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Author(s)	Mc Menamin, Ruth
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National University *of* Ireland, Galway

"Evaluating Conversation Partner Programmes: Perspectives of people with aphasia"

Ruth Mc Menamin

PhD (Medicine – General Practice)

National University of Ireland, Galway

Supervisor(s):
Professor Anne MacFarlane[1] and Professor Peter Cantillon[2]

[1]Professor of Primary Healthcare Research, Graduate Entry Medical School, University of Limerick, Limerick, Ireland.
[2]Professor General Practice, Clinical Science Institute, National University of Ireland, Galway, Galway, Ireland.

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Declaration

I, the **Candidate**, certify that the Thesis is all my own work and that I have not obtained a degree in this University or elsewhere on the basis of any of this work. This work is submitted to fulfil the requirements of the degree of Doctor of Philosophy at the National University of Ireland, Galway.

The four articles presented have been previously published in peer reviewed journals. The author's contribution to each article is detailed in Table 0.1:

Table 0.1: PhD researcher's contribution to the 4 articles included in this thesis

Article	Title	Author(s)	Contribution of the PhD researcher to each article
1	Addressing the long term impacts of aphasia: How far does the Conversation Partner Programme go?	**McMenamin, R.**, Tierney, E., & MacFarlane, A.	• Article conception and design – PhD researcher lead with support from supervisor AMacF. • Review of literature – PhD researcher lead. • Drafting of manuscript – PhD researcher lead. • Critical revisions of manuscript – PhD researcher lead (with consultation from supervisor AMacF and co-author ET) • Final editing, preparation and submission of manuscript to the target journal *Aphasiology* – PhD researcher.
2	Who decides what criteria are important to consider in exploring the outcomes of Conversation Approaches?	**McMenamin, R.**, Tierney, E., & MacFarlane, A.	• Article conception and design - PhD researcher lead with support from supervisor AMacF. • Review of literature - PhD researcher lead. • Drafting of manuscript – PhD researcher lead. • Critical revisions of manuscript - PhD researcher lead (with consultation

			from supervisor AMacF and co-author ET) • Final editing, preparation and submission of manuscript to the target journal *Aphasiology* – PhD researcher.
3	Impacts of service learning on Irish healthcare students, educators and communities	**McMenamin, R**., McGrath, M. & D'Eath, M.	• Article conception and design - PhD researcher lead with consultation from MMcGrath. • Review of literature - PhD researcher lead with support from MMcGrath. • Drafting of manuscript – PhD researcher lead. • Critical revisions of manuscript - PhD researcher lead with MMcG • Final editing, preparation and submission of manuscript to the target journal *Nursing and Health Science* - PhD researcher.
4	'Training socially responsive healthcare graduates: Is Service Learning an effective educational approach?'	**McMenamin, R**., Mc Grath, M., Cantillon, P., & MacFarlane, A.	• Article conception and design - PhD researcher lead. • Review of literature - PhD researcher lead with support from MMcGrath. • Data extraction and quality appraisal - PhD researcher with MMcGrath • Drafting of manuscript – PhD researcher lead. • Critical revisions of manuscript - PhD researcher lead with support from AMacF and PC (supervisors) • Final editing, preparation and submission of manuscript to the target journal *Medical Teacher* - PhD researcher.

Apart from due acknowledgements, it is entirely my own work.

Signed: ____________________ **Date:** ________________

Ruth McMenamin

Abbreviations

CPP – Conversation Partner Programme
ESRI - Economic and Social Research Institute
HSE – Health Services Executive
IASLT – Irish Association of Speech and Language Therapists
ICPHR - International Collaboration of Participatory Health Research
NPT - Normalisation Process Theory
NUI, Galway – National University of Ireland, Galway
PAR - Participatory Action research
PCCC – Primary Community Continuing Care
PCT - Primary Care Team
PHR- Participatory Health Research
PLA – Participatory Learning and Action Research
PRA – Participatory Rural Appraisal
PWA – Person or People with Aphasia
RCSI - Royal College of Surgeons in Ireland
RCSLT – Royal College of Speech and Language Therapists
SL – Service Learning
SLT – Speech and Language Therapist
WHO – World Health Organisation

List of publications

This article based thesis is based on the following four research papers:

1. **Mc Menamin, R**.; Tierney, E.; MacFarlane, A. (2015) ‘Addressing the long term impacts of aphasia: How far does the Conversation Partner Programme go?’ Aphasiology *29*(8), 889-913. doi: 10.1080/02687038.2015.1004155

2. **Mc Menamin, R**.; Tierney, E.; MacFarlane, A. (2015) ‘Who decides what criteria are important to consider in exploring the outcomes of Conversation Approaches? A Participatory Health Research Study.’ Aphasiology *29*(8), 914-938. doi: 10.1080/02687038.2015.1006564

3. **Mc Menamin, R.**, Mc Grath, M. and D’Eath, M. (2010) ‘Impacts of service learning on Irish healthcare students, educators, and communities’. Nursing and Health Sciences 12, 499–506 doi: 10.1111/j.1442-2018.2010.00568.x

4. **Mc Menamin, R.**, Mc Grath, M., Cantillon, P., MacFarlane, A. (2014) ‘Training socially responsive healthcare graduates: Is Service Learning an effective educational approach?’ Medical Teacher April *36*, 291-307. doi: 10.3109/0142159x.2013.873118

Background

Stroke is the most common cause of disability in the western World. Approximately 176,000 new individuals in the United Kingdom and Ireland are diagnosed with stroke annually with up to one third experiencing aphasia. Aphasia is a chronic language disorder impairing comprehension, expression, reading, writing and spelling. The majority of people living with aphasia are over 65 years and live in the community. One of the most disabling impacts of aphasia is the way that it excludes the person from everyday conversation. People with Aphasia (PWA) frequently experience social isolation and marginalisation. The Conversation Partner Programme (CPP) is a community based aphasia intervention that emphasises communicative competence and life participation. Currently there is no national or international system for evaluating CPPs. Following policy imperatives for Patient and Public Involvement (PPI) and the recommendations of the World Report on Disability (WHO) it is important to involve service users in service design and evaluation. However, PWA are often excluded *because* of their communication disability. To create a CPP evaluation system PWA and other key stakeholder groups[1] must determine core evaluation criteria. Service Learning (SL), the pedagogical tool used to implement the CPP in this study must also be examined because the mode of delivery is central to stakeholders' perceptions and experiences.

Aims

The primary aim is to: (1) use a Participatory Learning and Action (PLA) approach to include PWA and other key stakeholders as *co-researchers*[2] in identifying CPP evaluation criteria. A secondary objective is to: (2) examine the effectiveness of SL the pedagogical tool underpinning the CPP.

Methods

Following a pilot study, the generation and analysis of qualitative data using a PLA approach was conducted. Using purposeful sampling, participants (n=26) including PWA (n=5); Speech and Language Therapists (SLTs)

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[1] Key stakeholder groups are participants who are considered to be ‘local experts’ of their own experiences (see also pages 75-76).

[2] Participants whose life or work is the subject of the research are involved in *all* stages of the research process, meaning that they are regarded as *co-researchers* (see also page 30).

(n=5); students (n=9); educators (n=6) and the CPP co-ordinator (n=1) were recruited and involved as co-researchers. Using PLA techniques to generate and analyse data (Flexible Brainstorming, Card Sort, Direct Ranking; Seasonal Calendar and PLA interviewing) in individual groups, or in interstakeholder groups (n=22), co-researchers explored the lived experience of aphasia and identified CPP evaluation criteria. The principles of thematic analysis guided the co-analysis of data generated with stakeholder groups. Data generated in Ireland were presented to a leading non-governmental organisation for PWA in the United Kingdom, as a preliminary exploration of the transferability of findings.

The effectiveness of SL was explored with key stakeholder groups using: (1) qualitative methods (PLA focus groups; interviews; orthodox focus groups) and (2) through a critical review of the SL literature in pre-professional healthcare curricula.

Results

In response to the primary research aims, co-researchers with aphasia generated eight themes in their own words to capture the lived experience of aphasia, including: (1) Back to pre-school; (2) Tiredness; (3) It's Like in Prison; (4) Emotions; (5) Not able to talk the words; (6) Escape; (7) Changing and Adapting; and (8) Family. The multi-perspectival analysis of the CPP resulted in the identification and prioritisation of evaluation criteria from the emic[3] perspective of stakeholders including: (1) shared understanding of structure, (2) clarity about the programme, (3) agreed evaluation mechanism, (4) linking with other organisations and (5) feedback. PWA reported that feelings of communicative incompetence were minimised and social connectedness was increased through participation in the programme.

In response to the secondary research objective, SL appears to be an appropriate pedagogical tool to underpin the CPP because it supports mutuality and reciprocity in university and community partnerships. However the inconsistency in terminology to describe SL internationally and

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[3] Individuals who have the experience (experiential knowledge) are considered to be the most knowledgeable about it. Therefore emic refers to the *insider'*s way of understanding and interpreting experience(s) (De Poy & Gitlin, 2015).

the paucity of robust methodological studies to establish effectiveness warrant further research.

Conclusion

This study critically interrogated communication disability as a barrier to inclusion in research. Using participatory research methods, PWA and other key stakeholders meaningfully participated as co-researchers in the evaluation of a primary care conversation intervention and examined the impacts of SL. This novel collaborative work generated new empirical evidence about the lived experience of aphasia and resulted in agreed CPP evaluation criteria. This study also found that SL is a suitable pedagogical tool to embed the CPP in a University setting. These findings will directly impact the Galway CPP and may be transferable to other similar conversation interventions nationally and internationally. Findings and methods will be of interest to healthcare professionals; service users; educators and researchers seeking to involve marginalised groups, especially people with communication disabilities, in scholarship and research.

Acknowledgements

I would like to express my deepest gratitude and appreciation for the excellent support and critical supervision provided by Professor Anne MacFarlane and Professor Peter Cantillon. A very heartfelt and special thanks to you Anne, for your wisdom, expertise and compassion. I am indebted to you.

Special thanks to Professor Andrew Murphy; Professor Declan Devane and Dr. Aideen O' Doherty, for their encouragement and guidance on my Graduate Research Committee. Also, sincere thanks to my colleagues and friends for the helpful discussions and positive encouragement throughout the evolvement of the research especially, Edel Tierney, Breda Kelleher, Mary O' Reilly de Brun, Tomas de Brun, Rachel Mc Evoy, Rozanne Barrow, Rena Lyons, Agnes Shiel, Lorraine Mc Ilrath, the GEMS Primary Healthcare Research Group and my colleagues in Health Sciences. I wish to extend warm and sincere thanks to all of my co-researchers for engaging in this research journey and for willingly sharing knowledge in our participatory spaces. Your involvement and commitment made this research possible.

Heartfelt thanks to my husband Steven, for his loving support and for believing that completing this PhD was always a certainty - here's to life without a PhD! Deepest thanks to my Mum who believed in me when I felt I had nothing left to give and who always reminded me that I was not alone. Also, thanks to my brother Brian and sister Rachel for their encouragement, good humour and support. To Carmel (RIP) who left along the way but continued to give us all strength from heaven. Finally, I dedicate this PhD to our son Luke who was born during the course of this study and despite his daily challenges has shown us that there are many different ways to co-create understanding and interpret the World. Luke you are and always will be my greatest teacher.

Chapter 1 Introduction

This thesis *"Evaluating Conversation Partner Programmes – perspectives of people with aphasia"* is presented in a research article based format (see figure 1.1). All of the articles, presented as Chapters within this thesis, are published in international peer reviewed journals. The articles were designed prospectively to address the identified study aims and objectives. Two articles presented in Chapter 4 and Chapter 5 address the primary research aims, both are qualitative using Participatory Learning and Action (PLA) research methods to include people with aphasia (PWA) and other key stakeholder groups in the exploration of aphasia and the multi-perspectival evaluation of a Conversation Partner Programme (CPP). The articles presented in Chapter 6 and Chapter 7 address the secondary objective of the study and explore Service Learning (SL), the pedagogical tool underpinning the CPP. Some formatting changes have been made to aid presentation and readability of the thesis. Figures and tables presented in each Chapter are numbered according to the articles. Relevant bibliographies are provided within each Chapter to improve clarity.

Figure 1.1 – Thesis Structure

Thesis Outline	**Chapter 1:** Introduction; Key literatures; Synergies across literatures; Research aims and objectives; Overview of articles; Concluding comments; References.
	Chapter 2: Ontology, Epistemology and rationale for the methodological approach.
	Chapter 3: Experiences of PLA and involvement (PhD researcher and Co-researchers with aphasia).
	Chapter(s) 4-7: Published Articles (Chapter 4 - Article 1); (Chapter 5 - Article 2); (Chapter 6 - Article 3); (Chapter 7 - Article 4).
	Chapter 8: Integration and synthesis of key findings with recommendations for future research; Methodological critque; Concluding statement; References.

Sections 1.1.1 – 1.1.3 present the context of the study.

1.1.1 Stroke, aphasia and the Irish context

Stroke is the third leading cause of death worldwide and the most common cause of disability in the western world, resulting in a considerable burden of care for families, health professionals and the wider community. The incidence of stroke in Ireland is approximately 375 per 100,000 of the population over 45 years, and with an increasing elderly population it is estimated that stroke will account for 6.2% of the total burden of illness in 2020 (Elkind, 2005). Many countries worldwide including Ireland have invested significant funds to develop stroke policies and services (Department of Health and Human Services, 2011; Irish Heart Foundation: Council for Stroke, 2010). Currently, an estimated 30,000 people are living in the community with stroke related disabilities requiring rehabilitation from a range of interdisciplinary healthcare professionals (Economic and Social Research Institute (ESRI) and Royal College of Surgeons in Ireland (RCSI), 2014). International best practice stresses the importance of timely rehabilitation, with delays negatively impacting the individual’s long-term outcomes.

The language disorder caused by stroke is called **Aphasia** and it is the focus of this research. The term ‘person or people with aphasia’ rather than stroke survivor, patient or client is used throughout this thesis to refer to participants with aphasia. This terminology aligns with the social model of disability and identifies the person before the diagnostic label assigned to the impairment. Approximately one third of the population with stroke will experience aphasia (van der Gaag et al., 2005). In the developed world the prevalence of aphasia following stroke ranges between .1–.4% of the population (Code & Petheram, 2011), and in Ireland up to 8,000 new people experience aphasia annually (Institute of public health (IPH) stroke briefing, 2012). People presenting with aphasia following stroke are more likely to have significant physical impairment, higher mortality rates and higher depression rates compared to those who do not have aphasia. Studies of long term recovery suggest that as many as 43% of people continue to have significant language disability at 18 months post onset (van der Gaag et al., 2005).

Aphasia impairs comprehension, expression, reading and writing - it is a chronic condition that impacts all aspects of a person’s life and the lives of families/carers (Chapey et al., 2008). One of the most disabling consequences of aphasia is the way that it excludes the person from normal conversation (Rayner & Marshall, 2003). Everyday conversation is as much about our social relationships as it is about the exchange of information; therefore, aphasia affects reintegration into community and participation in life events (Howe, Worrall, & Hickson, 2008). It is a complex all-encompassing disorder because like every other individual, the person with aphasia does not live in isolation but rather interacts in his/her broad social context e.g. family, workplace, community, etc. (Marshall, 2002). Gradually, social interactions and networks decline and the person with aphasia may experience exclusion at an infrastructural, interpersonal, and personal level (Cruice, Worrall, Hickson, & Murison 2005; Parr, 2007). The World Report on Disability (World Health Organization and The World Bank, 2011) highlights the widespread perception that people with cognitive, *communication*, or behavioural difficulties tend to be the most excluded disabled populations in society. Perhaps this is because people who behave, think, or *communicate* in atypical ways are more easily relegated to the fringes of communities compared to people with other types of disability e.g. visual or physical impairments (Murphy, Scheer Murphy, & Mack, 1988). People with communication disability are often denied their right to “participate in education, work, community, and political life, to access healthcare, social protection and justice, because their communication challenges mean they are denied personhood” (Wickenden, 2013 p16). This marginalisation limits the individual’s potential capacity to develop key resources such as employment, finance, self-esteem, confidence and to make active contributions to civil society (Pound, 2011).

The population most at risk of stroke and aphasia are people over 65 years living in the community. The preferred treatment option of older people is to receive healthcare services in the home setting. National and international evidence suggests that early discharge with community rehabilitation is as clinically effective as traditional hospital care and is as acceptable to people living at home post stroke (Department of Health and Children (Ireland), 2001a; Walker, Sunnerhagen & Fisher, 2013). Thus, appropriate primary care services and supports from a range of healthcare professionals including SLTs are vital. Speech and language therapists (SLTs) are responsible for providing life-changing treatment, support and care for anyone experiencing difficulties with communication and/or eating, drinking and swallowing following stroke (Royal College of Speech and Language Therapists (RCSLT), 2015). The Bacon report (Bacon, 2001) states that in Ireland: *“Speech and language therapy services provide assessment, diagnosis, treatment, advice and counselling to people of all ages with communication disorders and feeding/swallowing disorders. Communication disorders may be associated with a wide variety of medical factors, and may also be associated with social, cognitive or linguistic impairment”* (p1). SLTs work in a variety of settings including: community care, hospitals, charitable organisations and in private practice (Irish Association of Speech and Language Therapists (IASLT), 2013). However in the Irish health sector the majority of SLTs are employed by the Health Services Executive (HSE) and work in Primary Community Continuing Care (PCCC) which is the focus of the next section.

1.1.2 Primary Care and Speech and Language Therapy

In Ireland, primary care is vital to the delivery of health care in the community and is defined by the Department of Health and children as an *“approach to care that includes a range of services designed to keep people well…..with a strong emphasis on helping the individual to improve his/her health and social well-being”* (Department of Health and Children (Ireland), 2001a p15). Primary Care Teams (PCTs) were set up in 2001 after the publication of the Irish Primary Care Strategy which set out a vision for PCTs with the intention of improving primary care services. Ideally, team members should include General Practitioners (GPs), practice nurses, practice managers and HSE staff. HSE staff include: Public Health Nurses (PHN), Registered General Nurses (RGN), Physiotherapists, Occupational Therapists (OTs), Speech and Language Therapists (SLTs) and administrative staff with additional support from other professionals when necessary. The Primary Care Strategy proposed an inter-disciplinary approach to primary care, with an initial set of ten demonstration sites based around PCTs (Curry, 2003; Department of Health and Children (Ireland), 2001a). In keeping with the WHO vision for primary healthcare (World Health Organisation, 2015) the Strategy encouraged community involvement to ensure that the local, national, social and environmental issues that influence health are addressed (Department of Health and Children (Ireland), 2001a). The HSE Strategy for Service User Involvement 2008-2013 was a further policy driver for community participation in PCTs. However the 2001 vision for PCTs in Ireland has not been realised to date. There are a range of problems with implementation of interdisciplinary team working in general (O'Sullivan, Cullen, & MacFarlane, 2014) and with community participation in particular (McEvoy & MacFarlane, 2013). Furthermore, in the Irish health sector, Speech and Language Therapy, like other primary care services, has been seriously affected by economic recession and is limited by a range of measures to control spending in primary care such as recruitment embargoes and inadequate budgets. A recent report shows that staffing of community therapies is under-developed and not sufficient to implement best practice in stroke rehabilitation (Economic and Social Research Institute (ESRI) and Royal College of Surgeons in Ireland (RCSI), 2014 p3). The negative impacts for PWA are evident because there is a lack of resources to provide long term communication interventions in the community. In the Galway region, SLTs working in primary care have collaborated with the Discipline of Speech and Language Therapy at the National University of Ireland (NUI), Galway to develop an innovative approach augmenting the resourcing of SLT services for PWA living in the community. This initiative is the focus of the next section.

1.1.3 The Conversation Partner Programme at the National University of Ireland, Galway

Conversation partner programmes (CPP) are designed to increase communicative access and reduce the psychosocial consequences of aphasia (Byng & Duchan, 2005). According to Turner & Whitworth (2006) conversation interventions centre on the belief that conversation partners can be trained to support and optimise communication with a person with aphasia. CPPs have traditionally targeted three primary groups including:

1. Familiar partners—family or friends (Booth & Swabey, 1999; Lock, Wilkinson, & Bryan, 2001);
2. Volunteers (Kagan, Black, Duchan, Simmons-Mackie & Square, 2001; McVicker, Parr, Pound & Duchan, 2009);
3. Healthcare professionals (Shale, 2004).

The CPP at the centre of this research creatively uses the resources of a novel service learning initiative at NUI, Galway. This initiative was developed in collaboration with service users and the speech and language therapy Primary Community Continuing Care (PCCC) team in the Health Services Executive, West (HSE West). Based on the social model of disability and a SL educational approach (both explained in further detail in sections 1.2.1 and 1.2.4), the CPP aims to provide a conversation intervention to PWA living in the Galway region in the absence of another existing service. The Galway CPP is based on a similar programme that was developed at Connect (Connect, the communication disability network) in 2001. Connect is a ‘not for profit’ organisation in the United Kingdom that works with and on behalf of people with stroke and aphasia. While the Connect model originally focused on training volunteers as conversation partners for PWA, the network subsequently expanded to work with Universities interested in training students as conversation partners.

In 2005 the PhD researcher (R.McMenamin) secured seed funding from the community knowledge initiative (CKI) at NUI, Galway (www.nuigalway.ie/cki), and with support from the course director, she introduced SL into the BSc Speech and Language Therapy curriculum as the pedagogical tool to underpin the development of the Galway CPP[4]. The SLT manager and a senior therapist working in Galway PCCC were trained at Connect in London along with the PhD researcher and the course director of the discipline of Speech and Language Therapy at NUI, Galway. Training focused on how to set up and run a conversation partner scheme.

The Galway CPP was established in 2005/2006, and the SLTs working in the local community refer approximately 5–20 new PWA into the programme annually. The majority of PWA choose to continue their participation across several iterations of the programme (one iteration equates to 7-10 conversation visits) over a number of years. For third-year students, a 1 day training course and participation in the SL CPP module is a mandatory requirement. Conversation Partner Programme training is

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[4] This was the first programme of its type in Ireland to train students as conversation partners. Other Irish universities have since established similar programmes.

delivered collaboratively by academic staff and aphasia trainers (PWA who volunteered to be trained as trainers). Training focuses on three key areas:

1. **Disability equality**
    a. Models of disability;
    b. Identifying and dismantling barriers to participation;
    c. Acknowledging people with aphasia as individuals rather than ‘patients’ or victims.
2. **Becoming a conversation partner**
    a. Learning conversation partner skills and reflecting on personal communication styles.
    b. A practical session with a trainer with aphasia to implement conversation skills.
    c. Feedback and reflection on communication skills provided by an aphasia trainer.
3. **Health and safety**
    a. Risk assessment;
    b. Teaching students how to take health and safety precautions;
    c. Teaching students how to organize and implement a buddy system for conversation visits.

(Mc Vicker S, 2007)

Following training, students are paired with a peer and matched with a person with aphasia based on interests and hobbies and on geographical location. While students may arrange their conversation visits with the person with aphasia at a mutually convenient time, space is allocated in students’ weekly timetables to support these visits. The weekly conversation visits to PWAs’ homes or other agreed locations (for example, nursing homes, coffee shops, restaurants) provide unique opportunities for students to learn about the lived experience of aphasia and apply theory to practice in a relaxed environment which is different from the classroom or clinical settings. Reflective blogs completed after each visit, along with fortnightly tutorials and assessment involving individual and group work facilitate students’ reflective practice and learning throughout the CPP. The programme is structured to provide the person with aphasia with: (1) the opportunity to practice conversation skills with unfamiliar interlocutors in their own home and (2) increase feelings of social connectedness. As discussed in section 1.1.1 PWA frequently experience isolation and marginalisation as a result of their communication disability.

The foregoing discussion was intended to set the context for the study; the next section provides an overview of four key literatures relevant to the research with a view to elucidating the knowledge gaps this study was designed to address. The literatures span an analysis of the social model of disability; Public and Patient Involvement (PPI); Participatory Health Research (PHR); Service Learning (SL). Section 1.2 includes the following:

- Overview of the key literatures;
- Analysis of the synergies across literatures;
- Account of the theoretical framing of the study focusing on the concepts of *reciprocity* and *inclusion;*
- Summary of the key literatures.

1.2 Key Literature Relevant to this Thesis

1.2.1 The social model of disability

In recent years the social model of disability has gained recognition in healthcare policies and service delivery in western and developing countries (Oliver et al., 2008). This model suggests that disability only occurs when society does not adapt to accommodate an individual's needs and, thus, limits the individual's capacity (Moore, Beazley, & Maelzer, 1998). For example, a wheelchair user will experience physical exclusion if buildings are not wheelchair accessible but if ramps are provided, access is possible and the wheelchair user's experience of (dis)ability is very different. As mentioned previously (section 1.1.1), people with communication impairments, are "at the bottom of the hierarchy of exclusion…and are often denied their human rights in the most fundamental of ways" (Wickenden, 2013 p16; World Health Organization & The World Bank, 2011). Psycho-emotional or social-relational disablism as described by Reeve, (2006) and Thomas, (2004) gradually create feelings of worthlessness perpetuating feelings of isolation. Carol Thomas suggests that 'disablism' is a form of social oppression resulting from imposed constraints of activity on people with disabilities and is therefore similar to other oppressing concepts such as ageism, sexism and racism (Thomas, 2007). Pound (2013) argues that disability is created by social and attitudinal barriers (which are open to change) and is not the result of the impact of the existing pathology (which does not change). Overall, the focus is on the entitlements and hopes of people with disabilities rather than the functional limitations caused by physical, mental, sensory or communication impairments (Oliver, 2009). Importantly, the social model of disability is a philosophy and way of working rather than a specific treatment technique (Byng & Duchan, 2005). Healthcare professionals adopting this philosophy have moved away from age old perspectives of 'the well' delivering services to the 'unwell' to integrate the principles of equity, accountability and reciprocity into rehabilitation (Pahl, 2000). Critical reflection on personal values, bias, prejudices and consideration of power relationships is integral to practice (Oliver, 2009; Swain & French 2008).

The CPP at the centre of this study is closely aligned with the social model of disability. PWA often experience communication as an unequal interaction and environmental factors can act as barriers to prevent communicative access. An unskilled interlocutor might not know how to provide communication ramps to support communication access for a person with aphasia (Finkelstein, French, & Oliver, 1993; Rayner & Marshall, 2003). However, training interlocutor's to become skilled conversation partners creates new expectations for interaction. Trained conversation partners focus on the communicative *competence* of the person with aphasia and the reacquisition of *skills to facilitate life participation* (Marshall, 2002). Reciprocity is a key feature of the interaction as both parties share expertise to dismantle environmental barriers and increase successful communication (Howe et al., 2008; Parr, Byng & Gilpin, 1997). Supporters of conversation approaches recognise the experiential knowledge of the aphasia expert and prioritise the therapeutic potential of positive communication experiences above linguistic gains (Kagan, 1995; Kagan et al., 2001; McVicker et al., 2009).

A broad range of methodologies including quantitative, qualitative, mixed methods and single case study designs have been used to evaluate conversation interventions. This body of work demonstrates potential benefits in well-being, increased social connectedness and improved conversation skills for both partners. PWA have been involved in elements of programme evaluation for example, McVicker et al. (2009) invited stakeholder groups (volunteers, referrers, and PWA) to complete an evaluative questionnaire at the end of their conversation intervention. The participants with aphasia completed a communicatively accessible questionnaire with the support of the referring SLTs. The questionnaire aimed to evaluate process and outcomes of the conversation scheme from the perspective of each individual stakeholder group (McVicker et al., 2009). While PWA have been involved in evaluating specific aspects of interventions, they are often limited in the nature of their involvement e.g. they frequently do not have the opportunity to influence outcomes or interact with other stakeholder groups to share *emic* or *insider* perspectives and co-create new knowledge. Furthermore and linked to this there is a heavy reliance on interview as the preferred method of data collection in studies involving PWA (Simmons-Mackie & Lynch, 2013). Although interviewing is flexible and theoretically sensitive to diversity, there is an increased risk of researchers imposing personal beliefs and interpretations onto data generated by people with communication impairments (Carlsson, Paterson, Scott-Findlay, Ehnfors, & Ehrenberg, 2007; Lloyd, Gatherer, & Kalsy 2006). This creates the possibility that important emic experiences have not been captured. Importantly, despite the increasing popularity of conversation interventions internationally, there is no agreed set of evaluation criteria across settings.

To involve PWA and others with communication difficulties in research and service evaluation, researchers must learn from the Aphasiology literature and understand that PWA *communicate* better than they *talk* (Chapey et al., 2008). By looking beyond the language and speaking impairments that make interaction difficult, it is possible to develop innovative methodological approaches that support communication access and participation. Health researchers have highlighted the importance of using the “complete research toolbox,” to support inclusion and not just traditional methods (Wuest, 2011 p875). There are good examples of the successful use of participatory data generation approaches to include people with other kinds of communication challenges in qualitative studies e.g. migrants (de Brun et al., 2015; MacFarlane et al., 2009; MacFarlane et al., 2012), Aboriginal people recovering from acquired brain injuries (ABI) (Keightley et al., 2011), people with schizophrenia (Schneider et al., 2004) and individuals with anterograde amnesia (Wu, Richards & Baecker, 2004). These warrant investigation as potential methodologies to involve PWA in health research. People with aphasia, as aphasia experts, should be given the opportunity to be involved in a *meaningful* way and evaluate the services they receive. This is also in keeping with the growing policy imperatives around Public and Patient Involvement (PPI) in general. The literature on PPI is important in terms of how to conceptualise and operationalise the involvement of PWA in research and development projects, to which we now turn.

1.2.2 Public and patient involvement (PPI)

Public and patient involvement is enshrined in health policies nationally and internationally (Department of Health and Children Health Service Executive, 2008; World Health Organisation (WHO), 2008), with evidence that service user involvement creates more equitable, inclusive services responding to community needs (Henderson, Koehne, Verrall, Gebbie, & Fuller, 2014; Houlihan, 2010; Kenny et al., 2013; Meier, Pardue, & London, 2012; Preston, Waugh, Larkins & Taylor, 2010; O'Reilly-de Brun et al, 2016). PPI is increasingly supported by public, professional and academic groups working in healthcare research and development (Abma, Nierse & Widdershoven, 2009; Kelly, Caldwell & Henshaw, 2006; Rhodes, 2012). The increase in PPI activities is based on a growing awareness that the experiential knowledge of service users can improve study quality, relevance, and utility (Popay, Collins with the PiiAF Study Group, 2014; Staniszewska, 2009). Involvement might result in service users influencing treatment decisions at an individual level or redesigning local services at a community level. Irrespective of the PPI activity involvement must mean that it is conducted 'with' or 'by' community members, rather than 'to', 'about' or 'for' them" (www.invo.org.uk). Service user involvement can be a mechanism for capacity building and empowerment when the environment is supportive. However if the aims and objectives are not agreed from the outset involvement can increase feelings of powerlessness. Therefore an awareness of power relations at all stages is critical and strongly advocated (Chambers, 2005).

A valuable overview of PPI models and frameworks is captured by Gibson, Britten, & Lynch (2012). A systematic review of conceptualization, measurement and effectiveness is detailed in Brett et al. (2010), and a critical review of involvement in primary care research and development projects is given by Tierney et al. (2014). Notwithstanding the growing momentum in PPI activities, a problematic pattern is emerging regarding the nature and involvement of service users. Apart from a minority of exceptions, it is known that marginalized groups are underrepresented in PPI initiatives; for example, people with disabilities are frequently excluded from research (World Health Organization & The World Bank, 2011). Failing to include underrepresented populations in research perpetuates exclusion and is directly opposed to the Declaration of Helsinki, which states that disenfranchised populations should be given proper access to participation in research (Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects, 2008), and the World Report on Disability, which states that there should be more involvement of people with disabilities in health research (World Health Organization & The World Bank, 2011). Therefore PPI should include a diversity of populations on a more equitable basis (Gibson et al., 2012). Neglecting the emic experiences of people with a communication or other disability on the grounds of an assumed inability to engage in PPI processes creates a gap in our knowledge about the illness and health experiences of large population groups. For PWA it is the very nature of their disability that often underlies their exclusion (Dalemans,Wade, Van den Heuvel, & De Witte, 2009). The suggestion that these individuals lack the cognitive capacity or communication ability to express their views reflects age-old beliefs about every disempowered group in society, including those with mental health difficulties, children and women, and serves only to further isolate an already marginalized group (Gillies, 2000; Proctor, 2001).

Thus, researchers should actively facilitate the inclusion and *meaningful* engagement of people with communication and other types of disability in PPI activities. The challenge is to identify, adapt and/or develop research methodologies that enact communicative access and, therefore, can support inclusion. This is difficult because the mechanisms used to involve service users in PPI health research and service development are not clear in published accounts (Tierney et al 2014). However, an emerging positive direction identifying mechanisms for meaningful engagement is provided in the Participatory Health Research (PHR) literature (Jagosh et al 2012), and this is the focus of the next section.

1.2.3 Participatory Health Research

PHR is informed by a rich variety of participatory research traditions from different countries and time periods. All of these traditions appear to have their foundations in broad social movements striving for a more democratic and inclusive society (International Collaboration for Participatory Health Research (ICPHR), 2013). Some of the various traditions informing PHR include: Participatory Rural Appraisal (PRA) and Participatory Reflection and Action (PRA) (Chambers, 1994a, 1994b; Narayanasamy, 2009); Liberationist research approaches (Freire, 1970; 1982); Action Research (AR) in organizational development (Lewin, 1948); Action Research in education (Carr & Kemmis, 1986; McNiff & Mellor, 2013); Participatory Research in the context of local, national, and international movements (People's Health Movement, 2013); Lay/Community Epidemiology, Popular Epidemiology e.g.(Watterson, 1995); Human Inquiry and Cooperative Inquiry (Reason,1998); Appreciative Inquiry (Reed, 2007); Community-Based Participatory Research (CBPR) (Minkler & Wallerstein, 2008); Action Science (Argyris, Putnam, & Smith 1985); Constructivist Research (Guba & Lincoln 1989); Feminist Research (Maguire P, 1987); Empowerment Evaluation (Fetterman DM, Kaftarian SJ, & Wandersman AH, 1995) and Democratic Dialogue (Gustavsen B, 1992) and Participatory Learning and Action (PLA) research (O' Reilly-de Brun & de Brún, 2010) developed from Chambers' work (Chambers, 1994a).

Participatory health researchers may align themselves with one or more of these traditions or draw on a range of sources adapting their specific approach to the context where the research is being conducted. Despite the diversity within PHR there is broad agreement in relation to key distinguishing features. PHR is:

- ***Participatory –*** the goal is to maximize stakeholders' participation throughout the research process;
- ***Locally situated -*** grounded in the reality of daily life and work in a specific place and time;
- ***A collective research process –*** key stakeholder groups are represented in the study;
- ***Collectively owned –*** stakeholders involved in the study own the research;

- ***Transformative through human agency*** –aims to create positive social change for stakeholders;
- ***Critically reflexive –*** considers power relationships in research and daily life;
- ***Focused on producing local knowledge* -** co-creates collective, local, dialogical and diverse experiential knowledge; tacit knowledge;
- ***Broad in terms of impact(s)* -** learning and research are inter-linked and aim for positive action;
- ***Based on a broad understanding of generalizability –*** produces local evidence that can be accumulated over time to strengthen participants' ability to take effective action on health issues;
- ***A dialectical process characterized by messiness* -** knowledge and action are generated by a facilitated, collective research process.

(International Collaboration for Participatory Health Research (ICPHR), 2013).

The goal of participatory health research (PHR) is to maximize the participation of those whose life or work is the subject of the research in *all* stages of the research process, meaning that they are regarded as *co-researchers* (International Collaboration for Participatory Health Research (ICPHR), 2013). Individuals' emic perspectives (experiential knowledge) are highly valued in the exploration of the research topic (De Poy & Gitlin, 2015). The researcher and participants co-create data that is intended to positively impact participants' lives. This way of working resonates with the aforementioned Involve (www.invo.org.uk) definition of involvement and typically follows a "spiral pattern" of exploration, with researchers and participants reflecting, planning, acting and observing together in repeated cycles (McNiff & Mellor 2013). These iterative processes support reflection and the reconstruction of experiences. Relational and reflective knowledge are produced with visible links between knowledge and action (Park, 2006).

Participatory health research approaches are increasingly being used in healthcare research internationally to include marginalised and disempowered communities resulting in a growing and compelling evidence base (Bryant et al., 2010; Makdisi et al., 2013; Jagosh et al., 2012; Macaulay et al., 1999; MacFarlane et al., 2012; MacFarlane et al., 2014; O'Reilly-deBrun et al., 2015; O'Reilly de Brun et al 2016).

In stroke research while there is evidence of an increase in the number of initiatives encouraging service user involvement (James Lind Alliance, 2012) only a small minority of studies have used a participatory health research approach. Buell (2013), writing about her work in Bolivia, suggested grass roots approaches to data collection such as Participatory Rural Appraisal (PRA) and key informant methods as a more sustainable approach to measurement and establishment of services for PWA. She highlighted the importance of building the capacity of people living with communication disability so that they could educate their communities and overcome some of the attitudinal barriers encountered on a daily basis. Pound (2013) reports that the use of Participatory Action Research (PAR) in her PhD research facilitated the development of tools to support conversation and raise awareness about aphasia and friendship. She emphasised the strengths of relational methods for researching friendship and the transformative potential of doing PAR with marginalised groups such as people with aphasia (Pound, 2013). However, to date no study using participatory health research methods involving PWA as co-researchers in service evaluation has been identified in the literature.

Service learning is the pedagogical tool underpinning the CPP of interest in this research, and to conclude this overview of key literatures, it is the focus of the next section.

1.2.4 Service Learning

Many students choose healthcare professional courses with altruistic motivations however few carry this altruism into practice after graduation. This perpetuates the disparities in healthcare services to rural, remote and isolated communities (Meili, Fuller & Lydiate, 2011). There is a growing international commitment to graduate socially responsive healthcare professionals with the skills, knowledge and desire to act as change agents in diverse and marginalised communities. Educators have explored a variety of innovative pedagogies to teach students social accountability and promote civic awareness. Service learning emerged as a pedagogical tool that fosters a sense of social responsibility and civic awareness inside and outside of the classroom (www.cki/nuigalway.ie). Service learning is a complex educational approach involving communities, students and institutions with the aspiration that partnerships are equally beneficial and reciprocal (Seifer, Hermanns & Lewis, 2000). The aim of SL to include and collaborate with local communities is in keeping with Freire's, (1970) social justice framework. Service learning programmes are reported to result in mutually beneficial community learning and engagement with active contribution to 'positive' social change (Hammersley, 2012).

Developed in the USA, and championed by Cashman & Seifer (2008), SL is largely based upon theories embedded in the experiential learning paradigm first posited by Dewey (1938; 1963), and later elaborated by Kolb (1984). These theories suggest that students' learning is enhanced with active engagement in experiential problem-solving and decision-making involving iterative reflection and (re)conceptualization. Service learning adds to the normal interpretation of experiential learning as an individual learning cycle with its emphasis on learning activities that establish reciprocity between learners/institutions and communities. Typically, during SL experiences, students participate in community engagement (often with marginalised or 'hard to reach' groups), linked to their academic programme. Students learn through action in the community with structured reflection (McKenna & Ward, 1996; Seifer et al., 2000). Through SL students have opportunities to critically examine their values and belief systems which prompt questions about personal stereotypes, prejudices and community healthcare experiences. Self-reflection is encouraged and supported by academic staff. Reflection may occur before, during and after SL engagements and is a key component of the educational approach. There are a range of resources describing SL (Holland, 2005; Zlotkowski, 2002) including a number of discipline-specific texts, (Elam et al., 2003; Flecky & Gitlow, 2011; Kazemi, Behan, & Boniauto, 2011; Mitschke & Petrovich, 2011). The collaborative nature and aims of SL appear congruent with the social model integral to the CPP (Byng & Duchan, 2005; Pound, Duchan, Penman, Hewitt & Parr, 2007) and PHR approaches.

1.2.4.1 The impacts of Service Learning

Service learning is reported to have several educational benefits including supporting students to: (1) Apply theory to practice in the community;(2) develop skills that are difficult to learn with traditional educational approaches; (3) gain an appreciation of the social determinants of health and foster a sense of social responsibility, accountability and caring for others (Azer, Guerrero, & Walsh, 2013). Service learning also supports students' professional identity formation, a core component of ''professionalism'', and a key strand in health care curricula (Batra, Chertok, Fisher, Manseau & Manuelli, 2009; Bentley & Ellison, 2007; Woollard, 2006). North American studies have dominated research focused on evaluating SL (Eyler, Giles, Stenson & Gray, 2000) and while there is a significant body of evidence to support the use of SL in North America (Cunningham, 2002; Forte, 1997; Reising, 2006; Williams & Reeves, 2004), there is a paucity of information on the impacts of SL in other geographical locations and contexts. New approaches in educational policy and practice should be supported by evidence (Evans & Benefield, 2001) with thorough evaluation prior to implementation (Dorfman, Murty, Ingram & Han, 2007). However in the absence of literature to demonstrate the effectiveness of SL nationally and internationally, educators cannot make informed decisions about the implementation of this pedagogical tool. At NUI, Galway small-scale internal evaluations provided some evidence that stakeholders valued the SL CPP experience and students reported benefits that seemed to align with the student learning outcomes identified by Eyler & Giles (1999). However a comprehensive examination of the effectiveness of the SL CPP was required to:

1. Explore the emic experiences of all stakeholder groups participating in the SL CPP at NUI, Galway;
2. Identify the reported student impacts of SL in the existing and emerging international literature with consideration of localisation issues (Boland & McIlrath, 2007).

1.3 Synergies across the literatures

There is a clear synergy across the four key literatures reviewed in section 1.2 with recurring themes evident in relation to *reciprocity* and *inclusion*. The overlapping features are presented in Table 1.1 and the overarching themes of reciprocity and inclusion are discussed below.

Table 1.1 Shared Features across literatures (Social Model of Disability; Patient and Public Involvement; Participatory Health Research; Service Learning)

Social Model of Disability (Oliver 2009; Turner and Whitworth 2006)	**Patient and Public Involvement** (Gibson et al 2012)	**Participatory Health Research** (Cornwall and Jewkes, 1995; Chambers 1994)	**Service Learning** (Eyler and Giles 1999; 2000)
1. People with disability are equal members of society and want to have equal interactions with other members of society with opportunities to learn, work and act in a reciprocal way.	Aims to involve diverse groups, professionals and researchers to learn work and act together in collaborative partnerships.	Aims to enable diverse groups and individuals to learn work and act together as equals in a reciprocal way.	Aims to support students to learn, work and act in a reciprocal way with communities they may not otherwise encounter (marginalised or 'hard to reach' groups) to create social awareness and a sense of equality.
2. Aims to dismantle social barriers and establish and maintain inclusive relationships built on trust, rapport and respect with others.	Aims to establish and maintain inclusive relationships built on trust, rapport and respect between key stakeholders.	Aims to establish and maintain inclusive relationships built on trust, rapport and respect between key stakeholders.	Aims to establish and maintain inclusive relationships built on trust, rapport and respect between key stakeholders.
3. Person with aphasia and interlocutor work together to dismantle communication barriers. Two-way sharing of expertise and resources to create	Aims to support stakeholders to share, enhance, and analyse their knowledge and plan together for positive action.	Aims to support stakeholders to share, enhance, and analyse their knowledge and plan together for positive action.	Aims to support stakeholders (students, community partners and institution) to share, enhance, and analyse their knowledge and plan together for positive action.

positive interactions.			
4. Aims to be democratic.	Aims to be democratic.	Aims to be democratic.	Aims to be democratic.
5. Aims to be dynamic.	Aims to be dynamic.	Aims to be dynamic.	Aims to be dynamic.
6. Aims to be empowering and life enhancing through increased social connectedness and reduced isolation.	Aims to be empowering and life enhancing through equal participation in PPI activities.	Aims to be empowering and life enhancing through equal participation in research process.	Aims to be empowering and the evidence suggests that SL experiences may be life enhancing for students.
7. Encourages critical self-reflection (therapist) on personal values; power relationships; personal prejudices.	Encourages critical self-reflection (researcher) on personal values; power relationships; personal prejudices.	Encourages critical self-reflection (researcher) on personal values; power relationships; personal prejudices.	Encourages critical self- reflection (student) on personal values; power relationships; personal prejudices.
8. Values experiential knowledge equally.	Aims to value experiential knowledge equally.	Values experiential knowledge equally.	Values experiential learning equally.
9. Relevant to all contexts including community.	Community based.	Community based.	Community based.
10. Aims to be a collaborative approach to aphasia rehabilitation and promote genuine participation.	Aims to be collaborative and promote genuine stakeholder participation.	Aims to be a collaborative methodological approach and promote genuine stakeholder participation.	Aims to be a collaborative educational approach and promote genuine stakeholder participation.

1.3.1 Theoretical Framing – Reciprocity and Inclusion

Reciprocity has been defined as “a reciprocal action or relation; a mutual exchange of commercial or other privileges” (Collins English Dictionary, 2014 p1351). The principle of reciprocity is fundamental to social exchange theory (Homans, 1958), and social equity theory (Adams, 1965). These theories focus on the exchange and value of social goods, exploring how relationships might grow or diminish on the basis of equitable trade in a dyad (Pound, 2013). The **social model of disability** emphasises equality in roles and relationships and encourages researchers and healthcare professionals to reflect on issues of power and control (Swain & French, 2008). Within the context of **PPI** and **Service Learning** *reciprocity* creates a shift in thinking from attitudes and relationships that perpetuate patient-hood to those that promote person-hood and active citizenship. This alternative lens in aphasia research supports the development of collaborative, participant led projects that have the potential to positively impact individuals and communities. The focus on reciprocity creates a paradigm shift away from medical model classifications that hold PWA as passive recipients of care and/or knowledge to a participatory paradigm where PWA are viewed as competent experts capable of generating new knowledge and directing research processes. The emphasis on equality and mutuality help to overcome stereotypes and prejudices (Abma et al., 2009). Expectations for involvement centre on the *meaningful* engagement of PWA as expert co-researchers who are supported to share their expertise and skill. Reciprocity does not de-value the role of the researcher in the study; rather; it creates collaborative relationships where experiential knowledge is valued equally and new knowledge is co-created. Reflection on reciprocity within research relationships supports the on-going consideration of power and competence, and helps the research team to think creatively about communication access and extending capacity collaboratively to ensure the *inclusion* of all stakeholders around the research table (Pound, 2011). Thus *reciprocity* permeates the theoretical underpinnings of this study and as Zhang & Epley (2009) note, it is the ‘‘glue that holds groups and societies together’’ (p786).

Inclusion of PWA in research depends on how the researcher perceives the communication attempts of participants with aphasia in terms of acceptability (Shotter, 1984). People with aphasia may use preferred communication strategies and resources (writing, pictures, gesture, etc.) to support engagement; however, these augmentative strategies do not ensure inclusion in the research process. Following the philosophy of the **social model of disability,** when researchers do not recognise the inherent competence of PWA in terms of their ability to be self-determining it is unlikely that they will modify the research encounter to support full participation (Simmons-Mackie & Damico, 1999). Researchers with a desire to support communication access must have internalised values of respect and competence for the communicator with aphasia. Researchers must also believe that the investment of time and effort to achieve inclusion is worthwhile (Simmons-Mackie N & Damico J, 2007). Training in supportive communication techniques (Kagan et al., 2001) will help researchers to unmask the communicative competence of the participant with aphasia and expand their understanding of what is acceptable in terms of communicative participation. When both parties share a willingness to interact using augmentative methods of communication, and want to collaboratively explore research questions, participation will be maximised. Importantly, PWA have the right and ability to participate as equals in **PPI and SL** activities. We know from participatory health research conducted in the field of **PPI** and from qualitative SLT research that the methodological difficulties of involving PWA in research are challenges that can be overcome. Through the use of innovative methodological approaches that support communication access and inclusion, PWA may be meaningfully involved in PPI activities. However theoretical claims of reciprocity and inclusion should be supported by the *illustration of these concepts in practice*. The exploration of the operationalision of the conceptual congruence across the Social Model of Disability; Patient and Public Involvement; Participatory Health Research and Service Learning with the overarching theoretical framework of reciprocity and inclusion will be provided in this thesis through:

- The empirical evidence presented in the published papers addressing the aims of the study (Chapters 4 to 7 and appendices G-H).
- A reflexive account of the PhD researcher and co-researchers experiences of PLA and the research process (Chapter 3).

- A critical review of the shared features across literatures (table 1.2) and the overarching theoretical framework in light of the empirical evidence generated and the PhD researcher's reflections (Chapter 8).

1.4 Concluding comments

In this Chapter, details of SLT community services for PWA have been provided. The foregoing discussion of key literatures and the connecting theoretical framing highlight problematic gaps in knowledge. Currently there is no international system for evaluating the CPP and there are concerns about the meaningful involvement of PWA in research work. Following policy imperatives for PPI, it is important to meaningfully include service users in the development of such an evaluation system. However, PWA are often excluded from such research and development work *because* of their communication disability. The social model of disability contests this exclusion and the call to "involve people with disabilities" is one of the recommendations of the World Report on Disability (World Health Organization & The World Bank, 2011**,** p.265). Researchers and practitioners are challenged to create international research links and conduct research about disability in collaboration with service users (World Health Organization & The World Bank, 2011). Policy makers emphasise that healthcare research will be improved through service user involvement. Experiential knowledge will contribute new perspectives on health issues and guide service design and delivery targeting population needs. However, it is important to support service user involvement from a position of equality with *meaningful* rather than tokenistic participation. The communication disability literature reports a growing body of evidence documenting the aspirations of individuals with communication disabilities to make active contributions to research and civil society (Pound, 2011). Researchers and healthcare professionals have a unique opportunity to build the capacity of PWA so that they are well positioned to share experiential knowledge and influence the direction of aphasia research and service design (Worrall, 2013).

The focus of this study is to create a CPP evaluation system. This necessitates that all stakeholder groups (researchers, SLTs; trained conversation partners and PWA) are *meaningfully* involved in the determination of core evaluation criteria. The mode of delivery of the CPP is central to stakeholders' perceptions and experiences, therefore the pedagogical tool used to implement the CPP should also be examined.

1.5 Research aims and objectives

The *Primary* research aims are to:

- Explore with people with aphasia their perceptions and experiences of aphasia and the Conversation Partner Programme;
- Explore with other key stakeholder groups their perceptions and experiences of the Conversation Partner Programme;
- Identify with all stakeholders evaluation criteria for the Conversation Partner Programme.

A *secondary* research objective involves:

- Exploring service learning as the pedagogical tool underpinning the Conversation Partner Programme.

A summary of the four articles included in the thesis is presented in the next section.

1.6 Overview of articles included in the thesis

Article 1: *'Addressing the long term impacts of aphasia: How far does the conversation partner programme go?'*

This article highlights the limited voice of PWA in the stroke literature compared to the general population. Following the interpretive paradigm the generation and analysis of qualitative data involves a Participatory Learning and Action (PLA) approach. Using purposeful sampling, participants included people with aphasia (n = 5) with experience of the CPP. Through (n = 5) 3 hour data generation sessions across 12 months using PLA techniques—Flexible Brainstorming and Card Sort—participants' unique perspectives of aphasia and the CPP were recorded. The principles of thematic analysis guided the co-analysis of data with participants. To explore transferability of findings, data generated in Ireland were presented to an international inter-stakeholder group at Connect (Connect, the communication disability network) in London, United Kingdom. Eight themes captured participants' lived experience of aphasia: (1) Back to Pre-

School; (2) Tiredness; (3) It’s Like in Prison; (4) Emotions; (5) Not Able to Talk the Words; (6) Escape; (7) Changing and Adapting; and (8) Family. Five additional themes captured CPP experiences: (1) Preference of location; (2) Speak easy; (3) Confidence; (4) Helping as partners and (5) Great expectations. This article contributes new empirical evidence about the ‘lived experience’ of aphasia and the CPP from the emic perspective of co-researchers; for example through the CPP the expertise and communication ability of participants was acknowledged and the negative feelings of communicative incompetence described in “Back to Pre-School” and “Not Able to Talk the Words” were minimised. Impacts of aphasia related to feelings of marginalisation captured in ‘Escape’, ‘It’s like in Prison’ and ‘Emotions’ may be addressed by the social aspects of the programme.

