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# PrAISED

Promoting Activity, Independence  
and Stability in Early Dementia

The Promoting Activity, Independence and Stability in Early Dementia (PrAISED) research programme is a NIHR funded project that has been designed to help people with mild cognitive impairment or early stage dementia to remain healthier and more independent for longer. We have designed an activity and exercise programme consisting of a combination of exercises, activities of daily living and memory strategies to help improve and maintain individual physical and mental health.

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### **Consultation on the implementation of the PrAISED (exercise in dementia) intervention**

Harling MR<sup>1</sup>, Gladman JRF<sup>2</sup> and Masud T<sup>1</sup>.

Author Affiliations:

1. University of Nottingham, Division of Rehabilitation and Ageing.
2. University of Nottingham, Nottingham University Hospitals NHS Trust and CLAHRC East Midlands.

Address for Correspondence:

Dr Martyn Harling, Division of Rehabilitation and Ageing, The School of Medicine, Queen's Medical Centre, Room B109, Nottingham, NG7 2UH. Email: [m.harling@nottingham.ac.uk](mailto:m.harling@nottingham.ac.uk)



## **INTRODUCTION**

The Promoting Activity, Independence and Stability in Early Dementia (PrAISED) research programme was set up to develop and evaluate (via a randomised controlled trial, RCT) an intervention to promote increased activity - the PrAISED intervention. Involvement in activity is associated with improved function, mobility, cognition, mood and general wellbeing in older people with mild cognitive impairment or early dementia ([van der Wardt et al., 2017](#)). The PrAISED intervention consists of exercises and everyday activities which are tailored so that individuals with memory problems are able to achieve their own goals, supported by visits from health professionals in the community. A consistent approach to delivering the PrAISED intervention is supported by a range of resources, such as a PrAISED manual and training events for those involved in intervention delivery. The PrAISED intervention is delivered by trained physiotherapists, occupational therapists, and rehabilitation support workers (RSWs) on a one-to-one basis. It was designed in this manner to optimise the guidance and advice with respect to the specific needs of people with early dementia and support long term adherence.

However simply proving that an intervention has a positive effect on health and wellbeing in an RCT is not sufficient to establish that intervention as common practice: the intervention needs to be adopted by practitioners delivering care to the potential beneficiaries. This discussion paper considers how the adoption of the PrAISED intervention might be achieved.

During the process of seeking funding for the PrAISED research programme, the research team had to envisage how it expected the intervention to be adopted if effective. The team was aware that exercise interventions tend to be undertaken by individuals as part of their lifestyle. Formal settings that support this are primarily located in the leisure industry or third sector, and by and large are not delivered by health professionals except as a part of the rehabilitation process

