

1. Overview

This manual seeks to provide information on the selection, support and supervision of REACT supporters. The REACT trial employed four part time REACT supporters (equivalent to 1.2 WTE) to support the site including responding to direct messages, stimulating and moderating forum activity, contributing blogs to the site and ensuring site resource directory information was up to date. All the supporters were relatives or friends of someone with severe mental health problems. All therefore had personal lived experience, although of very different types. Experiences of prior work roles was varied, although all supporters were educated to degree level. Principles on which training and supervision are based are informed by best practice for clinical professionals (CQC, 2013) adapted to accommodate the differing needs and background of supporters.

2. Rationale for Relatives

REACT is designed to offer relatives information and support to help them cope with the challenges associated with caring for a relative with bipolar disorder or psychosis. Some of those challenges are linked to the individual they are caring for and others are linked to frustrations with limitations of social and health systems in providing access to formal clinical, financial and social support. It is crucial to have Relatives supporting the REACT intervention so that they have personal experience of the issues raised by people using the site and can readily able to empathise with these drawing upon their own lived experiences in a sensitive and appropriate manner. This support also has more credibility with other carers, as supporters can convey a sense of having experienced similar situations. Professional staff are another potential option but will typically lack this experience and are usually constrained by the requirements of their professional role and employer policies. In contrast, carer supporters are likely to feel more free to engage with criticism of service provision from relatives and discuss additional options that relatives might chose to explore, without feeling required to defend the service in question.

3. Number of supporters

As indicated above, 1.2 WTE supporters were employed in the REACT trial to support the activities of up to 400 trial participants. In practice, this ratio worked well as many of those in the treatment arm either did not post or did so early in their engagement with the site, but then less so or post infrequently throughout. However it would be worthwhile for future implementation of the intervention in practice to explore additional support for carer linked absence requirements, illness and annual leave.

A relatively small proportion of those recruited engaged very actively with the site throughout. This pattern is consistent with ratios of active to passive forum site use in non-

mental health settings and increasing awareness that less active forum members can still obtain important knowledge and benefit from their modes of site engagement (Cranefield et al., 2015).

New REACT supporters may be somewhat anxious about how best to deal with relatives' concerns. This can be mitigated by access to individual and group supervision giving space to discuss and normalise these concerns. It is also important that supporters are given adequate time to draft and review (with support from peers and clinical supervisor) before posting initial responses. Over time and with support, confidence in drafting responses in this unfamiliar format will increase and be more quickly undertaken. Supporters built up a bank of knowledge informed by previous posts created across the team, that they were able to draw upon as the trial progressed to inform responses to new posts. Based on the REACT trial the minimum resource for REACT is 1.2 WTE REACT supporters with two additional bank REACT supporters providing ad hoc cover when necessary. This allows some time with supporter overlap for supervision, communication and training as well as some flexibility when supporters want to plan leave or when there were periods of sickness absence and other commitments (including sudden needs to attend to urgent caring duties of their own). However, it is worth noting that the flexibility this level of resource provides is limited and for long term implementation higher levels of resourcing could helpfully be considered.

4. Training of Supporters

The primary focus of the REACT supporter training is on enabling supporters to be familiar with the REACT toolkit content and functions and become confident in providing timely forum posts and personal message responses to relatives as well as logging any risk issues.

- a. *Peer to peer training.* REACT supporters can be encouraged to set up regular peer support sessions from the beginning of their contracts. This should include briefing and support on the nature of peer to peer support including review of this process in wider supervision. This is intended to be a supportive environment in which to share information and learning, to share and allay concerns and to develop ideas for enhancing site activity.
- b. *Technical training.* REACT supporters obviously need to be very familiar with the REACT site. This means understanding REACT module content, what is in the REACT resource directory and how to access automated emails informing them that someone has posted or contributed to the forum. REACT supporters therefore need to review the site in detail as part of their induction period. This includes sessions with their clinical supervisor, line manager, and the IT/digital support. Bank supporters should be offered the same level of training here as other REACT supporters.
- c. *Clinical training.* REACT supporters bring their personal experience of caring to their job. This is an asset because the supporters will typically be highly motivated to offer other relatives help and support and will have important lived experience that they can draw on to inform this. However, it is crucial that REACT supporters fully understand the nature of their role. This is to provide empathic emotional support and to guide relatives to the best

use of the toolkit and associated resources to deal with their concerns. Clinical supervision helps train the supporters in this role. Relevant issues include:

i. Risk of doing too much Understandably, REACT supporters care deeply about the concerns raised by relatives on the site. However, this needs to be tempered by the nature of the support required in this role. Getting too deeply involved with individual relatives risks having insufficient time and energy to provide support to the wider group of carers using the site. Supervision can help here in providing time and space to reflect on priorities and to review patterns of engagement with particular carers and the extent to which these seem helpful or not.

