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In it for the long haul: a reflective account of collaborative involvement in aphasia research and education

Simon Horton ^a, David Barnston^b, Janice Barnston^b, Colin Bell^b, Joyce Bell^b, Chris Coath^b, Ian Duffy^b, Jytte Isaksen ^c and Linda Watson^b

^aSchool of Health Sciences, University of East Anglia, Norwich, UK; ^bSuffolk and Norfolk Aphasia Research Collaboration, UK; ^cDepartment of Language and Communication, University of Southern Denmark, Odense, Denmark

ABSTRACT

Background: The involvement of service users and supporters/advocates in healthcare education and healthcare research has developed an increasingly high profile in recent years, but relatively little is known about collaborations involving people with aphasia and family members.

Aims: To reflect on and learn from the experience of collaboration, examining the ways in which the involvement of people with aphasia and family members was carried out over a fifteen-year period in the context of a UK university.

Methods and procedures: We have taken a reflective longitudinal case study approach, and used constructs from implementation theory as sensitizing concepts in a cross-sectional analysis of documents in four key activities: the Conversation Partner scheme; Reaching Further Out; Supported Communication to Improve Participation in Rehabilitation; the Aphasia Research Collaboration. We then produced narrative accounts which run through the whole period of the study. Through this process, we as authors also reflected on our own experiences of collaboration.

Outcomes and results: Conversation Partners (CP), integrated into the speech and language therapy practice placement, was the basis for almost all subsequent involvement. We deepened and strengthened the scope of the CP collaboration through funded workshops – Reaching Further Out – facilitated by Connect. Increasing the visibility of our collaboration enabled us to attract institutional support to develop our first major research undertaking, where people with aphasia played a key role in highlighting the need for the study, developing and implementing the intervention, taking part in project oversight, and helping disseminate the findings. The Aphasia Research Collaboration began as a partnership between speech and language therapy students and people with aphasia and has continued in various forms. Four narrative threads run through the period of this study: the importance of systems and people being adaptable; the contribution of leadership and commitment to continuity; a commitment to act and learn together; the importance of understanding value.

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Aphasia; patient and public involvement; collaboration; higher education; research; public engagement

Conclusions: Collaboration between people with aphasia, family members, and academic staff has been a collective accomplishment, where careful attention to learning, negotiation and adjustment have led to sustained involvement. In the future, where collaborations may be increasingly mediated through online technologies, all those involved must ensure that these are supported by robust and inclusive processes.

Background and aims

The involvement of service users and supporters/advocates in healthcare education and research has developed an increasingly high profile in recent years. In the United Kingdom (UK), for example, involvement in healthcare education is a requirement for health and social care programmes (Health & Care Professions Council, 2018; Nursing and Midwifery Council, 2018; Winn & Lindquist, 2019). In the context of health and social care research, involvement of people who use services, often called “experts by experience” has been growing steadily since the 1990s (e.g., Croft & Beresford, 1990). In the UK involvement is framed in terms of an active partnership, essential for designing and delivering high-quality research (INVOLVE, 2020; National Institute for Health Research, 2014), underpinned by a range of arguments based on rights to involvement, the value of experiential knowledge, and the quality and relevance of Patient and Public Involvement (PPI)-informed research (see Keenan et al., 2019).

Involvement of people with aphasia in education and training

Since the pioneering work of Aura Kagan (1998), people with aphasia have been involved in training family members and others in supported conversation. McVicker et al. (2009) at UK Connect used an approach to conversation partner training (CPT) where “people with aphasia . . . having themselves been trained and supported, gave direct feedback to the volunteers about their conversation skills” (p. 57). This approach has now been used in a range of educational, research and service settings (e.g., Cameron et al., 2015, 2017; Horton et al., 2015, 2010; Jagoe & Roseingrave, 2011; Sokhi et al., 2019).

The argument for using CPT to improve the confidence and skills of health professionals in communicating with people with aphasia is overwhelming (e.g., Knight et al., 2006; Leach et al., 2010; O’Halloran et al., 2011), while the case for introducing such approaches to pre-qualification clinical training is growing (e.g., Finch et al., 2013; Jagoe & Roseingrave, 2011), with benefits to students and people with aphasia alike (Cameron et al., 2015; Swart & Horton, 2014). The involvement of experts by experience more generally has been shown to help the development of students’ interpersonal skills and empathy (e.g., Perry et al., 2013), as well as enabling them to better link theory to practice (e.g., Unwin et al., 2018). However, apart from studies of CPT, very little has been published on the role of people with aphasia as educators generally in pre-qualification health and social care education, nor on their role in other aspects of higher education, such as quality assurance or during the admissions process.

Involvement of people with aphasia in research

While several studies have examined the role of PPI in research generally (e.g., Brett et al., 2014; Keenan et al., 2019; Wilson et al., 2015), little has been written about the practice of involving people with aphasia. Indeed, including people with aphasia in research that is not directly about language or communication – even as participants – has been a major challenge over the years (see Dalemans et al., 2009; Townend et al., 2007). However, involvement of people with aphasia as collaborators in research – for example, generating ideas, carrying out research, advising on lay summaries (as in this special issue), or developing participant information sheets and consent forms – has grown in recent years and benefited from a focus on practical ways in which involvement may be facilitated (e.g., McMenamin & Pound, 2019; Palmer & Patterson, 2013; Young et al., 2007).

We agree with Foot et al. (2014) who argue that: “we lack clarity about the business of involving people in health. What is it? Why do it? What does the evidence say? What are the benefits? How do I start? ... involving people is not one ‘thing’, and there is not a single lever that policymakers, service designers and citizens can pull to make it happen” (p. 6). Guidance documents on involving experts by experience in healthcare education and research do exist (e.g., Hewlett et al., 2006; INVOLVE, 2020; Towle & Godolphin, 2015). However, with the exception of this special issue (see Cruice et al., *in press*; Mc Menamin et al., *in press*; Shiggins et al., *in press*), there has been little examination of the collaborative involvement of people with aphasia as PPI (see Isaksen et al., *in press*, for a discussion of terminology, methods and outcomes in PPI) in ways that address the questions posed by Foot et al. (2014).

In this paper therefore, we aim to reflect on and learn from the experience of collaboration, examining the ways in which involvement was carried out in practice over a fifteen-year period at a UK university, asking: how possible was it to put involvement into practice and integrate involvement into the setting; what resources or institutional constraints influenced the way things were done in practice; what roles did people with aphasia, academic staff and others have, and what motivated them to be involved; how were efforts co-ordinated; and how much did people involved commit to involvement? We reflect on the meanings and benefits of involvement for those involved, and how collaborations can be sustained and expanded in the future.

Methodology

Study design

We have taken a longitudinal retrospective case study approach (e.g., Lewis, 2007; Neale, 2016; Saldaña, 2003; Thomson, 2007; Thomson & Holland, 2003; Yin, 2018), which enables us to integrate multiple sources of evidence, including reflective analysis by people involved (see Becker & Renger, 2017; O’Reilly et al., 2018), and examine change over time (Lewis, 2007; Thomson & Holland, 2003). Reflection and analysis in this study are framed by several assumptions.

Firstly, we argue that involvement of people with aphasia is an “intervention”. Rather than conceptualising “intervention” as is generally understood within a clinical model, we have assumed here that “intervention” involves activities and actions by educators,

researchers, people with aphasia and family members in attempts to change (and improve) processes or practices, whatever they may be (Richards, 2015a) and wherever they take place.

Secondly, we take the stance in line with Richards (2015b, p. 49) that PPI – or here, involvement of people with aphasia and family members – “can be seen as a complex intervention itself”, characterised by a number of components that interact with each other (Medical Research Council, 2008), while taking implementation and context into account (e.g., Datta & Petticrew, 2013; Hawe et al., 2009; May et al., 2016). Studies of PPI in healthcare and research settings have shown how the organisational culture can impact significantly on the success or otherwise of implementing involvement (e.g., Abelson et al., 2007; Jordan et al., 2014; Renedo et al., 2015). Organisational systems are themselves dynamic, entailing multiple and diverse activity settings, which interact with the intervention and may produce changes in both the intervention itself and the setting (e.g., Hawe et al., 2009; May et al., 2016). As PPI is a “peopled” intervention, we anticipate that members may themselves experience change through their involvement and that collaborations will evolve over time (see Hewlett et al., 2006).

Finally, we argue that examining, understanding, and learning from the practicalities of making involvement happen will benefit from a set of concepts to aid our thinking “in terms of the insights they provide and the directions of inquiry they suggest” (Gilgun, 2019, p. 112). We have therefore applied concepts from May’s (2013) theory of implementation to the analysis of the data, where “implementation” is defined as a process undertaken by one or more people “to bring into operation new or modified practices that are institutionally sanctioned” (May, 2013, p. 4).

