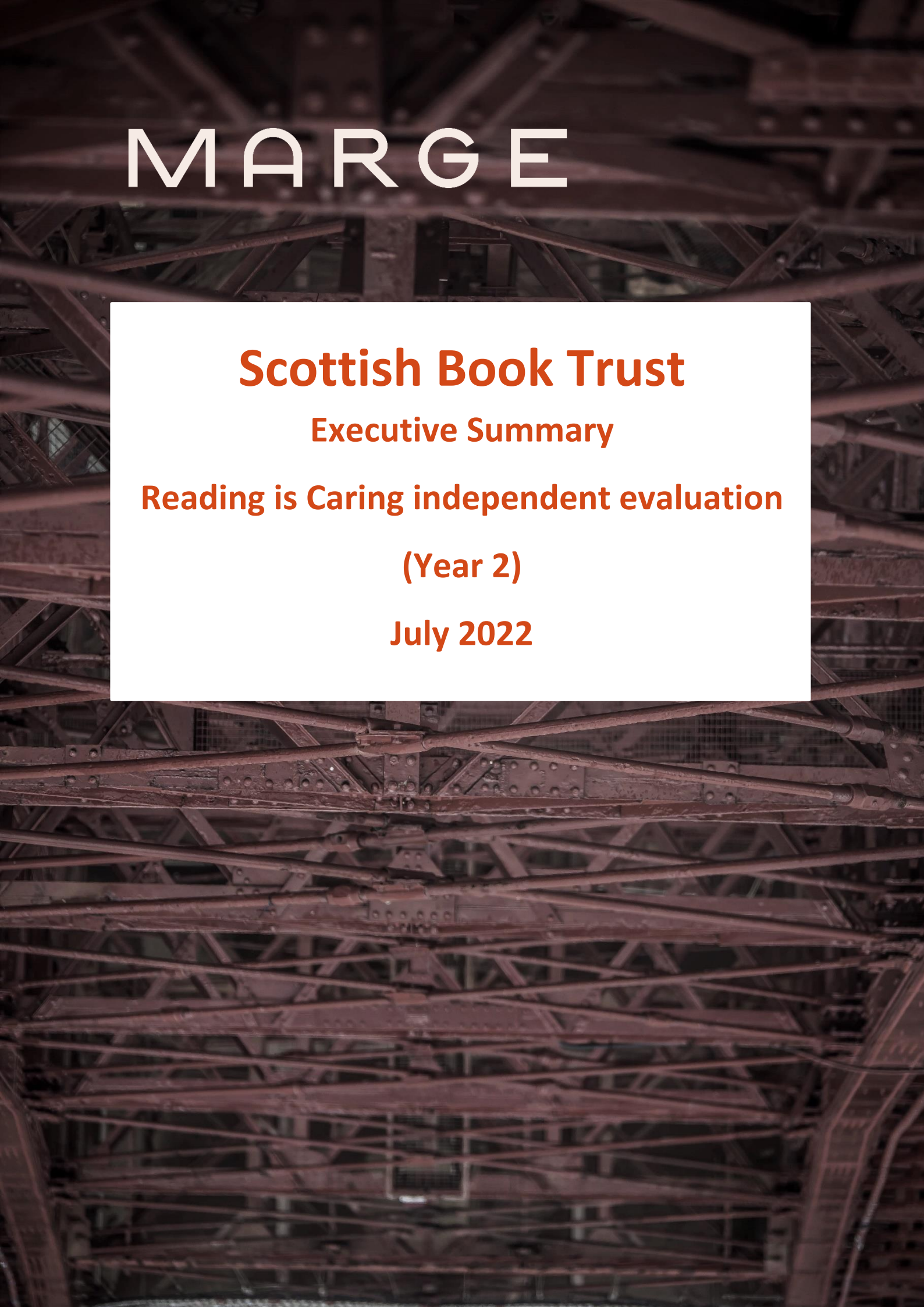

Scottish Book Trust

Executive Summary

Reading is Caring independent evaluation

(Year 2)

July 2022

The findings in this executive summary relate to evidence captured and made available between January 2021 and July 2022.

