The facilitators and barriers to improving functional activity and wellbeing in people with dementia: A qualitative study from the Process Evaluation of Promoting Activity, Independence and Stability in Early Dementia (PrAISED)

# Appendix 1. Interviews conducted as part of the study

First set of interviews

Participants living with dementia and caregivers

Therapists

Therapists

All therapists delivering PrAISED

All therapists delivering PrAISED

All therapists delivering PrAISED

All therapists delivering PrAISED

Participants living with dementia and caregivers

Control group

Control group

Control group

Control group

Intervention group

Intervention group

Baseline (6 months)

Intervention group

Intervention group

Follow up (12 months)

Second set of interviews

Baseline (2 months into lockdown)

Follow up (end of lockdown)

# Appendix 2. Topic guide for participants with dementia and caregivers (First set of interviews)

**Pre-interview**

* Researcher introduces himself and engages in small talk to break the ice with participants (e.g., give thanks for being invited over, gives compliments about the home, and asks how the person is doing on the day).
* Researcher explains his professional role and the purpose of the visit
* Researcher goes through the Information Sheet with the participants. The following will be clearly explained:

1. The interview will be audio-recorded to have an accurate record of what was said
2. Anything mentioned during the interview is confidential and no one except members of the PrAISED research team will know what was said
3. In using any information in a report, the participant’s anonymity will be maintained
4. Participation is totally voluntary
5. The participants can withdraw at any time and the research team can use the information collected thus far, unless the participants specifically withdraw consent for this.

* Researcher asks if participants have any concerns / questions / doubts.
* Researcher seeks informed consent
* Researcher asks participants if they are comfortable being interviewed together or they prefer being interviewed alone

**Interview**

*General questions*

1. Do you feel that being involved in the study has been beneficial?
2. If so, what are the positive results of the activities?
3. Have you experienced any negative effects of the activities?
4. Do you think the programme has enabled you to enjoy more your daily activities?
5. I would like to start by asking your views around exercise…

*Personal beliefs*

• How important do you think being active is to help people stay healthy?

• How important do you think being active is to help people stay independent?

*Motivation*

• Why did you decide to take part in the programme?

• Were you encouraged by anyone to take part or was it your own choice?

• What helps you keep going with the programme?

• On a scale from 1 to 10, how much do you feel you want to continue with the

Activities, once the programme has finished?

*Autonomy and control*

• Is it important for you to decide what you do, or do you prefer to leave it to others?

• (If yes to previous question), how much have you been able to make those decisions?

• How could we make you feel more involved?

*Intervention characteristics*

• Does the programme of physical activities suit your needs and preferences?

• What part of the programme of physical activities do you like the most?

• What part do you like the least and how could this be improved?

*Self-efficacy and emotional support*

• Do you feel you are able to do the activities as well as you would expect?

• Do you have any concerns or anxiety about taking part in the programme/doing the

activities?

• Did you receive encouragement and support from your therapist(s) and caregiver(s)?

• Is there anything that would help you feel more confident to do the activities?

*Support (Practical)*

• Do the therapists give you practical support? For example, do they show you how to

do the activities, when to do them and where to do them?

• Does your (caregiver role) give you practical support? For example, does he / she remind

you how to do the activities, when to do them and where to do them?

• What could be done to better support you?

*Independence*

• How has the study programme affected you? (e.g., on your health and activity)

• Has it given you greater independence?

• Have you noticed a change in your quality of life?

• Are there any activities you would like to be able to do that are not part of the

programme?

*Expectations*

• Have you any personal goals you would like to achieve from the study?

• If yes, what goals are you looking to gain?

• Do you think you can achieve these goals, and do you need support to do this?

**Final remarks**

* Any final thoughts and feedback on the programme?
* Would you be happy to meet up again in three months’ time to see how you are doing?

# Appendix 3. Topic guide for therapists (First set of interviews)

***Pre-interview***

My name is ………………………., I am a ………………………. working on the PrAISED trial.

This interview is for the PrAISED process evaluation; for this we are aiming to carry out interviews with participants, caregivers and therapists, to look at how the intervention works.

The session is going to be digitally audio-recorded, it is totally confidential, participation in the interview is voluntary and you can withdraw at any time. Do you give your consent to take part?

Can I ask you to introduce yourself and what your professional experience of working with people with dementia is?

Do you have any questions or concerns about the interview?