Article 2: *‘Who decides what criteria are important to consider in exploring the outcomes of conversation approaches?’*
Conversation interventions for PWA are increasingly implemented with no recognised system for evaluating these interventions. Following policy imperatives for patient and public involvement, it is important to include service users in the development of evaluation criteria. However, people with aphasia are often excluded from such research and service development initiatives because of their communication disability. This study was designed to include people with aphasia and other key stakeholders as co-researchers in the development of evaluation criteria for a conversation partner programme (CPP). Following the interpretive paradigm the generation and analysis of qualitative data involved a participatory learning and action (PLA) approach. Using purposeful sampling, participants (n = 20) included: people with aphasia (n = 5); speech and language therapists (n = 5); speech and language therapy graduates and undergraduates (n = 9) and the university coordinator (n = 1). Through (n=18) individual and inter-stakeholder data generation episodes (PLA focus groups and interviews) using participatory techniques (Flexible Brainstorming, Card Sort, Direct Ranking, Seasonal Calendar), evaluation criteria were identified. The principles of thematic analysis guided the co-analysis of data with participants. Data generated in Ireland were presented to an international inter-stakeholder group at Connect (Connect the communication disability network) in London, United

Kingdom, for preliminary exploration of transferability of findings. Co-researchers identified, agreed and prioritised the following evaluation criteria in order of importance: (1) shared understanding of structure, (2) clarity about the programme, (3) agreed evaluation mechanism, (4) linking with other organisations, and (5) feedback. "Shared Understanding of Structure" was ranked the most important criterion and related to the nature and number of participants, opportunities for group meetings, socialising, and stakeholder interaction. "Feedback", the criterion ranked least important, detailed responsibilities about summarising programme experiences and sharing this information between stakeholders. This article demonstrates how participants with aphasia and other key stakeholders can be meaningfully included in multiperspectival service evaluation and re-design. The outcomes of this collaborative work bridge the gap between policy imperatives around involvement and actual practice and will be of interest to all those designing, delivering, evaluating and participating in conversation interventions nationally and internationally.

Article 3: *'Impacts of service learning on Irish healthcare students, educators, and communities'*

In 2001 the National University of Ireland, Galway (NUI, Galway) launched the Community Knowledge Initiative (CKI).This project planned to promote civic engagement across the institution and strengthen links with local, national and international communities. With the support of seed funding from CKI in 2005/2006 the disciplines of Occupational Therapy and Speech and Language Therapy integrated Service Learning (SL) into their undergraduate curricula. Service learning was implemented to underpin the conversation partner programme in year three of the four year BSc in speech and language therapy. While preliminary findings suggested positive student impacts in the domains of academic performance, civic awareness and personal and professional skills (Eyler & Giles, 1999; Claus and Michel, 2000) further exploration with all stakeholder groups was warranted. Following a pilot study, purposeful sampling was used to recruit participants in existing SL partnerships affiliated with the disciplines of Speech and Language Therapy and Occupational Therapy at NUI, Galway. Through interviews and focus groups the impacts of SL from the insider perspective of key stakeholder groups including: (1) students (n=24); (2) educators (n=8) and (3) community partners (n=10) were explored. The principles of thematic analysis guided the analysis of data. Findings in relation to students suggested that service learning had the capacity to: (1) support personal development; (2) enhance academic performance and (3) increase civic awareness. Through SL students appear to reflect on individual biases and prejudices creating a new understanding about the impacts of illness and disability at an individual and societal level. Primary impacts for community partners involved accessing resources (students and services) while educators appreciated opportunities to link academic theory to practice and engage with the community. Although some impacts of SL were consistent with previous findings, further research is necessary to explore how SL can be used to meet the discipline-specific learning objectives of pre-professional healthcare programmes and local community needs.

Article 4: *'Training socially responsive healthcare graduates: Is Service Learning an effective educational approach?'*
Health care educators strive to train graduates who are socially responsive and can act as ''change agents'' for the communities they serve. Service learning (SL) is increasingly used to teach the social aspects of health and develop students' social responsiveness. However, the effectiveness of SL as an educational intervention has not yet been established. We aimed to assess the evidence for the effectiveness of SL through a critical review of the literature. Seven electronic databases were searched up to 2012 and included all articles on SL for pre-professional healthcare students. Hand searching was also conducted. A total of 1485 articles were identified; 53 fulfilled the search and quality appraisal criteria and were reviewed across Eyler and Giles' (1999) six identified domains of potential SL effects: (i) personal and interpersonal development; (ii) understanding and applying knowledge; (iii) engagement, curiosity and reflective practice; (iv) critical thinking; (v) perspective transformation and (vi) citizenship. This review highlights the idiosyncratic nature of SL therefore exploring questions via the interpretive paradigm around (1) the terminology of SL; (2) how SL experiences lead to particular academic and partner outcomes; (3) evaluation approaches particularly focused on the aims of SL and (4) how the long term impacts will address the gaps in our understanding of this educational approach. Research focused on creating an agreed and consistent language to describe SL and the evaluation of SL in relation to

its explicit aims appears to be fundamental to progressing SL as an educational approach. This article highlights the need for impact studies based on the interpretative paradigm, aligned with the principles of social accountability including all stakeholder perspectives.

Table 1.2 Overview of the 4 articles included in the thesis

	Article 1	**Article 2**	**Article 3**	**Article 4**
Aim	To explore aphasia and the conversation partner programme from the emic experiences of people with aphasia	To generate evaluation criteria from a multi-perspectival evaluation of the conversation partner programme	To explore the impact(s) of service learning from the perspective of students, community partners, and educators.	To assess the evidence base for the effectiveness of service learning in pre-professional healthcare curricula
Design	Empirical Study	Empirical Study	Empirical Study	Literature Review
Methodological Approach	Qualitative - using participatory learning and action research approach for data generation	Qualitative - using participatory learning and action research approach for data generation	Qualitative – using interviews and focus groups for data generation	Critical review of the literature
Number of Participants	(n=5)	(n=20)	(n=38)	Not Relevant
Data analysis	Inductive thematic analysis (co-analysis with stakeholders)	Inductive thematic analysis (co-analysis with stakeholders)	Inductive thematic analysis	Deductive theoretical analysis
Main Results	Eight themes captured co-researchers lived experience of aphasia including: (1) Back to pre-school, (2) Tiredness, (3) It's like in prison, (4) Emotions, (5) Not able to talk the words, (6) Escape, (7)	Conversation partner programme evaluation criteria agreed and prioritised by co-researchers included: (1) shared understanding of structure, (2) clarity about the programme,	Five themes captured the impacts of service learning across stakeholder groups including: (1) service learning is an eye-opening experience; (2) service	Service learning experiences appear highly valued by educators and students. The effectiveness of this pedagogical tool remains unclear. The aims of service

	Changing and adapting and (8) Family. Five additional themes captured perceptions of the CPP. Emic experiences of co-researchers indicate that the CPP addresses some impacts of aphasia e.g. increasing successful communication and reducing marginalisation.	(3) agreed evaluation mechanism, (4) linking with other organisations, and (5) feedback. This research bridges the gap between policy imperatives around involvement and actual practice and will impact the design, delivery and evaluation of the programme for all stakeholders.	learning is an opportunity to enhance professional development; (3) engaged scholarship enhances academic outcomes; (4) service learning creates shared knowledge and resources; and (5) service learning provides a broader relevance for the University.	learning to: (1) establish reciprocity between all stakeholders and (2) increase students' social responsiveness - require evaluation. Establishing a consistent terminology internationally in the field of service learning is critical.
Conclusion	Conversation approaches aligned with the social model of disability can positively impact feelings of communicative competence and social connectedness for some people living with aphasia in the community.	Using participatory research methods people with aphasia and other key stakeholders engaged in a multi-perspectival evaluation of the CPP. The agreed evaluation criteria with will directly impact the CPP in question and may be transferable to other similar programmes nationally and internationally.	Service learning has the potential to positively impact students' personal development, academic performance and increase civic awareness. Educators and community partners value the reciprocal partnerships and mutual learning.	Service learning experiences are idiosyncratic in nature therefore impact studies based on the interpretative paradigm, aligned with the principles of social accountability and including key stakeholder groups are necessary.

Appendix A includes the rationale for the selection of journals where the articles are published. Copy right permission from the individual journals is presented in Appendix B.

The next Chapter is devoted to a detailed description of the researcher's ontological and epistemological stance with rationale for the chosen methodological approach.

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Chapter 2 Methodology

2.1 Introduction

As stated at the end of Chapter 1 the purpose of this Chapter is to present a detailed description of the researcher's ontological and epistemological stance with rationale for the chosen methodological approach. The centrality and novelty of the participatory methods used for the primary research aims warrants particular attention because this was the largest empirical component of the PhD.

To re-cap the *Primary* research aims sought to:

- Explore with people with aphasia their perceptions and experiences of aphasia and the Conversation Partner Programme;
- Explore with other key stakeholder groups their perceptions and experiences of the Conversation Partner Programme;
- Identify with key stakeholders evaluation criteria for the Conversation Partner Programme in question.

2.1.1 Understanding Paradigms – Ontology; Epistemology; Methodology

The term *paradigm* can be defined as the '*basic belief system or world view that guides investigation*' (Guba & Lincoln, 1994 p.105). Thus a paradigm refers to a set of very general philosophical assumptions about the nature of the world (ontology) and how researchers can understand it (epistemology). These philosophical assumptions are often shared by those working in a particular domain or tradition and serve as the basis for defining what constitutes "good research" (Guba & Lincoln, 2011; Kuhn, 2012). Ontological assumptions are concerned with what the researcher believes constitutes social reality and this determines whether the researcher will manipulate and measure variables in order to test hypotheses or whether he/she will explore meaning in words and behaviours (Blaikie, 2009). The *host of assumptions* held by the researcher influences every aspect of the research process, e.g. the generating, analysing and reporting of research findings. The researcher's epistemological stance is concerned with 'the possible ways of gaining knowledge of social reality, whatever it is understood to be, i.e. claims about how what is assumed to exist can be known' (Blaikie, 2009 p 8). In addition to including ontology and epistemology, paradigms also typically include specific methodological approaches connected to these assumptions, and highlight studies that demonstrate these assumptions and methods. The epistemology (preferred relationship between the researcher and the researched) and the methodological approach (preferred techniques for collecting information about the world) will logically follow the ontological stance adopted (Maxwell, 2013). Therefore the researcher's methodological approach is underpinned by, and reflects specific ontological and epistemological beliefs and methodology is concerned with 'techniques or procedures used to collate and analyse data' (Blaikie, 2009 p8). Ontology, epistemology and methodology are interconnected elements of the selected research paradigm and it is broadly accepted that 'ontology logically precedes epistemology which logically precedes methodology'(Hay, 2002 p5). The interrelationship between the different components of research is clearly shown in Figure 2.1.

Figure 2.1 The interrelationship between the building blocks of research

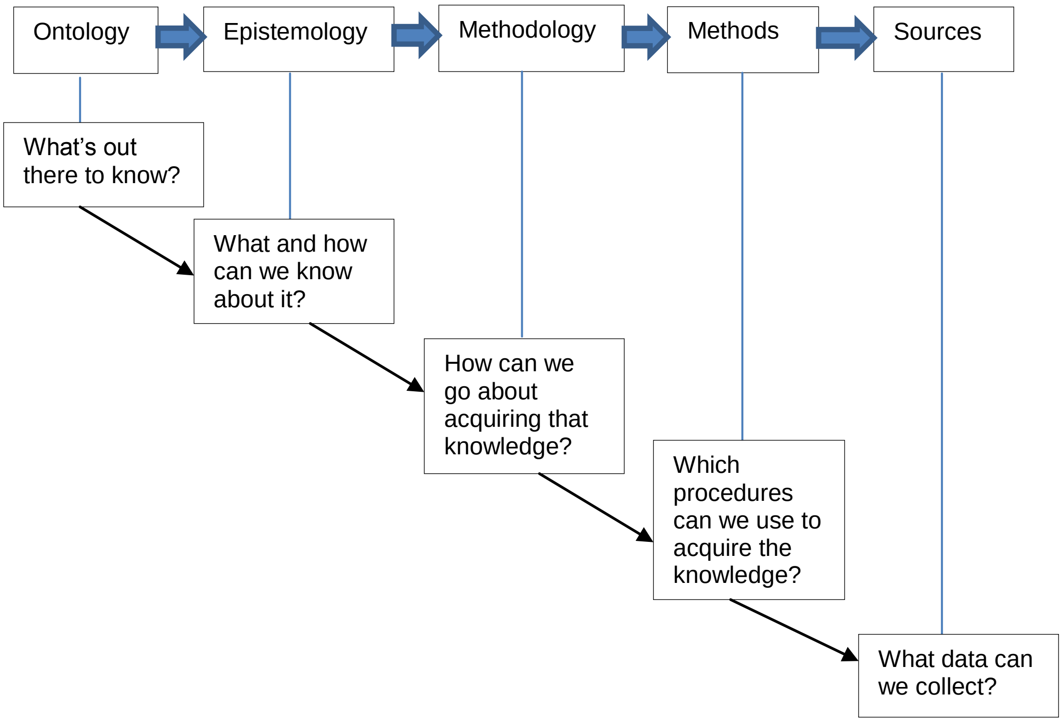

Figure adapted from (Hay, 2002 p64)

2.1.2 Choosing an ontological, epistemological and methodological approach

In practice, choosing an ontological, epistemological and methodological approach is not a linear process and involves careful consideration of the literature, discussions with experts and personal reflections. In this research, both quantitative and qualitative study designs were explored at the outset *vis a vis* emerging knowledge of literature about the social model of disability, contemporary policy imperatives for public and patient involvement and participation in health research and service learning as a pedagogical tool (see Chapter 1 section 1.2). Learning and final decisions about ontology, epistemology and methodology followed from there. Details of this journey are presented below.

As a starting point, the PhD researcher focused on study design and Table 2.1 provides a summary of design options considered. The core question used to interrogate the various options was *"Will this design support the collaborative exploration of the primary research aims where the emic perspectives and experiential knowledge of local experts are valued equally in the research process?"*

Table 2.1 Methodological approaches considered for this study

Design (Option 1)	**Quantitative Cohort Study**
Key features	• Cohort study- repeated measures over time; useful for demonstrating associations; • Involves a *Participant Group* (people with common characteristics) and a *Control group* e.g. (people living in the same community matched for age, sex etc.); • Data gathered is generated by the longitudinal observation of the individuals over time; • Data is collected at regular intervals thereby reducing potential memory problems. This may be important for people with aphasia participating in the study because PWA may present with a co-morbid dementia and/or memory problems.

Potential for PhD study	• People with Aphasia (PWA); • Common characteristics - Acquired Brain Injury; Aphasia; CPP; Student engagement, Living in the Community; • Measures to be repeated could include; standardised language assessments, Quality of Life measures, and/or functional communication measures.
Key limitations/ issues for PhD study	• Expensive to conduct; • Sensitive to attrition; • Time involved generating data; • Relies on the researchers capacity to stay in touch with all the participants; • This approach does not align with the PhD researcher's ontological and epistemological stance because it is a top-down rather than bottom-up approach. The stages in the research process are pre-determined and led by the researcher with limited opportunity for participants to influence the research process; • This approach does not align well with the social model of disability underpinning the CPP or the features of service learning e.g. reciprocity; mutuality; reflexivity etc.; • Using a cohort methodology would not support the inclusion of participants as co-researchers in the collaborative exploration of the research questions.
Design (Option 2)	**Qualitative Grounded Theory Study**
Key features	• Grounded Theory (GT) could be used to develop theory (formal or substantive) about the Conversation Partner Programme (CPP); • History of GT -symbolic interactionism which gives a strong theoretical background to the approach. • Can use elements of GT while primarily using other approaches e.g. PLA or case study approach; • Researcher needs to have some perspective of the direction of the study but this can be very loose as data generation with the participants will decide the important issues;

	• GT – can use constant comparative analysis to analyse data; • Theoretical sampling – the researcher decides who will be interviewed next in the data collection process – interviews become self-directing.
Potential for PhD study	• Could use GT to look at the research issues from the perspective of the service users i.e. PWA; • Variety of options/tools for data generation which may facilitate communication with PWA; • Data driven approach; • A GT approach would not support the inclusion of participants as co-researchers in the collaborative exploration of the research questions.
Key limitations/ issues for PhD study	• Grounded Theory (GT) is used to generate new theory in qualitative research. This study is focused on the lived experience of aphasia and the identification of Conversation Partner Programme evaluation criteria rather than the generation of new theory; • Participants are not usually included as co-researchers in the co-creation of knowledge and action in a GT study.
Design (Option 3)	**Qualitative Case Study**
Key features	• System of inquiry into an event or a related set of events which aims to describe and explain any phenomena; • Goal of Case study is to explore and describe the case in the fullest and most comprehensive way possible; • A case can be a person, event, group of people –multi-perspectival approach; • Need to define the case, the boundaries of the case and the product of the case as early as possible e.g. **intrinsic case study** – the case itself is of particular interest; **Instrumental Case study** – where a case is examined to learn about a bigger issue; • Case study can draw on aspects of other approaches e.g. elements of grounded theory - theoretical sampling, constant comparative analysis, iterative and reflexive

	process, coding framework etc.; - Case study provides a structure to deal with various types of analysis.
Potential for PhD study	- Case study may be relevant particularly if the aim is to find out more about a case e.g. the Conversation Partner Programme; - The case study approach could be used with an action perspective; - There are examples of case study approaches focused on evaluation of therapy and education programmes; - The research could focus on the relationship between the educational programme and its impact on Service Learning or Service Learning principles and how they inform the Conversation Partner Programme; - Event of education programme; Event of strategy of communication between the student and the people with aphasia - transferring learning into a wider community; - The Conversation Partner Programme as a vehicle to learn about else e.g. service learning principals which would become an instrumental case study.
Key limitations/ issues for PhD study	- Need to consider whether it would be better to choose one approach and align with a pure research methodology rather than mixing approaches e.g. a case study with a participatory focus; - Participants are not usually included as co-researchers in the co-creation of knowledge and action.
Design (Option 4)	**Participatory Learning and Action (PLA) Study using Qualitative Methods**
Key features	- The goal of PHR and of PLA as one form of PHR is to maximize the participation of those whose life or work is the subject of the research in *all* stages of the research process meaning that they are regarded as *co-researchers* (International Collaboration for Participatory Health Research (ICPHR), 2013). PLA aims to be: - ***Participatory –*** the goal is to maximize stakeholders' participation throughout the research process;

	• ***Locally situated* -** grounded in the reality of daily life and work in a specific place and time; • ***A collective research process* –** key stakeholder groups are represented in the study; • ***Collectively owned* –** stakeholders involved in the study own the research; • ***Transformative through human agency*** –aims to create positive social change for stakeholders; • ***Critically reflexive* –** considers power relationships in research and daily life; • ***Focused on producing local knowledge* -** collective, local, co-created, dialogical and diverse experiential knowledge; tacit knowledge; • ***Broad in terms of impact(s)* -** learning and research are inter-linked and aim for positive action; • ***Based on a broad understanding of generalizability* –** produces local evidence that can be accumulated over time to strengthen participants' ability to take effective action on health issues; • ***A dialectical process characterized by messiness* -** knowledge and action are generated by a facilitated, collective research process. ***Critical reflection** is a key feature of PLA and the researcher must continually reflect on the 'taken for granted' issues impacting study quality and rigour and power relations with stakeholder groups throughout the study.
Potential for PhD study	• Using PLA the research questions could be explored from the emic perspective of participants acting as equal partners in all aspects of the research process; • PLA values the experiential knowledge of co-researchers equally which aligns with the social model of disability and service learning; • PLA offers visual and practical methods and materials that could be adapted to support communication access

	for the participants with aphasia in the research process; • Participation, inclusion, reciprocity and mutual learning are key features of PLA which aligns with the PhD researchers' ontological and epistemological stance. These features also resonate with the features of the social model of disability and service learning which underpin the Conversation Partner Programme; • Data-driven collaborative research to explore and understand the Conversation Partner Programme; • Through PLA co-researchers could engage in a multi-perspectival, democratic analysis of the Conversation Partner Programme to identify evaluation criteria; • Critical reflection is a key feature of PLA. The PhD researcher is very familiar with reflection techniques from her experience of implementing the CPP and her knowledge of service learning; • PLA aims to equalizes power relations in the research process which fits well with the social model of disability, service learning and importantly the PhD researcher's aim for the study; • The involvement of participants as co-researchers in the collaborative exploration of the CPP may improve sustainability of the programme and the involvement of participants over time; • There are examples of the successful use of PLA with other stakeholder groups experiencing communication challenges (MacFarlane et al., 2009; MacFarlane et al., 2012);
Key limitations/ issues for PhD study	• To adopt PLA as the methodological approach the PhD researcher must have an internal value system that aligns with the theoretical assumptions and practice of this approach; • The researcher will need to let go control of the study and embrace the co-design, data co-generation and co-analysis elements and opportunities for new learning and new directions. This may be challenging given the

	external demands and time pressures associated with completion of the PhD.

Ultimately selecting a methodology is a matter of judgment and judgments about methodologies involve both suitability and personal bias (Blaikie, 2009). At the end of the decision making process the PhD researcher determined that a PLA study design was the strongest match with the primary research aims (see memo 2.1). In terms of suitability, PLA had significant scope to:

- Maximize stakeholders' participation throughout the research process;
- Equalize power relationships between researchers and participants;
- Value experiential knowledge as different but equal;
- Co-create dialogical and diverse experiential knowledge and learning.

In terms of practical factors and personal preferences the PhD researcher was drawn to the explicit identification of 'learning' in the title of PLA because it visibly connects 'learning' and 'research' as inter-linked elements in the research process. The PhD researcher also had access to:

- Training in PLA methods in the locality;
- PLA trainers and facilitators who were willing to share their expertise and knowledge;
- An experienced PhD supervisor who had successfully used PLA with a population group who had communication challenges similar to those experienced by people with aphasia (MacFarlane & O'Reilly de Brun 2009; MacFarlane & Glynn, 2008; MacFarlane et al., 2012; MacFarlane et al., 2014).

Box 2.1 PhD researcher's reflective memo on choosing a methodological approach

Guided by my supervisor I read key texts and arranged teleconferences with experts in selected methodological approaches including: Case study designs; Cohort studies; Grounded theory and Participatory research approaches. Through reading and listening to the tacit and explicit knowledge of these experts I developed a greater awareness of my own: ontological beliefs i.e.(participants construct their own individual social reality through their actions and interactions) (Guba & Lincoln 1994); epistemological stance (i.e.in my role as researcher I am intrinsic to all *phases of the research process) (Creswell, 2013) and preference for a methodological approach i.e.(to meaningfully include stakeholders as co-researchers in all aspects of the study). I had a willingness to engage in an equal partnership with participants as co-researchers and a genuine intent to look at the research questions from their unique perspectives. Therefore it became clear that methodologies with the following features would not be suitable for this study:*

- *Fixed approaches with pre-determined hypotheses, standard research conditions and methods that have their own coherence and logic e.g. cohort study*
- *Traditional linear approaches to designs with a logical progression of stages or tasks, from problem formulation to the generation of conclusions or theory with no capacity for iterative processes (Creswell, 2013);*
- *Approaches that involve collecting data from large samples and aggregating the data across individuals or situations;*
- *Approaches that would not allow the researcher to explore participants' emic experiences e.g. cohort study and involve participants as co-researches in study design and outcomes e.g. 'standard' grounded theory or case study qualitative research.*

Through reflection and discussions with my supervisor I realised that a qualitative rather than a quantitative approach with a broader and less restrictive concept of "design" would address the research questions and align with my inclusionary ethos. The chosen methodological approach needed to:

- *Be democratic with an ethos of inclusion, reciprocity, trust, collaboration and action;*
- *Involve participants in all aspects of the research process (Macaulay et al., 1999; MacFarlane et al., 2012);*
- *Focus on participants meaning and explore their understanding and perceptions of aphasia and the CPP i.e. taking an "interpretive" approach to this research (Creswell J W, 2013; De Poy & Gitlin, 2015);*
- *Focus on a small number of individuals and preserve their*

individuality in the analysis;

- *Be flexible and non-sequential in design allowing for iteration between data generation and analysis.*

I was aware from reading the literature that qualitative methods had been used to involve PWA in research. However it appeared that there was an over-reliance on qualitative interviewing as the dominant methodological approach. Many studies had exclusion criteria based on the type and/or severity of aphasia thereby excluding some people with aphasia who may have wanted to participate in the research. There appeared to be no evidence of the use of inclusive participatory approaches with this population group. I wanted to ensure that the ways that different stakeholder groups experienced and interpreted the CPP would be the central focus of the research process and stakeholders' different perspectives would become the subject of interaction and negotiation. Through my reading and conversations with my supervisor and other research experts I had a growing awareness of patient and public involvement in healthcare and the call for service users to have 'a voice' in research and development initiatives. I was very excited by the growing body of literature reporting the use of participatory methods in the field of healthcare internationally particularly with migrant populations (MacFarlane et al., 2009; MacFarlane et al., 2012; MacFarlane, O' Reilly de-Brún, & de Brún, 2008). The communication challenges (comprehension, expression, reading, writing and spelling) faced by people who do not speak the language of the community where they live are similar to the difficulties faced by people with aphasia. I wondered whether the innovative qualitative participatory methods, (specifically, participatory learning and action (PLA) research) reported in the literature with migrants could enable the meaningful involvement of PWA and other stakeholders in this study. Could PLA be used to involve PWA and other key stakeholders to creatively explore the research questions and collaboratively identify evaluation criteria that would support all groups to improve and sustain the programme? Based on the evidence in the literature and consultation with PLA experts I selected Participatory Learning and Action (PLA) research as the methodological approach for this study. PLA materials and methods were agreed as part of the co-design process with co-researchers. A *variety of PLA materials e.g.(large sheet of blank flip chart paper, coloured stickies, pictures, symbols, markers, pens, paper) could be used with PLA techniques e.g.(Flexible Brainstorm; Card Sort; Direct Ranking; Seasonal Calendar) to co-generate and co-analyse data within and across stakeholder groups (Chambers, 2004; O'Reilly-de Brún & de Brún, 2011) in response to the primary research aims.*

To appreciate the conceptual framework contributing to PLA (drawing on qualitative methods), the PhD researcher then identified important paradigms through which researchers approach studies that utilise participatory research methods. Learning about these paradigms was essential to facilitate understanding of the broader ontological and epistemological assumptions underpinning PLA as the chosen methodological approach. Relevant paradigms are summarised in the following section.

2.2 Relevant paradigms

The selected paradigms presented here do not represent an exhaustive list. The PhD researcher acknowledges that other paradigms also contribute important theoretical perspectives for example, feminist theory emphasising marginalised groups, power relations and every day experiences (Maguire, 2006) has strong resonance with the principles and practice of PLA. This discussion focuses on selected paradigms which the PhD researcher determined made an important contribution to her understanding of the theoretical underpinnings of PLA:

- Participatory Health Research;
- Critical theory;
- Interpretive Theory;
- Social Constructionism.

2.2.1 Participatory Health Research (PHR)

Participatory Health Research (PHR) is informed by a rich variety of participatory research traditions from different geographical locations all of which aim to create a more democratic and inclusive society (see Chapter 1 section1.2.3). From an epistemological viewpoint this means that social reality is not pre-given or deterministically pre-defined but rather co-created, through collaborative forms of inquiry (International Collaboration for Participatory Health Research (ICPHR), 2013). The ICPHR argue that PHR, and participatory research more generally, cannot be confined to a narrow set of epistemological principles (Fals-Borda & Rahman, 1991). The richness and appeal of PHR is the diversity of paradigms, strategies of inquiry, and methods of analysis that researchers can draw upon and utilize. This inherent plurality is intrinsic to the epistemological strength of PHR however the diverse and complex history of PHR involving a range of disciplines can create tensions and contradictions regarding its methods, outcomes and implications (International Collaboration for Participatory Health Research (ICPHR), 2013; Koch & Kralik, 2006; Reason & Bradbury, 2006).

The ICPHR suggest that PHR is a research paradigm rather than a research method (International Collaboration for Participatory Health Research (ICPHR), 2013). Thus PHR has a distinctive approach which contains underlying assumptions about what constitutes social reality. For the ICPHR, the primary underlying assumption is that *participation* by the people whose lives or work is the focus of the study fundamentally affects all aspects of the research (International Collaboration for Participatory Health Research (ICPHR), 2013). The inclusion of the experiential knowledge of local experts alongside the researchers' knowledge is the hallmark of PHR. Contributions are valued equally and the focus is on the co-creation of knowledge in a collaborative, empowering and practical way (Onwuegbuzie, Burke Johnson, & Collins, 2009). The ICPHR hold specific beliefs about the relationship between the: (1) researcher and the researched; (2) facts and values; and the (3) nature of knowledge. These relationships determine suitable methods in PHR (ICPHR 2013). Implicit is the goal of equal engagement between the researchers and co-researchers. The researcher acts as a facilitator with a conscious awareness of the impact of power relations on the evolving partnership process. In participatory research, learning and research are not considered separate entities; rather, social learning (learning together and from each other) is a fundamental component of the research process. The multiple cycles of 'look, reflect; act' underpin the dynamics of co-creating knowledge. All stakeholders learn as co-researchers to differing degrees but the aspiration is that the process is transformative i.e. the learning changes the way researchers and co-researchers see the world and themselves (Schneider et al., 2004).

2.2.2 Critical Theory

The critical paradigm is prevalent in politically oriented emancipatory research often using naturalistic, subjectivist methodologies (De Poy & Gitlin, 2015). It is a social theory focused on critiquing and changing society rather than just understanding or explaining it. Critical theory questions any society that upholds difficult conditions or marginalisation of particular groups of people. Like post-positivists and interpretive researchers, critical researchers believe that social reality is historically organised and that it is produced and reproduced by people. The ability of individuals to change and improve their social circumstances is restricted by diverse forms of social, cultural and political domination. For example PWA who wish to take public transport but have difficulty reading may be restricted by written timetables that are not communicatively accessible. The shared goal of researchers who approach investigation through critical theory is to learn about social justice and the ‘lived experience’ of people as a way to foster social change and the empowerment of isolated and oppressed groups. Critical research focuses on the oppositions, conflicts and contradictions in contemporary society, and seeks to be emancipatory (i.e. it should help to eliminate the causes of alienation and domination) (Kemmis, 2006). Critical researchers primary criticism of both post positivist and interpretive researchers is that they are in a position of power in their role of ‘expert’ researcher interacting with participants who are less powerful in the research process (Kemmis, 2006).

Critical theory informs a range of approaches including PLA. Critical theorists deconstruct the idea that there is a single truth that can only be explored though a single method of inquiry. Critical reflection is a key feature of critical theoretical approaches because it allows the researcher and the co-researchers to question the 'natural' state and challenge the mechanisms for order maintenance which is connected with generating knowledge capable of producing practical, social actions and change (Crotty, 2009). Similarly, critical reflection (see section 2.4 below ‘Critical Reflexivity’) and knowledge co-creation (see Chapter 4; section 4.3.7 and chapter 5; section 5.3.8) is a key feature of practice in PLA. The emancipatory and mutual learning aspirations of critical theory are shared by researchers using PLA. Empowerment of stakeholders is a goal of critical theorists and a desirable outcome of the process of PLA (see Chapter 3: section 3.4.1 Theme 5 ‘Benefits’). Qualitative data analysis methods are the primary analytical tools used in critical research studies and the principles of thematic analyses (Silverman, 2013) guided the co-analyses of data in this PLA study. The PhD researcher’s desire to listen to the voices and experiences of PWA and other stakeholders as equal contributors in the research process aligns with the philosophical assumptions of critical theory and the choice of PLA as the methodological approach. Finally, PWA, a recognised marginalised group in society (see Chapter 1 section;1.1.1), were included as co-researchers in this study and critical research often involves marginalised or oppressed groups in the co-construction of knowledge with a social reform agenda.

2.2.3 Interpretive Theory

The interpretive paradigm which posits that social reality is locally and specifically constructed ‘by humans through their action and interaction’ (Guba & Lincoln, 1994 p.14) fits well with the study questions because the emic perspectives of the identified ‘local expert’ groups (see sections 2.3 and 2.3.2 below) is considered fundamental to understanding aphasia and the CPP. Evaluation criteria could only be identified and agreed through the co-construction of knowledge from the interaction of the PhD researcher and the key stakeholder groups. Interpretive researchers attempt to understand and explain phenomena by accessing the meanings people assign to them (Blumer, 1969). The search for meaning in this study through PLA data co-generation and co-analysis resulted in the co-creation of new knowledge and understanding from the emic perspective of all stakeholder groups. For the interpretive researcher, social reality is influenced by culture and historically it has been situated in experiences through which people create subjective and inter subjective meanings as they interact with the world (Denzin & Lincoln, 2011). Similarly, the PhD researcher recognised that as part of the world being explored through the research aims she would be involved in all phases of the research process.

2.2.4 Social constructionism

Social constructionism focuses on the *processes* by which *people interpret*, *organise and ascribe meaning* to their individual experiences through *communication* with other *social actors* (Dwivedi & Gardner D, 1997). A social constructionist epistemology is regarded as producing relative knowledge i.e. that there is no one truth but the possibility of plurality of truths associated with different constructions of reality (Blaikie, 2009). This plurality of meaning has strong resonance with PHR and PLA. The focus of social constructionism is the collective generation and transmission of meaning (Crotty, 1998) which aligns with the data co-generation and co-analyses techniques used in PLA (see Chapter 4;section 4.3.7 and Chapter 5; section 5.3.8). Within social constructionism social actors construe their own reality. Therefore when this paradigm is applied to the primary research aims, it emphasises the importance of socio-cultural and environmental aspects of the construction of meanings, related to the experience of aphasia and the CPP (Bury, 1986).

2.2.5 Summary

While developing knowledge about relevant paradigms underpinning PLA, the PhD researcher also pursued learning to understand the origins of PLA and its operationalization in practice. In the final section of this Chapter, a detailed description of PLA as a methodological approach is presented. This includes an overview of its operationalization in this study in terms of relevant stakeholder groups, sampling and recruitment, training and application in fieldwork – data generation, data co-analysis and critical reflexivity. While there are similarities with paper 1 presented in Chapter 4 and paper 2 presented in Chapter 5 the emphasis here is on a more conceptual description of operationalization. The published papers present the actual implementation of PLA with key stakeholder groups.

2.3 Participatory Learning and Action Research

Participatory Learning and Action (PLA) research (O’ Reilly-de Brun & de Brún, 2010), was developed from Chambers (1994b), and has been used to move beyond tokenistic participation to meaningful stakeholder involvement. The goal was to operationalize the conceptual framework of inclusion and reciprocity detailed in Chapter 1 (section 1.3.1) to address the primary research aims (Chapter 1; section 1.5).

PLA is an adaptive strategy that enables diverse groups and individuals to learn, work and act together in a co-operative manner, to share, enhance and analyse their knowledge and to plan together for positive action (Chambers, 1994a). Founded on the principles of (1) democracy, (2) equity, (3) liberation and (4) life enhancement (De Poy & Gitlin, 2015), PLA aims to promote genuine participation and involvement of relevant stakeholder groups. Taking a PLA approach involved listening to and learning from the perspectives of key stakeholders, who were seen as 'local experts' of their own experiences. The research process became "with" or "by" rather than "to," "about," or "for" participants (INVOLVE, 2014). Through stakeholder involvement the focus was on breaking down boundaries, sharing experiences and building understanding. There was an explicit acknowledgement of the complementarity between different forms of understanding, rather than a hierarchy of knowledge in the research process (Tritter & McCallum, 2006).

2.3.1 Training in PLA and the application of techniques for data co-generation and data co-analysis

The application of PLA in this research was strongly supported by the PhD researcher's training in PLA methods over a two year period at the Centre for Participatory Strategies at Clonbur in Co. Galway. Through this training it became clear that using a 'PLA mode of engagement' and a range of PLA techniques could support inclusion and reciprocity in the data co-generation and co-analysis process. Learning PLA strategies for example (ice-breaker techniques; democratic decision-making processes for ground rules; introducing the study) to build relationships of trust, rapport and respect within and across stakeholder groups was important for early fieldwork (see Chapter 3, section 3.2.3). PLA materials and techniques could be selected with co-researchers and adapted to meet individual communication needs and preferences as part of the co-design process (see Chapter 3, table 3.1 and chapter 4; section 4.3.7). In addition to developing skills in research methodology, training also emphasised the importance of skill development in terms of facilitation, negotiation, conflict resolution, and advocacy. PLA facilitation is a complex task because facilitators are responsible for supporting the co-creative, collective processes of knowledge generation in a respectful and democratic way. Attitudes and behaviours that mirror the fundamental human values of dignity, respect, mutuality and reciprocity must be nurtured and maintained (International Collaboration for Participatory Health Research (ICPHR), 2013). Co-facilitation was recommended by the PLA trainers to ensure that no individual was disenfranchised around the stakeholder table. The PhD researcher realised that co-facilitation would be essential in this study given the diversity of communication challenges experienced by participants and the particular need for advocacy on behalf of the participants with aphasia. Training also highlighted ‘good practice’ in fieldwork (see Appendix C) and the importance of thorough advance preparation e.g. creating checklists e.g. (reflection tools and data storage files) and resources (e.g. PLA materials see Chapter 4; section 4.3.7 and figure 4.1) and feeling confident operating relevant equipment e.g. (digital audio recorder; digital camera).

2.3.2 Operationalization of PLA

In terms of the operationalization of PLA in this study the PhD researcher conceptualised the local experts as:

(1) People with aphasia;
(2) Students (graduate and undergraduate);
(3) SLTs in the community who refer people with aphasia into the CPP;
(4) Educators implementing SL at NUI, Galway.

Full details of sampling and recruitment of these stakeholder groups for fieldwork, as well as consent issues, are provided in Chapter 4 (section 4.3.4) and Chapter 5 (section 5.3.6). The consent process for PWA is detailed in Chapter 4 (section 4.3.6) and for other stakeholder groups in Chapter 5 (section 5.3.7). The PhD researcher’s reflections about informed consent with participants who have a communication disability are detailed in Chapter 3 (section 3.2.1). Following the PLA approach the research process sought to encourage each of these local expert groups to bring their specific knowledge and expertise to the research endeavour and to play a pro-active role in the study including:

- Shaping decisions about project development and design (see Chapter 3; section 3.2.4);
- Shaping appropriate research questions (see Chapter 3; section 3.2.2 ‘Piloting’);

  - Generating data for co-analysis within and across stakeholder expert groups (see Chapter 4; section 4.3.7 and Chapter 5;section 5.3.8)
  - Identifying and agreeing evaluation criteria for the CPP of interest (see Chapter 5 (PLA techniques).

The study design involved three phases of research with individual stakeholder groups and inter stakeholder mixed groups (see table 2.2).

Following PLA training and consultation with experienced PLA researchers the PhD researcher made a decision to include a co-facilitator in all fieldwork involving PLA methods. Edel Tierney[5] (co-author on paper 1; Chapter 4 and paper 2; Chapter 5) acted as a co-facilitator in PLA sessions across the research phases with all stakeholder groups (see Chapter 3; section 3.2.4).

Table 2.2 Research phases, expert stakeholder groups and PLA sessions

Research Phases and Stakeholder Groups	**PLA sessions**
Phase 1: People with Aphasia (n=5)	5 x 3hours PLA data co-generation and co-analysis sessions
Phase 1: SLTs (n=5)	5 x PLA Interviews
Phase 1: Students (n=9)	2 x 3hours PLA data co-generation and co-analysis sessions
Phase 1: Conversation Partner Programme coordinator (n=1)	1 x 2 hour PLA interview
Phase 2: Interstakeholder Group (n=9) • People with Aphasia (n=4) • Speech and Language Therapists (n=4)	3 x 3 hour PLA data co-generation and co-analyses sessions

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[5] Edel Tierney was trained as a PLA facilitator by the Centre for Participatory Strategies (CPS) Ross Wood, Clonbur, Co. Galway, Ireland by Mary O'Reilly-de Brún and Tomas de Brún.

• Students (n=2) • Conversation Partner Programme coordinator (n=1)	
Phase 3: Preparation and Planning for International Interstakeholder Group • People with Aphasia (n=5)	1 x 3hr PLA focus group session
Phase 3: International Interstakeholder group (n=4) • People with Aphasia (n=2) • SLT and Connect Conversation Partner Programme coordinator (n=1) • Volunteer Conversation Partner (n=1)	2 x 3hr PLA focus group sessions

2.4 Critical Reflexivity

Reflective processes central to issues of authenticity, transparency, transferability and to the PhD researcher's explicit value base were considered throughout the study. The dialogical processes of PLA are dependent on how issues of power are acknowledged and understood (International Collaboration for Participatory Health Research (ICPHR), 2013). The PhD researcher reflected on power issues in terms of how each voice was heard during fieldwork sessions and how co-researchers were supported to engage in discussion and debate. The literature cautions that claims about empowering participants should not be exaggerated (Kemmis, 2006; Maguire, 2006) and competing agendas within the research process should be acknowledged (Baum, MacDougall, & Smith, 2006). No conflicting agendas were identified in this study and the PhD researcher aimed to promote inclusion and reciprocity through the enactment of communication access. The social model of disability (Oliver, 2009) provided a foundation for reflecting on power dynamics because it stimulated: (1) a social critique about the communication challenges faced by PWA; and (2) thinking about how the facilitators and co-researchers could work collaboratively to dismantle environmental barriers. As discussed in Chapter 1 (section 1.1.1), aphasia is caused by stroke however communication disability is frequently the consequence of social factors not under the control of the person with aphasia. Environmental blocks which prevent communication access create communication challenges which may result in the experience of disability (see Chapter 1; section 1.2.1). In addition to the reflection and co-analysis with participants during fieldwork the PhD researcher documented and recorded what was happening in the entire research process (see Appendix D; example of session reflections). Critical reflection was continually used to question the ‘taken for granted’ obstacles impacting study quality and rigour and issues of communication access, inclusion and reciprocity (Gadamer, 1979). The PhD researcher considered the everyday challenges (attitudinal and environmental barriers) faced by people living with communication disability in the community and considered the mechanisms for promoting social connectedness through the CPP (Crotty, 1998).

2.5 Chapter summary

This Chapter has outlined the PhD researcher’s ontological and epistemological stance with rationale for the chosen methodological approach to address the primary research aims. Clearly, the theoretical underpinnings of PLA draw on the principles and practice of various theories and other social movements. A leading goal of PLA research is the empowerment of other usually less powerful stakeholders through the co-construction of knowledge and action. The process and outcomes of data co-generation and co-analysis with PWA is provided in Chapter 4 (paper 1) and with other key stakeholder groups in Chapter 5 (paper 2).

The next Chapter gives a detailed description of the process and experience of using PLA to involve PWA as co-researchers and their experiences of this role, and a reflexive account of the PhD researcher’s experiences of using PLA to involve PWA in this research.

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Chapter 3 Experiences of PLA and Involvement

3.1 Introduction

Chapter 2 described the PhD researcher's ontological and epistemological stance and the rationale for choosing Participatory Learning and Action (PLA) research as the methodological approach. Here I present empirical evidence about the process and experience of using PLA to involve PWA as co-researchers and their experiences of this role. I intentionally switch to the active voice in this Chapter to capture my influence on data co-generation and co-analysis. The evidence presented specifically relates to the experiences of participants with aphasia rather than other stakeholder groups. The reasons for this are twofold: Firstly the participants with aphasia are the primary stakeholders in this study and are the most excluded group in the published literature (see Chapter 1 section 1.1.1); secondly, the diversity of communication difficulties within this group created specific challenges for the PhD researcher to overcome in order to achieve communication access and inclusion. The processes involved in co-creating an accessible and inclusive study using PLA should be clearly elucidated for readers and future researchers.

The Chapter is divided into two sections: In Part 1, data on our use of PLA to co-create accessible research processes for PWA is presented. In Part 2, evaluation data about participants' experiences of the methodological approach and of acting in the role of co-researchers is reviewed. Four key data sources contribute relevant empirical evidence to support the PhD researcher and co-researchers experiences. Table 3.1 provides a brief description of each data source (column 1) and shows the information contained in each data code (column 2). The abbreviated data codes in column 3 are used throughout this Chapter to indicate specific set(s) of empirical evidence.

Table 3.1 Data Sources and Data Codes

Data Source - Description	**Data Code – includes information about:** (PLA Phase; Session Number; Stakeholder Group; Data Source; Date)	**Data Code:**
PLA Charts – Diagrams of the 'raw data' co-generated by stakeholder group(s). PLA charts are visual records and may include different types of materials depending on stakeholders' preferences (e.g. symbols, coloured stickies with written words or phrases, photographs). PLA techniques (Flexible Brainstorm; Card Sort; Direct Ranking; Seasonal Calendar) result in the co-creation PLA charts.	Phase 1: Session 1.1 and 1.2: PWA: PLA Charts: 20/02/2013 Phase 1: Session 2.1 and 2.2: PWA: PLA Charts: 26/02/2013 Phase 1: Session 3.1 and 3.2: PWA: PLA Charts: 27/02/2013 Phase 1: Session 4.1 and 4.2: PWA:PLA Charts: 06/03/2013 Phase 2: Session 1: Interstakeholder: PLA Charts: 05/11/2013 Phase 2: Session 2.1 and 2.2: Interstakeholder: PLA Charts: 12/11/2013 Phase 2: Session 3.1 and 3.2: Interstakeholder: PLA Charts: 29/11/2013 Phase 3 (Preparation): Session 1.1 and 1.2: PWA: PLA Charts: 22/01/2014	P1S1PWAC1 P1S2PWAC2 P1S3PWAC3 P1S4PWAC4 P2S1ISC1 P2S2ISC2 P2S3ISC3 P3S1PWAC1
Researcher debriefing/reflection notes –The facilitator and co-facilitator had structured reflection and debriefing following each fieldwork session.	Phase 1: Session 1.1 and 1.2: Researcher reflection and debriefing notes: 20/02/2013 Phase 1: Session 2.1 and 2.2: Researcher reflection and debriefing notes: 26/02/2013 Phase 1: Session 3.1 and 3.2: Researcher reflection and debriefing notes: 27/02/2013 Phase 1: Session 4.1 and 4.2: Researcher reflection and debriefing notes: 06/03/2013	P1S1RR P1S2RR P1S3RR P1S4RR

Reflection notes and a sustainability analysis were recorded during these formalised sessions in a supportive environment.	Phase 2: Session 1: Researcher reflection and debriefing notes: 05/11/2013 Phase 2: Session 2.1 and 2.2: Researcher reflection and debriefing notes: 12/11/2013 Phase 2: Session 3.1 and 3.2: Researcher reflection and debriefing notes: 29/11/2013 Phase 3 (Preparation): Session 1.1 and 1.2: Researcher reflection and debriefing notes: 22/01/2014	P2S1RR P2S2RR P2S3RR P3S1RR
Transcripts from digital audio recording – All fieldwork sessions were taped on a digital audio recorder with participants' permission. Recordings were reviewed by the PhD researcher with partial transcriptions. Selected sections were transcribed verbatim.	Phase 1: Session 1.1 and 1.2: PWA: Transcripts: 20/02/2013 Phase 1: Session 2.1 and 2.2: PWA: Transcripts: 26/02/2013 Phase 1: Session 3.1 and 3.2: PWA: Transcripts: 27/02/2013 Phase 1: Session 4.1 and 4.2: PWA: Transcripts: 06/03/2013 Phase 2: Session 1: Interstakeholder: Transcripts: 05/11/2013 Phase 2: Session 2.1 and 2.2: Interstakeholder: Transcripts: 12/11/2013 Phase 2: Session 3.1 and 3.2: Interstakeholder: Transcripts: 29/11/2013 Phase 3 (Preparation): Session 1.1 and 1.2: PWA: Transcripts: 22/01/2014	P1S1PWAT P1S2PWAT P1S3PWAT P1S4PWAT P2S1IST P2S2IST P2S3IST P3S1PWAT
Photographs – All fieldwork sessions	Phase 1: Session 1: PWA: Photographs: 20/02/2013	P1S1PWAP

were photographed by the co-facilitator using a digital camera with participants' permission. Photographs provided a visual record of PLA techniques, materials, charts and stakeholder groups. Co-researchers selected photographs to take home as personal "keep sakes" of the study.	Phase 1: Session 2: PWA: Photographs: 26/02/2013 Phase 1: Session 3: PWA: Photographs: 27/02/2013 Phase 1: Session 4: PWA: Photographs: 06/03/2013 Phase 2: Session 1: Interstakeholder: Photographs: 05/11/2013 Phase 2: Session 2.1 and 2.2: Interstakeholder: Photographs: 12/11/2013 Phase 2: Session 3.1 and 3.2: Interstakeholder: Photographs: 29/11/2013 Phase 3 (Preparation): Session 1.1 and 1.2: PWA: Photographs: 22/01/2014	P1S2PWAP P1S3PWAP P1S4PWAP P2S1ISP P2S2ISP P2S3ISP P3S1PWAP

3.2 Part 1 – The Experience of using PLA to involve PWA in research

This section presents data about the PhD researcher's experiences of using PLA to involve PWA as co-researchers in the evaluation of a primary care conversation intervention. My reflections and the co-facilitator's reflections are italicised and presented verbatim within double quotation marks to elucidate our experiences of the research process.

Theoretical constructs and practical tools from the field of participatory health research (Chambers, 1994a, 1994b) and aphasiology (Cruice, 2007; Dalemans, de Witte, Wade, & van den Heuvel, 2010; Kagan, Simmons-Mackie, Gibson, Conklin, & Elman, 2010) combined with advice from my aforementioned PLA trainers and PhD supervisor informed the design of interactive PLA sessions. My Speech and Language Therapy background and my training in qualitative research and PLA methods contributed to the co-creation of communicatively accessible research processes with my co-researchers. Together we identified individual communication needs and dismantled barriers to participation. Maintaining communication access throughout the study was an iterative process involving continuous reflection, direction from co-researchers and subsequent modification.

Following each data generation session I engaged in structured reflection with my co-facilitator (see Chapter 2; section 2.4 and Appendix D). In this supportive environment we discussed our individual and shared experiences of what had worked well, what we should continue doing, and what we should stop doing. This sustainability analysis stimulated thinking about how we might maximize participation and inclusion during PLA data co-generation and co-analysis. Our reflections often resulted in modifications to subsequent sessions (e.g. slower pace and less complex language, etc.). We allowed extra time for fieldwork to support comprehension during the explanation of project documents, techniques, and instructions because language processing requires significant effort and a relaxed environment is important for PWA (Johansson, Carlsson, & Sonnander, 2012). The adaption of project documents facilitated participants' comprehension, for example, I developed aphasia-friendly meeting agendas, information sheets, consent forms and PowerPoint presentations (see Appendix E) (Aleligay, Worrall, & Rose, 2008; Rose, Worrall, Hickson, & Hoffmann, 2012).

The flexible nature of PLA enabled the co-creation of a comfortable setting with freedom of movement. Participants understood the voluntary nature of contributions and their role as co-researchers in the study. The co-researchers offered me advice about my rate of speech, use of questions, and the timing and duration of breaks which improved my pacing and facilitation skills in our fieldwork sessions (see box 3.1).

Box 3.1 Memo on Critical Reflection and PLA facilitation

Critical reflexivity meant considering how power and powerlessness affect the daily lives of PWA in this study because capturing their 'lived experience' of aphasia and their perceptions of the CPP were the primary research aims. Through my PLA training and continuous reflection (personal; team and reviewing data sources - audio recordings; PLA charts etc.) I developed my facilitation skills and I learned from my experiences with co-researchers. I questioned my role(s) in the study and knowledge based on power differentials between myself and co-researchers. I reflected on the expertise of PWA gained through their lived experience and the social exclusion faced by people with communication disabilities. I saw my facilitation role as a partnership between myself, the co-facilitator and our co-researchers. The purpose was to promote empowerment and active engagement in response to research questions.

Following data co-generation sessions we reflected on the process: what could have happened differently; what went well and what we should change to improve communication access and support sharing in the group. I learned to modify my communication style to support individual needs and preferences in the group so that no individual was disenfranchised around the individual or inter-stakeholder tables. My learning and gradual skill development gave me confidence to encourage themes to emerge as well as add to the analytical process. We allowed data to evolve over time and we embraced all new and unexpected learning in the research process.

Being comfortable with silences and allowing space for uncertainties and unpredictability resulted in unexpected insights and outcomes. I spent a lot of time reflecting on important issues e.g. (1) genuine engagement in participatory knowledge spaces; (2) co-researches knowledge as unique and equal; and (3) moving beyond the ethos of inclusion and reciprocity to actual enactment through communication access. I reflected on how I was influencing interpretations, judgments and outcomes. I was aware of the limitations of the study particularly in relation to the generalizability of findings given our small sample sizes.

3.2.1 Consent

Using a PLA mode of engagement, we (facilitator and co-facilitator) discussed the content of adapted consent forms with each individual, aiming to ensure that participants were self-determining and well informed at enrolment (Brady, Fredrick, & Williams, 2013). On completion of the consent process we reflected that:

“Signing the consent forms took longer than expected because we gave each individual participant time to ensure they understood the forms and consent was given in full understanding of what participation involves” (Facilitator and Co-facilitator) (data code: P1S1RR).

