# An online supported self-management toolkit for relatives of people with psychosis or bipolar experiences: the IMPART multiple case study

Fiona Lobban,[1*] Duncan Appelbe,[2] Victoria Appleton,[1]
Golnar Aref-Adib,[3] Johanna Barraclough,[1]
Julie Billsborough,[4] Naomi R Fisher,[1†] Sheena Foster,[4]
Bethany Gill,[1] David Glentworth,[5] Chris Harrop,[5]
Sonia Johnson,[3] Steven H Jones,[1] Tibor Z Kovacs,[5]
Elizabeth Lewis,[1] Barbara Mezes,[1] Charlotte Morton,[3]
Elizabeth Murray,[6] Puffin O'Hanlon,[3] Vanessa Pinfold,[4]
Jo Rycroft-Malone,[7] Ronald Siddle,[5] Jo Smith,[8]
Chris J Sutton,[9] Pietro Viglienghi,[5] Andrew Walker[1]
and Catherine Wintermeyer[1]

[1]Division of Health Research, Lancaster University, Lancaster, UK
[2]Clinical Trials Research Centre, University of Liverpool, Liverpool, UK
[3]Division of Psychiatry, University College London, London, UK
[4]McPin Foundation, London, UK
[5]Participating NHS trust, UK
[6]Research Department of Primary Care and Population Health, University College London, London, UK
[7]School of Health Sciences, Bangor University, Bangor, UK
[8]School of Allied Health and Community, University of Worcester, Worcester, UK
[9]Division of Population Health, Health Services Research & Primary Care, University of Manchester, Manchester, UK

*Corresponding author f.lobban@lancaster.ac.uk
†In memoriam

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**Disclaimer:** This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

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# Scientific summary

## The IMPART multiple case study

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# Scientific summary

## Background

Digital health interventions are increasingly being developed to support delivery of health care. Digital health interventions are particularly suited to providing education and support to people with long-term health conditions and their relatives. However, despite substantial investment in development, successful implementation of digital health interventions into routine clinical practice is rare. We need to understand how to overcome barriers to implementation.

The Relatives' Education And Coping Toolkit (REACT) was a supported self-management toolkit, offering evidence-based information and support for relatives of people with psychosis or bipolar disorder. REACT consisted of 12 comprehensive psychoeducation modules, a resource directory and an interactive forum and direct messaging service facilitated by 'REACT supporters' (clinical team members). This study investigated implementation of REACT within early intervention for psychosis teams in NHS mental health trusts in England. The overall aim was to identify critical factors affecting uptake and use of REACT to inform an implementation plan. A parallel study tested the clinical effectiveness and cost-effectiveness of REACT.

## Objectives

- Measure uptake and use of REACT by NHS early intervention for psychosis teams and relatives.
- Identify critical factors affecting REACT implementation.
- Identify resources required (and cost implications) for successful implementation of REACT in early intervention for psychosis teams.
- Investigate the impact of REACT delivered by early intervention for psychosis teams on self-reported relatives' outcomes.
- Develop a REACT implementation plan and related resources to facilitate widespread use and dissemination.
- Use findings from this study to inform theories of implementation of digital interventions in real-world practice.

## Methods

This was a theory-driven multiple-case study design using a mixed-methods approach, integrating quantitative assessments of outcome (delivery, use and impact of REACT) and qualitative assessments of mechanisms of implementation through observation, document analysis and in-depth interviews. Our cases were six NHS trusts in England. We used normalisation process theory to understand work undertaken by staff to facilitate implementation, and the non-adoption, abandonment, scale-up, spread and sustainability framework to integrate this with key factors affecting relatives' engagement with REACT and barriers to implementation in the wider context.

In phase 1, we developed a provisional implementation theory by identifying factors we hypothesised would influence successful implementation of REACT. Our study theory was informed by normalisation process theory; specific hypotheses were further refined by a systematic review of relevant literature, qualitative analysis of data from an earlier feasibility study for REACT and stakeholder workshops of staff and relatives at each participating trust.

In phase 2, we tested our hypotheses. We developed and iterated an implementation plan that was intended to target implementation barriers, and made this available in successively more developed forms across three waves. All six participating NHS trusts were given implementation plan version 1 at the start of phase 2. In wave 1, we conducted detailed case studies in two trusts. Significant barriers were identified and shared with stakeholders in the two trusts in wave 2 to collaboratively design implementation plan version 2 in these trusts. Further data were collected to test the impact of implementation plan version 2 and identify remaining barriers. Implementation plan version 3 was developed and delivered in the wave 3 trusts.

In phase 3, we synthesised data across all trusts and developed a national implementation plan for REACT (implementation plan version 4). We used local 'data analysis days' to engage staff in analysing trust-level data; key staff involved in REACT roles across all trusts in integrating findings across trusts; and the whole project team, including carer researchers, as participants in a final 2-day 'explanatory framework event' during which we produced implementation plan version 4.