***Instructions***

* *Before asking the questions explain each heading before asking the questions i.e. ‘I would like to ask you some questions about your motivation*
* *You may have to pick a couple of questions from each section if the interview is taking a long time (this could be varied for each participant*
* *Please ask all questions in red*

***Interview***

*General questions*

1. What is your understanding of PrAISED?
2. Can you explain your experiences of the programme so far?
3. What are your views on the programme’s effectiveness?
4. I would like to start by asking around your views on physical activity *(if interviewee is physiotherapis*t), on activities of daily living *(if interviewee is Occupational Therapist or support worker)* …

*Personal Beliefs*

1. Do you feel that your views have altered since taking part in PrAISED?

*Motivation*

1. Why did you become involved in the programme?
2. What aspects of the training and delivery of PrAISED have a positive or negative impact on your motivation?
   1. Prompt re negative or positive if needed
3. Is there anything that could be done to increase/maintain your motivation to continue using the programme?

*Expectations*

1. What expectations do you have of your role within PrAISED?
   1. i.e., what were your expectations of being part of the PrAISED project?
2. Have your expectations that you had at the beginning of PrAISED been fulfilled?
3. What are your professional goals in PrAISED?
4. Did you anticipate any barriers to delivering the programme?
   * 1. Can you explain these?
5. Did you anticipate any facilitators to delivering the programme?
   1. i.e., what did you think would help you deliver the intervention?
      1. Can you explain these?
6. Did you anticipate that the intervention would improve the quality of life of the participants and their caregivers?

*Autonomy and control*

1. Did you have as much input as you would like in tailoring PrAISED for individual patients?
2. To what extent do you feel that your input as an experienced therapist is valued by patients / caregivers?

*Self-efficacy*

1. How competent in your professional role do you feel, to deliver the intervention?
2. What could be improved in the training to boost your confidence to deliver the intervention?

*Support (Practical and emotional)*

1. What support have you had to take part in the PrAISED programme
   1. How supportive is your PrAISED clinical team?
   2. How supportive are your colleagues outside of PrAISED?
2. How useful has contact with the University been?
   1. what in particular has been helpful?
3. How have you found the training you received in PrAISED (e.g., initial training and ongoing support, like the teleconferences)?
   * 1. What in particular was successful or not successful (Case studies, discussions?
4. Did you find the training met your needs in the way that you like to learn?
   * 1. Can you explain this
5. Did you feel you had enough training to effectively deliver the intervention?
6. What could be done to make you feel better supported whilst involved in PrAISED?
7. How collaborative do you feel that the person with dementia and their caregivers are in undertaking the PrAISED programme?

*Intervention characteristics*

1. How much do you feel that the intervention fits into your aspirations and professional development as a therapist?
2. Are there any aspects of the programme think work effectively or don’t work effectively?
   1. Prompt re. work effectively/don’t work effectively
3. How could the programme be improved?
4. How does your involvement in PrAISED fit into your working routine?
   1. Do you feel overburdened as a result of taking part?

*Final remarks*

1. Any final thoughts on the programme?
2. Would you be happy to meet up again in three months’ time for further feedback.

# Appendix 4. Topic guide for participants with dementia and caregivers (Second set of interviews – i.e., during the COVID-19 lockdown)

**Pre-interview**

* Researcher introduces himself and engages in small talk to break the ice with participant (e.g., give thanks for accepting to talk over the phone, asks how the person is doing on the day).
* Researcher explains his professional role and the purpose of the call
* Researcher ensures that the participants have read the Information Sheet (previously sent through mail), prior to signing the consent form. The following will be clearly explained:

1. The interview will be audio-recorded to have an accurate record of what was said
2. Anything mentioned during the interview is confidential and no one except members of the PrAISED research team will know what was said. The only circumstance where confidentiality will be breached is if during the interview, information is disclosed about a potential risk of harm for the participant. In this case, the information will be reported by the researcher to a senior clinician within the PrAISED team and an action plan discussed and implemented, as appropriate.
3. In using any information in a report, the participant’s anonymity will be maintained
4. Participation is totally voluntary
5. The participant can withdraw at any time and the research team can use the information collected thus far, unless the participant specifically withdraws consent for this.

* Researcher asks if participant has any concerns / questions / doubts.

**Interview**

Just to explain, I would like to get your opinion on the effect the recent coronavirus has had on you, but first want to ensure that you are happy to discuss this. It has been a difficult time for everyone, and I would not want to cause any extra stress. Are you comfortable talking about the impact the recent changes in PrAISED caused by the coronavirus pandemic have had on you?

