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Ronald McDonald Family Rooms
Literature review plan

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ABBREVIATIONS

RMHC   Ronald McDonald House Charities

FCC   Family-centred care

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ACKNOWLEDGEMENTS

1 INTRODUCTION

Ronald McDonald House Charities (RMHC) Australia is commissioning research to build an evidence base on the value of their support program for families with seriously ill children. This project is a review of the Australian and international literature on the role, alternatives to, and value of Ronald McDonald Family Rooms, including their economic costs and benefits, and impact on the wellbeing of children, families and the hospital. Family Rooms are 'clinical-free spaces' that aim to offer support to families with children who are hospitalised, outpatients or undergoing same day surgery, by providing services, for example kitchen and laundry facilities, and embracing an approach to care that focuses on the family as a whole (family-centred care). The review will report on existing evidence from all relevant fields, including child, family, health care and service system perspectives, in order to draw evidence-based practice implications about the ways in which Family Rooms and their alternatives can have a positive impact on families' and children's wellbeing and health care effectiveness. Central to the success of the review is the identification of all relevant national and international studies, comparing relevant findings, interventions and research methodologies across different settings and disciplines, and building on the research findings of current and previous RMHC Global research. The findings of the literature review will be complemented by summaries of routinely collected administrative data on the use of the Family Rooms in Australia. They will inform the development of RMHC investment strategies and research program and be of interest across different communities of research and practice that operate family-centred programs and require evidence of their effectiveness, for example government, nongovernment and private providers.

RMHC is a quasi-federated organisation with a national body and local House Chapters that support families with seriously ill children via a suite of programs, of which the Family Rooms are a key strategic priority. A unique feature of the RMHC structure lies in the corporate relationship with McDonalds Australia Ltd (McDonalds). As McDonald's preferred charity, RMHC receives significant funding from the corporation.

Family Rooms reflect an approach to care that focuses on the family as a whole. When a child is admitted into hospital, the whole family is affected (Shields, Pratt, Davis, & Hunter, 2007), rendering a need for the impact of the child's admission on all family members to be considered by the hospital, nurses, and doctors. 'Family-centred care' (FCC) is an approach to paediatric health care founded on the belief children's and families' wellbeing are best achieved by involving the whole family in the plan of care, enabling them to meet the needs of their child (Shields, Pratt, & Hunter, 2006). Although there is no agreed definition of FCC in the literature, there is a growing agreement on the principles that inform FCC (Kuo, Houtrow, Arango, Kuhlthau, Simmons, & Neff, 2012), in particular, information sharing, respect and dignity, partnership and collaboration, negotiation, and care in the context of family and community. These principles qualify FCC as the main theoretical framework within which to investigate and understand the function of Family Rooms in Australia and internationally (Impact Group, 2013).

This review will explore the available evidence on the role, alternatives to, and value of Family Rooms from the perspectives of all parties involved, i.e. the children and their families, House Chapters, volunteers, hospital staff members and main stakeholders, and with reference to a wide range of health and wellbeing outcomes and their relevance in relation to FCC and support. This approach will enable RMHC to identify best practices, understand how support can be best delivered to families and children and contribute to the international evidence base.

2 AIMS AND OBJECTIVES

The review aims to provide a comprehensive account of the Australian and international literature on the ways in which Family Rooms or alternative facilities can have a positive impact on families' and children's wellbeing and health care effectiveness. The objectives are:

1. To observe the experience of the children, adults and staff members about the use, advantages and disadvantages of the Family Rooms.

2. To identify academic literature and research reports commissioned by government and other agencies on:

   a) the value and unique characteristics of the Family Rooms, including their economic costs and impact on the wellbeing of the children, families and hospital staff members.

   b) the views and expectations of help and support of families and hospital staff members regarding the Family Rooms.

   c) alternative models of support for the Family Rooms and how they compare.

3. To summarise routinely collected administrative data on the use of the Family Rooms in Australia (data to be provided by RMHC).

4. To tabulate, map, and summarise the identified evidence with reference to the international and Australian national contexts, and any other relevant settings emerging from the review, e.g. children, adults, and staff members.

