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RESEARCH REPORT

The impact of participation in research for speech and language therapy departments and their patients: A case example of the Big CACTUS multicentre trial of self-managed computerized aphasia therapy

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Abstract

Background: In order to conduct research that is meaningful to speech and language therapy services and their patients, it is often desirable to conduct the research within routine clinical services. This can require considerable time and commitment from speech and language therapists (SLTs). It is therefore important to understand the impact that such participation in research can have.

Aims: To explore the impact of research participation in the Big CACTUS study of self-managed computerized aphasia therapy conducted in 21 UK NHS speech and language therapy departments.

Methods & Procedures: An online survey was sent to SLTs who took the lead role for the study at their NHS Trust to evaluate the impact of study participation in three domains: capacity-building, research development and health services. The questionnaire, based on the VICTOR framework for evaluating research impact, included Likert scale statements and closed and open-ended questions. The results from open-ended questions were coded and analysed using framework analysis in NVivo 12 and the data from closed questions were analysed descriptively.

Outcomes & Results: A total of 12 SLTs returned the survey. Nine codes were identified from open-ended questions and 20 predefined from the literature. Analysis of the responses demonstrated the perceived impact including improvements in practices and access to therapy, investments in infrastructure, increased SLT profile, and impact on research culture among SLTs. The usefulness of the intervention during the COVID-19 pandemic was also highlighted.

Conclusions & Implications: The results suggest participation in Big CACTUS has resulted in improvements in patient care and SLT research capacity and culture in speech and language therapy departments.

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KEYWORDS

capacity-building, computer-assisted therapy, impact assessment, rehabilitation research

What This Paper Adds

What is already known on the subject

- Practice-based research is encouraged to assist with the clinical relevance of the research findings. Participation in research can be seen as an activity that is additional to the core business of patient care and it can be difficult to secure time to participate or conduct research in clinical settings. Impact evaluation initiatives of individual trials facilitate early identification of benefits beyond the trial.

What this paper adds to existing knowledge

- This study describes specific examples of the impact on services, staff and patients from SLT participation and leadership in the Big CACTUS speech and language therapy trial in clinical settings.

What are the potential or actual clinical implications of this study?

- Clinical services participating in research may benefit from improved clinical care for patients both during and after the study, an improved professional reputation, and increased research capacity and culture within the clinical settings.

INTRODUCTION

We conduct research into speech and language therapy to understand how best to help our service users and to have a positive impact on the lives of people with communication disorders and the work of speech and language therapists (SLTs). The main objective of measuring research impact is to identify any demonstrable contribution that research-derived knowledge achieves beyond academia. Impact evaluations have traditionally been associated with automatic data-collection systems such as journal impact factors, h-indexes, peer-reviewed articles and alternative academic metrics. However, it has been recognized that these metrics do not reflect the real value of research (Belter, 2015). This fact has prompted the development of multidimensional frameworks including different domains for demonstrating the diverse benefits that research can offer to people, organizations and practices at various levels (Cruz Rivera et al., 2017). Among the well-known and large-scale frameworks used to evaluate impact is the Payback framework, developed by Buxton & Hanney (1996) in the UK. This outcome-based framework covers societal benefits and traditional academic met-

rics. Another notable framework is the Research Impact Framework (RIF), developed by Kuruvilla et al. (2007). It includes four impact areas: research-related, policy, service and societal.

In a review by Milat et al. (2015), 31 published studies of impact assessment in healthcare and public health were identified. These studies often used the aforementioned frameworks to underpin their data collection. Only four of the studies sought the views of non-academic end users and only one assessed the impact of a health intervention study. A scoping review of the stroke rehabilitation research literature completed by the first author before this study did not identify any published evaluations of the impact of research in this field.

In healthcare in the UK, NHS managers are interested in impact of research participation at the local level to services, the workforce and patient experience (Jones et al., 2020). Whilst other frameworks described are applicable to healthcare research impact in general, the VICTOR framework was developed specifically to make visible the impact of research in NHS organizations with a focus on nursing and allied health professions (Jones et al., 2020). This framework was underpinned by concepts from

existing frameworks including Payback and RIF. A co-design process involved the generation of impact themes with stakeholder groups including research leaders, health and care professionals and patient representatives. Rich narratives were assimilated into subthemes and themes which led to the creation of six domains of impact: health benefits of participants, service and workforce changes, research profile and capacity, economic benefit, organizational influence, knowledge production and exchange. This informed the development of the VICTOR tool/questionnaire, designed to provide a guiding framework within a structured interview, or as a self-completed questionnaire to gather impacts from researchers, research participants, managers and clinical teams (i.e., beyond the level of the academic perspective). The prototype tool was piloted in 12 NHS organizations by collecting 24 impact questionnaires. This ensured construct and content validity of the tool (Jones, 2020).

The study presented here reports an evaluation of the short- and medium-term impacts directly for NHS speech and language therapy departments that participated in a randomized controlled trial: Big CACTUS (Palmer et al., 2019). The trial evaluated the effectiveness of a self-managed computerized word-finding intervention for patients with aphasia post-stroke compared to usual care. The VICTOR tool was used to collect data as it was based on existing frameworks and was specifically designed and tested for measuring the impact of allied health intervention research studies on the NHS, matching the context of the Big CACTUS study. This is the first published use of VICTOR beyond the 24 impact cases used in its development and validation. The trial, funded by the National Institute of Health Research (NIHR), Health Technology Assessment (HTA) programme [ISRCTN68798818], was a pragmatic randomized controlled trial, conducted within 21 speech and language therapy departments in 20 NHS Trusts in the UK. Six trusts served predominantly urban populations, seven served predominantly rural populations and seven were mixed. The trial evaluated the effectiveness of self-managed computer therapy as an approach to delivering therapy (i.e., whether it works in practice) rather than efficacy (i.e., whether it can work under ideal conditions). Therefore, we designed the study to be towards the pragmatic end of the pragmatic-explanatory continuum: SLTs within participating NHS Trusts were responsible for recruiting participants, implementing, and delivering the computer therapy approach and measuring outcomes in the trial. SLTs received some extra research funding for recruiting participants and conducting outcome measures only. No research funding was provided for delivering the intervention (therapist time, software, hardware, technical support). These activities were covered within existing

SLT resources or using the NHS Trusts' usual procurement procedures. See Palmer et al. (2019, appx 6) for the pragmatic-explanatory continuum indicator summary (PRECIS2) of Big CACTUS.