(Continue if yes)

Thank you, I would like to start by asking what impact the recent changes in PrAISED due to the coronavirus pandemic have had on you…

As an introductory question, have you stayed in the house?Has this made you feel more isolated and lonelier?

*Personal beliefs*

How important do you think being active is now that you are staying at home?

Have you been thinking more about your health now than you were before coronavirus? Could you tell me more?

*Motivation*

Are you able to carry on being active while at home?

Is there anything that helps you keep going with the programme, now that you are at home?

How much do you want to continue with the activities, now that you are at home?

Is there anything else that would help you keep active whilst you are unable to go out?

*Autonomy and control*

How do you feel now that you need to stay at home and cannot do the activities you like outdoors?Do you feel less in control of your daily activities?

*Intervention characteristics*

Have you been able to follow the PrAISED programme as before?

How have you felt about receiving the therapists support by telephone (substitute with any other means used)?

What have been the positive and negative changes with this new approach?

Do you think the PrAISED programme is as effectively delivered without face-to-face interaction? If yes, have you any thoughts on what characteristics would make it work better for you?

*Self-efficacy*

Do you feel you are still able to do the exercises and activities now that you therapists cannot visit you in person, due to the Coronavirus pandemic?

Have you still receivedencouragement and support from your therapist(s) and caregiver(s)?

Is there anything that would help you feel more confident to do the activities?

*Social opportunity and emotional support*

How did it feel when your therapist could no longer visit you?

How has staying at home changed your social life? Are you able to talk to other people outside your home?

Have you found other ways to socialise with others (phone, computer)?

Is there anything that would have helped you feel more emotionally supported?

*Support (Practical)*

Do the phone sessions (substitute with any other means used) that you receive from therapists help you understand how to do the activities, when to do them and where to do them?

Have you experienced any problems trying to do the exercises without the therapists being with you?

Have you been more worried about falls without face-to-face support from the therapists?

Does your (caregiver role) give you practical support? For example, does he / she remind you how to do the activities, when to do them and where to do them?

Does your (caregiver role) give you more support, now that the therapists are not visiting?

What could be done to better support you to do the exercises?

*Independence*

How has staying at home affected your independence? (e.g., on your health and activity)

Do you feel more dependent on others?

Have you noticed a change in your quality of life?

Are there any activities you would like to do that you cannot do at home?

*Expectations*

Have your personal goals changed as a result of staying at home due to the coronavirus?

If yes, what goals are you looking to gain now?

Do you think PrAISED is supporting you to achieve them?

**Final remarks**

Any final thoughts and feedback on the programme?

# Appendix 5. Topic guide for therapists (Second set of interviews – i.e., during the COVID-19 lockdown)

***Pre-interview***

My name is ………………………., I am a ………………………. working on the PrAISED trial.

This interview is for the PrAISED process evaluation; for this we are aiming to carry out interviews with participants, caregivers and therapists, to look at how the intervention works.

The session is going to be digitally audio-recorded, it is totally confidential, participation in the interview is voluntary and you can withdraw at any time. Do you give your consent to take part?

Can I ask you to introduce yourself and what your professional experience of working with people with dementia is?

Do you have any questions or concerns about the interview?

***Instructions***

* *Before asking the questions explain each heading before asking the questions i.e. ‘I would like to ask you some questions about your motivation*
* *You may have to pick a couple of questions from each section if the interview is taking a long time (this could be varied for each participant*
* *Please ask all questions in red*

***Interview***

To begin with, what is your overall view around the impact of the change from face-to-face support to remote support in PrAISED?

What do you feel the main barriers to the remote support have been, for you as a therapist and for participants?

Have you been able to apply the PrAISED principles remotely? How has your clinical practice changed?

Have you been able to use any video support, or did you only work on the phone? How did you find this shift?

How do you feel that the participants have responded to the shift from face-to-face to remote support?

How do you feel in relation to the support that you have been given by your team and the PrAISED team?

How do you feel that participants and caregivers have responded in terms of motivation to keep engaged in the process during lockdown?

How do you feel in a relation to video support? Is it something implementable, is it something that is out of the question with this population?

Do you feel that overall, in this lockdown situation the caregivers have become given more central in supporting the participants (and therapists) to engage with PrAISED? How has the relationship and dynamic between participant, caregiver and therapist changed as a result of remote delivery?

Looking back at these last 3 months, do you think there has been any value in doing this? Have there been any unexpected positive in this new way of delivering PrAISED?