5. To identify gaps in the reviewed literature and suggest priorities for improving the evidence base

6. To identify preferred research and evaluation methodologies to determine the effectiveness of family room type interventions.

3 METHODOLOGY

The methodology is designed to provide an inclusive, transparent and reproducible review of the literature across all relevant fields including child development, family support, health care, health service organisation, health economics, psychology and social services. It consists of three key methods:

- Observations in the Family Rooms of three hospitals in NSW—Gosford, Randwick and Newcastle—to inform the analytical framework for the literature review search and analysis.

- A narrative literature review informed by a purposive review methodology.

- Univariate and bivariate statistical analyses of administrative data on the use of Family Rooms in Australia.

3.1 SITE OBSERVATIONS

The literature review will be designed following observations in the Family Rooms of three hospitals in NSW—Gosford, Randwick and Newcastle—with staff and families. The site observations will consist of participant observation, a method used in research on community and health care service delivery (Fudge, Wolfe, & McKevitt, 2008). This entails observing how the Family Rooms are working, in terms of the relationships among family members, relationships between family members and volunteers and between family members and hospital staff members. The researchers will be introduced to the staff members at each site by a representative of the RM House Chapters. Site visits will include informal discussions with House Chapter staff and volunteers.

3.2 LITERATURE REVIEW

The narrative literature review will be informed by a purposive review methodology, which aims to offer a comprehensive panorama of the outcomes and perspectives associated to the use of Family Rooms.

Previous RMHC Global research has identified families, children, and hospital/clinical service providers as three main beneficiaries of Family Rooms (Lantz, Pollack, & Franck, 2012). This review will focus on a total of five outcomes groups, the three identified by Lantz and colleagues (2012) plus two further ones which have emerged as relevant from the three site observations that have taken place in June 2014: the health and social system, and the wider community, e.g. the RM volunteers. Table 1 shows the five outcome groups and the keywords that will be used to address them in the literature searches.

Table 1: Keywords for the five main outcomes groups of the RM Family Rooms

Outcome groups	keywords
Families	Famil*, parent*, carer*, guardian*, relative*, sibling*, guest*
Children	Hospitali?ed child*, newborn*, neonate*, infant*, teenager*, adolescent*, minor, kid*, boy*, girl*
Hospital/clinical service provider	Hospital, doctor*, nurse*, hospital staff, NUM
Community	Volunteer*, voluntary worker*, charit*, unpaid, altruis*, activis*, peer or self-help group, budd*
Health and social system	Corporat*, non-government, NGO*, public, private, voluntary, social policy, ethic*, public health, politic*, interest*, implication*

Note. The asterisk and the question mark are 'wild cards' that entail respectively all possible endings of a word and different spellings.

Two sets of search strategies (or queries) will be adopted to retrieve literature concerning the outcomes that Family Rooms and alternatives have in each of the five outcome groups identified in Table 1. All search strategies will be based on the same logical structure, which entails grouping search terms into thematic groups (as in Table 1) and using the Boolean operator AND to combine the keywords concerning each thematic group in a specific logical order.

FIRST SET OF SEARCH STRATEGIES

Table 2 reports the four thematic groups of keywords that will be used for the first sets of search strategies: the target population, e.g. families of hospitalised children; Family Rooms and alternative facilities; the setting, i.e. hospitals; and the process factors that generate outcomes in the five groups in Table 1, e.g. support. The keywords that tap on process factors will be used as a complementary search strategy to the keywords on Family Rooms and alternative facilities in order to cast as wide a net as possible on relevant literature. Similarly, in order to explore as many different outcomes as possible, the searches will not be limited to a list of specific outcomes.