The study concluded that self-managed word-finding therapy on a computer, set up by a SLT and supported by an assistant or volunteer in addition to usual care was a low-cost intervention resulting in a mean of 28 h (SD = 25.6) more therapy practice than received with usual care alone (3.8 h, SD = 7.4) and with a clinically significant improvement in personally relevant word-finding compared with usual care alone. Generalization to improved conversation was not identified, however.

METHODOLOGY

Design

This study used an online cross-sectional survey, designed on the Qualtrics platform Version 06/2020 (<https://www.qualtrics.com>), to evaluate the impact of the Big Cactus trial to date from the perspectives of SLTs who were principal investigators (PIs) for NHS Trusts in the trial. This approach was used in keeping with the VICTOR framework on which the impact questions were based. The questionnaire included closed and open-ended questions. Quantitative data were collected to enable impact across sites to be summarized, and qualitative data to understand the extent of the impact and provide illustrative examples of impact at individual sites.

Participants

All the SLTs who were PIs at the 21 speech and language therapy departments (from 20 different NHS Trusts) involved in the Big CACTUS trial were eligible to participate. We contacted PIs as these people were the point of contact for the study and the people who had been directly trained on the study procedures and intervention delivery by the study team. They were also the therapists' conducting recruitment, and implementing the intervention, including obtaining and tailoring software and hardware for patient participants, assessing and monitoring patient participants, and recruiting and training volunteers/SLT assistants. Palmer et al. (2020) provides a description of the eligibility criteria for PIs. Broadly, the majority held predominantly clinical roles and had between 5 and 20 years of clinical experience treating people with aphasia. Their level of seniority was representative of the majority of the SLT workforce (Agenda for Change bands 6 and 7). Ethical approval was granted by the School of Health and Related

Research (SchARR) ethics committee of the University of Sheffield on 26/05/2020.

Survey design

The majority of survey questions were adopted from the Research Team and Practitioner Questionnaire of the VICTOR framework. Additional areas of questioning were developed by the authors: six statements to evaluate the level of satisfaction with participation in the Big CACTUS trial and open-ended questions to assess changes in behaviours linked to the intervention offered by the study. The questionnaire included expansion open-ended questions (O’Cathain & Thomas, 2004). This is a subcategory to corroborate closed question findings, provide more elaborated information, and uncover areas not covered by closed questions.

The questionnaire included three sections (see Appendix 1 in the additional supporting information) evaluating three domains of the VICTOR framework: improving health and health services, research development, and capacity-building. The first section, the impact on participating therapists, focused on the domain capacity-building at the individual level. This section asked for any changes in behaviours, knowledge, or attitudes promoted by the research that boosted individual work capacities and new skills. The second section focused on domains of research development and improving health and health systems. Research development included research awareness, new research skills, and research initiatives within sites. Improving health and health systems specifically focused on service changes and benefits for participants and carers. This section asked about access to new therapies, better processes of care, new infrastructure and workforce. The third section mainly focused on the domain capacity-building at the organizational level, but also evaluated the improving health domain. This final section assessed changes in behaviours and practices of patients, staff, and NHS speech and language therapy departments directly linked to use of the computerized speech and language therapy offered by the study. The first section used a 5-point Likert rating scale and sections two and three employed open-ended questions to invite qualitative description of impact examples. Section two followed the same structure as the VICTOR questionnaire, and sections one and three were developed by the study authors.

A total of 26 questions were included, six Likert-type statements and 20 open-ended questions: 13 questions taken from the VICTOR questionnaire and seven added by authors. The time needed to complete the questionnaire was approximately 40 min. Before distributing all ques-

tionnaires, an internal pilot was completed with one of the SLT PIs eligible to complete the survey. The original survey did not require significant changes following the internal pilot feedback, therefore the information provided in the pilot survey was included in the final analysis and results.

Recruitment and data collection

All eligible participants were invited to participate by email. The online materials, accessed from a Qualtrics survey link in the invitation email, included a covering letter with the information about the purpose of the study, a page with instructions for survey completion and consent. The instruction page included statements to confirm that participating therapists understood the purpose of the project, the freedom to withdraw at any point, and their voluntary participation. On agreement with the aforementioned statements, the rest of the questionnaire was available for completion.

The survey was available from 1 July to 1 August 2020. Reminder emails were sent on 27 July. All responses were anonymous to protect the identity of the participant and their NHS Trust.

Data analysis

All submitted responses were analysed by first author SJ who was independent of the Big CACTUS study and had no relationship with the PIs (responding therapists). Data generated by Likert scale questions (section 1) was categorical and data from open-ended questions (sections 2 and 3) was predominantly nominal. Categorical data were analysed in Excel, using descriptive frequency statistics. Nominal data were downloaded and transferred into a spreadsheet in Excel for qualitative analysis in NVivo software version 12.

To analyse open-ended questions, framework analysis was applied, following the five steps recommended by Kiernan and Hill (2018) (Table 1). This approach allows a systematic categorization of the raw data into selected domains, maintaining transparency in data analysis to mitigate potential bias.

