

**Evaluation of the  
Community Engaged Scholars Programme (CES-P) at  
National University of Ireland, Galway**

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## Executive Summary

The Community Engaged Scholars Programme (CES-P) at NUI Galway is a new initiative introduced by PPI Ignite @ NUI Galway. It is based on a programme originally developed in the US at the Medical University of South Carolina (MUSC). The programme aims to build partnerships between researchers and community organisations, to facilitate ongoing research that is underpinned by the principles of PPI and aims to improve public health.

The first Irish pilot of CES-P was delivered by PPI Ignite @ NUI Galway in 2019/2020. It was funded through the HRB's Knowledge Exchange and Dissemination Scheme (KEDS). A cohort of three community-academic partnerships participated in the pilot CES-P (NUI Galway). This report, commissioned by PPI Ignite @ NUI Galway, is an evaluation of the pilot CES-P (NUI Galway). The main objectives of the evaluation were to: (1) provide an understanding of the adoption, implementation and delivery of CES-P in an Irish context, and (2) assess the impact of the CES-P.

Public and patient involvement (PPI) in research, a term commonly used in Ireland to describe stakeholder engagement in the research process, involves research that is done 'with' or 'by' the public rather than 'to', 'about' or 'for' them (INVOLVE, 2007). In community-academic partnerships, which draw on traditions of *community based participatory research* (CBPR), the emphasis is on joint decision-making between the community and academic partners, with the community organisation having a defined role and involved throughout the research process. Both PPI and CBPR are underpinned by a set of principles. There are many advantages to community-academic partners. However, as they can be challenging, much work has gone into identifying factors and strategies that facilitate community-academic partnerships.

Training to prepare researchers and community partners for PPI and equip them with the knowledge and skills to participate as equal partners has long been recommended as a strategy. Small grants have been identified as a useful way to promote and foster community-academic partnerships. The original CES-P developed at MUSC incorporates training and seed funding as well other strategies such as mentoring to facilitate community-academic partnerships, and these are also key components of CES-P (NUI Galway). A key element of both programmes is co-design and co-production of research by the academic-community partnership addressing an agreed research question of interest to both partners. The partnerships complete a small research study, adopting PPI across all phases, and share results with a range of stakeholders.

This evaluation of the pilot CES-P (NUI Galway) included a process and an impact evaluation. It adopted a mixed-methods approach, including a documentary review, interviews with staff at PPI Ignite @ NUI Galway, focus groups with members of the community-academic partnerships participating in the programme, and analysis of evaluation forms completed by community and academic partners. The study evaluated the competitive selection process, the interactive training, and mentoring. It examined how the partnerships conducted their research projects and evaluated how they worked together to make joint decisions across the entire cycle of their research projects. It assessed both beneficial and challenging or negative impacts.

### Competitive selection process

The evaluation found that the competitive selection process worked well and that it was an advantage for PPI Ignite @ NUI Galway to have MUSC involved in and input into the review process. Despite tight schedules and logistical challenges, PPI Ignite @ NUI Galway succeeded in incorporating PPI into the review process, a process that was highly regarded by the public reviewers participating. This is commendable. A somewhat contradictory aspect of CES-P (NUI Galway) is that community and academic partners are expected to work together in a partnership to collaboratively prepare the application and identify research priorities and questions before training on partnership building.

The three partnerships selected to participate in CES-P were partnerships between:

- The Irish ME/CFS Association (<http://www.irishmecfs.org/>), represented by Orla Ní Chomhraí and Tom Kindlon, and Dr John Cullinan, a health economist.
- A group of psychologists, led by Dr Oonagh Meade, and CROÍ (<https://croi.ie>), represented by Denise Dunne and Irene Gibson.
- Dr Ruth McMenamin, a lecturer in speech & language therapy at NUI Galway and the Irish Heart Foundation, represented by Martina Greene and the Ballinasloe Stroke Support Group.

A key finding of the evaluation is the many differences between the partnerships, with regard to: the type of partnership; the health conditions under study and, hence, the associated community of interest; researchers' disciplinary backgrounds; the ways in which members of the community of interest were involved in the partnership; partners' prior experience of working together; and the nature of the research project. More details about the three partnerships and differences between them are provided in the full report.

### Interactive training component

Like the original CES-P (MUSC), interactive training is an integral part of CES-P (NUI Galway). CES-P (NUI Galway) is designed around six workshops on: CBPR Partnership Readiness; research ethics; research methods, PPI in health research, and sharing research results. It has a smaller number of training sessions than CES-P (MUSC) with some differences in the topics covered and time allocated.

The workshop on CBPR Partnership Readiness was strongly informed by CES-P (MUSC) and delivered by a visiting Professor from MUSC. Its focus on CBPR principles, the exercises undertaken, and the resources introduced (e.g. Are We Ready? Toolkit, logic models) were identified by community and academic partners as being particularly important. The workshop had a very positive impact on community and academic partners and on the relationship between the partners. However, there was consensus that more time should be allocated for training on this topic.

The workshop on research ethics provided an overview of this topic and addressed issues such as informed consent and GDPR legislation. The workshop was of most value to and yielded the most benefit for community partners. Both community and academic partners expressed a desire for the workshop to be more practical and suggested ways by which this could be achieved. The workshop on research methods covered both quantitative and qualitative research methods. Participants had differing knowledge, experience and skill

sets. For participants with little previous experience of qualitative research, the most important aspect of the workshop was learning about qualitative research methods, and their value and usefulness for PPI in research. This learning had a positive impact on community and academic partners alike and had an impact on partnerships' research design, particularly in one partnership.

The interactive workshop on PPI in health research, which covered several different aspects of PPI in research, contributed to an increased knowledge and understanding of PPI in research among community and academic partners. The workshop on sharing research results, which was delayed due to public health restrictions relating to the COVID-19 pandemic, was very positively evaluated by the community and academic partners.

Overall, the CES-P (NUI Galway) workshops were rated very positively by community and academic partners. In response to heavy workloads, demanding schedules and needs of participants with health conditions, the training programme was delivered flexibly. This was highly valued by participants. There was a desire on the part of community and academic partners for the training to become even more inclusive of and accommodate the specific needs of people living with the health conditions on which the partnerships' research focuses. Participants would also welcome greater facilitation of peer support between the partnerships throughout CES-P.

#### Research Projects, underpinned by PPI

In each partnership, the community and academic partners conducted a research project, underpinned by PPI principles, aimed at improving the health and wellbeing of people living with the condition of interest (community of interest). The partnerships involved their community of interest in varying ways, which, in turn, influenced the ways in which the partnerships used PPI in their research projects. The evaluation highlighted that where a community organisation, but not the community of interest, is involved as a partner, the community of interest tends to be excluded from key decisions taken by the partnership around identifying the priority area of focus, refining research questions or research design.

Each of the three partnerships completed and submitted an ethics application to the university REC. While this process was fairly straightforward for two partnerships, the third experienced delays in obtaining ethical approval, and delayed subsequent stages of their research. Navigating the ethical approval process can present challenges, especially for research projects taking a participatory approach and involving 'vulnerable groups.' This is not unique to CES-P (NUI Galway). Potentially, PPI Ignite @ NUI Galway could learn from steps taken at MUSC to address such challenges. The COVID-19 pandemic was a challenge that no-one could have anticipated at the start of CES-P (NUI Galway).