What is your view now on PrAISED, what are your expectations? Have they changed? What has PrAISED become for you now?

What can we learn from the experience of the lockdown for future implementation of interventions? Do you have any new insight that might be helpful for the future?

**Final remarks**

Any final thoughts and feedback on the programme?

# Appendix 6. Case-studies

**Case study 1. Interaction of factors generating a negative experience of PrAISED**

Participant 1001 is a man in his early 80s; caregiver 1001 his wife in her 60s. The participant and the caregiver had very different views on PrAISED and the participant only participated in the programme through the caregiver’s insistence. While the participant was compliant throughout the programme, he only engaged passively without a commitment to achieving goals. Although the participant recognised that his physical health had deteriorated over time, he seemed quite contented with where he was and with his sedentary activities, including reading newspaper and doing sudoku. The caregiver was of the opposite view and showed frustration at the participant’s attitude. The caregiver also felt that the participant’s deterioration was the cause of her staying at home most of the time and becoming socially isolated. She was much younger than the participant and she contended that she aspired to have a more active life outside the house. The caregiver appeared depressed and unable to create a constructive communication with the participant. She reported constantly trying to encourage the participant to engage with PrAISED and/or to do physical activity (e.g., walking together), but to no avail. As well as contending that he was satisfied with his life, the participant reported a lack of motivation to engage in exercises that were seen as too simple, repetitive, and boring. Further, engagement was hampered by a sense of defeat, due to the constant comparison with his former self (he had been a PE teacher and professional swimmer) and the awareness that he would never be able to match his previous physical fitness. He was therefore reluctant to do his swimming sessions out of the inevitable disappointment in himself. This led to no achievement of benefits from PrAISED, bar the social opportunities presented by therapy visits, which inevitably finished at the end of the 12-month programme.

**Case study 2.** **Interaction of factors generating a positive experience of PrAISED**

Participant 7 is a man, Caregiver 7 is his wife, both in their late 70s. In the first interview, the participant and caregiver reported that the participant was resistant to accept the inevitable changes that ageing, and dementia entailed. The participant had been a very active cyclist in the past and was struggling to accept his deteriorating physical health. In the interview, the word dementia was only rarely used, and the participant kept hinting at the fact that the changes he was experiencing were typical of ageing. The caregiver downplayed the symptoms of dementia in an evident attempt to safeguard the person’s emotional health and self-esteem. The participant reported feeling depressed. He had experienced several falls and had lost confidence in himself. At the time of the first interview, the participant wished to be able to walk independently again to his local bowls club, which was the centre of his social life. To achieve this, he appeared very committed to the programme and had the full support of his wife and his family. The caregiver, however, appeared also extremely anxious about his husband’s risk of falling, which made her risk averse. At the time of the interview, the couple were still re-negotiating social / domestic roles (what to do, what is dangerous). In the second interview, both participant and caregiver reported experiencing great progress. Through full engagement with the programme, no more falls had occurred. The participant had been able to get fitter and regain his balance and confidence. There had been a boost in his quality of life, because he had been able to accomplish his goal (walking to the bowls club and spending time with his friends). He confirmed he felt emotionally better and accepting the changes of dementia, though he was still struggling to fully come to terms with the condition. The caregiver appeared less anxious and more positive about the effects of PrAISED as well. Both participant and caregiver were positive that the participant would continue to exercise after the end of PrAISED.

**Case studies 3 and 4. Same factor (rapport with therapist) being a facilitator in one participant and a barrier in another**

For participant P11, the good rapport developed over time with the RSW proved a key ingredient in ensuring uptake of the exercise programme and the benefits associated with it. P11 had a history of being a very independent woman, who had been active and into sports throughout her life. She had a strong support system in place through her husband’s commitment to keep her active. This was further compounded by access to private personal training who boosted her opportunities to keep moving. In the presence of all these facilitators, good rapport with and support from the RSW functioned as a further enabler of the participant’s independence. P18 on the contrary reported having no friends and that he had minimal social contact. He lived with his wife in a rural area, far from opportunities to exercise in the community. Country roads were not conducive to independent walks as the associated risks were aplenty. In this case, the RSW came to be seen as a unique (and the sole) opportunity for exercise, sociality, and a change in routine. P18 developed feelings of attachment and dependency to the RSW and close to termination of support feelings of anxiety had developed. The participant stated that he would “deteriorate if he (the RSW) isn’t looking after me” and that without him he “couldn’t cope”. This resulted in the participant being pessimistic about the future and whether he would be able to continue his exercise routine.