After familiarization with the data, predefined codes were combined with emerging codes from responses and organized according to the impact domains covered by the survey to provide a working analytical framework. Table 2 shows predefined codes generated from the literature and codes that emerged from the data. Both authors (RP was the chief investigator of the Big CACTUS study and familiar with the PIs) checked the grouped codes and differences

TABLE 1 Stages of framework analysis

		Description
1	Familiarization	Read all responses to identify emerging categories
2	Construction a working analytical framework	Include predefined codes from literature and identify emerging codes from the raw data. Group codes in main categories
3	Indexing	Application of codes from the analytical framework to the raw data
4	Charting	Enter and Rearrange the data into superordinate categories to facilitate analysis without removing the original observations
5	Mapping and interpretation	Find patterns and relevant themes

TABLE 2 Working analytical framework

Selected domains		Coding labels	
Categories		Predefined codes	Emerging codes
Capacity-building	Capacity-building at individual level	Training opportunities New knowledge/new skills Changes in personal practices	Exploring career opportunities Sense of purpose in the workplace
	Capacity-building at organizational level	Changes in roles and structures (workforce) Collective improvements, initiatives or skills Providing information and guidance	Building confidence Teaching skills Increased SLT profile
Research development	Research culture	Developing research awareness Willingness and interest in research	Evidence-based practice for and beyond aphasia
	Research capacity	Involvement in other trials Gaining research experience New research networks	Postgraduate research training qualifications
Health benefits	Patient experience	Access to therapy Improvements in process of care/practices Health literacy Support groups Quality of life	Patient empowerment New provision for carers
	Improving the health system	Awareness of research findings Changes in guidelines Investments in infrastructure (computer therapy resources)	Benefits during COVID-19 pandemic.

were discussed and resolved. Finally, the framework was applied to sort raw data, followed by description of findings according to main categories and interpretation of common patterns within each domain.

RESULTS

A total of 12 out of 21 eligible therapists completed the questionnaire (a 57% response rate). Section 1 of the survey was fully completed by all 12 responding therapists, sections 2 and 3 were completed by 10 and nine responding therapists, respectively. Not all therapists who answered 'yes' in the closed questions provided additional comments. Data on responding therapists were deliberately not col-

lected in the survey to protect the identity of the individual therapists and NHS Trusts.

Main results from closed questions

The impact of participation in Big CACTUS on therapists

Most of the responding therapists agreed or strongly agreed that as a result of participation in the Big CACTUS trial SLTs gained training and knowledge, individual clinical practices changed, and awareness about research and interest in participating in future research activities increased. Although, none of the responding therapists

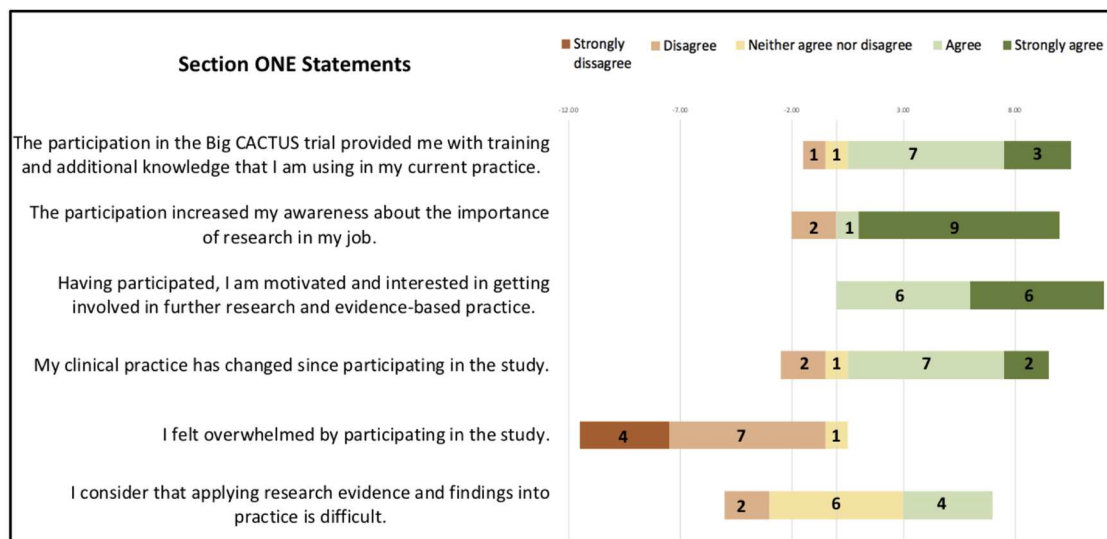


FIGURE 1 Impact of the participation in the trial on therapists [Colour figure can be viewed at wileyonlinelibrary.com]

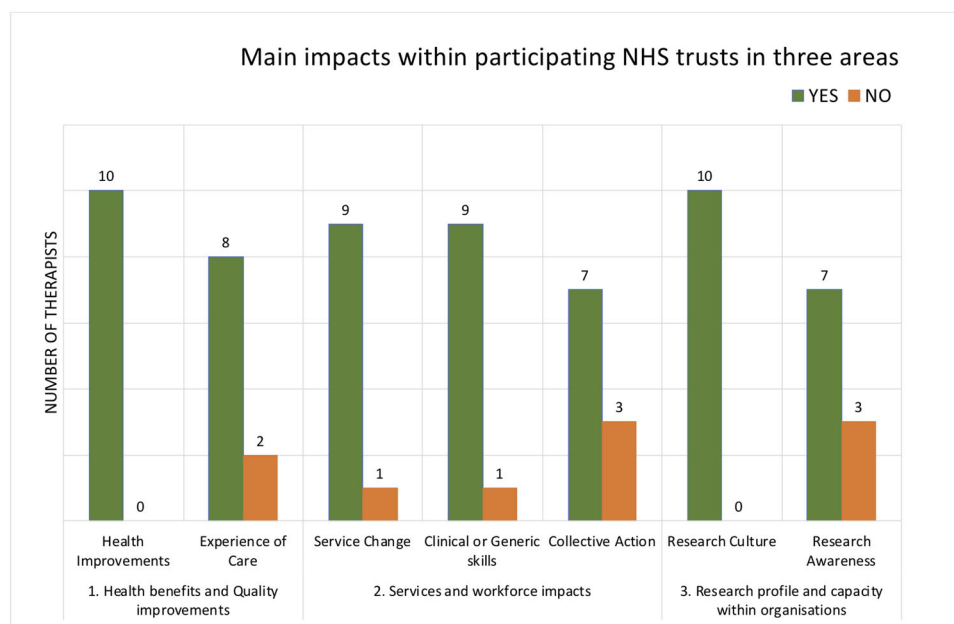


FIGURE 2 Main impacts of participation in Big CACTUS reported by responding therapists [Colour figure can be viewed at wileyonlinelibrary.com]

reported feeling overwhelmed by participating in the study, four agreed that translating evidence into practice is difficult (Figure 1).