All three partnerships used qualitative research approaches in their research projects. However, they took different approaches to data collection and analysis. The extent to which data collection and analysis was collaborative varied, highlighting that more attention could be placed in future iterations of CES-P (NUI Galway) on training on collaborative data collection and analysis. This may need to be accompanied by training or mentoring to equip community and academic partners with the skills to do this.



The mentoring component in CES-P (NUI Galway) proved to be extremely important in upskilling the community and academic partners in one partnership, equipping them with the necessary skills to carry out qualitative research. Potentially, mentorship could also be used in CES-P (NUI Galway) to support partnerships to develop skills to effectively facilitate PPI groups, another area identified by partners as a skills gap.

CES-P (NUI Galway) had many positive impacts on the researchers, community partners, on the relationships between the community and academic partners, and on the research process. There were positive, but unanticipated, impacts on the community organisation and the university. While the benefits of CES-P (NUI Galway) far-outweighed the challenging or negative impacts, it will be crucial that PPI Ignite @ NUI Galway takes steps to mitigate any challenging or negative impacts in future iterations of CES-P (NUI Galway).

The funding model adopted by CES-P (NUI Galway) is to award small grants to support community-academic partnerships to undertake pilot projects and prepare a larger grant proposal. Using small grants to foster community-academic partnerships is not without its challenges (Kegler et al., 2016). Building partnerships and undertaking PPI in research takes time, and the additional time demands was one of the biggest challenges for partnerships, especially for academic and community partners whose workloads were already high and who had competing demands. The time required to build partnerships and undertake a research project should not be underestimated.

With micro-funding, it may be expected that only modest results will be achieved. Nevertheless, a model of CES-P, based on the original CES-P (MUSC), had been successfully developed and implemented at NUI Galway, and the staff at PPI Ignite @ NUI Galway have now experienced and developed expertise in delivering such a programme. There is an opportunity to build on the lessons learned from the development and implementation for the next iteration of CES-P (NUI Galway). As a result, CES-P (NUI Galway) has grown a small cadre of academic researchers in NUI Galway and staff in community organisations who have the knowledge, experience and skills to build community and academic partnerships and undertake PPI in research. These community and academic partners have an opportunity to build on the research undertaken to date and secure grant funding to take their research further. There is also the potential for this cadre of community and academic partners to support and mentor the next cohort of community-academic partnerships grant-funded through CES-P (NUI Galway). The expertise gained and the lessons learned (see overleaf) by the organising team and the community and academic partners participating in CES-P (NUI Galway) should not be lost. CES-P (NUI Galway) is a unique programme in Ireland that will be of interest to and huge value to academic and community partners who are genuinely interested in working together and using a CBPR approach to address issues of importance to people living with a variety of health conditions.

# **Pilot Community-Engaged Scholars Programme (CES-P) at National University of Ireland, Galway (NUI Galway)**

## **Lessons from an Evaluation**

### **General**

- Adapting the multi-component, Community-engaged Scholars Programme to an Irish context and implementing it is a complex undertaking.
- The involvement, at key points, of colleagues with in-depth knowledge and experience of the original CES-P, and interest in creating effective community-academic partnership, is a real advantage when implementing a programme such as this in a new context. Key points include the review process and facilitation of training on community-academic partnerships.
- Staff at PPI Ignite @ NUI Galway have developed expertise in delivering CES-P in an Irish context.
- CES-P requires an 18-month timeframe for delivery at least.

### **Application and competitive selection process**

- CES-P (NUI Galway) grant call information session is essential not only to communicate information about the grant application process, but also to inform potential applicants about CES-P, how it works and requirements, e.g., commitment from community and academic partners to attend interactive training sessions.
- While there are challenges associated with incorporating a public review into the competitive selection process, it is feasible, and worthwhile, if done well.
- Public reviewers would welcome an opportunity to meet with applicants as part of the review process, resources permitting.

### **Community-academic partnerships**

- CES-P (NUI Galway) was the catalyst for the formation of one new community-academic partnership and provided the opportunity for two existing partners to work together collaboratively on a research project underpinned by PPI for the first time.
- There are many differences between community-academic partnerships. Differences relate to the number of partners; the type of community organisation; the health conditions under study and, hence, the associated community of interest; the disciplinary backgrounds of researchers; the ways in which members of the community of interest are involved in the partnership; partners' prior experience of working together; partner's prior experience of PPI in research; and the nature of the research project.
- The characteristics of community-academic partnerships have implications for the way in which PPI is included in research projects.

### **CES-P (NUI Galway) interactive training**

#### **Workshop on CBPR Partnership Readiness**

- The workshop on CBPR Partnership Readiness is a critical component of CES-P (NUI Galway) and extending this element of the interactive training is advisable
- The Are We Ready? Toolkit is an extremely useful resource for community-academic partnerships, but needs to be adapted to the Irish context

- Logic modelling and developing a Memorandum of Understanding are useful tools for community-academic partnerships
- Partnerships' assessment of their 'goodness of fit' impacted positively on community and academic partners, the partnership and the research process.
- Given the heavy workloads and competing demands of some community and academic partners, and the negative impacts that this can have, assessment of the capacity of partners to undertake training and collaborate on research projects underpinned by PPI is of vital importance at this stage of CES-P (NUI Galway).

#### Workshop on research ethics

- The workshop on research ethics is particularly useful for community partners.
- Community partners may need additional and ongoing support with research ethics from academic partners throughout the research process
- Incorporating more practical elements into the workshop on research ethics in future iterations of CES-P (NUI Galway) would be beneficial for community partners

#### Workshop on Research Methods

- Including quantitative and qualitative research methods in the workshop on research methods has its merits, but can be challenging because of the varying levels of knowledge, skills and experience among community and academic partners. Challenges may be overcome to some extent by tailoring the workshop to the needs of participants.
- The qualitative research element in this workshop is critical for academic and community partners with limited knowledge or experience of qualitative research methods. Gaining knowledge about qualitative research can have a major impact on partnerships' research design.
- Some community partners may be reluctant to adopt qualitative research methods out of concern that it could be dismissed as "anecdotal" or not reflective of common patient experiences
- Academic and community partners may need to be upskilled to undertake qualitative data analysis; a greater focus could be placed on qualitative data analysis and collaborative data collection and analysis in the workshop on research methods.

#### Workshop on PPI in research

- Providing training on PPI in research to community-academic partnership is valuable, as experience of PPI in research among CES-P (NUI Galway) participants, although varied, was, in general, limited.

#### Interactive training in general

- The addition of an introductory/induction session may be useful for some community and academic partners, and would be particularly useful for community partners who are new to research or have little experience of this type of programme or working in collaboration with academic researchers.
- Incorporating flexibility into interactive training is highly valued by participants, especially community partners with heavy workloads and competing demands.
- There is a strong desire among both community and academic partners for interactive training to be as accessible and inclusive as possible for members of the community of interest.

- Community-academic partnerships would welcome the development of a network of partnerships and peer support encouraged and facilitated.