The case study setting

Speech and Language Therapy (SLT) programme and Faculty structure

The new three-year undergraduate speech and language therapy (SLT) programme at the University of East Anglia, UK, enrolled its first students in 2004. The programme was embedded in the then School of Allied Health Professions (AHP), which included physiotherapy (PT) and occupational therapy (OT) programmes, and together with the School of Nursing and Midwifery (NAM) and the School of Medicine Health Policy and Practice formed the Institute of Health, later re-named the Faculty of Medicine and Health Sciences. This also incorporated the Centre for Interprofessional Practice (CIPP) and was linked to the School of Pharmacy (in the Faculty of Science).

The new programme was an opportunity for fresh ideas and innovative approaches to SLT education. Two key decisions by the then joint course directors are directly relevant to this study: firstly, by setting up a Conversation Partner (CP) scheme as part of the first-year Practice Placement module, the programme had formal ties with Connect, the communication disability network, which had trialled a CP scheme in London (see McVicker et al., 2009). Secondly, by creating a 3rd year research module, where students worked on projects initiated by research-active members of staff, the potential for collaborative involvement of people with aphasia in research was set in place.

Academic and support staff

The lead author (SH) was initially responsible for the CP programme and subsequently became key to co-ordinating involvement of people with aphasia and family members. Two other academic staff from the SLT programme and a PhD student – also an SLT – were also integral to the involvement of people with aphasia in education, student training, and research. Support staff included members of the Practice Placement team, who were involved in administration of the CP scheme; and the School's general office team, whose duties included inviting people with aphasia to be involved in training or other activities; booking rooms for training; dealing with parking and travel expenses. Faculty or other support staff from the university were involved in other activities and events from time-to-time.

Materials

We have used multiple sources of documentary data. [Table 1](#) sets out the key data sources, document types, and documents we have drawn on.

We have chosen materials which we considered significant to our area of interest, seeking out what might add to or challenge our thinking (see Gilgun, 2019). These include published and unpublished documents; accounts and analysis by individuals and groups involved in the collaboration, including the academic leads for involvement; other academic and support staff; people with aphasia, family members and students. Ethical permission was obtained contemporaneously from the Faculty of Medicine and Health Sciences Research Ethics Committee for all materials involving data collection from research participants. This included collaborative and participatory research studies involving SLT students and people with aphasia (see Hersh et al. (2021) for a discussion of ethical issues related to PPI and involvement of people with aphasia).

Data analysis

May's (2013) theory of implementation proposes four context-dependent constructs: *capability*; *capacity*; *potential*; and *contribution*, which we have used to examine the success or otherwise of the CP scheme and CP training, educational, research and other PPI initiatives in terms of: how well these fitted in with existing institutional practices (*capability*); how people – administrative staff, academics and people with aphasia – were prepared for and understood their particular roles within these initiatives (*capacity*); how motivated they were to take part (*potential*); and their overall levels of commitment to make the various initiatives happen in the long term (*contribution*). In a process of deductive qualitative analysis (DQA) (Gilgun, 2019), we examined the links between the constructs of May's (2013) theory and our data. We used these theoretical constructs as "sensitizing concepts", that is, to help us notice and name aspects of the material and phenomena which we might otherwise have overlooked, but also to reject or adapt the theory where there was a lack of fit. The process of positive case analysis enabled us to "construct theory and descriptions that account for patterns and exceptions to general patterns over the course of the research" (Gilgun, 2019, p. 113) in cross-sectional and temporal dimensions (Thomson & Holland, 2003) [Figure 1](#).

Table 1. Case study materials: key data sources, document types, and documents.

Area of involvement	Data sources	Document types or context	Documents
Education, quality monitoring and admissions	Conversation Partners (CP) and Conversation Partner Training (CPT)	CP & CPT administration and process	Feedback reports to Connect Letter to clinicians "Training the trainers" flier (2007–08) ^a CP training records; CPT feedback CP demographics Practice Educators Handbook (2011) CPT options for involvement CP Network reports
		CP development	UEA Annual Fund application (2007) Development & Alumni Relations Office (2007) "Reaching Further Out" workshop presentation "Reaching Further Out" project reports CP development proposal to the Strategic Health Authority Presentation to the Tavistock Trust for Aphasia (2005)
		CP dissemination	Horton et al. (2007) British Aphasiology Society (BAS) presentation Horton et al. (2010) UK CP Network 6 years on. 14 th IARC Presentation, Montreal Guyon et al. (2010) Learning in Partnerships poster (LIPP), City University, London Swart and Horton (2014) Horton (2015) 'In it for the long haul': invited presentation (Gothenburg, Sweden)
Undergraduate student dissertation projects		Dissertation administration	Associate Tutor (Teaching Assistant) contract ^b Invitations for people with aphasia involvement ARC 2013–14; ARC 2015–16 team meeting minutes ARC 2015–16 student research diary
		Meeting minutes and documentary records	ARC 2015–16: PI reflective diary, interim and final findings Student dissertation (2014): "A collaborative research experience" Horton, Bell et al. (2014) INVOLVE conference poster ARC (2015–16): showcase meeting video
School and Faculty Learning Teaching Quality (LTQ)		LTQ Committee documents	Health & Care Professions Council ^c consultation report: Faculty Service User (SU) involvement LTQC report on SU involvement Performance & Quality Assurance Framework (PQAF) report (2014) PQAF action plan Service User group meeting feedback
		School documents	

(Continued)

Table 1. (Continued).

Area of involvement	Data sources	Document types or context	Documents
Teaching development projects	Experts by experience (EBe) committee documents	Involvement invitation letter EBe committee terms of reference EBe meeting minutes	
	Service user accessibility record Applications for internal funding Un-published papers, reports and conference presentations	Central Car Park usage return UEA Teaching Fellowship application (2012–13) Horton (2007) Unit 5 assignment (Development of Research Practice), MA in Higher Education Practice Horton, Lane et al. (2014) presentation (Centre for the Advancement of Interprofessional Education conference) Teaching Fellowship SU involvement final report	
Research	Funded research projects	Project documents: Supported Communication to Improve Participation in Rehabilitation (SCIP-R) (2011–14)	Supported Conversation Skills for Stroke Care Staff: presentation of draft project outline (2008) SCIP-R grant application (2009) Press release (2010) People with aphasia invitations to participate Focus Group materials & records User involvement: feedback Horton, Lane, et al. (2013a) BAS ; Horton, Lane, et al.(2013b) UK Stroke Forum Horton et al. (2015)
	Un-funded research projects	Participant interviews	Supporting communication for access and participation video: https://www.youtube.com/watch?v=Ce8r_OZDj4&feature=em-upload_owner#action=share Conversation Partners scheme study: interviews Development of a telerehabilitation device process study (TREAD): participant interviews
Public engagement	Invited presentations	Stroke and aphasia community	Horton (2015) East of England Stroke Forum Horton (2019) BAS Clinical Symposium, keynote presentation: Strictly inclusion
	Academic community		UEA Knowledge Exchange event flier (2012) Horton, Bell et al. (2013) UEA, Fulbright Visiting Scholar meeting Horton (2016) (UEA, Chief AHP Officer meeting)

^aSee Appendix

^bAssociate Tutor contract, a type of contract used by the School to formalise and fund one-off “teaching assistant” roles.

^cUK regulatory body for Healthcare Professionals

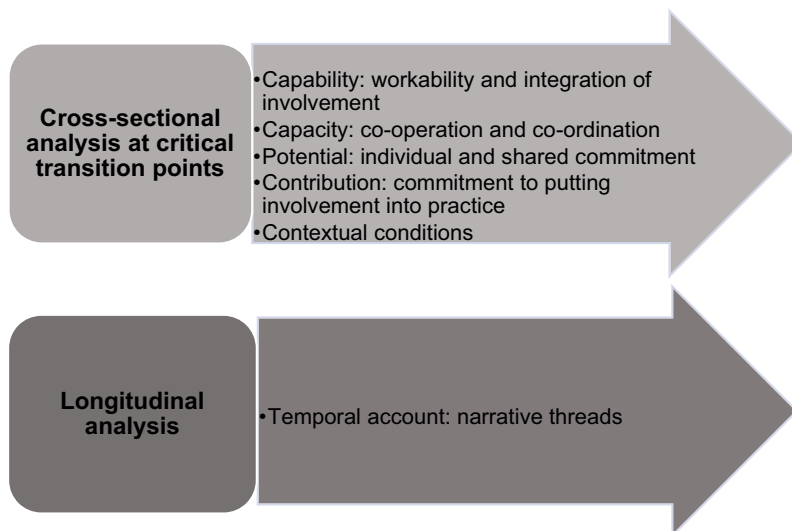


Figure 1. Cross-sectional and longitudinal analysis.

Because of the wealth of material and the extensive period reported in the study, we have focused on four activities for cross-sectional analysis, identifying what we felt to be transition points or instances which exemplify critical moments. For these, we created provisional codes from readings of the materials, which were then subject to testing, revision, or replacement (Gilgun, 2019). In so doing, we also focus on the relationship between involvement and the context(s) in which it took place (see Thomson & Holland, 2003).