Research impact in participating NHS Trusts

The majority of responding therapists reported positive impacts after trial completion in three areas: health benefits for participants and carers, service and workforce, and research profile within organizations (Figure 2). The most reported impacts were acquisition of new skills,

enhancement in research culture, and improvements in clinical practices along with the experience of care for patients. Conversely, low numbers of responding therapists reported changes in guidelines (3/10), workforce (2/10), or new networks and collaborations (4/10) after study participation.

Changes in behaviours and practices

The majority of responding therapists indicated that the study intervention, computerized aphasia therapy, is being

provided to stroke patients since the end of the trial in that study participants requested to continue using it (three sites), it is being delivered to new patients with aphasia (five sites) and provided to patients with long-term aphasia (one site).

Eight of the 12 responding therapists stated that some technological investments have been made to continue offering computer-based therapy. Five sites started using other applications and software for aphasia. Although not all respondents provided figures on the number of patients now receiving computer therapy per year, some reported figures ranging from 20 to 100 in different NHS Trusts.

Framework analysis open-ended questions

The working analytical framework used to analyse raw data is summarized in Table 2. A total of 29 codes, organized into six categories, were clustered into the three impact domains specified in the survey. The main findings are presented by domain and illustrated with participant's quotes (P: participant number, Q: question number). The most coded themes centred on improvements in practices, investments in infrastructure, increasing SLT profiles, and willingness to participate in research.

Domain 1 capacity-building

Capacity-building at the individual level

Participating therapists gained knowledge about the research process and new skills in setting up, personalizing, and tailoring the vocabulary of the computer therapy software used by the study (StepbyStep). They described being enthusiastic and confident about making computer therapy an integral part of rehabilitation therapy.

skills in gaining consent, skills in explaining therapy, awareness of research methods, use of QOL (quality of life measures). (P8-Q13)

My own clinical skills in the practicalities of setting up the software are much better! I feel comfortable with the software having had time to learn it and can use it readily and easily. (P1-Q13)

It was highlighted that the trial results have prompted therapists to develop other approaches to achieve generalization of the word-finding gains evidenced in the trial, and also to measure conversational therapy outcomes in routine practice.

I also am now keener to see how we can make the computer programme an integral part of therapy and evaluate ways to measure outcomes in conversation. What do we need to do? What did we miss? (P10-Q29)

The study's emphasis was on the use of a computer patient centred programme. The additional concentration was also on the carryover to conversation. Although this has not been clearly shown in the study the need to include this has been an essential more developed addition in my approach to therapy. (P10-Q13)

Capacity-building at an organizational level

A large number of comments were focused on an increased SLT profile from participation in a large multicentre trial. Knowing the trial results, that it does improve word-finding ability in people with aphasia, built confidence to incorporate computer therapy into everyday practices amongst whole teams and not just therapists who had participated in the research, leading to new approaches to providing therapy. Also, participation in the study enabled therapists directly involved to cascade their learning by providing training opportunities for community groups and wider SLT team members to become familiar with the computer software.

StepbyStep software was already being used prior to the study but now there is an evidence base for its use so clinicians may be more confident in using it and explaining why this therapy has been selected to help with word finding. (P11-Q12)

Regarding collective improvements, three areas were mainly reported. First, an increased awareness of the available software, apps and online therapy packages for aphasia. Second, a collective interest in incorporating computer therapy into their practice. Third, the introduction of new approaches within services, for instance meetings to review research evidence, the use of new outcome measures, and interest in exploring computer-based therapy by other disciplines. However, three responding therapists reported some limitations that have disbanded these initiatives and constrained participation in other trials including staff changes and limited capacity and resources within NHS Trusts.

The marked increase in offering patients computer-based therapy has been good

evidence of the change in therapy approach. (P10-Q28)

Initially a few like-minded clinicians created a small group, but staff changes resulted in the group disbanding. In terms of wider partnerships, we also reached out in Stroke to surrounding areas to share best practice etc. but again due to distances and staff changes it often lapses for long periods. (P4-Q20)

As obtaining informed consent is an integral part of recruiting participants to a research project and the Big CACTUS study used new approaches to obtaining informed consent from people with communication disorders in line with the Mental Capacity Act (2005), participation of SLT departments in the study has influenced the ways in which SLTs assess mental capacity in routine practice.

The impact of the study has been that it was a major innovator for change in the use of the computer programme approach, obtaining consent, mental capacity, research involvement, the impact of carers and the involvement of patients. I think it provided a very good scaffold of what is needed to look at SLT and therapy approaches. (P10-Q29)

An increase in dissemination activities related to the study results and better-informed support offered from SLT teams were reported. For instance, providing information about computer-based therapy for individual patients, and training activities to explain the software and disseminate trial findings to new therapists, students, other professions and disciplines, and local support groups.

I share the booklets produced as part of the study with SLT students and new starters to ensure they are aware of it, and offer demonstrations to show them how to use the software. (P1-Q25)

The emphasis on better and more informed support from SLT and Rehabilitation assistants with patients has been a good move forward from the research. (P10-Q15)

No specific changes in management structures were reported. However, some new roles among the SLT teams included being in charge of setting up the software, supporting remote therapy, offering advice on computer ther-

apy to other team members, and teaching responsibilities as mentioned before.

the local PI has been identified as a key 'link' for team members to contact for advice/support in relation to computer therapy and research. (P12-Q14)

Domain 2 research development

Research culture

The majority of responses mentioned an increased interest in exploring future opportunities in research, including research roles. Also, a change in research awareness, specifically in areas such as data collection, research methods, and the Trust research processes. Having participated in the Big CACTUS project, responding therapists described how research felt more like something that was okay for them to be part of and less of an 'Ivory tower' occupation.

Participating in research really opened my eyes to how this data is collected and used. Research feels less elite than it used to do. (P3-Q18)

An understanding of the Trust process has been also an important factor. Referrals into the research support team is now more widely known. (P10-Q18)

This study was really the first one that SLT services in (xx Trust) had been a part of and so the impact/interest/awareness in it has been big. I think before this study it was perhaps felt that it wasn't something we could contribute to as we are not part of a teaching hospital etc, but this was a misconception. (P1-Q18)

After the study, some SLT teams started sessions to review new evidence in all areas of clinical relevance as a regular agenda item in peer group sessions, and discussion activities, which represents an enhancing of evidence-based practices for and beyond aphasia. Some responding therapists expressed a sense of contribution to developing the evidence base of the profession after participating in the trial.