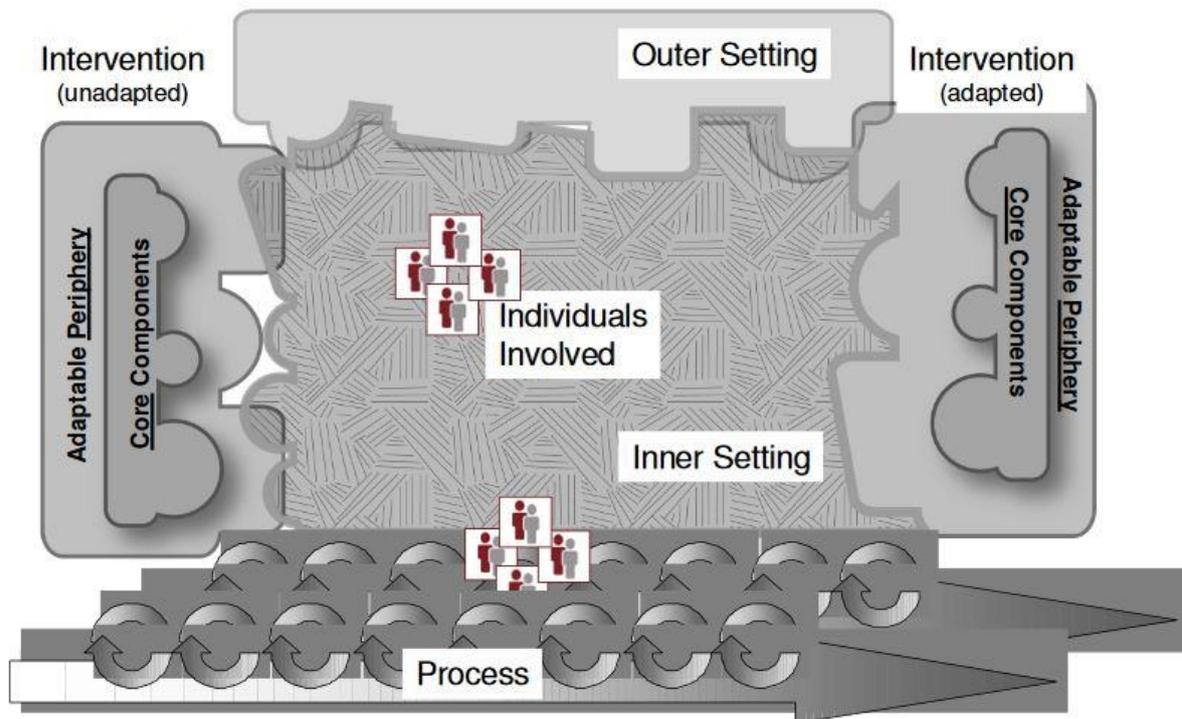
after an illness or injury. For example, exercise classes aiming to prevent older people from falling, although initially tested by health professionals in a research role, are increasingly available in leisure centres or provided by charities such as Age UK. The research team decided that it should develop and evaluate the PrAISED intervention using the control and expertise necessary to ensure that the right core components were in place, and hence developed an intervention delivered by health professionals. However, at the outset it was assumed that if the PrAISED intervention was found to be successful in the RCT, the subsequent adoption of it would inevitably need to take place in the leisure and third sectors.

## **IMPLEMENTATION SCIENCE**

Implementation science is a relatively recently emerging branch of applied health research concerned with the process of adoption of research knowledge, aiming to overcome what is known as the “know-do gap” or the “second translational gap”. These terms refer to situations such as when an intervention has been proven to be effective in trials and yet has not been adopted. Implementation research has led to the development of implementation theories that aim to provide generalisable models of how new research knowledge is translated into everyday practice. Applying the positive findings of a RCT of the PrAISED intervention is an example of the need to draw upon implementation science.

## **THE CONSOLIDATED FRAMEWORK FOR IMPLEMENTATION RESEARCH (CFIR)**

The Consolidated Framework for Implementation Research (CFIR) by [Damschroder et al. \(2009\)](#) (Figure 1) is emerging as the most commonly used example of a generalizable, implementation theory. It is based on an analysis of a large number of previously evolving theoretical notions and models.



**Figure 1** CFIR Framework (Damschroder et al., 2009) Available at: [https://static-content.springer.com/esm/art%3A10.1186%2F1748-5908-4-50/MediaObjects/13012\\_2008\\_182\\_MOESM1\\_ESM.pdf](https://static-content.springer.com/esm/art%3A10.1186%2F1748-5908-4-50/MediaObjects/13012_2008_182_MOESM1_ESM.pdf)

The CFIR posits that the implementation or adoption process has five major domains; the intervention, inner setting, outer setting, individuals involved and process. Figure 1 shows that in the CFIS model an “unadapted intervention” – which refers to an intervention as defined and demonstrated in a research study – is introduced into a specific “inner setting” – which refers to a specific clinical service – and that the process of implementation or adoption involves the adaptation of that intervention. The inner setting of the CFIR model can be subdivided into four sections: networks and communications, culture, implementation climate and readiness for implementation. The adaptation process is a function of the interactions between the unadapted intervention, the inner setting in question, the individuals involved, the processes they use and the wider economic and political context or “outer setting” in which the adoption takes place.

