CAREGIVERSPRO MMD

UNIVERSITY OF Hull

PO2.17b CAREGIVERSPRO-MMD: An online platform to support people living with dementia and their carers – UK pilot update

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Background

There is a significant gap in dementia support post diagnosis; such support is not consistently available across the UK (Mountain & Craig, 2012). With financial pressures on the NHS (Department of Health, 2016), as well as an aging population (Office for National Statistics, 2017) and increasing numbers of people living with dementia (Prince et al., 2014), there is a need to explore cost-effective technologies to help address this gap.

CAREGIVERSPRO-MMD (CGPRO) is a social networking and information sharing platform, designed for dyads consisting of People with Dementia (PwD)/Mild Cognitive Impairment (MCI) and their informal caregivers (CG). It is an online, self-help community, where users can:

- Befriend and interact with one another
- Access information and advice
- Keep an online journal
- Set appointment reminders
- Play cognitive stimulation games

The platform is monitored and updated daily by researchers; users are supported by individual and group training sessions. Four European sites are participating in the project: UK, France, Italy and Spain. Here, we provide a progress report on the UK site's experiences and findings to date.
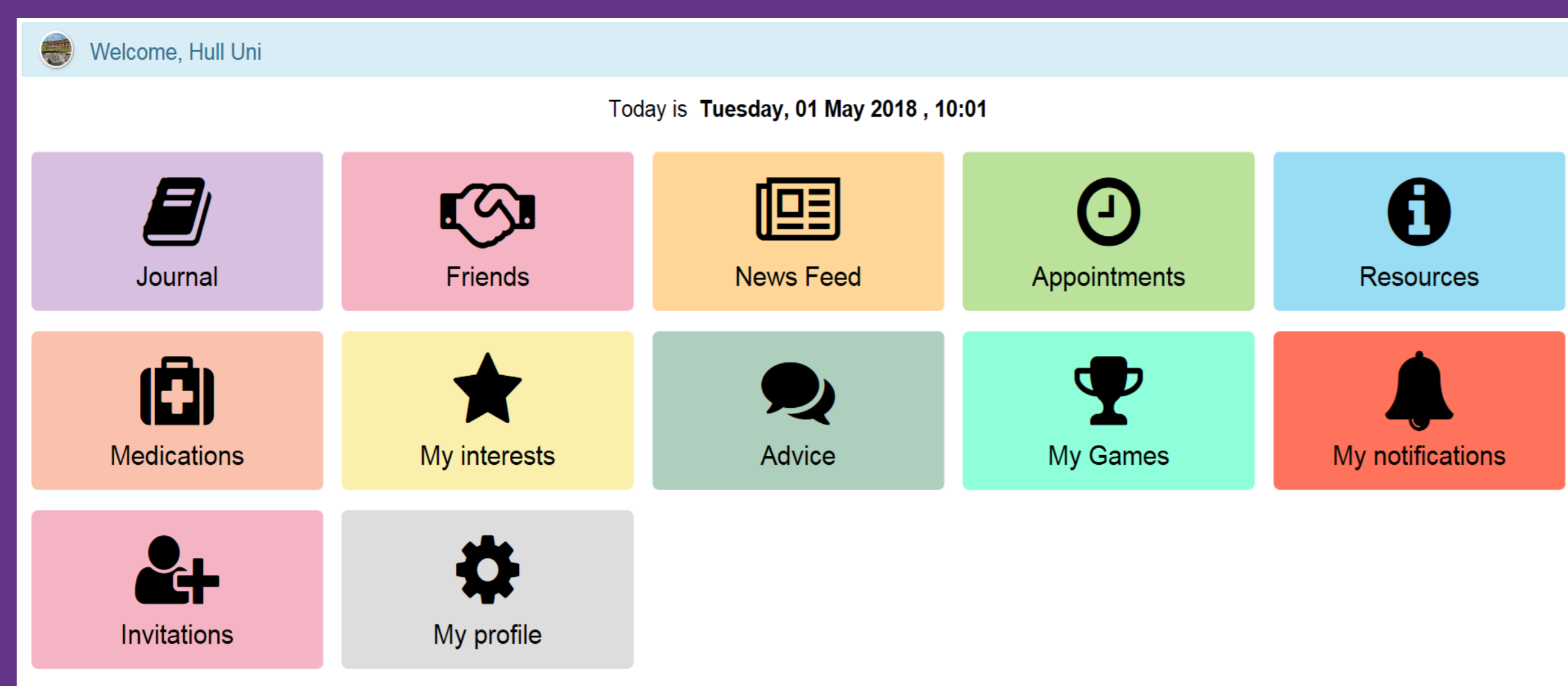
Aims

The primary aims of the study are to determine whether use of the CGPRO platform:
- **Improves quality of life for PwD/MCI**
- **Reduces stress and worry for caregivers**

Other areas of investigation include measurements of depression, anxiety, activities of daily living, perceived social support, adjustment, medication adherence and resource utilisation.

Method

Design

This research is a randomised controlled trial. Measurements are recorded at baseline (0), 6, and 12 months by blinded researchers. Two groups will be compared: dyads using the platform (the intervention group) and a control group consisting of dyads which do not have access to the platform.

Participants

100 dyads were recruited and randomly allocated to a control (n=49) or intervention (n=51) group. To date, there has been a 25% drop-out rate. Average age overall (excluding withdrawals): M = 67.79 (SD = 12.60). 61.3% had a diagnosis of dementia.

Procedure

The intervention group are provided with access to the platform via a tablet device and receive training in how to use this. All interactions with the platform are logged so that individual use of parts of the platform can be compared to outcome measures. Qualitative data is also being collected via analysis of platform content, focus groups and structured interviews to explore user experiences.

Lessons so far from the CGPRO Pilot:

Platform usage:
- Users' previous experience with ICT varies across the group and does not appear to impact the level at which a user engages with the platform.
- Between 13/02/18 and 31/07/18, PwD/MCI logged a total of 2870 visits to the CGPRO platform, while CGs logged a total of 4540 visits (excluding training activities).
- Between 09/03/18 – 13/09/18, there were:
- 430 total posts/messages created by participants on the News Feed. (311 CG, 119 PwD/MCI)
- 94 were private messages (76 of which created by CGs, 18 from PwD/MCI)
- 330 were posts shared with friends (231 CG, 99 PwD/MCI)
- 638 comments on News Feed posts (448 CGs, 190 PwD/MCI)

Feedback from focus groups and interviews:
- Participants value access to an online peer support group; however do not feel confident making online friends they have not first met in person.
- Participants appear to value receiving information on and discussing a range of issues, that are not solely focused on dementia and caring; this includes sharing information and ideas from everyday life.
- Online games are popular and appear to have increased engagement with the platform for some users.
- Individual and group training have been essential in promoting learning and engagement, social networking and use of the platform.

Conclusions

The above findings suggest that online support for PwD/MCI and their CG's should not concentrate solely on a problem focus but also enable people to share and celebrate positive experiences. In addition, any technology intervention offered to PwD/MCI and their CG's cannot survive as a stand-alone intervention. The delivery of ongoing training and support for users is an important consideration in the future deployment of ICT solutions for PwD/MCI and their caregivers.

References
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