Please note that the main report includes direct testimonials and content related to end-of-life care which some readers might find triggering.

Any enquiries about this report should be directed to Koren Calder.

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About the programme

Reading is Caring (RiC) uses reading to support people living with dementia and anyone who cares for them. Through a free workshop programme, family and professional care partners are trained to create personalised and shared reading experiences for those they care for. The workshops are tailored and delivered either as 1 – 1 or in small groups[1], with participants encouraged to explore the life story of the person living with dementia (PLWD). As a result they have time to reflect on their relationship with the PLWD, learn shared reading story skills and gather specific reading materials and objects for life story (and often sensory) book boxes. The ultimate aim of the programme is to use reading in a positive way to support the relationships and wellbeing of people living with dementia, but equally those who care for them.

Reading is Caring is funded entirely by donations to Scottish Book Trust. The programme is generously supported by the Appletree Trust, Better World Books, the D'Oyly Carte Charitable Trust, the DWF Foundation, the McCarthy Stone Foundation, the Sir Iain Stewart Foundation, the William Syson Foundation, and donors who wish to remain anonymous.

The main report evaluates Year 2 of the programme, defined as January 2021 – July 2022. This executive summary provides a short overview of the key findings[2].

Covid-19 context

It is important to understand the context in which Reading is Caring (Year 2) has been delivered when reviewing the findings within this evaluation.

The UK-wide lockdown, which started on 23 March 2020 impacted the timeframe, nature of project delivery and capacity of participants to engage with Reading is Caring in the Pilot Year (Year 1). This continued into Year 2, so all RiC training workshops continued to be delivered in an online format rather than face to face. The introduction of various tiered systems across the UK and further lockdowns in January 2021 disrupted health services, staff, and engagement with the programme as it had done in 2020. Even when the last of the restrictions started to be lifted in Scotland in Spring 2022[3], health and social care organisations, grassroots community voluntary support organisations and charities were reeling to reset and recover from the previous two years. Many had yet to reopen or function at pre-pandemic capacity and delivery. At the time of writing, Covid-19 case numbers are continuing to rise, with one in 15 people in Scotland estimated to have the virus and on average 1660 patients in hospital with Covid-19 (week ending 24 July 2022)[4]. As a result, NHS services – and its professional staff team – are extremely stretched.

The evaluator therefore recognises that the ability to recruit, design and deliver activity continued to be compromised in Year 2 as it did in the pilot year, despite restrictions being lifted.

[1] In Year 2 which this report covers, these sessions have been delivered online.
[2] Note that methodological limitations should be reviewed for context and these are available in the main report appendices.
[3] The legal requirement to wear face coverings in certain settings like shops ended on 18 April 2022. The remaining restrictions around self-isolation and testing were removed in May 2022.
[4] https://publichealthscotland.scot/our-areas-of-work/covid-19/covid-19-data-and-intelligence/covid-19-weekly-report-for-scotland/

What is the evaluation setting out to measure?

A new logic model for Reading is Caring (Year 2) was created collaboratively with the project team[5]. It outlined a series of intended outputs and outcomes[6] that the programme intended to collectively deliver for People Living with Dementia (PLWD), Family Care Partners and Professional Care Partners. The main evaluation report assesses whether these outputs and outcomes have been met, to review whether the programme has achieved its ultimate aim. A process evaluation was also conducted, to consider the ambitions, recruitment process, project design, project management and staff support.

Headline facts and figures

[5] This was created in February 2022 when the independent evaluator was appointed.
[6] Outcomes are defined as the benefit, difference or change the project team want to make for beneficiaries as a result of Reading is Caring (Year 2).

Key findings

The below narrative provides an overview of the top-level findings in the main report, structured by the three beneficiaries[7].

Person Living with Dementia (PLWD)

- It is highly likely that the number of people living with dementia engaged in the Year 2 programme is greater than reported (104 with a target of 105). This is attributed to the anecdotal reports of professional care partners who have put their training into action with more than one PLWD this year.

- The tailored, personalised design of the programme is a critical contributing factor for bringing positive (and often striking) benefits for the PLWD including a sense of agency and positive mental health and wellbeing. There is a commonality between family and professional care partners' anecdotal reflections about the experience of the programme for their PLWD. Whilst not robust, their similar experiences do give us some confidence in the data even though it is not directly from the PLWD themselves.