The core components of the unadapted intervention that are responsible for its effectiveness need to remain unchanged, but the intervention's non-essential "peripheral" components may need to be adapted in order to be acceptable to and feasible in the specific setting. Individuals within the inner setting have differing characteristics, holding a range of views and personal and professional perspectives which may need to be challenged when introducing a new intervention into the organisation in which they work. In the CFIR, "process" refers in particular to the process of change necessary to introduce new ways of working, reflecting the fact that some systems are more open to change and others are less so. The adoption process is not expected to be a single stage or linear one, it is generally achieved using multiple steps, sometimes going backwards before going forwards again, as reflected by the number and directions of the arrows in Figure 1. Specific health care services are open systems, rather than closed systems, which means that they are influenced by outside factors such as health policies, funding and legal or ethical constraints. In the CFIR these influences become part of the "outer setting".

## **DESIGN OF THE STUDY**

As a preliminary phase in the preparation for the implementation of the PrAISED intervention, we undertook a brief consultation exercise asking relevant informed people to imagine how the PrAISED intervention might be applied to the third and voluntary sectors, using the CFIR to aid the interpretation of the responses.

One-to-one discussions with key health and social care professionals, chosen if they had knowledge of the current PrAISED intervention and/or experience of working in the third or leisure sectors (the sectors where the PrAISED intervention might be delivered in the future), were undertaken. The informants were a convenience sample of individuals known to the PrAISED team or working within the PrAISED project. Seven people were interviewed in

November and December 2017: three occupational therapists; two physiotherapists; a manager of a health and social care team and a local authority commissioning manager. All of the interviews were conducted by MH (Research Fellow with responsibility for implementation and dissemination), using an interview schedule (Appendix A) developed with the relevant sections of the CFIR in mind. Interviews were electronically recorded with permission of the informants in order to gain an accurate, contemporaneous record of the interaction. Although this was not a formal research study, the information generated during the interviews was analysed using a thematic approach ([Braun & Clarke, 2006](#)), using the CFIR to guide the choice of the themes. In order to maintain the confidentiality and anonymity of the informants, direct quotes have not been used.

## **FINDINGS**

### **CFIR: Inner setting**

Informants in the consultation exercise were positive about the possibility of delivery of the PrAISED intervention by the third sector or leisure industry. A common view expressed was that NHS bureaucracy has a tendency to stifle creativity and innovation – the implication being that adoption might be more effectively carried out within these sectors than within the NHS. For example, third sector innovation might encourage greater involvement in the intervention through more effective marketing strategies rather than relying on recruitment via referral as is usual for NHS services. This would increase the population level impact of the PrAISED intervention by increasing the numbers and diversity of those involved.

However, the most obviously cited potential risk of delivering the PrAISED intervention outside the NHS was to the fidelity of the core components and hence effectiveness of the intervention. Innovation as part of the process of adaptation to specific settings and circumstances may lead to the core

components of the PrAISED intervention being diluted or corrupted. Such core components include the intensity and duration (the PrAISED intervention is over a year, yet typical courses in the third sector last for between six and eight weeks) and the nature of the intervention (the PrAISED intervention is highly individualised at the outset and then adapted to develop progression over time, something many exercise classes do not do). This risk was seen as highly likely given the external settings or contexts in which these sectors operate: the third and leisure sectors may be motivated to minimise costs and maximise income which could affect both the intensity and individualised elements of the intervention as well as to whom it is made available. Thus it was envisaged that one challenge would entail finding the correct balance between innovation, financial viability and fidelity. Accordingly, some form of quality assurance system would be required during adoption in order to ensure fidelity with the core components of the PrAISED intervention.