We recognized that some PWA might present with memory difficulties, whereas others might simply not ask for additional information even if they wanted it because of their communication impairment. Thus, in accordance with best practice in qualitative research, we viewed informed consent as a process, never assuming that any individual’s consent was long lasting. We used our PLA training to work with participants keeping them informed about aspects of the study central to their ongoing participation, with the understanding that they could leave the study at any time if they so wished. Despite data generation spanning 1 year, there was no attrition from the group during the course of the project.

3.2.2 Piloting

The research questions and PLA techniques were explored with representatives from all individual stakeholder groups (see Chapter 2; table 2.2) and two researchers who were trained in PLA methods[6]. Following piloting, changes were made to improve the explanation of project information, PLA techniques (verbal and written), and timing of sessions. The piloted questions were too long and linguistically complex to be easily understood and the advice of the participants with aphasia (*n* = 2), was particularly important for improving comprehension and accessibility, For example:

Pilot question 1: *"If you were talking to someone very close to you about Aphasia, what kinds of things would you say/think of to explain how Aphasia has affected **YOU**?"*
Revised question: *"How does aphasia affect **Me** and my **Family**?"*

Questions 2 and 3 in the pilot were revised and replaced by a single question:
Pilot question 2: *"If you were telling a good friend about the student coming to visit you what kinds of things would you say/think of?"*
Pilot question 3: *"If you had the opportunity to speak directly to the University about the student visits what would you say to help them improve the experience for **YOU?**"*
Revised question: *"What difference does the conversation partner programme make to **ME?**"*

The value of piloting was evident following the first data co-generation session with the aphasia experts: *"Piloting the techniques and the questions was very important for the session today. The design and wording of questions was very important"* (Facilitator) (P1S1RR).

3.2.3 Fieldwork: Introduction to the research and "ice-breaker"

The introduction to the research involved an "ice-breaker" and an accessible PLA PowerPoint presentation describing the aims and

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[6] Dr. Rachel Mc Evoy and Ms. Edel Tierney (co-author on paper's 1 and 2) were trained as PLA facilitators by the Centre for Participatory Strategies (CPS) Ross Wood, Clonbur, Co. Galway, Ireland by Mary O'Reilly-de Brún and Tomas de Brún.

participatory ethos of the study. Ice-breakers are commonly used in PLA to build participant confidence and encourage engagement. I selected a symbol-based ice-breaker which had the additional benefit of reducing verbal demands and supporting the communication ability of participants. I placed pictures of shoes in the middle of a large table where all participants could see and access them. A PowerPoint slide was displayed with the following written instruction, which was repeated out loud: “Pick a shoe. Tell us why you have picked this particular shoe. What does it say about you?”(see Appendix C). The facilitators and participants took turns to explain why they had chosen a particular shoe. The ice-breaker encouraged participants to interact freely with each other and to demonstrate their communication competence and areas of challenge. We reflected on the activity in our debriefing notes following the session:

“The shoe ice-breaker was specifically chosen as a symbol-based ice-breaker which the participants engaged with and seemed to enjoy” (Facilitator and Co-facilitator) (P1S1RR).

During the ice-breaker activity I observed differences in communication abilities across the group and used my speech and language therapy skills to address arising challenges: *“I noticed that some people in the group had comprehension difficulties, with evidence of literal interpretations. There was also evidence of tangential speech …”* (Facilitator) (P1S2RR).

Overall the PLA ice-breaker was characterized by positivity and active participation, which set the tone for the full PLA session.

3.2.4 Data co-generation and co-analysis

PLA sessions were designed based on team planning, constant consultation with stakeholders, and researchers’ structured debriefing (see Chapter 4; section 4.3.7 and Chapter 5; section 5.3.8). The PhD researcher reviewed emergent data including: (1) PLA charts; (2) critical reflections; (3) audio recordings, and (4) photographs taken during fieldwork (see table 3.1 above). There was evidence of fun and peer-support from the outset which is reflected in the following extracts from the facilitators and, also, participants with aphasia:

"I think participants valued the peer-support and humour in the group. There was lots of laughter in the midst of the research work. There was a sense of team when the session was completed and I think the participants are looking forward to the next session" (Facilitators) (P1S1RR).

In the following exchange, Gary[7] is talking about what caused his stroke and aphasia. He jokes that perhaps his stroke was caused by his wife's shopping trips! This is a good example of the humour that permeated the data co-generation and co-analysis sessions.

Co-facilitator: (18:47.2–18:49.1) … so it wasn't stroke, it was aphasia?

Gary: (18:49.1–18:58.3) Yes, yeah. I don't know any, I had a stroke but I don't know, like Neil, I don't know what causes, maybe the wife going up shopping (Laughter) ... (P2S1IST).

A variety of PLA techniques were used to co-generate data in an inclusive way, specifically the Flexible Brainstorm, Card Sort, Direct Ranking, and Seasonal Calendar techniques. Significantly, and in recognition of their role as co-researchers, individual stakeholder groups were involved in selecting which PLA techniques to use in Phase 1 and inter-stakeholder groups were involved in this decision making in Phases 2 and 3 (see Chapter 2; table 2.2). Table 3.2 shows the PLA techniques (Chambers, 2004; O'Reilly-de Brún & de Brún, 2011) and materials chosen across the research phases. A detailed description of each PLA technique is provided in Chapters 4 and 5. Here, as evidence of the co-researchers' involvement in decision making, I emphasize the "Co-design" column in Table 3.2 which highlights how co-researchers influenced the adaptation and use of PLA materials to support communication and accessibility. Inductive thematic analysis (Silverman, 2013) guided the co-analysis of data (see Chapter 4; section 4.3.7:Chapter 5; section 5.3.8 and Appendix F for further data analysis details). Transferability of findings was explored in Phase 3 (see Appendix H).

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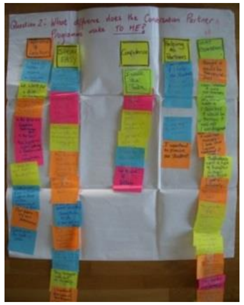
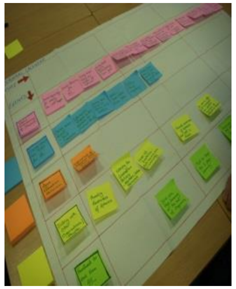
[7] Pseudonyms have been used throughout the Chapter to ensure confidentiality for all participants

Table 3.2: PLA techniques co-selected for data co-generation and co-analysis across research phases

PLA Technique(s)	Photographic example of PLA technique(s)	Purpose	PLA Materials and Process	Co-design (examples)	Data Source(s)
Flexible Brainstorm **Phase 1** (Individual groups) **Phase 2** (Inter-stakeholder group) **Phase 3** (International Inter-stakeholder group)		Ideas generated in response to research question(s) No restriction on the number of ideas/perspectives an individual could generate. Group agreed to represent one idea only per stickie.	Varied materials to suit individual communication needs and preferences e.g. blank flip chart page, colored stickies, pictures, symbols, markers, pens, paper.	Some co-researchers chose to write single word(s) and talk about their idea(s), others chose a picture to represent intended meanings, the majority who had difficulty writing requested that the facilitator(s) wrote on their behalf. Co-researchers suggested colour coding stickies for all research questions – after their experience of Q 1 as colour coding created a visual link between the individual and their idea.	Flexible Brainstorm chart(s) Photographs of co-generated chart(s) Digital Audio Recording 

PLA Technique(s)	Photographic example of PLA technique(s)	Purpose	PLA Materials and Process	Co-design (examples)	Data Source(s)
Card Sort **Phase 1** (Individual groups) **Phase 2** (Inter-stakeholder group)		Categorization of ideas generated in Flexible Brainstorm. Card Sort created commonly-generated record of co-researchers agreed groupings and categorization of diverse experiences from their *insider* perspective.	The Flexible Brainstorm chart and materials as above. Facilitators asked: What ideas belong together? Why do these ideas belong together?'	Extra time required to arrive at consensus. 'Cross-checking' information in the group Colour-coded stickies - valuable visual connection to the individual experiences - Supported decision making in the categorization process.	Card Sort chart(s) Photographs of co-generated chart(s)
Direct Ranking **Phase 1** (Individual groups) **Phase 2** (Inter-stakeholder group)		Mechanism to express priorities and preferences about categorization from Card Sort.	The Card Sort Chart and an equal number of colored paperclips for each co-researcher. Co-researchers cast votes according to a single agreed criterion e.g. 'the most important evaluation criterion to the least important'. Voting resulted in prioritization of identified	Process and outcome discussion of voting enhanced knowledge about shared ideas and priorities Co-researcher with aphasia suggested breaking voting token in half to give two half votes instead of one vote. Placing votes on one idea vs. category of ideas	Direct Ranking chart(s) Photographs of co-generated chart(s)

PLA Technique(s)	Photographic example of PLA technique(s)	Purpose	PLA Materials and Process	Co-design (examples)	Data Source(s)
			themes.		
Seasonal Calendar **Phase 2** (Inter-stakeholder group)		Mechanism for planning implementation of evaluation criteria for conversation intervention across agreed time-line. Actions and responsibilities mapped across stakeholder groups	The Direct Ranking Chart; colored stickies; Pens; Markers and Flip Chart paper. Left-hand vertical axis - agreed evaluation criteria Horizontal axis – elements within each criterion detailing tasks to be completed by individuals responsible	Suggested by co-researchers. Headings Roles Seasonal Calendar technique moved beyond original research aims to implementation. Color-coded category headings and related elements on chart.	Seasonal Calendar chart Photographs of co-generated chart
Interviewing the PLA technique		To determine sufficiency of data and data saturation. Member checking and review.	PLA chart reviewed and discussed by group. Additional ideas added to existing chart. Task complete when group decide nothing new to add.	Co-researchers chose to write new information on their color coded stickies	Photographs of completed chart

Co-researchers directed decisions about study design and outcomes during the course of the study. On completion of question 1 the group made important design decisions to enhance the recording of written data and improve communication access:

1. The facilitators should write idea(s) shared by an individual on colour-coded stickies when requested. Facilitators reflected: *“Writing for participants who could not write themselves worked well because it allowed people time to get their message across without the pressure of writing e.g. one idea per stickie”* (Facilitator and Co-facilitator) (P1S1RR).

2. Use colour-coded stickies so that each individual can be visually connected to his/her contribution(s) on the PLA charts. *“Colour coding the stickies in this way worked very well because it connected participants to their stickies and their ideas … Each participant’s contributions were clearly represented on the chart and could be easily identified with the colour coding. Participants valued being able to see their own ideas quickly”* (Facilitator and Co-facilitator) (P1S3RR).

This exchange demonstrates the value of colour-coding for both co-researchers and facilitators.

David: (14:26.4–14:28.4)	I thought I did very well there [pointing at the orange stickies on the Flexible Brainstorm chart].
Facilitator: (14:28.4–14:32.2)	*You did very well, I’m just checking...*
Co-facilitator: (14:32.2–14:38.7)	This is the good thing about the colours isn’t it? You can see all the things you had to say...
Facilitator: (33:43.7–33:59.7)	*I’m just checking in with you in case there is anything you need to add; if there’s not, that's okay.*
David: (33:59.7–34:08.8)	I should have put something down here to say, our home is first preference.

Facilitator: (34:08.8–34:11.5)	We can say that, David is orange…'Our home is first *preference' in terms of the location.* (P1S3PWAT)

The facilitators reflected on PLA materials and colour coding in Phase 1:

"the PLA mode of engagement and the PLA materials e.g. coloured stickies; pictures; writing tools and so forth supported participants to communicate what they wanted to say and to represent it clearly … Participants reported being very surprised by all that they had to say"..(Facilitator and Co-facilitator) (P1S3RR).

3. *"*Use a tick on the stickie to indicate when more than one person shares the same idea instead of duplicating the idea on separate stickies: *"Participants discussed and agreed to indicate intensity of response [using a tick] on stickies that resonate with more than one participant rather than duplicate stickies"* (Facilitator) (P1S2RR).

Finally, in the following extracts I present some examples of how co-researchers directed decisions about PLA techniques, which we recorded in our debriefing/reflection notes:

"Participants actively contributed to the design of the session and to the decisions about whether to use the Direct Ranking Technique on the data generated and categorised in response to question 1" (Facilitator) (P1S2RR) and in response to question 3, *"participants chose not to categorize the Flexible Brainstorm charts with a 'Card Sort'"* (Facilitator) (P1S4RR).

3.3 Part 1 - Conclusion

We used PLA to co-create a multi-perspectival democratic evaluation of a conversation intervention from the emic perspective of co-researchers. The time investment at the outset to identify practical barriers to the involvement of participants with aphasia as co-researchers' and their influence on study design and outcomes resulted in more accessible and inclusive research processes. The following memo about using PLA to include people with aphasia as co-researchers gives some insight into the paradigm shift I experienced during the research process (See box 3.2).

Box 3.2 PhD researcher's reflections on Participatory Learning and Action Research

As an educator and a speech and language therapist I have a toolkit of techniques that I use to include people with communication disabilities and students in different aspects of treatment, teaching, service delivery and evaluation. I am comfortable creating written materials and pictures, and working with technology and paper-based resources to support interaction. Inclusion through practical steps to enable communication access has always been part of my work and ethos. Through PLA I have learned new techniques that can be adapted to support communication access and inclusion in the research context. Learning and adapting PLA techniques (e.g. card sort, flexible brainstorm, direct ranking etc.) with participants seemed to be a natural extension to my existing toolkit of inclusionary strategies. However the realisation that these techniques could be successfully used to create reciprocity and mutuality in research with people with diverse communication disabilities was new and exciting. The PLA approach establishes an engaged environment where stakeholders participate in a dynamic and evolving interaction with all aspects of the research process including materials and resources. However PLA is more than the creation of a context where people who are normally excluded or marginalised are involved through communication access. Embracing PLA is more about a way of working and an ethos of inclusion, reciprocity, democracy and mutual learning. This value system resonates with the social model of disability and the relational knowledge produced by genuine involvement in PPI activities. The philosophy of PLA and the mode of engagement has created an unexpected theoretical shift in terms of my constructs and values. This paradigm shift has involved a change in my belief system about power relations and different knowledge(s) in the research process. My reflections on the theoretical and practical implications of involving participants as co-researchers in qualitative participatory research involve continuous learning. Adopting PLA as my methodological approach is partly about learning and implementing the inclusionary PLA techniques and practices but also about understanding *my constructs of inclusion and power and how these influence me as a researcher and how I influence the research process and outcomes. I have questioned my personal beliefs and biases about what it means for participants to actively engage as co-researchers and I have come to understand that valuing experiential knowledge as different but equal in the research process is a core construct. By co-creating participatory spaces the 'voice' of all stakeholders can be heard, acknowledged, and valued. Our knowledge(s) within the research process contribute different ways of understanding that are complementarity rather than hierarchical. Participants in their role of co-researchers have unlimited potential to impact research design and outcomes democratically changing the direction of the study as required. To achieve this level of collaboration I spent time reflecting on any desire I had to 'control' the study, particularly given time pressures and the requirement to account for my activity and progress within specific periods to the PhD governance committees. Through acknowledging these pressures and my personal prejudices I began to embrace reciprocity, respect and mutual learning as key components of research encounters. I wanted to equalise power relations and engage with co-researchers not just as more empowered participants, but as equal collaborators, teachers, evaluators, and research experts in all aspects of the study. I worked with participants together as a team in equal partnership and this way of working created participatory spaces for collaboration and mutual learning. We reflected together throughout the study about how we could co-create accessible research process and support inclusion so that everyone involved had adequate opportunities to respond to research questions in a democratic and respectful way. Critical self-reflection was a core feature throughout the research process and the emergent learning from reflection and from my co-researchers ultimately resulted in a transformative paradigm shift for me as an individual and as a researcher.*

On completing data co-generation and co-analysis sessions the PhD researcher recorded the following reflection:

"I honestly do not think it would have been possible to generate the quantity and quality of data with PWA using any other method of data collection/generation. I think the PLA techniques and materials are very

suited to supporting communication and contributed to an accessible and relaxed research environment" (Facilitator) (P1S4RR).

3.4 Part 2 - PWA Experiences of PLA and Acting in the Role of Co-researchers

This section presents data about participants' experiences of PLA and of acting as co-researchers. Different types of evaluation data were gathered throughout the research process (see Table 3.3 and Appendix G). Participants' words are presented verbatim within a double quotation mark. The extracts preserve the style of speakers with aphasia, inclusive of hesitations, distortions and non-traditional grammar.

Table 3.3: Types of Evaluation Data

Type of Reflection	Description of Reflection	Data Generated	Data Code(s)
Immediate Session Reflections	Following PLA sessions co-researchers' were invited to respond to the question "Would anyone like to say how it felt to participate in the session today?"	Co-researchers shared 9 separate verbal accounts of their PLA session experiences.	P1S3PWAT P1S4PWAT
Between Session Reflections	Following the first session, and for each subsequent session, participants brought symbols to represent their experiences of acting as co-researchers.	Co-researchers shared 13 separate symbols with descriptions of intended meanings (see 'Symbols Table' in Appendix G)	P1S2PWAT P1S3PWAT P1S4PWAT
Overall Session Reflections	Following the completion of fieldwork, participants shared their overall experiences of PLA and being co-researches in response to the question: *"What is your experience of participating in this research study?"*	Co-researchers using the PLA Flexible Brainstorm technique generated 56 separate ideas about their experiences.	P3S1PWAT P3S1PWAC1

3.4.1 Participants' experiences of acting as co-researchers in a PLA study

Theme 1: Accessibility and inclusion.

Co-researchers reported democratic research processes and support to share their individual perspectives in a relaxed way. "We had time to listen to other people in the group; it was democratic" (Neil) (P3S1PWAT). "Talk with others – say something; I never had a chance before to say something … I felt listened to" (David) (P3S1PWAT). "Equality" (William) (P3S1PWAT). "Experience of talking, speech, conversation … I was talked to" (Gary) (P3S1PWAT). The effort required to communicate in a group situation with aphasia was noted by participants and some were surprised by the quantity of information they successfully communicated during PLA sessions: "We are all strangers in the group; when you meet new people it is hard to get it [talk] out … being in a group speaking is difficult … not here" (Gary) (P3S1PWAT). "After first few sessions I was very tired; I didn't think I had that much to say" (Neil) (P3S1PWAT). "Tiring … I thought I never could say so much … I never had a chance of speaking what I want to say in other groups" (David) (P1S3PWAT). The egalitarian research processes and opportunity to share ideas in a supportive, inclusive environment were appreciated: "I think it's great to see the seven of us … we can talk, you can talk about different things and we're just ordinary people at that stage" (Anne) (P1S3PWAT). Co-researchers reported satisfaction with the opportunities provided to share their perspectives: "We all said our say" (Anne) (P3S1PWAT); "We were all on the same course – what we wanted it came in a circle" (Gary) (P3S1PWAC1).

Theme 2: PLA as a methodological approach.

Participants had definite ideas about PLA versus other methodological approaches: "I wouldn't agree with the interview technique – in the group there is more discussion and debate … there was teamwork in the group" (Neil) (P3S1PWAC1); "Interview is one way – not really sharing my experiences" (David) (P3S1PWAC1:22/01/2014). Through PLA, one co-researcher stated: "Made myself understood" (Anne) (P3S1PWAC1) and Gary reported: "Make me talk … the research made me talk" (Gary) (P3S1PWAC1). Allowing time for participants to communicate ideas was important: “You didn’t finish what we were trying to say” (David) (P3S1PWAC1); “As a group we had a chance to talk” (Anne) (P3S1PWAC1). The size of the group was an important factor in facilitating participation: “In big groups I am not able to speak; it’s too much hassle” (William) (P3S1PWAT); “The small size of the group works well” (Anne); “We expected you to help us in the group” (William) (P3S1PWAT). Participants commented on PLA materials and charts, agreeing that they supported communication and memory recall: “Stickies are a big help” (Anne) (P3S1PWAC1); “When you write it down, you can see it, it’s a reminder” (Neil) (P3S1PWAC1); and “Stickies are a very good idea” (All) (P3S1PWAC1). The opportunity to view other stakeholders’ perspectives through PLA charts was appreciated: “Had opportunities to see [through PLA charts] what other people [SLTs and students] had to say” (Neil) (P3S1PWAC1). Following the completion of fieldwork, Neil, reviewing all PLA charts created across stakeholder groups, commented: “… there was a lot of stuff there [looking at PLA charts] and … you’re not going to get in to all this stuff you know? You’re not!” (Neil) (P1S4PWAT). The PLA use of symbols created an accessible, participatory way to gather and record co-researchers’ experiences, while sharing personal perspectives appeared to deepen trust relationships and respect within the group: “The symbols give insight into other people” (Neil) (P3S1PWAC1). Co-researchers were alert to the PLA mode of engagement: “I was very happy with the whole process” (William) (P3S1PWAT); “In the room I’m very happy … we are contented and that’s important” (Gary) (P3S1PWAT). Participating in the study as co-researchers required effort: “Tiring” (Gary) (P1S3PWAT). Speaking about PLA as a methodological approach, William stated, “I am a believer!” (William) (P3S1PWAC1).

Theme 3: PLA peer support.

The aforementioned principles of PLA and the time invested in establishing stakeholder relationships in phase 1 were worthwhile and resulted in peer support between group members: “People were willing to listen and give you more than a chance to speak” (Neil) (P3S1PWAT); “Just do it as good as you can and as nice as you can and as relaxed as you can; end of story” (Neil) (P1S4PWAT). Gary reported that because of the group he had new motivation to improve his communication ability, “I think the tortoise wants to be like the hare again … All of us we’ve said, we can speak our mind here. No interruptions at all. So that’s good” (Gary) (Symbol: Toy tortoise) (P1S4PWAT). Participants valued the views of co-researchers and recognized that sharing created new learning: “People gave you ideas in the group” (Neil) (P3S1PWAC1); “What did I mean? So helping, we can talk here” (Gary) (Symbol: Picture of stacking turf) (P1S3PWAT); “Research is about change ... I’d like to know what others feel” (David) (Symbol: Picture of planting) (P1S3PWAT). Working as a co-researcher seemed to create a sense of solidarity and pride among group members: “It’s nice to know you are not alone” (David) (P3S1PWAT); “It’s nice to know you are ALIVE … the camaraderie in the group” (William) (P3S1PWAT). Speaking about the group Neil said: “It’s a good job, really good job, I think so anyway … a very good job … I’m proud of ye all” (Neil) (P1S4PWAT). Co-researchers remained committed to the group and to the project: “I would love to know how you get on” (David) (P3S1PWAT); “We want to see the end results” (Gary) (P3S1PWAT); “We are always thinking – what’s NEXT?” (Anne) (P3S1PWAT) and, “We be back … we’ll be back …” (Neil) (P1S4PWAT).

Theme 4: Fun and enjoyment.

All participants reported a sense of enjoyment and fun in their role of co-researchers: “Love the group, beauty of it … beautiful … very much so … very much so” (Neil) (Symbol: Salmon and Chocolate bar) (P1S2PWAT); “I can’t read, I can’t write anymore but I enjoyed the group … Great! Great! Great!” (William) (P3S1PWAT); “Thoroughly enjoy it” (William) (Symbol: “Imelda May” compact disc) (P1S2PWAT); “Happy and contented … I feel very comfortable in the group” (Gary) (P3S1PWAT); “I’m very pleased I attended the meetings” (David) (P3S1PWAT). Some of the symbols shared by co-researchers represented the sense of fun in the group, for example: “Absolutely, I thought it was wonderful experience … we had fun as well ... I thought we had fun …” (Neil) (Symbol: Circus ticket) (P1S4PWAT). Participants reported feeling excited about the PLA sessions: “The first meeting I didn’t know what it would be like; after that I was looking forward to coming” (Neil) (P3S1PWAT) and disappointment when attendance was not possible – “I found it fantastic – I was heartbroken I couldn’t come when I was ill” (Anne) (P3S1PWAT).

Theme 5: Benefits.

Co-researchers recognized the importance of their role in the study: “Participating in the group is helping” (William) (Symbol: Pen and paper) (P1S4PWAT); “We got help and we gave back a small piece of help to you, that’s what I get out of it” (Gary) (Symbol: Photograph of fancy dress) (P1S2PWAT); “This is important to me now” (David) (Symbol: Fossil) (P1S2PWAT). Participants recognized that their lived experience of aphasia and the CPP contributed valuable knowledge to the study: “I felt I had something … I wasn’t wasting your time” (Anne) (P3S1PWAT); “I’m glad it was useful for you too” (Neil) (P1S4PWAT). Co-researchers shared perceived personal gains from the study: “Participating in the group ... it makes me feel better … makes me feel a bit of sanity to myself you know” (Neil) (Symbol: Coffee menu for deluxe coffee maker) (P1S3PWAT); “Since I’ve been here I have hopefully I have got better or not better but better than usual in talking and that means an awful lot to me” (David) (Symbol: Pencil and paper) (P1S4PWAT); “I think this session was the best thing that ever happened to me … I feel great … A vote of thanks … and if you ever need anyone … we’ll be back” (David) (P1S4PWAT); “Experience, a good experience now and a great achievement, some great people … I’m a great believer” (William) (P1S4PWAT); “I feel elated ... I didn’t think we had so much to say … but I’m happy that we did” (Gary) (P1S4PWAT); “Very interest … well I have to try and get it into shorter words … in there … very interested … you know what I’m saying ...” (Anne) (P1S3PWAT). Following stroke and aphasia the group had a shared perception that society viewed them differently, but being part of the research team gave an outward appearance of normality: “Walk into the room and see ‘normal people’” (Gary, and all agreed) (P3S1PWAT). This sense of “being normal” extended beyond the research setting to home and other contexts: “We are doing something … I have something to talk about when I go home” (Anne) (P3S1PWAT); and “We’ve great news” (William) (Symbol: iPhone) (P1S3PWAT). Some participants reported transformative experiences in relation to identity, confidence, and their sense of wellbeing during the study: “I felt respected” (All) (P3S1PWAT); “It shows what we can do … we are not fools … we are very important” (Anne) (P3S1PWAT).

3.5 Chapter summary

This Chapter illustrates how the participants with aphasia (n=5) were involved as co-researchers in a multi-perspectival evaluation of a primary care conversation intervention. The experiences of participants of acting as co-researchers were recorded through participatory evaluations. I have presented empirical evidence about: 1) our use and reflections on PLA as a methodological approach to include PWA as co-researchers and 2) PWA perceptions of this role. Throughout the study I experienced PLA as a transformative research paradigm that helped equalize power relations and resulted in: (a) reciprocity, (b) an inclusive study design, (c) enhanced credibility of data and outcomes, (d) new learning, (e) increased multi-stakeholder ownership of the CPP, and (f) improved sustainability of the CPP. These experiences resonate with co-researchers' reported experiences which included: (a) democratic and equitable partnerships (within and across stakeholder groups and researchers); (b) accessible research processes; (c) sufficient opportunities to successfully communicate their emic experiences in a relaxed and supportive environment; (d) respect and value in the research process; (e) the suitability of the methodological approach; (f) knowledge creation and learning; (g) commitment to the research process including outcomes and (h) personal transformations in the domains of confidence, identity, and self-worth. The empirical evidence presented in this Chapter represents scholarship that makes knowledge claims which may be transferable beyond the immediate setting. This study could be used as a 'case study' demonstrating successful collaboration both in terms of research processes and outcomes. Future studies could "scale up" (International Collaboration for Participatory Health Research (ICPHR), 2013) (see Chapter 8 section 8.3.2) the case presented in this research thereby strengthening the transferability of findings.

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Chapter 4 Paper 1: Addressing the long-term impacts of aphasia: How far does the Conversation Partner Programme go?

4.1 Abstract

4.1.1 Background

Approximately 176,000 new individuals in the United Kingdom and Ireland are diagnosed with stroke annually with up to one third experiencing aphasia. Qualitative research methods are increasingly used to capture the complexity of service users' experiences of health and illness; however, the voice of service users with aphasia continues to be limited in published healthcare literature. This participatory research study included people with aphasia as co-researchers in the exploration of aphasia and a Conversation Partner Programme (CPP).

4.1.2 Aims

To describe participants' insider (emic) experiences of (1) aphasia and 2) a CPP.

4.1.3 Methods and Procedures

Following a pilot study, the generation and analysis of qualitative data involved a Participatory Learning and Action (PLA) approach based on the interpretive paradigm. Using purposeful sampling, participants included people with aphasia (*n* = 5) who had experience of the CPP. Through (*n* = 5) 3-hour data generation sessions across 12 months using PLA techniques -Flexible Brainstorming and Card Sort - participants' unique perspectives of aphasia and the CPP were recorded. The principles of thematic analysis guided the co-analysis of data with participants. To explore transferability of findings, data generated in Ireland were presented to an international inter-stakeholder group in Connect UK.

4.1.4 Outcomes and Results

Participants identified eight themes describing the lived experience of aphasia including (1) Back to Pre-School, (2) Tiredness, (3) It's Like in Prison, (4) Emotions, (5) Not able to talk the Words, (6) Escape, (7) Changing and Adapting, and (8) Family. Five additional themes were co-generated capturing the value of the CPP. It appeared that because the CPP training and programme acknowledged the expertise of individuals

with aphasia and provided opportunities for conversations with unfamiliar people, the negative feelings of communicative incompetence described in “Back to Pre-School” and “Not able to talk the words” were minimised. Feelings of marginalisation captured in “Escape”, “It’s like in Prison” and “Emotions” were reported to be reduced through the social aspects of the Programme.

4.1.5 Conclusions

Aphasia changes communication situations and interpersonal relationships often resulting in psychosocial impacts and disempowerment. The CPP contributed to promoting successful communication and reducing social exclusion. Participants reported transformative experiences related to identity, independence, and confidence. These outcomes are encouraging as marginalisation and vulnerability to “secondary handicap” are recognised long term risks of aphasia. Findings will be of interest to those living and working with people with aphasia and to those designing, delivering and participating in CPPs.

4.1.6 Keywords

conversation approaches; impacts; emic; qualitative; participatory health research; insider

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4.2 Introduction

Approximately 176,000 (Institute of Public Health (IPH) Stroke Briefing, 2012; Stroke Association, 2015) new individuals in the United Kingdom and Ireland are diagnosed with stroke annually with up to one third experiencing Aphasia (Code & Petheram, 2011). The voices of these people are frequently absent from the published stroke literature compared to other population groups (Carlsson, Paterson, Scott-Findlay, Ehnfors, & Ehrenberg, 2007). Through qualitative research the insider perspective or emic perspective (Creswell, 2013) of aphasia is emerging, and people with aphasia (PWA) are teaching us about the lived experience of aphasia (Simmons-Mackie & Lynch, 2013). This emic perspective (Creswell, 2013), has taught us that adapting to life with aphasia and re-negotiating normal activities of daily living (e.g., finances, housework, work, social life, and leisure interests) is more difficult in the presence of a communication disability (Parr, Byng, & Gilpin, 1997; Pound, Parr, & Duchan, 2001). We know from previous research that family and friends can become anxious about communication, and attempts at normal conversation may result in feelings of fatigue, discouragement, and sadness (Le Dorze & Signori, 2010; Michallet, Tétreault, & Le Dorze, 2003). Others may perceive the person with aphasia differently, for example more difficult to talk to, less likable, less interested in achievement, less capable of endurance with less capacity to care for others (Croteau & Le Dorze, 2001). Partners often become the primary carers with additional responsibilities (Hammell, 2001) and new behaviours such as overprotectiveness and assuming the speaker role in conversation may develop thereby excluding the person with aphasia (Croteau, Vychytil, Larfeuil, & Le Dorze, 2004; Halle, Duhamel, & Le Dorze, 2011; Purves, 2009). Personal relationships and social networks may gradually decline for both the person with aphasia and family members resulting in increased isolation and disconnection (Cruice, Worrall, Hickson, & Murison, 2003; Northcott & Hilari, 2011).

Listening to the emic perspective (Creswell, 2013) has taught us that our efforts to understand aphasia must extend beyond the language and speaking problems to include the complex changing experiences and representations of all those negotiating life with aphasia (Barrow, 2008). Dealing with the uncertainty about the meaning of stroke and aphasia in terms of personal identity, relationships, professional and financial status are long term challenges (Dalemans, de Witte, Wade, & van den Heuvel, 2010; Pound et al., 2001). We need to co-design rehabilitation goals and develop interventions that help the person with aphasia and his/her family experience successful communication (Barrow, 2011). Conversation approaches are an increasingly popular intervention that emphasise communicative competence, reciprocity and life participation (McVicker, Parr, Pound, & Duchan, 2009).

4.2.1 Conversation partner training approaches

Aligned with the social model of disability, conversation approaches are designed to increase communicative access and reduce the psychosocial consequences of aphasia (Byng & Duchan, 2005). According to Turner and Whitworth (2006) conversation training interventions centre on the belief that conversation partners can be trained to support and optimise communication with a person with aphasia and have traditionally targeted three primary groups including: (1) familiar partners - family or friends (Booth & Swabey, 1999; Lock, Wilkinson, & Bryan, 2001); (2) volunteers (Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001; McVicker et al., 2009; Rayner & Marshall, 2003) and (3) healthcare professionals (Shale, 2004). Training interlocutors to become skilled conversation partners creates new expectations for the person with aphasia and the conversation partner. Conversation opportunities are increased as the competence of the person with aphasia is revealed and the risk of marginalisation is reduced (Turner & Whitworth, 2006). Supporters of conversation approaches recognise the therapeutic potential of conversation and value the expertise of the person with aphasia. Social interaction is prioritised above linguistic gains and positive communication experiences are promoted (Kagan, 1995; Kagan et al., 2001; McVicker et al., 2009). However the evidence on the impacts of conversation interventions for PWA is limited. The present study addresses this gap in knowledge by listening to the emic perspective of a small group of PWA with experiential knowledge of a Conversation Partner Programme (CPP).

Emerging evidence of the emic perspective (Pound, Duchan, Penman, Hewitt, & Parr, 2007) in published aphasia literature is regarded as a positive direction in the design of this study. However, the use of interviewing as the single predominant data collection method in qualitative studies is striking. As recommended by Simmons-Mackie and Lynch (2013), alternative research methods and data collection strategies should be considered. There is a growing body of literature reporting the use of participatory methods in the field of healthcare internationally (MacFarlane et al., 2009 , 2012) with the suggestion that these methods are particularly useful to include marginalised groups typically excluded from the research process (MacFarlane, O' Reilly de-Brún, & de Brún, 2008). This study is innovative as we applied participatory research methods to include PWA as co-researchers in a three-phase research project. Here we report Phase I that involved an exploration of their emic experiences of (1) aphasia and (2) a CPP. We are reporting this study on behalf of PWA who participated in this research as participants and co-researchers.

4.3 Methods

4.3.1 Study setting

The conversation intervention used is based on the CPP developed at Connect (the communication disability network, 2001), London in 2001. A detailed description of this programme is available elsewhere (McVicker et al., 2009). While the Connect conversation scheme originally focused on training volunteers as conversation partners, the network subsequently expanded to include universities across the United Kingdom and Ireland.

At the National University of Ireland (NUI), Galway, in the west of Ireland the CPP is an integral part of the the 4-year BSc in Speech and Language Therapy. The programme is run in collaboration with the local community Speech and Language Therapy service (Primary Community Continuing Care (PCCC) Health Services Executive (HSE) West, 2015). Community speech and language therapists (SLTs) refer approximately 5–20 new PWA into the programme annually. The majority of PWA choose to continue their participation across several iterations of the programme over a number of years.

For third-year students, CPP training and participation is a mandatory requirement. These students are trained as conversation partners, paired with a peer and matched with a person with aphasia based on interests and hobbies and geographical location. Students' weekly conversation visits to PWAs' homes or other locations provide unique opportunities to learn about aphasia and apply theory to practice in a relaxed environment which is different from the classroom or clinical settings. Weekly reflective logs, fortnightly tutorials, and assessment involving individual and group work facilitate students' reflective practice and learning throughout the programme (see Table 4.1 for detailed CPP information).

Table 4.1 Conversation Partner Programme Details

Conversation Partner Programme	**Speech and Language Therapists in training**	**People with aphasia**
Participants	Third-year undergraduate students (25-30 students)	People with aphasia living in the local community referred by community speech and language therapists working for the public health service. Partners include males and females aged between 21-90 years with an acquired brain injury resulting in aphasia. All participants have been discharged from acute health services and are living in the community e.g. family homes nursing homes
Module content	Students work in pairs and complete 10-12 visits with a person with aphasia. Students use supportive communication techniques to facilitate conversation	Visits take place in a variety of locations depending on conversation partners' preferences e.g. family home, coffee shop, restaurant, nursing home, Speech and Language Therapy office, University
Monitoring	Weekly reflective blogs Fortnightly class tutorials with academic staff	The PWA can contact the referring SLT and/or the CPP co-ordinator based at the

		university at any time during the programme
Credits	Students must pass all components of the module to complete the module. There is no compensation between components	
Assessment	Completion of conversation partner training (1-day programme); participation in 10-12 visits with PWA; completion of weekly reflective blog; participation in fortnightly tutorials. Students work in small groups to prepare a poster presentation on aphasia-related themes	
Duration	1-2 Semesters 7 Hours per week (1 day)	Visits take place over 10-14wks

4.3.2 Study Design

This participatory study is designed following the principles of a Participatory Learning and Action (PLA) (O' Reilly-de Brun & de Brún, 2010) approach based on the interpretive paradigm. PLA is an adaptive strategy developed from work by Chambers (1994) that enables diverse groups and individuals to learn, work, and act together in a co-operative manner, to share, enhance, and analyse their knowledge; and to plan together for positive action. PLA emphasises three key components:

1. **Participatory** research projects undertaken in rural and urban settings.
2. **Learning** is an essential part of the process – two-way or

multidirectional.

3. **Action** is about more than appraisal – it is about taking positive action.

Founded on the principles of (1) democracy, (2) equity, (3) liberation and (4) life enhancement (De Poy & Gitlin, 1998), this methodological approach promotes genuine participation and involvement of participants. The multidisciplinary backgrounds and PLA experience of the three authors supported the adaption of PLA techniques and materials for use with PWA. The first author is a SLT with over 15 years experience of working with PWA and has coordinated the CPP at NUI, Galway for almost a decade. The second author is a psychologist with many years experience of working with people with intellectual disability and communication challenges. The third author is a social scientist and academic and has been involved in collaborative/partnered participatory research with a broad range of stakeholder groups nationally and internationally for over 10 years. All three authors are trained PLA facilitators[8] and through their combined clinical, PLA, and research expertise, they ensured the research process was communicatively accessible for the co-researchers with aphasia.

4.3.3 Pilot study

The research questions and PLA techniques were piloted with trained PLA experts (*n* = 2) and PWA (*n* = 2) to test relevance and understanding. As a result of the pilot several changes were made to improve the explanation and clarity of PLA techniques, timing, methods, materials, session facilitation and research questions.

4.3.4 Sampling and recruitment

The majority of studies that have included PWA have sampled on the basis of a general diagnosis, such as stroke, or with inclusion/exclusion criteria based on the person's communicative and/or cognitive ability. During recruitment we deliberately avoided exclusion criteria that may convey that some participants were not "good enough" for our study (Carlsson et al., 2007). We recognised that including PWA as co-researchers irrespective of

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[8] The authors were trained as PLA facilitators by the Centre for Participatory Strategies (CPS) Ross Wood Clonbur Co. Galway Ireland by Mary O'Reilly-de Brún and Tomas de Brún.

the severity of their communication disability would contribute a unique perspective to the study that would not otherwise be achieved.

Purposive sampling (Creswell, 2013) was used to obtain the study sample. Using this sampling technique allowed us to select PWA living in the West of Ireland affiliated with NUI, Galway, CPP. A letter was sent to 10 PWA (five females and five males) of varying age ranges who had experience of the CPP. This letter invited PWA to participate in the research. In accordance with our ethical approval a maximum of five people could be recruited to this stakeholder group with up to three reminders about the study to each person. It was not ethical to contact potential younger and/or female participants a fourth time and from our recruitment drive four males and one female agreed to participate. There were no exclusion criteria, and participants were not screened for cognitive, hearing, and/or visual problems.

4.3.5 Participants

Four men and one woman with a mean age of 73 years agreed to participate in this study. Time elapsed since stroke ranged from 3 to 10 years with an average participation in 3 iterations of the CPP, that is, 30 conversation visits, 10 visits per annual iteration of the programme. Communication diagnoses and severity determinations were based on (1) the objective assessment reports from the referring SLTs documented in the speech and language therapy records, (2) the SLT researchers' confirmation of communication diagnoses with each referring SLT, and (3) informal observations of participants throughout the study. All participants had functional comprehension in conversation with either mild or mild to moderate comprehension difficulties. There was greater variability in expressive language ability, with a range of mild, moderate and moderate to severe disability. Similar to the Parr (2007) study, styles of communication varied as each person had adapted to communicating with aphasia in different ways, and had developed preferences for varied communication strategies. Most used gesture, intonation, facial expression, with occasional single written words or letters to supplement their speech. Nobody used drawing, word lists, or portable communication devices, and one person who presented with the most severe expressive disability did not spontaneously use any augmentative means to support communication. Table 2 shows some characteristics of the five participants with aphasia.

Given the older age range of participants, we have also included details about the possibility of co-morbid dementia. All names in this table and throughout the paper have been changed to protect confidentiality.

Table 4.2 - Characteristics of People with Aphasia

Name, age and years since stroke	**Sex**	**Participation in the CPP**	**Communication diagnosis** (from (1) SLT records; (2) discussion with referring SLT; (3) SLT researcher's observations of participants	**Co-morbid dementia**	**Medical diagnosis**	**Employment**	**Domestic situation**	**Research sessions attended (*n* = 8)**
David, 83 years and 3 years	M	3 times	Moderate expressive aphasia with moderate-severe literacy difficulties	No evidence in SLT records; on discussion with SLT or during data generation sessions.	Stroke	Retired	Home with family	*n* = 6
William, 85	M	4 times	Severe expressive	No evidence in SLT records;	Stroke	Retired	Home with family	*n* = 5

Name, age and years since stroke	**Sex**	**Participation in the CPP**	**Communication diagnosis** (from (1) SLT records; (2) discussion with referring SLT; (3) SLT researcher's observations of participants	**Co-morbid dementia**	**Medical diagnosis**	**Employment**	**Domestic situation**	**Research sessions attended (*n* = 8)**
years and 10 years			aphasia	on discussion with SLT or during data generation sessions.				
Gary, 60 years and 4 years	M	3 times	Mild-moderate expressive aphasia and moderate-severe apraxia of speech	No evidence in SLT records; on discussion with SLT or during data	Stroke	Retired	Home with family	*n* = 8

Name, age and years since stroke	**Sex**	**Participation in the CPP**	**Communication diagnosis** (from (1) SLT records; (2) discussion with referring SLT; (3) SLT researcher's observations of participants	**Co-morbid dementia**	**Medical diagnosis**	**Employment**	**Domestic situation**	**Research sessions attended (*n* = 8)**
				generation sessions.				
Neil, 69 years, and 6 years	M	4 times	Cognitive communication impairment affecting memory, planning, and organisation; some word finding difficulties	No evidence in SLT records; on discussion with SLT or during data generation sessions.	Stroke	Retired	Home with family	*n* = 7

Name, age and years since stroke	**Sex**	**Participation in the CPP**	**Communication diagnosis** (from (1) SLT records; (2) discussion with referring SLT; (3) SLT researcher's observations of participants	**Co-morbid dementia**	**Medical diagnosis**	**Employment**	**Domestic situation**	**Research sessions attended (*n* = 8)**
			and severe literacy difficulties					
Anne, 69 years and 4 years	F	3 times	Moderate aphasia with tangential speech and moderate literacy difficulties	No evidence in SLT records; on discussion with SLT or during data generation sessions.	Stroke	Retired	Home with family	*n* = 4

4.3.6 Consent

There are methodological issues related to obtaining informed consent when the participants being invited to consent have a communication disability. Some suggest that the complexities of providing informed consent to PWA might explain why the voice of this population group is limited in the literature (Carlsson et al., 2007). Strategies to address the ethical issues related to obtaining informed consent from people with communication disabilities have been reported e.g. (e.g., Parr, 2007; Philpin, Jordan, & Warring, 2005). In this study we aimed to facilitate participants' understanding of consent forms by presenting oral and written information in an aphasia-friendly format, for example, we adjusted language and used illustrated communication resources (Rose, Worrall, Hickson, & Hoffmann, 2012). We discussed the content of all consent forms with each individual as this strategy has been posited as the most effective way of improving participants' understanding of what informed consent involves (Flory & Emanuel, 2004; Penn, Frankel, Watermeyer, & Müller, 2009). Given that PWA with accompanying memory difficulties and/or co-morbid dementia may sign a consent form and then later forget what they had signed or even that they had given consent, we did not assume that participants' consent was long-standing. Rather we reviewed consent following each data generation session throughout the study (Usher & Arthur, 1998). All aphasia friendly consent forms including (1) project; (2) photo and (3) recording forms were approved by the NUI, Galway research ethics committee.

4.3.7 Data co-generation

A variety of PLA data generation techniques were used to create data with co-researchers, specifically the Flexible Brainstorming and Card Sort techniques. Importantly, and in recognition of their role as co-researchers, these two techniques were selected and agreed with co-researchers as part of the co-design process. Both PLA techniques have been used in international research settings (Chambers, 1994, 2004; O'Reilly-de Brún & de Brún, 2011). In the current study, these techniques were used to generate, organise, and display participants' data, and an accompanying "PLA interview" (O'Reilly-de Brún & de Brún, 2011) was used to explore, synthesise, and co-analyse the data.The key features of the selected techniques and materials are that they offered a mechanism for sharing, discussing, and evaluating knowledge in a supported communication environment that was dynamic and could be adapted to suit individual communication needs and preferences. Through five data generation sessions of approximately 3 hours each across 12 months, participants' unique perspectives of aphasia and the CPP were co-generated and co-analysed. With participants' consent we took photographs during the data generation sessions. This had multiple purposes. First, it allowed us to visually record the co-selected PLA techniques, materials used, and active engagement of participants with the PLA techniques (see Figure 1). Second, the photographs provided a visual record of the data recorded on the Flexible Brainstorm and Card Sort charts, which was a valuable way of reminding participants about the data generated across sessions. In this way the photographs contributed to the qualitative analytic process with participants throughout the project. Finally for each session, we printed and displayed the photographs on blank charts and invited participants to choose any that they desired to take home as a personal keepsake and to share with others, for example, family and friends. The selected photographs were a tangible, visual reminder of the research work, and they acted as a ramp to communication with others about the activity during the data generation sessions. All sessions were taped with permission on a digital audio recorder.

Figure 4.1 Photographs from the data generation sessions. (left) examples of PLA materials used; (right) participants engaging with the PLA Flexible Brainstorm technique.

PLA Technique – Flexible Brainstorm

To answer the research question "How does aphasia affect me and my family?" co-researchers engaged in a PLA technique called "Flexible Brainstorm" (O'Reilly-de Brún & de Brún, 2011). A Flexible Brainstorm is a fast way of using varied materials (large sheet of blank flip chart paper, coloured stickies, pictures, symbols, markers, pens, paper) to get information and ideas that can be arranged, re-arranged, connected, and discussed for different purposes (O'Reilly-de Brún & de Brún, 2011). The PLA materials were centred on the table, and participants selected materials to suit their individual communication preferences. Some chose to write single word(s) and talk about their idea(s), and others chose a picture to represent their intended meaning; the majority who had difficulty writing requested that the facilitators wrote on their behalf. Therefore on instruction from an individual, the facilitator wrote verbatim what the person wanted to record and checked that the intended meaning had been captured accurately before the PWA placed the stickie on the Flexible Brainstorm chart. There was no restriction on the number of ideas an individual could share; however in the interest of clarity the group agreed that they would only represent one idea on each stickie. Following review of the Flexible Brainstorm chart generated in response to Question 1 in Phase 1, the co-researchers suggested colour coding stickies for all subsequent research questions. Each participant chose a set of coloured stickies, which became "their colour" for the duration of the activity. The visual record of ideas on colour-coded stickies connected the person to the shared experience and enabled participants to identify "their stickies" quickly on the chart, for example, David could see that all of the orange stickies on the chart represented his ideas. Adopting colour coding as a strategy during data generation is a practical example of participants co-designing the research process.

Interviewing the technique

The process of sharing and recoding ideas continued until everyone had said all that they wanted to say in response to the research question. Sufficiency of data collected was determined by "interviewing" the emerging data. This means that the group reviewed the completed chart to identify potential gaps. They were encouraged by the facilitator to discuss anything surprising or striking about the experiences shared. If any additional information was generated co-researchers were invited to record the new ideas on their colour-coded stickies and place them on the chart. When the group agreed that there was nothing new to add, data saturation was reached and the Flexible Brainstorm was complete. The Flexible

Brainstorm technique was a foundation activity for the second PLA “Card Sort” technique (O’Reilly-de Brún & de Brún, 2011). Figure 4.2 shows Photo examples of the Flexible Brainstorm technique and co-created chart.

Figure 4.2: Photo examples of the Flexible Brainstorm technique and co-created chart.

PLA technique – card sort

A Card Sort is a variety of cards (or symbols) that participants sort, usually into bundles or categories. Card Sorts are a method of categorisation that facilitate participants to (1) organise and share large amounts of information,(2)move and connect information, and (3) “cross-check” information with each other (O’Reilly-de Brún & de Brún, 2011). Co-researchers reviewed the populated Flexible Brainstorm chart and engaged in a Card Sort process - sorting, organising, and analysing the data into meaningful groupings. The researcher asked co-researchers two questions: (1) “What stickies belong together?” and 2) “Why do these stickies belong together?” Reading individual stickies aloud supported the group to reflect on the data and group similar elements.

Data Co-Analysis

The principles of thematic analysis (Creswell, 2013; Silverman, 2013) guided the co-analysis of data. Through the PLA Card Sort (described earlier), co-researches identified, analysed and extracted patterns within the data generated during the PLA Flexible Brainstorm (described earlier) in response to the research questions. The group reviewed the individual elements on the Flexible Brainstorm chart and communicated their rationale for organising data to reflect patterns in semantic content (i.e., linked elements with a shared meaning/connection). They synthesised the data in a way that captured the key elements and represented the associations that connected the groupings together. When this was complete the co-researchers engaged in interpretative analysis (Smith, Bekker, & Cheater, 2011) by extracting descriptive categories that represented the groups' emic perspectives of aphasia and the CPP (i.e., co-researchers reviewed the co-generated meaningful groupings and agreed on categories of analysis). The group reviewed the individual elements generated during the Flexible Brainstorm, and through negotiation and debate the co-analysis of data progressed from description to interpretation resulting in co-created themes and emic patterns of meaning (Braun & Clarke, 2006).

The second stage of co-analysis provided an opportunity for co-researchers to move elements between categories if they "fitted better" in a different category. Category headings were also reviewed, discussed, and changed if desired in a democratic way with group agreement. Category headings did not have to comply with any syntactic rules or academic writing style and often included simple phrases or headings such as "Back to Pre-School"; "It's Like in Prison" (see Table 2). The categorisation process continued until all individual elements had been grouped under agreed themes. Arriving at consensus took time but similar to our experience in the Flexible Brainstorm technique, the colour-coded stickies provided a valuable visual connection to the individual personal experiences recorded, and this appeared to support decision making in the categorisation process and agreement of emergent themes.

Following the same process outlined above in "Interviewing the technique", the group determined data saturation and closed the "Card Sort". The completed Card Sort chart was a clear, commonly generated record of co-researchers agreed groupings and categorisation of diverse experiences from their emic perspectives. The PLA Flexible Brainstorm and Card Sort techniques were repeated for Question 2 "What difference does the CPP make to me?" (see Figure 4.3 for photo examples of the Card Sort technique and co-created chart below). Details of the co-created and co-analysed data in response to both research questions are presented in the "Results" section.

Figure 4.3: Photo examples of the Card Sort technique and co-created chart.

To explore transferability of findings, data generated in Ireland was presented to an international inter-stakeholder group (SLT (*n* = 1); PWA (*n* = 2) and trained conversation partner (*n* = 1)) at Connect (the communication disability network) in London, UK . This group was asked how the findings from the Irish study resonated with their experiences of Aphasia and the CPP in the United Kingdom.

4.4 Results

4.4.1 Study aim 1

To explore co-researchers' emic experiences of aphasia we asked: *Q1 "How does aphasia affect me and my family?"* The group generated 75 separate elements during the Flexible Brainstorm in response to this question. These elements were linked and categorised into eight different themes during the Card Sort technique[9] (see Table 3).

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[9] The card sort categories are the emergent themes and are described in detail below

Table 4.3: Flexible Brainstorm and Card Sort chart co-generated in response to "How does aphasia affect me and my family?"