The interest in research has gone wider than simply in terms of StepbyStep and we had



a very successful and interesting study day around dysphagia. (P4-Q15)

Research capacity

For some NHS Trusts, the Big CACTUS trial was the first opportunity to be part of a research project. Furthermore, responding therapists from four sites reported having participated or are currently participating in other research initiatives such as the Linguistic Underpinnings of Narrative in Aphasia (LUNA, 2018) project, and participation in The National Confidential Enquiry into Patient Outcome and Death (NCEPOD, 2019) and Parkinson's audit.

New research networks and collaborations were also reported: internal collaborations with research support teams and external collaborations with government research organizations, for example, National Institute for Health Research (NIHR), Trust lead for nursing, midwifery & AHP research, and the Trust Research and development (R&D) team. Additionally, participation in the trial has been used to support funding requests and applications to undertake research training opportunities at postgraduate level.

and feel more connected with the NIHR than ever before (receiving email alerts about the new evidence base etc and sharing these with the team). (P1-Q20)

Domain 3 health benefits

Patient experience

Among the improvements mentioned in this area, the computer therapy approach trialled in Big CACTUS was described as a patient-centred approach and an alternative form of providing therapy for patients with aphasia that represents a new model of care.

The majority of responding therapists agreed that computer therapy has represented an alternative to access therapy more regularly, provides an increased therapy dose and is a flexible alternative for patients 'when they wish and as frequently as they wish' (P12-Q15). For patients with long-term stroke it has provided an opportunity to receive therapy where they would not have done before. Furthermore, the inclusion of family carers in the therapy process provided them with new skills and provision to offer better support and help to patients using computer therapy at home.

people with aphasia are able to receive more therapy, instead of relying on a weekly face to

face visit or feeling lost when services end. (P1-Q16)

Several people with long-term aphasia (20 years+ in one case) have done so. (P12-Q24)

Some participants had not used a computer before but did so successfully—this encouraged them or their carers to consider the use of computer therapy or apps going forward. (P12-Q09)

One important emerging code was patient empowerment. Four responding therapists described that the trial intervention enabled patients to have more independent practice and select their own words and vocabulary of interest. After trial completion, participating patients and families had increased awareness of aphasia support groups, were keen to be involved in research, and have considered the use of other communication therapy apps. Furthermore, six responding therapists remarked on improvements in patients' communication, mood, well-being, and a sense of purpose by taking part in research.

Step by Step software enables clients to have greater influence over the vocabulary they want to practise in therapy and they are able to make choices more easily than if asked to generate core vocabulary independently as they select items from a 'menu'. (P11-Q29)

Some people became aware of new local support groups just through being in touch with SLT services again, which were not available at their time of discharge (P1-Q11)

Improving the health system

The acknowledgement of the study results has encouraged the use of computer-based therapy and supported investments and funding in computer therapy resources. Some participating NHS Trusts have invested in tablets, laptops, iPad, and headsets, others have incorporated new licences, or the software package offered by the study has been updated since the end of the Big CACTUS trial. Some responding therapists illustrated a growth in health literacy about computer-based therapy for aphasia among staff and patients which has furthered a greater request from patients. Given that, computer-based therapy has become the norm as part of the aphasia pathway in some participating trust and can be continued to be offered to patients.

A number of iPads have been sourced from the Trust IT Dept and therapy apps installed to ensure equity of access for patients in the local area. (P12-Q22)

On the basis of the research involvement; funding was made available to allow more access to Step by Step for stroke patients across the county, this has been continued. In general there has been an increase in using computer therapy (P4-Q12)

Increasing knowledge and access to computer therapy for SLT in general has led to an increased request from patients. (P10-Q24)

Three responding therapists perceived that StepbyStep, the software used in the trial, can be complex, labour intensive, and time consuming, which promoted the use of other aphasia software options.

We have used Step by Step. However, because it is quite a complex programme access to other programmes such as Tactus and Cuespeak have been used. (P10-Q25)

Some responding therapists perceived more adherence and compliance with some of the recommendations included in current guidelines. Specifically, by offering support for carers and more therapy opportunities for patients to achieve the target recommended by NICE guidelines on Stroke rehabilitation in adults (2013) '*offer at least 45 min of each relevant stroke rehabilitation therapy for a minimum of 5 days per week...*'

I think generally because the approach allows for more access to therapy, people with aphasia are able to receive more therapy, ... so I guess further adherence to clinical guidelines which suggest how much therapy people with aphasia should receive has been achieved. (P1-Q16)

Finally, an important emerging code was the benefits of computer therapy during the COVID-19 pandemic. A consistent view was that due to the pandemic there was low priority and restrictions on the number of home visits and face-to-face appointments. Consequently, it was perceived that computerized therapy has been very much used with greater recognition of the benefits.

This has proved particularly useful at the moment where due to Covid 19, we are limiting the number of home visits we conduct

... and people with aphasia therefore have access to self-directed work (where they may not have had access to anything before). This has undoubtedly resulted in improved care for patients in the long term. (P1-Q12)

DISCUSSION

This study was conducted to identify the impact of the Big CACTUS trial since study completion within NHS Trusts, from the participating SLTs perspective. It is important to note that no audit of computer therapy use was conducted before or after the Big CACTUS study and therefore impacts described in this survey do not represent objectively measured change.

The online questionnaire identified benefits in three impact domains proposed by the VICTOR framework: capacity-building, research development, and healthcare benefits. We found that taking part in the Big CACTUS trial was a positive experience for therapists involved which provides context for their perspectives. The most frequently referenced benefits by responding therapists were improvements in therapy access, changes in clinical practices, an improvement in SLT profile, and an increase in research culture. In contrast, impact on changes in the workforce, new networks, and guidelines were reported less frequently. Using the domains evaluated by the study, the following describes the importance of these findings and potential implications for practice.