ii. Sending messages that might be seen as advice

Whilst REACT supporters are chosen to have significant personal experience to bring to bear, they are not qualified clinical professionals. As such, their role is to provide empathic support and to facilitate site use, not to directly advise carers on what they should do. The importance of this is further underscored by the contact between supporters and carers being restricted to forum and direct message. This means that supporters will often not have a complete picture of the situation under discussion or the perspective of other people involved (beyond that of the individual carer). Hence, responses are focused on responding empathically to the concerns raised by carers and indicating potentially helpful aspects of the site in relation to this. Sometimes relatives are seeking information not covered in the site and supporters may investigate these questions along with their supervisors to provide a response. This additional information can also then be used to update the REACT resources directory and/or to inform blogs to be shared with the wider group of relatives.

iii. Differentiating befriending or therapy from the REACT role.

REACT supporters draw on their own caring experiences to do their job. This is particularly relevant to empathising with carers using the site. Whilst this is a strength of the role, there may be situations when the situations described by a particular carer resonate so strongly with the supporter that this can present a challenge in relation to their support role. If REACT supporters find themselves identifying too strongly with a particular carer this is an important topic for clinical supervision. By providing time and support to reflect on this supporters can be helped to avoid going beyond the boundaries of their role. This can also be where having a number of supporters is helpful so that carers don't expect to always communicate with a particular individual on the REACT supporter team.

iv. Living with the limitations of what is possible remotely

Digital interventions have many potential strengths in terms of offering flexible accessible and non-stigmatising support. However, it is inherent in the REACT toolkit that the relationships between supporters and carers are different from those that would be experienced in a face-to-face support group. In the latter, there would be a limited number of people present over a fixed period and the group facilitator would typically learn a substantial amount about each individual. With REACT, some carers

will share extensively and consistently, others not at all and others will engage actively with the site at times and withdraw without warning at others. Due to the scale of the carer group it is not feasible or appropriate for the REACT supporters to follow-up carers who are not posting. This is different from how a group facilitator may contact a group member who had missed a group. This can be frustrating for supporters and again is a relevant supervision topic to allow time to consider this limitation in the context of offering support to a large group of people who would otherwise typically receive very little help.

v. Considering the bigger picture of helping across the participant group.

As noted above, patterns of use of the site will vary substantially across carers. Those who post/message regularly can flag up issues that supporters might think could usefully be discussed with the wider carer group. REACT supporters can therefore use the blog facility of the site to cover themes that appear to be of a broad relevance. These can be especially useful for the carers who are not active posters but do visit the site from time to time and for those who actively monitor the site but don't tend to engage directly with forums or private messaging. As noted below it is important for REACT supporters to be given time and support to consider issues around personal disclosure and confidentiality in relation to their stories as indicated in more detail in section 14 below.

5. Supervision:

Supervision should be led by an experienced clinician and take place fortnightly for up to 1.5 hours. This provides a space for all of those involved in the REACT supporter role to discuss relevant issues in a supportive environment. In between these sessions on alternate weeks, REACT supporters can meet to provide each other with Peer support. Issues typically covered in supervision include:

i. Clinical issues raised on the site including through forum and instant messaging posts. This can include in depth discussion of the communication with a particular carer or review of patterns of communication and site activity more broadly. This will also include time to review any risk issues that might have come up on the site including those dealt with since the previous supervision and those pending that require a decision. Urgent risk issues are dealt with in between supervision between REACT supporter and individual supervisor through ad hoc meetings.

ii. Site cover to accommodate staff leave, training and sickness absence. This also covers organising messages for planned closure periods such as Christmas breaks. It is important that this element of supervision does not detract from time to discuss clinical issues. If there are more complicated issues with cover these will need to be addressed through operational management meetings.

iii. Supporter wellbeing. This provides time for supporters to reflect, if they wish, on any issues that might be impacting on their wellbeing. This can include domestic/personal issues impacting on the work role or material raised on the site that has been difficult to deal with. Included in this section is also shared consideration of approaches to manage work issues including taking time out when required. Specific strategies are described in the Supporter manual.

iv. Other issues as required. This can include review of planned blog posts, ideas for update/refinement of site materials/ technical issues/ site promotion.