We have also constructed a longitudinal account of involvement by using “through lines” (Saldaña, 2003). We reviewed and reflected on the cross-sectional analysis to develop what are essentially a series of narrative threads. These describe themes over time, in order to “capture an essence of the journey travelled, to explore how change occurred . . . and how people experienced the changes, or absence of changes” (Lewis, 2007, p. 552).

We have also included personal reflections of the authors for analysis in response to questions about: the specific benefit/rewards of involvement; the personal importance of involvement; impact on quality of life and motivation; the uniqueness of the experience of collaboration; the impact on the everyday life of participants (e.g., students; people with aphasia and family members; academics); the future of this collaboration. In addition, authors reflections on cross-sectional and longitudinal analysis are included. Apart from SH and JI, all authors are people with aphasia or family members. Authors' reflections in the text are attributed to individuals using their initials in bold.

Findings

Our findings are first set out as a 15-year timeline of involvement, showing the diverse activities of our collaboration. These activities are then displayed in the three key areas of education, research and public engagement, with some contextual information. We go on

to set out results from cross-sectional analysis of four key activities, followed by a longitudinal narrative account of and reflections on our collaboration.

Involvement timeline

Involvement of people with aphasia began in 2005 with the first in-house CP training of speech and language therapy students. [Table 2](#) shows the chronology of involvement from 2005 to 2020 grouped in four-year periods.

People with aphasia and family members have been involved in a diverse range of activities, with number and types of involvement growing over time. Some activities or activity types (e.g., CPT for SLT students; CPT for OT & PT students) have been sustained, while others have had a limited timeframe (e.g., Admissions: applicant interview panels; Supported Communication to Improve Participation in Rehabilitation (SCIP-R); REhabilitation and recovery of peopLE with Aphasia after StrokeE (RELEASE)). People with aphasia and family members collaborating in the research at UEA outlined below did not have specific research methods or PPI training. Numbers of people with aphasia and family members involved in any one activity have varied considerably, from one or two people to twelve or thirteen. This usually depended on a combination of the requirements of the activity and the desire on the part of people with aphasia and/or family members to be involved.

Activity settings

Involvement has taken place in a range of discrete activity settings. [Tables 3 and 4](#) set out overviews of activity settings for involvement in the context of education and research, respectively.

We have set out each activity or activity type in terms of those taking part, roles, purpose of involvement, resources and funding (see Hawe et al., 2009) in order to better understand in detail how involvement relates to and may or may not become embedded in the context in which it takes place.

We now go on to set out cross-sectional analysis for four key activities.

SLT student practice education: the conversation partner scheme

Conversation Partners (CP) has been the conceptual foundation and basis for almost all subsequent involvement of people with aphasia in education and research initiatives over the years:

To think this all started with a request to join a project in 2005 to be involved with SLT students having conversations with aphasic people ... (LW)

[Figure 2](#) gives an overview of the links between the Conversation Partner scheme and involvement in activity types, with some examples of activities.

Many people with aphasia have been involved in CP, although people have come and gone during this period. In the first instance SH approached contacts in the local SLT community to invite people with aphasia, who might be interested in becoming a CP trainer to prepare students for CP placement. Within four years of the first “training the

Table 2. Involvement timeline: collaboration in key activities, events and projects.

	2005 – 2008	2009 – 2012	2013 – 2016	2017 – 2020
Education, quality monitoring and admissions	<p>Conversation Partner speech therapy (SLT) student training (CPT) (2005-present)</p> <p>Involvement in Interprofessional Learning (IPL) programme (2005–17)^a</p> <p>Reaching Further Out: workshops facilitated by Connect (2007)</p> <p>CPT piloted with medical, physiotherapy (PT) and occupational therapy (OT) students (2008)</p> <p>Filming and editing Stroke & Aphasia DVD (2008–2012)</p>	<p>Classroom teaching (2009-present)</p> <p>CPT for stroke unit staff (Anglia Stroke & Heart Network) (2010)</p> <p>CPT for stroke researchers (Norfolk & Norwich University Hospitals NHS Trust) (2010)</p> <p>Foundations in Clinical Research MSc presentation (2012–17)</p> <p>School of Health Sciences (UEA) programmes course reviews (2012–17)</p>	<p>CPT integrated into 2nd Year PT & OT student timetable (2013-present) – annual training</p> <p>Aphasia Research Collaboration (ARC): SLT student dissertation projects (2013–16)</p> <p>Teaching Fellowship: Service User Involvement Steering Group (2013–14)</p> <p>Faculty Experts by experience steering group (2013–19)</p> <p>CPT for specialist rehabilitation staff (2014–15)</p> <p>Practice Quality Assurance Framework (PQAF) meeting and action planning (2014)^b</p> <p>Admissions: applicant interview panels (2014–18)^c</p> <p>Tavistock Trust for Aphasia Student Prize panel (2014-present)</p> <p>Nursing student pilot CPT (2015)</p> <p>AHP & Nursing: Values Charter project (2016)</p> <p>Stroke Rehabilitation in the home environment (Norwich Electronic Assistive Technology Suite) (2016)</p>	<p>CPT piloted with 2nd Year pharmacy students (2018–19)</p> <p>SLT programme Open Days (2018–19)</p> <p>School of Health Sciences post-offer applicant visiting days (2018-present)</p> <p>CPT integrated into 2nd Year pharmacy student timetable (2019–20)^d</p>
Research	<p>Contribution to WHO World Report on Disability (2011)</p> <p>Supported Communication to Improve Participation in Rehabilitation (SCIP-R) (2011–14)</p> <p>Stroke research development scrutiny meeting (2012)</p> <p>PhD student projects (2012-present)^e</p>	<p>Development of a tele-rehabilitation device to enhance walking recovery early after acquired brain injury (2015–19)</p> <p>Bid development: Online peer-support for stroke survivors to prevent social isolation, promote well-being and reduce Emotional distress (ONLINE) (2013–2016)</p> <p>Video version of Participant Information Sheet (PIS): Functional Strength Training after stroke (FeStivAPP) (2016)</p>	<p>REhabilitation and recovery of people with Aphasia after Stroke (RELEASE) (2016–17)</p> <p>Bid development: Intergenerational research Proof of Concept study (2017–18)</p> <p>Bid development: Asset-based approaches to life after stroke: mapping the stroke pathway for people with aphasia: (2018)</p> <p>Aphasia Accessible Patient Research Experience Survey (PRES) (2018)</p> <p>Review of Experts by Experience paper prior to publication (2019)</p> <p>FeStivAPP: an app to deliver functional strength training to people after stroke (2019–20)</p> <p>Development of an asset-based process for the inclusion of adults with impairments of capacity and/or communication in ethically-sound research (project ASSENT) (2018-present)</p> <p>British Aphasiology Society Clinical Symposium presentations (2019)</p> <p>Bid development: Guided Graded Exercise Therapy Self-Help delivered via app for stroke survivors experiencing post-stroke fatigue (2019)</p> <p>Bid development: Guided graded exercise self-help to improve post-stroke fatigue in stroke survivors in the community: a randomised controlled feasibility trial and supporting process evaluation (2020)</p> <p>Suffolk & Norfolk Aphasia Research Collaboration (SNARC Aphasiology Special Issue (2020)</p>	

(Continued)

Table 2. (Continued).

	2005 - 2008	2009 - 2012	2013 - 2016	2017 - 2020
Involvement of people with aphasia				
Public engagement	<p><i>Paintaphasia</i> exhibition: exploring the impact of stroke and aphasia. Elizabeth Fry Building, UEA (April-June 2007)^f</p>	<p><i>Paintaphasia</i> exhibition. Primary Health Care Conference, UEA (July 2010)^g</p> <p>Interview re SCIP-R research: Radio Norfolk (2011)</p> <p>Quality, Innovation, Prevention & Productivity (QIPP) Education in Practice Conference (2011)</p> <p>'Stripping it Bare': UEA public engagement event (2012)</p> <p>Knowledge Exchange event UEA: showcasing stroke & aphasia DVD (2012)</p>	<p>Fulbright Visiting Scholar presentation, UEA (2013)</p> <p>UEA 50th Anniversary event (2013)</p> <p>UK Stroke Forum poster presentation (2013)</p> <p>East of England Stroke Forum demonstration (2015)</p> <p>Norfolk & Norwich University Hospital Stroke Study Day presentation (2015-16)</p>	<p>'Pint of Science' public engagement talk (2017)</p> <p>Psychology 'Meet-Up' (2017)</p> <p>Norwich Science Festival aphasia stand & workshops (2017)</p>

^aIPL includes IPL1, IPL2, IPL3 & IPL4 which relate to the years of undergraduate study. After the academic year 2016–17 IPL was no longer delivered by the Centre for Interprofessional Practice and transitioned to Health Schools. IPL2, IPL3 & IPL4, where most experts by experience involvement took place have not been delivered since.

^bThe Practice Quality Assurance Framework (PQAF) addressed the relationship between education institutions and practice learning partners (i.e., clinical placements) in relation to standards of healthcare education.