All informants expressed the view that any third or leisure sector organisation delivering the PrAISED intervention would not be able simply to deliver the PrAISED intervention without additional resources. Whilst it is difficult to predict exactly what resources may be required, delivering the PrAISED intervention in the third sector or leisure industry will require some basic administrative resources and exercise equipment. To maintain fidelity, it is envisaged that all those delivering the PrAISED intervention will require access to the PrAISED manual and training materials and all participants will require a file containing PrAISED documents pertaining to the physical activities, activities of daily living and motivational materials. Access to such materials is relatively simple, as the PrAISED intervention is manualised and would be available on-line. Care must be taken to permit some degree of adaptation of the intervention to local circumstances (e.g. translation to languages other than English) without losing core components of the intervention. As well as the administrative materials necessary to assure fidelity to the PrAISED intervention, participants may need to be issued with, or to purchase basic equipment related to exercise, such as

variable cuff weights and step equipment. This basic requirement for the intervention could prove difficult if resources are limited. Such issues could affect the degree to which the intervention is delivered irrespective of socio-economic status. If not adequately addressed, this could lead to increased inequality with only those able to cover the cost of the equipment themselves being able to participate in the PrAISED intervention.

In the PrAISED research programme the PrAISED intervention was primarily delivered in the participants' homes. This choice was made for many reasons, including individual preferences, to avoid the disorientation and fear of group settings experienced by many people with cognitive impairment, and to enable the one-to-one input necessary to create truly individualised intervention programmes. However, exercise programmes in the UK are increasingly delivered in communal settings. This is partly a response to the ProAct65 study which demonstrated an advantage of a group exercise programme over a home based one ([Ilfie et al., 2015](#)) for community-dwelling (non-cognitively impaired) older adults, and partly justified on economic grounds. It is likely therefore that there will be some pressure during the adoption stage for the PrAISED intervention to be delivered in centralised group settings. This could adversely affect the delivery of core components of the intervention and further emphasises the need to define the core components of the PrAISED intervention.

### **CFIR: Individuals Involved**

When considering the "individuals involved", Damschroder et al. (2009) pointed out that those involved in implementation make choices and wield power in organisations. They are influenced by individual mindsets, norms, interests and affiliations and are carriers of cultural, organisational and professional mindsets. This aspect of the CFIR is an important area for consideration when

contemplating delivery of the PrAISED intervention in an alternative setting to that used in the PrAISED research programme.

The PrAISED intervention trialled in the RCT was delivered by qualified physiotherapists, occupational therapists and rehabilitation support workers (RSWs). The RSWs work under guidance from qualified staff, reinforcing adherence to the intervention. The professionals who delivered the PrAISED intervention had many years of experience working with older adults. This study explored whether the PrAISED intervention could be delivered by volunteers or non-professionals specifically trained to deliver the intervention. In general all of the informants in the consultation exercise felt that the PrAISED intervention could be delivered by trained, but non-professionally qualified workers, albeit with some concerns about the nature and intensity of the intervention.

Since all of the professionals currently engaged in delivering the PrAISED programme during the RCT are employees of an NHS trust, governance is assured by adherence to the trust's policies and procedures. Staff with a professional qualification are also accountable to their professional bodies. Informants in the consultation exercise acknowledged that organisations outside the NHS may well have different or more limited governance arrangements, affecting issues such as risk assessment, referral mechanisms, accountability, liability and record keeping. Informants felt that with careful consideration, the problems raised by differing governance arrangements could be overcome – as has been achieved for the training of Postural Stability Instructors for strength and balance exercise classes for older people and those at risk of falls (see <https://www.laterlifetraining.co.uk/>).

The PrAISED intervention was designed to be tailored to each individual participant's goals, interests and level of ability, which was considered key to ensuring motivation to adhere to the programme. Both the physical activity and

the cognitive tasks may be adjusted in response to changes in participants' abilities, as well as the timing and amount of support provided by staff. Such an adaptive approach to the programme requires a certain degree of knowledge and experience from individuals delivering the programme. It is also labour intensive in terms of monitoring and facilitating how the programme is planned and delivered for each participant. The issues of initial training, ongoing support and supervision of staff involved in delivering the PrAISED programme were raised by all informants as crucial in ensuring the fidelity of the intervention. Concerns were raised about the responsibility and costs of training staff, especially given that staff turnover may be higher in the third sector and leisure industry than in the health service. This implies that there is a need to facilitate and maintain a suitably skilled workforce in the third and leisure sectors, which may require public health and policy initiatives (e.g. tax breaks and grants for training) as well as commitment by the third and leisure industries to the training of their workforces. Where public health and commissioning organisations are involved, they would need to examine the organisational competencies of the third sector and leisure organisations from which they commission or purchase services.

