Project Protocol

Title

Implementing an evidence-based adherence protocol into the Cystic Fibrosis service at Queensland Children’s Hospital

Project Team Roles & Responsibilities

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| --- | --- |
| **Chief Investigator** **Bianca Richards,** Occupational Therapist, LCCH Cystic Fibrosis service | Role and responsibilities:* Study design
* Obtain ethical and governance approvals
* Manage research budget
* Monitor research processes and project oversight
* Participant recruitment and consent
* Data collection and analysis
* Dissemination of findings (reports, publications and conferences)
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| **Associate Investigator****Dr Megan Simons,** Occupational Therapist/ Clinical Consultant, LCCH Occupational Therapy Department; Researcher, Child Health Research Centre, The University of Queensland.  | Role and responsibilities:* Provide advice on research design and implementation plan
* Mentor and supervision of novice researcher
* Assist with ethics preparation
* Assist with administration of grant monies
* Assist with project oversight
* Collaborate on manuscript writing and dissemination

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| **Consultant Investigator** **Prof Jenny Ziviani,** Associate Professor in Occupational Therapy School of Health and Rehabilitation Sciences, University of Queensland | Role and responsibilities:* Provide advice on implementation plan and research design
* Liaison regarding implementation process
* Editing and feedback on documentation
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| **Consultant Investigator** **Dr Sonya Osborne,** Senior Implementation Scientist, Australian Centre for Health Services Innovation (AusHSI) at Queensland University of Technology | Role and responsibilities:* Provide advice on research design, implementation plan and evaluation
* Mentor novice researcher
* Provide consultation, support and guidance on ethics preparation and submission
* Provide consultation, support and guidance on administration of grant monies
* Provide consultation, support and guidance on project oversight
* Collaborate on manuscript (writing, critical review and feedback)
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| **Research Assistant (TBC)** | Role and responsibilities:* Participant recruitment and consent
* Data collection and analysis
* Collaborate on manuscript writing and dissemination
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Resources

Funding/support has been secured from the Children’s Hospital Foundation via the 2018 General Health Services Research Grant Round for the following resources:

1. Backfill of clinical time to facilitate clinical investigator role (0.4 FTE)

2. Research Assistant time (0.6 FTE)

3. Statistician consultation

4. Implementation science consultation (AusHSI)

All iCARE protocol assessment and intervention forms will be provided in kind by Alexandra Quittner who has consented to their use in this project.

* + Treatment Adherence Questionnaire- Cystic Fibrosis
	+ Knowledge of Disease Management questionnaire
	+ Observed Skills Checklist
	+ iCARE protocol and clinical resources

Background

Literature Review

Cystic fibrosis (CF) is a life limiting, genetic disease that affects approximately 450 children across Queensland and Northern New South Wales [1]. All children with cystic fibrosis are required to complete a significant and often complex treatment regimen that includes oral medications, nebulised medication, nutritional supplements, increased caloric intake and daily physiotherapy to manage their disease progression.

Despite advances in the management of children with cystic fibrosis, a common barrier to providing medical care is patient adherence to prescribed treatments [2]. The World Health Organization defines adherence as “the extent to which a person's behaviour (in terms of taking medication, following diets, or executing lifestyle changes) coincides with medical
or health advice"[3]. It is estimated that the rates of adherence in the Cystic Fibrosis population are approximately 40-50% indicating that a large proportion of patients are not consistently following the advice provided by the health care team regarding medications and other treatments [4-5]. The reason for this is unclear but may be related to the variability in processes used by different clinicians in implementing recommendations or reasons related to patient and family uptake of recommendations in treatment regimens.

Reduced adherence to treatment results in adverse effects for both the individual and the health care system. Poorer adherence is associated with lower lung function, more frequent pulmonary exacerbations [6], increased morbidity, reduced health related quality of life and earlier mortality [7]. Patients with poorer adherence to treatment regimens require more frequent use of intravenous (IV) antibiotics, have increased hospital admissions and incur higher costs to the health care system [8-9]. Research evidence suggests that consistent use of objective assessment tools and validated educational, behavioural, and support strategies are core elements of an effective adherence promotion intervention [10].