^cThe SLT programme moved to applicant telephone interviews in 2018–19, while other programmes moved to a consultation PPI model, where experts by experience were not involved in interviewing.

^dAlthough pharmacy student CPT is now timetabled, it has been put on hold due to the current Covid-19 pandemic.

^eInvolvement with PHD student projects: 1) functional therapy for people with aphasia in an Early Supported Discharge service (PIS & Consent form development; ethical review; student mentoring); 2) aerobic exercise within stroke rehabilitation (protocol development; PIS and Consent form development); 3) rights-based rehabilitation (project design and accessibility issues; PIS and Consent form development; project advisory group membership; support for recruitment; support for data analysis and dissemination).

^f*Paintaphasia* is a series of eleven works by Peter Eccleshare (d. 2012). See http://www.uea.ac.uk/about/media-room/press-release-archive/-/asset_publisher/a2JEGMIFHPhv/content/a-stroke-of-genius for the press release from the UEA archive.

^gOne of two art exhibitions at a three-day international Primary Health Care conference <http://www.nationalhealthexecutive.com/Health-Care-News/primary-health-care-in-the-spotlight-at-three-day-conference>



Table 3. Involvement in educational contexts: activity, people taking part, roles, purpose, resources and funding.

Activity	People taking part	Roles	Purpose of involvement	Resources	Funding
Conversation Partner Training (students) ¹	People with aphasia Student health care professionals Academic SLT staff	To provide training in supported communication skills To learn supported communication skills To recruit people with aphasia as trainers To organise room bookings; to prepare and organise training, including 'training the trainers' and preparation for students; to debrief and to collate feedback from trainers and trainees To organise: room bookings; travel & parking for trainers; remuneration for trainers	To provide supported communication training for student health care professionals in preparation for upcoming practice placements. To increase student communication skills, confidence, and knowledge about communication disability.	Accessible parking / taxis for trainers. Accessible training room (s). Communication materials e.g. pen, paper, maps etc. Refreshments for trainers.	School funds: ● academic and support staff salaries ● travel and out-of-pocket expenses for trainers ● training materials ● refreshments for trainers Trainers may claim payment for work done at an hourly rate if they wish. ² UEA Annual Fund grant 2006-7
Reaching Further Out workshops	Placement Office and School support staff People with aphasia Academic lead for CP scheme and SLT colleague Placement Office support staff Connect consultant	To work with academic staff and Connect consultant to develop a strategy for extending the scope of CP training. To work in collaboration with people with aphasia to develop a strategy for extending the scope of CP training. To co-ordinate attendance and support arrangements for workshops. To facilitate collaboration and participation in workshops.	To develop a strategic initiative to extend the scope of CP training to a wider student body to enhance student learning and performance across a wide range of Schools in the university. To consider possible future research.	Accessible parking / taxis for people with aphasia. Accessible meeting room. Communication materials e.g. pen, paper, maps etc. Refreshments. Office & clerical costs. Consultancy funding. DVD development and production.	

(Continued)

Table 3. (Continued).

Activity	People taking part	Roles	Purpose of involvement	Resources	Funding
Conversation Partner Training (Health and Social Care professionals)	People with aphasia Health and social care professionals Academic SLT staff	To provide training in supported communication skills To learn supported communication skills To prepare and organise training, including 'training the trainers' and preparation for trainees; to organise travel & parking for trainers and trainees. To invite trainees and organise attendance; to provide premises for training.	To provide in-service training for health and social care professionals in supported communication. To increase staff communication skills, confidence, and knowledge about communication disability.	Accessible parking / taxis for trainers at university or NHS premises. Accessible training room (s). Communication materials e.g. pen, paper, maps etc. Refreshments for trainers.	School funds: ● academic staff salaries ● travel and out-of-pocket expenses for trainers ● training materials Trainers may claim a payment for work done at an hourly rate if they wish. NHS or Social Services fund NHS or social work staff time for in-service training.
Interprofessional Learning (IPL) programme ³	People with aphasia and other experts by experience Cross-schools student health care professionals Academic staff from the Centre for Interprofessional Practice Academic staff from health schools and pharmacy Support staff from the Centre for Interprofessional Practice	To provide insights into the lived experience of disability through video presentations and / or discussions with students. To learn about the lived experience of disability. To develop and deploy training materials; to prepare people with aphasia and other experts by experience for the activity; to organise and enable student and experts by experience discussions; to collate feedback from experts by experience, students and other academic staff. To support students and experts by experience in discussions To organise: documentation and arrangements for the activity; travel & parking for experts by experience; remuneration for experts by experience	To provide opportunities for health and social care students to learn from other professions and experts by experience. To improve care quality by enabling health and social care students to develop knowledge, skills, attitudes, values and behaviours that enable effective interprofessional team working and build on partnerships with experts by experience.	Accessible parking / taxis for experts by experience. Accessible meeting room (s). Conference venue. Materials e.g. meeting documents; conference packs etc Refreshments for all.	Faculty of Medicine & Health Sciences funds academic and support staff salaries. IPL budget funds travel and out of pocket expenses for experts by experience.

(Continued)

Table 3. (Continued).

Activity	People taking part	Roles	Purpose of involvement	Resources	Funding
Classroom teaching ⁴	People with aphasia Student health care professionals Academic staff	To provide insights into the lived experience of stroke and aphasia. To learn about the lived experience of stroke and aphasia. To prepare people with aphasia for classroom teaching; to prepare students for sessions involving people with aphasia; to support people with aphasia in presentations as appropriate. To help organise travel & parking, and remuneration for people with aphasia.	To provide an opportunity for students to learn about stroke and aphasia through the lived experience of people with aphasia.	Accessible parking / taxis for people with aphasia. Accessible classroom space. Handouts as appropriate.	Schools fund: <ul style="list-style-type: none"> ● academic staff salaries ● travel and out-of-pocket expenses for people with aphasia People with aphasia may claim a payment for work done at an hourly rate if they wish.

(Continued)

Table 3. (Continued).

Activity	People taking part	Roles	Purpose of involvement	Resources	Funding
Speech & language therapy (SLT) student research dissertations: the Aphasia Research Collaboration (ARC) ⁵	People with aphasia 3 rd Year student SLTs	To be involved in doing research To learn about undertaking research as part of a team, and then individually to write up and submit a research dissertation. To learn about doing research in collaboration with people with aphasia. To supervise students and to support people with aphasia becoming involved in doing research. To organise travel, parking and remuneration for people with aphasia. To support the involvement of people with aphasia who are new to research.	The research dissertation is designed "to equip students with research skills and knowledge which will help them to engage in the culture of enquiry within their profession". ⁷ Working with people with aphasia in research is designed to: extend students' existing knowledge of the lived experience of aphasia; and to equip them with insights, skills and knowledge through close collaborations.	Accessible parking / taxis for people with aphasia. Accessible classroom space. Dissertation Handbook and learning materials as appropriate. Fortnightly team meetings in the Winter term. Supporting documents for students and people with aphasia. Recordings (video and / or audio) made and minutes taken.	School funds: ● academic salaries ● travel and out-of-pocket expenses for people with aphasia Involvement mentor funded through an Associate Tutor contract with the School.
Faculty and Schools Learning and Teaching Quality monitoring	Experts by experience, including people with aphasia and family members	To ensure that experts by experience involvement is producing optimum impact for student learning.	To influence strategy and practice relevant to experts by experience involvement for education in the Schools of Health.	Accessible parking / taxis for experts by experience. Accessible meeting rooms. Minutes and Agenda paperwork.	Faculty and school funds: ● academic salaries ● travel and out-of-pocket expenses for experts by experience
● Practice Quality Assurance Framework (PQAF) meeting and action planning	Faculty academic staff, including Experts by experience	To enable and support experts by experience involvement in committee and to review group work.	To raise matters of concern regarding experts practice, and to address problems raised by experts by experience, students, and faculty members.		
● Faculty Experts by Experience Committee Programme and Module Review	Faculty support Lead	To report to Faculty on experts by experience involvement.	To act as ambassadors for experts by experience involvement in the schools of health.		
● SLT Reference Group ⁸	Faculty support staff	To assist the good running of meetings and help prepare documentation. To organise: travel & parking for experts by experience; remuneration for experts by experience.			

(Continued)

Table 3. (Continued).

Activity	People taking part	Roles	Purpose of involvement	Resources	Funding
Admissions interview panels ^g	Experts by experience, including people with aphasia Applicants Faculty support staff Student guides University Equality & Diversity Officer	To interview applicants in relation to disability-related scenarios using pre-set questions. To undergo application interviews and respond to questions in a given time frame. To oversee the good running of applicant interviews and organise documentation. To set up interview rooms, brief applicants before interviews and guide them to interview rooms. To prepare academic staff and experts by experience through Equality & Diversity training.	To influence the process of applicant selection from the perspective of experts by experience, addressing applicant factors such as empathy competence.	Accessible parking / taxis for experts by experience. Accessible materials for experts by experience station. Accessible interview rooms. Equality & Diversity training materials.	Faculty and school funds: ● academic staff salaries ● support staff salaries ● travel and out-of-pocket expenses for experts by experience

^aCPT includes timetabled training for SLT, PT and OT students, with medical, nursing and pharmacy students having taken part in CPT pilots. Of these, 2nd year pharmacy students took part in two pilots, with training due to be introduced into the timetable in 2019–20.