6. Management of risk

All forum posts and private messages are reviewed by REACT supporters for potential risk. For the purposes of these communications risk is divided into low and high. Low risk is defined as no indication of immediate or serious threat of severe harm or risk to life but either:

- clear evidence of high levels of distress
- or concerns for risk of harm or abuse towards participants or others (safeguarding risks)

Low risk posts are responded to by the REACT supporter who detects them with a standardised email to the carer, where distress is the primary issue. If there seems to be a potential safeguarding issue then the supporter should discuss with their clinical supervisor and if necessary use NHS Trust safeguarding team to discuss potential risks. If it is decided there is a safeguarding issue then it is necessary to report this to the local authority for the person for whom you are concerned.

High risk is defined as the presence of clear evidence of immediate and serious risk to life or child welfare. If immediate risk of severe harm or death is detected then an emergency call should be made to police (risk to life) or social services (other risk to child).

Any concerns that might constitute a risk issue but fall outside these definitions should be discussed as urgent with the clinical supervisor to decide on a form of action.

7. Site Cover

It is important to have more than one person able to support clinical supervision. Supporters will need to have a clinician that they can access to discuss risk issues during working hours from Mon-Friday. It is therefore important that supporters don't review the site outside these times, as if they detect a risk issue they will not have access to a supervisor for consultation. To be resilient this system has to allow for the lead supervisor having periods of leave, sickness absence or work responsibilities that make them

periodically unavailable. It is therefore sensible to have at least two other clinicians with a knowledge of REACT who can step in to provide this cover. Supporters will need access to a shared calendar that indicates when the lead supervisor will not be available and who is the next point of contact in the supervisory team. Contact details for all supervisors need to be made available to REACT supporters with the order of contact made clear. In practice this task is unlikely to be overly onerous for the additional clinicians as our experience is that when REACT supporters are appropriately trained and supported calls to clarify potential risk issues become less frequent (moving from several times per week to closer to weekly).

8. Holidays

There are two aspects to holiday cover.

- i. It is important to establish well in advance whether there are any periods when relatives need to be informed that supporters will not be covering the site. This has typically been required for bank holidays and periods such as Easter or Christmas when the host institution was closed. Even when the Trust is still open, such periods can be times when both supporters and supervisors are on leave. Our experience is that where relatives are informed a reasonable time ahead of this situation they are accepting of this. This is helped by ensuring that relatives are aware from the outset that the REACT toolkit is not an emergency advice and intervention service, but a digital support and information resource supplementary to what they already have access to.

- ii. Planning ahead for holidays is also crucial. As far as possible REACT supporters need to plan to avoid taking holiday at the same time. Similarly the lead supervisor aims to avoid periods of leave that overlap with additional back up supervisors. Considering these issues as part of group supervision is an appropriate way to avoid gaps in cover for the site.

9. Sickness

REACT supporters will, as with all staff, have periods on sickness absence. These can be required for physical and or mental health reasons. It is important the supporters take sickness absence when needed and that return to work is planned to ensure that they are well and able to fulfil their roles on return. Given supporters have been chosen for their carer experience, some may feel driven to return to work too early before they have recovered. Whilst understandable, this is not in their, or their relatives', best interest. Having a small ad hoc group of REACT supporters, who can fill in for the main REACT supporter is crucial to help to cover absence issues and to support flexible returns to work where this is required. It is important to offer all reasonable practical support to REACT supporters, including of course time for necessary clinical appointments and use of occupational health services where required.

10. Emotional supervision

REACT supporters, as noted above, are offered group supervision which covers both operational aspects of their role and supporter wellbeing. However, REACT supporters may well feel that they would prefer to discuss certain aspects of the challenges they might be facing in a more private setting. As such, they can be offered individual supervision sessions to complement the group support, which offers additional time to reflect on any emotional impact of the role including resonance between the supporter's personal experience and the issues being raised by relatives on the REACT site. This combination of support provides the right balance of professional input to help REACT supporters continue to fulfil the responsibilities of their role without compromising their health.

Where there are sustained problems linked to stress or personal mental health issues it might be that the REACT supporter feels they would benefit from counselling or psychotherapy. The main supervisor role in the relation to this would be to offer flexibility to allow the REACT supporter to attend clinical sessions of this type. They should be accessed independently of the REACT service and not be delivered within the clinical team as this would lead to an unhelpful blurring of roles.