## Results

Over the data collection period (18 months), across all six trusts, 281 staff accounts were created, 355 relative invitations were sent, 310 individual relatives were invited (excluding repeat invitations) and 159 relatives registered for an account. Registered relatives were predominantly white, educated females aged > 50 years. The mean number of logins for the whole group was 3.78 (standard deviation 4.43), but there was wide variation, ranging from 0 to 31 logins (median 2 logins, interquartile range 1–8 logins).

The mean total time spent on the website was 40.6 minutes (standard deviation 54.54 minutes), with a range of 0–298 minutes (median 20.1 minutes, interquartile range 4.9–57.5 minutes). These levels of engagement compare relatively favourably with other online interventions, which often show very low engagement.

Key influences on implementation were identified.

Staff working in early intervention for psychosis teams were under great pressure, with heavy caseloads and multiple competing priorities. In some trusts, this was aggravated by high levels of staff absence and rapid staff turnover. Staff found it difficult to prioritise the support of carers when struggling to meet service user needs. Staff and relatives agreed that REACT could offer an appropriate way to increase access to information and support for carers, but only if delivered as part of a comprehensive care package, including face-to-face support. Staff who used REACT felt that it facilitated communication with relatives and saw it as a valuable resource for staff and relatives and an appropriate way to meet national and local clinical targets. However, they did not feel that REACT had saved time in supporting relatives, and had perhaps even led to an increase in contact.

Relatives were generally very positive about the content of REACT. They valued the comprehensiveness of the modules and hearing the experiences of other relatives and service users through the videos. However, many relatives reported technical issues with accessing the toolkit, and were disappointed by the low level of activity on the forums, which made them reluctant to post messages. As staff became aware of relatives not logging into REACT or lack of activity on the forum, they became less motivated to refer more relatives, creating a vicious cycle working against sustained use.

Staff also reported practical difficulties when using REACT, and technical failures, which made them frustrated. REACT did not fit with their current ways of working, which were primarily paper based and community located. This incompatibility was exacerbated by a lack of up-to-date mobile technology to facilitate sharing REACT with relatives in their homes. Staff felt that they needed more support and training to use digital health interventions and had specific fears about being trolled online and risk management. Fundamentally, they saw human relationships as the main agent of change in mental health services, and felt that digital health interventions potentially threatened this.

A key barrier to staff engagement was that REACT was offered in the context of the IMPlementation of A Relatives' Toolkit (IMPART) research study and, consequently, staff saw the responsibility to drive it forward as belonging to the research team rather than clinicians. They also recognised that REACT's availability might be limited to the period of the research study; the lack of longer-term funding made them question the value of changing their current working patterns to accommodate REACT.