^bEarly on in the SLT programme trainers were given £20 vouchers as a token of thanks. This was later discontinued after the health schools merged as this was thought to be inconsistent with what was happening elsewhere. Claims for “work done” were introduced.

^cMost experts by experience involvement took place in IPL2, IPL3 & IPL4, and included involvement of people with aphasia and family members.

^dClassroom teaching has involved a number of people with aphasia presenting accounts of their experiences to SLT, PT, OT, medical and Clinical Psychology students.

^eThe name “The Aphasia Research Collaboration” (ARC) was coined by the first group who met and worked together.

^fA mentor for people with aphasia joined the first ARC group in 2013–14. The mentor was funded through an Associate Tutor contract, a type of contract used by the School to formalise and fund one-off “teaching assistant” roles.

^gQuoted from the SLT Undergraduate Dissertation Guidelines for Students and Supervisors.

^hThe terms of reference for this group talks about having service users in the membership, but in reality, it was made up of clinicians

ⁱExperts by experience, including people with aphasia became part of the admissions process when the School of Health Sciences began to use mini-multiple station interviews, where an expert by experience occupied one “station”.

Table 4. Involvement in selected research projects: activity, people taking part, roles, purpose, resources, and funding.

Activity	People taking part	Roles	Purpose of involvement	Resources	Funding
Supported Communication to Improve Participation in Rehabilitation (SCIP-R) ¹	People with aphasia	To generate research ideas and collaborate in grant application. To collaborate with researchers on design of the intervention. To create training materials. To carry out the intervention. To participate in project oversight through Steering Committee membership. To collaborate with academic researchers on dissemination.	To provide unique insights into the experience of rehabilitation from the perspective of people with aphasia in all aspects of project design, delivery and dissemination. To work in collaboration with academic research staff.	Parking and accessible meeting venues. Travelling and all out of pocket expenses. Face to face group meetings: all materials provided in aphasia accessible formats. Printed copies of agenda / notes available at all meetings. Newsletter. Research team members available to support communication. Regular breaks. Refreshments provided.	National Institute for Health Research: Patient Benefit (RfPB)
	Academic research staff	To generate research ideas and lead on grant application. To collaborate with people with aphasia on design of the intervention. To work with people with aphasia on project oversight. To collaborate with people with aphasia on dissemination. To learn about aphasia and its impact on the person and communication. To be trained in supported communication. To use supported communication in rehabilitation as appropriate.			
	Trial participants (stroke rehabilitation clinicians)				
Development of a tele-rehabilitation device to enhance walking recovery early after acquired brain injury	Stroke survivors: people with aphasia	To collaborate with researchers, software developers, and clinicians on design of the device.	To provide unique insights into the development of a device to enhance walking recovery from the perspective of stroke survivors.	Parking and accessible meeting venues. Travelling and all out of pocket expenses. Research team members available to support communication. Research team members available to support physical involvement with the device.	NHR Brain Injury HTC – Innovation Small Funding Competition.
	Academic research staff	To lead and support device design; to support stroke survivor involvement.			

(Continued)



Table 4. (Continued).

Activity	People taking part	Roles	Purpose of involvement	Resources	Funding
REhabilitation and recovery of people with Aphasia after Stroke (RELEASE)	Software development team Physiotherapy clinicians Hardware technician People with aphasia and family members RELEASE research team members	To collaborate on device design, focusing on software development. To collaborate on device design, focusing on clinical aspects. To collaborate on device design, focusing on hardware development. To participate in project oversight. To inform interpretation of the results from the perspective of people with aphasia. To inform dissemination plan. To collaborate with researchers in dissemination of findings To collaborate with people with aphasia in developing a greater understanding of the practical implications of the findings. To benefit from the perspective of people with aphasia and how best to share the results so that they will reach people with aphasia and family members. To collaborate with people with aphasia in dissemination of findings.	To provide unique insights into the experience of rehabilitation from the perspective of people with aphasia in all aspects of project design, delivery and dissemination. To work in collaboration with academic research staff.	Parking and accessible meeting venues. Travelling and all out of pocket expenses. Face to face group meetings: materials provided in aphasia accessible formats. Printed copies of agenda / notes available at all meetings. Research team members available to support communication. Regular breaks. Refreshments provided.	National Institute for Health Research: Health Services and Delivery Research.
Aphasia Accessible Patient Research Experience Survey (PRES)	Experts by experience: people with aphasia & family members	To develop survey content for the PRES. To develop the format and presentation of the PRES. To iteratively change and adapt the survey. To advise on the process for delivering the survey. To advise on the different mediums the survey would be delivered in. To usability test the survey in both paper and iPad versions. To present findings at the launch of the survey. To present at the launch event of the survey. To co-author a resultant publication.	To advise on what is most important for people with aphasia when taking part in research. To identify the barriers to and facilitators of research participation for people with aphasia. To advise on the most accessible formats for the survey for people with aphasia and how to make the processes for implementing surveys accessible in both paper and iPad versions.	Supported Conversation techniques. Face to face group meetings: all materials sent in advance of the meeting and options for people to send their comments through in advance of the meeting. Printed copies available at all meetings. All materials produced in aphasia accessible formats. Card sorting to indicate most important issues for people with aphasia. Regular breaks provided with refreshments.	Clinical Research Network Digital Accelerator Grant.

(Continued)

Table 4. (Continued).

Activity	People taking part	Roles	Purpose of involvement	Resources	Funding
	Academic research staff	To bring together the research team and agree roles and responsibilities with team members.			
		To participate in co-production. To prepare accessible materials for meetings and provide communication support.			
		To conduct usability testing. To present findings at the launch of the survey.			
	NHS clinician	To represent NHS clinician perspective. To take part in co-production and group facilitation.			
	PPI manager from the National Institute for Health Research (NIHR) Clinical Research Networks (CRN) East of England	To conduct usability testing. To co-lead the project and organise rooms and catering. To take part in co-production. To ensure that the final products met the needs of the CRN. To liaise with Research Nurses to understand their needs and how the survey would be implemented. To co-ordinate publicity for the survey. To present at the launch event.			

(Continued)

Table 4. (Continued).

Activity	People taking part	Roles	Purpose of involvement	Resources	Funding
Development of an assent-based process for the inclusion of adults with impairments of capacity and/or communication in ethically-sound research (project ASSENT)	People with aphasia	To contribute to a working group, collaborating with representatives from other stakeholder groups including adults with: intellectual disabilities and their supporters, autistic spectrum disorders, supporters of people with dementia, people with mental health disorders, and researchers.	To collaborate on the production of information sheets and consent forms, a questionnaire targeted at researchers, an interview schedule targeted at a range of stakeholders. To receive and review the research findings from the project, and to decipher the key messages for researchers that will inform the development of reusable learning object (evidence-based guidance on including adults with impairments of capacity and/or communication in ethically-sound research).	Communication cards (pictures and words) Printed material (meeting agenda, minutes, information) in: standard text, easy text, easy read and audio according to individual preference. PowerPoint to guide meeting objectives Supporters present to scaffold language Communication tactics	Nuffield Foundation (travel and attendance time paid to group members)
	Researchers	To participate in a project advisory group alongside representatives from Office of the Public Guardian, Ministry for Justice, HRA, research team members, and other user stakeholder groups. To set the agenda to address project objectives To negotiate and provide the range of resources required for members to participate in the groups To produce all printed material in a range of formats to suit the capacity and/or communication needs of participants To feedback on progress to the Research Team			

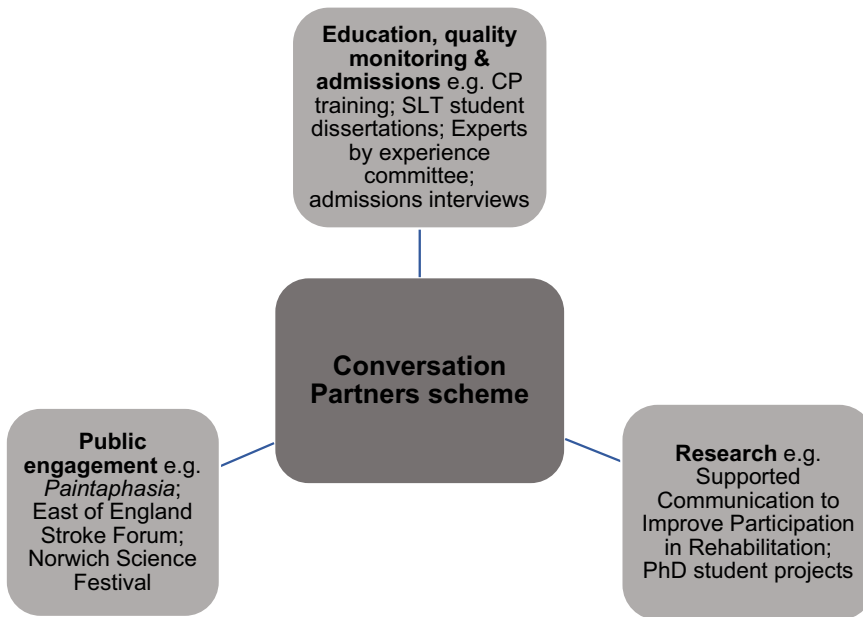


Figure 2. Overview of involvement activities linked to the Conversation Partner scheme.

trainers” initiative in 2005, twenty-one people with aphasia had trained as trainers, with around twelve people regularly involved in training. Later, through a PhD student’s work with the local Aphasia Café, we developed closer ties with and further involvement of people with aphasia and family members, especially in research initiatives.