### **Research projects, underpinned by PPI**

- The way in which a community-academic partnership use PPI in research is linked to the way in which the community of interest is involved in the partnership. Where a community organisation, but not the community of interest, is involved as a partner, the community of interest tends to be excluded from key decisions around identifying the priority area of focus, refining research questions and research design.
- Navigating the ethical approval process can present challenges for community-academic partnership, especially for research projects taking a participatory approach and involving 'vulnerable groups.' There is potential for PPI Ignite @ NUI Galway to learn from steps taken by CES-P (MUSC) to address challenges in the ethical review process encountered by participants.
- Community and academic partners would welcome guidance and training on facilitating a group for the purposes of PPI in research (as opposed to facilitating focus groups), which could be addressed through interactive training, mentoring, or a combination of both.
- The timeframe for the research projects must be designed to align well with other relevant timeframes, e.g., REC submission dates

### **Mentorship**

- Mentorship can be useful for upskilling community and academic partners. There is potential to make greater use of mentorship in future iterations of CES-P (NUI Galway). This may require PPI Ignite @ NUI Galway to provide greater support to partnerships to help them identify specific ways in which mentorship could add value to and be utilised by the partnership.
- There is potential for the first cohort of community and academic partners to support and mentor the next cohort of community-academic partnerships grant-funded through CES-P

### **Impacts of CES-P (NUI Galway)**

- CES-P (NUI Galway) has both beneficial and challenging or negative impacts. The beneficial impacts are many and wide-ranging and far out-weigh the number of challenging or negative impacts. Building partnerships and undertaking PPI in research takes time, and the additional time demands that CES-P places on both academic researchers and community partners, and the impact that this can have, should not be underestimated. Mitigation of challenging or negative impacts is critical.
- CES-P (NUI Galway) has led to the development of a small cadre of academic researchers in NUI Galway and staff in community organisations who have the knowledge, experience and skills to build community and academic partnerships and undertake PPI in research

## Chapter 1: Introduction

Internationally, there has been increasing recognition of the importance of involving the public and patients in research (Richards, 2017) and, in Ireland, public and patient involvement (PPI) in research is increasingly in evidence (Murphy et al., 2020). PPI is now a priority and requirement of many funding bodies (Blackburn et al., 2018). The Health Research Board (HRB) has been at the fore in spearheading PPI in health and social research. A key action of the HRB's 2016-2020 Strategy was to 'develop and promote public and patient involvement (PPI) within the HRB and in HRB-supported projects and programmes' (HRB, 2016: 29). The latter was exemplified by PPI Ignite, a scheme initiated by the HRB with support from the Irish Research Council, whereby universities across Ireland are awarded funding to help them create the right environment, training, support and processes to help researchers engage public and patients in their research from the start. The National University of Ireland, Galway (NUI Galway) is one of five universities awarded funding under this scheme. The PPI Ignite @ NUI Galway team works with researchers, the public and patients to ensure that the voice of the patient shapes and influences health and social care research, with a view to enhancing the quality, relevance and impact of the research.

In 2019, PPI Ignite @ NUI Galway introduced a new initiative, the Community Engaged Scholars Programme (CES-P) at NUI Galway. The main objective of this programme is to build a partnership between a researcher or research team and a community organisation, to facilitate ongoing research that is underpinned by the principles of PPI and aims to improve public health. CES-P (NUI Galway) is based on a programme originally developed in the US at the Medical University of South Carolina (MUSC), an international partner of PPI Ignite @ NUI Galway.<sup>1</sup>

PPI Ignite @ NUI Galway delivered the first Irish pilot of the CES-P (NUI Galway) in 2019/2020. The programme is funded through the HRB's Knowledge Exchange and Dissemination Scheme (KEDS), a grant scheme that supports researchers and knowledge users to work together to shape and deliver knowledge exchange activities that will improve the exchange and translation of research findings into policy and practice. A cohort of three community-academic partnerships participated in the pilot CES-P (NUI Galway).

This report is an evaluation of the pilot CES-P at NUI Galway, commissioned by PPI Ignite @ NUI Galway. The evaluation had two main objectives:

- to provide an understanding of the adoption, implementation and delivery of CES-P in an Irish context, and
- to assess the impact of the CES-P (both its training and support elements). The primary focus is on the impact of the programme on the partnership, and on the academic and community partners.

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<sup>1</sup> In this report, the original programme is referred to as CES-P (MUSC) to distinguish it from programme adopted by PPI Ignite @ NUI Galway, which is referred to as CES-P (NUI Galway). In Chapter 4, sub-section 4.1, table 1 compares the key elements of CES-P (NUI Galway) vis-à-vis CES-P (MUSC).

## Chapter 2: Community-Academic Partnerships in Research

This chapter focuses on community-academic partnerships in research. The chapter discusses the key overarching terms that are used and presents the principles underpinning such partnerships. A brief overview of the advantages of community academic partnerships is provided and key strategies for overcoming partnership challenges outlined.

### 2.1 Community involvement in research and key overarching terms

Different overarching terms are used to describe stakeholder engagement in the research process (Van Bekkum et al., 2016; Hoekstra et al., 2020). In Ireland, the term public and patient involvement (PPI) in research is gaining traction and the definition most widely used is that proposed by INVOLVE: research that is done ‘with’ or ‘by’ the public rather than ‘to’, ‘about’ or ‘for’ them (INVOLVE, 2007). This definition has been adopted by the HRB. For the HRB,<sup>2</sup> ‘public’ means everyone in Ireland who has an interest in health and social care as a public service including potential users of services; ‘patient’ means people who use services such as patients, service users, clients or their carers; and ‘involvement’ means the active involvement between people who use services, carers, the general public and researchers, but not the use of people as participants in research (or as research ‘subjects’).

The HRB clearly and explicitly identifies patients and the public as the constituents to involve in research. However, organisational and policy visions for public engagement differ with respect to ‘who’ to involve and ‘how’, and there is a third type of ‘publics’ not explicitly mentioned by the HRB, i.e. ‘communities.’ (Miller et al., 2018). Miller et al. (2018) found that whereas policy visions for public engagement tend to focus primarily on patients, research is generally split between public and patient involvement, on the one hand, and community involvement, on the other. The distinction between ‘patients’ and ‘communities’ is important as each is seen to provide a different form of expertise and imply different types of research. Patients are seen to provide expertise derived from their personal experience of health conditions, and their involvement encourages researchers to pay attention to the various types of health research that could inform improved health outcomes and high-quality care. When communities or community organisations are involved, the expertise provided is seen to be derived from collective experiences of health conditions, and their involvement encourages researchers to pay attention relevant to health inequities and social determinants of health (Miller et al., 2018).

Engaging communities in addressing problems related to health is believed to be important because of the complex contextual issues at play and the significant contribution that communities can make. It has led to calls for more participatory research, and participatory approaches to research have grown (Israel et al., 2001). PPI in research that focuses on community involvement draws on traditions of *community based participatory research* (CBPR), a term that is widely used in the US (Hoekstra et al., 2020). Coughlin et al. (2017: 1) describe CBPR as ‘a collaborative approach to research in which the research process is driven by an equitable partnership that is formed between relevant community members, organisational representatives and academic researchers.’ However, the term CBPR is used in many ways and often interchangeably with other terms (Israel et al., 1998).

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<sup>2</sup> <https://www.hrb.ie/funding/funding-schemes/public-and-patient-involvement-in-research/>.