Back to Pre-school	Tiredness	It's Like in Prison	Emotions	Not able to Talk the Words	Escape	Changing and Adapting	Family
Lost all my talk, letters, writing, reading the whole lot	Physical tiredness affects ability to get words	Not able to converse	Frustrated	Putting ideas into words	Two talking over each other – I have to get out	Slowly and surely it's coming good	Good family and friends important
Know exactly in my mind when I write and I write rubbish. Second time correct what I've written	Reading the paper even if it is the most important thing if I'm tired I have to leave it and come back again	I was a go, go, go person – I will never be able to drive again	Angry Later (not when I got the stroke)	Crossroads related to getting the words out. Trying to get the word and sentence gets lost	Groups very difficult – cross over talking and noise	Crossing the road is difficult	Family support is very important
Slower speech very very slow	Meet students – grand for first 10 min but if I get tired that's it	Social life nil	Frustration	Very good in the mind but difficult to get words	Noise is difficult	Different ways of doing things. Realise we can do something else	Friends did not visit for a while
Used to do computer and	Very tired – words won't	You miss people –	Only getting half	It's all here (in mind). How	Have to get out when you	Other ways of doing things	Close family are

Back to Pre-school	Tiredness	It's Like in Prison	Emotions	Not able to Talk the Words	Escape	Changing and Adapting	Family
that sort of thing but since I had the stroke I wasn't able	come out	can't go out as you did before the stroke	way – e.g. shopping Get upset and Cross	much can you get out is the difficulty	are in a crowd – related to noise	– we know it without knowing it	the only ones who give you time
Re-learn everything like a baby	Tiredness related to effort put into language things (reading, writing, talking)	What is there for us to do? (related to loneliness and missing people)		Other things that can affect you getting the words out e.g., knee being very sore	Loneliness – in a crowd people wouldn't talk to you because of aphasia	We improve going along but not 100% - aphasia and doing things	
Not 100% writing	Different type of tiredness – not 100%	Haven't driven since stroke		Understand up here – mind – Frustrated	Feel invisible (linked to people talking over you)	Point to the bus or train timetable	
Spelling – cannot tell the difference between letters	I'll answer the phone but if it's evening I'm not able	Since stroke can't go to Mass every morning (related to getting out)		Like driving on the road – you come up to a traffic light and you have to stop but you weren't able to go again 'cause the sentence is	Cross talking difficult. It's the sound/noise – I have to give up	Getting a lot better (related to getting the words out)	

Back to Pre-school	**Tiredness**	**It's Like in Prison**	**Emotions**	**Not able to Talk the Words**	**Escape**	**Changing and Adapting**	**Family**
				gone			
Left with half – only get half things (related to reading, writing and speech		Won't go out the way you used to – Afraid, crowds, people won't spend time seeing what you want		It's all hear (pointing to head) but how much can you get out (pointing to mouth)	People talking over you to your wife/partner – very annoying	Let someone else order food for you	
Reading very slow		What is there for us to do? (related to feeling down)		Know person- easier to get words	I love music but cannot listen to it	In the restaurant point to what you want	
Reading, writing, spelling, speaking, understanding – different levels				If it's face-to-face it's easier when you know somebody	Hate people telling me what I want to say	Perceptions of self – better than you think you are, e.g., going to Quest	
Reading – not able				Don't know person – more	They (people) won't give	Perceptions of others –	

Back to Pre-school	Tiredness	It’s Like in Prison	Emotions	Not able to Talk the Words	Escape	Changing and Adapting	Family
				difficult	you time to say what you want to say	bus driver thinking we are “Loo-La”	
				The Phone – know the person - easier	Walk alone (in crowds) People talking to each other	Partners thinking that you are not able to do things, e.g., going to Quest	
				Same phrases for phone e.g. “Hello” “How are you” “Hold on there” – Can recognise voices			
				I don’t answer the phone now			

Later we describe each theme separately but emphasise that there are inter-relationships between some themes, for example, the references to negative emotions in Themes 1, 4 and 5.

Theme 1a: Back to Pre-school

The elements grouped in this theme related to the linguistic impacts of aphasia. The degree of language impairment varied across participants, for example, “lost all my talk, letters, writing, reading the whole lot” (Gary). Anne described being “left with half – only get half things – reading, writing and speech” while other co-researchers focused on specific linguistic deficits: (1) speech, “slower speech very very slow” (William); (2) writing, “know exactly in my mind when I write and I write rubbish…” (David); (3) spelling, “spelling – cannot tell the difference between letters” (Neil); (4) reading, “Reading – not able” (David); (5) computer, “used to do computer and that sort of thing but since I had the stroke I wasn’t able” (Anne), and so on. The group co-generated the theme “Back to Pre-School” to capture the shared experience of communication challenges and the need to “re-learn everything like a baby” (Gary) from a very basic level.

Theme 2a: Tiredness

The elements grouped in this theme related to feelings of tiredness. Co-researchers explained that the experience of tiredness following stroke and aphasia is different from the normal tiredness of everyday life; “different type of tiredness – not 100%” (Anne). The majority agreed that tiredness whether physical or mental increases communication difficulties, for example, “Reading the paper even if it is the most important thing if I’m tired I have to leave it and come back again” (Anne); another co-researcher explained the effect of physical tiredness on word finding ability “very tired the words won’t come out” (Gary). Tiredness makes answering the telephone and meeting the conversation partners more challenging; “I’ll answer the phone but if it’s evening I’m not able and meet students – grand for first 10 min but if I get tired that’s it” (Anne). There was a shared belief amongst the majority of the group that the level of tiredness was directly connected to communication effort - “tiredness related to effort. Language things - reading, writing, talking” (Gary). One co-researcher reported that tiredness did not affect him in that way -“tiredness really doesn’t affect me that much … although I go to bed early (since the stroke)” (Neil). Neil reported that his challenges with word finding, reading and writing were always the same and his physical and/or mental tiredness did not make them worse.

Theme 3a: It's Like in Prison

The elements grouped in this theme related to the negative impact of aphasia on normal conversation. All co-researchers experienced difficulties communicating in groups "Not able to converse" (David). Consequently, social activities gradually reduced "Won't go out the way you used to – afraid, crowds, people won't spend time seeing what you want" (David). The reduction in social interaction created feelings of loneliness and isolation "You miss people – can't go out as you did before the stroke" (Anne); "What is there for us to do?"(Anne). Daily activities that were part of life before stroke and aphasia are no longer possible, for example, "driving, going to Mass every day, socialising" (Anne). One co-researcher reported "Haven't driven since the stroke" (Neil) and another said "I will never drive again" (Anne). Some co-researchers also perceived a change in personal identity, for example, "I used to be a go, go, go person..." (Anne) These experiences of not being able to converse and live life in the same way as before aphasia created a shared sense of being in prison.

Theme 4a: Emotions

The elements grouped in this theme related to the negative emotions experienced by the group following stroke and aphasia. All co-researchers were consistent in reports of "frustration", "sadness", "anger" (Gary, William, Neil, Anne, David), "upset and cross" (Anne) as a consequence of living with aphasia. Not being able to complete normal activities, for example, shopping "only getting half way" (Anne) resulted in feelings of weariness and annoyance.

Theme 5a: Not Able to Talk the Words

The elements in this theme related to co-researchers' experiences of good cognitive ability but poor communication ability. The group shared the frustration of word-finding difficulties and communication breakdown, for example, "understand up here – mind – frustrated" (William). All agreed that they were "very good in the mind but difficult to get the words" (David). "It's all here – in mind- how much you get out is the difficulty" (Gary). One co-researcher explained that pausing to search for a word resulted in losing the whole sentence - “like driving on the road - you come up to a traffic light and you have to stop but you weren’t able to go again ‘cause the sentence is gone” (Gary). Gary’s sharing triggered a memory of a similar experience for Neil “Crossroads - trying to get the word and sentence gets lost” (Neil). Participants reported that word-finding ability is affected by other situations and factors, for example, “other things that can affect you getting the words out e.g. knee being very sore” (Anne) or “tiredness” as discussed in Theme 2a. Talking appears to be easier with familiar people. Gary explained “Know the person – easier to get words”…. “don’t know person – more difficult” (Gary). The context and nature of the communication also appears to be an important factor in successful communication – “If it’s face-to-face it’s easier…” (William). Experiences of using the telephone varied, for example, “the phone know person easier” (Anne) while Neil shared “I don’t answer the phone now.” One co-researcher developed a strategy that involved using a set of memorised phrases to answer the phone, for example, “same phrases for phone ‘Hello’ ‘How are you’ ‘Hold on there’” (William). This strategy enabled him to answer the phone successfully and allowed time for his partner to “take over” speaking.

Theme 6a: Escape

The elements in this theme related to co-researchers’ experiences of trying to communicate in crowded environments. Co-researchers explained that group interactions are particularly challenging, for example, “groups very difficult – cross-talking and noise” (David). Gary shared “have to get out when you are in a crowd” and all agreed. Co-researchers reported making deliberate efforts to avoid groups/crowds for a variety of reasons, for example, feelings of (1) isolation - “loneliness in a crowd people wouldn’t talk to you because of aphasia” (Anne), “feel invisible people talking over you” (David), “walk alone people talking to each other”(William); (2) annoyance -“Crowds of people also people talking over you to your wife/partner very annoying hate people telling me what I want to say” (David) {All agreed}. The noise levels, cross-talking and feelings of exclusion created a common desire to escape or avoid group situations.

Theme 7a: Changing and Adapting

The elements in this theme related to the ways that co-researchers have changed and adapted to life with aphasia. William explained that he felt "slowly and surely it's {talking} coming good" and Neil shared that he feels he is "getting a lot better." Anne felt that "we improve going along but not 100% - aphasia and doing things." The group reported that everyday tasks are still challenging, for example, "Crossing the road is difficult" (Neil) but that they had developed some compensatory strategies - "other ways of doing things – we know it without knowing it" (Gary); "Point to the bus or train timetable ... bus driver thinking we are Loo-La" (Anne); "Let someone else order food for you" (David), "In the restaurant point to what you want" (Gary). Co-researchers explained that the way they perceive themselves and their ability are often different from the way that family members perceive them, for example, "better than you think you are" (Anne and Neil) while "partners thinking that you are not able to do things" (Anne). The group felt that living with aphasia necessitated new ways of coping with normal tasks.

Theme 8a: Family

The final theme in response to Question 1 related to co-researchers' experiences of support after stroke. All agreed that "Family support is very important". There was intensive discussion about the support received from family versus friends. The group shared that "good family and friends important" (David and all agreed) and "close family are the only ones who give you time" (Gary). Co-researchers described the decline in social networks following stroke and aphasia "friends did not visit for a while" (Gary and all agreed).

4.4.2 Study Aim 2

To explore co-researchers' emic experiences of the CPP we asked: *Q2 "What difference does the Conversation Partner Programme make to me?"* The group generated 47 separate elements during the Flexible Brainstorm and categorised these elements into 5 different themes during the Card Sort technique. Data generated and co-analysed is set out in Table 4.

Table 4.4: Flexible Brainstorm and Card Sort chart co-generated in response to "What difference does the Conversation Partner Programme make to me?"

Preference of Location	Speak Easy	Confidence	Helping as Partners	Great Expectations
I think it is better at home (you have more time)	One to one and two to one. Both student should get a chance	I walked the talk	I feel proud if I help the students	I thought it would be therapy at first
We went for a drive in the beginning	One to one very easy. Easy to have conversation	Different talks, different conversations, different topics	It was good for me	When I realised it was not therapy I was very disappointed – waste of time
Brought me to a film "the King's speech"	Easy conversation when the environment was quiet and company good	They (students) were very good. They gave me a chance to talk.	I was conscious to give each student a chance	I expected it would be therapy. It was not (disappointed)
In the office (speech therapy office) is the best	Able to have good conversation. Found it easier to talk	I got more brave with the talk	I wanted to please the student	When I realised it was not therapy I was fine. I never mentioned it again
The hotel and restaurant	Brought me out of my anti-social feeling	I was terrified – how will I talk to her?		The students were a type of therapist in their own right
I have to meet them in quiet places	It has got me more involved, something to do, it has got me out.	Not afraid of talking		I got on famously
I have met them in the coffee shop, in the restaurant, off the bus	They tried to find out my interests then we had a good conversation			One student was dominant (remained the same)
Speaking in the home is better	It was the first time I was left off on my own without family			They got better with experience

Preference of Location	Speak Easy	Confidence	Helping as Partners	Great Expectations
	They (students) brought me out of myself			The girls know what you are going through
	I looked forward to them (Students) coming out			I can talk to the girls like my own family
	One to one easier than in a crowd			They put me at ease. I had no problem
				Students + teachers (therapists) were excellent
				Student taught me card tricks (jogged my memory)
				(Students) nice girls were a waste of time
				They didn’t do anything that was any good
				They talked nonsense
				They didn’t help
				I wasn’t happy about them

Later we describe each theme separately but, again, emphasise the connections with themes (1a-8a) generated in response to Q1. These connections show how the CPP addressed some of the challenges of aphasia, presented earlier, from the emic experiences of co-researchers.

Theme 1b: Preference of Location

The elements in this theme captured the variety of locations where co-researchers met their conversation partners, for example, "The hotel and restaurant" (William) "I have met them in the coffee shop, in the restaurant, off the bus" (Anne); the cinema "Brought me to a film –'the King's speech"' (David); and the car "We went for a drive in the beginning" (Gary). One person preferred to meet his conversation partner in the clinic "in the speech and language therapy office is the best" (William). The weekly meeting often involved "getting out" which resonates with the aforementioned theme 3a "It's Like in Prison". The location of the meeting influenced the communication – "I think it is better at home have more time….speaking in the home is better" (Anne), Gary shared "I have to meet them in quiet places". The elements in this theme have strong connections with Themes 5a "Not able to Talk the Words" and 6a "Escape" described earlier.

Theme 2b: Speak Easy

The elements grouped in this theme related to the quality of conversation experienced during the programme. The majority of co-researchers agreed that they were "Able to have good conversation found it easier to talk" (David), "One to one very easy … easy to have conversation" (William), "Easy conversation when environment quiet and company good" (Gary). The positive experiences of engaging with one or two conversation partners also relate to theme 6a "Escape". It is noteworthy that while the student conversation partners were unfamiliar to the PWA the conversation experiences were mostly positive – "They tried to find out my interests then we had a good conversation" (David) (connected to Theme 5a "Not able to talk the Words"). Most co-researchers looked forward to their conversation partner visits and considered them a social experience – "I looked forward to them coming out" (David); "It has got me more involved, something to do, it has got me out" (Anne); "Brought me out of my anti-social feeling" (David); "They (students) brought me out of myself" (Gary). For the majority, participating in the CPP provided a new sense of independence – "It was the first time I was left off on my own without family" (Anne). Co-researchers focused beyond their personal communication challenges to the needs of their conversation partner, for example, "One to one and two to one - both student should get a chance"… "I did say to her how I suppose it was hard for her as well" (Anne) and "tried to include the quieter one" (David). Four of the five co-researchers reported enjoyable, comfortable, conversations during the programme; however, one person reported no positive conversation experiences.

Theme 3b: Confidence

The elements in this theme captured a positive change in co-researchers' level of confidence with conversation overtime. At the beginning of the CPP Anne shared "I was terrified – how will I talk to her?" but as the programme progressed people grew in confidence "Not afraid of talking" (William), "I got more brave with the talk" (Gary), and 'I walked the talk' (Neil). The trained conversation partners contributed to this change "they were very good they gave me a chance to talk" (Gary). The experience of conversing with new people was challenging but enjoyable. As William explains "different talks, different conversations, different topics." The unfamiliarity of the conversation partners in the CPP resonates with theme 5a "Not able to talk the words".

Theme 4b: Helping as Partners

The elements in this theme related to the opportunity to help others through the CPP. Anne explained that "It was good for me….I feel proud if I help the students" (Anne). Rather than focusing on word-finding ability, co-researchers were conscious of their conversation partner, for example, "I was conscious to give each student a chance" (Anne) and "I wanted to please the student" (David). This theme has connections with theme 3a "It's Like in Prison" and theme 7a "Changing and Adapting".

Theme 5b: Great Expectations

The elements in this theme related to co-researchers' expectations of the CPP prior to and during participation. Some people thought the CPP would be speech therapy, for example, "I thought it would be therapy at first when I realised it was not therapy I was fine I never mentioned it again" (David). Gary felt that "students were a type of therapist in their own right". However Neil was disappointed that the CPP was not therapy – "When I realised it was not therapy I was very disappointed – waste of time" and as a result he felt that the CPP had no value for him "they didn't do anything that was any good, they didn't help….I wasn't happy about them." (Neil). The majority felt that the conversation partners were empathetic, for example, "The girls know what you are going through. … I can talk to the girls like my own family" (Gary), "I got on famously" (David) which resonates with Theme 5a 'Not able to Talk the Words'. Some co-researchers developed new behaviours, for example, "Student taught me card tricks jogged my memory"... "Now I get audio books and its great, on top of the world" (David). These adaptions connected with Themes 1a "Back to Pre-school" and 7a "Changing and Adapting." Some of the group believed that the student conversation partners also benefited from the programme "They got better with experience" (Gary) and "students were excellent" (William).

4.5 Discussion

PWA have a fundamental right to express their unique perspectives and show the competencies that are "masked" by aphasia (Kagan, 1995). This participatory research study did not exclude participants based on the severity of their aphasia but rather empowered one small group of people with varying communication abilities to share their emic perspectives of aphasia and the CPP resulting in important empirical data about conversation interventions. The detailed account shared by co-researchers of the complex nature of aphasia and the emic experiences of the CPP generated through PLA techniques provides a unique contribution to the existing literature base. Key findings include the positive value of the CPP in acknowledging the expertise of the individual with aphasia and providing opportunities for conversations with unfamiliar partners. The negative feelings of communicative incompetence described in "Back to Pre-School" and "Not Able to Talk the Words"' appear to be reduced for some through participation in the programme. Impacts of aphasia related to feelings of marginalisation captured in “Escape”, “It’s Like in Prison” and “Emotions” may be partly addressed by the social aspects of the CPP.

These findings supported the existing literature in terms of aphasia and the value of conversation approaches. Participants shared the life changes following stroke and aphasia in their own words – “It’s Like in Prison,” “Tiredness,” “Not Able to Talk the Words,” “Escape,” “Emotions” and “Back to Pre-School.” The linguistic deficits described in “Back to Pre-School” and the psychosocial impacts spanning the other seven themes are well recognised in the literature (Chapey et al., 2008; Hersh, Worrall, Howe, Sherratt, & Davidson, 2012). The numerous and varied references to negative emotions, for example, you “feel invisible – people talking over you,” “frustration,” “anger,” “sadness,” “embarrassment” are reported across a range of studies (Barrow, 2008; Basso, 2010; Bright, Kayes, McCann, & McPherson, 2013). Interestingly, all participants in this study experienced isolation and disconnection when they were surrounded by other people “loneliness – in a crowd people wouldn’t talk to you because of aphasia.” Perhaps it is the lack of engagement of others and their poor communication skills and understanding of how to talk to PWA that transforms communication difficulties into a disability (McVicker et al., 2009).

Conversation training supports family, healthcare professionals and friends to unmask the competence of the person with aphasia. The finding that participants valued the CPP in terms of enhanced social relationships, increased self-confidence, and positive identity changes reflects previous studies where improvements in psychosocial well-being were noted following participation in conversation interventions (Lyon et al., 1997; Penn, 1998; Savage, Donovan, & Hoffman, 2014) The fear of communication with unfamiliar partners reduced as the CPP progressed, for example, “I got more brave with the talk” and “Not afraid of talking” reflect findings that the number of conversational interactions and transactions increases following participation in a conversation programme with trained communication partners (Kagan et al., 2001; Rayner & Marshall, 2003). Other positive experiences included a sense of achievement, “I got on famously”; pride, “I feel proud if I help the students” and a belief that the CPP was valuable to both partners, “It was good for me," and "they got better with experience" reflects important feelings of self-worth and connection when one considers the risk of secondary disability for people with chronic communication disability (Proctor, 2001). While the literature clearly acknowledges the impact of aphasia on family members and friends (Halle et al., 2011; Pound et al., 2001; Sorin-Peters & Patterson, 2014), it is noteworthy that the co-researchers in this study in response to the question *"How does aphasia affect me and my family?"* focused on the importance of family support in helping them adapt to life with aphasia - "family support is very important" rather than on how family members were affected by aphasia. In future studies to explore the impact of aphasia on family members from the emic perspective of the person with aphasia, co-designing a question related to the adaption of family to "living with aphasia" (Pound et al., 2001) may stimulate the generation of more specific data.

The use of PLA is a novel and key feature of this research. Participants reported many benefits of working in a participatory way including: mutual support, peer acknowledgement, and understanding of the difficulties involved in communicating to a group, encouragement and reinforcement from others to persist with communication attempts, and to use supportive communication strategies. The group listened to each other's perspectives which stimulated further sharing and enhanced learning around the stakeholder table. PLA techniques and materials were selected by participants to suit their communication preferences and the colour coded stickies gave participants a sense of continuity and identity throughout the data generation cycle, for example, *"I never thought I could say much ... so much"*. The positive experiences of acting as co-researchers in a participatory study resonate with findings from other studies using similar designs (MacFarlane et al., 2009) and are discussed further in separate methodological paper.

4.5.1 Methodological critique

We used an innovative participatory approach to include five PWA as co-researchers to capture their lived experiences of aphasia and the CPP. We acknowledge that the small sample size of older, pre-dominantly male, retired participants with aphasia living at home in this study may impact the validity and generalisability of findings. However, sharing of data generated in Ireland with an inter-stakeholder group in the United Kingdom may contribute to the transferability of findings. The participants represented a select group of people with mixed aphasia interested in the CPP from a particular cohort. While a mixed receptive, expressive functional aphasia may reflect the majority of PWA, we recognise that the emic experiences and data generated by people with other types of aphasia (e.g., receptive only or expressive only) and ranges of severity (e.g., severe comprehension difficulties) may differ from the data generated by our co-researchers. Recruiting people with a pure receptive or expressive aphasia and a more gender balanced group with younger participants was beyond the scope of this study, and we acknowledge these limitations. Participants were all over 60 years with a high degree of motivation to discuss their experiences of the programme which was linked to a specific university site. While some older PWA may present with a co-morbid dementia, we did not experience this amongst our co-researchers; however, it is an important consideration for future studies. Despite their older age-range and data generation spanning 12 months, there was no attrition from the group nor did there appear to be any loss of connection with the data over time. The PLA charts and photographs co-created across the research phases served as valuable visual reminders of the co-generated data. As explained previously, we displayed and reviewed the PLA charts and photographs of co-researchers actively engaged in the research techniques at the beginning of each data generation session. This review process supported re-immersion with the data and visually re-connected co-researchers with their co-created charts. The colour coded stickies quickly linked individuals with their unique contributions and appeared to support memory recall. Finally, we acknowledge positionality issues - the first author was the co-ordinator of the CPP and involved in the study as a co-researcher and PLA facilitator. This required awareness of and movement between *insider/outsider* positions during the course of the work. The involvement of the second author as an “outsider” facilitator was an important feature to counter the effect of any bias the first author may have had on data generation, and multidisciplinary team meetings of all three authors for analysis stimulated reflexivity about the data and its meanings.

4.6 Conclusion

The co-researchers in this study were courageous, honest, and realistic in sharing their emic experience of coping with life with aphasia and exploring what difference the CPP made to them. The participatory research approach enabled participants to share their emerging and established experiences in their own words. While the findings are not generalisable, this emic perspective and use of participatory methods contributes new data to the evidence base. PLA methods require ingenuity, creativity, and emotional involvement on the part of the researcher and the co-researchers in all phases of the research process. Working within such ill-defined boundaries and surrendering control in the design and process of the study is different from other qualitative methodologies. These methods will not suit all researchers. We believe that proving the efficacy of the participatory approach to the research community is a challenging but worthwhile task. Future studies may want to explore the emic experiences of younger, working people with receptive aphasia or expressive aphasia or a group with mixed aphasia of varying severity levels. The perspectives of these groups in relation to the lived experience of aphasia and the CPP may differ from the co-researchers in this study. We encourage colleagues to consider the use of participatory research methods as a potentially empowering, transformative and innovative methodological approach to include PWA as co-researchers in health research studies.

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4.10 ORCID

Ruth Mc Menamin http://orcid.org/0000-0002-9485-3148

Edel Tierney http://orcid.org/0000-0001-6393-8539

Anne Mac Farlane http://orcid.org/0000-0002-9708-5025

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Chapter 5 Paper 2: Who decides what criteria are important to consider in exploring the outcomes of conversation approaches? A participatory health research study

5.1 Abstract

5.1.1 Background

One of the most devastating consequences of aphasia is the disruption to normal conversation. The Conversation Partner Programme emphasises communicative competence and life participation. Currently there is no recognised system for evaluating this intervention. Following policy imperatives for patient and public involvement, it is important to include service users in the development of evaluation criteria. However, people with aphasia are often excluded from such research and service development initiatives because of their communication disability. This study was designed to include people with aphasia and other key stakeholders as co-researchers in the development of evaluation criteria for a Conversation Partner Programme.

5.1.2 Aims

To describe the multi-perspectival co-generation of Conversation Partner Programme evaluation criteria using a participatory research approach.

5.1.3 Methods & Procedures

Following a pilot study, the generation and analysis of qualitative data involved a Participatory Learning and Action (PLA) approach based on the interpretive paradigm. Using purposeful sampling participants (n = 20) included: people with aphasia (n = 5); speech and language therapists (n = 5); speech and language therapy graduates and undergraduates (n = 9) and university coordinator (n = 1). Through (n = 18) individual and inter-stakeholder data generation episodes (PLA focus groups and interviews) using participatory techniques (Flexible Brainstorming, Card Sort, Direct Ranking, Seasonal Calendar), evaluation criteria were identified. The principles of thematic analysis guided the co-analysis of data with participants. Data generated in Ireland were presented to an international inter-stakeholder group at Connect, UK, for preliminary exploration of transferability of findings.

5.1.4 Outcomes & Results

Conversation Partner Programme evaluation criteria agreed and prioritised by co-researchers in order of importance included: (1) shared understanding of structure, (2) clarity about the programme, (3) agreed evaluation mechanism, (4) linking with other organisations, and (5) feedback. “Shared Understanding of Structure” was ranked the most important criterion and related to the nature and number of participants, opportunities for group meetings, socialising, and stakeholder interaction. “Feedback”, the criterion ranked least important, detailed responsibilities about summarising programme experiences and sharing this information between stakeholders.

5.1.5 Conclusions

People with aphasia and other key stakeholders were meaningfully involved in the identification of evaluation criteria for a Conversation Partner Programme. The outcomes of this collaborative work bridge the gap between policy imperatives around involvement and actual practice and will impact the design, delivery, and evaluation of the programme for all stakeholders. Findings will be of interest to professionals in this clinical area and to those exploring innovative methodologies to include marginalised service users, especially people with communication disabilities in research.

5.1.6 Keywords

conversation approaches; multi-perspectival evaluation; qualitative; insider; emic; participatory health research

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5.2 Introduction

Patient and public involvement (PPI) in healthcare have increased significantly in the last decade (Neuwelt, 2012). This positive direction is recognised and supported by policy and legislation internationally (Staniszewska, 2009) with policy statements increasingly advocating PPI (Department of Health, 2001; Department of Health and Children [DoHC] Health Service Executive [HSE], 2008). Many argue that service user involvement has ethical and political underpinnings and is a citizenship right requiring no further justification (Oliver et al., 2008). Health services research and development are intrinsically linked, and PPI has the potential to (1) create more democratic research processes and (2) be a transformative experience for participants (Dewar, 2005). Service users are in a unique position to co-design services, improve quality and safety, minimise costs on inappropriate design, and highlight issues of accessibility and acceptability (Pearson et al., 2013). However, people with aphasia (PWA) are often excluded from such research and service design initiatives *because of their communication disability.* As researchers and practitioners we must address this imbalance and consider how and to what extent PWA contribute to service planning, development, and evaluation. In this article, we begin by describing conversation training approaches and available evaluation evidence and then outline key considerations for involving PWA in evaluating a conversation intervention. We report our methods and findings on behalf of the PWA who were participants and co-researchers in this process.

5.2.1 Conversation training approaches

In keeping with the social model of disability, conversation approaches aim to increase communicative access by training conversation partners to support and optimise communication (Kagan, 1995) and have traditionally targeted three groups (Turner & Whitworth, 2006): (1) familiar partners - family or friends (Booth & Swabey, 1999; Lock, Wilkinson, & Bryan, 2001); (2) volunteers (Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001; McVicker, Parr, Pound, & Duchan, 2009; Rayner & Marshall, 2003) and (3) healthcare professionals (e.g., Shale, 2004). The psychosocial consequences of aphasia are reduced as positive conversation opportunities are increased (Byng & Duchan, 2005). Trained conversation partners reveal the competence of the person with aphasia (Kagan, 1995;

Kagan et al., 2001) and social interaction is prioritised above linguistic gains (Kagan et al., 2008; McVicker et al., 2009).

5.2.2 Evaluating conversation approaches

To date, a broad range of methodologies including quantitative, qualitative, mixed methods, and single case study designs have been used to evaluate conversation interventions. Experimental studies have provided important information about the impacts of conversation approaches on large samples with potential aggregation across individuals and situations (Kagan et al., 2001, 2004; Rayner & Marshall, 2003). Qualitative designs, on the other hand, are flexible and non-sequential allowing participants to influence the research process across iterations. The unique contexts and characteristics of participants are considered, and individuality is often preserved during analysis and dissemination (Johansson, Carlsson, & Sonnander, 2012). Mixed method approaches have combined quantitative and qualitative measures to explore psychosocial and communication outcomes of conversation interventions (e.g., Fox, Armstrong, & Boles, 2009; Hickey, Bourgeois, & Olswang, 2004). There are also several examples of case study designs using multiple methods in this area (Barnes, Candlin, & Ferguson, 2013; Bronken, Kirkevold, Martinsen, & Kvigne, 2012; Cunningham & Ward, 2003).

From this body of work, we have learned that conversation approaches can result in enhanced well-being, increased social interaction, and improved conversation skills for PWA and conversation partners. However the existing research offers limited empirical evidence of effectiveness which is fundamental to support implementation (Turner & Whitworth, 2006). As previously noted, following PPI initiatives, PWA should be central to service evaluation and re-design. To date while many studies appear to have included PWA in some aspect(s) of evaluation, the *level of involvement* varies greatly. Therefore the possibility exists that we are missing some important elements of the emic perspective (knowledge and perspective determined by lived experience) (Creswell, 2013), which could enhance the evaluation and design process.

5.2.3 Considerations for meaningful involvement of PWA in research

A valuable overview of PPI models and frameworks is captured by Gibson, Britten, and Lynch , (2012) with a systematic review of conceptualisation, measurement, and effectiveness detailed in Brett et al. (2010) and a critical review of involvement in primary care research and development projects by Tierney et al. (2014). From these recent contributions it is clear that problems persist in the field of PPI in terms of facilitating meaningful service user involvement. Enabling meaningful, as opposed to tokenistic, participation requires innovative methods to make the research process accessible. Specifically, according to INVOLVE (UK national advisory group), meaningful participation occurs when there is active involvement by members of the public in research and organisations. The research process becomes “with” or “by” rather than “to,” “about,” or “for” service users (INVOLVE, 2014). This definition resonates strongly with the principles and ethos of participatory research approaches (International Collaboration for Participatory Health Research (ICPHR), 2013). Examples of how participatory research has enhanced our understanding and inclusion of service user involvement are evident in the literature (Jagosh et al., 2012; MacFarlane et al., 2012).

In this study we draw upon theoretical constructs and practical tools from the field of participatory research approaches (see Chambers, 1994). Specifically, we use Participatory Learning and Action (PLA) research (O’ Reilly-de Brun & de Brún, 2010), developed from Chamber’s work (1994), aiming to move beyond tokenistic participation to meaningful service user involvement. We aim to illustrate how PLA can be used to include PWA and other key stakeholders (speech and language therapists (SLTs) and students) as research participants but also as co-researchers in a multi-perspectival evaluation of a Conversation Partner Programme (CPP).

5.3 Methods

5.3.1 Study setting

In 2005/2006, led by the first author, and in collaboration with the local commmunity (Speech and Language Therapy Department Primary Community Continuing Care (PCCC) Health Services Executive (HSE) West, 2013) and Connect (the communication disability network), a Conversation Partner Programme (CPP) was integrated into the 4-year

BSc undergraduate Speech and Language Therapy curriculum at the National University of Ireland, Galway (NUI, Galway), Ireland. CPP training and participation is a mandatory requirement in the curriculum. The design of this particular programme is based on the Connect model of training, which is described in McVicker et al. (2009). The NUI, Galway CPP typically spans 14 weeks and includes 10 conversation visits and is described in McMenamin, Tierney, and Mac Farlane (2015):
"Community Speech and Language Therapists (SLTs) refer approximately five to twenty new PWA into the programme annually. The majority of PWA choose to continue their participation across several iterations of the programme over a number of years. Third year students are trained as conversation partners, paired with a peer and matched with a person with aphasia based on interests and hobbies and geographical location. Students' weekly conversation visits to PWAs' homes or other locations provide unique opportunities to learn about aphasia and apply theory to practice in a relaxed environment which is different from the classroom or clinical settings. Weekly reflective logs, fortnightly tutorials and assessment involving individual and group work facilitate students' reflective practice and learning throughout the programme." The lived experience of aphasia and the impact of involvement in the CPP for PWA have been reported separately (McMenamin et al., 2015).

5.3.2 Study design

As mentioned earlier, this study is designed following the principles of PLA research (O' Reilly-de Brun & de Brún, 2010), a form of participatory research (Chambers, 1994) based on the interpretive paradigm. This adaptive strategy aims to enable diverse stakeholder groups to learn, work, and act together in a co-operative manner, to share, enhance, and analyse knowledge, and to plan together for positive service changes (O'Reilly-de Brún & de Brún, 2011). Importantly PLA focuses on enabling stakeholders who are often marginalised or excluded to be recognised as experts of their own lived experiences and to have a "voice" in the research process. PLA aims to create a partnership between these and (usually) more powerful stakeholders and emphasises the co-construction of research between all involved. PLA techniques for data generation are interactive in nature, encouraging stakeholder involvement in reflection and thematic analysis (Silverman, 2013) of the emergent data. The techniques often involve visual and verbal elements supporting participation for stakeholders who have communication challenges (e.g., people who do not speak the language of the community where they live) (MacFarlane et al., 2009; O’Reilly-de Brún & de Brún, 2011) or as in the current study PWA. McMenamin et al. (2015) describe how the authors’ expertise contributed to making the research process communicatively accessible for co-researchers:

> The multidisciplinary backgrounds and PLA experience of the three authors supported the adaption of PLA techniques and materials for use with PWA. The 1st author is a SLT with over 15 years’ experience of working with PWA. The 2nd author is a Psychologist with many years’ experience of working with people with intellectual disability and communication challenges. The 3rd author is a social scientist and academic and has been involved in collaborative/partnered participatory research with a broad range of stakeholder groups nationally and internationally over the last decade. All three authors are trained PLA facilitators[10] and through their combined clinical, PLA and research expertise they ensured the research process was communicatively accessible for the co-researchers with aphasia.

5.3.3 Research phases

This study included three research phases (see Table 1). In phase 1, the emphasis was on creating individual stakeholder groups (PWA; SLTs; students) and documenting their independent perspectives about aphasia and the CPP. Through these individual PLA data generation sessions (using PLA focus groups and PLA interviews) all stakeholders’ experiences of the CPP were captured, and “current practice” was established.

In phase 2 representatives from the individual groups were invited to come together as an inter-stakeholder group to share knowledge, expertise, and ideas and listen to each other’s perspectives. This inter-stakeholder group reviewed the data about the CPP generated by the three individual groups

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[10] The authors were trained as PLA facilitators at the Centre for Participatory Strategies (CPS) Ross Wood Clonbur Co. Galway Ireland by Mary O’Reilly-de Brún and Tomas de Brún.

in Phase 1 and worked in partnership to identify and agree a set of evaluation criteria for the programme.

In Phase 3, to explore the transferability of findings, the evaluation criteria generated from the emic perspectives of the Irish group were reviewed by an international inter-stakeholder group at Connect (the communication disability network) to discuss findings and compare with the UK experience. Data generated in Phase 3 (see Appendix H) are not included here as this article focuses on the involvement of PWA, SLTs, students and the first author as CPP co-ordinator in Phase(s) 1 and 2 with specific attention to data generated about the CPP and its evaluation.

Table 5.1: Research phases and aims

Research phases	**Aim of each phase**
Phase 1 (individual stakeholder groups)	To explore individual stakeholder groups emic experiences and perceptions of aphasia and the CPP
Phase 2 (inter-stakeholder groups)	To explore the inter-stakeholder groups co-analysis of the shared and different perspectives of the CPP arising from the individual stakeholder groups in Phase 1. To identify and agree CPP evaluation criteria
Phase 3 (international inter-stakeholder group)	To explore the transferability of findings generated in the Irish context

5.3.4 Pilot study

The research questions and PLA techniques were piloted with trained PLA experts (*n* = 2), PWA (*n* = 2), SLTs (*n* = 5), Connect CPP coordinators (*n* = 2), students/volunteers (*n* = 3), and university educators (*n* = 3). Following piloting, changes were made to improve the explanation of PLA techniques (verbal and written), timing, methods, materials, and clarity of the research questions.

5.3.5 Sampling and Recruitment

In Phase 1 purposive sampling (Creswell, 2013) was used to enable the selection of people with experience of a specific CPP from key stakeholder groups affiliated with NUI, Galway. As described by McMenamin et al. (2015), sampling and recruitment were supported by existing links with stakeholder groups involved in the CPP: “A letter was sent to 10 PWA (5 female and 5 male) of varying age ranges who had experience of the CPP. This letter invited PWA to participate in the research. In accordance with our ethical approval a maximum of 5 people could be recruited to this stakeholder group with up to three reminders about the study to each person. It was not ethical to contact potential younger and/or female participants a fourth time and from our recruitment drive 4 males and 1 female agreed to participate. There were no exclusion criteria and participants were not screened for cognitive, hearing, and/or visual problems.”

The seven SLTs contacted were not trained as conversation partners but all had experience of referring PWA into the CPP to be matched with the trained student group. Seven graduates (this study was conducted after graduation) and 21 undergraduates who were trained as conversation partners and had participated in the CPP during their degree programme as students at NUI, Galway were also contacted by email. This stakeholder group is similar to the “volunteer” group identified by Turner & Whitworth (2006). Participant information sheets and consent forms outlining details of the study and contact details (email and telephone number) for the first author accompanied the correspondence. SLTs and members of the student group wishing to participate were invited to respond to the first author directly.

From this recruitment drive individual stakeholder groups were formed for Phase 1. Participants from the individual stakeholder groups in Phase 1 were subsequently invited to participate in Phase 2. All views were represented around the inter-stakeholder table[11]. Table 5.22 shows an

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[11] *The people with aphasia had the largest representation around the inter-stakeholder table as 4/5 continued their participation in Phase 2; 4/5 SLTs participated in Phase 2 with 2 SLTs present at each inter-stakeholder session; 2/9*

overview of stakeholder groups across the research phases (i.e. Phases 1 - 3).

Table 5.2: Individual groups and inter-stakeholder groups across the research phases.

Research phase and stakeholder group	PLA sessions
Phase 1: people with aphasia (*n* = 5)	5 x 3 hr PLA focus group sessions
Phase 1: SLTs (*n* = 5)	5 x PLA interviews
Phase 1: students (*n* = 9)	2 x 3 hr PLA focus group sessions
Phase 1: CPP coordinator (*n* = 1)	1 x 2 hr PLA interview
Phase 2: inter-stakeholder Group (*n* = 9) • People with aphasia (*n* = 4) • Speech and language therapists (*n* = 2) • Students (*n* = 2) • CPP coordinator (n=1)	3 x 3 hr PLA focus group sessions
Phase 3: international inter-stakeholder group (*n* = 4) • People with aphasia (*n* = 2) • Speech and language therapist and coordinator of the Connect CPP (*n* = 1) • Volunteer trained as a conversation partner (n = 1)	2 x 3 hr PLA focus group sessions

5.3.6 Participant Characteristics

McMenamin et al. (2015) describe the characteristics of the PWA who participated in the study:

> Four men and one woman with a mean age of 73 years agreed to participate in this study. Time elapsed since stroke ranged from 3 to 10 years with an average of participation in 3 iterations of the CPP i.e. 30 conversation visits, 10 visits per iteration of the programme.

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graduate/undergraduate group participated in Phase 2 - both were undergraduate students.

Communication diagnoses and severity determinations were based on: 1) the objective assessment reports from the referring Speech and Language Therapists (SLTs) documented in the Speech and Language Therapy records; 2) the SLT researchers' confirmation of communication diagnoses with each referring SLT and 3) informal observations of participants throughout the study. All participants had functional comprehension in conversation with either mild or mild to moderate, comprehension difficulties. There was greater variability in expressive language ability, with a range of mild, moderate and moderate to severe disability. Similar to the Parr study (Parr, 2007), styles of communication varied as each person had adapted to communicating with aphasia in different ways, and had developed preferences for varied communication strategies. Most used gesture, intonation, facial expression, with occasional single written words or letters to supplement their speech. Nobody used drawing, word lists or portable communication devices and one person who presented with the most severe expressive disability did not spontaneously use any augmentative means to support communication. Given the older age range of participants we were aware of the possibility of co-morbid dementia however none of the participants with aphasia presented with any symptoms of dementia.

Speech and language therapists

Five SLTs agreed to participate and included various grades: manager (*n* = 1), senior (*n* = 3) and staff (*n* = 1) with clinical experience ranging from 7 to greater than 20 years. All were female and age ranges were between 28 and 47 years.

Graduates and undergraduate SLTs in training

Four graduates between 2 to 7 years post qualification were recruited. Two were in full-time employment while the other two were between posts. Three were female and one male and ages ranged from 22 to 40 years. The five undergraduates were in the third year of the 4-year BSc in Speech and Language Therapy. All graduates and undergraduates had been trained as conversation partners using the Connect model (Connect - the communication disability network) of training and had participated in the CPP at NUI, Galway, Ireland.

5.3.7 Consent

The process of consent was approved by the NUI, Galway, Ethics Committee. Each participant had the opportunity to read and discuss aphasia friendly project, audio recording, and photo information sheets. Signed consent forms are stored in accordance with the ethical approval requirements of the first author's institution. Data generation sessions were photographed and taped on a digital audio recorder with participants' permission. Detailed information on the consent process is provided in Mc Menamin et al. (2015).

5.3.8 Data co-generation and co-analysis

In *Phase 1* participants in the individual stakeholder groups used their selected PLA techniques to co-generate data in response to the following questions:

1. What are the best things about CPP?
2. What are the worst things about the CPP?
3. What would improve the CPP for me?

A variety of PLA data generation techniques were used - Flexible Brainstorming, Card Sort, Direct Ranking, and Seasonal Calendar (Chambers, 2004; O'Reilly-de Brún & de Brún, 2011), and all analyses followed the principles of thematic analysis (Silverman, 2013). The techniques were explained, discussed, and agreed with co-researchers as part of the co-design process in Phases 1 and 2. The selection of techniques for each research question varied across groups, reflecting participants' preferences and priorities (Simmons-Mackie & Lynch, 2013).

A PLA Flexible Brainstorm technique was used in Phase 1 as a creative way of generating information and ideas from participants' unique experiences of the CPP[12]. In summary, PLA materials including a shared blank flip chart sheet, coloured markers and coloured stickies, pens, paper, key words, symbols, and pictures were centred on the table for easy access. Participants chose materials to suit their communication preferences and needs and used these materials to communicate their emic experiences of the CPP. Data generation was democratic, inclusive,

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[12] A full procedural account of using Flexible Brainstorm, Card Sort and PLA Interviewing techniques with PWA are described in McMenamin et al. (forthcoming)

and voluntary with no pressure on any individual to communicate verbally. There was no restriction on the number of ideas an individual could share; however, in the interest of clarity the group agreed that each stickie/symbol/picture could only represent one idea. The data generated were flexible and could be easily arranged, rearranged, clustered, and connected for other PLA techniques for example, the Card Sort categorisation technique (O'Reilly-de Brún & de Brún, 2011).

The PLA Card Sort technique was used as a categorisation method to support the organisation and sharing of complex information in an easily retrievable way. In Phase 1, participants reviewed their populated Flexible Brainstorm charts and began sorting, organising, and analysing data into meaningful groupings. Material was categorised according to participants' emic perspectives with the group often acting as good "cross-checks" on each other. The facilitators supported the categorisation process in a participatory way using supportive communication techniques. When all the individual elements were co-analysed and grouped into meaningful bundles, participants began to negotiate, debate, and co-generate overarching category headings assigning individual elements to the agreed themes. For a more detailed description of the PLA Card Sort technique with co-researchers, see Mc Menamin et al. (2015).

5.3.9 Phase 1 and Phase 2 data

At the end of Phase 1, the role of the first author was to synthesise the co-analysis of data generated by individual stakeholder groups during the first research phase. Quality and rigour checks were integrated into the syntheses process through reflection, debriefing, discussion, and commenting between all three authors.

In Phase 2 the inter-stakeholder group viewed the PLA charts developed by the individual groups in Phase 1. Also the first author summarised and presented her perceptions about the similarities and differences across individual stakeholder groups about the CPP. The focus in this phase was on the inter-stakeholder groups' reflections on the formal synthesis of responses to Question 3 "What would improve the CPP for me?" This was presented on a PLA chart – a synthesised Card Sort (see Table 5.3). The inter-stakeholder group worked collaboratively to review and validate the synthesis. The outcome was a revised Card Sort chart which displayed the multi-perspectival picture of “best practice” for the CPP. The emerging categories and elements were the agreed CPP evaluation criteria.

Two further PLA techniques and the process of “interviewing the technique” were then used by the inter-stakeholder group on the final agreed Card Sort chart in *Phase 2*:

1. PLA Direct Ranking technique to prioritise which evaluation criteria were most important.
2. PLA Seasonal Calendar technique to progress planning for the implementation of the CPP evaluation criteria.

As there is no detailed description of using these two PLA techniques with PWA in the literature, the full procedural details are presented below.

PLA Direct Ranking Technique

Direct Ranking provided a mechanism for co-researchers to express priorities and preferences about the emergent categories of CPP evaluation criteria. The facilitators checked that (1) the final Card Sort chart was clearly visible and (2) each participant had 10 colour-coded voting tokens (10 coloured paperclips) with each token representing one vote (see Figure 5.1).

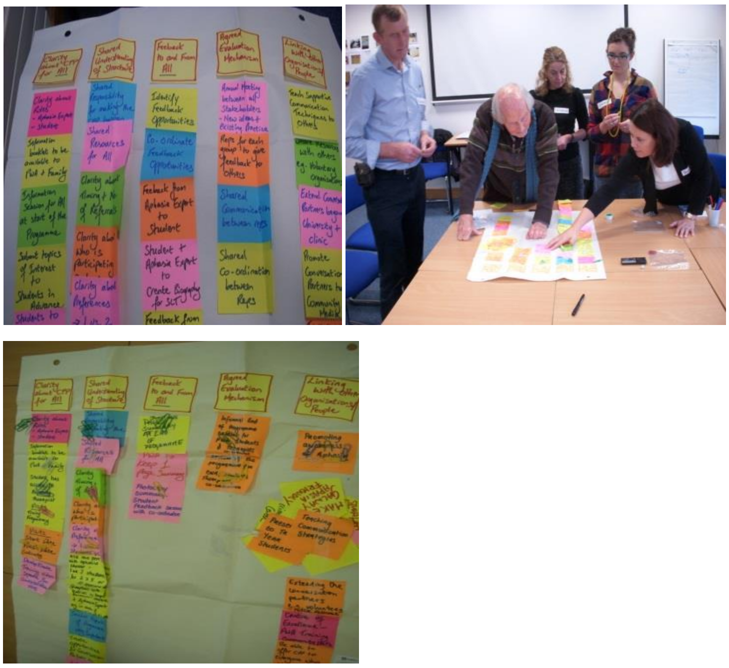

Figure 5.1: Photographs of PLA Direct Ranking Technique

The second author, as the facilitator for the Direct Ranking technique supported the inter-stakeholder group to review the category headings and elements on the final “Card Sort” chart by reading individual stickies aloud. She then explained the Direct Ranking technique, gave an example of how to vote and highlighted that the number of paperclips placed on a category indicated the strength of the vote. Participants could place all of their paperclips on a single category if they believed that category was the most important for evaluating the CPP or they could distribute their paperclips across categories as they wished. One person with aphasia asked whether the paperclips should be placed only on the category heading during voting. Following discussion the group agreed that the paperclips could be placed anywhere on the category (heading or elements). Co-researchers were invited to cast their votes according to a single agreed criterion, for example, “most important evaluation criterion to least important evaluation criterion”. As agreed with the group, the first author participated in the voting process in her role of CPP co-ordinator.

The second part of the Direct Ranking involved reviewing and counting the votes allocated to each category. When all co-researchers were satisfied that the votes were counted and added correctly, the facilitator invited the group to reflect on the emergent prioritisations and share perspectives about the process and outcomes. This discussion enhanced knowledge around the inter-stakeholder table (See Table 5.5 in the Results section).

PLA seasonal calendar technique

Participants decided to progress the research beyond the generation of CPP evaluation criteria to planning the implementation using the PLA Seasonal Calendar technique (see Table 5.6). Following a discussion about the timeframe that would capture the progression of the CPP, the agreed timeline included three stages: “Before the Programme”, “During the Programme” and “After the Programme”. The facilitator wrote the timeline on individual stickies inviting co-researchers to place them along the top horizontal axis of the chart. On the left-hand vertical axis the CPP evaluation criteria were positioned, that is, “Clarity about the CPP for All”, “Shared Understanding of Structure,” and so on. Taking each criterion and related elements (see Table 5.3 for individual elements that made up each category) in order of priority as emerged from the Direct Ranking, the facilitator invited the group to write verbs/action words on each stickie to facilitate the implementation of tasks, for example, the group agreed to rewrite “Clarity of Roles – PWA and Student” as “Clarify roles of PWA and student”. Colour-coding category headings and related elements (e.g., “Shared Understanding of Structure” and all the attached elements were written on pink stickies) created a clear visual link between groupings on the Seasonal Calendar chart.

Co-researchers discussed the actions required to complete each task and plotted responsibilities across participant groups (e.g., SLTs, PWA, students, CPP coordinator). Photographs of the Seasonal Calendar technique and chart are shown in Figure 5.2.

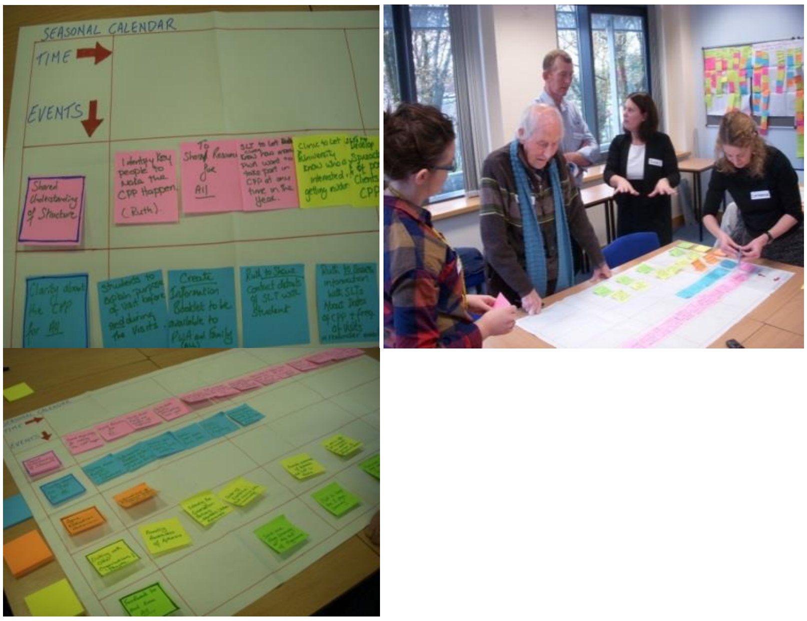

Figure 5.2: Photographs of the PLA Seasonal Calender technique and co-created chart.

Interviewing PLA techniques

The inter-stakeholder group “interviewed” both the Direct Ranking and Seasonal Calendar techniques meaning that the facilitator encouraged participants to review and discuss the charts before deeming the techniques complete. Participants were invited to share anything surprising or striking about the PLA techniques, process, and/or outcomes. When the group agreed that there was nothing new to add or say, the PLA technique(s) were closed.