11. Distress management

REACT supporters should have substantial experience of a caring role. The strengths this brings to the role have been enumerated above. However it is important that both supporters and supervisors are alert to signs of distress in supporters. This could be triggered by posts or messages with which the supporter over-identifies because it resonates with their experience. Alternatively this can occur when individuals engaging with the site are leaving posts that are challenging of the supporters or disputing the constraints of their role. Finally it could occur were supporters to be repeatedly exposed to either type of post and/or particularly severe and detailed accounts of despair from relatives. To date the evidence has been that whilst carers do report complex, challenging and difficult situations, these are scenarios that the supporters and indeed other carers are able to respond to constructively and empathically. As noted above, clinical supervision to give REACT supporters time to process site activity they have found distressing (as well as each supporter having their own wellbeing plan, as outlined in the REACT supporter manual) is important for managing these experiences. These recommendations are consistent with evidence for protective and risk factors for vicarious trauma in clinicians repeatedly exposed to the detail of their clients' stories (Baird and Kracen, 2006).

12. Personal commitment

REACT supporters are selected for their experience of a caring role in mental health. This means they are likely to feel strong personal commitment to the role and to those carers using the site. This can lead to feelings of frustration if they feel that the site, or the systems around it is not functioning optimally. As a result, the emotional tone of some supervision can be quite high. The strength of the supervisor not themselves being a relative, is in their being able to support reflection on the issues causing frustration, the reasons for these and where possible consideration of potential solutions. Supervisors can also usefully signpost REACT supporters towards relevant resources and research relevant to their work. Within the bounds of professional behaviour, supporters can periodically find it useful to express their frustrations and are then often very creative as a team in exploring potential solutions to these. One trigger for frustration can be a desire to do more than a digital format permits, or to go beyond the bounds of what the role allows. As indicated earlier, it can be important to reflect in relation to this on the purpose of REACT as being to offer a useful self-management support resources to many more people that could possibly be seen face to face, so that the scale of the support counterbalances its limitations in terms of depth for each individual.

13. Support for supervisors

Supervisor well being is important. If the supervisor does not feel well supported, he or she will then not be able to function effectively in their role. The supervisors themselves needs to be familiar with the REACT site and associated systems. They also need to be familiar with what people are posting in messages and forums and how supporters are responding. They also oversee and support supporters in their activities promoting the site, drawing up topical blogs and dealing with risk issues. Although this is an important role it is likely that supervisors will be fitting these activities around their wider clinical and managerial responsibilities with the Trust. There is therefore a risk that the supervisor deals with the issues raised by supporters but not their own emotional reactions to these situations. Having more than one supervisor can be very helpful in avoiding this problem. Peer support for supervisors can be a time efficient and effective means of dealing constructively with issues raised in managing and supporting REACT supporters.

14. Confidentiality issues both within training and broader guidance.

Training for REACT supporters needs to cover the issue of confidentiality in some detail. The first aspect of this is the need to keep confidential the details of activity on the site, as with any sensitive clinical material, particularly personally identifiable information. This is consistent with the confidentiality guidance offered for other forms of clinical activity. The other issue is the extent to which REACT supporters remain anonymous both in relation to

their work on the REACT site and any associated activities promoting REACT or being involved in publications or report coming from its delivery. REACT supporters may be concerned about being identified in a carer role per se and also because this might identify the people they care for. There is no right or wrong answer here. It is crucial in training that supporters are given time to reflect on this issue and what they do or don't want to reveal about themselves in a safe, person-centred environment. Some supporters might be perfectly happy to have their pictures and name displayed and others may not. It is also likely that people's views may change over time and it is crucial that this is accommodated. As indicated in the Supporter manual the consensus from our work to date is that providing anonymity should be the default position for supporters.

15. Top 10 tips.....

1. REACT supporters need to have extensive and first hand caring experience with a relative or close friend, in order to be able to draw on this experience to support relatives using the toolkit.
2. Training is crucial in peer support, and technical aspects of the Toolkit (with appropriate technical back-up).
3. Clinical training for the role needs to include guidance in self-care and how to support relatives without offering advice.
4. Regular clinical supervision with a qualified clinician is crucial to cover clinical and risk issues, site cover and to maintain supporter wellbeing.
5. A clear protocol is needed for responding to emails indicating relatives are at potential risk of harm to self or others. This needs to balance sensitivity to risk with the costs of over – reacting to distress which could disengage the relative.
6. Back up clinical supervisors are needed to cover periods of leave for the lead supervisor
7. Group and, if required, individual supervision can help REACT supporters work through issues linked to their own wellbeing included those triggered by the experiences of relatives on the REACT site.
8. Having more than one supervisor provides a peer support resources for the supervision team
9. Supporter confidentiality is an important issue likely to vary from individual to individual and over time. So offering support, information and time to reflect on decisions about this is important.
10. The caring experience of REACT supporters and their diverse skills are strengths for offering effective empathic support to relatives.

16. References

- Baird, K. & Kracen, A. C. (2006). Vicarious traumatization and secondary traumatic stress: A research synthesis. *Counselling Psychology Quarterly*, 19, 181-188.
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