PPI has been defined as a spectrum. According to IHRF (2015; 2016), it ranges across six levels, from the lowest level - 'None' - to the highest level – 'Participation'. The goal of PPI in research is to achieve a true partnership between public/patients and researchers, leading to improved research quality, relevance and outcomes (IHRF, 2015). Community-academic partnerships would be positioned towards the higher end of the IHRF spectrum of PPI, somewhere between levels four and five, whereby there is joint-decision-making between the community and academic partners, with the community organisation having a defined role and involved through the research process.

## 2.2 Principles underpinning community-academic partnerships in research

A set of principles have been drawn up for PPI. For example, INVOLVE (2015) has developed a framework of values and principles, intended as a framework for best practice for public involvement in research. There are six values in the framework - respect, support, transparency, responsiveness, fairness of opportunity and accountability – that serve as overarching ideals that are important to PPI. The principles describe these ideals in more detail, and information and examples are included on how each principle should be put into practice. More extensive PPI values have been produced by Gradinger et al. (2015) and Ní Shé et al. (2020). For a detailed review of principles underpinning research partnerships, see Hoekstra et al. (2020).

A set of CBPR principles have also been developed. The original CBPR principles developed by Israel et al. (1998) have since been revised (Israel et al., 2003) and capture the key elements that need to be integrated into a CBPR approach (see Box 1).

### **Box 1: Nine key principles underpinning CBPR**

- CBPR recognises the community as a unit of identity
- CBPR builds on strengths and resources within the community
- CBPR facilitates collaborative, equitable partnership across all phases of the research
- CBPR integrates and achieves a balance between research and action for mutual benefit of all players
- CBPR promotes co-learning and empowering process that attends to social inequalities
- CBPR emphasises local relevance of public health problems and ecological perspectives that recognise and attend to multiple determinants of health and disease
- CBPR disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process.
- CBPR involves a long-term process and commitment.
- CBPR involves systems development through a cyclical and iterative process

(Israel et al., 2003)

### 2.3 Advantages and unique strengths

There are many advantages to community-academic partners. The following are among the advantages identified by Israel et al. (1998). Community and academic partners bring diverse skills, knowledge, expertise and sensitivities to the partnership, which can be used to jointly address complex problems. They can lead to strengthening the research capacity of both partners. Researchers may be encouraged to become more self-reflexive, engaged and self-critical. Community-academic partnerships can enhance the relevance and usefulness of research data. By involving people with lived experience of a health condition, the quality and validity of research may be improved. They can generate the capacity to recruit research participants. The research findings can be used by all involved and to influence policies or programmes that will benefit the community of interest and potentially lead to the redirection of resources. Through partnerships, communities may become more trusting of researchers. The health and well-being of the communities involved may be improved directly as the research may help to address the needs that have been identified through the research. By increasing their power and control over the research process, the health and wellbeing of the communities involved may be improved indirectly.

### 2.4 Community-academic research partnerships: Challenges and facilitators

Despite the many advantages, the actual conduct of research for community-academic partnerships can be challenging. The range of challenges identified can be organised into three broad categories: community research partnerships; methodological issues; and broader social, economic, political, institutional and cultural issues (Israel et al., 1998). These challenges are inter-related. To overcome these challenges, factors and strategies that facilitate community-academic partnerships have been identified. For a detailed overview of strategies that facilitate community-academic research partnerships, see Hoekstra et al. (2020).

Partnership is at the heart of community engaged research, but many issues can arise for community-academic partnerships (Israel et al., 1998; Andrews et al., 2012). Lack of trust and perceived lack of respect between community and academic partners is the most frequently mentioned challenge, and trust, once established, cannot be taken for granted. Power differentials between community and academic partners is another frequently mentioned challenge. Conflicts can arise, both between members within an organisation and across organisations. Conflicts can be associated with different perspectives, priorities, assumptions, values, beliefs and language. There may be conflicts over funding or conflicts associated with different emphases on task and process. Challenges related to how the community is defined and who represents the community can also arise. Undertaking CBPR is a time-consuming process; it requires a commitment of time to establish and maintain trusting relationships, as well as the time it takes to conduct the research.

A wide range of strategies are proposed to overcome partnership challenges including jointly developed operating norms; identification of common goals and objectives; democratic leadership; presence of community organiser; involvement of support staff/team; and researcher roles, skills and competencies. Prior experience and familiarity of working collaboratively between community and academic partners has been found to facilitate partnerships, especially where partnerships were based on positive and trusting relationships (Israel et al., 1998; Stockdale et al., 2006) and the value of 'unfunded



connections' has been highlighted (Michener et al., 2013). Having written documentation of each partners' commitment, such as a memorandum of understanding (MOU) or contract, has been shown to be particularly useful for community partners participating in CBPR.

Methodological issues arise for community-academic partnerships and can present challenges such as the inability to fully specify all aspects of research upfront. To address the methodological challenges the following are recommended: methodological flexibility and different criteria for judging quality; involvement of community members in research activities; conduct community assessments/diagnoses; development of jointly agreed upon research principles; conduct educational forums and training opportunities; involve partners in the publishing process; and create interdisciplinary research teams.

With respect to broader social, political, economic, institutional, and cultural issues, there are many challenges such as competing institutional demands. To address the broader challenges, the following are recommended: broad-based support (top-down and bottom up); and actions promoting policy changes.

## 2.5 Training and seed funding

Training to prepare academic researchers to conduct CBPR has long been recommended, as has training to enhance the knowledge and skills of community partners to participate as equal partners and share power and control over research (Israel et al., 2001). Formal training in CBPR is said to lead to better appreciation of CBPR principles and more likely to sustain partnerships. Formal education and training programmes have been designed to support community organisations and academic partners to engage with CBPR and develop a better understanding of it. Attendance of researchers at training is necessary (Tendulkar et al., 2011). Mentoring on CBPR approach has also been identified as useful (Kegler et al., 2016)

The provision of financial and other incentives is recommended as a strategy to overcome some of the challenges that community-academic partnerships face such as lack of trust, time involved in developing and maintaining partnerships and preparing collaborative proposals (Israel et al., 1998; Israel et al., 2001). While different models of funding can be used, small grants have been identified as a useful way of providing seed funding to stimulate and foster project development by community-academic partnerships, and to facilitate pilot grant submissions (Tendulkar et al., 2011; Michener et al 2012; Kegler et al., 2016).

The Community Engaged Scholars Programme (CES-P) developed by the Medical University of South Carolina (MUSC) (Andrews et al., 2013; Jenkins et al., 2020) offers an example of a programme that incorporates training and seed funding as well many of other strategies that facilitate community-academic partnerships referred to in sub-section 2.4. CES-P adopted by PPI Ignite @ NUI Galway is based on the CES-P originally developed at MUSC. An overview of CES-P (MUSC) is provided in Appendix I. Table 1 in Chapter 4 compares the key elements of CES-P (NUI Galway) and CES-P (MUSC).

## Chapter 3: Methodology

The evaluation of the CES-P (NUI Galway) is a summative evaluation. It adopted a mixed-methods approach, with two key elements:

- (a) a process evaluation, to provide an understanding of workings of the CES-P (NUI Galway); and
- (b) an impact evaluation, to assess if the CES-P (NUI Galway) has succeeded in increasing the capacity of the three community-academic partnerships to conduct research, underpinned by principles of PPI, to improve the health of local communities.

### (a) Process evaluation

The process evaluation examined CES-P (NUI Galway) adoption and implementation, mechanisms of impact, the context, and the extent to which the programme is likely to become embedded in the university. It involved a documentary review and interviews.