The informants were unanimous in the view that it was possible to deliver a tailored programme outside the NHS in the third or leisure sectors, but at the same time there was also a unanimous view expressed that all people in receipt of such an intervention needed to be overseen by a staff member with an overview of how the intervention was delivered. Some informants suggested that this individual could be in a position similar to that of a 'care manager', an approach used in health and social care where the patient or client is expected to be managed. Such roles are not typically used in the third and leisure sectors, where service users are viewed as either customers or simply as people who are expected to take responsibility for themselves. The views of our informants may be unduly influenced by exposure to health care systems in which a clinician usually takes on some form of case management role, but may

also reflect a recognition that people with early dementia are not simply customers with an ability to easily take responsibility for themselves. This issue needs to be carefully considered if a programme which is person-centred and tailored to the lifestyle, abilities, interests, needs and ambitions of each participant is to be retained.

## **DISCUSSION**

In this consultation exercise we found that whilst our informants raised no absolute objections to the potential application of the PrAISED intervention in the third and leisure sectors, a number of significant areas of potential concern as well as some areas of opportunity were raised. There were many reasons why the fidelity (and hence effectiveness) of the PrAISED intervention might not be maintained – related to differences between the NHS and third and leisure sector workforces, organisational and governance structures and working practices. Our informants felt strongly that, in order to be effective, the intervention needed to be highly personalised which is inevitably resource intensive as this implies interventions that are one-to-one (rather than group) and home based rather than located in a communal facility. It was however presumed that, for many reasons, the third and leisure sectors would find this difficult to operationalise. The informants also recognised that the third and leisure sectors might be more likely to carry out innovative developments of the intervention, which might improve access, market penetration and efficiency. Yet informants also recognised that, just as innovation could improve the intervention, it could also water it down, rendering it less effective.

The authors recognise that this exercise is far from an exhaustive and complete exploration of all aspects of the potential implementation of the PrAISED intervention. A particular limitation is that we did not consult potential participants or with third or leisure sector providers. Nevertheless, it provides a “thought experiment” to anticipate future implementation issues.

For example, further work is required:

- to examine what steps are needed, if any, to prepare the third and leisure sector workforces so that they can deliver the PrAISED intervention
- to develop a quality assurance process that can establish whether the fundamental elements of the PrAISED intervention are being delivered
- to examine the degree to which the governance concerns raised by our informants are justified
- to examine whether or how individualised assessment and treatment planning can be reconciled with intervention delivery in groups and in communal settings
- to examine how the elements of case management identified by our informants might be provided in third sector and leisure organisations
- to explore further how the third and leisure sectors, and potential participants in the intervention feel about implementation of this intervention beyond the trial setting

Some of the above issues will be considered by the process evaluation alongside the PrAISED RCT, but others will need to await the findings of the RCT.

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There are several hyperlinks to sources of information throughout the text of this document. Click on the links highlighted in blue or copy and paste the link into your browser to gain access to the original source.

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## **APPENDIX A – Interview Schedule**

Do you feel that the third sector or leisure industry would want to take on the PrAISED programme?

Do you think they would be capable of doing so?

Could the PrAISED programme be delivered by volunteers or non-professionals?

And if so, do you feel they would require more training?

Do you foresee any problems or issues in a third sector/leisure industry provider funding and/or supporting the 'material' resources (weights, household equipment etc...) necessary to engage in the PrAISED programme?

Do you feel that NHS Trusts and the third sectors/leisure industry differ in terms of governance and regulation?

Do you feel that it is possible to deliver the PrAISED programme as a more group based intervention?

Do you have any ideas about how delivery in the third sector or leisure industry might be funded (NHS – free as per health care? Social Care - means tested? or personal – self funded?)

Do you think alternative funding streams are likely?