Capacity-building

This domain reflected on the development of higher and sustainable levels of knowledge and skills and the expansion of infrastructure through planning and organization to offer better quality of practices at an individual or organizational level (DeCorby-Watson et al., 2018).

This study identified positive findings in four of the six capacity-building principles described in the literature by Cooke (2005): improvements in dissemination activities, investments in infrastructure, networking and collaborations, and increase of the SLT profile. At an individual level, the survey found that participation in Big CACTUS provided new knowledge, skills and training opportunities, strengthened confidence in the use of computer-based therapy, and led to changes in clinical practice. At an organizational level, the most significant benefit was the increased profile of the SLT profession.

These results reinforce similar findings by other authors, who have recognized that trial participation provides clinicians with a better understanding of research findings,



increases interest in using study results, and exploits the information gained by the research (Boaz et al., 2015). Similarly, strengthening and promoting the use of new skills acquired among participating staff, facilitates the consolidation of the benefits of the research, which can be used to expand and modify current practices (Cooke, 2005). Therefore, for Big CACTUS, these identified benefits can ease future attempts to use computer therapy, support the development of collective initiatives, and improve the provision of computer therapy in the long term. It must be noted, however, that systemic difficulties such as turnover of staff was perceived by some responding therapists to limit sustainability of capacity developed and continuation of improvements made. Such difficulties with sustainability of improvements in healthcare are well documented in the literature generally and recent SLT implementation literature within this journal (Stirman et al, 2012; Shrubsole et al, 2022).

Research development

This domain focuses on activities at different levels to promote, support and develop individual or collective research projects, expand clinical and academic research activities, strengthen collaborations, and create a research culture within organizations (Cooke et al., 2018).

This study found positive changes in three of the six principles of research capacity development described by Gee and Cooke (2018): promoting the dissemination of research findings, supporting linkages and collaborations, and developing research skills and confidence in the health service workforce. The survey results showed that all responding therapists identified an increase in research culture with a greater interest in research involvement and evidence-based practice, which represents a welcoming environment for research projects within NHS Trusts. Also, an increase in research capacity was identified within five participating sites through the participation in other trials after the end of Big CACTUS and the development of new research networks, including external and internal collaborations. It is important to acknowledge that the responding therapists were drawn from the group of therapists committed to supporting the Big CACTUS project for 5 years and as such were likely to be a group already receptive to the potential research might offer.

In keeping with the evidence that teams with better research knowledge, culture, and awareness facilitate knowledge translation activities (Alison et al., 2017), these findings revealed opportunities to implement the computer therapy offered by the Big CACTUS trial. Furthermore, encouraging staff participation in research con-

stitutes an opportunity for clinicians to apply research evidence to daily practice, understand the practical procedures of research initiatives, and boost research capacity within organizations (Jones et al., 2013).

Healthcare

Given the fact that the topics covered by this domain are extensive, this study focused on examining changes in clinical practices, patient empowerment, health literacy, development of guidelines and policies, infrastructure investments, and workforce. In the current study, most of the responding therapists perceived positive changes in clinical practice represented by increased therapy dose and opportunities to access therapy, which prompted perceived improvements in patient experience. Additionally, three valuable impact findings were: (1) computer speech and language therapy has allowed long-term patients with aphasia to access computer therapy (often face-to-face therapy is not available beyond a few months post-stroke); (2) most of the participating SLT departments have invested in equipment to provide computer therapy after trial participation; and (3) some practices applied during the study are still in use within NHS Trusts. These results can be explained by three mechanisms. First, the evidence of the potential benefits of a higher therapy dose in aphasia. Knowing that the average therapy dose for aphasia is probably insufficient, and more hours of therapy per week are needed to improve communication disabilities (Bhagal et al., 2003), there is a growing interest in providing intensive therapy to patients with aphasia. As mentioned by Basso and Macis (2011), individuals with chronic aphasia can benefit from therapy if it is 'sufficiently prolonged or intensive', something that is not always feasible with face-to-face therapy but represents an opportunity provided by computer therapy.

Second, it is common that research activities promote investments in infrastructure and resources to conduct research and remain in place after trial completion (Ozdemir et al., 2015). Third, it is recognized that there is an association between organizations that are active in research or participate in large and well-conducted trials with improved healthcare performance, the development of research networks, and the formalization of research efforts within their structures, regardless of the trial results (Thangaratinam & Khan, 2015; Boaz et al., 2015).

Survey results showed that computer therapy is perceived to complement traditional therapy and promote independent practice among patients. These findings are similar to those reported by Van de Sant-Koenderman (2011), who mentioned that computer technology in aphasia not only increases the amount of recommended therapy

but also offers patients the opportunity to take greater control of their rehabilitation therapy at their own pace.

Although some responding therapists perceived an impact of the computer therapy on individual patients' quality of life, this information needs to be interpreted with caution considering that the Big CACTUS trial did not find significant differences in quality-of-life improvement between the computer therapy and control groups (Palmer et al, 2019). Additionally, survey findings underlined the importance of carers participation in the study. As stated by NHS (2016), this is a role that contributes to promoting the use of new technologies at home, communicating patients' experiences to the SLT team, and identifying what works in the process of care.

One unanticipated impact of Big CACTUS was the acknowledgement that the self-managed computer approach has been useful and practical during the COVID-19 pandemic, enabling continuity of care for patients when face-to-face therapy was interrupted. This result corroborates the ideas of Kearney from NHS Confederation (2020), who described how COVID-19 pandemic has transformed NHS services to online routine care, especially with long-term conditions. We can say that the specific characteristics of the computer speech and language therapy, such as home-based practice, tailoring exercises to patient's needs, low costs, and accessibility, explain the identified opportunities of computer therapy for patients in the context of the COVID-19 pandemic. Although the COVID-19 pandemic has affected the capacity to provide face-to-face rehabilitation therapy for patients with aphasia, it has also driven the development of emerging remote services and online technologies, including computer rehabilitation therapy; which could represent an opportunity of expansion and research in this area (Kong, 2021). It is likely that the pandemic, therefore, played a part in accelerating and consolidating the impact of Big CACTUS research evidence.

