both advantages and disadvantages over non-integrated health services.

In your own view, what are the main **advantages** of a MDT model in a renal genetics clinic **for team members**? You may list up to four advantages.

- Advantage 1 (1) _____
- Advantage 2 (2) _____
- Advantage 3 (3) _____
- Advantage 4 (4) _____

Page Break

Q15
MDT models in health services are described as having both advantages and disadvantages over non-integrated health services.

In your own view, what are the main **disadvantages** of a MDT model in a renal genetics clinic **for team members**? You may list up to four disadvantages.

○ Disadvantage 1 (1) _____

○ Disadvantage 2 (2) _____

○ Disadvantage 3 (3) _____

○ Disadvantage 4 (4) _____

End of Block: Part A: Questionnaire

Start of Block: Part B: Survey

JS

Q16
The following have been suggested as **advantages** of a MDT model in renal genetics services.

From this list of possible advantages of a MDT model, please rank from 1-4 the advantages that are most important to you. If you disagree with any of the statements below, please number it with a 9. You may leave any remaining statements blank.

A MDT model in renal genetics...
_____ improves diagnostic outcomes. (1)
_____ increases team members' sense of well-being through social support. (2)
_____ enhances team members' professional learning and development. (3)
_____ enables team members to feel that their knowledge and contribution is valued by their peers. (4)
_____ increases team members' confidence in the decision-making process. (5)
_____ promotes accurate communication across specialties. (6)
_____ enables timely access to relevant clinical and/or patient information for team members. (7)

Page Break

Q17
The following have been suggested as **disadvantages** of a MDT model in renal genetics services.

From this list of possible disadvantages of a MDT model, please rank from 1-4 the disdvantages that are most important to you. If you disagree with any of the statements below, please number it with a 9 instead.

A MDT model in renal genetics...
_____ is not an efficient use of team members' time. (1)
_____ creates challenges in unifying priorities and objectives across team members. (4)
_____ is not a financially sustainable model of care delivery. (3)
_____ is difficult due to inherent differences in approaches and communications styles across team members. (6)

Page Break

Q18
The following question is split over three pages.

Please indicate to what extent you agree or disagree with the following statements by selecting the appropriate answer. If you believe a statement is not applicable you may select N/A. Compared with a care delivery model in which renal and genetic services are not integrated, a MDT model in renal genetics clinics...

	Strongly Disagree (1)	**Disagree** (2)	**Neutral** (3)	**Agree** (4)	**Strongly Agree** (5)	**N/A** (8)
is not an efficient use of team members' time. (1)	○	○	○	○	○	○
promotes accurate communication across specialties. (4)	○	○	○	○	○	○
provides sufficient time to adequately discuss and make decisions about patient management. (3)	○	○	○	○	○	○
weakens professional relationships across disciplines. (5)	○	○	○	○	○	○

Page Break

Q19 Please indicate to what extent you agree or disagree with the following statements by selecting the appropriate answer. If you believe a statement is not applicable you may select N/A.

Compared with a care delivery model in which renal and genetic services are not integrated, a MDT model in renal genetics clinics...

	Strongly Disagree (1)	**Disagree** (2)	**Neutral** (3)	**Agree** (4)	**Strongly Agree** (5)	**N/A** (6)
decreases team members' confidence in the decision-making process. (1)	○	○	○	○	○	○
enhances team members' professional learning and development. (2)	○	○	○	○	○	○
reduces inefficiencies in administrative tasks (e.g., multiple emails or phone calls to contact health professionals or patients). (3)	○	○	○	○	○	○
carries inherent challenges in unifying priorities and objectives across team members. (4)	○	○	○	○	○	○

Page Break

Q20 Please indicate to what extent you agree or disagree with the following statements by selecting the appropriate answer. If you believe a statement is not applicable you may select N/A.

Compared with a care delivery model in which renal and genetic services are not integrated, a MDT model in renal genetics clinics...

	Strongly Disagree (1)	**Disagree** (2)	**Neutral** (3)	**Agree** (4)	**Strongly Agree** (5)	**N/A** (6)
enables health professionals to feel that their contribution is valued by their peers. (2)	○	○	○	○	○	○
does not improve diagnostic outcomes for patients. (4)	○	○	○	○	○	○
carries inherent challenges in overcoming differences in approaches and communication styles across team members. (3)	○	○	○	○	○	○
decreases team members' sense of well-being through social support. (5)	○	○	○	○	○	○

Page Break

Q21 We welcome any further comments or insights you may have about the operation or value of MDT models in renal genetics clinics.

_____

_____

_____

_____

_____

Q22 If you have any further comments about the survey, please enter them here.

_____

_____

_____

_____

_____

End of Block: Part B: Survey