The ‘I Change Adherence and Raise Expectations (iCARE) Protocol’ was developed in the United States of America by Quittner et al (2010). This protocol aims to more effectively and systematically target adherence barriers for young people with cystic fibrosis. The iCARE protocol utilises the strengths of multiple methods of adherence intervention including educational, organisational and behavioural approaches [11]. At each clinic visit adherence is reviewed and problem solving is supported with families, this assists clinicians to address individual barriers to adherence as identified by the families. By embedding annual assessment of disease management knowledge and treatment skills into standard care, it is anticipated that multidisciplinary teams will be able to provide tailored education to patients [12]. The protocol has since been rolled out across at least 18 sites in the USA for children aged 11-20 years. Preliminary results of randomised controlled trials indicate the iCARE protocol is a feasible, clinic-based approach to adherence intervention.

Research Rationale/Justification

The Lady Cilento Children’s Hospital (LCCH) utilises significant multidisciplinary resources to support families to manage their daily treatments with the aim of increasing adherence to comply with best practice medical care. An audit of routinely collected monthly service delivery data revealed that occupational therapy contributes approximately 0.6 to target patient adherence in the Cystic Fibrosis population at a cost of approximately $54,000 per annum. This breaks down to at least 18 hours per week of occupational therapy clinical time attributed to targeting and monitoring adherence. Adherence also represents a significant portion of clinical time of the dieticians, physiotherapists and psychologists. Despite this considerable resource allocation (clinical hours), there is currently no standard or consistently used evidence-based model of care in place at LCCH to guide clinicians on how to effectively assess adherence and provide adherence promotion interventions.

A retrospective chart audit was completed in January 2018 to evaluate the current multidisciplinary adherence promotion interventions provided for children with Cystic Fibrosis at Lady Cilento Children’s Hospital. Results highlighted wide variation in the clinical services provided to families. The frequency and type of adherence promotion interventions offered is inconsistent and also presents significant inequities in care. Audit data also revealed that intervention modalities were varied and included patient education in clinic, home based observations of treatment skills, frequent phone/email monitoring, motivational coaching and behavioural contracting. The frequency of client appointments made also varied from weekly to three monthly reviews. The absence of a consistent, systematic approach to adherence promotion processes at LCCH is not aligned to current best practice recommendations outlined above.

This project presents an opportunity for the Cystic Fibrosis service of LCCH to improve the experience and health outcomes for young people with cystic fibrosis, as well as improving the way services are delivered, through the introduction of an innovative evidence-based adherence promotion practice model (the iCARE protocol) into routine clinical care.

To date, the iCARE adherence promotion protocol has been described in the North American context. This study will explore the feasibility of implementing iCARE, and acceptability and sustainability of the program in the Australian context. The study has been purposely designed using an implementation research approach, which promotes “the systematic uptake of research findings and other evidence-based practices into routine practice” [[15](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4573926/#CR15)]. By using this approach, the research project will contribute to existing adherence promotion literature by not only providing some evidence of feasibility and effectiveness of the iCARE adherence promotion protocol in the Australian context but by providing insight into the process and experience of implementing and sustaining an evidence-based adherence promotion protocol in a real clinical setting.

Additionally, consumers are infrequently represented in the literature when describing adherence promotion interventions. Thus, the research will capture the implementation experience from the perspectives of staff and consumers (children and their family and care givers); an area that has not yet been explored.

Research Question

What contextual factors from the perspectives of clinicians and consumers are associated with successful implementation of the iCARE (I Change Adherence and Raise Expectations) adherence promotion protocol?