- Shared reading may not suit every PLWD, but it is worth attempting given the benefits described by care partners.

- The indicative findings suggest there may be a potential role for shared reading in end-of-life care for people living with dementia and their care partners. It may be worth investigating whether there are any routes to promote shared reading through the Death Positive Library initiatives that are happening across the UK with library services[8]. This may also link with the pilot activity that SBT intend to do in Year 3 with library partners.

Family Care Partner

- The target of reaching 70 family and professional care partners was successfully achieved.

- Family care partners were overwhelmingly positive about their experience with RiC, with high levels of satisfaction leading to positive word of mouth recommendations to other family and professional care partners, and grassroots support organisations.

- There are pros and cons to holding training on a 1-1 basis versus in a group. SBT may wish to consider offering a choice to participants in the future and/or whether to bolster ground rules at the start of group training sessions to encourage confidence in speaking about personal circumstances and to try shared reading in front of others.

- There were few suggestions for improvement. Where these existed, they related to ideas about the training – such as including more breaks and greater consideration of the presentation design.

[7] There are several limitations within the methodology which should be noted: these can be reviewed in the main report along with the list of data sources drawn upon for evidence.

[8] Libraries Connected suggested a UK-wide framework for the death positive library movement following the work on Engaging Libraries, a public engagement programme funded by Carnegie UK, Wolfson and Wellcome. https://www.librariesconnected.org.uk/news/death-positive-libraries-national-framework

- The RiC programme has developed new skills and knowledge for family care partners across three core areas: general understanding of dementia, how to 'do' shared reading as a technique (and the impact it can have on the PLWD) and specific knowledge on reading materials and where to find them. It may be worth further exploration in subsequent evaluations of the indicative finding that RiC may be filling a gap in knowledge of dementia and its implications at pre-diagnosis and diagnosis stages for some participants.

- The findings indicate that the critical success factor for developing confidence in shared reading is having highly skilled and empathetic trainers who provide reassurance, encouragement, and a chance to practice shared reading.

- RiC provides a genuine way for family care partners to continue enjoying activities together with their loved one, away from tasks which are 'dementia first' such as personal care and feeding. Family care partners independently described their time undertaking shared reading as 'quality', and a way to make meaningful memories. In turn, we can assume that family care partners potentially rediscover a sense of self-identity, with time spent during shared reading temporarily 'removing them' from their carer role.

- There are several health and wellbeing benefits cited by family care partners which could be explored in greater detail in future evaluations. These include reduced anxiety, relaxation, and improvements to mood, with evidence across four of the five ways to wellbeing[9] recorded in the findings.

- The findings include some striking unintended outcomes, including the co-creation of future training content thanks to the ideas and input that family care partners give during their workshops. Depending on capacity, some of the more practical ideas from participants' feedback could be followed up by SBT – for example, exploring intergenerational links with Bookbug and RiC; and developing a RiC opportunity for bereaved family carers who have participated in the training (to use reading for recovery and to reduce social isolation).

Professional Care Partner

- The output target of reaching 70 family and professional care partners was successfully achieved.

- Professional care partners reported high levels of enjoyment and therefore satisfaction with the programme, and as a result this is driving word of mouth recommendations to Adults Health and Social Care (AHSC) colleagues (and also family care partners). There were no suggestions for improvement with the programme made by professional care partners across the evidence supplied by SBT nor that collated by the independent evaluator in the later stages of Year 2.

- Professional care partner RiC 'ambassadors' could be more proactively harnessed to generate training bookings, especially if they are given specific promotional materials with messaging aimed at professionals which can then be passed onto colleagues[10]. There are also clear routes into strategic management/Board through some of the professional care

[9] https://neweconomics.org/2011/07/five-ways-well-new-applications-new-ways-thinking.

[10] The evaluator notes that the RiC programme has – at the time of writing – created a new suite of marketing materials.

partners who have taken part in Year 2. These could be useful for SBT to exploit to generate programme 'buy in' at a higher level[11].