Some trainers started as CPs being visited by SLT students in the community, but then joined the trainers’ group. As **DB** points out, CPs who are visited also contribute to student education and training, although this is less recognised. For example, a UEA “Training the trainers” flier from 2007–08 (see Appendix) emphasises the expertise of trainers in terms of the “skills and experience” they have to offer, while people with aphasia visited by students are characterised as being “socially isolated”. In an evaluation of the CP scheme (Guyon et al., 2010) SLT students emphasised the importance of learning from relationships and authentic experiences over the course of their visits.

Several contextual factors appear to have predisposed CP to uptake and further development.

Philosophical context: values in practice and student education

The CP scheme and associated involvement of people with aphasia as student educators was framed by the values underpinning Connect as an organisation, including “respect” – valuing difference; “participation” – people have the right to participate fully in choices and decisions about therapy and life; “equality” – equal rights and new opportunities for people with communication disability (Byng et al., 2002, p. 101). There is no doubt that the approach epitomised by the CP scheme did not fit with the medical model within which much speech and language therapy was carried out at the time (see Byng et al., 2002). Indeed, the view that people with aphasia had expertise to offer in terms of student

education was sometimes greeted with scepticism by family and friends. However, the practical steps towards involving people with aphasia in the scheme both as trainers and recipients of student visits, benefited greatly from good relationships between academic staff and like-minded local SLTs. The CP scheme at UEA also became part of the Connected UK CP Network (see Horton et al., 2010), which provided a valued support network.

Practice placement: workability, collective action, and monitoring

The CP scheme was set up as part of SLT practice placement, integrated into the overall placement strategy, linking education, learning, practice and theory, with access to institutional resources and administrative capability of the School and the Placement Office. Despite this, we consistently had problems booking suitable rooms for training, as these were timetabled centrally, impacting negatively on CP trainers' capabilities and experiences during training sessions. Room layout should be flexible to accommodate CP training set-up, and any Personal Evacuation Plans (PEPs) should be considered for safety of trainers and staff responsible in the event of fire.

Placement Office and other administrative staff had to get used to the concept and practicalities of "patients" as trainers and learn to enable their role as educators to be integrated into School systems. But the role of people with aphasia as experts by experience soon received enthusiastic support from administrative staff across the School. The roles of all those involved – CP trainers, academic and administrative staff and students – became better understood and clearer with practice. Students' ongoing learning from community visits to people with aphasia was enabled through reflective tutorials. We monitored the experience of training through loosely structured "de-briefs" with CP trainers and students, while also collecting more formal feedback from students on their learning experiences. The CP scheme essentially constituted an ensemble of practices, through which participants made sense of their own roles as well as the needs of the scheme and acted accordingly.

In the next section, we examine an example of how steps to promote and develop the CP collaboration were placed on a more formal footing.

Reaching further out: towards closer collaboration and greater presence

Connect had originally developed the CP scheme through a funded programme ("Reaching Out"). In 2007 SH together with an academic colleague successfully applied to the UEA Annual Fund in a bid to develop a local initiative – "Reaching Further Out" (RFO) – designed to strengthen and deepen the scope of the CP collaboration.

Beyond SLT: CPs developing a presence in the wider institutional context

In line with the remit of enhancing the student experience and being aligned with "the objectives of the UEA community as a whole" (Development & Alumni Relations Office, 2007, p. 9) the bid fitted the institutional parameters by focusing on direct benefits to students across the Health Schools, and extending the scope of a currently funded programme. The bid also emphasised the need for monitoring change through individual and collective assessment in order to "provide the relevant Directors of Teaching/Learning with evidence for including this programme as a core-funded area in the future" (Annual Fund application, 2007, p. 3).

The RFO workshops were the first occasions where we discussed – as a group – our past work and future directions. We focused on the experience of aphasia expertise as a trainer or CP in the community, reflecting on positive experiences and difficulties, discussing what we would do differently and how to shape future work. Up until now CP training had only taken place once a year with SLT students, so SH was motivated by the need to maintain the viability of the CP trainers’ group and develop new projects, as well as directing “substantial efforts to developing a meaningful dialogue with group members to establish a research-related capacity or strategy” (Horton, 2007, Unit 5 assignment, pp. 8–9). People with aphasia participated having expressed how the CP scheme made them feel useful by contributing to student education, gaining a sense of purpose and reclaiming agency in terms of control and ownership over life (see Swart & Horton, 2014). This was an opportunity to collectively agree on the purpose and potential value of future work and to set out the collective action needed to put it in place. SH was tasked with engaging with cross-Faculty colleagues to develop a programme of new initiatives. We focused on five activities: contributing to the Interprofessional Learning Programme (IPL); CP training pilots for: medical students; physiotherapy (PT) and occupational therapy (OT) students; nursing students; and developing materials for a DVD focusing on stroke, aphasia and supported communication (SC).

Facilitators and barriers to uptake of cross-Faculty involvement

As can be seen from the timeline in Table 2, implementation and normalisation of CP involvement had variable success across these new initiatives.

CP training pilots in this initiative only led to integration of CP training with PT and OT students in the long term. Key factors preventing uptake were: overcrowded teaching timetables (medical and nursing students); lack of resources, capacity and commitment in medical and nursing schools to support involvement; a mismatch between the philosophy of CP training and the perceived needs of medical and nursing students, where the focus of communication skills training was on “consultation skills”. Student feedback from medical and nursing students (where a CP training pilot eventually took place in 2015) was very positive, but not enough to motivate the relevant leads in these Schools to commit to enabling involvement. PT and OT Course Directors, on the other hand, committed enthusiastically to CP training for 2nd Year students, and with some adaptations training was timetabled from 2013 onwards. Commitment of the lead academic for pharmacy was also a key factor in integrating CP training for 2nd Year pharmacy students from 2019-20 onwards.

Individual and team commitment of academic and support staff at the Centre for Interprofessional Practice (CIPP) was also key to successful uptake and integration of CP trainers, who were involved in several Interprofessional learning (IPL) activities, not as “trainers” per se, but rather as experts by experience; later, family members also became involved; preparation for activities was always thorough and CP involvement well-supported:

We always felt well prepared and supported by the IPL team, led by NAME, for all the activities/events that we participated in (**CB & JBe**)

In the case of IPL, administrative re-organisation in 2017 meant that Faculty-wide IPL was discontinued, and CP involvement essentially ceased.

Our collaboration gradually became more visible across Faculty. The proposal from the RFO workshop to get involved in research to prove the value of CP training attracted attention from the School's Research Director, and so institutional support for our first major research undertaking began.

Supported Communication to Improve Participation in Rehabilitation (SCIP-R)

The Norfolk Conversation Partner Trainers group is listed as one of the partners involved in preparing the funding application:

Conversation Partners came up with the idea and we were involved in every aspect through to appearing on the radio publicising the project, making a YouTube video and disseminating the findings (LW)

The group's participation is listed as being both "consultation" (e.g., one-off meetings) and "collaboration" (e.g., ongoing partnerships) (see Isaksen et al., [in press](#)). Here we focus on the nature of the collaboration and how it played out over the course of the research study.

Contexts of collaboration: implementing involvement

Nineteen CP trainers were invited to consider taking part in five activities in this study: developing "supported communication" training in stroke rehabilitation (co-producing the intervention); assessing stroke staff skills in "supported communication" (intervention training outcomes); training stroke staff in "supported communication" (implementing the intervention); being part of the project steering committee (research governance); helping to publicise the results of the study (dissemination).

Workability and integration. Sixteen members took part in focus group discussions to develop and refine the intervention in a process of co-production. As a result of this work, the intervention's primary focus became "all about the person" and was readily integrated into the intervention package. Focus groups took place in the familiar setting of the university, with good physical access and support from SC-trained academic research staff. Implementing involvement in pre- and post-intervention assessment and training proved more challenging.