Research Aims

The aims of this project are:

1. to successfully implement and sustain an evidence-based adherence promotion protocol into routine clinical care delivered at the Lady Cilento Cystic Fibrosis clinic
2. to determine the feasibility and acceptability of implementation of the iCARE (I Change Adherence and Raise Expectations) adherence promotion protocol into the Lady Cilento Children’s Hospital Cystic Fibrosis Clinic
3. to explore the perspectives of clinicians and consumers (parents and children) relevant to the implementation of the iCARE adherence promotion protocol

Expected Outcomes and Impact

By incorporating research design components; qualitative data analysis, systematic fidelity monitoring and use of implementation science theory into this quality improvement process, the expected outcomes of the project include:

1. Acceptability to clinic staff: Staff perceptions will generally be positive about the viability of changing adherence care processes.
2. Acceptability to consumers: Consumers will report that the implemented changes are acceptable for their child’s health care. Qualitative data will explore the perceptions of consumers about the family centeredness and effectiveness.
3. Increasing fidelity to the prescribed treatment components compared to time of initial introduction of the protocol
4. Exploration of clinicians’ and consumers’ attitudes and experiences of receiving/ providing adherence related assessment and intervention in a CF centre

Project Design

Methodological Approach

An implementation study design using a mixed methods approach will be utilised to evaluate the iCARE implementation process. The four-phase Replicating Effective Programs (REP) framework (REF-Kilbourne)[[1]](#footnote-1) (see Figure 1), developed to translate effective health services interventions into community‐based settings, will inform implementation. Theories underpinning the REP framework include:

1. *Tax’s Action Anthropology*, whereby a third party facilitates interaction and exchange between two cultures, eg research and practice; its aim is on community development–enabling participants to actively engage and be part of the process.
2. *Rogers’ Diffusion of Innovation*, which asserts that diffusion of an innovation passes through certain communication channels among members of a social system over time; it seeks to explain how, why, and at what rate new ideas and technology spread; and
3. *Bandura’s Social Learning Theory*, which describes the relationship between behaviour change and a person’s beliefs about their ability to change and the results of change; it posits that people learn from one another via observation, imitation, and modelling.



Figure Replicating Effective Programs (REP) framework

Embedding the iCARE protocol into routine service delivery requires a change in attitude and behaviour on the part of the staff as well as the client. Thus, the REP framework is an ideal implementation framework because it focuses on key stakeholder engagement through all phases of implementation of the new model of service delivery. Using a mixed-methods approach will allow for the collection quantitative data in terms of service use, delivery and adherence to the iCARE model as well as rich qualitative data to understand the barriers and facilitators to program feasibility, acceptability and sustainability.

The Consolidated Framework for Implementation Research (CFIR) (REF-Damschroder) will be used to guide evaluation of the factors influencing implementation; knowing these factors will allow for appropriate interventions to be included in the implementation strategy. The CFIR is a widely cited and rigorously developed determinants framework for implementation that was developed through a process of consolidating earlier published literature, including nineteen previously developed frameworks such as the Greenhalgh dissemination and sustainability model (2004). The CFIR consists of five domains, each domain broken down into a number of constructs identified in the literature as impacting successful implementation (see Figure 2).

Figure . Constructs of the Consolidated Framework for Implementation Research (CFIR) by Damschroder et al 2009 (figure from Ament et al 2012).

Research project setting

This project will be conducted at the Lady Cilento Children’s Hospital Cystic Fibrosis Clinic. The Cystic Fibrosis Clinic is an outpatient clinic conducted in the Lady Cilento Children’s Hospital 5A. The clinic runs three times a week. All patients within Queensland are able to access this clinic; however some are seen on outreach visits (which are staffed by LCCH CF clinic multidisciplinary team). The clinic is staffed by respiratory physicians, cystic fibrosis nurses, physiotherapists, social workers, occupational therapists and dieticians.

Participants

The study participants will include patients and their families or carers and staff.