- Professional care partners have gained new skills and knowledge through taking part, especially in learning new techniques for person-centred care. Their feedback indicates they are using their RiC experience with more than one PLWD which shows the potential ripple effect that can occur through training one professional. Whilst it may be impractical for professional care partners to record exact numbers, it may be worth exploring whether there is a robust way to estimate the broader PLWD reach for Year 3[12].

- Time is a barrier for professional care partners engaging with the training and subsequent shared reading activities including the completion of reading diaries. The findings also suggest that some professional care partners also struggle accessing reading materials and may need greater support from SBT with this.

- As with family care partners, professional care partners have helped co-create the training sessions by sharing their suggestions. Although the training is rated highly, this input is likely to have strengthened the product given that it is being built on by people with lived experience of dementia.

- Whilst the findings do not robustly evidence any specific improvements to professional care partners' continual professional development, they are likely to have benefitted by expanding their toolkit of person-centred care approaches. In addition, the life story book box approach with RiC helps increase their knowledge about those they look after, and in certain cases has indicatively brought them closer.

- As with family care partners, professional carers attributed their confidence in shared reading to the exceptional training. Although isolated rather than common feedback, comments around the training being more difficult than expected, and perceptions shared with them from family care partners that support with reading 'is not needed' may be interesting to explore further to see if this is a common rather than limited occurrence. For example, do family or professional care partners assume they know 'how to read' and therefore do not see the benefits of learning a shared reading technique? Does this perception have a negative implication on recruitment? Does the messaging around the programme need to be altered in some way to mitigate this? Communicating the benefits of the programme and investigating the immediate perceptions of the programme name may be something for SBT to consider within the market research currently being undertaken[13]. The evaluator recognises that having greater provision in Year 3 and beyond with tools like the trailer may more readily contribute towards an increased sense of what RiC is all about. In addition, thinking about the different ways to recruit family care partners vs professional care partners who may respond to different messages is already being put into place by the RiC team.

[11] The evaluator acknowledges there are plans within the RiC strategy for SBT senior management to meet with senior leaders in AHSC organisations including at grassroots level to enable a 'top down' approach with recruitment as well as the existing 'bottom up' one. This is highlighted further in section 4.

[12] For example, professional care partners could be asked to estimate the number of PLWD they have undertaken shared reading with per month, or over the year using a scaled response choice (e.g. 1 – 5) rather than a specific number.

[13] SBT are currently undertaking market research to explore ways to best recruit participants to the programme for Year 3.

There is an opportunity to collect more evidence on how shared reading and life story book boxes can be used within, and benefit, other care areas such as physiotherapy. Whilst there is limited evidence of a propensity to use shared reading in other settings, there is great support for the programme and a clear intention to continue using it in the future. There are examples where professional care partners have proactively been creative in the public spaces within their care setting, for example creating a wall display of poetry. It would be worthwhile collating examples of these from those who have taken part to inspire others in future training sessions.

Profile

The majority of participants attended from the Scottish Borders (designated as one of 32 council areas that borders the City of Edinburgh, Dumfries and Galloway, East Lothian, Midlothian, South Lanarkshire, West Lothian and the English counties of Cumbria and Northumberland). The programme also successfully reached those in the most deprived communities of Scotland (with 22 of 31 participant postcodes profiled being in SIMD 1, SIMD 2, or SIMD 3, where SIMD 1 is the most deprived and SIMD 5 the least deprived).

Process

The RiC process evaluation allows for a reflection of exploratory research questions raised in the original evaluation strategy. It broadly finds that:

Aims and ambitions

Targets were set correctly, although as noted earlier, it is difficult to accurately measure the impact of professional care partners and their reach of PLWD which is likely to be much higher than reported.

There are challenges for recruitment in rural areas, with greater signposting to services and grassroots support available in the city. Without professional referrals or the ability to cold call in rural areas, it was difficult to reach people living with dementia and their carers through solely digital marketing channels during the pandemic.

Recruitment

The majority of activity during Year 2 had to be delivered during Covid-19 restrictions. This negatively impacted recruitment routes, for example reaching carers via doctors, dentists, or other non-health settings. Access via dementia cafes or reminiscence hubs was also impeded and some dementia cafes have still yet to reopen at the time of writing (with those who have opened reporting low attendance). A pilot will run with libraries in Year 3 as a new way to try and reach family carers.