Framing participation: roles, resources, motivation and commitment. Clinical managers on the intervention unit spoke of their commitment to the research and encouraged their staff to participate. In order to facilitate rehabilitation staff participation, assessment and training had to take place at NHS sites. Here, finding suitable accommodation was to prove challenging. Firstly, the CP trainers were seen as "patients" rather than co-researchers or collaborators, with no rights of access to spaces on the rehabilitation unit. Suitable spaces were eventually secured, but even then, these were subject to last-minute changes, and the shift to new rooms sometimes meant that access for CP trainers was laborious (e.g., long walks for those with mobility restrictions). NHS staff participation in assessment and training was governed by shift working; we had to ensure that trainers, who made huge efforts getting to the hospital had enough work to do at any

one time, and that staff actually turned up. This was not always the case. When staff did not attend appointed sessions there was frustration, puzzlement and disappointment.

Most academic members of the Trial Steering Committee (TSC) had never met stroke survivors or people with aphasia before and were not necessarily skilled in adjusting their communication. Better preparation for them would have facilitated CP trainers' involvement. Acronyms and technical expressions are widespread in clinical trials talk, so LW and CB as well as SH had to make sure that these were clearly explained. Academic members of the TSC had to learn to appreciate new perspectives on trial conduct.

Collective assessment

Focus groups with CP trainers at the end of the study enabled us to learn about the experience of involvement. Key issues were: the assessment/training protocol had not been well-aligned to the expectations of CP trainers; that it would have helped them to have had access to staff training materials; too little time was made available for intervention training "conversations" and feedback. In terms of communication access, CP trainers highlighted how difficult it was to follow what was being said in larger groups, where individuals may have felt inhibited to talk; group discussions should be carefully managed.

Although people with aphasia played a key role in highlighting the need for this study, developing and carrying out the intervention, taking part in project oversight and helping disseminate the findings their involvement was framed by the strict parameters and tight timetables in the conduct of clinical trials. In the final cross-sectional analysis, we examine collaboration in education and research that was less tightly constrained by formalised, nationally governed processes.

The Aphasia Research Collaboration

Here we consider both the educational and research aspects of the ARC, in two iterations (2013–14 and 2015–16). Each of these embody different research approaches but each involved SLT 3rd Year dissertation students and people with aphasia, with a PPI mentor (2013–14 only) and SH as lead.

Learning about doing research: getting on the same page

The ARC (2013–14) was the first occasion when members of the group had set out to do research themselves; students were in the same boat. People with aphasia were motivated in part by a desire to help students' education, but also to focus on:

areas they were affected by and which they felt warranted further research (student interview, from 2014 dissertation: 'A collaborative research experience').

SH had an obligation to student education, but also to facilitate meaningful involvement of people with aphasia, which meant ensuring that there were adequate resources throughout; he felt that transparency was vital, but also that the project had to be addressed efficiently:

... thinking about the standard research process we need to be attentive to all the things that go into research, enabling involvement and not letting collaboration drift (SH interview, from 2014 dissertation: 'A collaborative research experience')

Students and people with aphasia learned not only about doing research but also about collaborating. Students discussed how they would not have learnt or got as much from the work without collaborating with people with aphasia; they learnt about fair, equitable and productive communication within a team; their clinical experiences in acute hospitals, for example:

had not prepared them for communicating as equals with people with aphasia (from 2014 dissertation: 'A collaborative research experience').

People with aphasia felt that students had made the collaboration easier by talking openly and without criticism; working with students was satisfying, and they all felt ownership of the research.

Mutual support, collaboration and collective action

Levels of communication impairment varied greatly among people with aphasia, and as one student (ARC 2013–14) observed, those with better communication skills were more included in group discussions. Participants with communication difficulties needed others to be respectful of the need for time and appropriate support so they could contribute to the project. Participants grew to appreciate the importance of strong balanced relationships and how these can impact positively on the success of a collaboration. In the ARC 2013–14 seven people with aphasia but only four students took part; in ARC 2015–16 this changed to six people with aphasia and six students, creating a much better support system for involvement.

The shift in ARC (2015–16) to a participatory research approach, and using methods such as World Café (<http://www.theworldcafe.com/key-concepts-resources/world-cafe-method>) and Appreciative Inquiry (e.g., Mathie & Cunningham, 2003) involved a set of values and practices, which essentially produced collaborative and collective action in themselves. In terms of implementation theory, people with aphasia and students had the freedom to explore and develop their own roles, norms of participation, resources and ways of co-ordinating action (capacity), as well as reflecting on their own motivations and commitment (potential).

This led to an initiative to make our work more widely visible through a “showcase” presentation by all involved to the Faculty and local community of people with aphasia and SLT clinicians. We were also connected through SH to the Collaboration of Aphasia Triallists research network Working Group 5 (Societal Impact and Reintegration), giving the work and the collaboration a degree of international connectedness. Through this latter connection, we were able to contribute substantially to an initiative exploring asset-based approaches to living with aphasia and a subsequent journal article (Shiggins et al., 2020).

A trajectory of collaboration: narrative threads

Conversation Partners as a concept enabled the establishment of a strong foundation for mutually beneficial collaborative working between UEA staff (academic/administrative/

technical) and those affected by aphasia and their supporters/advocates. Here we highlight four main themes running through the timeline of our collaboration.

Adaptability: systems and people

The CP scheme and its constituent elements fitted well into existing School and Faculty structures, even as these developed over the years. However, problems of involvement and normalisation arose when institutional systems did not accommodate the perspectives or needs of people with aphasia. This might be because: inflexibility was “baked in” to the system (e.g., centralised timetabling and room allocation); the system was philosophically at odds with the values inherent in CP training (e.g., consultation skills approaches); or changes were made without consultation (e.g., discontinuing the IPL programme; changes to the admissions process; changes to accessible car parking). We have seen too, in the context of research, how systems may not be adaptable; careful attention must be paid to ensure inclusion, especially for people with more severe communication impairments where large groups are gathered. In addition, there have been barriers to full inclusion through poor physical access, disabled parking situated in the wrong places, or poor and dated on-site infrastructure.

In addition, at times, “consultation” can become confused with “collaboration” in the context of research:

I felt that I had missed something. It was great to hear the results of the research, but I don't believe I was involved (CC)

Without collective assessment and tangible opportunities to “fold in” learning to some next stage of education, research development or dissemination, involvement can feel superficial. The most successful and satisfying examples of involvement seemed to be those where people were meaningfully involved in developing an idea, a product or a performance (e.g., presentation or dissemination); or incrementally exploring their own individual and collective roles in co-ordinating action and producing some output:

Not just a ‘tick box’ exercise – ideas noted and acted on. You feel like you're actually contributing. I feel involved and I feel very positive about being involved (LW)

Research projects usually have a limited lifespan, but institutional entities have the potential for continuity. The next section examines the apparent reasons for continuity or otherwise of involvement activities.

Continuity: leadership, commitment, and visibility

There is no doubt that committed leadership has been vital for continuity and the viability of our collaboration. While commitment may come from individuals, it is also supported (or not) by the institution through resources or funding for a post. Activities have fallen away where leaders have left the university (e.g., the experts by experience committee), and there was apparently no institutional commitment for an activity to continue. Of course, it is not just leaders who commit and therefore enable involvement to become “the way we do things here” (May, 2013, p. 10) – many others may be involved:

Commitment from staff at all levels has been outstanding and, most importantly, human! (ID)

Since our initial meeting we have had great support from all the staff at the university such as when a student is unable to make appointment etc. David was asked to help with training of the various medical courses, on this he was firstly supported by other trainers and university staff. **(DB & JBa)**

There is no doubt too that involvement needs resources, material and otherwise. For academic staff involvement activities and projects can be taxing in terms of workload and time commitments:

Heavy on preparation – at a time of tight deadlines and other priorities I had to put in a lot of work to: timetabling (room booking/availability) around students' and people with aphasia's availability (and what might be reasonable demands on time vs what might be necessary/sufficient for the project) (SH research diary)

Being able to anticipate time and resources needed for an inclusive approach – it's been overwhelmingly different; I think the biggest thing is the time aspect ... (Project Principal Investigator)

We found that increasing the visibility of our collaboration was vital in maintaining viability and developing new activity. This started in earnest with the RFO meetings, but has included publicising the scheme and highlighting the role of people with aphasia and family members within the university (e.g., internal news roundup for staff) and beyond (e.g., local media; public engagement activities) so as to foreground what we considered to be the essential and novel aspects of our collaboration. Awareness of aphasia is generally low in communities, and rights as well as well-being are at risk.

Just because we can't speak doesn't mean we don't have a voice **(LW)**

Leadership, commitment and collective action have led to a growth in the number and range of collaboration activities over the years. In the next section, we show how collective agreement about the purpose of collaboration and concerted action has led to a sense of cohesion.

Cohesion and learning: developing a community of practice

The CP scheme entails a range of values which have essentially underpinned our development as a collaboration. Where these values have been shared across diverse groups – people with aphasia, family members, clinicians, academics, researchers and aphasia organisations – and these groups have committed to act together and learn from the experience, the foundations for a community of practice have been laid down. This can be seen in action in the SLT CP scheme, in some of the CP training developments, and in some research initiatives, where those involved have committed to learning and improving practice:

Being part of a successful collaboration, having our voice heard can provide everyone involved with a learning experience (ARC member with aphasia)

A great deal of energy, commitment and openness is needed to bring together diverse groups, where the understanding is that learning from the experience is a vital part of developing a community of practice.