Patients/ Families:

* Inclusion Criteria
	+ Patients with a diagnosis of Cystic Fibrosis/ parent of child with a diagnosis of Cystic Fibrosis
	+ Patient attending the Lady Cilento Children’s Hospital CF Clinic during implementation phase of iCARE protocol
	+ Participant has provided informed consent
* Exclusion Criteria
	+ Patient did not attend the LCCH Cystic Fibrosis clinic within the implementation phase
	+ Patient is receiving care as an inpatient

Staff:

* Inclusion Criteria
	+ Participant has provided informed consent
	+ Staff providing care to children at the LCCH CF clinic during the implementation phase
* Exclusion Criteria
	+ Participant chooses not to provide informed consent
	+ Staff did not provide care at the LCCH CF clinic during the implementation phase

Recruitment

Recruitment will occur between October 2018- March 2019. It is anticipated that this study will recruit approximately 15-20 clinicians who are regularly involved in treating children at the cystic fibrosis clinics at Lady Cilento Children’s Hospital, as well as 10-15 consumer representatives.

Training:

* As the iCARE protocol is being rolled out across the clinic and will be considered standard practice, all staff will receive training in the adherence promotion protocol.

Recruitment #1: Focus groups:

* All staff in the Cystic Fibrosis care team will be approached and invited to participate in the focus groups via the CF business/ team meeting. Participation in the focus groups is voluntary. The researchers will recruit a representative sample that includes senior leaders, clinical staff, members of each allied health/ medical profession and clinicians of variable levels of experience. The anticipated recruitment numbers for focus groups is 10-12.
* The researchers will also recruit 5-10 consumers (child, adolescent and parent with varied level of disease severity and frequency of clinic attendance). Consumers will be approached at the CF clinic and invited to participate in a focus group/ interview to determine their perspective on adherence promotion interventions used by clinic staff.

Recruitment #2: Interviews

* 8-10 Staff members and 5-10 consumers will be recruited to participate in follow up staff interviews. The clinical investigator and research assistant will approach consumers at the clinic following/ during their clinic appointment during January / February 2019 and recruit consumers for interviews.

Participants are asked to consent to participation at each recruitment point (i.e. pre- and post-implementation. As such, a new pool of participants can be recruited at each time point. No longitudinal data is being collected. Therefore, participant withdrawal will not impact upon data collection/ analysis.

Consent

All participants will be provided with an information sheet outlining the purpose of the research and their rights and responsibilities when participating in the study. A consent form will be provided to all participants by the clinical investigator or research assistant at time of recruitment. Staff and consumers will be informed that participation in the research is voluntary, any information provided will be confidential and they can choose to withdraw at any time. Participants will be offered the opportunity to ask any questions of the researcher and are informed that they may choose to take additional time to consider participation as required. Signed consent will be required prior to participation.

Staff or consumer’s decision not to participate in the research will not affect future relations in the LCCH CF clinic or within Children’s Health Queensland.

Patients/ Families:

* Patients/ families will be informed that changes have been made to aspects of clinical care throughout the clinic and associated clinic processes. All potential participants will be informed that the information provided will be utilised for service evaluation as well as for research purposes.
* Patients/ families will be recruited at their clinic appointments for in depth interviews following the clinic implementation. These patients are required to have accessed the clinic for consultant review within the implementation period.
* Consumers representing the child, teen and parent perspective will be recruited.

Staff:

* Staff are required to have attended the general staff training sessions and participated in the adherence promotion protocol implementation in the CF clinic.
* Staff from each discipline will be recruited (Social work, Occupational therapy, Physiotherapy, Dietetics, Nursing, Medicine) to create a representative sample of the clinic’s multidisciplinary staff.

Data Collection/Gathering

To address the aims and answer the research question both quantitative and qualitative data will be collected as follows and described below :

Qualitative data:

1. **Semi structured interviews.** Interviews will be audio-recorded and transcribed verbatim.
2. **Focus groups.** Focus groups will be audio-recorded and transcribed; field notes will be included in this data set.

Quantitative data:

1. **Protocol checklists** will be used as part of the implementation process; these will be routinely collected by the researcher to evaluate level of adherence to implementation in the clinic.
2. **Retrospective chart** **audit** using a **fidelity checklist.**  Audits will be completed to review care provided during implementation and checklists used to monitor fidelity to iCARE protocol components.
3. **Technical assistance logs.** The ongoing consultation process, top up training and alterations to processes will be recorded in the research technical assistance log

Qualitative data (via interview/ focus group) will be collected at two key time points: pre-implementation and post-implementation. Interviews/ focus groups will be conducted with clinicians involved in the Lady Cilento Children’s Hospital Cystic Fibrosis clinic and families/ patients that access the service. Thematic analysis of this data will explore the implementation process, barriers and facilitators experienced and evaluate perceived acceptability and sustainability of using the iCARE protocol according to the perspectives of clinicians and consumers.