**Documentary review:** This involved a review of relevant CES-P (NUI Galway) materials including the call for applications; the original applications submitted; materials related to the interactive training session such as trainer presentations, recordings of the training sessions and the 'Are We Ready?' Partnership Readiness toolkit. Research outputs from the partnerships such as presentations at PPI conference were also viewed.

**Interviews:** Interviews were conducted with staff at PPI Ignite @ NUI Galway and focus groups with members of the community-academic partnerships grant funded to participate in the programme. At interviews, participants were invited to collectively reflect on CES-P (NUI Galway). The interviews were guided by a topic schedule, which was informed by a literature review. PPI Ignite @ NUI Galway provided input and the three community-academic partnerships reviewed the topic schedule. Due to public health restrictions associated with COVID-19, all interviews were conducted virtually using Zoom.

### (b) Impact evaluation

At the end of each training session, the academic and community partners attending completed an evaluation form, in which they rated, using a Likert scale, their overall impression of the session as well as the session content, presentation, teaching strategies, presenter knowledge and preparation, and relevance. They also provided qualitative feedback about the session, including on its likely impact on the partnership. The forms were analysed for this evaluation.

The perceived impact of CES-P was discussed in focus groups with the three partnerships and in interviews with programme providers. These discussions focused on the impact of CES-P on partnership readiness to undertake research, capacity of partnership to plan and undertake research, capacity to do this according to PPI principles, the impact on the research process and on the researchers and community partners involved. The framework developed by Hoekstra et al. (2020) on the impacts of research partnerships is used in this evaluation to report on the impacts of CES-P (NUI Galway) (Section 4.5).

## Chapter 4: The Community-Engaged Scholars Programme (NUI Galway)

This chapter describes CES-P (NUI Galway) and its key components in concise detail and presents the findings from the evaluation.

- Section 4.1 provides a brief overview of CES-P (NUI Galway)
- Section 4.2 describes the application and competitive selection process, and the three partnerships selected for grant funding
- Section 4.3 focuses on CES-P (NUI Galway) interactive training and mentoring
- Section 4.4. focuses on the research projects undertaken by the partnerships and the approach taken by the partnerships to underpin their research with PPI
- Section 4.5 presents the findings on the perceived impacts of CES-P (NUI Galway)

### 4.1 Overview of CES-P (NUI Galway)

The purpose of CES-P (NUI Galway) is to support the development of partnerships between academic researchers and community organisations, to facilitate ongoing research which is underpinned by the principles of PPI and aims to improve public health. It seeks to achieve this by:

- incentivising academic researchers and community organisations to form a partnership and provide funding of up to €5,000 to support a partnership to undertake a small-scale study;
- fostering and developing the capacity of community-academic partnerships to conduct research through the delivery of face-to-face and online group interactive education and training.

The main aims of CES-P are:

- To advance a PPI co-learning curriculum for community and academic partners
- To promote and foster equitable partnerships between public and patients/patient organisations /community groups, researchers and other stakeholders (e.g. health care professionals), where partners work together to make joint decisions across the full research cycle, i.e. from collaborative identification of health research questions and priorities to dissemination of research results
- To stimulate subsequent partnership applications for further research funding

The overall goal of the Community Engaged Scholars (CES) Programme is “to build a cadre of community-academic partnerships that are successful in securing extramural funding to conduct research and programme initiatives that are meaningful, useful, and influence the health of participating communities” (Andrews et al. 2014).

**Table 1: Key elements of CES-P (NUI Galway) and CES-P (MUSC)**

	<b>CES-P (MUSC)</b>	<b>CES-P (NUI Galway)</b>
<b>First year of programme</b>	2009/2010	2019/2020
<b>Programme length</b>	Designed as an 18-month programme	Designed as a 12-month programme. Extended to 18 months in first year
<b>Funding model</b>	Small grants to community-academic partnerships to undertake pilot projects and prepare a larger grant proposal. Grants of \$5,000 in first year, raised to \$10,000 thereafter	Small grants of €5,000 to community-academic partnerships to undertake pilot projects and prepare a larger grant proposal
<b>Application selection process</b>		
Applicant information session	Yes	Yes
Competitive Section Process	Yes	Yes
Reviewed by public and academic reviewers	Yes	Yes
<b>No. of awards per year</b>	Average of 3.75	3
<b>Interactive training</b>	Integral component Monthly 3-hour group interactive training sessions over a 12-month period	Integral component Six training sessions over an 18-month period
<b>Session topics</b>	1: History and definitions of CBPR 2: Partnership Readiness I 3: Partnership Readiness II 4: CBPR panel 5: Community assessment and problem identification 6: Data collection and analysis 7: Evaluation Part I 8: Evaluation Part II 9: Academic-community partnership panels 10: Dissemination and communication 11: Sustainability of CBPR partnerships and projects 12: Final session	1: Introduction to CBPR/PPI and Are We Ready? Toolkit 2: Research Ethics; CBPR Partnership Readiness 3: Qualitative and Quantitative Research 4: PPI in health Research; Partnership follow-ups 5: Sharing Research Results 6: Grant writing and PPI in grant applications
<b>Mentorship</b>	Yes	Yes
<b>Pilot projects</b>	Yes	Yes

CES-P (NUI Galway) is a multi-component programme that includes seed funding for partnerships, a training component and mentoring. The five key elements of CES-P (NUI Galway) are:

- (1) funding
- (2) a competitive selection process;
- (3) an intensive training and mentoring programme;
- (4) co-design and co-production of research by the academic-community partnership addressing an agreed research question of interest to both partners; the partnerships have to complete a small research study, adopting PPI across all phases
- (5) sharing of results with the public, health professionals, researchers and policymakers.

CES-P (NUI Galway) is based on a programme originally developed in the US at the Medical University of South Carolina (MUSC). Table 1 compares the key elements of CES-P (NUI Galway) and CES-P (MUSC).

## 4.2 The application and competitive selection process

Funding of €15,000 was available to support three community-academic partnerships to participate in CES-P (NUI Galway). PPI Ignite @ NUI Galway used a competitive selection process to select three community-academic partners.

### 4.2.1 CES-P (NUI Galway) grant call

The CES-P (NUI Galway) opened with a call for applications. Community-academic partnerships interested in undertaking collaborative research underpinned by PPI were invited to apply for funding. Applications for CES-P (NUI Galway) had to be from teams comprising at least one community partner and one academic partner. For the purposes of CES-P (NUI Galway), the following definitions were used:

- *Community partner* is as an individual / patient / member of the public who maintains a primary affiliation, whether employed or volunteer, with a community organisation.
- *Community organisation* is defined as an organisation that has: (1) a documented interest in improving the health of the relevant community (e.g., through a mission statement); and (2) a history of serving the health needs and interests of the relevant community. Community organisations may include, but are not limited to, community-based organisations, community-based health provider organisations, patient organisations, charitable organisations, schools and/or advocacy groups.

A briefing / Q&A session was held for interested community-academic partners (see Box 2 for timeline). The evaluation found that the information session, which was well attended, was essential not only to communicate information about the grant application process, but also to inform potential applicants about CES-P, how it works and the requirements, e.g., commitment from community and academic partners to attend interactive training sessions. From the perspective of academic researchers, attending the information session also provided an opportunity to meet other researchers with a shared interest and join together to prepare a grant application.