Value: impact on participants and the institution

Value in terms of the benefits of our collaboration can be viewed through time in terms of the perceptions of participants (e.g., academic staff, students or people with aphasia and family members) and the institution (e.g., programmes, healthcare professionals). We see value as “co-created” (see Hardyman et al., 2015) through interactions arising from involvement, be it in educational or research contexts.

Personal benefit in terms of psychosocial impact, connectivity, communication practice and skills development have all been highlighted by the authors:

Involvement with the U.E.A initiatives has brought meaning (self-worth and valuable activity), dialogue with peers, acceptance, respect, satisfaction, advice and enjoyment (**ID**)

I feel I can be useful helping to contribute to their [students] education and this in turn helps self-esteem, confidence and acceptance of having a disability (**DB**)

However, not everyone involved has found the experience consistently rewarding – some because they were uncertain about their role and did not know whether their contributions made any difference; others because they felt involvement has not helped them personally or was too taxing. There is a strong sense that, while people with aphasia and family members were motivated initially to participate for certain reasons, their motivations have continuously evolved according to their experiences of involvement.

We also have a sense of the value of involvement to students, both as individuals and as “the future of healthcare”:

I think you would be surprised if you could see the perception of some of the general public who seem to think if you can't articulate your thoughts you have no brain. So this scheme is helping to give some understanding to the generation of the future as I am sure students discuss their course and experiences with other students, friends, and family. (**DB & JBa**)

We know from formal feedback that students are extremely positive about the value of supported conversation skills training, and that interacting with CP trainers gives them more confidence and a greater understanding of communication barriers faced by people with aphasia.

Academics and other research project participants have expressed great appreciation for the involvement of people with aphasia, especially where they were experienced and confident in expressing their views:

Their keenness to explore the ideas initially I wondered if I'd be having to discuss everything and then asking continually what do you think what do you think I don't think I asked them once they brought ideas forward they developed their own ideas and I think that development made me feel that they were totally engaged (Research Project, Principal Investigator)

Gathering information about the experience and effects of involvement for all participants has proved to be vital to learning for development and sustainability.

Discussion

We have presented a longitudinal case study of collaboration between people with aphasia, family members and staff at one UK university. This has not been a study of how to do involvement (see Cruice et al., *in press*; Shiggins et al., *in press*) rather

a reflective exploration of what we have learned from our attempts to enact collaborative involvement across an extensive range of activities over a number of years. A conceptual framework for implementation (May, 2013) has helped guide our analysis and reflections.

We deliberately set out to explore and understand the contextual process of involvement across a range of activities (May et al., 2016). We found that invoking the “time-and-space-bounded patterns of behaviour” (Hawe et al., 2009, p. 269) inherent in all our involvement activities, has helped overcome the constraints of viewing involvement as a packaged programme or a linear model, which can be easily followed, categorised as “consultation” or “collaboration”, for example (but see Isaksen et al., *in press*). The dynamics of context as an unfolding process (May et al., 2016) have played a key role in the success or otherwise of involvement. Philosophical context and value systems, institutional practices and participation frames have all played their role. What worked quite readily in one context (e.g., CP training for education at university) was frustratingly difficult to implement in another (e.g., CP training for research in an NHS hospital), where personal and collective commitment could barely compete with existing institutional constraints. We have learned perhaps that we should use our understanding of the contextual dynamics of implementing involvement to better prepare for future work – for example, by strategically investing energy in preparing all those taking part, or promoting particular parts of the system or process to improve uptake of involvement or achieve better outcomes (Hawe et al., 2009).

The success or otherwise of involvement has also been dependent on the expectations and understanding of roles of those taking part, and how actions were co-ordinated (May, 2013). In common with other studies (e.g., Wilson et al., 2015) for example, we found that co-ordination by key individuals was important for effective and sustained involvement in any activity. The CP scheme has always been led by an academic SLT within the institution of practice placement and all its resources; in the context of research, our work on video dissemination for SCIP-R was led and efforts co-ordinated by academics from the university scriptwriting and film, television and media studies M.A. programmes with access to local cognitive, material and human resources (May, 2013).

While the role of people with aphasia as CP trainers of students generally fell within “institutionally sanctioned rules [and] . . . membership behaviour” (May, 2013, p. 6), their role in other training contexts (e.g., in SCIP-R) did not necessarily align with expectations and rules of membership. In other activities, roles had to evolve. So, people with aphasia (and family members) became experts by experience in IPL, a role needing good preparation and a clear rationale (e.g., Winn & Lindquist, 2019); they became researchers and co-producers of research in contexts where roles were initially uncertain, but which developed – or did not – in ways that were individually and collectively understood and agreed (see Keenan et al., 2019). Our experience of participatory research in the Aphasia Research Collaboration (ARC) seemed to produce the most creative and powerful collaboration because it enabled the relationship between “capacity” (role understanding and co-ordination of effort) and “potential” (motivation and shared commitment) to evolve and flourish (see May, 2013; May et al., 2016).

Monitoring involvement activities in terms of their impact, through individual and collective assessment has been important in enabling us to learn and modify, and in some cases to justify activities. But it has also enabled us to introduce new developments. We found, for example, that CP training had to be made visible in terms of benefits to

students, so as to develop new training initiatives within the institution; and that research collaborations between students and people with aphasia needed careful management in order to ensure equitable access for all. Understanding impact in terms of the experiential value of involvement has been the most beneficial approach (see Hardyman et al., 2015). So we argue that insights into the experience of involvement of people with aphasia, family members, students, academics and researchers are critical to understanding the reasons why some involvement activities are successful and become normalised, and why others are unsatisfactory and need adjustment, or perhaps fail completely (see Brett et al., 2014).

Conclusions

We have shown how meaningful involvement was produced through connections between diverse entities in particular ways at any one time. Our collaboration has been a collective accomplishment, marked by a distinct set of values and practices, which have the potential to challenge the status quo and the inflexibility of systems, and where careful attention to learning, negotiation, and adjustment have led to sustained involvement. But how can continuity be achieved? Innovative change – for example, a more prominent role for experts by experience within existing School or Faculty structures – has the potential to help sustain this and future collaborations, and we have shown how institutional leadership and commitment are vital to normalising meaningful involvement.

In these days, we must also be mindful that full and safe involvement of people with aphasia and family members now and in the future needs to be enabled in new ways. In the midst of the COVID-19 pandemic, people with aphasia and family members are using social media in ever-increasing numbers (see Mangialardi & Murphy, 2020), and at UEA CP training and CP placement are going online (Neil Coull, personal communication). In the light of what we have learned from our experiences, all those involved will need to ensure that collaborations mediated through existing and new technologies are supported by robust and inclusive processes.

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We have prepared and completed this account under the most unusual (COVID-19 pandemic) circumstances. As authors we were unable to physically meet and discuss the paper and have had to rely on online communications. This is clearly not ideal and has been particularly challenging for people with aphasia and family members, who are also experiencing the profound impact of social isolation brought about by the pandemic restrictions.

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ORCID

Simon Horton  <http://orcid.org/0000-0002-2133-1410>

Jytte Isaksen  <http://orcid.org/0000-0002-2502-029X>

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APPENDIX

Conversation Partners flyer (2007–08)

 <p>School of Allied Health Professions UNIVERSITY OF EAST ANGLIA NORWICH NRA 7TJ</p>  <h3>Training Conversation Partners for people with aphasia</h3> <p>Students study to become speech and language therapists at the University of East Anglia in Norwich. In their first year they are trained to become Conversation Partners with people with aphasia.</p> <p>We are looking for people with aphasia to join the existing training team to help in early training of students.</p> <p><u>Conversation Partners</u> 'Conversation Partners' is a programme developed by Connect in London. In the 'Conversation Partners' programme at UEA students visit a person with aphasia once a week for six months and have conversations. People with aphasia who are socially isolated have found the programme very helpful.</p> <p><u>Student training</u> Students have training at the University to prepare them to be Conversation Partners. 'Aphasia experts' - people with aphasia trained to be trainers - help with this training. They give students experience of conversation, feedback on the students' conversational skills, and advice on how to make improvements.</p> <p>- 1 -</p>	<p><u>People with aphasia: training to be a trainer</u> We always need new aphasia experts. People with aphasia who want to become trainers would attend a short course. They would, for example, learn about aphasia and conversation; what makes 'good' and 'bad' conversation and about giving constructive feedback to students.</p> <p><u>What are the benefits to you as a person with aphasia?</u></p>  <ul style="list-style-type: none"> • Share your skills, experience & expertise • Help other people to communicate better • Try out new things • Gain confidence in your own abilities • Meet and talk to new people <p>Are you interested in becoming a student trainer? Would you like more information?</p> <p>Please contact: Simon Horton or the Placement Office at UEA (telephone numbers supplied)</p> <p>- 2 -</p>
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