Table 2: Search terms

Thematic groups	Keywords
Target population	Keywords for children and families from Table 1
Family Rooms and alternative facilities	Family room, Ronald McDonald, family space, design, construction, room*, lounge*, play area/space/room/facilit*, starlight, sitting area, waiting area, inpatient space*, amenit*, facilit*, kitchen*, dining area/space/room/facility*, eating, refresh*, vending machine*/area/space/room/facilit*, kettle, tea and coffee, snack*, refrigerator, microwave, shower, bathroom*, toilet*, laundry, washing machine, dryer, overnight stay, lodging, sleep*, wall bed*, hospital stay, guest hous*, accommodation, residence, inn, cottage*
Setting	Hospital*, clinic, ward, unit, health centre, hospice, asylum, infirmary, sick bay, dispensary, surgery centre, emergency room, sanitarium
Process factors	Support*, help*, service*, aid, coping, break, rest, stress relie*, resilience, relax, assist, relieve/relief, respite, economic/financial, burden/hardship/difficulties, family-centred care, partnership-in-care, parental involvement, nurse-parent partnership, parental participation, care-by-parent

Note. The asterisk and the question mark are 'wild cards' that entail respectively all possible endings of a word and different spellings.

All the keywords related to each thematic group in Table 2 will be searched together using the Boolean operator OR – e.g. (famil* OR parent* OR carer* etc.) – and then combined with each other, using the Boolean operator AND, as in the following example:

- Family Rooms and alternative facilities keywords AND Setting keywords

- Target population keywords AND Setting keywords AND Process factors keywords

- Target population keywords AND Family Rooms and alternative facilities keywords AND Setting keywords

This set of search strategies will allow us to address the following type of research questions related to the study objectives 1a, 1b, and 1c: What are the characteristics of Family Rooms and similar alternative facilities? What forms of help and support are available to families with hospitalised children? What outcomes do families and children experience from using Family Rooms or alternative facilities? What is the role of the different mechanisms that can generate such outcomes?

SECOND SET OF SEARCH STRATEGIES

The second set of search strategies will target more specifically the outcomes that Family Rooms and alternative facilities generate in the three outcome groups of Table 1 that are not fully covered by the first set of search strategies, i.e. hospital and clinical service providers, the health and social system, and the wider community. The keywords of each of these three thematic groups will be first searched together using the Boolean operator OR, and then combined with the keywords of the thematic group 'Family Rooms and alternative facilities' using the Boolean operator AND, as in the following examples:

- Hospital/clinical service provider keywords AND Family Rooms and alternative facilities keywords

- Health and social system keywords AND Family Rooms and alternative facilities keywords

- Community keywords AND Family Rooms and alternative facilities keywords

This set of search strategies will allow us to address the following research questions related to the study objectives 1a, 1b and 1c: What outcomes do hospital staff members experience from using Family Rooms or alternative facilities? What are the policy and public health implications of having Family Rooms in hospitals? What are those of alternative facilities?

The searches will be undertaken in the following databases relevant for the social study of health and illness in hospital settings:

- MEDLINE,

- PsycINFO (for psychology),

- CINAHL Plus (nursing)

- Social Sciences Citation Index (for Sociology and economic disciplines)

- APAIS-Health (Australian Public Affairs Information Service)

Keywords will be searched as Subject Headings, where available, and in all fields of each database in order to get an idea of the amount of literature available. In the likely event of there being too many references, the searches will be limited to Title and Abstract fields, which allow targeting more relevant studies.

The searches will cover January 2004 to June 2014. This allows us to identify and retrieve specific older works that have informed the more recent debate as well as other relevant older literature through the analysis of existing review studies.

Grey literature (informally published material) will be identified using similar search strategies in the search engine Google, which allows using limiters to search across specific web sites or domains and limiting to pdf format (most grey literature is made available in pdf). Relevant national websites, such as FAMILY: Australian family & society abstracts, Australian Government departments, RMHC, and hospital websites will be trawled and the following two databases dedicated to grey literature will be searched:

- OpenGrey. System for Information on Grey Literature in Europe (http://www.opengrey.eu/search/request?q=carers)

- New York Academy of Medicine: The Grey Literature Report (http://www.greylit.org/) and

Titles and abstracts of studies identified by the searches in each of the mentioned databases will be downloaded in an Endnote library (a powerful reference manager program). The Titles and Abstracts of the retrieved literature will be screened based on their relevance. Inclusion and exclusion criteria will be discussed with RMHC to ensure transparency and inclusiveness. In order to be as inclusive as possible, studies will not be excluded based on their design, e.g. randomised controlled trials, qualitative studies. However, the strengths and weakness of the retrieved literature – i.e. design, execution, analysis, and sample size – will be noted and reported in the main report.