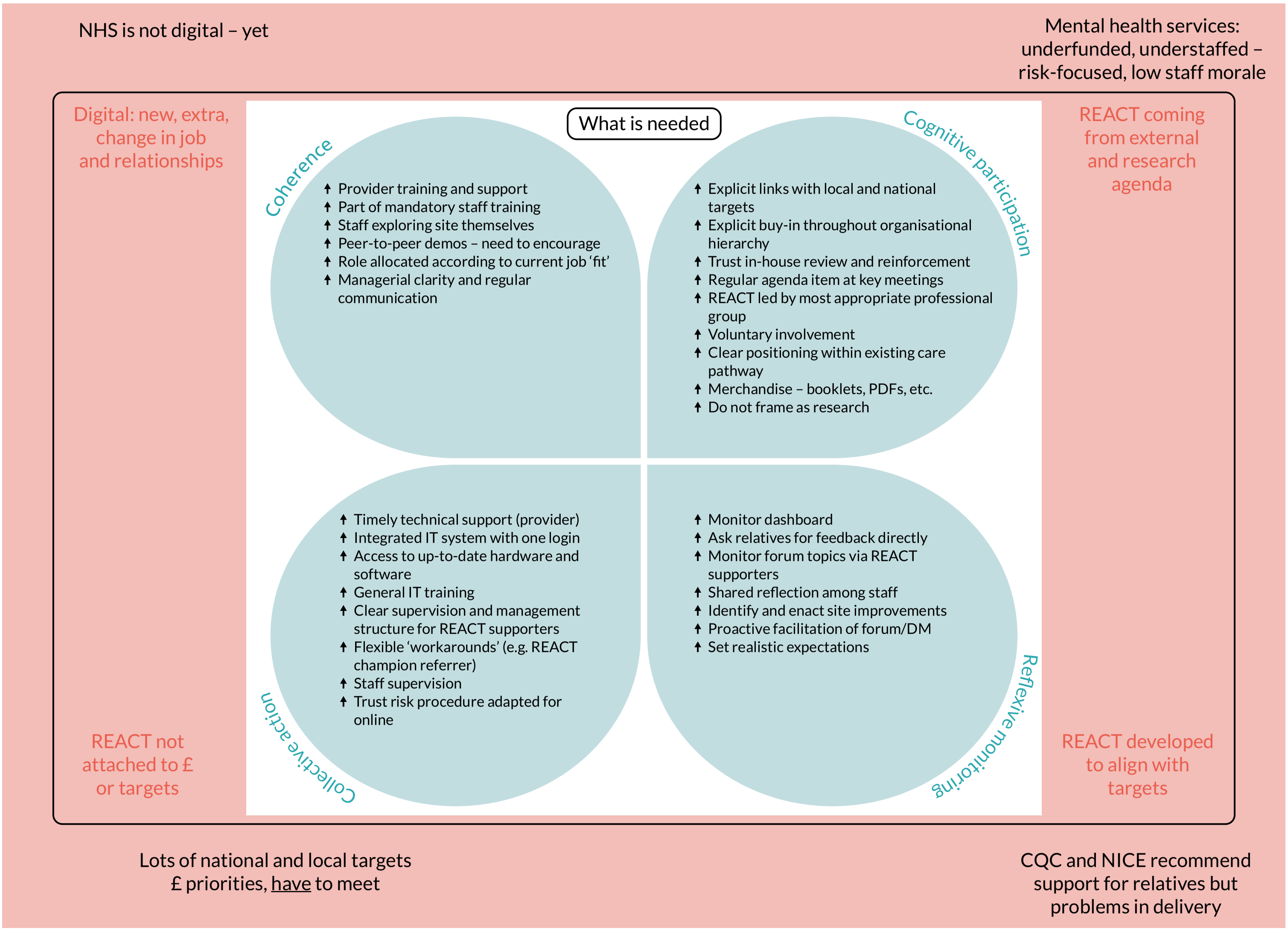
Relatives reported high scores on the General Health Questionnaire-28 at baseline, with approximately 60% scoring above a threshold for clinically significant distress. These levels of distress were consistent with those previously reported for relatives in early intervention for psychosis services. From baseline to the 12- and 24-week follow-ups, there was a pattern of declining mean scores for distress, social dysfunction, depression, anxiety and insomnia, and increases in carer well-being and eHealth literacy. However, none of these changes were statistically significant. The changes were small, and only a small proportion of relatives chose to complete the online measures at each of the baseline ($n = 56$, 35%), 12-week ($n = 21$, 13%) and 24-week ($n = 20$, 13%) follow-ups.

Each iteration of the implementation plan was designed to enhance uptake and use. Implementation plan version 1 consisted of an online 'how-to' manual with detailed instructions about roles and responsibilities for key staff involved in implementing REACT; face-to-face training sessions at each trust; and the appointment of an IMPART lead to oversee the setting up of REACT in each trust. Guidance to relatives about using REACT was embedded within the toolkit.

Implementation plan version 2 focused on making REACT more visible and user friendly to staff. It added REACT promotional booklets, business cards and branded merchandise; e-mail nudges for staff and relatives; an easier-to-remember Uniform Resource Locator (URL); a trust protocol for integrating REACT into existing care pathways and allocating key REACT roles; and a more user-friendly dashboard so staff could easily monitor invitations to relatives.

Implementation plan version 3 further improved each of the elements in implementation plan version 2 and added a 'request access' button for relatives to invite themselves to REACT; staff induction packs for new staff members; a new 'REACT champion' role; an updated online manual that included 'how-to' videos; a regular e-mail update to keep staff informed about relatives' activity on REACT; and printable Portable Document Format (PDF) 'tasters' of the module content to share with relatives during home visits.

There was some evidence that each version of the implementation plan led to more invitations to use REACT, although the relationship was far from straightforward, with wide variation between trusts. However, early intervention for psychosis teams struggled to allocate time and supervision for REACT supporter roles. Relatives were keen to use the online forum, but low levels of activity within each trust meant that this failed to gain sufficient momentum to establish a peer community. Therefore, implementation plan version 4 proposed fundamental changes in the way in which REACT is offered. Rather than each NHS trust hosting a separate REACT forum, restricted to relatives in that trust, REACT could be available from one centrally located and funded source, supported by dedicated, trained REACT supporters, and open to all relatives from trusts that adopt REACT. This would overcome the challenges experienced by staff in this study in dedicating time to the REACT supporter role and accessing supervision. It would also create a much larger population of relatives accessing REACT, generating a critical mass to stimulate an active forum. *Figure a* illustrates ways that REACT could be enhanced.