A new member of staff joining the RiC team has meant designated time to develop professional marketing materials rather than relying on in-house versions. These, and (hopefully) an ability to access more family and professional care partners face to face in Year 3 will allow the RiC team to sell the different benefits for each beneficiary (rather than a ‘one size fits all’ approach). For example, there is a need to convey to care partners that the time they put into training in shared reading is received back as ‘tangible time’ i.e. there is a relevant, specific benefit from attending training such as less stressful mealtimes.

The report finds that anecdotally, some dementia organisations are reticent to engage in the project. This is perceived by the RiC team as either due to Covid-19 barriers and/or a lack of understanding about the programme and its benefits. There have also been instances where professional care partners have met with the SBT project team and received an overview of the approach, but then do not commit to attending workshops. It is important to acknowledge that 'behind the scenes' administrative activity such as this takes up staff time, without necessarily a successful result.

There is a potential loss of skills when professional care staff leave. They may take those skills elsewhere, or conversely do not have the opportunity to use them at all. Positively however, once family and professional care partners are recruited and take part in the training, they are keen to keep in touch, tell others, or re-engage.

The report finds that there is potential to further explore the fit of RiC through the Scottish Social Prescribing Network (SSPN).

Project design and delivery

Continuing the delivery of online sessions during Year 2 (whilst restrictions were still in place) has opened up access for those who are unable to leave their PLWD and has meant that SBT have not needed to use their assigned respite budget.

The team continues to take an iterative approach to project design and reducing barriers for participation wherever possible. For example, they have created DVD films of content for use in Year 3 for those who are particularly isolated or time poor.

Despite family and professional care partners signing up to training, they do not always attend due to last minute barriers such as poor health, looking after the person they care for, changes in staffing etc. Rearranging the training then adds more administrative time into the process for SBT staff.

The personalised, tailored training is key to a successful experience for participants and is what makes RiC unique and well-received. This needs to be kept at the heart of the programme.

At times it is necessary to manage the expectations of care partners – balancing their knowledge of the person they care for with encouraging them to have an open mind about which reading material may work best (and that the focus is on common interests).

The team are keen to widen scope to reach a broader demographic of family care partner/PLWD (and envisage doing this in years 4/5/6 by implementing a 'train the trainer' scheme where those with similar lived experiences are therefore better placed to deliver than the current team).

Project management

The lead-in time is described by one member of the project team as 'uniquely unreliable'. It takes time to encourage carers to attend and is a 'slow burn' – sometimes results are not tangibly seen until many weeks (if not months) down the line.

Family care partners and professional care partners will sometimes have different experiences, needs and sensitivities to be mindful of – as a facilitator the team have found it is important to be alert to these and respond accordingly.

Communication can be challenging and complex when dealing with care partners, especially when they are bereaved. It is important to have a suitable communication system in place to deal sensitively and appropriately with those who are, or have, engaged with the RiC programme.

Although the evaluation needs some slight realignment, delivery of RiC is now in line with funding cycles which will strategically be more helpful for the team in terms of planning and delivery.

The RiC team have been approached by people wanting to become volunteers. This is not something that can be co-ordinated at the moment.[14]

Time has been well spent this year, building on learning from the pilot and getting foundations laid for subsequent years of the programme. As a result of the agile, experimental way of working, the RiC forward plan is stronger as time has been taken to carefully consider what the programme should/should not do and what the best routes to success are. However, work for Year 2 has had to be delivered chronologically instead of in parallel due to the capacity of the team – with a second member of staff starting later than had originally been anticipated. This understandably impacted progress and what could be achieved in the time available.

The two members of designated RiC staff complement each other in approaches and skills – this should make for a strong Year 3 and beyond.

Evaluation started late this year and there will need to be some tweaks for Year 3 to enable data to be collected that more readily reflects the needs of the revised evaluation framework.

Staff support

SBT managers have been proactive in sourcing trauma support for RiC staff which is appreciated. RiC staff members feel supported by colleagues and able to approach them should they need.