## **Box 2: Timeline for CES-P (NUI Galway) competitive selection process**

08 March 2019	Call opened
14 March 2019	Briefing/Q&A Session
08 April 2019	Deadline for submissions
23 April 2019	Awardees notified

### 4.2.2 Competitive selection process

PPI Ignite @ NUI Galway received applications for funding from six community-academic partnerships. Applications were welcomed from both existing and newly formed community-academic partnerships. Four of the applicants were from partnerships in which the academic and community partners had previously worked together, although not necessarily on research projects. Two were newly formed partnerships.

All six applications met minimum eligibility requirements. The applications were reviewed by three members of the public, drawn from two existing PPI panels at NUI Galway, and by five academic reviewers. The public review process was facilitated by two PPI Ignite @ NUI Galway staff members. Following a presentation by the PPI Ignite @ NUI Galway staff members, the public reviewers discussed and provided feedback on each application. The applications were reviewed separately by academic reviewers according to pre-determined review criteria: significance; partnership; proposed pilot research study; environment & community; and overall. Following a ranking of the six applications by the academic reviewers and input from the public reviewer's deliberations, three community-academic partnerships were selected for inclusion in CES-P (NUI Galway).

The evaluation identified three notable aspects of the review process. First, the involvement of and input from a colleague from MUSC was a real advantage for the review process. Second, the public reviewers rated the process as a positive experience, as revealed in their feedback to PPI Ignite @ NUI Galway. They liked the approach used and really enjoyed participating in the review process. They valued the discussions about PPI in the applications at the review meeting and learned a lot about PPI from participating in it. The public reviewers felt that in the future, resources permitting, it would be useful to have an opportunity to meet with the applicants and ask questions as part of the review process. Third, given the tight schedule and the logistical challenges of incorporating a public review into the review process, it is commendable that the PPI Ignite team @ NUI Galway succeeded in incorporating a public review and that it was so highly rated by public reviewers.

### 4.2.3 The community-academic partnerships selected

Three partnerships were selected to participate in CES-P:

- A partnership between the Irish ME/CFS Association, represented by Orla Ní Chomhraí and Tom Kindlon, and Dr John Cullinan, a health economist. The Irish ME/CFS Association (<http://www.irishmecfs.org/>) is an advocacy organisation with approximately 300 members, which strives to improve the situation for people with ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) and to give them information to empower themselves.

- A partnership between a group of psychologists, led by Dr Oonagh Meade, and CROÍ, represented by Denise Dunne and Irene Gibson. CROÍ (<https://croi.ie>) is a charitable organisation focusing on the prevention of, recovery from and wellbeing after cardiac disease and stroke. The organisation, which is active in the West of Ireland, was the catalyst for the establishment of the CROÍ Heart and Stroke Centre in Galway, a purpose-built facility, operating as a centre for prevention, research, education, patient and family support and rehabilitation. CROÍ's work involves facilitating and collaborating in research in the areas of heart disease, stroke, diabetes and obesity.
- A partnership between Dr Ruth McMenamin, a lecturer in speech & language therapy at NUI Galway and the Irish Heart Foundation, represented by Martina Greene and the Ballinasloe Stroke Support Group.

Table 2 describes the characteristics of the three partnerships, showing differences between the partnerships with regard to:

- the type of partnership (number of partners and type of community organisation)
- the health conditions under study and, hence, the associated community of interest
- the disciplinary backgrounds of the researchers
- the ways in which members of the community of interest were involved in the partnership
- partners' prior experience of working together
- the nature of the research project

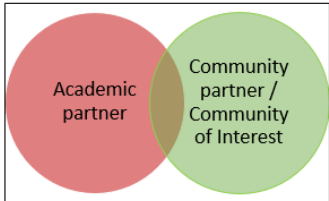
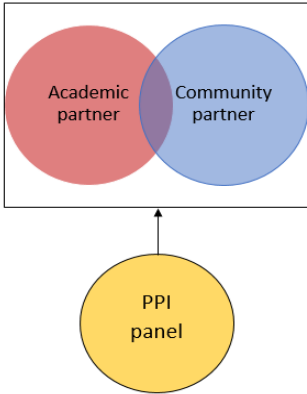
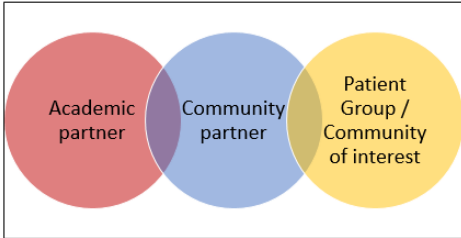
The differences between the partnerships had implications for the ways in which PPI was included in the partnerships' research projects, which is explored in more detail in Section 4.4. A difference between the partnerships worth mentioning here relates to their prior experience of working together. As Table 2 shows, two of the partnerships were pre-existing. In Partnership A, the academic partner had discussed the possibility of doing a collaborative research project with the community organisation and had been looking at ways to do this. Partnership B had been looking for ways to build on the success of previous work with the community organisation and develop better and more formal links with the community partner. The academic partner had discussed the possibility of doing a collaborative research project with the community organisation and had been looking at ways to do this. The CES-P (NUI Galway) call provided these two existing partnerships with the opportunity to carry out a collaborative research project underpinned by PPI:

'We were looking for something, funding, for a possibility to drive our research forward and CES-P provided that opportunity to get started' (Academic partner)

The CES-P (NUI Galway) grant call was clearly the catalyst for the creation of the third successful partnership, which a newly formed partnership:

'Partnership would not have happened without CES-P. We all have very busy work lives, but CES-P made me stop and think about partnership, who would be a good partner in this, how would this work, what are the important questions to answer, that was really good. It's good to have the opportunity to take time out to do that (Academic partner)

**Table 2: Characteristics the three community-academic partnerships**

Partnership	Partnership A	Partnership B	Partnership C
<b>Type of partnership</b>	Dyadic - Partnership between an academic partner and a patient-led community organisation	Dyadic - Partnership between academic researchers and a multi-purpose community-based organisation	Tripartite - Partnership between academic researcher, a community organisation and a group of people from the community of interest
<b>Community of interest</b>	People living with ME/CFS	People living with heart disease and their family members	People living with stroke and aphasia and their family members
<b>Disciplinary background of researcher</b>	Health economist	Psychologists	Speech and language therapist
<b>Support staff</b>	The community co-lead was supported by another staff member from the community organisation. Part of the budget was used to employ a research assistant to help with participant recruitment and data collection.	The academic co-lead was supported by two other academic researchers. The community co-lead was supported by another employee from the community organisation. An intern on placement at the university was available to help with completing the ethics application and a research assistant was employed for a short period to help with data collection.	Support with data collection was provided for a short period through the summer internship programme.
<b>Involvement of community of interest in partnership</b>	<p style="text-align: center;">Partnership A</p>  <p style="text-align: center;">Community of interest integrally involved in the partnership – the community partner co-lead, volunteer member of the community organisation and the research assistant were all living with ME/CFS</p>	<p style="text-align: center;">Partnership B</p> 	<p style="text-align: center;">Partnership C</p>  <p>A group of people was convened to be the third partner on this partnership. Members of the group had experience of stroke and aphasia, either as patients or</p>