5.4 Results

5.4.1 Individual stakeholder perspectives (Phase 1) - The best and worst things about the CPP

In response to Question 1 “What are the best things about the CPP?” there was resonance across individual stakeholder groups that the CPP is confidence building for both the PWA and the students. All groups commented on the relaxed nonclinical environment as a positive aspect contributing to easy conversation and a social outlet for PWA. The PWA and the students felt that the relationship between conversation partners was equal and collaborative which was different from other experiences involving intervention from SLTs and other healthcare professionals. The CPP provided an opportunity for PWA to practice conversation skills with unfamiliar people, and this was viewed by all groups as positive. The SLTs commented on the cost effectiveness of the CPP and saw the programme as a potential long-term solution for people living with aphasia.

The stakeholder groups had different ideas about their roles and contributions to the CPP. At the outset the PWA believed they were sole beneficiaries from the programme. However the other three stakeholder groups valued the unique contribution of the PWA in teaching the students about the “lived experience of aphasia.” The CPP coordinator was unique in identifying Service Learning (SL) as an appropriate pedagogy to underpin the CPP and provide students with an opportunity to apply theory to practice. The students and the SLTs appreciated the time for structured reflection as a core component of SL. One stakeholder with aphasia differed from all other stakeholders reporting that the CPP “was a waste of time” and he did not benefit from participation.

In relation to Question 2 “What are the worst things about the CPP?” stakeholders identified cost of travel, structure, organisation, and clarity of the CPP as aspects that could be improved. The lack of an agreed evaluation mechanism to improve structure, delivery, and redesign was a shared concern. Perceptions about whether the programme was a form of speech and language therapy differed across groups. The SLTs, university coordinator, students, and some PWA understood that the CPP was different from traditional speech and language therapy. One PWA was very dissatisfied with this realisation and did not value this form of intervention. Stakeholders across individual group's generated different ways to improve the CPP (see Table 5.4).

Finally in relation to Question 3 there was a high level of agreement about "current practice" and what would create "best practice" across stakeholder groups although the dominant focus of each individual group differed for example:

1. SLTs viewed the CPP from a service delivery perspective. They were interested in how the CPP might benefit the PWA in the first instance and the students in the second with the backdrop of caseload demands and cost-effectiveness as considerations.
2. PWA viewed the CPP as an opportunity to practice talking with new people, "get out and about" and "help the students."
3. Students were interested in the "lived experience of aphasia", improving communication skills and supporting conversation partners.
4. The CPP coordinator aimed to ensure the programme ran smoothly, benefiting all participating stakeholders.

5.4.2 Synthesis of Phase 1 data for Phase 2 inter-stakeholder group work

The first author's synthesis of phase 1 data (described earlier) about the CPP was prepared as a combined card sort. The chart included five category headings with 25 elements across the categories. "Clarity about the CPP for All" and "Shared Understanding of Structure" had some interconnections related to the organisation and transparency of the CPP while "Feedback to and from All" and "Agreed Evaluation Mechanism" had similar ideas centred on evaluation and redesign. Table 5.3 shows the Card Sort chart presented to the inter-stakeholder group in Session 1 Phase 2.

Table 5.3: Card Sort chart presented to the inter-stakeholder group in Phase 2 by first author following synthesis from data generated with individual stakeholder groups in Phase 1.

Clarity about CPP for all	Shared understanding of structure	Feedback to and from all	Agreed evaluation mechanism	Linking with other organisations/people
Clarity of roles – PWA and student	Shared teaching, resources, responsibility for making CPP happen	Identify and coordinate feedback opportunities	Annual meeting all stakeholder reps - new ideas and existing processes	Teach supportive communication techniques to relevant others
Information booklet to be available for PWA and family	More visits	Combined feedback from PWA and student to SLT	Identify reps for each stakeholder group who would liaise with whole group	Share resources with others, e.g., voluntary organisations
Information session at the start of the programme	Clarity about referrals and participation	Feedback from PWA to student, e.g., communication rating form	Shared communication and coordination between reps	Extend conversation partners beyond university and clinic - get out into community/media
Submit conversation topics in advance	Clarity about who is participating each year (for SLT)	Biography of both PWA and student		Increase the awareness of communication partners facilitating conversations
Ask about stroke and aphasia	Clarity about PWA preferences - 1 vs. 2 students etc.	SLT – what worked well/ did not work well in conversation		
	Swapping partners during programme			
	Contact with student			
	Socialise more – opportunities for conversation partners to meet			

As described in methods, the inter-stakeholder group engaged in an active and thorough review of Table 5.3 moving elements between categories, creating new elements, rejecting some, and changing others. The outcome of this co-analysis and validation was 32 well-defined elements categorised to five themes that were agreed and understood by co-researchers[13]. Reviewing the Card Sort chart resulted in clarity and greater ownership of the emergent evaluation criteria and elements (see Table 5.4).

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[13] The card sort categories are the emergent themes/CPP evaluation criteria and are described in detail below

Table 5.4: Completed Card Sort chart following inter-stakeholder analysis and validation (Phase 2).

Clarity about CPP for all	Shared understanding of structure	Feedback to and from all	Agreed evaluation mechanism	Linking with other organisations/ people
Clarity about roles: • Aphasia Expert • Student	Shared responsibility for making the CPP happen	Joint (PWA & student) one-page summary at end of programme	Informal end of programme session for PWA, students, therapists, and coordinator	Promoting awareness of aphasia
Information booklet to be available for PWA and family	Shared resources for all	PWA to keep one-page summary	Review of programme for PWA, students, therapists and coordinator	Extending the conversation partners, e.g., voluntary – active retirement
Student has access to referring SLT	Clarity about the timing of referrals and the number of referrals	Photocopy summary. Student feedback session with CPP coordinator		Centre of Excellence – PWA training community/SLTs
Visits – timing and frequency	Clarity about who is participating each year (for SLT)			Be able to offer CPP to everyone who wants it – regardless of geographical location
Visits – start date/Finish date Continuity	Ask the PWA to choose 1 or 2 students for 2 x 5 or 10 sessions			Media
Develop/create training video separate from CPP visits	Clarity about who is participating each year			Teaching communication strategies to • Make Galway aphasia

Clarity about CPP for all	Shared understanding of structure	Feedback to and from all	Agreed evaluation mechanism	Linking with other organisations/ people
				friendly • Government departments • Córas Iompair Éireann • Transition year students • Family members • Local shops/restaurants • Home Helps • Croí • Quest • Primary care centre
	Clear contact between student and aphasia expert, e.g., in case of cancellations			
	Social aspect of programme very important			
	Create opportunities for conversation partners to meet			
	Referral dates for therapists - ongoing			

Clarity about CPP for all	Shared understanding of structure	Feedback to and from all	Agreed evaluation mechanism	Linking with other organisations/ people
	referral (during year)			
	Clarify who is responsible for administration			
	Administrator to contact key SLT prior to sending correspondence (about the CPP to PWA)			
	PWA can contact their SLT or/and CPP co-ordinator at any time with queries about the programme			
	Don’t be afraid to talk about aphasia			

Later we describe each criterion highlighting inter-relationships between themes where relevant.

Theme 1: Clarity about CPP for all

The elements in this theme captured important features about the clarity of the CPP for all stakeholders. The group discussed the confusion experienced by some in relation to the purpose of the programme and agreed three separate ways to resolve this including:

- “Clarity about roles: aphasia expert and student”’ (all stakeholder groups to be consistent in their explanation of the CPP).
- “Information booklet to be available for PWA and family” (to be co-created by an inter-stakeholder group).
- “Create training video separate from CPP visits” (to capture conversations between trained students and PWA participating in the programme for teaching/information purposes).

Shared information about conversation visits before they begin is important for all stakeholders for example, “timing and frequency,” “start and finish dates,” “continuity of visits” (when the programme ends) to ensure transparency across groups. Finally, the group discussed dealing with student issues as they arose and agreed that students should have contact details of both the referring SLT and CPP coordinator as sources of support during the programme. Theme 1 has strong links with Theme 2 “Shared Understanding of Structure”.

Theme 2: Shared Understanding of Structure

The elements in this theme captured issues about the structure of the CPP and how to optimise organisation. Participants agreed there should be “shared responsibilities for making the CPP happen” across stakeholder groups. The person “responsible for administration” should contact the “SLT prior to sending correspondence about the CPP to PWA” as updated information may be available (e.g., PWA may no longer wish to participate, have moved). The referral issues, for example, “timing and number of referrals” resonated with the clarity issues about the timing and frequency of visits in Theme 1 “Clarity about CPP for All”. The group discussed the number of SLT referrals compared to the number of actual participants each year. Clarity about this issue is important particularly for the SLT stakeholders. There was agreement that the PWA should have:

- The opportunity to express communication preferences/needs (e.g., "PWA to choose 1 or 2 students for 5 or 10 sessions").
- "Clear contact between student and PWA, e.g., in case of cancellations."
- Details to "contact their SLT (even if discharged from therapy) and/or the CPP coordinator at any time with queries throughout the programme" which linked with Theme 1: Clarity about CPP for All.

The inter-stakeholder group agreed that the "social aspect of programme is very important" and we should "create opportunities for conversation partners to meet".

Theme 3: Feedback to and from all

The elements in this theme captured issues about feedback between stakeholder groups. Participants agreed that the student conversation partner and the person with aphasia should co-create a one-page summary about their experiences of the CPP at the end of the programme –"Joint (PWA & Student) one page summary at end of programme'. Following debate and discussion about where this summary should be stored the group agreed "PWA to keep one page summary." In this way the joint summary can be photocopied by the student for the CPP coordinator and the referring SLT. Feedback between stakeholder groups is an important criterion to assess whether the CPP is working well from a variety of perspectives and connected with Theme 4 "Agreed Evaluation Mechanism."

Theme 4: Agreed Evaluation Mechanism

The elements in this theme captured sharing information about the CPP, for example, what is working well, not working well, and what should change for the next iteration of the programme. The inter-stakeholder group engaged in a lively debate about the best way(s) to gather this information with final agreement that an end of programme meeting for all stakeholder groups should be included as part of the CPP structure – "Informal end of programme session for PWA; students; SLTs and CPP co-ordinator." Invitations should be sent to all participants – "Review of programme for

PWA; students; Therapists and Co-ordinator" to capture multi-perspectival CPP experiences in a participatory way. The group agreed that the social component of the programme should be maintained through a relaxed, informal gathering including refreshments that resonated with Theme 2 "Shared understanding of structure."

Theme 5: Linking with other Organisations/People

The elements in this theme related to developing public awareness about aphasia, supportive communication strategies, and the CPP. Establishing new contacts and taking advantage of media opportunities should be pursued. The groups were very motivated to: (1) expand the CPP beyond the current structure and format – "extending the conversation partners, for example, voluntary (agencies) and active retirement (groups)" and (2) "make Galway an aphasia friendly city." All participants pooled ideas about local amenities that would benefit from communication training provided by an inter-stakeholder team (PWA, SLTs; students; CPP coordinator), for example, public transport staff, transition year students, home helps, primary care centres, local shops, restaurants, and voluntary organisations. The group agreed that the CPP should be expanded – "be able to offer CPP to everyone who wants it – regardless of geographical location". This is an ongoing challenge as PWA living in more remote rural areas currently cannot access the programme.

Direct Ranking: Inter-stakeholder Group (Phase 2)

Through the PLA Direct Ranking technique, the inter-stakeholder group expressed priorities and preferences and indicated categories of equal weight for the CPP evaluation criteria. Consensus was reached about the most important evaluation criterion to the least important, for example, "Shared Understanding of Structure" was allocated the most votes (*n* = 16) denoted by 16 paperclips while "Feedback to and from All" received the least number of votes (*n* = 5) denoted by five paperclips. The highest ranked categories, that is, "Theme 2: Shared Understanding of Structure" (16 votes) and "Theme 1: Clarity about CPP for All" (14 votes) have strong resonance and interconnections as previously discussed. These two themes had clear majorities receiving almost double the votes of the other three themes. The joint third- and fourth-ranked themes, that is, "Agreed Evaluation Mechanism" and "Linking with Other Organisations/People" received 7.5 votes each. The half vote reflects co-researchers' deep consideration of category prioritisations and the voting process. One co-researcher with aphasia asked whether he could break one of his paper clips in half to give him two half votes instead of one vote. The colour coding of voting tokens provided a visible representation of each individuals' votes on the final agreed Direct Ranking chart enabling PWA to view the voting outcomes very clearly. The emergent evaluation criteria (category headings on the stickies at the top of the chart) were rearranged and presented in order of priority. Table 5 shows the agreed prioritisation of CPP evaluation criteria in ascending order from the least important to the most important criterion. As there were five participants with 10 votes each, the total number of votes cast was 50.

Table 5.5: Results of inter-stakeholder direct ranking of CPP evaluation criteria (Phase 2).

CPP Evaluation Criteria	Number of votes
Shared understanding of structure	16
Clarity about CPP for all	14
Agreed evaluation mechanism	7.5
Linking with other organisations/people	7.5
Feedback to and from all	5

Seasonal Calendar: Inter-stakeholder Group (Phase 2)

The inter-stakeholder group in Phase 2 used the PLA Seasonal Calendar technique to map the agreed CPP evaluation criteria and arising actions from these criteria onto a timeframe in which to complete the tasks. The agreed timeline is shown across the horizontal axis of the chart, that is, "Before the Programme"; "During the Programme"; "After the Programme" with the five evaluation criteria along the vertical access, that is, "Shared Understanding of Structure" "Clarity about the CPP for All," etc. The individual elements (*n* = 37) are mapped across the timeline with the agreed stakeholder group(s) responsible for implementing the particular task, for example, "Identify key people to make the CPP happen (CPP Coordinator)". The majority of tasks (*n* = 15) are assigned to "Before the Programme" with the minority allocated to "After the Programme" (*n* = 8). Participants agreed that some elements should be included at several stages along the timeline; for example, “SLTs to develop spreadsheet of possible clients for CPP” is included “Before the Programme” and “During the Programme” as referrals to the CPP can be made by SLTs throughout the calendar year. The elements that cross the timeline are denoted by an arrow for ease of identification (*n* = 5). Table 5.6 represents the Seasonal Calendar chart co-created by the inter-stakeholder group showing the planned implementation of the CPP evaluation criteria.

Table 5.6: Seasonal calendar: CPP evaluation criteria mapped onto timeline for implementation by inter-stakeholder group (Phase 2)

	Time line for CPP		
Evaluation Criteria	**Before the programme**	**During the programme**	**After the programme**
Shared Understanding of Structure	• SLTs to develop spreadsheet of possible clients for CPP • Identify key people to make the CPP happen (CPP coordinator) • SLT to let clinic know how many PWA want to take part in CPP at any time in the year • Clinic to let University know who is interested in getting involved • PWA expresses their preference about number of students and number of visits • Administrator to contact key SLT prior to sending correspondence • Clarify who is responsible for administration.	• SLTs to develop spreadsheet of possible clients for CPP • PWA and students to cancel appointments with adequate time • To share resources for all • Create opportunities for Conversation Partners to meet (university and administrator) • PWA and students to share phone numbers if comfortable • Students talk about aphasia with PWA • Keep the social aspect of CPP (PWA and student)	Social event includes the evaluation meeting
Clarity about the CPP for all	• Students to explain purpose of visit before and during the visits	Students to explain purpose of visit before and during the	Develop/create training video separate from

	Time line for CPP		
Evaluation Criteria	**Before the programme**	**During the programme**	**After the programme**
	• Create information booklet to be available to PWA and family (all) • CPP coordinator to share contact details of referring SLTs with students • CPP coordinator to share information with SLTs about dates of CPP and frequency of visits in reminder e-mail	visits	conversation partner visits (all)
Agree evaluation mechanism			• Informal end of programme session – PWA, SLTs, students, CPP coordinator • Social event includes the evaluation meeting
Linking with other organisations/people	• Centre of excellence – PWA training SLTs and community • Extending the conversation partners, e.g., volunteers, active retirement • Promote awareness of aphasia	• Centre of excellence – PWA training SLTs and community • Extending the conversation partners, e.g., volunteers, active retirement • Promote awareness of	• Centre of excellence – PWA training SLTs and community • Extending the conversation partners, e.g., volunteers, active

	Time line for CPP		
Evaluation Criteria	**Before the programme**	**During the programme**	**After the programme**
	and CPP in media • Be able to offer CPP to everyone who wants it regardless of geographical location	aphasia and CPP in media • Promoting awareness of aphasia (all)	retirement • Promote awareness of aphasia and CPP in media
Feedback to and from All		• Write joint one-page summary at the end of programme (PWA and student) • Photocopy one-page summary (student, SLT, coordinator)	PWA to keep the one-page summary

5.5 Discussion

The need to design and deliver services that respond to the on-going health and social needs of service users is fast becoming an international priority. Healthcare policy, research, and development activities worldwide show increased PPI, highlighting the importance of including the *insider* voice. Conversation approaches of all types report positive outcomes (Basso, 2010; Kagan et al., 2001; McVicker et al., 2009; Rayner & Marshall, 2003). To what extent the experiential knowledge of PWA is included in programme evaluation and redesign varies greatly. This study offers (1) a multi-perspectival evaluation of a conversation training intervention from the emic experiences of participants; (2) an innovative participatory health research approach for service design, development, and evaluation that is consistent with the living with aphasia framework (Byng & Duchan, 2005; Pound, Duchan, Penman, Hewitt, & Parr, 2007; Pound, Parr, & Duchan, 2001); and (3) an illustration of how to use PLA to include PWA and other key stakeholder groups as participants and co-researchers throughout the research process.

The analysis and synthesis of generated data across the research phases revealed the complex nature of emic experiences and interpretations of the CPP. Key emergent criteria relate to ensuring a shared understanding of structure, organisation, and purpose of the programme. Co-researchers were enthusiastic in their vision for the future of the CPP aiming to (1) promote public awareness of aphasia, (2) change the way the general public “talk” to PWA, and (3) increase positive communication experiences for PWA in society. Very specific ideas were generated about how to achieve these goals – for example, PWA selected local shops, restaurants and services (e.g., bus services), suggesting that these should be offered training in supportive communication techniques and Galway would become “an aphasia-friendly city.” There was a high degree of motivation to “extend the CPP” to groups not currently involved, for example, “active retirement”, “primary care centre,” and “voluntary organisations”. Involving new organisations would be a sign of success in future iterations of the programme. The desire to use the CPP to influence the way society communicates with PWA shows stakeholders’ ambitions and vision.

The numerous and varied references by co-researchers to the valued features of the CPP, for example, “easy conversation,” “social outlet for PWA,” opportunity to “practice conversation skills with unfamiliar people,” “relaxed environment” for example, own home, “confidence building,” “sense of importance,” “improved communication skills,” “cost-effectiveness” and “learning about aphasia” are consistent with previous findings reported across a range of papers in the existing literature (McVicker et al., 2009; Rayner & Marshall, 2003; Savage, Donovan, & Hoffman, 2014). However, despite the reported positive impacts and increased popularity of conversation approaches, robust research on the effectiveness of these interventions is sparse (Turner & Whitworth, 2006). The current literature describes a global appraisal of conversation training approaches (Fox et al., 2009; Jagoe & Roseingrave, 2011; McVicker et al., 2009) with no clear set of specific evaluation criteria from the emic experiences of participants. Our findings add an original contribution to the existing literature by providing a detailed description of what criteria PWA and other key stakeholders believe to be important in evaluating a conversation training programme from their unique perspectives. The co-researchers’ decision to move beyond identification of evaluation criteria to map implementation and design the future of the CPP reflects meaningful involvement in the research process.

In Phase 2 engaging representatives from all stakeholder groups in participatory dialogue using PLA techniques was a challenging task. It was difficult to negotiate and find times that suited representatives from all groups for face-to-face PLA sessions. Persistence was necessary, but worthwhile, as the data generated by the PLA inter-stakeholder group was qualitatively different from data generated by individual cohorts. For example, in the individual group (Phase 1) the PWA shared a belief that they were the primary benefactors form the CPP with little to offer the other stakeholder groups. However this view changed as the inter-stakeholder group discussed the value of learning from people with experiential knowledge of the daily challenges of aphasia. The co-researchers with aphasia listened to, and acknowledged, the ways in which the students, SLTs, and CPP coordinator benefited from and appreciated their contributions to the programme. This new understanding of reciprocal benefits changed the PWAs’ original perspectives about their role in the programme which related directly to the second highest ranking evaluation criteria “Clarity about CPP for All”. Another striking feature of the inter-stakeholder data was how strongly aligned the individual groups were in their views of “CPP best practice”. This resonance across groups is consistent with previous studies (e.g., McVicker et al., 2009) where different perspectives of the CPP were captured. Perhaps, in a different inter-stakeholder group, more divergence of views may occur.

5.5.1 Methodological critique

We used an innovative participatory health research approach to identify CPP evaluation criteria from the multi-perspectival emic experiences of a small group of PWA and other key stakeholders. We acknowledge the limitations of our sample - this is a small sample size of older, predominantly male, retired participants with aphasia living at home. The participants with aphasia represented a select group of people with mixed aphasia interested in the CPP from a particular cohort. While a mixed receptive, expressive functional aphasia may reflect the majority of PWA, we recognise that the emic experiences and data generated by people with other types of aphasia (e.g., receptive only or expressive only) and ranges of severity (e.g., severe comprehension difficulties) may differ from the data generated by our co-researchers. Recruiting people with a pure receptive or expressive aphasia and a more gender-balanced group with younger participants was beyond the scope of this study, and we acknowledge these limitations. While some older PWA may present with a co-morbid dementia, we did not experience this amongst our co-researchers; however, it is an important consideration for future studies. Despite their older age-range and data generation spanning 12 months, there was no attrition from the group nor did there appear to be any loss of connection with the data over time.

In relation to the other stakeholder groups, the majority of graduate and undergraduate participants were in their 20s and the SLT stakeholder group were all female with age ranges between 28 to 47 years which again may represent views from a particular cohort. The participants represent a select group of stakeholders affiliated with a CPP specific to a single university site. All were self-selecting and highly motivated to engage with the research process and share their emic experiences. We acknowledge that the participants included in the inter-stakeholder group are not representative of the communities from which they come, and this is a limitation of our study impacting the validity and generalisability of findings. Preliminary work on sharing the data generated in Ireland with an inter-stakeholder group in the United Kingdom in Phase 3 may contribute to the transferability of findings; however, this is a first step and further exploration of resonance across different groups and contexts is required.

Finally, it is important in qualitative research to consider issues of positionality. The first author was the coordinator of the CPP and involved in the study as a co-researcher and PLA facilitator. The movement between *insider/outsider* positions is acknowledged and may have positively biased the data although the involvement of the second author as an “outsider” facilitator was an important feature to counter such an effect. The third author also remained an “outsider” to ensure quality and rigour across the research phases. Issues of positionality will be reported in a separate methodological paper McMenamin et al. (2015).

5.6 Conclusion

In this study a small group of PWA and other key stakeholders were meaningfully involved in the identification of evaluation criteria for a conversation training intervention using PLA. The use of PLA to engage PWA as co-researchers in service design and evaluation resonates strongly with the principles of the living with aphasia framework (Byng & Duchan, 2005; Pound et al., 2007). The outcomes of this collaborative work bridge the gap between policy imperatives around involvement and actual practice and will impact the design, evaluation, and redesign of our CPP for all stakeholders. Preliminary findings suggest some resonance between the UK and Irish contexts although this requires further exploration. This study may also be of interest to professionals in this clinical area and to those exploring new approaches to include marginalised service users, especially people with communication disabilities in research. Future studies should consider using participatory health research approaches to engage PWA of different age ranges with varying types and severity of aphasia and other key stakeholders as co-researchers in outcomes-based studies. Through partnership in the research process, we can learn from the emic experiences of PWA and other groups with communication disability, identifying and confirming important key variables in service design, development and evaluation.

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5.10 ORCID

Ruth Mc Menamin http://orcid.org/0000-0002-9485-3148
Edel Tierney http://orcid.org/0000-0001-6393-8539
Anne Mac Farlane http://orcid.org/0000-0002-9708-5025

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Chapter 6 Paper 3: Impacts of Service Learning on Irish Healthcare Students, Educators and Communities

6.1 Abstract

This study investigated the impact of service learning on healthcare students, educators and community partners in Ireland. Using a qualitative approach with focus groups and interviews, participants' perceptions of the impact of service learning were recorded, transcribed and analysed. The findings in relation to students reflect previous research: service learning has the capacity to support personal development, enhance academic performance, and increase civic awareness. The primary impacts for community partners involved accessing students and services. The educators appreciated the opportunities to link academic theory to practice and engage with community partners. The results identified that the evaluation of learning outcomes was challenging because of both the evolving nature and breadth of learning achieved by all the stakeholders. However, our findings suggested that some impacts of service learning are consistent between Ireland and the USA. Further research is needed to explore whether the impacts of service learning are comparable across other cultures and contexts.

6.2 Key words

Communities, experiential learning, healthcare educators, healthcare students, qualitative research, service learning.

6.3 Introduction

Civic engagement and participation have been acknowledged as an important issue for higher-education institutions (Zlotkowski, 2007). A range of teaching and learning pedagogies has been proposed to facilitate the development of civic competence amongst university students, including service learning (SL), which is an experiential learning approach that aims to foster civic awareness and participation (Bailey et al., 2002). During SL experiences, students participate in community engagement, which is linked to their academic programme (Mc Kenna & Ward 1996; Erlich, 1997). Students learn through action in the community and reflection in the classroom (Seifer, 1998). Service learning is underpinned by a reciprocal partnership between students, communities and educators.

Although there is a significant body of evidence to support the use of SL from the USA (Forte, 1997; Cunningham, 2002; Huessin & Musa, 2004; Williams & Reeves, 2004; Reising, 2006), there is a paucity of information on the impacts of SL in other contexts. One study was identified that considered the impacts of SL on Irish nursing students (Casey & Murphy, 2008); however, no studies were found that considered the impacts of SL in the broader healthcare disciplines. This article presents an overview of the findings from research that sought to explore the impacts of SL on students, educators, and community partners (not-for-profit or governmental agencies that form a service-learning partnership) in the School of Health Sciences at the National University of Ireland, Galway.

6.3.1 Literature Review

Theoretical underpinnings of service learning

Service learning draws on the theories of experiential learning of Dewey and Kolb, which suggest that learning is enhanced when students are actively involved in gaining knowledge through experiential problem solving and decision making (Dewey, 1963; Kolb, 1984). Service learning is different from other types of experiential learning (e.g. placements in schools or hospitals) for two main reasons. Firstly, SL has an explicit goal to impact students’ sense of civic awareness and citizenship (Panici & Lasky, 2002). Although SL might support the development of academic, professional and personal skills its primary aim is to enhance students’ civic competence. Secondly, SL experiences strive to benefit the community partner and the student equally by emphasizing both the service that is being provided and the learning that is occurring (Cashman & Seifer, 2008).

Outcomes of service learning

Research considering the impacts of SL has primarily focused on learning outcomes that are achieved by students including: (i) enhanced ability to link theory to practice and engage in reflection; (ii) changes in attitudes towards, and awareness of, the community; (iii) personal and interpersonal development; (iv) increased civic awareness and engagement; and (v) improved critical thinking skills (Eyler & Giles, 1999; Callister & Hobbins-Garbett, 2000; Hammer *et al.*, 2007;Casey & Murphy, 2008; Hunt, 2007;). Less attention has been paid to the impacts of SL on community partners or educators; however, there is some evidence to suggest that SL does positively influence both of these groups (Eyler *et al.,* 2001).

Irish experience of service learning

In 2005 and 2006, the School of Health Sciences at the National University of Ireland, Galway was the first Irish healthcare school to introduce SL into the Bachelor of Science in Occupational Therapy (OT) and Bachelor of Science in Speech and Language Therapy (SLT) programs. For full details of the programs, please see Appendix 1 at the end of this Chapter. Preliminary evaluations (McMenamin, R. & McGrath, M., 2008, unpubl. data) suggested that the impacts of SL that were experienced by Irish students, community partners, and educators were similar to those that have been found in previous research (Panici & Lasky, 2002); however, further study was required to fully understand the impacts of SL in this context.

6.4 Aim of the Study

This study aimed to investigate the impact(s) of SL on all stakeholders (students, community partners and educators) in an Irish context.

6.5 Method

6.5.1 Design

A qualitative approach was used to explore the impact(s) of SL on all stakeholders. The generation of a new theory was beyond the scope of this study. However, we adopted the principles of grounded theory (Glaser & Strauss, 1967), which attempt to derive a general explanation of a process based on participants’ views (Creswell, 2003). These principles guided the process of data collection and data analysis.

6.5.2 Participants

The participants were recruited from undergraduate students, graduates, educators, and community partners who had engaged in SL with either the OT or SLT discipline at the National University of Ireland, Galway. The inclusion criteria required that participants had experienced SL and were willing to share these experiences with the researchers. Purposive sampling (Silverman, 2005) ensured that a diverse range of participants were included. Participant details are summarized in Table 6.1.

Table 6.1: Information about the participants

Participants	**Occupational Therapy (*n*=20)**	**Speech and Language Therapy (*n*=18)**
Graduate **One Focus Group (*n*=8)**	Focus Group: *n*= 4 (female; age range: 22-24 years)	Focus Group; *n*=4 (female = 3, male = 1; age range: 22-24 years)
Undergraduate **One OT Focus Group (*n*=8)** **One SLT Focus Group (*n*=8)**	Focus Group; *n*=8; (female; age range 19-21 years)	Focus Group; *n*=8; (female; a range: 19-21 years)
Community Partner **One Focus Group (*n*=4)** **Three Individual Interviews**	Focus Group *n*=4 (female)	Interviews: *n*=3 (female =2, male =1)
Educator †	Interviews: *n*=4; (female =3, male =1; junior =3; senior =1)*	Interviews; *n*=4; (female; junior =3, senior =1) *

6.5.3 Ethical Considerations

Ethical approval was sought and received from the Research Ethics Committee at the National University of Ireland, Galway, prior to commencing the study. The data were collected between November 2008 and April 2009. All the participants were advised that participation in the study was voluntary and that they could withdraw from the study without bias or prejudice at any time. Informed consent was obtained from all the participants prior to the data collection. The participants were assured that anonymity and confidentiality would be maintained throughout the study.

Some of the participants in the study had aphasia post stroke, which had a varied impact on their ability to read, write, understand and express themselves verbally. Therefore, the authors provided “aphasia friendly” information sheets and consent forms to these participants. Supportive communication techniques (UK Connect, 2008) were used during the interviews.

6.5.4 Data Collection

The third author was responsible for conducting the interviews and focus groups. Individual interviews (*n*= 11) and focus groups (*n*=4) were conducted in a quiet room in the University and were recorded on a digital recorder. The typical length of the interviews was 45 min and 90 min for the focus groups. A moderator participated in each of the focus groups to manage the time and record information about the discussions (e.g. non-verbal signals of agreement/disagreement). The experiences of the first two authors in implementing SL and a thorough review of the literature guided the development of the topic guides for the focus groups and interviews. The participants were asked to talk freely about the following topics: (i) experiences and understanding of SL; (ii) perceived impacts of SL on students; (iii) perceived impacts of SL on community partners; and (iv) perceived impacts of SL on educators. The topic guide was piloted with participants from each stakeholder group in order to increase its validity. The pilot did not reveal any ambiguity with the topic guide and resulted in only one minor change in the ordering of questions.

6.5.5 Data Analysis

Adhering to the iterative nature of qualitative analysis, the audiotaped recordings of the interviews and focus groups were listened to repeatedly to ensure familiarity with data. The data then were transcribed verbatim from the audiotaped recordings. The transcripts of all the interviews and focus group were analysed manually by the third author, using thematic content analysis (Burnard, 1991; Graneheim & Lundman, 2004). This method of analysis has emerged from the grounded theory approach of Glaser and Strauss (1967) and research on content analysis (Burnard, 1991). Open coding was used to freely generate categories from the transcribed data. The categories were collapsed and reduced into higher-order headings. These higher-order categories were reviewed and repetitious categories were eliminated in order to create a final list. The first and second authors then generated category lists independently from the transcribed raw data without seeing the third author's list. All three authors discussed the category lists and modifications were made as necessary. This process was implemented to increase the validity of the categorization method. The transcripts were reviewed again using the agreed coding list. During the writing-up phase of the study, the authors had use of the agreed final coding list and referred back to the complete transcripts where necessary.

6.5.6 Rigour and trustworthiness

Detailed accounts of the research strategy, data analysis, and results were maintained so that a clear audit trail was available. This ensured dependability and conformability of the data. In order to minimize researcher bias, the third author, who was not involved in the design or delivery of the SL modules, was responsible for the data collection and analysis.

6.5.7 Results

Five main themes were identified. These were: (i) SL is an eye-opening experience; (ii) SL is an opportunity to enhance professional development; (iii) engaged scholarship enhances academic outcomes; (iv) sharing knowledge and resources; and (v) SL provides a broader relevance for the university.

Service learning: an eye-opening experience

This theme describes the realities that occur as a result of working in unfamiliar social contexts. The students reported that the SL experience provided them with a unique opportunity to work with groups in society whom they would not typically encounter. Through these encounters, the students were challenged to reflect on and modify previously held beliefs and stereotypes and to consider the everyday realities of life for marginalised groups in Irish society. As one community partner commented:

> They found out how people find it so difficult....you know the isolation, you know the loneliness, the access to services

Although students were intellectually aware of the difficulties experienced by marginalized groups, many found it shocking to experience the everyday reality of social exclusion when working with community members. Through these encounters, the students gained insight into the consequences of inequity and many of them identified a personal need to challenge the status quo:

> You got to see the human side of it and that these people are struggling so hard.... so you feel like you're part of the revolution, as it were, for the [names group] community (graduate).

> I think it has opened our eyes about the community and how unaware of the challenges that aphasia present to people (student).

The opportunity to share in the everyday lives of others also prompted the students to reflect on their own life and, in particular, on their own personal beliefs about issues, such as the distribution of power and resources in society, the inclusion of people with disabilities, attitudes towards people who are marginalised. The students reported that SL experiences helped them to realize the complexity of social issues and challenged previously held views, leading to a more complete understanding of the topic. As a graduate noted:

> We realised that everybody has a story... you see them [homeless people] on the street and think it's their own fault, but yet I can see how that happened.

Opportunity to enhance professional development

This theme describes how SL experiences were seen as providing additional opportunities for professional development, in terms of professional identity, skills, and employability. Many of the students reported that, because their SL experiences were situated in the community rather than a clinical setting, they were challenged to explain their professional role and knowledge to audiences who often had no previous contact with OT or SLT. In preparing this explanation, the students were forced to reflect on their professional knowledge base and to find new ways of explaining themselves to diverse audiences. Through this reflection and dialogue with the community, the students reported a new sense of understanding of their profession and an awareness of how they fitted within a social, rather than biomedical, approach to rehabilitation. As one graduate described:

> It really forced us to get to really think about what our job does and how do you define it. So, from that point of view, it really prepared you for the profession.

Both the students and educators reported that SL provided opportunities for the students to develop skills, including specific clinical skills, and broader professional skills, such as communication and teamwork. The nature of the SL setting influenced the type of skills that students developed. For example, many of the OT students report learning about specific diagnoses that they had not encountered previously, including epilepsy and visual impairment. These students reported that the SL experience provided them with the opportunity to practise their OT skills; for example, in conducting OT assessments, planning interventions, and evaluating therapy outcomes. Practising these skills gave the students confidence in their ability to deal with future similar situations because they were, as this graduate noted:

> … not just listing off these references from books that I'd learnt of by heart during college. I'd done it for real.

Engaged scholarship enhances academic outcomes

This theme describes the impact of SL on students' academic performance. The nature of the SL experience was reported to be qualitatively different to that of other learning approaches, which influenced the students' effort and output. The students reported that because their learning experiences were embedded in a community context, they felt an enhanced sense of engagement and commitment to their studies. This commitment led the students to engage more deeply with their academic component of the SL modules than they might have done with the academic material for other modules. One student suggested:

> It was more meaningful as well … because any kind of learning, you

> really took it on board, whereas sometimes you can just do surface learning. Whereas, with SL, you really wanted to know more.

Service learning also was associated with an increased breadth of learning by the academic staff. They reported that, when compared with other learning experiences, the complex nature of the issues that were addressed in the SL experiences supported the students to adopt a holistic approach to addressing problems. The academic staff and community partners also reported that the complexity of the social issues addressed through the SL projects encouraged students to draw from and connect their learning across the entire curriculum, rather than to rely on material that was specific to a particular module.

Sharing of knowledge and resources

Service-learning projects were described by all the participants as adding value to the community, both through the direct acquisition of services for community organizations and through the potential to influence future healthcare professionals in relation to social issues.

The community partners consistently reported that students brought significant time, knowledge, and enthusiasm to their services. For many of the community partners, the presence of the students enabled them to provide services to their client groups that would not have been possible otherwise. This was seen as a primary outcome of SL for the community by the partners. One community partner noted:

> Students are very much helping us to offer a service that it would be difficult for us to offer at that level without their input.

The students reported being happy with this outcome, as it made them feel that their work was worthwhile and this enhanced the value that they placed on their academic learning. None of the students appeared to consider that this provider–recipient relationship was problematic, perhaps reflecting a less sophisticated understanding of the dynamics of partnerships. One graduate commented:

> People were glad to see us coming because we were doing work that they really wanted to be done.

However, the community partners and educators acknowledged that this service provision had the capacity to disrupt the power dynamic in the relationship between the university, as an institution, and the community. Some of the educators and community partners expressed concern over the capacity of such partnerships to be truly reciprocal, with one community partner suggesting that, for the most part, the partnerships were driven by the needs of the university, as an institution, rather than by the needs of the community.

However, other community partners reported that, as the relationship between the university and the community developed, this power dynamic changed to a more equal partnership. The community began to find a way to assert its needs in the negotiation of outcomes:

> We are getting smarter on how we approach putting SL opportunities out there.... whereas [in the beginning], a bit more airy- fairy (community Partner)

The community partners who explained this level of planning in relation to SL projects also reported that SL provided an opportunity to engage young people with issues of marginalization and exclusion. The community partners said the opportunity to work with young healthcare professionals was valuable because it allowed them to educate the students about issues, such as social justice, that were not typically included in traditional curricula. They also mentioned that successful SL experiences encouraged students to consider career opportunities outside of the mainstream health services:

> Isn’t it wonderful that they have had hands-on experience of [names organisation] …then, they can actually make a decision, “Is it for me or not?”

Service learning: providing a broader relevance for the university

This theme describes how SL bridges the gap between the university, as an institution, and the broader society in which it is situated. The participants described SL as promoting the civic mission of higher education and ensuring that academic practice continues to have relevance to the local, national, and international contexts.

The educators identified that SL aims to prepare students for critical citizenship and active participation in society. In this way, SL was perceived to be pivotal in fulfilling the civic mission of higher education:

> … that notion of the university being kind of linked with the community it’s based in and not seen as … geographically being located in a place but not, if you like, interfacing with the community, you know, around it (educator).

Service-learning projects also provided an opportunity to break down the traditional barriers that might exist between “town” and “gown”. Many of the individual SL projects included the sharing of university space with members of the broader community. This idea of opening the door of the university was highlighted as an important mechanism in strengthening the relationships between the university and the broader community.

In addition to breaking down the barriers that might exist between the university and community, SL projects also provided enhanced relevance and purpose for the work of the university. The educators spoke of the need to ensure that research and teaching were grounded in the reality of practice and identified SL as one method through which theoretical knowledge could be linked to the real-world context. The relationships that were developed with the community as a part of the SL modules were seen as critical to supporting relevance in teaching and research:

> We, as an academic community, can be a very kind of, can be on the one hand on a pedestal, or the other hand, can be just remote from everyday life and everyday environment, learning about things from books ... So, I think that broadening of our perspective on how we learn and how we teach is very healthy for a university (educator).

6.6 Discussion

Healthcare educators strive to produce graduates who will contribute actively to the improvement of public health. Service learning is designed specifically to develop a sense of caring for others, social responsibility, and active community participation (Piper *et al.*, 2000). Through community-university partnerships, the application of theory to practice (and vice versa) can become a reality. Although some critics of SL contend that community engagement is devoid of academic rigour, others believe that it is intellectually demanding, creates a sense of civic awareness and promotes students' moral development (Delve *et al.*, 1990). The results of this study suggest that SL has the capacity to support personal development, enhance academic performance, and increase civic awareness, which is consistent with previous research from other healthcare groups (Casey & Murphy, 2008). It also appears that SL stimulates students to expand their thinking beyond personal aims and objectives to the broader social context and to reflect on individual biases and prejudices. Students have a new understanding of how people with illness and disabilities are affected in their everyday life. This new understanding, which is developed through SL experiences, might facilitate students' participation in life, both as citizens and future healthcare professionals.

Community partners appear to value the opportunity to work with educators and students. In the SL experiences described here, the students provided interventions to people with chronic disabilities in the absence of services from local healthcare providers. The community partners identified accessing students and services as the most important impact of SL. Community partners are a rich and unique source of knowledge and, through SL, community members are acknowledged as valued teachers. The integration of community knowledge into curricula might facilitate students' understanding of illness and disability. The community partners certainly seemed to welcome the opportunity to influence students' career choices and personal development. The concepts of civic awareness, reflection, and reciprocity are core features of SL (Jacoby, 2003); however, these concepts were not identified as major impacts of SL by the community partners in this study.

The impacts of SL, as perceived by the educators in this study, seemed to mirror the impacts for the students. The educators recognised that SL can bridge academic learning with applied settings and that this supports students to realize the interconnections between theory and practice (De Martini, 1983; Calderon & Farrell, 1996). They also seemed to appreciate that students who engage with the community during their academic training may enhance their civic awareness and professional and cultural competence (Goddard & Gribble, 2007). The educators did not report any negative impacts of SL, which is interesting given that those who engage in this resource-intensive teaching process are rarely rewarded for their work through promotion or tenure (Bringle *et al.*, 2000; Shaefer, Hink & Brandell, 2000).

The broad range of SL impacts identified in this study suggests that learning outcomes could be difficult to design. However, the flexible integration of learning outcomes will allow new and unexpected learning to emerge (Peterson, 2009). Although civic engagement is an explicit aim of SL, our findings suggests that other outcomes may be equally important.

Implications for Practice

Significant changes are necessary in healthcare education if we want to produce graduates who are socially aware and see the person before the disability or disease. Some researchers suggest that the gap between theory and practice "remains an elusive ideal" (Van de Ven, 2007: 265); however, SL might offer part of the solution to this problem. The evidence from the literature to date and the findings of this study suggest that universities should invest in fostering students' civic awareness through SL. Educators should implement SL and be rigorous in their evaluation of the outcomes for all stakeholders. It would be interesting to note whether or not the impacts of SL that were identified in this study are comparable with other Irish SL programs. We also need further research to help us understand the potential benefits and challenges of SL for professional education programmes in European, Asian and African contexts.

Limitations of the research

The authors acknowledge that the students' and educators' perceptions of the impacts of SL that have been presented here were generated by very homogonous participants. The inclusion of participants from different geographical locations with different learning, teaching, health, and social experiences might create a richness of data that is not represented here and might contribute to data saturation. Purposeful sampling was used to recruit participants; however, the participants volunteered from each target group to participate in the study. It is reasonable to hypothesize that the persons who participated were interested in the topic, motivated, and enthusiastic. Future research should aim to include a wider audience to ensure all views are represented.

6.7 Conclusion

The impacts of SL identified in this study are largely consistent with the results from the literature (Eyler & Giles, 1999; Panici & Lasky, 2002). However, as we move forward, there are many questions that need to be addressed. We need to learn more about the relationship between theoretical knowledge and SL. How do students reinterpret theory through the lens of practice and vice versa? What is the nature of the processes of reasoning in the two domains and how do they influence each other? (Moore, 2000). Finally, how exactly does SL meet the discipline-specific learning objectives of healthcare programs?

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Appendix 1 Service learning in occupational therapy and speech and language therapy

Service learning	**Occupational therapy**	**Speech and language therapy**
Participants	Third-year undergraduate students (25-30 students)	Third-year undergraduate students (25-30 students)
Module Content	The students work in small groups (2-3) in order to collaborate with the community organization to address the occupational needs of service users; 12 workshops address topics, such as civic engagement, social justice, and the social determinants of health	The students work in pairs and complete 10-12 visits with a person with aphasia who is living in the local community; during the visits, the students use supportive communication techniques to facilitate the conversation
Monitoring	Weekly reflective blogs, participation in weekly professional supervision with academic staff, fortnightly large-group solution that is focused problem-solving tutorials	Weekly reflective blogs, fortnightly large-group solution that is focused on problem-solving tutorials with the academic staff
Credits	13	Pass/ fail module: the students must pass all the components of the module to complete the module; there is no compensation between components
Assessment	Poster presentation (40%); 3000 word paper (60%)	Completion of conversation partner training program; participation in 10-12 visits with a community

		partner; completion of a weekly reflective blog; participation in fortnightly tutorials; the students work in small groups to prepare a poster presentation, based on themes related to service learning, as selected by the module leader
Duration	Two semesters (24 Weeks), 7 h per week (1 day)	Two semesters (24 Weeks), 7 h per week (1 day)
Selection of community partners	The partners are selected based on two criteria: (i) a lack of availability of occupational therapy services within the organization or via the public health service; and (ii) an interest in, and capacity to engage with, student occupational therapists; examples of partners include organisations that provide services for people who are homeless, outreach services for youth at risk, and support services for refugees and asylum-seekers	The community partners are referred by community speech and language therapists who are working for the public health service and include men and women who are aged between 21 and 90 years with an acquired brain injury, resulting in aphasia, who have been discharged from acute health services and are living in the community.

Chapter 7 Paper 4: Training socially responsive healthcare graduates: Is service learning an effective educational approach?

7.1 Abstract

7.1.1 Background

Health care educators strive to train graduates who are socially responsive and can act as “change agents” for communities they serve. Service learning (SL) is increasingly being used to teach the social aspects of health care and develop students’ social responsiveness. However, the effectiveness of SL as an educational intervention has not been established.

7.1.2 Aim

To assess the evidence for the effectiveness of SL.

7.1.3 Method

Seven electronic databases were searched up to 2012 and included all articles on SL for pre-professional health care students. Hand searching was also conducted.

7.1.4 Results

A total of 1485 articles were identified, 53 fulfilled the search and quality appraisal criteria and were reviewed across six domains of potential SL effects: (i) personal and interpersonal development; (ii) understanding and applying knowledge; (iii) engagement, curiosity and reflective practice; (iv) critical thinking; (v) perspective transformation and (vi) citizenship.

7.1.5 Conclusion

While SL experiences appear highly valued by educators and students the effectiveness of SL remains unclear. SL is different from other forms of experiential learning because it explicitly aims to establish reciprocity between all partners and increase students’ social responsiveness. Impact studies based on the interpretative paradigm, aligned with the principles of social accountability and including all stakeholder perspectives are necessary.

7.2 Practice Points

- Service learning is a complex educational approach involving communities, students and institutions with the aspiration that partnerships are equally beneficial and reciprocal.
- Social accountability is being integrated as a core standard in the accreditation of health care education and service learning has been used to teach students social accountability.
- Working in partnership with the “different other” appears to help students develop a deeper appreciation of the vulnerabilities that marginalised segments of the population experience and nurture a purposeful sense of social responsibility.
- The unique nature of SL experiences makes it difficult to generate definite and generalisable outcomes
- Future research should aim to conduct more robust evaluations in this increasingly important and life changing aspect of medical education.

7.3 Introduction

Traditional didactic classroom or clinical settings have been criticized for failing to prepare graduates for 21st century practice (Hoppes & Hellman, 2007; Cole & Carlin, 2009). Modern health care professionals must be capable of developing collaborative partnerships with the health sector, policy-makers and communities in order to identify and treat priority health needs (Frenk et al., 2010; Sales & Schlaff, 2010). Furthermore, the internationalization of health care education requires that graduates become global citizens with the skills, knowledge and experience to positively influence the health and well-being of global populations (McKimm & McLean, 2011). Health care systems, whether local or global, depend on health care professionals to be socially responsive and willing to act as “enlightened change agents” in diverse contexts and communities (Larkins et al., 2013). There is growing international commitment to meet this challenge for example, the Global Consensus for social accountability of Medical Schools (2011) is working to integrate social accountability as a core standard in the accreditation of health care education, while the Training for Health Equity Network (2008) are developing a common evaluation framework for social accountability. AMEE's (Association for Medical Education in Europe) and ASPIRE (International recognition of excellence in Medical Education) initiative have piloted criteria for the assessment of social accountability in 20 Countries to date. Key reports including the Institute of Medicine's: (1) Health Professions Education: A Bridge to Quality, (2) Educating Physicians: A Call for Reform of Medical Schools and Residency and The Independent Global Commission on Education of Health Professionals for the 21st Century' (Frenk et al., 2010) emphasize the importance of teaching and evaluating social accountability in health care education. Accreditation bodies are creating education and training standards which include community engagement and public health dimensions (McKimm & McLean, 2011). This drive to graduate socially responsive students creates the need for a suitable pedagogical approach to teach the social aspects of health. Educators have explored a variety of innovative pedagogies; however, service learning (SL) has been suggested as an experiential and transformative educational approach. SL supports building collaborative partnerships between communities and institutions with a balance between meeting identified community needs and defined student learning outcomes (Seifer et al., 2000).

7.3.1 Service Learning Theoretical Framework

Service learning was developed in the USA, and has been championed by Cashman & Seifer (2008). This pedagogy is largely based upon theories embedded in the experiential learning paradigm first posited by Dewey (1938, 1963) and later elabortated by Kolb (1984). These theories suggest that students' learning is enhanced with active engagement in experiential problem solving and decision-making involving iterative reflection and (re)conceptualization. SL adds to the normal interpretation of experiential learning as an individual learning cycle with its emphasis on learning activities that establish reciprocity between learners/institutions and, communities (McMenamin et al., 2010). The aim of SL to collaborate with local communities in a reciprocal way is in keeping with (Freire, 1972) social justice framework.

7.3.2 Service Learning Outcomes

SL is reported to have several educational benefits including supporting students to: apply theory to practice in the community; develop skills that are difficult to learn with traditional educational approaches; gain an appreciation of the social determinants of health and foster a sense of social responsibility, accountability and caring for others (Azer et al., 2013). SL also supports students' professional identity formation, a core component of "professionalism", and a key strand in health care curricula (Woollard, 2006; Bentley & Ellison, 2007; Batra et al., 2009). North American studies have dominated research focused on evaluating SL (Eyler, 2000). Eyler & Giles (1999) propose a theoretical framework identifying six broad categories of student learning outcomes including: (i) personal and interpersonal development, (ii) understanding and applying knowledge, (iii) engagement curiosity and reflective practice, (iv) critical thinking, (v) perspective transformation and (vi) citizenship (Eyler & Giles, 1999). The relevance of these learning outcomes to contexts beyond North America is uncertain as transferring curriculum innovation from one culture to another involves a process of localization which may influence the application of the innovation and the outcomes achieved (Boland & McIlrath, 2007). SL is a resource intensive pedagogy (Eyler, 2000) as building relationships between communities, students and universities requires considerable effort. The commitment to maintain equal and collaborative relationships over time means that SL partnerships are continually changing and are unique (Karasik & Wallingford, 2007). Given the demands of intensive health care curricula and the short academic year some educators and students may prefer more predictable traditional approaches to teaching and learning social accountability (Dharamsi et al., 2010a). New approaches in educational policy and practice should be supported by evidence (Evans & Benefield, 2001) with thorough evaluation prior to implementation (Dorfman et al., 2007). However, in the absense of clear evidence of SL effectivness or understanding of localization educators cannot make informed decisions about the implementation of this pedagogy. There are a range of resources describing the features of SL (e.g. Zlotkowski, 2002; Holland, 2005) including a number of discipline specific texts, (Elam et al., 2003; Flecky & Gitlow, 2011; Mitschke & Petrovich, 2011; Kazemi et al., 2011). Neither these texts, nor the current evidence on the impacts of SL, which is largely based on North American data can inform international SL and social accountability agenda's.

This review is necessary and timely as it considers the new and emerging international SL literature and aims to (i) discuss the nature of evaluation approaches; (ii) identify the reported impacts of SL for health care students focusing on social accountability outcomes and (iii) provide guidance on priority areas for future research.

7.4 Methods

7.4.1 Search Strategy

A systematic approach based on Best Evidence Medical Education (BEME, 2003) guidelines was used to search the following seven databases for English language, peer-reviewed studies, with a timeframe up to and including February 2012: CINHAL Plus; British Education Index; Australian Education Index; PubMed; PsychInfo; SCOPUS and ProQuest. The term "Service Learning" originated in North America however a wide range of terminology exists to describe the work of SL internationally (Hunt & Swiggum, 2007). The diversity in SL terminology became apparent during the search process. Combinations of the following keywords were used to identify relevant studies on the impacts of SL for pre-professional health care students: service learning; community based learning; pedagogies for civic engagement; civic engagement; civic awareness and undergraduate health care and learning outcomes.