Finally, it is frequently stated that it takes 17 years for research to 'get into practice' on average. Some of this time lag is related to research processes and time delays within this (first gap in translation), and some of the time is related to getting research evidence used in practice (second gap in translation) (Morris et al., 2011). Sanders (2016) describes how getting research into practice requires the integration of explicit knowledge (research results) with tacit knowledge (experience from daily practice). He explains how explicit knowledge needs to be useful for the end user. Research is often conducted in contexts that are controlled and therefore different to clinical practice contexts reducing the immediate usefulness or applicability and transferability of the knowledge. Tacit knowledge requires time for end users to reflect on integration of explicit knowledge with their clinical experiences and

reflection time is often in short supply. This study has demonstrated impact at trial sites within 2 years of trial completion (4 years since the last participant was randomized to the trial). We propose two factors that may have accelerated the impact of the trial and its findings. First, Big CACTUS was a pragmatic trial conducted within SLT departments with the population care is typically provided for and implemented within this context by SLTs using standard Trust processes. This may have increased applicability and transferability of the knowledge created, reducing the translational gap. Second, engaging SLTs in the study to identify participants and provide the intervention may have provided an opportunity to reflect and integrate explicit and tacit knowledge of these staff members who still remained in the SLT departments after the trial completion.

STRENGTHS AND LIMITATIONS

This study has some important strengths. The primary research involved 12 principal investigator SLTs representing impact at 12 different NHS Trusts across the UK. The use of a validated instrument (VICTOR framework) for measuring impact, the application of the framework analysis, and double coding provided transparency and trustworthiness of the results. To improve reliability, each domain was evaluated using different questions, which functioned as a control to verify the consistency between answers.

Another strength is that this project explored the impact on capacity-building and research development independently. These domains are considered relevant contributors to support individual or organizational research initiatives, encourage the co-production of research, and mobilize evidence to clinical practice (Cooke et al., 2018). For the Big CACTUS trial, the identification of resources in those areas is likely to have facilitated the impact of the study.

However, some of the limitations are the low response rate (only 12 of the 21 PIs participated) which will have affected the range of views elicited with the potential risk of non-response bias and the lack of detailed qualitative information of some impact areas. The diversity of respondents was limited to the PIs/lead therapists at the participating sites. It was not known the extent to which these respondents' sought views from other staff at their sites and how many staff with different roles they may have been representing in their responses. Engaging staff at sites beyond the PIs may have broadened the perception of impact captured in this study. As ethics approvals for this study restricted collection of specific data about the sites which may have been identifiable, we do not



know how similar the responding NHS Trusts were to each other or how representative they may have been of other NHS Trusts that were not involved in the Big CACTUS study. Due to the scope of the impact evaluation, minimizing respondent burden by keeping the questionnaire short was difficult. This may have increased the risk of abandoning the questionnaire and submitting less detailed responses (Story & Tait, 2019). Although the survey format constituted a pragmatic approach to explore opinions during the COVID-19 pandemic, the depth of the data gained by open-ended questions in a survey is not as rich as that possible from interviews and other potential areas of impact may not have been elicited. Moreover, the focus on capturing change in the questionnaire resulted in requesting qualitative explanations for 'yes' answers, that is, where change was perceived. This introduced a bias implicitly suggesting to respondents that positive answers were more welcome than negative ones. This resulted in a missed opportunity to capture negative experiences that may be helpful in designing research to better facilitate participation. The lack of balance also meant that we did not take the opportunity to elicit views on where and why impact may have been limited.

Further evaluations should involve end-users and other stakeholders, use interviews, and measures of additional indicators, both positive and negative. These approaches may cover other domains not assessed in the current project and offer more in-depth data about the impact of SLT department participation in the Big CACTUS trial. Finally, this impact evaluation was limited to impact specifically observed within SLT departments that took part in the Big CACTUS trial and is therefore not representative of its wider impact. Additional areas of impact to investigate over the medium and long term include: influence of Big CACTUS findings on Stroke guidelines for SLT both nationally and internationally (mention of this was made in the survey results but it was potentially too soon for changes in guidelines to have been made); uptake of computer therapy approaches in SLT departments across the UK and beyond; and impact of Big CACTUS findings on the ongoing development of StepbyStep software and other SLT computer therapy applications.

CONCLUSIONS

This primary research constitutes the first step in measuring the impact of the Big CACTUS trial. The impacts perceived to be directly relevant to clinical practice were identified as: (1) the use of computer therapy to improve accessibility and continuity of care for patients with aphasia in the long term; (2) the impact of computer therapy

on increasing therapy dose and encouraging more active patient participation; and (3) enabling access to therapy in circumstances when traditional approaches are limited, such as the recent COVID-19 pandemic.

Other forms of impact included participation in the trial influencing investment by NHS Trusts in technology to offer computer therapy to new patients. Furthermore, being part of the Big CACTUS trial had an impact on raising the profile of the SLT profession within participating NHS Trusts, fostering research participation, improving research networking, leading to take up of research training opportunities, and influencing whole team focus on evidence-based practice.

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CONFLICT OF INTEREST

Dr Rebecca Palmer, second author, declares her role as the grant holder and chief investigator of the Big CACTUS project used as a case example in this paper.

DATA AVAILABILITY STATEMENT

Data contributing to this paper are available from the authors upon request.

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REFERENCES

- Alison, J.A., Zafiroopoulos, B. & Heard, R. (2017) Key factors influencing allied health research capacity in a large Australian metropolitan health district. *Journal of multidisciplinary healthcare*, 10, 277.
- Basso, A. & Macis, M. (2011) Therapy efficacy in chronic aphasia. *Behavioural Neurology*, 24(4), 317–325.
- Belter, C.W. (2015) Bibliometric indicators: opportunities and limits. *Journal of the Medical Library Association: JMLA*, 103(4) 219.
- Bhagal, S.K., Teasell, R. & Speechley, M. (2003) Intensity of aphasia therapy, impact on recovery. *Stroke; A Journal of Cerebral Circulation*, 34(4), 987–993.
- Boaz, A., Hanney, S., Jones, T. & Soper, B. (2015) Does the engagement of clinicians and organisations in research improve healthcare performance: a three-stage review. *BMJ Open*, 5(12), e009415.