Descriptive data will be collected throughout the project via technical assistance logs (field notes), clinician-reported fidelity checklists and retrospective chart audit fidelity measures. The descriptive data will be analysed to quantify number and type of issues experienced in implementation, modifications (planned or unplanned) to the implementation plan and review staff fidelity to the iCARE protocol.

\*Fidelity assessment will be used to monitor the consistency of protocol components were delivered in the clinic. Its purpose is to assess the degree to which the protocol is being delivered as intended and establish the level of congruency between the outlined processes and true clinical practice. Fidelity will be assessed via self report (protocol checklists) and retrospective chart auditing (fidelity checklists).

Implementation Plan

The REP program, as it will be adapted for use in this study, is described below and presented in Figure 3.

1. *Pre-Conditions Phase*: The researchers will review the iCARE intervention protocol, existing adherence promotion intervention, clinic processes and resources. From this, the team will determine the core components of the iCARE intervention and create an implementation strategy that will support translation into the existing LCCH clinic structure and resourcing.
2. *Pre- Implementation Phase:* The iCARE protocol, business case and draft implementation plan will be presented to the Cystic Fibrosis care team. The researchers will recruit staff and consumers to participate in focus groups to provide key stakeholders’ feedback on the proposed implementation. Following completion of the planned focus groups and consumer engagement, the training package, implementation plan treatment pathway and resources will be modified.
* Staff will receive training in the modified adherence promotion protocol and treatment pathway. Training will be led by the clinical investigator. All staff presentations, recruitment and training will be conducted within staff hours. Staff will not be expected to attend training outside of work hours. Where possible, staff education and training will be integrated in existing CF meetings.
1. *Implementation* Phase: All children and family’s accessing the clinic will receive the iCARE adherence promotion protocol as part of their routine clinic attendance. The research team will continue to collaborate with consumers and staff to troubleshoot, provide feedback and booster training as indicated. The implementation plan will continue to be modified and refined according to staff and consumer input. The researchers will record all facilitator input via technical assistance and training logs. Retrospective chart audit and a protocol checklist will be utilised to monitor fidelity and uptake of each aspect of the protocol into routine care.
2. *Maintenance and Evolution:* Following two months of clinic implementation, the implementation process will be evaluated by the research team. Participants (staff and consumers) will be recruited to complete a one-to-one, semi-structured interview with the researcher / research assistant. Data analysis will occur to evaluate the implementation. This evaluation will inform final changes to be made to the training package, implementation plan and resources. The researchers will prepare the manuscript and resources for wider dissemination and future training needs.

**Pre-Conditions Phase**

*Jul–Aug 2018*

* Prepare orientation and business case
* Meet with senior management
* Identify core intervention components
* Draft intervention package

**Pre-Implementation Phase**

*Sep–Nov 2018*

* Staff orientation
* Recruitment # 1
* Staff and consumer focus groups
* Refine training package
* Create LCCH adherence intervention pathway and resources
* Staff training

**Implementation Phase**

Jan –Apr 2019

* Ongoing consultation
* Booster training
* Fidelity monitoring (chart audit and checklist)
* Refinement of intervention pathway and training

**Maintenance + Evolution**

*Mar –Jun 2019*

* Recruitment # 2
* Qualitative interviews with staff and consumers
* Evaluation
* Determine changes
* Prepare package for wider distribution

Figure REP framework applied to the iCARE study

Following the completion of the 12-month project (as per project implementation outline in Appendix 2), it is anticipated that the iCARE protocol will continue to be used in the clinic as standard care, if deemed acceptable to staff and consumers and sustainable within the existing resourcing of the clinic.