Inclusion/exclusion criteria

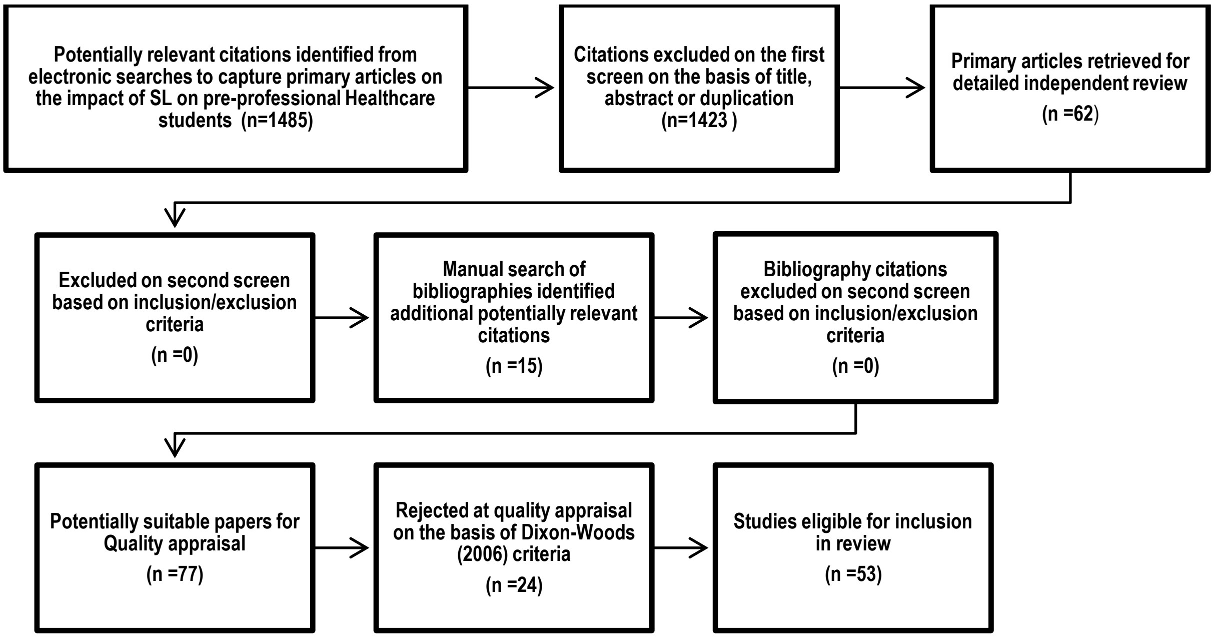
Bringle & Hatcher's (1996) definition of SL guided the SL inclusion criteria:
…SL is a credit-bearing educational experience in which students participate in an organised service activity that meets identified community needs….unlike extracurricular voluntary service….meaningful service activities are related to course materials…unlike practica and internships…the experiential activity is not necessarily skill-based within the context of professional education. (Bringle & Hatcher, 1996, p222).

Papers relating to student volunteer experiences that were not credit-bearing and experiential learning activities that were not identified as SL were excluded. Student disciplines were restricted to pre-professional medicine, nursing and midwifery, physiotherapy, occupational therapy, speech and language therapy, human nutrition and dietetics, pharmacy, psychology, podiatry, and social work. Studies involving other student groups were included if any of the eligible disciplines were involved in the same study (e.g. Krout et al., 2010); however, only data relating to the outcomes of the eligible student disciplines were considered.

Study identification

The seven databases searched identified 1485 potential papers. The abstract of each paper was independently reviewed and this double coding system produced the initial results. One-thousand four-hundred and twenty-three papers were excluded as they did not comply with the inclusion criteria. Where there was disagreement or uncertainty regarding the relevance of citations the full text article was retrieved and read independently by two authors. Any discrepancies in classifying outcomes were discussed prior to making final decisions regarding the inclusion or exclusion of the article. Hand searching the bibliographies of the 62 papers fulfilling the inclusion criteria identified a further 15 relevant papers. Full text papers of the 77 potentially relevant studies were assessed independently by two authors (Figure 7.1).

Figure 7.1: Literature search and article identification



Data extraction

Data extraction and quality appraisal from the set of 77 identified studies were carried out by two authors and checked by a third author using a specifically designed coding form. Coding differences were resolved through discussion between the authors. The coding process in a critical review usually involves making a judgement on the quality of studies included which determines the quality of data analysed and ultimately informs conclusions. Conventional critical reviews frequently adopt a quality appraisal system that results in a “hierarchy of evidence”. However, this approach was not easily applied to the current review for two reasons: (i) it was essential to consider the wider social, philosophical and ethical issues underpinning policy and practice (Evans & Benefield, 2001) and (ii) the literature set included both quantitative and qualitative methodologies. Therefore we adopted a more inclusive approach to quality appraisal using criteria suggested by Dixon-Woods et al. (2006) including:

- Clarity of the research aims and objectives.
- Clarity and appropriateness of the research method.
- Description of the research process.
- Availability of data to support the research findings and conclusions.
- Clarity and appropriateness of the data analysis method.

Based on these criteria papers that failed to provide sufficient detail regarding the research method and/or research process were excluded resulting in a further (*n* = 24) ineligible papers. A total of (*n* = 53) papers were accepted for final detailed review. Key features of the studies are summarised in Tables 7.1 and 7.2. Given the nature of this study, ethical approval was not required.

Review aim 1: The nature of Service Learning Evaluation Approaches

Table 7.1: Papers included in the Review

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
Green et al.(2011)	To determine the effect of an international service-learning experience in Honduras on the cultural competence of the participants.	Mixed Methods: Questionnaire – pre-test and post-test scores compared. Interviews analysed	Quantitative component did not use self-report	Nursing and medical students (*n* = 7)	**Positive Impact Reported:** International service-learning experience was successful in increasing the participants' ability to provide culturally congruent care.
Groh et al. (2011)	To examine the impact of a service learning experience on senior nursing students' self-rated	Quasi experimental: Questionnaire – Self- evaluation pre and post experience	Some self- report- students rated themselves on 10 items.	Nursing students (*n* = 306)	**Positive Impact Reported:** Significant positive difference demonstrated for both leadership

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	competency in leadership skills and social justice interest.				skills scores and social justice scores
Kaf et al. (2011)	To examine changes in students' attitudes toward adults with dementia following an SL experience.	Mixed Methods: Questionnaire Reflective Journal	Quantitative component did not use self- report	Audiology (*n* = 19) Speech Pathology (*n* = 24) Total (*n* = 43)	**Positive Impact Reported:** Direct contact with older adults through Service Learning resulted in more positive attitudes toward older adults in residential facilities.
Leung et al. (2011)	To compare the effects of a Service Learning project with a self-	Experimental: Randomised controlled trial	Not self - report	Medical (*n* = 28) Nursing (*n* = 75) Total (*n* = 103)	**Positive impact immediately post SL experience but gains not**

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	directed online learning programme on medical and nursing students' knowledge about aging and their attitudes towards older adults.				**maintained:** Participants in the service learning group showed significantly greater knowledge of aging, understanding of mental health needs in old age & had a more positive attitude toward older adults. At 1 month these results were not maintained.
Liang En et al. (2011a)	To compare the ability of two	Quasi-experimental:	Some Self Report measures **–**	Medical students (*n* = 64)	**Positive impact reported:**

Source	Aim(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	programs providing medical care to low-income populations (clinic-based v home-based approach) to teach community medicine skills in an Asian medical school.	Cross-sectional study - self-administered anonymised questionnaire	students rated their perception of gains across 9 domains		Service Learning superior at teaching communication skills, teamwork, identifying social issues, gaining knowledge, and applying knowledge. Improved knowledge on long-term management of chronic diseases. Service-learning programs, in the Asian context, have potential educational value

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
					for medical students in a wide range of domains.
Loewenson & Hunt) &(2011)	To examine nursing students' attitudes toward homelessness before and after participation in a service-learning clinical rotation with families experiencing homelessness.	Quasi-experimental: Questionnaire – Pre-and post-test	Some self-report measures - students rated their perception of attitude change.	Nursing students (*n* = 23)	**Positive impact reported:** Results suggest a positive influence on students' attitudes and support the value of integrating service-learning clinical opportunities with homeless individuals into nursing curricula.
Long et al.	To determine the	Quasi-	Some self-report –	Medical students	**Positive impact**

Source	***A*****im(s)**	**Study Design & Data collection**	**Self-Report vs. Non Self-Report Measures used**	**Study Population & Sample Size**	**Key findings**
(2011)	impact of an 8-week service learning programme on medical students reported comfort, effectiveness and willingness to lead and the extent of their self-knowledge about their own leadership abilities.	experimental : Questionnaire – Pre- and Post- test	students rated their perceptions of changes in their leadership skills post SL	(*n* = 41)	**reported:** Significant positive improvement in perceived comfort in leadership activities. No perceived effectiveness or willingness to take a leadership role. No significant difference found in perceived comfort or willingness to change leadership style.
Meili et al. (2011)	To explore student reflections on their experiences during	Qualitative: Two structured open-ended written	Not Self-report	Medical students (*n* = 14)	**Positive impact reported:** Service-learning

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	the MTL programme which is designed to teach medical students the social aspects of medicine via service learning.	response questionnaires.			can encourage altruistic medicine and teach social accountability to medical students.
Mitschke & Petrovich (2011)	To examine student learning outcomes that resulted from a service learning partnership between graduate-level social work students in a diversity course and a community health clinic	Qualitative: Inductive technique for deriving conclusions from general observations using content analysis. Review of student papers and reflections to identify themes.	Not Self-report	Social work students (*n* = 24)	**Positive impact for some reported:** For some students, service learning can provide a unique opportunity to alter the way that they see others and their personal and professional

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	serving Latino immigrants and Burmese refugees.				responsibility they have to community. For others service learning created a passion for advocacy, a commitment to social justice, or a vow of service that can follow students throughout their lifetime.
Pakulski (2011)	To examine the utility of a university-based service learning clinical intervention programme that	Quasi-experimental: Self-rating questionnaires - Pre- and post-service learning	Some self-report measures – Students rated their perception of their knowledge and skills pre- and	Speech & Language Pathology students (*n* = 28)	**Positive Impact Reported:** Statistically significant improvement between pre- and

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	provides education and clinical experience for pre-service Speech & Language Pathologists and other pre-professionals.	experience	post- service learning experience		post-questionnaires of knowledge and skill related to intervention for families of children who are deaf or hard of hearing and who are auditory based language learners by a single group of students.
Reading & Padgett) (2011)	The development of ASL skills through a service learning experience.	Experimental: Controlled trial	Not self-report	Speech & Language Therapy and Audiology Total (*n* = 32)	**Positive impact reported:** SL valuable teaching method for ASL. Service learning

Source	Aim(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
					increases cultural awareness and skill level.
Schindler (2011)	To teach research skills, clinical skills, and increase comfort in working with the mental health population to Occupational Therapy students using a Service learning approach.	Quasi-experimental: Survey – pre and post	Some self-report measures – Students rated their perceptions of changes in their competence and comfort of working with people with mental health issues.	Occupational Therapy students *n* = 78	**Positive impact reported:** Results indicated that the Occupational Therapy students gained comfort with the population and competence in their clinical and research skills
Vogt et al. (2011)	To examine the experiences of student nurses at a summer	Qualitative: Reflective journals analysed through a process of coding,	Not self-report	Nursing students (*n* = 26)	**Positive impact reported:** Camp positively increased students’

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	residential camp for children with diabetes using a service-learning framework.	content analysis, and theme development.			knowledge of diabetes. Reflective journals identified themes of anxiety, fatigue, responsibility, and increased student confidence. Also empathy for the lifestyle of children with diabetes.
Liang En et al. (2011b)	To evaluate the learner reported educational value of a service learning program for medical and nursing students.	Mixed methods: Cross-sectional survey Qualitative feedback on experiences analysed using thematic analysis	Some self-report measures – Students rated their perceived gains from SL experience	Medical (*n* = 240) Nursing students (*n* = 34) Total (*n* = 274)	**Positive impact reported:** Students reported that the service learning experience benefited their learning in

Source	Aim(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
					leadership skills; communication skills; teamwork; critical thinking skills; ability to identify social issues; action skills; ability to see consequences; acquisition of knowledge and application of knowledge.
Zucchero (2011)	To explore student learning outcomes following a service learning experience in a lifespan	Mixed methods: Pre- and post- test Quiz Qualitative analysis of student reflections	Not Self Report Measures	Psychology and Occupational Therapy students Total (*n* = 66)	**Positive impact reported:** Students' knowledge of older adults increased significantly from

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	developmental psychology course.				pre-test to post-test. Qualitative analysis found that service learning resulted in positive outcomes in three groups; intrapersonal development, emotional learning, value/ benefit.
Amerson (2010)	To evaluate the self- perceived cultural competence of nursing students on completion of service learning projects with local and international	Quasi-experimental: Questionnaire - Pre and post	Some self-report measures - Self Perceived cultural competence after SL	Nursing students (*n* = 69)	**Positive impact reported:** Following service learning students had significantly higher levels of self- assessed cultural competence.

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	communities as part of a community health nursing course.				
Dauenhauer et al. (2010)	To develop and evaluate an intergenerational service-learning course designed to promote social work gerocompetencies.	Mixed methods: Survey & analysis of electronic journal & Interviews.	Survey – Some self-report measures	Social Work Graduate (*n* = 9) & Undergraduate (*n* = 2) Nursing (*n* = 1) Interdisciplinary health (*n* = 1) Total (*n* = 13)	**Potential positive impact:** Intergenerational service learning coursework may help foster geriatric competencies among graduate & undergraduate social work students.
Faria et al. (2010)	To report qualitative student outcomes as a result of	Qualitative: Inductive content analysis to analyse students' reflective	Not self-report	Social Work Graduate (*n* = 24) & Undergraduate (*n* = 7)	**Positive impact reported:** Service learning fosters

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	participating in a university-community partnership course	journals		Nursing (*n* = 2) Interdisciplinary health (*n* = 2) Non matriculated graduate student (*n* = 1) Total (*n* = 37)	competencies in working with older people. Students' experienced educational growth, personal and professional learning.
Horowitz et al. (2010)	To explore students' perceptions of their service learning experience and intergenerational sessions.	Quasi-experimental: Questionnaire.	Some self-report measures	Occupational Therapy Students (*n* = 22)	**Positive impact reported:** Positive perception of service learning.
Krout et al. (2010)	To build a multidisciplinary base for	Quasi-experimental: Student	Some self-report	Gerontology, Psychology, Occupational	**Positive impact reported:** Increased

Source	***A*im(s)**	**Study Design & Data collection**	**Self-Report vs. Non Self-Report Measures used**	**Study Population & Sample Size**	**Key findings**
	gerontology Service Learning (SL) at the college by extending SL activities to other departments and to engage students from many majors with elders to identify, plan, and execute activities that benefited them and the community.	satisfaction pre- and post- test survey		Therapy, and Health Promotion and Physical Education, Speech Pathology and Therapeutic Recreation students Total (*n* = 129)	understanding of: ability to work and communicate with elders (96.6%) and of service-learning (95.1%). Students reported experience was: relevant to course (99.2%) and valuable educationally (98.3%). Almost 9 in 10 reported more positive attitudes toward elders, and 92% were pleased with their service learning

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
					experience. High levels of student satisfaction.
Dharamsi et al. (2010a)	To conduct a detailed exploration of the international service-learning (ISL) experience of three medical students.	Qualitative: Phenomenological approach - critical incident technique used to analyse student reflections and essays.	Not self-report	Medical students (*n* = 3)	**Positive impact reported:** Increased meaningful sense of what it means to be vulnerable & marginalised, heightened awareness of the social determinants of health and the related importance of community engagement. Greater appreciation of the

Source	Aim(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
					health advocate role.
McMenamin et al. (2010)	To investigate the impact(s) of Service Learning on students, community partners, and educators in an Irish context.	Qualitative: Thematic content analysis used to analyse data from Focus groups & Interviews with students, community partners and educators.	Not self-report	Educators (*n* = 8) Undergraduate OT & SLT students (*n* = 16); Graduate OT & SLT (*n* = 8) Community partners(*n* = 7) Total (*n* = 38)	**Potential positive impact:** Student outcomes: Service learning has the capacity to support personal development, enhance academic performance and increase civic awareness.
Brown (2009)	To determine if a faith based Service Learning activity would improve nursing students' knowledge and	Quasi-experimental: Questionnaire – comparison of Pre- and Post-self-assessment results.	Some self-report measures	Nursing students (*n* = 55)	**Positive impact reported:** Significant increase in self-rated knowledge of service learning, community needs,

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	skills related to community mental health.				enthusiasm for service learning. A significant change was found in self-reported group skills and oral communication skills No significant change was found for communication, creativity or written skills.
Horacek et al. (2009)	To challenge the students development of inter-professional competencies and	Quasi-experimental: Questionnaire – Pre- and Post-self-assessment	Some self-report measures	Dietetic, nursing, social work, child and family studies students Total (*n* = 41)	**Positive impact reported:** Interdisciplinary education is necessary and can

Source	Aim(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	to contribute to the creation of community partnerships.	survey.			be implemented successfully via service learning for upper-class health care students. Interdisciplinary education can improve university-community relationships and enhance students' cultural and professional competence.
Ngai (2009)	To examine how service learning programme characteristics - involvement with	Quasi-experimental: Survey	Some self-report	Medical (n = 12) Social science (n = 24) Total (n = 113)	**Positive impact reported:** Involvement with service users and psychological

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	users, agency support & class experience – and psychological engagement interact to affect students' learning outcomes.				engagement has a significant positive effect on personal development and civic engagement. Agency support and class experience have no significant effect on personal development or civic engagement but they are predictors of psychological engagement.
Casey & Murphy (2008)	To explore student experiences' of service learning.	Qualitative: Thematic analysis of focus groups;	Not self-report	Nursing students (*n* = 30)	**Positive impact reported:** Participants

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
		individual interview and group interview data.			reported that service learning supported development of cultural sensitivity, to learn about caring for people in different cultures.
Furze et al. (2008)	To evaluate the impact of an inter-professional community-based educational project on students' attitudes toward other health care professions and older adults.	Mixed Methods: Survey Reflective journals Focus Group	Not self-report	Nursing, Occupational Therapy, Physical Therapy, and Pharmacy students Total (*n* = 64)	**Positive impact reported:** Inter-professional community-based learning had a significant impact on some students' attitudes toward older adults. Positive impact on some students'

Source	Aim(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
					perceptions of other health care professions.
Kearney (2008)	To describe the design of a Service Learning course for Pharmacy and to assess outcomes in terms of student learning and relevance of learning.	Quasi-experimental: Questionnaire	Not self-report	Pharmacy students (*n* = 195)	**Positive impact reported:** Students were able to articulate knowledge in the areas addressed by the Service Learning course, relevant to the education of pharmacists.
McWilliams et al. (2008)	UNCMSHAC is a voluntary SL programme which aims to influence students' attitudes	Quasi-experimental Pre/post- test questionnaire	Not self-report	Inter-disciplinary health professional students Total (*n* = 100 approx. annually)	**Positive impact reported:** Programme evaluation (qualitative and

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	toward older adults, meet core competencies and serve the needs of the community.				quantitative) showed that UNCMSHAC is an effective Service Learning programme and is satisfactory to the majority of students.
Johnson (2007)	To assess the effectiveness of a Service-Learning advanced pharmacy practice experience (APPE) in a diabetes camp to improve student confidence in	Quasi-experimental: Survey, Reflections and online quizzes.	Some self-report measures	Pharmacy students (*n* = 8)	**Positive impact reported:** APPE experience in a diabetes camp improved students' confidence in their knowledge and ability to manage diabetes, and gain experience working

Source	***A*im(s)**	**Study Design & Data collection**	**Self-Report vs. Non Self-Report Measures used**	**Study Population & Sample Size**	**Key findings**
	diabetes - knowledge and related skills.				with an interdisciplinary team in a unique real-world environment.
Neill et al. (2007)	To measure student perceptions of inter-professional practice following a collaborative learning experience in rural community offering mobile wellness services to the older adult.	Quasi-experimental: Pre/post -test Questionnaire	Not self-report	Nursing (*n* = 56) Physical and Occupational Therapy (*n* = 24), Dietetics (*n* = 20), Physician assistant Pharmacy, Social work & Health education students (*n* = 14) Total (*n* = 114)	**Positive impact reported:** Significant change in students' perception of professional competence and autonomy. Co-operation and resource sharing within and across professions. Understanding of value and

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
					contributions of other professionals from pre-test to post-test.
Champagne (2006)	To develop an innovative approach for determining the effectiveness of Service Learning projects in developing students' competency in the 7 areas of responsibility for entry-level health educators identified by NCHEC.	Mixed Methods: Survey questionnaire Written Reflections Annotated Portfolios Triangulation of data from the 3 assessment methods.	Some self-report measures	Mixed Healthcare students Total (*n* = 12)	**Positive impact for some reported:** 3/5 groups perceived SL contributed to competency development. Early assessment may allow for modification of SL to increase the possibility of students developing professional skills

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
					and competencies.
Goldberg et al. (2006)	To determine the impact of a Service Learning experience on students' self-reported competency in relation to dysphagia.	Quasi-experimental: Questionnaire - self-report	Some self-report measures	Speech Pathology Students (*n* = 83)	**Positive impact reported:** Each group had a significant positive change in self-reported levels of competency across all relevant domains.
Michaels & Bilek-Sawhney (2006)	To evaluate students' perceptions of the effectiveness of a service learning course in developing advocacy skills.	Quasi-experimental: Questionnaire	Some self-report measures	Physical Therapy Students (*n* = 26)	**Positive impact reported:** 92% of respondents (*n* = 24) felt that the service learning experience enabled them to

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
					act as an advocate.
Ngai (2006)	To explore the impact of a Service learning programme on student outcomes.	Quasi-experimental: Questionnaire	Some self-report measures	Arts, science and medical students Total (*n* = 93)	**Positive impact reported:** 90% of students reported that the service learning programme enhanced personal development and social commitment.
Poulin et al. (2006)	To compare traditional field placements with a service learning experience in relation to development of	Mixed Methods: Questionnaire Content analysis used to analyse Focus Groups	Some self-report measures	Social work students (*n* = 62)	**Positive impact for some reported:** No differences were identified between groups on scores relating to

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	micro and macro practice skills.				micro skills. The service learning group had significantly higher scores relating to macro practice skills. SL provided a richer learning experience than traditional learning. SL allowed integration of theory and practice. Enhanced sense of commitment to social work practice.
Bentley &	To explore the	Quasi-	Some self–report	Nursing students	**Positive impact**

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
Ellison (2005)	impact of a service learning project on nursing students.	experimental: Questionnaire	measures	(*n* = 58)	**for majority reported:** 16/20 students reported that SL increased their understanding and application of knowledge. 18/20 reported increased awareness of needs of community. 19/20 reported a belief of responsibility towards community and ability to make a difference. 18/20 more comfortable working with

Source	Aim(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
					people different from themselves. 15/20 more aware of own prejudices. No significant difference was found for test scores on either exam.
Nokes et al. (2005)	To explore whether participation in a service learning programme made a difference in critical thinking, cultural competence and civic engagement.	Quasi-experimental: Pre- and Post-Questionnaire	Not self-report	Nursing students (*n* = 16)	**Negative impact on critical thinking and cultural competence scores.** **Positive impact on civic engagement scores.** Following

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
					completion of service learning: Critical thinking scores were significantly lower. Cultural competence scores were significantly lower. Significant increases in civic engagement scores.
Reynolds et al. (2005)	To develop a substantive theory to explain how the service learning experiences of students linked	Mixed Methods: Qualitative - Constant comparative method of analysis of student	Not self-report	Physical Therapy students (*n* = 165)	**Positive impact reported:** Service learning complemented existing clinical education

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	with the educational objectives for preparation of physical therapists.	reflections. Quantitative data from survey for 1 cohort of students analysed.			programmes through providing opportunities for (i) expected learning outcomes - social responsibility, understanding individual and cultural difference, communication, education professional behaviour and professional development. (ii) unexpected outcomes of lesser interest - examination, intervention,

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
					outcome measurement evaluation. SL provided opportunities not available in clinical education e.g. consultation, administration, management in various care delivery systems, prevention and Wellness.
Beling (2004)	To examine the impact of service learning on Physical Therapy Students’	Experimental: Controlled Trial	Not self-report	Physical Therapy Students (*n* = 40)	**No difference with SL reported:** Both groups demonstrated increased

Source	Aim(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	knowledge and attitudes about elderly people or its impact on the development of critical thinking.				knowledge and attitudes towards older people. There was no significant difference between groups in relation to improvements. The service learning group did not demonstrate significant improvement in critical thinking skills.
Dorfman et al. (2004)	To compare attitude change in five successive cohorts of inter-	Quasi-experimental: Questionnaire	Not self-report	Social Work , Aging Studies Nursing, Health, Leisure, and Sport	**Positive impact on some measures. No impact on other**

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	generational service learning students.			Studies students. Total (*n* = 59)	**measures.** Significant positive attitudinal changes towards older people. No significant change in attitudes toward working with older people or in attitude toward own ageing.
Kearney (2004)	To determine what students learn through Service Learning based on their self-assessment of their learning.	Quasi-experimental: Questionnaire	Some self-report measures	Pharmacy Students (*n* = 127)	**Positive impact reported:** Statistical increases in students' oral communication, written communication,

Source	Aim(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
					analytical and critical thinking, and leadership skills from SL course; students' SL experiences and reflective activities will make them more competent professionals, more aware of the needs of the populations they serve, and more aware of ethical issues in the public arena.
Williams &	To explore the	Qualitative:	Not self-report	Medical social	**Positive impact**

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
Reeves (2004)	impact of a service learning experience on students' learning.	Constant comparative analysis of journals, focus groups, course evaluations.		work students (*n* = 21)	**reported:** Service learning experience positively impacted learning about personal and professional self.
Beling (2003)	To determine whether service learning influences knowledge, misconceptions and bias regarding ageing among physical therapy students.	Experimental: Randomised Controlled Trial	Not self-report	Physical Therapy Students (*n* = 40)	**No difference with SL Reported:** Experimental and control groups demonstrated significant improvements with educational intervention. There was no significant difference in overall knowledge scores between

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
					the groups following intervention.
Elam et al. (2003)	To examine elective Service Learning programmes based in local community agencies where small groups of students perform an asset–needs assessment and design a service project based on their findings.	Mixed Methods: Surveys, interviews, reflection questionnaires, evaluations.	Some self-report measures	Medical students (*n* = 23)	**Positive impact reported:** The SL experience humanized medical education and grounded priorities toward helping others. Also opened some students' eyes to community needs. Intent to volunteer in community clinics on entering medical practice expressed by some.

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
Dorfman et al. (2003)	To determine the impact of a service learning experience on attitudes towards older people and community service.	Mixed Methods: Controlled Trial Student open ended questions analysed using constant comparative methods.	Not self-report	Social work and non-social work students. Total (*n* = 49)	**No difference with SL for some measures** **Positive Impact on other measures.** No significant difference between groups in attitudes towards community service or attitudes toward older people. SL group had more positive attitude toward working with older people and toward their own ageing.
Hegeman et al. (2003)	To explore changes in student	Quasi-experimental:	Some self-report measures	Gerontology, social sciences, nursing,	**Positive impact on some**

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	attitude toward the Aged, community service work and working with the elderly and chronically ill or disabled.	Pre-test/post-test design		allied health, architectural technology, management/ communication. Total (*n* = 912)	**measures. No Impact on other measures.** Statistically significant changes in attitudes towards older people. No statistically significant change in attitude toward community service or toward careers in ageing services.
Sedlak et al. (2003)	To describe the growth in critical thinking skills as a result of service learning	Qualitative : Content analysis of students' reflective journals.	Not self-report	Nursing students (*n* = 94)	**Positive impact reported:** SL had positive impact on development of students': (1) professional

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
					perspective (caring for others & communication skills), (2) community perspective (focus on promoting health & awareness of diversity); (3) critical thinking skills in written reflections.
Burrows et al. (1999)	To help promote positive relations between medical schools and the communities they serve.	Quasi-experimental: Questionnaire including qualitative analysis of open ended questions. Review	Some self–report measures	Medical students (*n* = 148)	**Positive impact reported:** Positive impact on student learning e.g. better prepared to face the “real world” of

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
		of student feedback.			medical care. SL has at least a short-term beneficial impact.
Peterson & Schaffer (1999)	To determine how effective a service learning experience is at promoting student learning?	Mixed Methods: Questionnaire Focus Group	Some self-report measures	Nursing students (*n* = 28)	**Impact of SL inconclusive:** Only significant difference related to students opinions that the SL programme had provided a service. Focus group data indicated mixed opinions about whether SL had improved students' collaboration & research skills.

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
Astin & Sax (1998)	To assess the effects of Service Learning on a wide range of student developmental outcomes.	Quasi-experimental: Survey with follow up survey.	Not self-report	Healthcare students Total (*n* = 3450)	**Positive impact reported:** SL substantially enhances students' academic development, life skill development and sense of civic responsibility. 35 outcome measures all positively impacted.
Osborne et al. (1998)	To assess the impacts of a service learning experience on student participants.	Experimental: Randomised Controlled Trial.	Not self-report	Pharmacy students (*n* = 93) 48 students undertook a service learning experience	**Positive impact on some measures. No impact on other measures:** Students participating in SL

Source	Aim(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
				45 students undertook traditional curriculum	showed statistically significant positive change in cognitive complexity, social competency, perceived ability to work with diverse others, and self-worth in social situations compared to non-SL learning participants. No significant difference between groups in level of self-esteem.
Forte (1997)	1/4 of the project objectives related to SL, i.e. giving	Mixed: Survey Analysis of student	Some self-report measures	Social work students (*n* = 20)	**Positive impact reported:** Students’

Source	*A*im(s)	Study Design & Data collection	Self-Report vs. Non Self-Report Measures used	Study Population & Sample Size	Key findings
	social work students macro-level experiences related to community through SL. Aim to increase student volunteerism.	reports.			perception of altruism and campus community expectations significantly increased. Positive changes observed on service related friends, volunteer role.

Table 7.2: Features of Papers Reviewed

Features of papers reviewed	Numbers
Type of Study	
Quasi-experimental	*N* = 26
Qualitative	*N* = 9
Mixed Methods	*N* = 13
Experimental	*N* = 5
Total number of papers reviewed	**53**
Journals where papers are published	
Nursing:	
Journal of Nursing Education	*N* = 3
Journal of Psychiatric and Mental Health Nursing	*N* = 1
Nursing and Health Sciences	*N* = 2
Nursing Education Perspectives	*N* = 4
Paediatric Nursing	*N* = 1
Total number of papers submitted to Nursing Journals	**11**
Allied Health Care:	
Advances in Health Science Education	*N* = 1
American Journal of Audiology	*N* = 3
American Journal of Pharmaceutical Education	*N* = 3
Communication Disorders Quarterly	*N* = 1
Journal of Allied Health	*N* = 1
Journal of Gerontological Social Work	*N* = 2
Journal of Inter-professional Care	*N* = 1
Journal of Physical Therapy Education	*N* = 3
Journal of Social Work Education	*N* = 2
Occupational Therapy in Health Care	*N* = 1
Social Work Education	*N* = 1
Topics in Clinical Nutrition	*N* = 1
Total Number of papers submitted to allied health journals	**20**

Medicine:	
Academic Medicine	*N* = 1
Medical Teacher	*N* = 3
Teaching and Learning in Medicine	*N* = 2
Total number of papers submitted to medical journals	**6**
Education:	
American Journal of Health Education	*N* = 1
College Teaching	*N* = 1
Educational Gerontology	*N* = 3
Gerontology & Geriatrics Education	*N* = 5
Michigan Journal of Community Service Learning	*N* = 2
Total number of papers submitted to education journals	**12**
Other Journals:	
Adolescence	*N* = 2
Journal of Human Behaviour in the Social Environment	*N* = 1
Journal of Public Health Management and Practice	*N* = 1
Total number of papers submitted to other journals	**4**
Geographical Location of Research	
Location:	
Canada	*N* = 2
Europe (Ireland)	*N* = 2
Asia (Hong Kong and Singapore)	*N* = 5
North America	*N* = 44

7.5 Results

Quantitative methods were used in (*n* = 31) papers; (*n* = 26) were quasi-experimental with pre- and post-questionnaires as their primary data collection tool, (*n* = 3) were Randomised Controlled Trials (RCTs) and the remaining (*n* = 2) were controlled trials. A mixed methods approach involving a combination of questionnaires and analysis of student reflections were used in (*n* = 13) studies while (*n* = 9) were qualitative. In all (*n* = 53) studies data were collected from students of various health related disciplines; the majority focused on student learning outcomes from a singular discipline (*n* = 33), with a minority from multidisciplinary student groups (*n* = 20). Sample sizes ranged from (*n* = 3) medical students in one qualitative study (Dharamsi et al., 2010b) to (*n* = 3450) students from multiple disciplines in a quasi experimental study (Astin & Sax, 1998). Examples of the methodological weaknesses identified included samples from single institutions (Beling, 2004; Bentley & Ellison, 2005; Champagne, 2006; Horacek et al., 2009; Leung et al., 2011; Liang En et al., 2011b; Loewenson and Hunt, 2011) with a variety of potential biases, for example, self-selection bias for students (Ngai, 2009; Green et al., 2011; Reading & Padgett, 2011) possible positive reporting bias (Kearney, 2004; Reynolds, 2005; Brown, 2009; Liang En et al., 2011b; Loewenson & Hunt, 2011) and social desirability bias (Casey and Murphy, 2008; Loewenson & Hunt, 2011). Of the 26 Quasi-experimental studies the majority (*n* = 20) used some form of self-report measure as did (*n* = 6) of the mixed method studies. Change over time was difficult to assess in some of the experimental, quasi experimental and mixed methods studies as no pre-test or control groups were included. Randomisation of participants did not occur in some studies (e.g. Beling, 2004; Ngai, 2006; McWilliams et al., 2008; Groh et al., 2011; Pakulski, 2011; Zucchero, 2011) with results being confounded by potential non-random differences within groups. We do appreciate that true random assignment is difficult and often not feasible. In a minority of studies outcome measures were assessed with tools not validated beyond that particular study (e.g. Groh et al., 2011; Schindler, 2011) or the outcome measures used had not been tested for cultural sensitivity (e.g. Leung et al., 2011). In other studies, the reported changes in students' knowledge or attitude was not definitely attributable to the SL programme (Kearney, 2008; Kaf et al., 2011; Loewenson & Hunt, 2011) while the generalisation of results from the quantitative studies was often problematic. Many studies reviewed (e.g. Forte, 1997; Elam et al., 2003; Dorfman et al., 2003, 2004; Champagne, 2006; Furze et al., 2008; Dauenhauer et al., 2010; Green et al., 2011; Kaf et al., 2011; Liang En et al., 2011a; Zucchero, 2011) used mixed methods to capture the variety of student learning outcomes described. Identifying the rationale for mixing methods, the specific techniques used or the type of analysis applied was frequently not clear.

Review aim 2: The impact(s) of SL for health care students

The results of each study were analysed using (Eyler & Giles, 1999) theoretical framework of student learning outcomes (Table 3). The six learning outcomes included in the framework are italicized in the results section for ease of identification.

Table 7.3: Theoretical Framework of Learning Outcomes (Eyler & Giles 1999)

Six categories of student learning outcomes	Description of each category in the theoretical framework
Personal and interpersonal development Studies identified in review (*n* = 38)	Self-awareness; communication skills; leadership skills; accept and tolerate diversity; cultural competence; connection and building relationships with others
Understanding and applying knowledge Studies identified in review (*n* = 28)	Understanding is more than acquisition of information or memorisation of theories; enabled to apply learning to real world problems.
Engagement curiosity and reflective practice Studies identified in review (*n*= 4)	Engaged in activities; curiosity and need to know more; remember material and use it to solve complex issues.
Critical thinking Studies identified in review (*n* = 6)	Face difficult community problems not easily understood or resolved; increased ability to self-monitor and analyse complex situations.
Perspective transformation Studies identified in review (*n* = 19)	New lenses for the world; moving from charity to active committed citizenship; agents for social change.
Citizenship Studies identified in review (*n* = 7)	Sense of social responsibility; connection to community; importance of social-justice; commitment to service; understanding social problems.

Given that the majority of studies reviewed (*n* = 38) reported student learning outcomes related to the category *Personal and interpersonal development* this group deserves particular attention. We will also focus on the categories *Perspective Transformation* and *Citizenship* as these categories resonate with the principles of social accountability.

Studies identifying impacts in the domain of students' *personal and interpersonal development* gathered data from the analysis of a combination of student reflective reports, focus groups and interviews. Key issues identified and reported in a number of studies (e.g. Burrows et al., 1999; Elam et al., 2003; Williams & Reeves, 2004; Bentley & Ellison, 2005; Amerson, 2010; McMenamin et al., 2010; Green et al., 2011; Casey & Murphy, 2008; Groh et al., 2011; Long et al., 2011; Zucchero, 2011) include: (i) self-awareness, (ii) communication skills, (iii) leadership skills, (iv) capacity to accept and tolerate diversity, (iv) cultural competence, and (vi) capacity to connect and build relationships with others.

Self-reflection is a metacognitive process that can occur before, during and after SL engagements and it helps students to understand themselves and the community situation (Azer et al., 2013). All of the studies reviewed identified reflection as a key feature of SL and an important process for enabling students to recognize underlying personal biases that display as professional attitudes and contribute to the development of professional identity.

SL provides opportunities for students to critically examine their values and belief systems through reflective practice which prompts questions about personal stereotypes and prejudices (Williams & Reeves, 2004; Casey & Murphy, 2008; Faria et al., 2010; McMenamin et al., 2010; Green et al., 2011; Mitschke & Petrovich, 2011; Zucchero, 2011) . For example Groh et al. (2011) found that nursing students (*n* = 306) had a significant positive change in self-rated leadership skills following a SL experience, while Long et al. (2011) reported no change in medical students' perceived effectiveness, willingness or understanding of leadership skills despite a greater appreciation of leadership roles.

SL takes place in community-based settings which introduces students to the concepts of health systems and disparity. This context may be suitable for teaching and learning social accountability. Many of the programmes supported students to feel increasingly comfortable with people who are excluded and marginalised in mainstream society. Partnerships often involved groups that students may not have previously encountered, e.g. people who are homeless, people with HIV, people experiencing poverty and health inequities, etc. (Burrows et al., 1999; Elam et al., 2003; Bentley & Ellison, 2005; Casey & Murphy, 2008; Amerson, 2010; Horowitz et al., 2010; McMenamin et al., 2010; Green et al., 2011; Liang En et al., 2011b; Mitschke & Petrovich, 2011; Reading & Padgett, 2011; Schindler, 2011). Working in partnership with the “different other” appeared to help students develop a deeper appreciation of the vulnerabilities that marginalized segments of the population experience and nurture a purposeful sense of social responsibility. Students began to question and reflect on the reasons for the health inequalities they encountered during their SL engagements. Making the Links (MTL) programme (Meili et al., 2011) was specifically designed to teach medical students the social aspects of healthcare through SL. The authors concluded that students learn social accountability by participating in SL and the experiences gained may encourage students to remain altruistic in their outlook and prompt future work in underserved areas.

SL is reported to encourage the formation of positive relationships with people of different socio-cultural backgrounds, leading to the development of communication skills and cross-cultural understanding (Meili et al., 2011). The opportunities to learn about and accept diversity appears to contribute to the development of students’ cultural competence. Green et al. (2011) reporting on an international SL experience in Honduras found that nursing and medical students (*n* = 74) improved their ability to provide culturally congruent care. Similar findings are evident in other studies (e.g. Casey & Murphy, 2008; Amerson, 2010; Reading and Padgett, 2011). Interestingly, Nokes et al. (2005) reported conflicting results with students’ cultural competence decreasing following SL engagement. The findings from Astin & Sax (1998) quasi-experimental multidisciplinary study involving 3450 students suggest that SL enhances students’ knowledge and acceptance of different races and cultures, understanding of indigenous social problems and fosters an increased commitment to future community service.

Perspective transformation appears to be strongly linked to social accountability as this category relates to how students view social problems, personal values and stereotypes. SL partners focus on the development of social capital (Hawe & Shiell, 2000), sharing resources and knowledge to promote advocacy and address differences in underserved communities locally and overseas. Nineteen studies reported that students had a desire to become agents for social change as they viewed the world through different lenses following SL engagements. Closely connected to *Perspective Transformation* is the category of C*itizenship.* Changes in this category were reported in several studies (e.g. Hegeman et al., 2003; Bentley & Ellison, 2005; Nokes et al., 2005; Ngai, 2006; Casey and Murphy, 2008; Brown, 2009; Groh et al., 2011) where students developed a new understanding of social problems, feelings of social responsibility and connection with community.

SL extends the learning environment by linking students' academic study to practice through meaningful and relevant service to the community (Furco, 2007). SL projects are designed, implemented and evaluated collaboratively with the intent of applying students' theory to practice while simultaneously targeting community identified needs. A number of studies (Burrows et al., 1999; Peterson & Schaffer, 1999; Beling, 2003; Bentley & Ellison, 2005; Goldberg et al., 2006; Johnson, 2007; Neill et al., 2007; Casey & Murphy, 2008; Kearney, 2008; Dauenhauer et al., 2010; Liang En et al., 2011b; Long et al., 2011; Pakulski, 2011; Reading & Padgett, 2011; Vogt et al., 2011; Zucchero, 2011) found that students gained a deeper *understanding and application of knowledge* through SL projects and experiences. *Critical thinking* is central to the understanding and application of knowledge. It is a complex process that is believed to involve cognitive skills and affective domains of reasoning and attitude (Scheffer & Rubenfeld, 2000). To develop critical thinking skills students must engage in a purposeful process that involves self-regulation, analysis, evaluation, interpretation, and assessment. Positive changes in students' *critical thinking* were reported in (Astin and Sax, 1998; Osborne et al., 1998;

Sedlak et al., 2003; Beling, 2004; Reynolds, 2005; Liang En et al., 2011b) studies with improvements in *engagement, curiosity and reflective practice* in (Beling, 2003; Ngai, 2006; Casey & Murphy, 2008; Faria et al., 2010) others. While many studies (Poulin et al., 2006; McWilliams et al., 2008; Brown, 2009; Horowitz et al., 2010; Krout et al., 2010) reported that students valued SL experiences this outcome may indicate "little more than that the students liked the innovation" (Abassi & Smith, 1999, p. 1265) and we must be wary of what Norman calls "me-too" research (Norman, 2006, p. 1). In these instances another form of experiential learning may have been equally, or indeed more suited, to achieve desired learning outcomes. Only a minority of studies reviewed (Forte, 1997; Astin and Sax, 1998; Kearney, 2004; Bentley & Ellison, 2005; Nokes et al., 2005; Michaels & Billek-Sawhney, 2006; Ngai, 2006, 2009; McMenamin et al., 2010) included measures related to the specific aims of SL creating uncertainty about the impact of SL on students' social responsiveness and the level of reciprocity achieved between partners.

Finally, participating in SL may support students to learn about interdisciplinary working (Meili et al., 2011). The health needs of people who are vulnerable are varied and complex. Involving inter-professional teams of students in SL engagements may facilitate collaborative approaches to service delivery and positively impact the health outcomes for community partners (Dharamsi et al., 2010b). Twenty (n=20) studies reviewed involved SL programmes with inter-professional student groups and all reported that SL positively influenced students' engagement in inter-professional learning.

Review aim 3: Priority areas for future research

The studies included in this review did fit with (Eyler & Giles, 1999) theoretical framework in terms of themes and content. However notwithstanding the limits of the six categorizations several of the areas identified in the single category *personal and interpersonal development* appear to overlap with the remaining five categories of learning outcomes. While we would not discourage researches from applying this framework to future impact studies in the domain of SL we would highlight the considerable overlap between categorizations and caution that the broad nature of the categories may not be helpful to identify specific learning outcomes. The difficulty in delineating between identified student learning outcomes may be a reflection of the challenges in definition and terminology which we experienced during the design of the search strategy, and which seems to permeate the field of SL. Clarifying what we mean by SL and “civic engagement” in different contexts and establishing a consistent terminology is an important area for future research.

The idiosyncratic nature of SL experiences poses challenges in identifying generalisable learning outcomes. The majority of studies reviewed used some form of self-report measure to evaluate the impact(s) of SL which do not provide objective assessment of student learning outcomes. The use of self-report measures may reflect the fact that most of the published studies in the field appear to be evaluation rather than research studies. Researchers should aim to evaluate the specific aims of SL, clearly identifying the impact(s) of SL on students’ social responsiveness and the level of reciprocity achieved between partners. There is evidence that the interpretative approach has contributed to the evaluation of other complex strategies for civic engagement, e.g. participatory research (Jagosh et al., 2012). This is a valuable paradigm to consider in future work. Studies focused on process rather than outcomes may expand our understanding of the impacts of SL. Many studies identified the need for long-term follow-up (e.g. Green et al., 2011; Long et al., 2011; Liang En et al., 2011a; Zucchero, 2011); however, only a minority (Burrows et al., 1999; Leung et al., 2011) described outcomes over time. This gap creates uncertainty about the long term effect and effectiveness of SL, another key focus for future research.

Finally, none of the studies reviewed directly addressed the issue of localization. The similar learning outcomes identified in Canada (Dharamsi et al., 2010b; Meili et al., 2011), Europe (Casey & Murphy, 2008; McMenamin et al., 2010) and Asia (Ngai, 2006, 2009; Leung et al., 2011; Liang En et al., 2011a) may indicate successful attempts at localizing SL internationally. Liang En et al. (2011b) concluded that SL programmes have potential educational value in an Asian context. However, we have highlighted the issue of localization (Boland & McIlrath, 2007) to encourage researchers and educators worldwide to consider the cultural adaption of SL and to address this issue in the literature.

7.6 Discussion

This study aimed to assess the evidence for the effectiveness of SL in pre-professional health care students by conducting a critical review of the literature which involved collecting, abstracting, analysing and synthesising data from 53 primary studies. Currently the published literature appears weak and diverse in nature and has not yielded compelling evidence about the impacts of SL on student learning outcomes.

We acknowledge that our results may be affected by various reporting biases including a potential: “language bias” as non-English-language publications were excluded, “location bias” as most of the papers reviewed originated in the global North, “publication bias” as unpublished material was not searched and “sampling bias” as specific databases were selected (Sterne et al., 2008). Our decision to limit the search strategy through definition and learning outcomes was a pragmatic response to the apparent lack of agreed definition and range of language in the field of SL. We acknowledge that our interpretations have impacted the results obtained and that our limiting criteria are debatable, not definitive. By restricting our search through definition and learning outcomes we may have excluded other potentially relevant papers. However, we do not claim, nor did we aspire to absolute comprehensiveness (Eva, 2008). Rather, we aimed to represent the available evidence fairly. We accept that our personal perspectives will affect our interpretations and that these are likely to be different from other authors. While we accept that our study has limitations, the findings suggest that we should question our rationale for implmenting SL in the absence of convincing outcome evidence or rigourous evaluation methods. Furthermore, a key strength of this review is the consideration of the emerging SL evidence from research beyond the North American context allowing us to consider the potential impact of localization.

The findings from this review are consistent with early reviews of SL which identified a resource intensive pedagogy with an unconvincing evidence base (Eyler et al., 2001). Despite this uncertainty, SL is being integrated in international healthcare education (Liang En et al., 2011b), necessitating radical curricula change (Casey & Murphy, 2008). The studies reviewed reported an extensive range of positive impacts for students participating in

SL programmes. The finding that students learn social accountability by participating in SL and that SL experiences may encourage altruism and prompt future work in underserved areas (Meili et al., 2011) is consistent with previous research. Previous studies have reported that SL increases students' awareness of community health needs whether local or global and the responsibility to address health inequities in marginalized populations (Smith et al., 2006; Saffran, 2013). Other studies have supported the finding that when students are given opportunities to engage with vulnerable groups the experience has a positive influence on their "comfort" levels and future willingness to work with these communities (Kuthy et al., 2005). The similarities between some of the reported outcomes of SL with existing research is encouraging however given the methodological weaknesses identified in many of the studies reviewed we suggest interpreting outcomes in the field of SL with caution. The reported effectiveness of SL is influenced by the type of methods and evaluation tools utilised. The diversity in terminology internationally to describe the work of SL is recognised in the literature (Hunt & Swiggum, 2007). Perhaps the range of terminology and the ongoing debate about what constitutes civic awareness and "good citizenship" led educators to evaluate learning outcomes that were more easily measured as the majority of studies reviewed did not include measures related to the explicit aims of SL, i.e. (i) to enhance students' civic awareness and (ii) create reciprocity in the partnerships between the university and community. Research focused on creating an agreed and consistent language to describe SL and the evaluation of SL in relation to the explicit aims of the pedagogy appear to be fundamental in progressing SL as an educational approach.

Finally, as we strive to produce graduates with a sense of social accountability and ability to work in diverse local and global communities we encourage educators to continue transforming tacit knowledge into tangible research questions. Currently, outcomes based research in the field appears weak and unconvincing which is perhaps what we might expect in terms of not being able to extrapolate outcomes from the particular to the general. Given the idiosyncratic nature of SL, exploring questions via the interpretive paradigm around, (1) the terminology of SL; (2) how SL experiences lead to particular academic and partner outcomes; (3) evaluation approaches particularly focused on the aims of SL and (4) the long term impacts will address the gaps in our understanding of this educational approach. This new evidence will empower educators to make informed decisions about the implementation of SL and whether it is a suitable pedagogy for integrating social accountability into healthcare curricula.

7.7 Conclusion

SL is a complex educational approach involving communities, students and institutions with the aspiration that partnerships are equally beneficial and reciprocal. Little is known about the effectiveness of SL and this paper confirms that outcomes based research in the field is problematic. Difficulties with definition, clear and distinct learning outcomes and the significant methodological weakness of existing data reflect the complex nature of SL, but this should not deter SL educators from attempting to conduct more robust evaluation studies that are located in the interpretive paradigm and that can elucidate the process and effects of SL interventions.

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7.9 Declaration of Interest

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Chapter 8 Conclusions and Recommendations

In this study *“Evaluating Conversation Partner Programmes – perspectives of people with aphasia”* the PhD researcher sought to address the *primary* research aims and *secondary* research objective including:

Primary research aims:

- Explore with people with aphasia their perceptions and experiences of aphasia and the Conversation Partner Programme;
- Explore with other key stakeholder groups their perceptions and experiences of the Conversation Partner Programme;
- Identify with all stakeholders evaluation criteria for the Conversation Partner Programme.

Secondary research objective:

- Explore service learning as the pedagogical tool underpinning the Conversation Partner Programme.

The final Chapter of the thesis is presented in three sections:

- Integration and synthesis of key findings with recommendations for future research;
- A methodological critique of the study;
- Concluding statement.

8.1 Integration and Synthesis of Key Findings with Recommendations for Future Research

The principal findings from all four articles, as they relate to each other, are drawn together in this Chapter, and discussed with reference to the overarching theoretical framing of *Inclusion* and *Reciprocity.* The aims of the study were addressed by the published papers in Chapters 4-7. Here it is important to critically reflect whether or not, the theoretical framing and conceptual synergies spanning:(1) the Social Model of Disability; (2) Patient and Public Involvement; (3) Participatory Health Research and (4) Service Learning were actually supported by the empirical data. A step-by-step approach will be taken to review whether each of the ten points identified in Chapter 1 (table 1.1) translated into the operationalization of this research. Shared features are bolded and italicized for ease of identification.

Recommendations for future research are suggested with reference to: (1) the existing evidence base; (2) new empirical outcomes from this study and (3) the PhD researcher's reflections.

1. The social model of disability, PPI initiatives, PHR studies and service learning programmes aim to invert traditional power dynamics and create ***collaborative partnerships characterised by equality*** between professional and lay experts. This goal is supported by the World Health Organisation report on disability which states that there should be more involvement of people with disabilities in health research (World Health Organization & The World Bank, 2011). However healthcare research and services are rooted in hegemonic practices of power and inequality (Whalley Hammell, 2006). In this study creating ***reciprocal research and practice relationships***, not dominated by historical hierarchical power structures was challenging (Cornwall & Jewkes, 1995; Gustafson & Brunger, 2014). Key factors supported the development of ***inclusive reciprocal relationships*** including: (1) the PhD researcher's internal values about the relevance of involving service users with aphasia as equal partners in both research and scholarship (Shippee et al., 2015) (see Chapter 1; section 1.1.3); (2) agreeing expectations with co-researchers and providing opportunities to influence all aspects of the research process and (3) undertaking training in PLA methods (Koch & Kralik, 2006; Reason & Bradbury, 2006; Simmons-Mackie et al., 2007) White & Verhoef , 2005). These factors combined with dedicated space for relationship building (see point 2) and critical reflection (see point 7) optimised ***meaningful participation*** and action (Popay, Collins and the PiiAF Study Group, 2014), (see Chapter 3 section 3.2.3-3.2.4; Chapter 4 section 4.3.7 and Chapter 5 section 5.3.8).