Overall summary and recommendations

The team has worked tirelessly to deliver Year 2 of the RiC programme, building on their learning from the pilot to create a strong foundation for subsequent years. It is testament to their resilience and tenacity that it has been such a success, achieving (if not exceeding) its targets as well as a range of intended and unintended outcomes described in this report. This is an exceptional result, especially given the Covid-19 context in which activity has been delivered, and by only one member of staff (working part-time) for the majority of Year 2[15].

Maintaining the personalised, tailored approach may mean fewer people engage with the programme, but the benefit to those individuals outweighs any lack of breadth. It should be

[14] The main reasons why this is not feasible currently include: 1) The project supports and trains those in existing caring relationships either professional care partners, and or family care partners or family friends who have an existing care relationship with the PLWD. Those who have contacted SBT who would like to volunteer are not in an existing caring relationship – SBT do not have the capacity at the moment to carry out safety checks, oversee quality control of the ongoing training (whereas professional carers have safety checks on them as part of their existing role etc.). 2) SBT are also using all their limited resources (time and income to spend on marketing materials etc.) to reach care partners (family/ professional). Expanding to include a volunteer programme would mean fundraising for a different project approach and an increase in staffing. 3) There are other organisations who currently work with volunteers and the elderly on reading projects, not necessarily those living with dementia, but they currently fill this space.

[15] This is covered in Section 2. A second member of staff (full time) joined the programme five months prior to the completion of Year 2.

preserved and continued in this way, with evidence of impact supplied to funders to demonstrate the value of spend per head.

This is a programme that *takes* care as much as it is *about* care – its person-centred approach and commitment of time from staff members is unique. However, the team rightly acknowledge that there are opportunities to diversify the demographics of care partners engaged. This is not possible without further refinements to the programme, which – sensibly – are being carefully considered, developed, and tested out over the forthcoming years (funding dependent) so that trainers' lived experiences can match those of participants.

The programme does not provide a carbon copy experience for participants, it needs to be flexible to meet the varying needs of care partners and their PLWD. To achieve this, an extraordinarily amount of time is required from the delivery team and a positive attitude of being willing to change, adapt and rethink approaches. The findings in this report demonstrate that despite the mitigating factors of Covid-19, the team's ability to be agile and flex the model has resulted in a successful programme.

This report indicatively finds that there have been numerous striking outcomes for the three beneficiaries. However, revising the evaluation tools and strengthening the approach for Year 3 will be necessary to enable more robust evidencing of intended as well as unintended outcomes. This will also be required to effectively monitor the usage of and behaviour with the new DVD offer and could potentially help estimate the wider reach of people living with dementia engaged through professional care partners. It would also be pertinent to investigate some of the more striking unintended outcomes indicatively raised in this report, such as plugging a dementia knowledge gap at pre-diagnosis and at diagnosis stages.

Pursuing partnerships with end-of-life palliative care and social prescribing partners could be considered in the forward plan as these may respond to opportunities highlighted by family and professional care partners in the findings, and open new avenues for widening the reach of – and engagement with – RiC.

The programme has – to date – predominately been delivered by one (part-time) member of staff. The team have rightly identified that to ensure the legacy of the project is protected, (for example if that staff member leaves their role) and to develop a streamlined communication approach, a new contact management system needs implementing.

Delivering training separately for family care partners and professional care partners may positively contribute even further to the personalisation aspect of the programme and more readily respond to the differing nuances of experience and need within each beneficiary group. SBT may also wish to explore the potential of supporting bereaved RiC 'alumni' in a separate or linked project to continue their reading experience.

Whilst there were few suggestions for improvement in the findings, the RiC team may wish to update the overall look and feel of the training presentation or have it professionally designed.

Professional marketing materials have been designed and produced to promote the programme in Year 3. It may be worthwhile supplying separate flyers with key messages for professional care staff to use with colleagues or family care partners which communicate

how to access reading materials (Overdrive/Library/Bookstore/Web links) – with an aim to reduce barriers in getting hold of suitable content.

Project aim achievement summary

Project aim	Status
To support the relationships and wellbeing of people living with dementia and their carers through shared reading and life story book boxes	Achieved

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