A copy of all included books and papers will be retrieved. These will be read and summarised in 'note cards' style summaries in a Word document. Notes will summarise the types of setting investigated and the main study findings, in particular those on the outcomes, needs, views, and relationships of the five outcomes groups mentioned above. The information collected in this document will be used to:

- Tabulate the findings

- Map the findings by drawing 'literature maps', i.e. visual summaries of the available evidence represented in a figure that can have either a hierarchical, flow-chart, or circle structure. Literature maps will allow us to graphically display the type and amount of evidence on Family Rooms and their impact on children and their families.

- Draw out common themes across the literature

- Summarise the literature in the final report

3.3 ROUTINELY COLLECTED QUANTITATIVE DATA

The routinely collected data on attendance of Family Rooms in Australia, which is provided to the research team by RMHC, will be analysed by reporting descriptive statistics, for example tables reporting percentages, averages and figures, such as for example bar charts, histograms and box plots.

4 OUTPUTS

Appropriate dissemination is essential in ensuring research findings inform policy and practice and we welcome the opportunity to work with the RMHC team on this. As a research team, we bring a unique skill set combining academic research skills with knowledge exchange expertise. Knowledge exchange is about research that is shaped by the information needs of those in practice at all stages of the research; a factor that contributed to the design of the participant observation aspect of the methodology.

We will develop a robust dissemination strategy for this project in collaboration with the RMHC team. Key products will include:

- A draft and final report of the results from the project for internal use and external publication.

- A package of PowerPoint slides demonstrating the key findings.

- A paper to be submitted in an international peer-reviewed journal.

- Presentation of findings at relevant conferences in Australia.

5 PROJECT MANAGEMENT

The research will be completed by 5 March 2015. All deliverables will be presented in draft to receive comment and make amendments and a final version agreed. The results will be submitted for a peer-reviewed publication to contribute to the evidence base on the value of Family Rooms.

Table 3: Research activities and timeframe

Activity	Time frame (month)
Project set up, initial meeting with RMHC and scoping of datasets	19th May 2014
Ethics application	May
Site observations	May/June
Literature review	June/July
Draft Report (followed by feedback from RMHC)	August
Final Report (for internal/board viewing)	October
Journal article submitted	November
Discussion and planning for next phase if agreed	November/December

The research team consists of Associate Professor Karen Fisher (Chief Investigator) and Dr Gianfranco Giuntoli (Research Associate).

Potential risks that may impact on the management of the research and collection of data are summarised in Table 4, drawing on the expertise and experience of the research team.

Table 4: Risk management

Risk	Impact	Likelihood	Remedial Action
Very high number of studies to review	High	Low/ Medium	Proximity searches and MeSH terms will allow us to manage this risk. Agreement would be searched with RMHC.
Different datasets produce different findings	Medium	High	Early decisions as to how to handle discrepancies and methods for triangulating findings from different datasets.
Research does not adhere to budget	High	Low	Careful planning. The budget represents excellent value for money as the researchers are experts in the area and have prior knowledge of the datasets which will ensure efficiency in many project tasks. The budget is based on previous experience of similar projects, all of which have reported on time and within budget. The risk is borne by SPRC.

Risk	Impact	Likelihood	Remedial Action
Research findings don't meet policy needs/report too technical for policy makers/no robust conclusions	High	Low	Methodology will be agreed with RMHC. The research team is highly experienced in producing accurate and accessible findings, and for producing accessible reports useful for policy and program development. Draft report will be provided for comment, to allow review and feedback to be included.
Delays/bureaucratic difficulties in accessing the three hospital sites	High	Low	The sites will be accessed as visitors introduced by RMHC managing staff.
Delays in receiving administrative data from RMHC	Medium	Low	The analyses will be undertaken only on available data, which will be sent by RMHC.

5.1 ETHICS

Human research activities are governed by the principles outlined in the National Statement on Ethical Conduct in Research Involving Humans (National Health and Medical Research Council, 2007). The Research Code of Conduct sets out the obligations on all University researchers, staff and students to be aware of the ethical framework governing research at the University and to comply with institutional and regulatory requirements.

This project has received ethics clearance from the UNSW Human Research Ethics Advisory Panel (application number 9_14_021).

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