		<p>People with heart disease were not directly involved as members of the partnership. However, a PPI panel comprising people with cardiac disease and family members was established to enable members of the community of interest to input into the research project.</p>	<p>family carers, and were affiliated to the support group.</p>
<p><b>Prior experience of working together</b></p>	<p>Pre-existing partnership - The community and academic partners had come to know each other through their involvement in a public awareness raising event.</p>	<p>Pre-existing partnership - Prior to CES-P (NUI Galway), the partners had at least three years' experience of working together on projects of mutual interest including on post-graduate student programmes and the delivery of health programmes to patients.</p>	<p>None</p>
<p><b>Nature of research project</b></p>	<p>Policy relevant research Study on the economic impacts of ME/CFS</p>	<p>Intervention study This partnership initially set out to develop an online cardiac rehabilitation programme, but prompted by the interactive training changed the focus of their research to examine attendance and non-attendance of patients with heart disease at community-based in-person cardiac rehabilitation programmes (see Section 4.4.2 for more details).</p>	<p>Public awareness raising study Research to inform the development, implementation and evaluation of a campaign to raise awareness of stroke and aphasia</p>

### 4.3 CES-P (NUI Galway) Interactive training

Like the original CES-P (MUSC), interactive training is an integral part of CES-P (NUI Galway). In its pilot phase, the CES-P (NUI Galway) interactive training was designed around six workshops (Box 3). At the time of the fieldwork for this evaluation, the first five workshops had taken place. This section briefly describes what was covered in these five workshops. It presents the perspectives of the community and academic partners and the organising team on the different workshops as well as issues raised about the design of workshops generally.

#### **Box 3: Interactive Training**

02 May 2019 Workshop 1: Introduction to CBPR/PPI and Are We Ready? Toolkit

16 May 2019 Workshop 2: Research Ethics; CBPR Partnership Readiness

30 May 2019 Workshop 3: Qualitative and Quantitative Research

13 Jun 2019 Workshop 4: PPI in Health Research, Partnership follow-ups

30 Apr 2020 Workshop 5: Sharing Research Results

26 Nov 2020: Workshop 6: Grant-writing and PPI in grant applications

#### 4.3.1 Workshop on CBPR Partnership Readiness

The first workshop on CBPR was strongly informed by the CES-P (MUSC) programme, and was delivered as a half-day workshop by a visiting Professor from MUSC, who has a long-standing interest in creating effective academic-community partnerships and was involved in developing CES-P (MUSC). The workshop focused on partnership readiness and discussed this concept and its key dimensions (goodness of fit, capacity and operations) with the partners, using the model of CBPR Partnership Readiness developed by Andrews et al. (2012).<sup>3</sup> The evidence-based 'Are We Ready? Toolkit'<sup>4</sup> was introduced at the workshop. The workshop was participatory and included small group work.

The depth in which the workshop addressed CBPR principles was highlighted by the organising team in interviews for this evaluation as being a particularly attractive element of the workshop. The workshop was rated very positively by community and academic partners. Six participants (two academic and four community partners) completed an evaluation form at the end of this workshop. Respondents rated their overall impression of the workshop as 'good' or 'very good'. They rated the session content, audio-visual aids, and resources and handouts as 'good' or 'very good'. Teaching strategies, the presenters' knowledge and presenters' preparation were also rated as 'good' or 'very good'. The positive feedback from the evaluation forms was reiterated in focus groups. Both community and academic partners reported that they found this workshop to be extremely useful and

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<sup>3</sup> See Appendix I for an explanation of the concept of partnership readiness and its key dimensions (goodness of fit, capacity and operations).

<sup>4</sup> An explanation of the *Are We Ready?* Toolkit is given in Appendix I.

thought the material covered was very important. They liked the small group work and participatory elements of the workshop:

‘... the bits I found the most helpful in the first sessions were the practical tasks, for example, ‘we want you to think about your readiness now in terms of your partnership’ or whatever and we would have a chat about the values that are important to each of us and with the group and where we got the chance to work together that was really good ...’ (Academic partner)

They valued the facilitator’s knowledge and experience of CBPR and CES-P:

‘... it was great to have someone as experienced as Caroline Jenkins as well that we could ask questions of and get an answer that had a lot of weight and confidence behind it’ (Academic partner).

However, one community partner described the session as ‘all very academic’ and found participation in it a ‘daunting’ experience.

In focus groups for this evaluation, all of the partnerships spoke about ‘goodness of fit’ (see Appendix I for an explanation) and the usefulness of this partnership readiness dimension and its key indicators - shared values, compatible climate, mutual benefit, and commitment. Key points raised by the partners were that it was important to know that the partners were a good fit; it helped to confirm or validate pre-existing perceptions of the partnership; it gave reassurance that the values of the partners were aligned and that they were ‘on the same page’, and it helped partners to feel more comfortable and more confident moving forward in the process. Considering questions such as ‘what could go wrong, what would partners do if the partnership breaks down, who owns the whole process’ were extremely worthwhile.

Operations, the third dimension of partnership readiness (see Appendix I for an explanation), was discussed at the workshops. In focus groups for this evaluation, the partners explained the processes that they had developed to work together:

‘We always planned meetings in advance. As we finished one meeting, we planned the next, set dates for the next meetings so it was structured and we never felt ‘I wonder what is happening’. There was good communication via email and it worked very well.’ (Community partner)

Transparent communication is a key indicator of operations readiness (Andrews et al., 2012). However, the extent to which the workshop influenced and helped the partnerships plan out their operations was unclear. Nonetheless, community and academic partners reported that, from their experience of undertaking collaborative research projects as part of CES-P (NUI Galway), good communication was extremely important, as were openness and flexibility, particularly given the high workloads and competing demands that most community and academics had.

‘Flexibility was important because we were so busy, with obstacles. We could have thrown our hands up and said ‘let’s forget it’ but I think because of our relationship has sustained it’.

The partners found the 'Are We Ready?' Toolkit and the exercises in it to be helpful.

'... it gave us a chance to start talking about stuff and we actually systematically went through the booklet so it was very helpful and it got us thinking about how we had formed the partnership, that it was actually a partnership, and that we should value it as a really important partnership and all that came from it. It was very helpful and something that we will use again' (Community partner).

The logic models were also found to be useful, particularly by one partnership:

... the thing that I found most useful from our first meeting then with our partnership was doing a kind of logic model for our partnership, which was interesting as sometimes you might do a logic model for a project but this was for our partnership and I like that ... (Academic partner)

While some of the exercises in the toolkit were completed by the partnerships at the workshop, all three partnerships took time after the workshop to complete the rest of the exercises. The partnerships participating in CES-P (NUI Galway) were encouraged to think through and develop an MOU. All three partnerships developed an MOU or similar document and all found it useful, although the time spent on developing it and the extent to which it was developed varied from one partnership to another.

The CBPR workshop was a three-hour workshop. An issue raised by the community and academic partners was that the workshop on CBPR partnership readiness felt rushed or hurried, a point echoed by the organising team, and in comments on the evaluation forms. Community and academic partners suggested that it would have been better if the material covered was spread over more sessions.

'The only negative was that a lot of material was covered. It was, if I remember, it might have been a two-day workshop condensed into two hours, which was very demanding and probably would have been better if it has been spread out over more time and may be attempted to cover a little less ground. That is my recollection' (Academic Partner).