   Recommendations:

   - *Engage participants to work together as equals as early as possible in the research process because this will create important foundations for collaborative partnerships;*
   - *Invest time and resources in methodological and skills training for researchers and co-researchers to support the development of collaborative partnerships and inclusion.*

2. Healthcare professionals, researchers and service users can ***work collaboratively*** with stakeholders to ***dismantle barriers*** and ***establish and maintain inclusive relationships*** built on ***trust***, ***rapport*** and ***respect***. While the literature suggests a range of strategies to dismantle barriers that block the participation of PWA in social and therapy contexts (Byng & Duchan, 2005; Kagan, Black, Duchan, Simmons-Mackie & Square, 2001; Simmons-Mackie, Savage & Worrall, 2014) evidence about how to promote *meaningful* participation in research is lacking (Popay et al., 2014; Simmons-Mackie et al., 2007). In this study the PhD researcher used her speech and language therapy expertise to provide communication ramps for the co-researchers with aphasia however it was the ***PLA mode of engagement*** that resulted in the co-creation of more ***inclusive, accessible research processes*** (see Chapter 3; section 3.3 and box 3.2). ***Relationship building*** within and across stakeholder groups was prioritised and the importance of this work cannot be over-emphasised. Fostering ***trust relationships*** in the early stages of the research process seemed to move participants beyond the basic ‘‘doing’’ work familiar from therapeutic interventions to feelings of being’, ‘belonging’, and ‘becoming’ (Wilcock, 1998). The bonding within the individual groups (homogeneous communities) in Phase 1 (e.g. PWA; SLTs; Students) was developed before connecting with the inter-stakeholder group (heterogeneous community) in Phase 2. In this way, participants who shared the lived experience of communication disability had gained confidence through interactions with peers and facilitators before engaging in the more linguistically complex mixed group. Additionally, the PhD researcher and co-facilitator had an opportunity to learn about the social realities faced by people living with aphasia in the individual group. This strategy worked well and both the individual and inter-stakeholder groups appeared to provide a ‘‘natural extension and expansion of community’’ (Mead, Hilton & Curtis, 2001 p136). The evidence of ***peer relationships*** which evolved throughout the course of the study (see Chapter 3; section 3.4.1; theme 3 ‘PLA peer support’ and Chapter 5 section 2.5 ‘Discussion’) are consistent with findings reported in other participatory studies (Adili, Higgins & Koch, 2012; de Brun et al., 2015; MacFarlane et al., 2014). The novelty of this research is the demonstration of

collaborative working and inclusive relationships between the PCCC; university and PWA in ***research, practice and scholarship.***

Recommendations:

- *To move beyond the ethos of inclusion, to the enactment of inclusive processes in research, researchers must take practical steps to co-create communication access with participants;*
- *To dismantle communication and attitudinal barriers researchers/ educators and/or healthcare professionals must be willing to invest time to build and maintain reciprocal relationships between professional and lay experts.*

3. To support stakeholder groups to ***share, enhance and analyse*** their ***knowledge*** the research process must create opportunities for all team members to ***acquire new knowledge*** and learn together for positive action (Gibson, Britten, & Lynch, 2012; MacFarlane et al., 2012). In this study the PhD researcher and co-researchers shared experiential and scientific knowledge in participative ***'knowledge spaces'*** (Elliott & Williams, 2008; Jasanoff, 2005). The literature suggests that ***knowledge co-creation*** may increase stakeholders' confidence, promoting more active engagement and reducing the risk of tokenistic involvement (Dewar, 2005; Jagosh et al., 2012; Salsberg et al., 2015). The PhD researcher and co-researchers participating in the study shared theoretical and experiential knowledge of aphasia. Through ***co-learning*** new understandings emerged and on occasion this resulted in ***transformation shifts*** for both the PhD researcher (see Chapter 3; box 3.2) and the participants (see Chapter 3; section 3.4.1 'Theme 5 Benefits' and Chapter 7; section 7.5). The co-researchers with aphasia experienced a gradual identity shift and increased confidence as they realized the importance of their role in the CPP and research process (see Chapter 3; Section 3.4.1; Theme 5 'Benefits'). In the individual group (Phase 1) the PWA shared a belief that they were the primary benefactors form the CPP with little to offer the other stakeholder groups. However this view changed as other stakeholder groups (students; SLTs) discussed the importance of the experiential knowledge the participants with aphasia contributed during the inter-stakeholder fieldwork sessions. From this ***sharing and co-learning*** the

PWA altered their original perspectives and began to see the uniqueness and value of their role (see Chapter 5; section 5.5 ‘Discussion’). Studies using participatory research methods with different population groups report similar ***transformative changes*** (Jones, Marshall, Lawthom & Read, 2013) highlighting the value of these inclusive methodologies. The primary outcome of ***co-learning*** from the multiperspectival evaluation of the CPP was the agreed evaluation criteria. These criteria were more reliable, valid and relevant to the local community because of the participatory research process (Ramsden, McKay, & Crowe, 2010).

Recommendations:

- *Create opportunities for co-learning to promote more active engagement and reduce the risk of tokenistic involvement in research and scholarship;*
- *Implement Participatory Health Research (PHR) methods to construct participatory spaces and maximise conditions for co-creating knowledge and positive transformative experiences for co-researchers.*

4. Creating democratic research studies and educational programmes that involve all stakeholder groups is challenging however ***democracy*** is a key principal of the social model of disability, PPI, PLA and service learning. There are good examples of ***democratic participation*** and decision making processes throughout this study. The ***egalitarian*** nature of the multi-perspectival evaluation of the SL CPP is evident in the research process. The democratic nature of the ‘PLA Flexible Brainstorm’, ‘PLA Card Sort’ and ‘Interviewing the technique’ processes are described in detail in Chapter 4 (section 4.3.7) while the ‘PLA Direct Ranking’ and ‘Seasonal Calendar’ techniques are described in Chapter 5 (section 5.3.9). The PLA Direct Ranking technique provides a key example of the ***democratic research processes*** in this study. In phase 2 the inter-stakeholder group used this technique to express priorities and preferences and indicate categories of equal weighting for the agreed CPP evaluation criteria. Consensus was reached about the most important evaluation criterion to the least important. Co-researchers acted as checks and balances on one another’s biases

thereby contributing to the ***validity of findings***. Similar ***democratic processes*** are reported in other studies using participatory research methods (Macaulay et al., 2011; MacFarlane & O'Reilly de Brun, 2009) and service learning programmes (Bauer, Moskal, Gosink, Lucena, & Munoz, 2005; Leung et al., 2011). The congruence in democratic approaches used in both the research and scholarship of the CPP are evident in the words participants used to describe PLA and service learning (see box 8.1).

Recommendations:

- *Use and continue to explore PLA as a methodological approach to co-create democratic processes in research and scholarsip with paticipants with aphasia.*

Box 8.1: Words co-researchers with aphasia used to describe PLA (see Chapter 3; part 2 themes 1-5) and SL educators used to describe service learning (see Appendix I) in Phase 1 data generation sessions.

EQUALITY TEAMWORK RECIPROCITY COLLABORATIVE

LEARNING THROUGH EXPERIENCE TRUST PARTNERSHIP

REFLECTION COMMUNITY INSIGHT DYNAMIC

RELATIONSHIP REAL LIFE EXPERIENCE

REAL WORLD LEARNING

ENJOYMENT PARTICIPATION ENGAGEMENT

DISCUSSION CAMARADERIE FUN

DEMOCRATIC RESPECT WONDERFUL EXPERIENCE

5. This study was ***dynamic*** with ***sustained involvement*** of stakeholder groups over time. The literature highlights the importance of dynamic engagement to ensure positive stakeholder experiences. Negative experiences may result in stakeholder withdrawal from the study which might adversely impact relationships and future collaborations (Doyle & Timonen, 2010). The CPP was established in 2005/2006 and continues to run on an annual basis (see Chapter 4; section 4.3). Data co-generation and co-analysis in the multi-perspectival evaluation of the programme spanned 1 year with no attrition from any stakeholder group. Using PLA techniques relational, ***dynamic*** data specific to the local context was generated. (International Collaboration for Participatory Health Research (ICPHR), 2013). The ***commitment*** of stakeholders to the research process was clearly demonstrated when the inter-stakeholder group decided to move beyond the original research aims to plan the implementation of the agreed CPP evaluation criteria (see Chapter 5; section 5.3.7 'PLA Seasonal Calendar technique').

   Recommendation:

   - *To achieve dynamic engagement and sustained involvement overtime - PPI; PHR and service learning initiatives should aim to create positive stakeholder experiences through meaningful participation.*

6. Participatory learning and action research was particularly suited to co-creating and ***enhancing knowledge*** within and across stakeholder groups (see Chapter 3; Part 2 section 3.4.1). Co-researchers with aphasia reported ***experiences of empowerment*** throughout the study (see Chapter 3; section 3.4.1; Theme 5 'Benefits'). These ***life enhancing*** experiences are in direct contrast to the social reality of living with aphasia evident in the empirical data (see Chapter 4; section 4.4.1'Theme(s) 1a-6a'). Attitudinal and environmental barriers frequently block PWA from full participation in everyday life. As described in Chapter 1 (section 1.2.1) people with communication impairments, are "at the bottom of the hierarchy of exclusion…and are often denied their human rights in the most fundamental of ways" (Wickenden, 2013 p16; World Health Organization & The World Bank,

2011). The co-researchers with aphasia reported experiences of psycho-emotional or social-relational disablism (Reeve, 2006; Thomas, 2004) in their daily lives *because* of their communication disability. However as part of the research team they experienced respect and a temporary outward appearance of normality (see Chapter 3; section 3.4.1 'Theme 5 Benefits'). Despite their lived experiences of marginalisation the co-researchers with aphasia were motivated to ***positively influence*** the local community and society. They shared a desire to: (1) *'make Galway an aphasia friendly city';* (2) develop public awareness about aphasia; (3) teach supportive communication strategies to staff in local coffee shops, restaurants and public facilities because this would improve communication interactions for people with aphasia and for others with communication disabilities, and finally (4) expand the CPP to include other groups (e.g. active retirement groups etc.) (see Chapter 5; 'Theme 5 Benefits'). People with aphasia are competent and well positioned to educate their own communities about the experience of communication disability. Being a visible, valued contributor in the community will also create opportunities for civic engagement and the development of new social networks (Pound, 2011). In this study the vision for social change and emancipation appeared to be targeted at the individual and local community level however the ambitions of co-researchers to positively impact society has relevance across contexts.

Recommendation:

- *Empower PWA to establish social networks and influence the direction of aphasia research nationally and internationally.*

7. The social model of disability, PPI; PHR and service learning encourage researchers, healthcare professionals, students and service users to be ***critically reflective*** and consider personal values, power relationships and personal prejudices. This study provides good examples of ***reflective practice*** across stakeholder groups in research; scholarship and practice. Co-researchers *(PWA; SLTs; Students)* were encouraged to ***reflect on data generated*** throughout the study by using the 'PLA interview technique' (see Chapter 4; section 4.3.7 'Interviewing the technique'). This involved the facilitators supporting participants to

review and discuss the PLA charts. Participants were invited to share anything surprising or striking about the: (1) PLA technique used; (2) process of data co-generation and/or co-analysis, and (3) outcomes/findings. When the group agreed that they had enough time to reflect on the charts and they had nothing new to add or say, the PLA technique(s) were closed. The literature emphasises the need for *process* evaluation to encourage reflection; improve the robustness of studies and optimise future collaborations between researchers and community (Shippee et al., 2015). The evaluation methods used in this research aimed to stimulate ***critical reflection*** and capture participants' experiences of: (1) PLA as a methodological approach and (2) acting as co-researchers. Different types of evaluation data were gathered throughout the research process within and across stakeholder groups which improved study quality and rigour (Gadamer, 1979)(Oliver et al., 2008) (see Chapter 3; table 3.3). The dialogical processes of the social model of disability; PPI; PLA and service learning are dependent on how issues of power are acknowledged and understood. Reflection on issues of authenticity; transparency; transferability and the PhD researcher's explicit value base were considered throughout the study (see Chapter 2: Box 2.1: Chapter 3 Boxes 3.1 and 3.2). The challenges (attitudinal and environmental barriers) faced by people with communication disability wishing to participate in research and scholarship were debated and discussed. Data about the PhD researcher's experiences of using PLA to involve PWA as co-researchers in the evaluation of a primary care conversation intervention are appraised in Chapter 3 (part 1).

Recommendations:

- *Use a variety of tools to support critical reflection for all groups because this will improve the robustness of the research and foster good will for future initiatives;*
- *Researchers should reflect on power dynamics and personal prejudices which may influence relationships with participants.*

8. Experiential knowledge embedded in ***co-researchers lived experience of aphasia and the CPP*** had a ***unique veracity*** that was not available through any other knowledge source in the study. In recognition of the

value and ***equality of experiential knowledge*** co-researchers were involved in all aspects of the research process e.g. (study co-design; data co-generation; data co-analysis; outcomes and recommendations for future studies). By acknowledging the expertise of PWA and providing opportunities for conversations with unfamiliar partners the CPP emerged as a relevant community service (See Chapter 4; section 4.4.1 'Theme(s) 2b and 3b'). The negative feelings of communicative incompetence described in "Back to Pre-School" and "Not Able to Talk the Words" appeared to be reduced through participation in the programme. Impacts of aphasia related to feelings of marginalisation captured in "Escape", "It's Like in Prison" and "Emotions" appeared to be partly addressed by the social aspects of the CPP (see Chapter 4; section 4.5 'Discussion'). All new and unexpected ***learning opportunities*** were embraced for example, planning the implementation of the CPP evaluation criteria (see Chapter 5; section 5.3.9 'PLA seasonal calendar technique'). The research process mirrored the experience of the CPP by aiming to ensure that the communication challenges resulting from aphasia were not experienced as an obstacle to ***equal participation*** (McVicker, Parr, Pound & Duchan, 2009).

Recommendations:

- *Disseminate evidence about the positive impacts of including the experiential knowledge of people with aphasia in research, scholarship and practice;*
- *Include people with aphasia as equals in PPI activities and embrace all new learning opportunities emerging from their unique contributions.*

9. This study provides a successful example of ***community based research and scholarship***. The innovative use of a service learning initiative resulted in collaborative working relationships between University, SLTs working in the PCCC and PWA living in the ***local community*** (see Chapter 1; section 1.1.3). All stakeholder groups valued the service provided by the SL CPP and this is reflected in the programmes successful implementation since 2005/2006. However to to ensure continued sustainability it was important to *meaningfully*

enage all stakeholders in a multi-perspectival evaluation of the programme. The philosophy and practice of ***reciprocity*** and ***inclusion*** established through the SL CPP were also present in the research process. This study generated outcomes specific to a local community and a single university site. If the process and outcomes of this ‘single case’ are ‘scaled up’ the potential for transferability of findings will increase (see section 8.3.2 below).

Recommendations:

- *Explore the process and outcomes of the scholarship and research of the CPP in different contexts and cultures;*
- *Compare different methods of engagement between stakeholder groups in research and scholarship and report the findings.*

10. This study demonstrates ***collaborative working*** to co-create ***genuine participation*** in the scholarship, practice and evaluation of the CPP. Points 1, 2 and 3 highlighted the importance of relationship building, co-learning and dismantling barriers in research and scholarship. Genuine participation was achieved through the co-creation of democratic research processes (point 4) and criticial reflection on study co-design, data co-generation and co-analysis. The PhD researcher and co-researchers’ evaluations and reflexive accounts provide empirical evidence of the experiences of ***reciprocity*** and ***meaningful engagement*** throughout the research process (point 7; Chapter 3; part 1 and part 2). Point 8 emphasised the veracity and value of experiential knowledge in the study and this equality of knowledge(s) contributed to ***collaborative relationships*** and ***stakeholder participation***. Point 6 and point 9 highlight the aims of co-researchers to continue their involvement in research and scholarship which reflect the positive transformatiion shifts (points 3 and 4) experienced through invovement.

8.1.2 Further opportunities for future research

The co-researchers in this study generated creative ideas for sharing outcomes and extending the CPP. Implementation of these initiatives will result in wider and more efficient dissemiantion of the research findings (see Appendix J for dissemination activities to date) (Jagosh et al., 2011). Furthermore, exploring the implementation of the agreed CPP evaluation criteria though the established ***'participatory spaces'*** is important. Normalisation Process Theory (NPT) offers a conceptual framework about implementation processes based on empirical generalisations developed within studies of implementation and integration processes (May & Finch, 2009). Normalisation process theory has been used as a heuristic device to enhance understanding of the implementation of various healthcare interventions in primary care (Mc Evoy et al., 2014; May & Finch, 2009). This theory may be a valuable conceptual framework to use in the analysis of how CPP evaluation criteria are being implemented into current practice. The PhD researcher eagerly anticiaptes being involved in these future research activities.

Recommendations:

- *Use Normalization Process Theory (NPT) to monitor the implementation of the agreed CPP evaluation criteria;*
- *Co-create and implement a dissemination approach with co-researchers to achieve wider and more targeted sharing of methods and outcomes.*

8.1.3 Summary

The conceptual synergies across literatures with the theoretical framing of reciprocity and inclusion have been thoroughly reviewed in the foregoing discussion. The conceptual links highlighted in Chapter 1 (table 1.2) are clearly evident in the operationalization of the study and align with philosophy of the social model of disability. This research demonstrates that it is possible to overcome the methodological difficulties of involving PWA and other stakeholder groups in PPI, PHR and service learning programmes.

The next section provides a methodological critique of the research. Part 1 evaluates the strengths of the study while Part 2 details limitations. Issues appraised in detail in the discussion sections of the individual papers are not re-considered here.

8.2 Methodological Critique

Part 1 Methodological Strengths

8.2.1 Research Design and theoretical Framework

The overall study design was conceptually robust with a consistent and integrated thread throughout (Crotty, 1998): (1) the use of PLA was consistent with the overarching PHR paradigm; (2) data co-generation and co-analysis methods (PLA techniques and PLA interviews) were consistent with the PLA approach (O' Reilly-de Brun & de Brún, 2010) and (3) service learning partnerships (University, PCCC and PWA living the community) were consistent with the aim of the pedagogical approach to create reciprocity and mutual learning. Finally, the CPP based on the social model of disability (Oliver, 2009) aimed to dismantle attitudinal and communication barriers to life participation for PWA. This conceptual robustness translated into the operationalization of the study (see section 8.1). This translation was the result of continuous critical reflection and co-design with stakeholder groups.

8.2.2 Sampling Frame and Recruitment

A key feature of the sampling process reported in Chapter 4 (section 4.3.4) and in Chapter 5 (section 5.3.5) was the focus on enabling the selection of the aforementioned “local experts” living in the West of Ireland affiliated with the NUI, Galway, CPP. Existing relationships with these groups may have facilitated recruitment and the establishment of rapport with participants. For example, at the time of the study travel was strongly curtailed within the HSE, resources were limited and the commitment to community participation was not a priority issue for clinicians. The SLTs may have participated because the PhD researcher is considered a colleague and the CPP is a valued intervention for PWA in the local community. The potential tensions reported in the literature when researchers enter the field ‘cold’ (Wellin & Fine, 2001 p325) and are considered ‘outsiders’ (Mewett, 1989 p82) did not impact this study rather the ‘insider’ positioning of the PhD researcher as CPP co-ordinator may have facilitated recruitment drives. The integration of multiple stakeholder perspectives was particularly important in this study because the research questions related to the experiences and priorities of both service users and service providers (Boote, Telford & Cooper, 2002). The purposeful sample achieved included stakeholders from all key groups who were well positioned to respond to the research questions and for whom study outcomes were of interest (Doyle & Timonen, 2010).

8.2.3 Consent

There are methodological issues related to obtaining informed consent when the participants being invited to consent have a communication disability. Some suggest that the complexities of providing informed consent to PWA might explain why the voice of this population group is limited in the literature (Carlsson, Paterson, Scott-Findlay, Ehnfors & Ehrenberg, 2007). The strategies implemented to facilitate participants' understanding of consent forms are a methodological strength (see Chapter 3; section 3.2.1 and Chapter 4 section 4.3.6) that may be replicated in future studies.

8.2.4 Data generation and analysis

The ultimate responsibility for the success of the study centred on the co-researchers as they willingly invested time and energy to respond to the research questions. The involvement of a co-facilitator was also important because the co-facilitator acted as an advocate on behalf of the co-researchers with aphasia. It was not clear at the conceptual stage of this research what PWA and other key stakeholders would say in response to research questions. However stakeholders shared perspectives, listened to each other, and co-generated rich, contextualised accounts of their emic experiences of aphasia, the CPP and service learning through a range of data generation and analysis techniques. The PLA methodological approach used to co-generate the agreed CPP evaluation criteria is considered a key strength of this study and was therefore discussed in detail in Chapter 3; section 3.2.3-3.2.4 and Box 3.2).

8.2.5 The influence of the researcher on the research process and findings

Researchers conducting qualitative studies openly acknowledge the potential influence of personal, professional and theoretical factors on the research process and outcomes. The PhD researcher acknowledged her influence on the research process and outcomes in terms of her: (1) world view, (2) experience of data generation; (3) theoretical knowledge and positioning of the literature and (4) personal positioning (Koch & Kralik, 2006 p140). Specifically, the PhD researcher was aware that personal insights gained from clinical practice with PWA and existing relationships with stakeholder groups through the CPP may influence the research process. To maximise study quality and rigour the PhD researcher recorded and analysed reflexive accounts of these influences and engaged in on-going self-critique and self-appraisal throughout the study (see Chapter 2; section 2.4 and point 7 in section 8.1 above). The facilitators' engaged in structured critical reflection and debriefing following all data generation sessions. An awareness of the level of participation reached by participants was important in identifying what specific techniques, methods and materials might optimise engagement. This reflective process frequently resulted in modifications to subsequent fieldwork sessions (see Chapter 3 section 3.2.4). Reflection was a critical component throughout the study (see Chapter 2 section 2.4 and point 7 above).

Issues of positionality were an important consideration in the study (Herr & Anderson, 2005). In the role of *CPP co-ordinator* the PhD researcher was a co-researcher and an 'insider' however as *PLA facilitator* she occupied an 'outsider' position. It was important to maintain an awareness of movement between insider/outsider positions during the course of the study. The PhD researcher was very explicit about her role and positioning throughout the research process with stakeholder groups. The involvement of the co-facilitator as an "outsider" facilitator in all fieldwork sessions was an important feature to counter the effect of any bias the PhD researcher may have had on data co-generation. The PhD supervisor also remained in an "outsider" role to ensure quality and rigour across the research phases. The PhD researcher reflected on her various roles in both the scholarship and research of the CPP (e.g. PLA facilitator (see Chapter 3: Box 3.1); PhD researcher; CPP co-ordinator; SLT and lecturer in Speech and Language Therapy). Critical discussions and peer reflections with the co-facilitator and PhD supervisor were very valuable to: (1) stimulate reflexivity; (2) consider positionality issues and (3) discern power relationships during the course of the study.

8.3 Methodological Limitations

8.3.1 Involvement issues

The PhD researcher aimed to achieve collaboration and genuine stakeholder participation throughout the research process however the limitations in the scope of this study are acknowledged. Future studies should involve co-researchers earlier in the design phase to determine research topics and contribute to: (1) ethical and funding applications; (2) research agendas; (3) search strategies and (4) dissemination opportunities. While the submission of a PhD thesis with the requirement for academic peer-reviewed publication and conference dissemination (see appendices J and K) was discussed at the outset with all co-researchers, these outputs do not meet stakeholders' dissemination needs (Grant, 2011; Seifer & Sisco, 2006). Future studies should co-create a dissemination approach jointly agreed by researchers and co-researchers. The dissemiantion plan should be personalized and accessible for individuals' different abilities and preferences even within the same population group e.g. people with communication disability (Gracia, Blasco & Andradas, 2011). This collaborative planning will optimise and target dissemination activities.

8.3.2 Sampling Issues

Co-researchers with aphasia

The small sample size of older, predominantly male, retired participants with aphasia living at home may impact the validity of findings from this study. The participants with aphasia involved as co-researchers represented a select group of people with mixed aphasia interested in the CPP from a particular cohort. Recruiting a larger and more gender balanced group with different types of aphasia from a variety of geographical locations was beyond the scope of this study. Recruiting a larger and more diverse sample of participants with aphasia should be a priority consideration for future studies (see Chapter 4 section 4.5.1).

Other stakeholder groups

The majority of graduate and undergraduate participants were female and in their twenties. All had been trained as conversation partners for PWA as part of their BSc in Speech and Language Therapy at NUI, Galway. The SLT stakeholder group were all female with age-ranges between 28 and 47 years which again may represent views from a particular cohort. Recruiting gender-balanced groups with greater diversity from other geographical regions involved in different CPPs was beyond the scope of this study. This is an acknowledged sampling limitation of the research (see Chapter 5: section 5.5.1 and Chapter 6; section 6.6). Future research should aim to include a more representative sample from different geographical locations with different affiliations, scholarship and social experiences to represent broader perspectives.

The critical review of the SL literature had several limitations which may have impacted review findings and these were acknowledged in Chapter 7 (section 7.6). The PhD researcher argues that the absence of evidence to demonstrate the effectiveness of SL does not indicate an absence of impact. It may suggest inadequate reporting with a lack of valid and reliable tools to capture the outcomes of SL for all stakeholders. Therefore while the evidence determining the effectives of SL has yet to be established, the findings from this study indicate that SL is a suitable pedagogical tool to implement the CPP. The reported positive impacts of SL (see Chapter 6; section 6.5.7) are congruent with the theoretical framing of reciprocity and inclusion. Future studies should include all stakeholders in reciprocal, inclusive relationships to develop robust evaluation tools that might elucidate the process and outcomes of SL in healthcare curricula (see Chapter 7; section 7.7).

8.3.3 Issues concerning generalizability

In qualitative participatory research the primacy of the local context has implications for the generalisation of results. Co-researchers provided a deep understanding of aphasia, the CPP and service learning in their own words from their emic experiences. This co-learning resulted in the co-creation of CPP evaluation criteria and *local evidence* about the programme. As Greenwood & Levin (2005) argue, co-generated, context specific knowledge requires a revision of traditional notions of generalization. The transfer of findings from this study to other studies is dependent on a clear understanding of the contextual conditions in the new setting. The research context, setting and profile of stakeholder groups were described in the published papers (Chapters 4-7). This detail will support colleagues to make judgements about the potential transferability of findings. Additionally, considerations and reflections about how the new setting differs from the setting in the west of Ireland where this study was situated are important to address (Macaulay et al., 2011). Realist review approaches aim to explore what works best for which population groups in different contexts (Jagosh et al., 2012; 2011) and this approach may have relevance for transferability considerations. The ICPHR consider each local participatory health research project as a single case study. ‘Scaling up’ (Salamander Trust, 2013; Wright , Gardner, Roche, von Unger & Ainlay, 2010) involves a broad analysis of a range of case studies while ‘scaling across’ involves one group of participants creating something locally with a different group implementing and developing the same idea in a different context (Wheatley & Frieze, 2011 p36).

Preliminary work on exploring the transferability of findings began in Phase 3 when data generated in response to the primary research aims was shared with an international inter-stakeholder group in the United Kingdom. In line with decisions made by the co-researchers with aphasia the international group were not asked to respond to the original research questions. Instead they focused on findings (PLA charts; photographs etc.) generated in the Irish context and considered whether the ideas and outcomes had relevance to them in their setting (see Appendix H; H2). Following this review they were invited to add new ideas to the existing data and to identify gaps and/or striking features. Thus the collaborative nature of the research was maintained and the ‘case’ was ‘scaled up’. While the data shared appeared to be transferable to the inter-stakeholder group in London the PhD researcher acknowledges that this exploration was a first step and further ‘scaling up’ of the case across different groups and contexts is required.

The next section presents a concluding statement about this study summarising key findings.

8.4 Concluding statement

The PhD researcher through empirically generated data and a critical review of the literature proposes that this PhD has:

- Highlighted the urgent need for researchers to develop innovative inclusive methodological approaches to involve people with aphasia and others with communication disabilities in PPI activities including research and scholarship initiatives **(Chapter 1; Chapter 4 and Chapter 5)**.

- Contributed new empirical data about the lived experience of aphasia and the CPP from the emic experiences of people with aphasia **(Chapter 4; Appendix H).**

- Identified, agreed and prioritized CPP evaluation criteria from a multiperspectival stakeholder analysis using PLA **(Chapter 5).**

- Contributed new evidence about the experience of implementing PLA to involve people with aphasia as co-researchers in service evaluation from the PhD researcher's and co-researchers' perspectives **(Chapter 3).**

- Contributed new evidence about the impacts of service learning on community, students and educators from the emic perspectives of stakeholder groups in an Irish context **(Chapter 6; Appendix I).**

- Synthesised data about the impacts of service learning in pre-professional healthcare curricula identifying gaps in knowledge and areas for future research **(Chapter 7).**

In a field of contradictions where the declared values and aspirations of PPI and primary care policy imperatives are 'inclusion' and 'reciprocity' people with communication disability are perpetually excluded. This study illustrates PLA as an empowering, transformative and innovative methodological approach to include PWA and other stakeholder groups as co-researchers in research and scholarship. This collaborative way of working bridges the gap between PPI policy imperatives and their operationalization. The process and outcomes of this study are exciting and promising and will be of interest to researches willing to co-create inclusive research studies. By embracing the experiential knowledge of people with communication disability as unique and equal, the diverse experiences of this under-representation population will be captured, in both research and scholarship. Involvement will provide valuable benefits for PWA and the wider field of PPI.

Silenced Voices

Voice is Life,
And life gives voice,
Listening fosters freedom,
Hearing heals hurts and holds hope.
Soul seek, truth tell, share,
And the gift of the Giver unfolds.
Words that mean much,
With the words wisdom and light,
Co-creation begins and co-learning takes flight.

Self-telling takes courage but sharing teaches the Giver and Receiver,
That different words need heard,
New knowledge needs named.
Change can occur and conquer,
The obstacles.

Listen!
And be humble in the hearing,
For the precious voice of ONE cannot be lost to the whole.
The story in colour must always be told.

Ruth Mc Menamin March 2016

8.5 References

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Appendices

Appendix A Rationale for Journal Selection

Careful consideration was given to the type of Journal that would best resonate with the aims, objectives, content and intended target audience of each of the five research papers. Hence the four Journals selected were based on their attention to implementation research and or the primary healthcare context and user involvement.

Aphasiology: Papers 1 and 2 are published in the journal Aphasiology. We chose this journal because it includes papers on all aspects of language impairment and related disorders resulting from brain damage. This journal has a wide international interdisciplinary readership including both researchers and practitioners. It was important to share the empirical evidence presented in in this paper about co-researchers emic experiences of aphasia and the conversation partner programme. These papers make an original contribution to the evidence base and introduce readers to the use of innovative participatory research methods as a successful methodological approach to involve people with aphasia in qualitative research.

Nursing & Health Sciences (NHS): Paper 3 is published in the journal Nursing and Health Sciences. We chose this journal to share our experiences of implementing Service Learning in our curricula. This international journal encourages Eastern and Western scholars to share their knowledge and experiences of educational approaches in health care to promote understanding and practices. Paper 3 highlights Service Learning as an increasingly popular pedagogy and this journal gave us the opportunity to enhance the international readerships' understanding of the impacts of this pedagogy for all stakeholder groups within an Irish context.

Medical Teacher: Paper 4 is published in the journal Medical Teacher. This paper investigates the effectiveness of Service Learning as pedagogical approach to produce socially responsive healthcare graduates. We provide a critical review of the literature concluding that while SL experiences appear highly valued by educators and students the effectiveness of SL remains unclear. This paper highlights the need for more impact studies based on the interpretative paradigm, aligned with the principles of social accountability and including all stakeholder perspectives. The readership of Medical Teacher includes those involved in the education of medical and healthcare students internationally and we chose this journal to target that audience.

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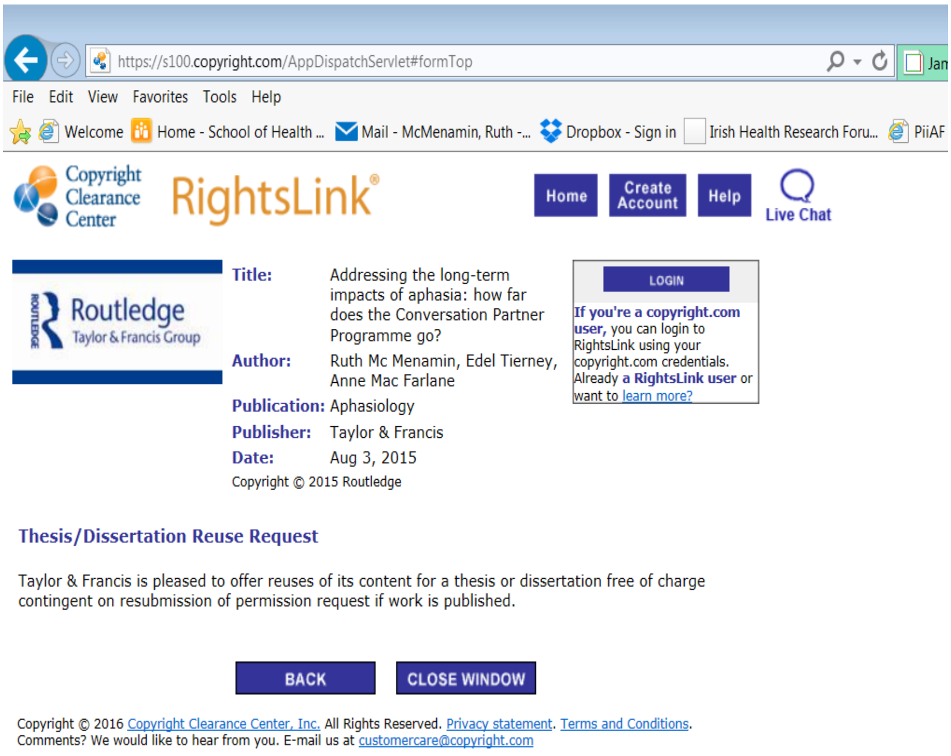

Title: Addressing the long-term impacts of aphasia: how far does the Conversation Partner Programme go?
Author: Ruth Mc Menamin, Edel Tierney, Anne Mac Farlane
Publication: Aphasiology
Publisher: Taylor & Francis
Date: Aug 3, 2015
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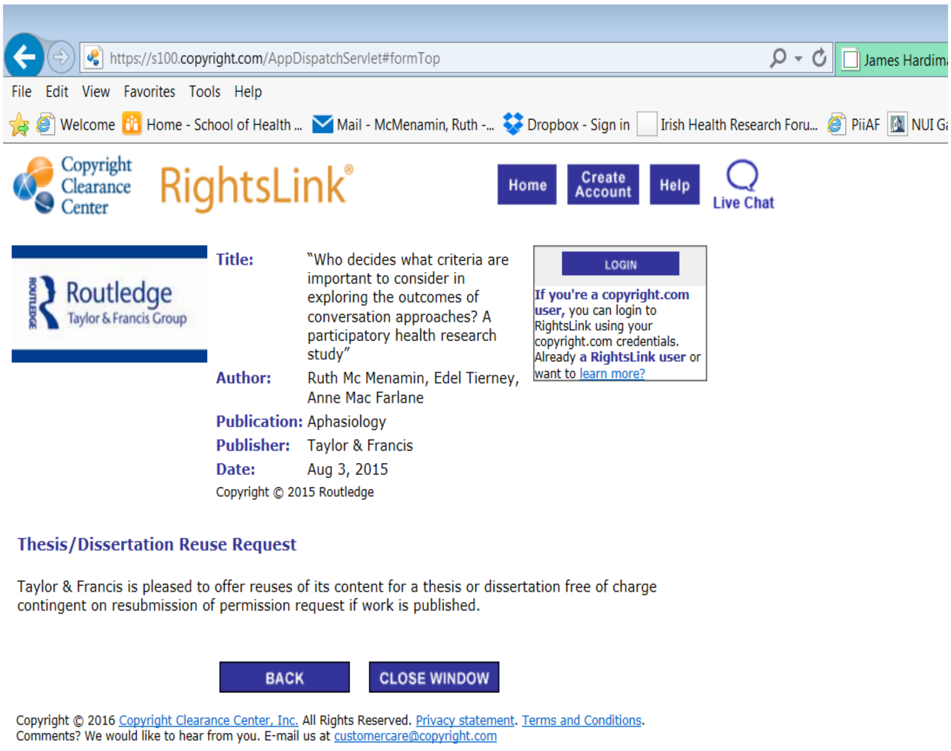

Title: "Who decides what criteria are important to consider in exploring the outcomes of conversation approaches? A participatory health research study"
Author: Ruth Mc Menamin, Edel Tierney, Anne Mac Farlane
Publication: Aphasiology
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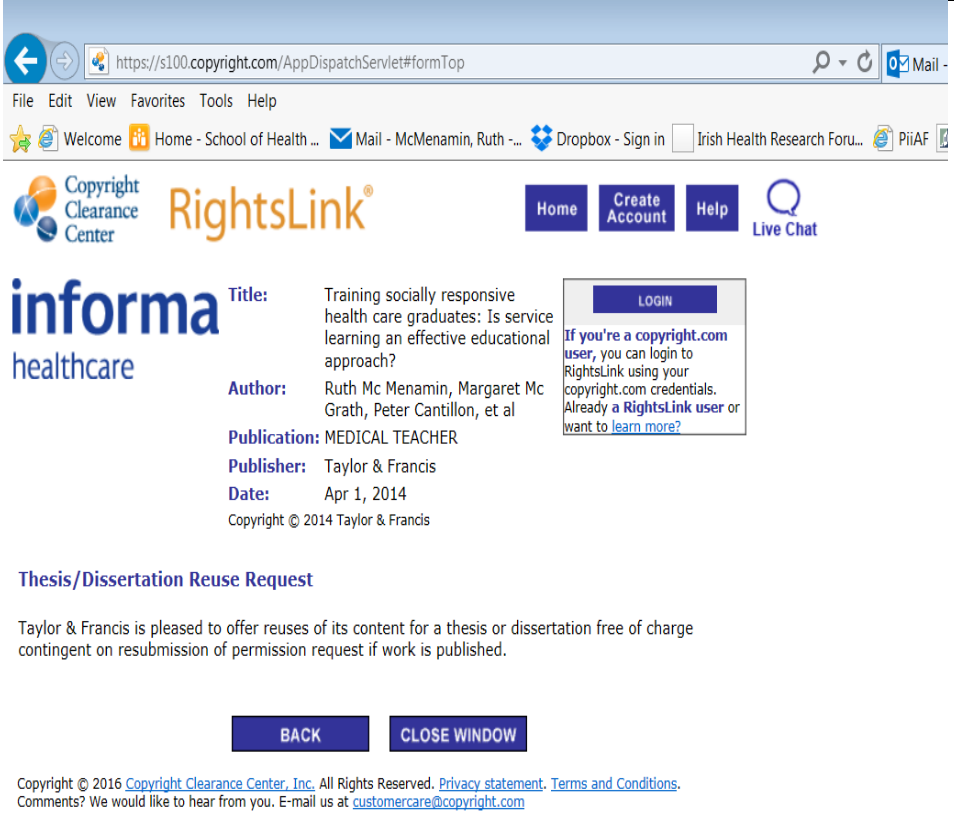

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Title:	Training socially responsive health care graduates: Is service learning an effective educational approach?
Author:	Ruth Mc Menamin, Margaret Mc Grath, Peter Cantillon, et al
Publication:	MEDICAL TEACHER
Publisher:	Taylor & Francis
Date:	Apr 1, 2014

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Appendix C Good Practice in PLA Fieldwork: Introductory notes for Fieldwork Session with PWA

Session 1 (document 1): Evaluating Conversation Partner Programmes – Perspectives of People with Aphasia

Evaluating Conversation Partner Programmes – Perspectives of People with Aphasia

Ruth Mc Menamin
Discipline of Speech & Language Therapy
National University of Ireland, Galway

Date: Tuesday 26th February 2013

Venue: Tutorial Room 2, School of Health Sciences, Aras Moyola, National University of Ireland, Galway.

Time: 10.30am – 1.10pm

Present: Ruth Mc Menamin (facilitator).
Edel Tierney (co-facilitator).

Five people with Aphasia participated in Session 1.

Activities:

10.30am – 11.40am

Welcome and Introductions

- Participants and facilitators introduced themselves and we agreed to wear hand-written name badges to remind ourselves of our names.

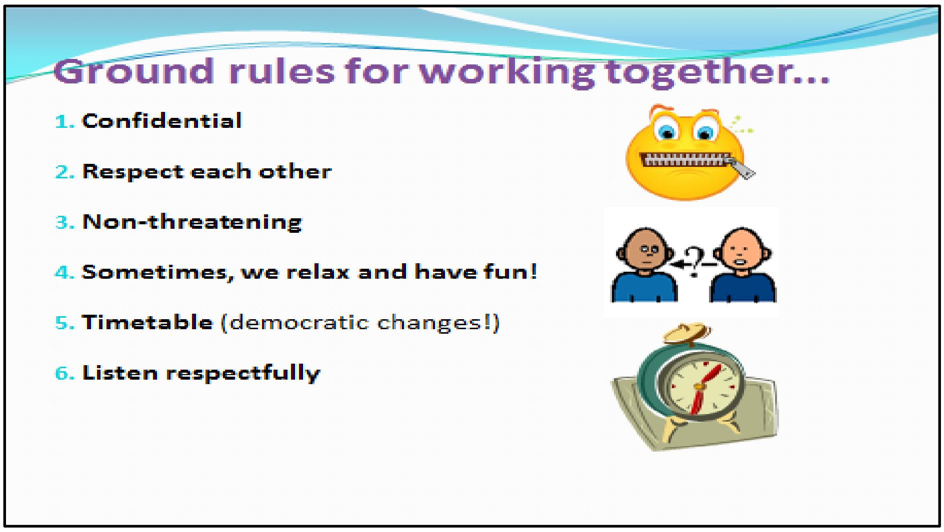
Power Point Presentation - Ruth presented a range of slides:

- Background to the research project:
    - The origins of this research
    - Funding and supervision
    - Involving people with aphasia in research
    - Participatory Learning and Action Research(PLA) approach
    - People with aphasia as aphasia experts
    - Other stakeholder groups
    - Purpose of today and next sessions

Setting agreed 'Ground-rules'

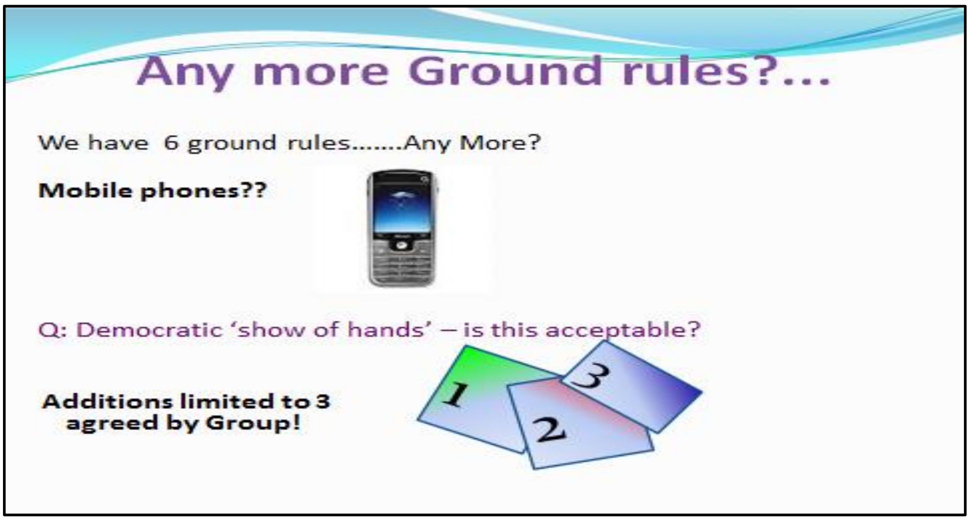
Ruth suggested six basic ground-rules for positive group interaction during the PLA data generation sessions. The suggested ground-rules were displayed on a power point slide (see example below).

Written text was kept to a minimum and pictures were included to augment the written text. Each suggested ground-rule was discussed and participants agreed to adopt all ground-rules. We agreed as a group to invite further suggestions for ground rules but that suggestions should be limited to a maximum of three additional ground rules (See power point slide below). One further ground-rule was generated and agreed by the group in relation to mobile phone use during sessions. Participants and facilitators agreed to either put their phones on 'silent' or to turn off their phones completely during our PLA sessions.



Ground rules for working together…

1. **Confidential**
2. **Respect each other**
3. **Non-threatening**
4. **Sometimes, we relax and have fun!**
5. **Timetable** (democratic changes!)
6. **Listen respectfully**



Any more Ground rules?...

We have 6 ground rules.......Any More?

Mobile phones??

Q: Democratic 'show of hands' – is this acceptable?

Additions limited to 3 agreed by Group!

We completed the presentation with:

- An opportunity for Questions & Comments; Practical Information e.g. nearest toilets, break time, finishing time etc.

Questions and Answers:

- Stakeholders discussed their experiences and perceptions of research. Nobody in the group had ever been asked to participate in research about their stroke or aphasia. Their only experience of research related to phone survey's which the participants reported not being able to participate in because of their aphasia. Some participants reported receiving postal surveys which again were difficult to respond to because of their reading and writing difficulties as a result of their stroke and aphasia.

The shoe ice-breaker:

The shoe activity was specifically chosen for this stakeholder group who all have aphasia. Because the shoe ice-breaker is picture/symbol based participants could actively participate in this activity even when verbal communication was difficult.

- The facilitator had cut various pictures of shoes and boots out of magazines and books in preparation for this task.
- The pre-prepared pictures were placed randomly in the centre of a large table where all participants could easily see and access them

- A power point slide was displayed with the following instruction which the facilitator also repeated out loud to the group:
- ***"Pick a shoe and tell us why you have picked this particular shoe and what it says about you"***
- The facilitators and participants took turns to explain why they had chosen a particular picture.

Engaging with this activity gave participants an opportunity to communicate something about themselves and learn a little about each other and the facilitators (Ruth and Edel) in a fun, non-threatening way.

Discussion following Power Point Presentation:

- Each participant shared the length of time since their stroke and the number of times they had participated in the Conversation Partner Programme.

Aphasia- Friendly Participant Information Sheets and Consent Forms:

Copies of **'Aphasia- Friendly Participant Information Sheets'** were provided to each person. All participants had received this information in the post prior to the introductory session. Following adequate time to read and digest this information, participants were asked for feedback and if they had any questions. There were none.

Aphasia-Friendly Consent Forms were provided to each participant including:

- Project Consent form
- Video recording consent form

- Photo consent form

We read through each Consent Form carefully, explaining each item and responding to any questions as they arose. Participants reported that the content was clear and they understood the information. Each participant freely chose the sign Consent Forms during the session and these were duly witnessed by Edel Tierney and Ruth Mc Menamin. The signed consent forms for each participant were subsequently safely stored in a locked filing cabinet in NUIG.

11.40 -12.10 TEA/Coffee

12.10-12.50 Participants engaged in responding to Question 1

Recording of Data Generation Sessions:

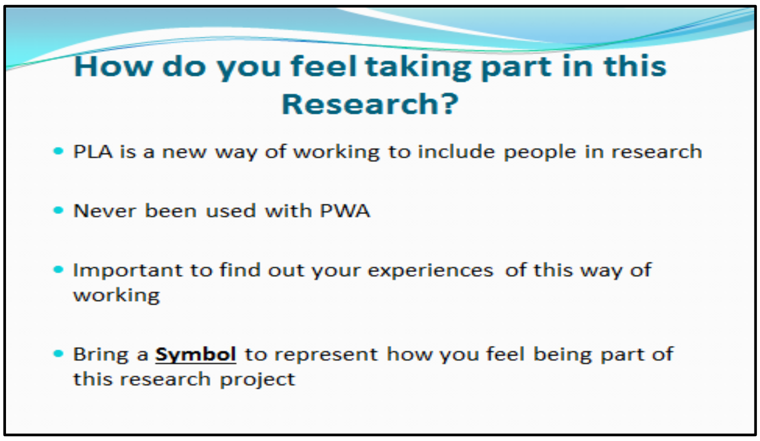
The researcher reminded the aphasia experts about **permission for recording** this part of the session:

- *The ethical approval for this study includes permission to video and audio record our discussion, and now is the time to capture all the important information and ideas you may share, so we would like to switch on the recording equipment now if that is still ok with everyone? Thank you.*

Question 1 – How does Aphasia affect ME and MY FAMILY? (See doc 2 & 3 for description of this process and the information co-generated and co-analysed in response to the question).

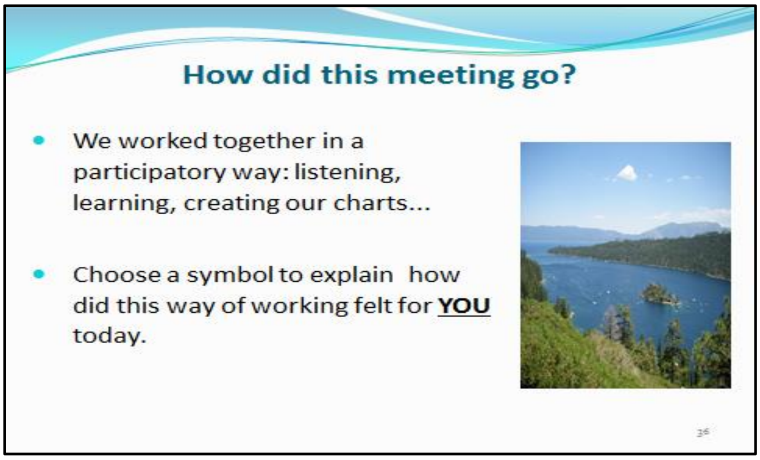
12.50 -1.00 Invitation to evaluate the research experience

"How does it feel for you to take part in this Research? If there was an object or picture or symbol that represented how you feel taking part in this research you might bring it along the next day and we'll start by looking at the picture or object or whatever it is and you might tell us why you chose that object to represent how you feel" (see slides below)



How do you feel taking part in this Research?

- PLA is a new way of working to include people in research
- Never been used with PWA
- Important to find out your experiences of this way of working
- Bring a **Symbol** to represent how you feel being part of this research project



How did this meeting go?

- We worked together in a participatory way: listening, learning, creating our charts…
- Choose a symbol to explain how did this way of working felt for **YOU** today.

1.00-1.05 pm: Next Meetings:

The dates, times and location for our next two meetings were discussed and agreed by all participants.

Next Steps.....

- When would suit to meet again?

Thank you!

1.05-1.10 pm Wrap-Up and Thanks!

Ruth and Edel thanked the aphasia experts for sharing their experiences and for their active participation. The session closed at 1.10pm

Appendix D Examples of Critical Session Reflections

Appendix D1 Reflection on Phase 1; PLA Session 2; Group 1 (Individual Group - PWA); 26th Feb 2013

SUSTAINABILITY ANALYSIS

SUSTAINABILITY ANALYSIS QUESTIONS:	Items:	What action needs to be taken?	Who will be responsible for this action?	Any other comment?
What should we <u>keep on doing</u>? What worked well?	1. The welcome was good and discussion of each participants' symbol worked very well; all participated and seemed to enjoy the symbol descriptions and the sharing contributed to a positive group dynamic. 2. The facilitation was well-paced 3. The tea/coffee arrived at a good time 4. The 'Card Sort' activity worked well but it did take more time than expected. 5. The PLA mode of engagement; PLA materials and supportive communication techniques			

SUSTAINABILITY ANALYSIS QUESTIONS:	**Items:**	**What action needs to be taken?**	**Who will be responsible for this action?**	**Any other comment?**
	complimented each other to provide a supportive and relaxed communication environment. 6. Interviewing the technique worked well as we used it to clarify participants' intended meanings 7. Writing for participants who could not write themselves worked well as it allowed people time get their message across without the pressure of writing e.g. one idea per stickie 8. Being professional but approachable is important for a well organised and enjoyable session 9. The explanation of questions and techniques worked as participants engaged in the process and seemed to understand what was being asked of them. 10. Digital recording and note-taking went well and is important for later reflection			

SUSTAINABILITY ANALYSIS QUESTIONS:	**Items:**	**What action needs to be taken?**	**Who will be responsible for this action?**	**Any other comment?**
	11. Participants spontaneously reported enjoying the session and gave very positive feedback at the start of the session when they were describing their symbols and also at the end of the session during the quick summary. 12. Participants actively contributed to the design of the session and to the decisions about whether to use the Direct Ranking Technique on the data generated and categorised in response to question 1.			
What should We stop doing? What needs to change?	Indicate intensity of response on stickies that resonate with more than one participant rather than duplicate stickies. Be aware that the 'Card Sort' is a complex language activity and that the effort participants make to debate			

SUSTAINABILITY ANALYSIS QUESTIONS:	**Items:**	**What action needs to be taken?**	**Who will be responsible for this action?**	**Any other comment?**
What could be done better next time around? How might we improve? What do we need to avoid?	and discuss bundles of stickies to arrive category headings is tiring.			
What should we start doing? What new things do we need to do?	Keep the symbol to represent participation in the group – that worked very well.			