Coherence

- Provider training and support
- Part of mandatory staff training
- Staff exploring site themselves
- Peer-to-peer demos – need to encourage
- Role allocated according to current job ‘fit’
- Managerial clarity and regular communication

Cognitive participation

- Explicit links with local and national targets
- Explicit buy-in throughout organisational hierarchy
- Trust in-house review and reinforcement
- Regular agenda item at key meetings
- REACT led by most appropriate professional group
- Voluntary involvement
- Clear positioning within existing care pathway
- Merchandise – booklets, PDFs, etc.
- Do not frame as research

Collective action

- Timely technical support (provider)
- Integrated IT system with one login
- Access to up-to-date hardware and software
- General IT training
- Clear supervision and management structure for REACT supporters
- Flexible ‘workarounds’ (e.g. REACT champion referrer)
- Staff supervision
- Trust risk procedure adapted for online

Reflexive monitoring

- Monitor dashboard
- Ask relatives for feedback directly
- Monitor forum topics via REACT supporters
- Shared reflection among staff
- Identify and enact site improvements
- Proactive facilitation of forum/DM
- Set realistic expectations

FIGURE a Ways to enhance implementation of REACT. CQC, Care Quality Commission; DM, direct messaging; IT, information technology; NICE, National Institute for Health and Care Excellence.

The costs of implementing REACT using implementation plan version 4 would be multifaceted. During the set-up phase, clinical staff, those with responsibility for organisational strategy, transformational change and information technology, and relatives would need to be involved in a joint review of the pros and cons of using REACT in their service. Policies (including risk management) would need to be adapted to accommodate the online nature of REACT. Key roles would need to be allocated, and pathways designed, specifying who would offer REACT, when, how and with what support. A mechanism would need to be established to review progress and update REACT and the implementation plan at regular intervals. The primary cost for this set-up phase would be staff time and a license fee to support the delivery costs of the REACT technology. Ongoing costs would primarily be staff time. The REACT champion would need time to promote REACT (facilitated by branded merchandise), attend training and support other staff to use REACT as required. Staff who had been identified to refer relatives to REACT would need time for training in how to use REACT and to get to know the website. Although there are no costs for software to use REACT, staff would need up-to-date mobile technology that allowed them to show the digital health intervention to relatives in their own homes.

This study suggests that adopting REACT would not necessarily reduce the amount of staff time dedicated to supporting carers, and might increase engagement with relatives. However, time currently spent supporting relatives is lower than needed to meet national clinical targets and deliver National Institute for Health and Care Excellence-recommended care. In the longer term, more support might have a positive impact on carer and service user outcomes (and save money), but this needs further testing.

## Conclusions

### *Implications for health care*

- Staff working in early intervention for psychosis teams need to be supported to work with relatives. This includes manageable caseloads, accurate recording of work done with relatives and clear recognition of the value of this in relation to service targets.
- Digital health interventions, such as REACT, should be developed, evaluated and implemented as part of technology-enabled services, rather than as stand-alone interventions. This should be driven by service demand, determined through organisational infrastructures that support meaningful involvement of service users and carers as well as of staff. This would require a long-term funding commitment to cycles of review and adaptation, rather than short-term cycles of failure and abandonment.
- Digital health interventions that aim to create supportive communities akin to the REACT group (forum) may be better implemented nationally, rather than locally by individual NHS trusts. If the digital health intervention includes a peer forum, then centralisation ensures a sufficiently large population to generate critical numbers of users to establish an active community. National implementation is likely to be more efficient in terms of training staff to moderate the forum and support the intervention.
- Clinical staff need reliable access to up-to-date mobile hardware and secure software. They need to work with integrated systems that require a single login, and training and support to develop their information technology skills and confidence. Risk policies need to be adapted for services delivered online and individual levels of responsibility need to be made clear.

### *Recommendations for future research*

- Where a clear need has been identified for development of a digital health intervention within a health-care setting, funding should be allocated for the iterative development, testing and long-term delivery of the technology in clinical practice. Time-limited research without a clear pathway into clinical services in unlikely to be a good use of public money.
- New methodologies are needed to support in situ design, testing and implementation of digital health interventions as part of integrated health-care services. These methodologies need to be agile enough to allow technologies to evolve as needed, while also being rigorous enough to ensure that health care remains evidence based.
- Digital health interventions are often promoted as a means to increase and widen access to health care, and as cost-effective to deliver. However, there are currently insufficient data to support either assertion. There was no evidence that REACT led to more relatives accessing education and support, or that relatives engaging with it differed on any key demographics from those who were traditionally offered face-to-face support. The substantial costs of developing and delivering REACT, the need for it to be constantly updated and adapted to accommodate changing needs, and the needs of staff for training and support suggest that costs of digital health interventions may be greater than originally anticipated. More health economic analyses of digital health interventions in mental health are needed.

## Trial registration

This trial is registered as ISRCTN16267685.

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