- Buxton, M. & Hanney, S. (1996) How can payback from health services research be assessed? *Journal of Health Services Research & Policy*, 1(1), 35–43.
- Cooke, J. (2005) A framework to evaluate research capacity building in health care. *BMC Family Practice*, 6(1), 1–11.
- Cooke, J., Gardois, P. & Booth, A. (2018) Uncovering the mechanisms of research capacity development in health and social care: a realist synthesis. *Health Research Policy and Systems*, 16(1), 1–22.
- Cruz Rivera, S., Kyte, D.G., Aiyegbus, O.L., Keeley, T.J. & Calvert, M.J. (2017) Assessing the impact of healthcare research: a systematic review of methodological frameworks. *PLoS Medicine*, 14(8), e1002370.
- Decorby-Watson, K., Mensah, G., Bergeron, K., Abdi, S., Rempel, B. & Manson, H. (2018) Effectiveness of capacity building interventions relevant to public health practice: a systematic review. *Bmc Public Health [Electronic Resource]*, 18(1), 1–15.
- Gee, M. & Cooke, J. (2018) How do NHS organisations plan research capacity development? Strategies, strengths, and opportunities for improvement. *BMC Health Services Research*, 18(1), 1–11.
- Jones, M.L., Cifu, D.X., Backus, D. & Sisto, S.A. (2013) Instilling a research culture in an applied clinical setting. *Archives of Physical Medicine and Rehabilitation*, 94(1), S49–S54.
- Jones, N.L., Cooke, J. & Holliday, J. (2020) Making occupational therapy research visible: amplifying and elevating the contribution and impacts. *British Journal of Occupational Therapy*, 84(4), 197–199.
- Kearney, M. (2020) NHS Reset: Is technology the answer to supporting patients with long term conditions after COVID-19 [online]. NHS Confederation. [Accessed 3 September 2020]. Available from: <https://www.nhsconfed.org/blog/2020/08/is-technology-the-answer-to-supporting-patients-with-long-term-conditions-post-covid19>
- Kiernan, M.D. & Hill, M. (2018) Framework analysis: a whole paradigm approach. *Qualitative Research Journal*, 18(3), 248–261
- Kong, A.P.H. (2021) The impact of COVID-19 on speakers with aphasia: what is currently known and missing? *Journal of Speech, Language, and Hearing Research*, 64(1), 176–180.
- Kuruville, S., Mays, N. & Walt, G. (2007) Describing the impact of health services and policy research. *Journal of Health Services Research & Policy*, 12(Suppl 1), 23–31.
- LUNA, Language Underpins Narrative in Aphasia. (2018) City, University of London, UK. [Viewed 3 February 2020]. Available from: <https://blogs.city.ac.uk/luna/>
- Milat, A.J., Bauman, A.E. & Redman, S. (2015) A narrative review of research impact assessment models and methods. *Health Research Policy and Systems*, 18(13), 18
- Morris, Z.S., Wooding, S. & Grant, J. (2011) The answer is 17 years, what is the question: understanding time lags in translational research. *Journal of the Royal Society of Medicine*, 104(12), 510–520.
- National Confidential Enquiry Into Patient Outcome And Death [NCEPOD]. (2019) Dysphagia in Parkinson's Disease [online]. NCEPOD. [Viewed 3 February 2020]. Available from: <https://www.ncepod.org.uk/Dysphagia.html>
- National Health Service [NHS]. (2016) A bite size guide to: Involving Carers 05428 [online]. NHS England. [Viewed 3 Sept 2020]. Available from: <https://www.england.nhs.uk/wp-content/uploads/2016/12/bitesize-guide-carers.pdf>
- National Institute For Health And Care Excellence [NICE]. (2013) *Stroke rehabilitation in adults. Clinical guideline CG162 [online]*. British Standards Publications. [Viewed 06 Feb]. Available from: <https://www.nice.org.uk/guidance/cg162>
- O’Cathain, A. & Thomas, K.J. (2004) ‘Any other comments?’ Open questions on questionnaires—a bane or a bonus to research? *BMC Medical Research Methodology*, 4(1), 1–7.
- Ozdemir, B.A., Karthikesalingam, A., Sinha, S., Poloniecki, J.D., Hinchliffe, R.J., Thompson, M.M., et al. (2015) Research activity and the association with mortality. *Plos One*, 10(2), e0118253.
- Palmer, R., Dimairo, M., Cooper, C., Enderby, P., Brady, M., Bowen, A., et al. (2019) Self-managed, computerised speech and language therapy for patients with chronic aphasia post-stroke compared with usual care or attention control (Big CACTUS): a multicentre, single-blinded, randomised controlled trial. *The Lancet Neurology*, 18(9), 821–833.
- Palmer, R., Dimairo, M., Latimer, N., Cross, E., Brady, M., Enderby, P., et al. (2020) Computerised speech and language therapy or attention control added to usual care for people with long-term post-stroke aphasia: the Big CACTUS three-arm RCT. *Health Technology Assessment (Winchester, England)*, 24(19), 1–176.
- Sanders, J. (2016) Getting research into practice: the challenge for improvement in healthcare. *Journal of Health Specialties*, 4(3), 172–177.
- Shrubsole, K., Rogers, K. & Power, E. (2022) Sustaining acute speech–language therapists’ implementation of recommended aphasia practices: a mixed methods follow-up evaluation of a cluster RCT. *International Journal of Language & Communication Disorders*, 57(1), 152–171.
- Stirman, S.W., Kimberly, J., Cook, N., Calloway, A., Castro, F. & Charns, M. (2012) The sustainability of new programs and innovations: a review of the empirical literature and recommendations for future research. *Implement Sci BioMed Central Ltd*, 7, 17.
- Story, D.A. & Tait, A.R. (2019) Survey research. *Anesthesiology*, 130(2), 192–202.
- Thangaratnam, S. & Khan, K.S. (2015) Participation in research as a means of improving quality of care: the role of a principal investigator in multicentre clinical trials. *The Obstetrician & Gynaecologist*, 17, 55–61.
- Van De Sandt-Koenderman, W.M.E. (2011) Aphasia rehabilitation and the role of computer technology: can we keep up with modern times? *International Journal of Speech–Language Pathology*, 13(1), 21–27.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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