Appendix D2 Reflection on Phase 1; PLA Session 2; Group 1 (Individual Group - PWA); 26th Feb 2013

DEBRIEFING REFLECTION

NAME: Ruth Mc Menamin

Role: PLA Facilitator

1. ***Please describe the participants with whom you worked.***

The group included: 5 people with aphasia

2. ***What was the topic?***

- We began session 2 with each participant and both facilitators in turn describing the symbol they brought to explain how it felt to be part of the research group last week.
- We reviewed our Flexible Brainstorm chart in response to question 1 “How does aphasia affect me and my Family?”
- We bundled together the stickies that shared a common link and agreed category headings for each bundle (Card Sort Technique)

3. ***What PLA technique did you choose to match this topic?***

The first 30mins of the session involved each participant describing how they felt participating in the first PLA session. Each person including Edel and Ruth brought a symbol to represent how the experience of the research felt. We then reviewed the Flexible Brainstorm chart and began bundling stickies that had a link together. This activity generated lots of discussion and lively debate. Arriving at agreed category headings took time as identifying and agreed headings involves negotiation which is a more complex language activity than generating items for a flexible brainstorm. Participants engaged in the PLA Card Sort with energy and interest. Edel and I in our roles as facilitator and co-facilitator supported the group in bundling stickies together. We regularly checked with the group that they were satisfied with the task as it moved forward. Participants agreed eight category headings in response to question 1. We offered writing support to any participant who wanted it for writing the category headings. This task took most of the session. Ruth explained the PLA Direct Ranking technique to prioritise the category headings identified. However we did not move use this technique in Session 2 rather we asked participants to consider whether this would be a valuable technique to use with the information we had created together.

4. ***Please attach completed RECORDING FORM and any NOTES to this form.***

See Reflections 2 on session 2

5. ***How long did your fieldwork take?***

The PLA session lasted two and a half hours with a break for tea/coffee and scones

6. ***What was your best learning from the fieldwork experience?***

We covered less than expected in this session. Bundling the stickies together from the Flexible Brainstorm is a complex task with participants need frequent clarification and reminders of what ideas were represented on the stickies. Identifying and agreeing category headings is a challenging task involving high level language activities e.g. negotiation, debate and finally agreement. The PWA were very willing to share their experiences and get involved in all aspects of the session. However ‘getting their message across’ takes time and space. Allowing time for silences and supportive communication techniques was very important in the group. The PLA mode of engagement and the PLA materials e.g. coloured stickies; pictures; writing tools etc. supported participants to communicate what they wanted to say and to represent it clearly on the Card Sort chart. .

My learning was that the participants are willing, motivated and eager to share their individual experiences, listen to each other and debate category headings in the group to arrive at agreement. This process requires time, good facilitation and a supportive communication environment. It was important to me in my role of Facilitator that every participant left the group feeling that they were listened to and that they had the opportunity to say all that they wanted to say in a relaxed supportive environment. I think everyone did have the opportunity to say all that they wanted to say and that people felt listened to and valued. I think the ‘Card Sort’ activity was challenging and participants were more tired after the session today than the first session.

7. ***What do you think was the best learning for your participant(s)?***

The PWA reported enjoying the session. I think they had a genuine feeling of having participated well in the group and communicating their individual stories. I think participants valued the peer-support and humour in the group. There was lots of laughter in the midst of the research work. There was a sense of ‘team’ when the session was completed and I think the participants are looking forward to the next session.

8. ***What key information was shared/generated during your fieldwork encounter? (Please feel free to attach a separate sheet if you do not have sufficient room to make your remarks in this space.)***

The PWA agreed category headings in the PLA ‘Card Sort’ activity for the Flexible Brainstorm generated in session 1. The technique worked very well but was challenging as participants debated, negotiated and discussed category headings before arriving at agreement. There was a lot of data generated during the Flexible Brainstorm in session 1 in response to question 1 so reviewing this material as a reminder took time. This review was necessary for re-connecting participants with what they had said and for supporting the grouping of stickies that shared a common link. The group approached the task with careful consideration and despite the communication challenges participants remained engaged with the task until it was completed and they were satisfied with the work that they had done and felt that they had nothing further to add. The group agreed 8 category headings for the data generated in the Flexible Brainstorm however agreeing category headings was difficult. I noticed that some people in the group had comprehension difficulties with evidence of literal interpretations. There was also evidence of tangential speech and supportive communication techniques played an important part in bringing participants back to topic. We interviewed the technique and ensured that everyone was happy the exercise was complete before discussing the next PLA technique – Direct Ranking.

9. What, if anything, would you do differently next time round?

Participants generated a lot of stickies during the Flexible Brainstorm in response to question 1 in session 1. A number of people in the group agreed with each other about many of the ideas/issues shared. For question 2 I think it would be good to show this ‘intensity of response’ on the ideas that people connect with. I could do this by putting the equivalent number of ticks on the stickie to represent the number of people who feel the idea/issue has resonance for them personally e.g. ‘Anger’ – all participants said they felt anger after their stroke. We could write a stickie for ‘Anger’ and then add ticks for the number of people in the group who also want to say something about the feeling of anger after their stroke.

I need to continue to be aware of the issues of Positionality – PLA facilitator vs. researcher vs. SLT. Continue to be conscious of role changes and what impact this may have on facilitating the group.

I agree with the group decision not to do a Direct Ranking Task on the Card Sort chart.

Appendix E Examples of Adapted Project Documentation

Appendix E1 Aphasia-Friendly Session Agenda

The Conversation Partner Programme Research (Phase 3)

Day 1 **Date:** 25th March 2014 **Venue:** Connect, London

Participants: Edel Tierney; Ruth Mc Menamin; Connect co-researchers

2.00 Welcome and Introductions

- Consent Forms
- Getting to know each other
- Working together

2.35 About the Research

- Ruth's update
- Charts and photographs

3.05 Tea or coffee and sandwiches

3.35 Conversation Partner Programme (CPP)

- **Question 1:** 'What do you think about our Conversation Partner Programme findings?'

4.45 How did it feel working in the group today?

- Round the group
- Symbols

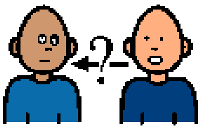
5.00 Close

Appendix E2 Aphasia-Friendly Project Information Sheet

Evaluating Conversation Partner Programmes – perspectives of people with aphasia

INFORMATION SHEET FOR SERVICE USERS Date: 24th January 2013 (Version number: 2)

PURPOSE OF STUDY



The purpose of the study is to develop an evaluation system for the Conversation Partner Programme.

Do I have to take part?

- NO, you do not have to take part
- Taking part is YOUR choice

If you would like to take part

- You will sign the Consent Form

If you decide to take part

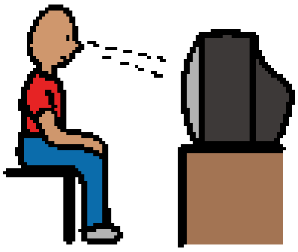
You are **still free** to **withdraw at any time** without giving a reason.

What you can expect if you participate

Discussions about the Conversation Partner progrmme – 1 hour each

BUT
If you get tired
we will stop and
start again on
another day.

The conversations will be videoed and watched by the researcher



The conversations will take place in NUI, Galway

Are there any **benefits to me for taking part?**

- You will contribute to research on the Conversation Partner Programme
- Your travel and expenses will be given back to you
- You will meet other people with aphasia and you will be given refreshments at all discussions

What happens at the end of the study?

- The videotapes will be stored safely and destroyed in 5yrs time.
- This research will be used to improve the conversation partner programme.

→

→

What If I have a complaint during my participation in the study?

If you have a complaint during the study CONTACT:

Ms. Ruth Mc Menamin
Discipline of Speech and Language Therapy
Aras Moyola,
National University of Ireland,
Galway
Telephone: 086 8854968
E-mail: ruth.mcmenamin@nuigalway.ie

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact 'The Chairperson of the NUI Galway Research Ethics Committee, c/o Office of the Vice-President for Research, NUI Galway, ethics@nuigalway.ie

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I am interested in being contacted about the possibility of participating in this study

Name: ____________________________

Mobile phone number:____________________________

Home phone number:__________________________

Time I would most like to be contacted:________________________

Appendix E3 Aphasia-Friendly Project Consent Forms

OÉ Gaillimh
NUI Galway

Title of Study: Evaluating Conversation Partner Programmes – perspectives of people with aphasia

CONSENT FORM FOR SERVICE USERS Date: 24th January 2013
(Version number: 2)

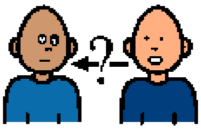
I ____________________________________ (Full name)

of ____ (Address)

Hereby full and freely consent to participate in the above mentioned study. The study aims to include people with aphasia in the evaluation of a Conversation Partner Programme

TICK

I read the information sheet about this research	 	
I asked questions and understand the information		

I had enough time to think about this research	 3 weeks to decide	
I know my participation is voluntary. I **can leave any time**.		
I understand the study is about the conversation partner programme		
I will be involved in the discussion sessions		
I agree to the discussions being audiotaped		
*I understand that anything I say will be kept **confidential***		

I agree that my conversations can be analysed by the researcher		
I agree that my audio recording will be kept safe until it is destroyed	 ⇓	

Signature of participant: ________________________

Witness: ________________________

Date: ________________________

What the researcher did:

I confirm that I have provided an Information Sheet and that consent has been given freely and voluntarily.

Signed:____________ **Status:**____________

Date:_______________

OÉ Gaillimh
NUI Galway

PHOTO Consent Form for participant groups (Version Jan 2013)

Title of Study: Evaluating Conversation Partner Programmes – perspectives of people with aphasia

Please tick the appropriate answer.

I confirm that I have read and understood the Information Leaflet about why photographs will be taken dated ____________ attached

I have had ample opportunity to ask questions all of which have been satisfactorily answered.

☐ **Yes** ☐ **No**

I understand that allowing my photo to be taken and used in this study is entirely **voluntary** and that I may withdraw the permission to use the photo at any time, without giving reason, and without prejudice. ☐ **Yes** ☐ **No**

I understand that I will have the opportunity to see the photograph(s) taken and to decide whether or not I am happy for those photographs to be used.

☐ **Yes** ☐ **No**

I understand that my personal details will remain confidential, my name will not be used to accompany the photograph ☐ **Yes** ☐ **No**

I have been given a copy of the Photo Information Leaflet and this photo Consent form for my records. . ☐ **Yes** ☐ **No**

☐ **I agree to have my photograph taken**

☐ **I do not agree to have my photograph taken**

Participant Name: ________________________

Participant Signature: ______________________

Date: ___________________

To be completed by the Principal Investigator or his nominee.

I the undersigned, have taken the time to fully explain to the above person the nature and purpose of using photos in this study in a manner that he/she could understand. I have explained the risks involved, as well as the possible benefits and have invited him/here to ask questions on any aspect of the study that concerned them.

Name: ________________

Signature: ________________

Date: ________________

Evaluating Conversation Partner Programmes – perspectives of people with aphasia;

Photo Consent form version Jan 2013 for the following groups:

- Group 1 (People with Aphasia)
- Group 2 (Student and Graduate Speech and Language Therapists)
- Group 3 (Speech and Language Therapists working in the PCCC HSE West)

Appendix F PhD researcher analysis of the co-analysis of data co-generated with stakeholder groups

Appendix F1 Example of analysis of Phase 1 data co-generated with the co-researches with aphasia

The PhD researcher:

- Review of Flexible Brainstorm charts and Card Sort Charts co-generated with the co-researchers with aphasia in response to Questions (1-4)
- Repeated review of the digital audio recording taken during each fieldwork session with the co-researches with aphasia (4x 3hr sessions)
- Mapping of the data co-generation and co-analysis process including:
  - Document 1 - Flexible Brainstorm process explained step by step
  - Document 2 - Card Sort process explained step by step
  - Tables created from the Flexible Brainstorm and Card Sort charts which clearly show the elements generated by participants in response to the research questions and the categorisation of these elements:
    - Question 1 (75 separate elements grouped under 8 category headings)
    - Question 2 (47 separate elements grouped under 5 category headings)
    - Question 3a (6 elements)
    - Question 3b (5 elements)
    - Question 4 (17 elements)
- Represented each category heading and its linked elements in the form of a Basic Radical diagram. This diagram shows the relationship of the elements to the category heading.
  - Question 1 (PWA) - (n=8) Basic Radical Diagrams)
  - Question 2 (PWA)-(n=5) Basic Radical Diagrams)
  - Written synthesis of each category and its elements identified by the co-researchers with aphasia including quotes to support the synthesis.

Appendix F2 - NVivo

The PhD researcher used NVivo in this study to manage data (digital Recordings and transcriptions of data) from all stakeholder groups.

NVivo use involved:

- Organisation and signing of a confidentiality agreement with QDA training (company responsible for training on NVivo).
- Import of all audio recordings for all fieldwork sessions with into NVivo.
- Repeated review of digital audio recordings in NVivo to identify sections for partial transcription.
- Training sessions with Ben Meehan (QDA training consultation) to set up groups within NVivo and data sources.
- Transcription of sections of audio recording from PLA sessions with connection to the audio timeline in NVivo.

Transcription was used to:

- Support the synthesis of the co-analysis with quotes from the digital recording e.g. explanation from participant as to what the category heading “It’s like in prison” means.
- Provide examples of co-design e.g.colour coding stickies etc.
- Provide examples of participants acting in the role of co-researchers e.g. directing the research process etc..
- Provide examples of co-researchers debating and discussing potential category headings.
- Provide examples of co-researches evaluations of the research process.

Appendix G Evaluation Data: Symbols Table

Symbols the co-researchers with aphasia chose to represent their involvement in the research

Symbol presented	Symbol meaning explained	How the symbol relates to experiences of acting as a co-researcher	Data Code
Picture of Neil holding a Salmon he caught and a Hershey's bar of chocolate	"…the beauty of the fish. I love fish. I love the salmon. I put lots of them down, away and I love Hershey's chocolate…" (Neil)	"Love the group, beauty of it…beautiful…very much so…very much so" (Neil)	P1S2PWAT
Imelda May Compact Disc	"The sound of music. I always have great time for music and the singing and dancing and ah singing and the music and the best sport ever all the time...music is the best entertainment by far…"(William)	"Thoroughly enjoy it…"(William)	P1S2PWAT
Photograph of Gary and others dressed up in Fancy dress going to a party	"We had great fund dressing up for that picture. We were at a party...we had good craic at the party. When we were picking the clothes we had...my wife would help me. I had. Help the son…"(Gary)	"We got help and we gave back a small piece of help to you that's what I get out of it…"(Gary)	P1S2PWAT

Symbol presented	Symbol meaning explained	How the symbol relates to experiences of acting as a co-researcher	Data Code
A Fossil	"I had joined Open University and I had one year gone and in second year I'm having my stroke…I didn't know what I was doing...I completely forgot all before me...fossils was the last course I done…"(David)	"This [research group] is important to me now...it makes me sad that I can't continue on…well the majority of what's been spoken last week, I feel like …I really can't have a conversation with anyone outside possibly my family because it's most embarrassing. I just can't get the words. I know what I want to say but I just can't..."(David)	P1S2PWAT
Daffodil	"Symbol of hope...the seasons go on regardless of what happens in your life...nature just goes on no matter how our lives have been effected during the year" (Co-facilitator)	"Real sense of hope from the group.. ..something very resilient about human beings that regardless of what happens we keep going. We just continue to trudge on until the next spring comes around again..." (Co-facilitator)	P1S2PWAT

Symbol presented	**Symbol meaning explained**	**How the symbol relates to experiences of acting as a co-researcher**	**Data Code**
Ceramic angel	“Made by an artist who had a stroke and severe aphasia. We worked together for a year while she was in hospital” (Facilitator)	“Reminded me of the group because for me the angel is a symbol of courage and hope. This group have great energy and have been very courageous in sharing how you have learned to live with aphasia. Privilege to be a part of the group” (Facilitator)	P1S2PWAT
Swiss army card pocket knife	“How coresearchers with aphasia reported adapting to life with aphasia. How people learned new ways of living and found their own tools” (Co-facilitator)	“People are their own Swiss army knife – have their own package of tools that help them through different circumstances” (Co-facilitator)	P1S3PWAT
Photograph of a beach in Sligo - West coast of Ireland	“Vastness of Standhill reminder of all shared stories and experiences. Stones on the beach symbols of the hard work we are doing to arrive at consensus about themes” (Facilitator).	“The experiences of coresearchers are vast like the sea. The hard work in the group is creating a calm place of shared understanding and clarity” (Facilitator)	P1S3PWAT

Symbol presented	Symbol meaning explained	How the symbol relates to experiences of acting as a co-researcher	Data Code
iPhone	“iPhone addict and a good way to ‘say hello and thank you and everything and calling and send a message and respond and sharing with others. And I’ve a recollection to hear up and talk with the iPhone and another iPhone” (William)	“We’ve great news…group comfortable, not uneasy and I’m happy” (William)	P1S3PWAT
Picture of planting	“…had to change lifestyle completely…change my way of living...I have as a hobby to change it...that’s what I can do, vegetables…” (David)	“research is about change...I’d like to know what others feel...would they have to change their life style? I have to” (David)	P1S3PWAT
Picture of stacking turf on the bog	“On your own you’re some good in the bog, when you have more people to help you, much better” (Gary)	“Maybe this group, we can talk, most of us anyway...what did I mean? so helping, we can talk here. No interruptions or anything. So for me that is great” (Gary)	P1S3PWAT

Symbol presented	**Symbol meaning explained**	**How the symbol relates to experiences of acting as a co-researcher**	**Data Code**
No Symbol – verbal explanation preferred	"My Life has changed. I try to get going again…I would like to get very independent, go myself" (Anne)	"I think it's great to see the seven of us. We can talk, you can talk about different things and we're just ordinary people at that stage. It isn't you know, the day we mightn't know the word, you were talking about turf and some other day I might say, oh what's turf? And I could be going around the World to know what's turf…we all did it but it's great to have a conversation about it" (Anne)	P1S3PWAT
Coffee menu for deluxe coffee maker	"...it's very very important to me and just in the morning I don't do it all day...first thing in the morning and I'm glad…" (Neil)	"Participating in the group...'it makes me feel better…makes me feel a bit of sanity to myself you know...that kind of thing…very much, very much" (Neil)	P1S3PWAT

Symbol presented	**Symbol meaning explained**	**How the symbol relates to experiences of acting as a co-researcher**	**Data Code**
Pen and Paper	“I’m so happy to write down the names and the numbers….and relaxed…and not too….well able but progress, progress, progressing” (William)	“Participating in the group is helping and reading is progressing and ah fantastic, yes...relaxed” (William)	P1S4PWAT
Book – ‘Talking about Aphasia’	“On the first page it says ‘My mind is 100% all the time, speaking is bad” (Facilitator)	“The group had shared something similar and just hope that through this research you feel your voice is being heard so that you are not just 100% in your mind but you are getting your message across as well” (Facilitator)	P1S4PWAT
Candle	“Hope and Light” (Co-facilitator)	“People were saying last week that there is always hope, they’re improving trying out new things, getting support from people and they’re here helping us do this research. There is always hope and some light somewhere and the candle for me symbolizes that” (Co-facilitator)	P1S4PWAT

Symbol presented	**Symbol meaning explained**	**How the symbol relates to experiences of acting as a co-researcher**	**Data Code**
Circus Ticket	“Circus is fun, absolute fun…” (Neil)	“Just do it as good as you can and as nice as you can and as relaxed as you can; end of story. It is fun…” (Neil)	P1S4PWAT
Toy Tortoise	“The story of the rabbit and tortoise. Facilitator is up there doing work for us…we met a lot of good people along the way...I think I got better” (Gary)	“I think the tortoise wants to be like the hare again…All of us we’ve said, we can speak our mind here. No interruptions at all. So that’s good. Even at home you get interrupted. But no way here” (Gary)	P1S4PWAT
Pencil and paper	“I’m dependent on that and I have a panic button and a phone that only has 3 knobs…”(David)	“Since I’ve been here I have hopefully I have got better. Or not better but better than usual in talking and that means an awful lot to me” (David)	P1S4PWAT

Appendix H Phase 3 data generated by the International Inter-stakeholder group at Connect, London

Appendix H1 Participants; Sessions; PLA Techniques

Participants – The international interstakeholder group included:

- PWA who had participated in the Conversation Partner Programme (CPP) in London (n=2)
- Trained Conversation Partner who had participated in the CPP in London (n=1)
- Conversation Partner Programme Co-ordination/Speech and Language Therapist (n=1)
- PLA Facilitator: Ruth Mc Menamin
- PLA co-facilitator: Edel Tierney

PLA Sessions: Date and Time:

- PLA session 1 - 25th March 2014 (2.00pm – 5.00pm)
- PLA session 2 - 26th March 2014 (10.00am-1.00pm)

PLA Techniques selected by the stakeholder group

- **PLA Flexible Brainstorm Technique**

  The International interstakeholder group chose to use the ‘PLA Flexible Brainstorm’ and ‘Interviewing the technique’ to respond to the three questions agreed with the co-researchers with aphasia in the ‘preparation for London PLA session’ on the 22/01/2014. These questions were designed to extend the Irish research findings to the international stakeholder group. Following an explanation of the PLA Flexible Brainstorm technique the facilitator and co-facilitator placed PLA materials in the centre of the table. Participants selected materials to suit their individual communication preferences and needs. Each participant chose a preferred colour for the pad of stickies. Some chose to write single word(s) and talk about their idea(s), while others chose a picture to represent their intended meaning; the majority who had difficulty writing requested that the facilitators wrote on their behalf. Therefore on instruction from a participat the facilitator wrote verbatim what the person wanted to record and checked that the intended meaning had been captured accurately before the participant placed the stickie on the Flexible Brainstorm chart. There was no restriction on the number of ideas an individual could share; however in the interest of clarity the group agreed that they would only represent one idea on each stickie. The process of sharing and recoding ideas on the Flexible Brainstorm continued until all participants had said all that they wanted to say in response to each of the three questions.

- **Interviewing the Technique**

  Following the co-creation of each Flexible Brainstorm chart in response the three questions presented the group engaged in "Interviewing the technique". Sufficiency of data was determined by "interviewing" the emerging data which involved the group reviewing the completed chart(s) to identify potential gaps. Participants were encouraged by the facilitators to discuss anything surprising or striking about the experiences shared. If any additional information was generated co-researchers were invited to record the new ideas on their colour-coded stickies and place them on the chart. When the group agreed that there was nothing new to add, data saturation was reached and the Flexible Brainstorm was closed.

Appendix H2 PLA charts co-generated by participants represented in table format

Table 1 represents the PLA Flexible Brainstorm chart co-generated by the interstakeholder group in response to **Question 1:** *What do you think about our Conversation Partner Programme findings?*

PLA Session 1: Location - Connect, London: Date - 25th March 2014

Table 1 co-created by the international inter-stakeholder group

Question 1: What do you think about our Conversation Partner Programme findings? **(26 Individual ideas co-generated)**
1. Similar issues about gaps in feedback (re. Conversation Partner Programme)
2. How do you get feedback about the visits from PWA
3. No gaps (between Ireland and UK)
4. Conversation partners with aphasia – Ireland and UK similar
5. Practical organisation of getting evaluations
6. Importance of conversation emerged from research
7. Slightly surprised by findings on clarity of structure. My experience was that the structure was made very clear to everyone involved
8. Agree with all experiences of aphasia
9. Struck me that Conversation Partner experience was very shared in Ireland
10. What about rural areas of Ireland – what do you do (to include people in CPP)?
11. Inclusive research
12. Very similar to Irish experience
13. Ideal World - matching according to interest/hobbies
14. Real – matching according to location and geography
15. Agree with all experiences of aphasia
16. Very similar to my experience in London as a Conversation Partner
17. Having 2 people with stroke and mix of people (discussing the research) is good
18. Agree with shopping experience
19. How do you evaluate what PWA get out of CPP

20. It takes a long time to evaluate > 5years
21. It's good
22. You are doing the same thing over there
23. Agree with their (PWA in Ireland) experience of isolation
24. Greater opportunities for Conversation Partners in London compared to rural Ireland
25. Ireland very strong in capturing people with aphasia perspectives
26. Wider experience of aphasia

Table 2 represents the PLA Flexible Brainstorm chart co-generated by the interstakeholder group in response to **Question 2:** *What do you think about the participatory way of doing research?*

PLA Session 2: Location - Connect, London: Date - 26th March 2014

Table 2 co-created by the international inter-stakeholder group

Question 2: What do you think about the participatory way of doing research? **(33 Individual ideas co-generated).**

1. Learn from each other
2. Share tips and ideas
3. Font 14 – 1.5 spacing – to make print more aphasia friendly
4. Power and beauty in the question
5. Road trip around the Country (to share research findings)
6. Relaxed way of doing research
7. Everyone can have their say
8. This method gives everyone a chance
9. Research results – will they be aphasia friendly too?
10. This approach gives time
11. Will you present this research academically?
12. Not too many words
13. Feels like no barriers between people in groups
14. 1-2 page summary with pictures
15. Aphasia friendly approach to research
16. Still use communication access in write up?
17. You can get your message across
18. It's good
19. There's post-its: one word or three words

20. What about younger people with aphasia?
21. Egalitarian approach
22. Great understanding of aphasia
23. Could we use this technique at Connect?
24. More inclusive
25. Time for Reflection
26. Gathers views with space and time
27. Equality
28. Interesting getting each other’s views
29. It’s different because there is a mix of people around the table
30. Reflective – thought provoking
31. Mixture of views – one by one
32. Equal – opportunity for everyone to have a say
33. Jolly site more interesting to read this type of research

Table 3 represents the PLA Flexible Brainstorm chart co-generated by the interstakeholder group in response to **Question 3:** *What do you think about the people with aphasia experiences of being co-researchers?*
PLA Session 2; Location - Connect, London: Date - 26th March 2014

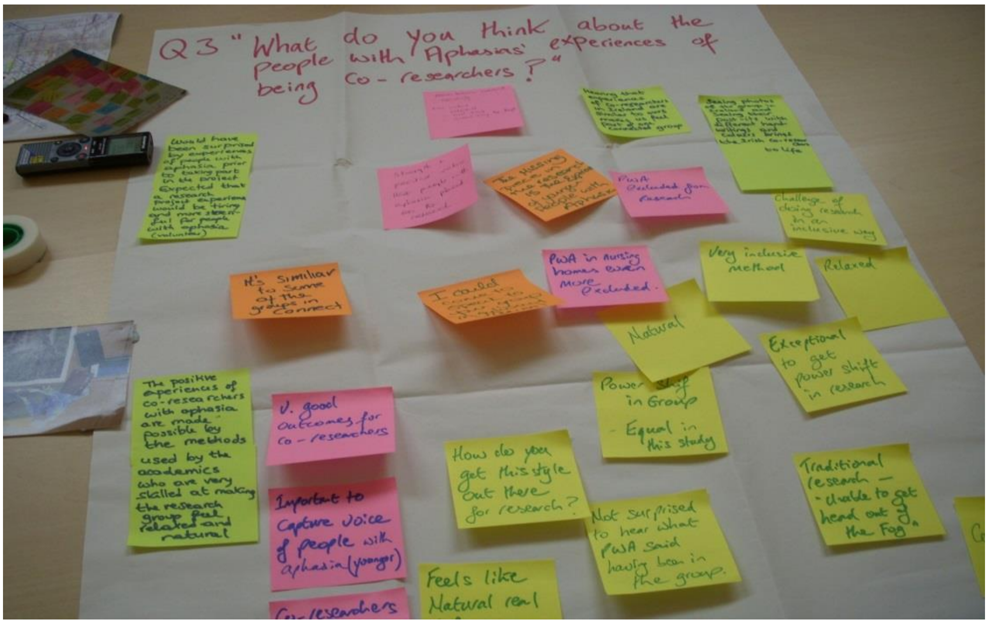
Table 3 co-created by the international inter-stakeholder group

Question 3: What do you think about the people with aphasia experiences of being co-researchers? (**28 Individual ideas co-generated).**

1. Would have been surprised by experiences of PWA prior to taking part in the project.
2. Expected that a research project experience would be tiring and more stressful for PWA
3. It’s similar to some of the groups in Connect
4. The positive experiences of co-researchers with aphasia are made possible by the methods used by the academics who are very skilled at making the research group feel relaxed was natural
5. Very good outcomes for co-researchers
6. Important to capture voice of people with aphasia
7. Co-researchers felt listened to, respected, heard.
8. Feels like natural real-life experience
9. How do you get this style out there for research?

10. I could come to speak to your group in Galway (PWA)
11. Strength and positive value that PWA placed on research
12. Power balanced re-dressed – Equality
13. True value in research
14. Relaxed
15. Had say
16. Hearing that experience of co-researchers in Ireland are similar to ours makes us feel part of the connected group
17. The missing piece of the research is the experience of younger people with aphasia
18. People with aphasia excluded from research
19. PWA in nursing homes even more excluded
20. Natural approach
21. Power shift in group – equal in this study
22. Not surprised to hear what PWA said having been in the group
23. Seeing photos of the group in Ireland and seeing their post-its with different hand writing and colours brings the Irish co-researchers to life
24. Challenge of doing research in an inclusive way
25. Very inclusive methods
26. Exceptional to get power shift in research
27. Traditional research – ‘unable to get head out of the fog’
28. Comfortable

Appendix H3 Photographs of PLA fieldwork with the International Inter-stakeholder Group



Example of a PLA Flexible Brainstorm chart co-created by the group in response to question 3.

Photographic example of the symbols the international inter-stakeholder group chose to reflect their participation in Phase 3 of the research.

Appendix I SL Educators Phase 1 data about Service Learning

Appendix I1 Participants; Sessions; PLA Techniques; Research questions

Participants:

- **Educators** - (n=5) All members of this group had experience of implementing and researching the pedagogical tool Service Learning in their undergraduate curricula (Occupational Therapy; Nursing; Speech and Language Therapy and Geography).
- **PLA Facilitator:** Ruth Mc Menamin
- **PLA Co-facilitator:** Edel Tierney

PLA Sessions: Date and Time:

- PLA session 1 - 17th December 2013 (2.00pm – 5.00pm)
- PLA session 2 - 18th December 2013 (10.00am-1.00pm)

PLA Techniques selected by the stakeholder group

- PLA Flexible Brainstorm Technique (Questions 1-3)
- PLA Card Sort Technique (Questions 1-3)
- PLA Direct Ranking Technique (Question 1)
- Interviewing the Technique (Questions 1-3)

Research Questions:

The suggestions questions for session 1 and session 2 with Service Learning Educators scheduled for the 17th and 18th December 2013 aimed explore stakeholders emic experiences and perceptions of Service Learning as a pedagogical tool. The suggested questions included:

Question 1: If you were telling a good friend about Service Learning what would you say/think of?

Question 2: If you were telling a friend about courses/modules that are particularly suited to service learning what would you say/think of?

Question 3: If you were telling a colleague about when to use service learning as a teaching approach what would you say/think of?

Prompt: What would you say is the best use of SL/ when is it not suitable

Question 4: If you were telling a colleague about the impacts of Service Learning experiences for students what would you say/think of?

Prompt: What are the positive impacts? What are the negative impacts?

These questions were considred by the group at the beginning of session 1 and no revisions or changes were considered necessary.

Reflections on the research questions following Session 1:

The PhD researcher re-considered the planned research questions (2-4 above) following a review of the audio recording from session 1(17th Dec 2013) and the PLA charts co-created in response to the 1st research question: *"If you were telling a good friend about Service Learning what would you say/think of?"* Following critical reflection and peer de-briefing with the co-facilitator the PhD researcher re-designed the planned questions (2-4) and re-placed them with two new questions for consideration by the group at the start of session 2. The SL educators had the opportunity to express their opinion/ideas about the suggested changes to the questions in light of the co-generated data captured on the PLA charts. Following a review of the charts all agreed with the suggested amendments. Therefore the SL educators responded to the following two questions in addition to question 1.

Question 2: *'In your experience what courses/modules are best suited to service learning?'*

Question 3: *'In your experience what are the impacts of service learning for all stakeholders?*

Appendix I2 PLA charts represented in Table Format

Table 1 represents the PLA Flexible Brainstorm chart categorised using the PLA Card Sort technique. The SL educators linked the **73 elements** identified in the Flexible Brainstorm in response to **Question 1:** *"If you were telling a good friend about Service Learning what kinds of things would you say/think of?"* and grouped them under **10 category headings** which were negotiated and agreed within the group.

PLA Session 1: Location – NUI, Galway: Date - 13th December 2013

Table 1 co-created by SL educators group

Relationships *(2 votes)*	**Partnership** *(8 votes)*	**Reflection** *(4 votes)*	**Values** *(5 votes)*	**Resource Dependent** *(2 votes)*	**Student Learning Process** *(8 votes)*	**Student Learning Outcomes** *(7 votes)*	**Wider goals of Service Learning** *(4 votes)*	**Challenges for Educators** *(5 votes)*	**What is Service Learning?** *(5 votes)*
Changes relationships between students themselves	Partnership with community groups	Critical Reflection as core (from students on experience in context)	Value based (personal)	Individual led-sustainability	Real world context	Learning what you can't learn from books	Broader understanding of health	Worrying time for me while students are abroad	Don't use the term service learning – 'Student engaged learning'
Changes the student-teacher relationship	Partnership as a process	Reflection	(Explicit aim) Citizenship / civic engagement	Heavy workload - ALL	Real life experience	The students 'grow up' as a result of the experience	Helps fulfil civic responsibility of University	What will happen when a major problem/incident arises	'Compulsory volunteering' as an alternative term to SL
Walking tight rope	Collaborative/ work partnerships	Reflection is key (student experience; partner experience; co-ordinator	Social Justice	Time consuming - ALL	Learning through experience	Life changing experience for students	Social change	Disappointment (negative attitude to SL – students)	America (term SL associated with the US)

Relationships ***(2 votes)***	**Partnership** ***(8 votes)***	**Reflection** ***(4 votes)***	**Values** ***(5 votes)***	**Resource Dependent** ***(2 votes)***	**Student Learning Process** ***(8 votes)***	**Student Learning Outcomes** ***(7 votes)***	**Wider goals of Service Learning** ***(4 votes)***	**Challenges for Educators** ***(5 votes)***	**What is Service Learning?** ***(5 votes)***
		experience)							
Boundaries – stretches/shifts boundaries	Collaboration - Dynamic	Critical Thinking	Community based development	Not resource neutral	Engaged Learning	Awareness of power	Enhances agency	Getting it/ not getting it (across different groups i.e. ALL)	Community and how is it defined /included
Peer monitoring at de-briefing	Requires good partnership building skills	Reflection – it's difficult	Community as resource	Stretched community partners	Active Learning	Enhanced personal development for students	Develop practical insight ALL (students, staff partners)	May reinforce negative attitudes	SL is not volunteering – its compulsory and assessed
	Reciprocity is key – giving back to the community is very important	Reflection as an outcome	Wish I had that opportunity when I was a student	Sustainability ?	Developing and applying practical skills	Problem solving	Critical citizenship for ALL	Lack of institutional support	Optional for some courses/students
			Something Special in Higher	Tensions between expectations	Working with community groups –	Personal development e.g. moral	Enhanced democratic participation		Connected to curriculum (credit

Relationships ***(2 votes)***	**Partnership** ***(8 votes)***	**Reflection** ***(4 votes)***	**Values** ***(5 votes)***	**Resource Dependent** ***(2 votes)***	**Student Learning Process** ***(8 votes)***	**Student Learning Outcomes** ***(7 votes)***	**Wider goals of Service Learning** ***(4 votes)***	**Challenges for Educators** ***(5 votes)***	**What is Service Learning?** ***(5 votes)***
			Education	Industrial Relation Issues	students would not have contact with otherwise	values and skills	for ALL		bearing)
				Student autonomy and responsibility	Enjoyment Student and staff	Culture and health impacts Cultural diversity			Continuum (of models e.g. translational – transactional)
						Insight (students)			Context specific (geography/institution)
									Assessments differentiates it from volunteering
									Discipline specific –

Relationships ***(2 votes)***	**Partnership** ***(8 votes)***	**Reflection** ***(4 votes)***	**Values** ***(5 votes)***	**Resource Dependent** ***(2 votes)***	**Student Learning Process** ***(8 votes)***	**Student Learning Outcomes** ***(7 votes)***	**Wider goals of Service Learning** ***(4 votes)***	**Challenges for Educators** ***(5 votes)***	**What is Service Learning?** ***(5 votes)***
									(concrete examples to illustrate)

PLA Session 1: Location – NUI, Galway: Date - 13th December 2013

The co-researchers selected the PLA Direct Ranking technique to express priorities and preferences and indicate categories of equal weighting for the identified categories co-generated in response to Question 1.

Results of SL educators PLA direct ranking technique in order of priority:

Partnership – 8 votes
Student Learning Process – 8 votes
Student learning outcomes – 7 votes
Values – 5 votes
Challenges for educators – 5 votes
What is Service Learning? – 5 votes
Reflection – 4 votes
Wider goals of Service Learning – 4 votes
Relationship – 2 votes
Resource dependent – 2 votes

Table 2 represents the PLA Flexible Brainstorm chart categorised using the PLA Card Sort technique. The SL educators linked the **52 elements** identified in the Flexible Brainstorm in response to **Question 2:** *"In your experience what courses/modules are best suited to Service Learning?"* and grouped them under **9 category headings** which were negotiated and agreed within the group.

PLA Session 2: Location – NUI, Galway: Date - 14th December 2013

Table 2 co-created by SL educators group

Reflective Space	**Operational Issues**	**Which students?**	**Theory meets Practice**	**Types of Courses**	**Values**	**Staff Attributes**	**Community as Partners/ Collaborators**	**Institutional Context**
Reflection Outcomes: Problem solving Power dynamic	Opportunities for flexible timetabling	? Mature students – socially /emotionally mature	Where skills knowledge can be applied	Professional programmes may have more immediate/obvious applications	Where concept of social change/justice are recognised as relevant	Where course leaders have skills in engagement	When community can identify relevant needs	Long term commitment
Reflection already part of education	Small numbers	Potential for all levels e.g. 1st year vs. 4th year vs. postgrad	That benefit students in articulating their	Vocational/ professional preparation	Value based e.g. social justice promote diversity	Courses with engagement champions (academic)	Project of use to community	Where academics are are supported?

Reflective Space	**Operational Issues**	**Which students?**	**Theory meets Practice**	**Types of Courses**	**Values**	**Staff Attributes**	**Community as Partners/ Collaborators**	**Institutional Context**
			knowledge plus expertise					
Space for critical discussion of values which underpin theory and practice	Modules with small student numbers	Later years of a course	at can bring a link between class based and practical contexts	Health Care Courses	Exploring everyday societal issues	With staff who can promote and assess reflection	Opportunity to include community as educator	Where the academic workload is acknowledged and rewarded
Where there is time allocated to reflection	Long term commitment	SL embedded across the curriculum i.e. more	provide real world experience in academic	Professional development modules	Dependent on the overall goals and anticipated learning		People with aphasia as Teachers	Affirming context

Reflective Space	**Operational Issues**	**Which students?**	**Theory meets Practice**	**Types of Courses**	**Values**	**Staff Attributes**	**Community as Partners/ Collaborators**	**Institutional Context**
		than one module	programme		outcomes/ courses			
Where reflective practice is valued	Modules which cross semester	Range of experiences across a course	here students may find themselves in an applied work context in the future	Potentially all courses – responsible citizens	? Education for critical engagement as value driven education			Challenging institutional philosophy on Service Learning
That test students expectations of themselves	With options (elective)		odules with a 'human dimension'	All courses have potential				Where institutional opportunities translates into

Reflective Space	**Operational Issues**	**Which students?**	**Theory meets Practice**	**Types of Courses**	**Values**	**Staff Attributes**	**Community as Partners/ Collaborators**	**Institutional Context**
from module outline/content								action
Identity gain – identity loss – new identity formation	Project doable in time frame			Interdisciplinary education				
	That fit into a voluntary space via a v community (IR)							
	Where there is academic credit?							

Table 3 represents the PLA Flexible Brainstorm chart categorised using the PLA Card Sort technique. The SL educators linked the **66 elements** identified in the Flexible Brainstorm in response to **Question 3:** ***"In your experience what are the impacts of Service Learning for all Stakeholders?"*** and grouped them under **8 category headings** which were negotiated and agreed within the group.

PLA Session 2: Location – NUI, Galway: Date - 14th December 2013

Table 3 co-created by SL educators group

Networking	**Impacts for Academics**	**Potential Impact for wider society**	**Outcomes for students**	**Impacts for Community**	**Benefits for University**	**School/ Discipline Impacts**	**Influence on Higher Education**
Engaged via research – relevant to community	Academics get out and about	Employers get more experienced/confident graduates	Enhances students CVs	Low cost labour for community	Positive PR	Academic programmes are enhanced 'widened'	Increased awareness of civic mission of Higher Education
Academics get to work with other engagement	Fodder for teaching	More socially aware student	Liberating for students	Feelings of competence	University – the quad gets Kudos	Diversifies learning and teaching	

Networking	**Impacts for Academics**	**Potential Impact for wider society**	**Outcomes for students**	**Impacts for Community**	**Benefits for University**	**School/ Discipline Impacts**	**Influence on Higher Education**
scholars							
Builds links for further collaboration e.g. research/ Community based research	Fodder for publication	Capacity of students of ‘agents of change is acknowledged by community	Enhance professional development (students)	Gives people with aphasia a meaningful role	Sharing knowledge	Makes programme attractive	
Community builds partnership with University	Enhanced potential for research funding	Social Change	Increased confidence and competence	Community need is addresses			
Opens university to community	Affirming – staff and students	Critically engaged citizens	Fun for students	Fun for community			

Networking	**Impacts for Academics**	**Potential Impact for wider society**	**Outcomes for students**	**Impacts for Community**	**Benefits for University**	**School/ Discipline Impacts**	**Influence on Higher Education**
Opening University to wider audience	Teaching satisfaction	More socially responsible graduates	Enjoyable for students	Opportunity to influence curriculum (from community)			
Shifting relationships between academics	Real examples for teachers to cite	Parents of (some students) have a connection to the learning	Students CV enhanced – employers feedback	Community-university-students – sharing knowledge resources			
SL as a gateway	Time consuming for academics	May not know impact for some time	Leaving the bubble - students	Leaving the bubble – community			
Relationship		Life rather than	Students aware	(Community)			

Networking	**Impacts for Academics**	**Potential Impact for wider society**	**Outcomes for students**	**Impacts for Community**	**Benefits for University**	**School/ Discipline Impacts**	**Influence on Higher Education**
Breakdown	Enjoyable for staff	diagnosis perspective	of class based learning	Needs are not addressed			
	Leaving the bubble - academics		Students more aware of own capabilities and skills	Community feels overwhelmed			
	Fun for academics		Some students don't get it	Addresses a (community) need			
	Time commitment staff		More autonomous professionals (students)				
	Challenges assumptions/biases		Challenge assumptions/ biases				

Networking	**Impacts for Academics**	**Potential Impact for wider society**	**Outcomes for students**	**Impacts for Community**	**Benefits for University**	**School/ Discipline Impacts**	**Influence on Higher Education**
	Opportunity lost - publication		Time commitments students				
	Professional reputation damaged		Students don't achieve goals – emotional disappointment				

Appendix I3 Photographs of PLA fieldwork with Service Learning Educators

Example of a PLA Flexible Brainstorm chart created in response to question 1: *"If you were telling a good friend about Service Learning what kinds of things would you say/think of?"*

Example of a PLA Flexible Card Sort chart created in response to the Question 1: *"If you were telling a good friend about Service Learning what kinds of things would you say/think of?"*

Example of a PLA Direct Ranking chart created to prioritise data from the Card Sort chart co-created in response to question 1. *Co-researchers voted according to a single criterion i.e. most important to least important information about SL.*

Appendix J Dissemination Activities

Conference Presentations:

- **MC MENAMIN, R.**, MC GRATH, M., CANTILLON, P. & MAC FARLANE, A. “Exploring the Impacts of Service Learning: A critical Review of the Literature” presented as a research platform presentation at *AMEE (International Association for Medical Education) conference, 26th-28th August 2013 Prague CZECH Republic.*

- **MC MENAMIN, R.** & MAC FARLANE, A. ‘Can participatory research methods be used to include People with aphasia as co-researchers in the evaluation of a primary healthcare intervention? presented as a platform presentation at *The Association of University Departments of General Practice in Ireland Annual Scientific Meeting (AUDGPI), 6-7th March 2014 University College Cork, Ireland*

- **MC MENAMIN, R.**, MC GRATH, M., CANTILLON, P. & MAC FARLANE, A. 2014. Training socially responsive healthcare graduates: Is Service Learning an effective educational approach? Presented as a poster presentation at *The Association of University Departments of General Practice in Ireland Annual Scientific Meeting (AUDGPI). University College Cork, Ireland*

- **MC MENAMIN, R**.; TIERNEY, E.; MAC FARLANE, A. (2014) ‘We all said our say’ – People with aphasia as co-researchers in the development of evaluation criteria for the conversation partner programme: a participatory research study” Royal College of Speech and Language Therapists Conference (RCSLT) ‘Mind the Gap: Putting research into practice’ 17-18 September 2014, University of Leeds, United Kingdom.

- **MC MENAMIN R**., MC GRATH M., CANTILLON P., MAC FARLANE A. (2014) "Training socially responsive healthcare graduates: Is service learning an effective educational approach?” Royal College of Speech and Language Therapists Conference (RCSLT) ‘Mind the Gap: Putting research into practice’ 17-18 September 2014, University of Leeds, United Kingdom.

- **MC MENAMIN, R**. & MAC FARLANE, A. (2014) “Participatory approaches in primary healthcare research: Towards including the excluded” Royal College of Speech and Language Therapists Conference (RCSLT) ‘Mind the Gap: Putting research into practice’ 17-18 September 2014, University of Leeds, United Kingdom.

- **MC MENAMIN, R**.; TIERNEY, E.; MAC FARLANE, “Reflections on the use of participatory research methods to include stroke survivors and primary care professionals as co-researchers in the evaluation of a primary care intervention” platform presentation at The Association of University Departments of General Practice in Ireland Annual Scientific Meeting (AUDGPI), 5-6th March 2015 Queens University Belfast, Northern Ireland.

- **MC MENAMIN, R**.; TIERNEY, E.; MAC FARLANE, A. “‘Let us talk’ - Including people with communication challenges as co-researchers in service evaluation: A participatory health research study” RESTORE Conference, March 26TH -27TH 2015, University of Limerick, Ireland.

Forthcoming conferences:

- **MC MENAMIN, R**.; TIERNEY, E.; MAC FARLANE, A. (2016). Invited speaker at the Public and Patient Involvement in Research; Summer school, June 21st (2016),University of Limerick, Ireland.

- **MC MENAMIN, R**.; GRIFFIN, M.; TIERNEY, E.; MAC FARLANE, A. (2016) Invited speaker at the Public and Patient Involvement (PPI) in research. Working as partners, making a difference conference 27th April (2016). National University of Ireland, Galway, Ireland.

- **MC MENAMIN, R**.; TIERNEY, E.; MAC FARLANE, A. (2016) “Can participatory research methods be used to include people with aphasia as co-researchers in service evaluation?” 30th World Congress of the International Association of Logopedics and Phoniatrics (IALP), 21st - 25th August, Dublin, Ireland.

- **MC MENAMIN R**., MC GRATH M., CANTILLON P., MAC FARLANE A. (2016) "Training socially responsive Speech and Language Therapists: Is service learning an effective educational approach?" 30th World Congress of the International Association of Logopedics and Phoniatrics (IALP), 21st -25th August, Dublin, Ireland.

Additional Presentations

- **MC MENAMIN, R**.; TIERNEY, E.; MAC FARLANE, A. "Including people with communication challenges as co-researchers in service evaluation: A participatory health research study" HRB SPHeRE Peer-Learning Event 2nd October 2015, Trinity College Dublin.

- "Researching Primary Care" Health Matters (National Staff Magazine of the Health Services Executive) Vol. 9 Issue 1 Spring 2013 p.19

- **MC MENAMIN, R**. & MAC FARLANE, A. (2014) 'We all said our say' – People with aphasia as co-researchers in the development of evaluation criteria for the conversation partner programme: a participatory research study" DVD presentation; September 15th-18th (2014) at Mc Gill University, Montreal. Presentation available via PRAM website (http://pram.mcgill.ca/seminars/index.php)

- **MC MENAMIN, R**.; TIERNEY, E.; MAC FARLANE, A. (2015) 'Can participatory research methods be used to include people with aphasia as co-researchers in the evaluation of a primary healthcare intervention?' Clinical Therapies Research Seminar Series, May 15th 2015, University of Limerick, Ireland.

- **MC MENAMIN, R.** Invited presentation at the Annual Network Partners meeting (2012) Connect, London, December 2012

- **MC MENAMIN, R.** Invited presentation at the Annual Network Partners meeting (2014) Connect, London, January, 2014

Research Meetings

I presented regular updates about my PhD research work at the Primary Health Care Research Group, Graduate Entry Medical School, University of Limerick, Ireland on the following dates:

- 14th October 2013
- 11th November 2013
- 13th December 2013
- 13th January 2014
- 10th February 2014
- 14th April 2014
- 19th May 2014
- 16th June 2014
- 25th-26th September 2014
- 17th November 2014
- 23rd February 2015
- 18th May 2015

Appendix K PhD Requirements

Ethical Approval

National University *of* Ireland, Galway
Ollscoil na hÉireann, Gaillimh

Ref: 10/NOV/22
15th December 2010

Ms Ruth McMenamin
Discipline of Speech and Language Therapy
School of Health Sciences
Aras Moyola
NUI Galway

Dear Ms McMenamin

RE: Ethical Approval for "Evaluating Conversation Partner Programmes - perspectives of people with aphasia"

I write to you regarding the above proposal which was submitted for Ethical review. Having reviewed your response to my letter, I am pleased to inform you that your proposal has been granted **APPROVAL**.

All NUI Galway Research Ethic Committee approval is given subject to the Principal Investigator submitting an annual report to the Committee. The first report is due on or before 31st November 2011. Please see section 7 of the REC's Standard Operating Procedures for further details which also includes other instances where you are required to report to the REC.

Yours Sincerely

Dr Saoirse NicGabhainn
Chairperson
Research Ethics Committee

OFFICE OF THE VICE-PRESIDENT FOR RESEARCH
15 DEC 2010
NUI, GALWAY

Office of the Vice-President for Research
Oifig an Leas-Uachtaráin um Thaighde

National University of Ireland, Galway,
Galway, Ireland.
Founded in 1845

Tel: +353 91 495312
Fax: +353 91 494591
e-mail: vpresearch@nuigalway.ie

Article Based PhD – NUI, Galway requirements

The National University of Ireland, Galway require that the PhD candidate submit “a minimum of three original, published (peer reviewed) research papers in international leading journals of appropriate impact factor for the area of research…in addition, the PhD candidate would normally be the first or leading author on the major part of the work. Joint publications may be included but the candidate must make explicit, their contribution to the work”. (Ref: University Guidelines for research degree programmes (2014; section 6.2.6 p 20)

PhD governance requirements

All PhD researchers registered at NUI, Galway are required to have a GRC committee monitoring PhD progress in accordance with University guidelines. I was fortunate to have *both* a steering committee and a Graduate Research Committee (GRC) to help me shape and achieve the aims of my PhD. During the lifetime of my PhD I submitted four detailed progress reports to my GRC and attended four annual meetings. My GRC committee assessed my progress, ensured that all project milestones were on target and formally approved progression of my PhD research annually. The format of my steering committee was less formal than the GRC and involved an agreed agenda, PowerPoint presentation of the research stages and discussion about targets and deliverables. My steering committee acted in an advisory capacity between meetings as required. I found this very beneficial and I received valuable advice from both my steering committee and GRC at different stages of my project e.g. in relation to study design, methodological rigour, dissemination and publication. My academic supervisor Professor Anne Mac Farlane attended all meetings of both committees and her contribution was invaluable in the development and completion of my PhD research.

Acknowledgement of Funding Agency

This research was partly funded by The Health Research Board (HRB) under ***HPF/2010/60 for Ruth McMenamin.*** The PhD researcher submitted all annual and final mandatory reports to the funding agency on schedule including annual (1) Scientific and (2) Financial reports and a final report on (3) Outcomes and Impacts. These reports were completed in collaboration

with Research Accounts at NUI, Galway and Professor Anne Mac Farlane (PhD academic supervisor).