Data Management

Data will be initially be stored in paper copy and audio recordings. Audio recordings will be transcribed and stored as password protected electronic files. Paper data will be stored in a locked filing cabinet in the LCCH or the Centre for Children’s Health Research buildings, in an area which requires swipe card to access. Data will be stored for 5 years following publication and consent forms retained for 15 years in accordance with the Retention and Disposal Schedule for Queensland Universities (section 601.2/C111). Research data in paper form will be shredded and stored in secured bins for removal.

Data Analysis

Qualitative Data

1. The qualitative data from staff and consumer interviews will be analysed through thematic analysis. Following transcription of audio recordings, the two coders (researcher and research assistant) will analyse transcripts using qualitative analysis to determine the key themes. A network of core themes and sub-themes will be developed.
2. Following the focus groups all changes/ adjustments to the protocol as well as key themes, barriers and facilitators will be recorded. These findings will be analysed and actioned to inform the implementation plan.

Quantitative Data

1. Information collected on staff checklists will be reviewed by the researcher weekly, for discussion integrated into a weekly clinical team meeting.
2. The fidelity checklist will be analysed weekly by the RA and clinical investigator (5/ week). Each researcher will separately review the charts selected and compare fidelity scores. Fidelity will quantified as a percentage (number of protocol components completed and documented compared to the total number of protocol components defined). The researchers will continue to analyse fidelity throughout rollout and report on final fidelity figures at the end of the implementation phase.
3. The technical assistance logs will be reviewed at completion of the project. Through use of narrative description key components impacting upon the implementation process will be described.

Results, Outcomes and Future Plans

A summary of the findings will be provided to the participants via email. Participants can indicate on the consent form whether they would like to receive a lay person summary of research outcomes via email at project completion.

The project outcomes will be disseminated via:

* Report to the Children’s Hospital Foundation
* Presentation/ report to the LCCH Cystic Fibrosis team
* Publish to peer reviewed Journal of Cystic Fibrosis
* Presentation at the 14th Australasian Cystic Fibrosis Medical Conference 2019
* Creation of implementation guide, teaching materials and resources which can be disseminated through local champions via state wide / national CF networks

Any personal information of the participants, or additional information for which the researchers have not received specific consent will not be disseminated. Once the project is completed the data will not be used for any other purpose.

Following the completion of the 12-month project, it is anticipated that the iCARE protocol will continue to be used in the clinic as standard care, if deemed acceptable to staff and consumers and sustainable within the existing resourcing of the clinic.

Risks

It is not anticipated that this research project will result in risks to participants. During focus groups/ interviews, participants may feel uncomfortable sharing their experiences or reflecting upon their experiences. This risk of psychological harm will be managed by informing participants that participation is confidential, optional and if there is a question which participants do not want to answer, their decision will be respected. It is at the participant’s discretion the information that they wish to disclose. The semi structured interview questions are aimed at evaluating the service rather than personal details of the participant or their individual circumstances. If participants experience psychological distress they will be reminded that they are able to access emotional support services including the Employee Assistance Service (for staff) and Social Work/ Acute Response Team (for consumers). For staff, critical reflection is a standard aspect of clinical practice and therefore this risk in minimal.

There will be a one-off time burden associated with participation in the interviews. Participants will be informed of the expected length of interview prior to commence and are able to withdraw consent if they wish.

Funding

Funding has been successfully secured from the Children's Hospital Foundation (Children's Health Queensland Hospital and Health Service) following successful application to the 2018 General Health Services Research Grants. Letter of Offer received 1 June 2018. Grant reference number: 50231.

Total grant amount: $77,447 + $20,000 Health Services Research Support

Appendix 1. I Change Adherence and Raise Expectations (iCARE) Protocol

1. Standardised assessment of disease and treatment related knowledge (annually)

2. Formal review of treatment skills (annually)

3. Assessment of adherence to all treatments (TAQ-CF % adherence)

4. Collaborative problem solving session

5. Written Treatment plan

Appendix 2. Project Implementation Outline

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