The workshop on CBPR partnership readiness impacted on the partnerships in varying ways. For existing partnerships, it was the first time that the community and academic partners had focused on or discussed the nature of their partnership. Prior to CES-P, the primary focus of discussions between partners had been on the tasks that had to be completed by their partnership or the research they intended to do. The workshop helped partners to shift away from a sole focus on tasks to towards thinking about their partnership.

'What was nice about CES-P was that the focus was on the partnership and what a partnership looks like and how do you develop that. Before it was more on the tasks that we were doing [as a partnership], so 'we're going to deliver this workshop' ... whereas this was more about thinking about two sides working together and that was nice' (Academic partner).

#### 4.3.2 Workshop on Research Ethics

The workshop on research ethics provided an overview of what research ethics is, what it involves, its historical evolution, and lessons from the past. It covered the issue of informed consent and changes relating to consent since the introduction of GDPR legislation.

Seven participants (two academic partners and five community partners) completed an evaluation form at the end of this workshop. All respondents rated their overall impression of the workshop as well as the session content, audio-visual aids and resources and handouts as 'good' or 'very good'. Teaching strategies, the presenters' knowledge and preparation were also all rated as 'good' or 'very good'. Most 'agreed' or 'strongly agreed' that the workshop was relevant and useful. According to feedback, the workshop ran overtime and this was a problem for several participants. Other comments made on the evaluation forms related to issues raised in focus groups for this evaluation and are incorporated below.

The evaluation revealed that all of the academic partners had good knowledge of research ethics, a lot of experience of applying to the university research ethics committee (REC) for ethical approval, and they were familiar with the material covered in the workshop. Some found it useful as a 'refresher', and especially being reminded of the common omissions or mistakes made on ethics application forms.

For community partners who were less familiar with research and research ethics, the material presented at the workshop gave them an understanding of research ethics, how the ethics application process worked, and enabled them to contribute to the research ethics application:

'Attending the research ethics sessions definitely helped me in contributing to the ethics application ...' (Community partner)

Where needed, academic partners provided additional support to community partners and took the time to explain aspects of research ethics or the application process and shared resources with them (e.g. templates for participant information sheets and consent forms). An interesting impact for one community partner was being able to apply the knowledge gained at the workshop to research generally and better reflect on and assess research against ethical standards generally:

'to be honest it was interesting to me in general as some research in our area isn't very good and I remember people saying to me about some research 'how did this get ethical approval?' and I could see their point but I didn't really get it until I did the ethics session ... so, it opened my eyes a lot and I find it really interesting'  
(Community partner)

Community partners familiar with the material covered believed that it would be more beneficial if the workshop was more practical. A number of suggestions were made: the workshop could be used to go through an ethics application systematically; provide information and discuss issues that community partners find particularly difficult such as data protection and related IT issues; provide sample templates (e.g., plain language information

sheets and consent forms) that community partners could use and guidance on how to use them.

“Like, the thing we almost stumble upon as community partners, you are fine with the research layout, but things like encryption on laptops and the real fine detail, and data protection as well, especially with GDPR.” (Community partner)

It was also suggested that PPI Ignite @ NUI Galway could develop a repository of this type of information and guidance which could be accessed by community organisations in general through its website.

#### 4.3.3 Workshop on Research Methods

The workshop on research methods covered both quantitative and qualitative research methods. Some academic and community partners were very knowledgeable and skilled in quantitative research methods. Those with less knowledge and experience found the content on quantitative research methods interesting, even when it was not relevant to their particular CES-P (NUI Galway) research project.

‘Not using statistical analysis, interesting to hear, get exposure to quantitative content, but not very relevant to our project.’ (Academic partner)

Qualitative research methods were relevant to all of the CES-P (NUI Galway) research projects. Not surprisingly, this part of the workshop was particularly useful for community and academic partners with little or no experience of qualitative research methods:

‘... as someone who mainly conducts quantitative research. the qualitative part was really useful for me’ (Academic partner)

For one partnership where partners had limited experience of qualitative research, the workshop proved to be ‘a key session for us [with] a lot of impact on our study’ (Community partner) and particularly valuable:

‘I was aware of ... qualitative research ... but within a half an hour of the presentation it really opened up to me the value of doing qualitative research in the context of what we were looking at and also gave us a template for what we realistically want to achieve and then some resources to develop that. The quantitative stuff I sat there and went ‘OK’, but the qualitative stuff, I said, ‘this is really what is needed’ (Academic partner).

The focus groups revealed that some community partners may be somewhat reluctant to adopt qualitative research methods out of concern that it would be dismissed as “anecdotal” or not reflective of common patient experiences. This perception is driven by previous negative experiences where patient voice and experience has been dismissed. The value placed on qualitative research by CES-P (NUI Galway), workshop facilitators and participants helped to shift this perception:

I was more resistant [to qualitative research] and there was a reason for it, historically ME patients are not listened to and what they say is dismissed as anecdotal and I prefer quantitative data for ME studies because it is easier to prove your point and harder for people to be dismissive if hundreds of people are saying it but I came around slowly because I could see that they [the academics] were taking this type of research seriously ...' (Community partner).

One academic partner suggested that the qualitative element of the workshop would have been of more value if it had been more practical and included exercises or tasks for participants such as coding text from interviews or focus groups. This view was echoed by community partners including those with experience of qualitative research but lacking qualitative data analysis skills.

Overall, the community and academic partners thought this session was good and believed there was value in including both quantitative and qualitative research methods. They appreciated the challenges inherent in delivering a session on research methods to a mix of community and academic partners, where some community partners have been involved in very little research prior to CES-P (NUI Galway), and where participants (both community and academic partners) had varying levels of knowledge, skills and experience of quantitative and/or qualitative research. This will be an ongoing challenge for CES-P (NUI Galway).

#### 4.3.4 Workshop on PPI in Health Research

The workshop on PPI in health research was an interactive workshop. Areas covered included what does PPI mean, how it occurs along a spectrum, why it is important to use PPI in research, distinguishing between research that does and does not constitute PPI in research, and incorporating PPI across the entire research cycle. In the focus groups for this evaluation, community and academic partners mainly talked about their approaches and experiences of incorporating PPI in their research projects, which will be reported on in section 4.4. However, some community and academic partners talked specifically about the workshop and how it had increased their understanding of PPI in health research.

'... prior to these workshops and training sessions, PPI piece seemed a little bit of a [vague] concept and it's a nice concept but this offered a lot more grounding and structure and a methodology to this and there are key principles and ... I think these sessions offered a really good framework' (Community partner).

It prompted some participants to reflect on the quality of PPI in research in which they had been involved prior to CES-P (NUI Galway).

'... we got structure on what PPI is, so we may have thought we were doing [PPI through] focus groups with patients in the past but may have been doing them badly (Community partner)

For some participants, it helped to shift their perspectives with regard to how the partnership would work and the approach the partnership should take to implementing the research project:

... [the] material covered in the workshop and the issues addressed were really important for us. Like, I think I changed my perspectives in terms of what I thought and in terms of how I saw the partnership working together. I recall there was a pyramid of PPI involvement. I guess you have ... at the bottom there was token like 'we'll chat to a few patients while we do our research' and at the top very shared collaborative research approach and I remember thinking 'let's aspire to be at the top of the pyramid or as close as possible, actually the academic researcher and the patient researcher working together, let's aim for that, that makes a lot of sense'. That was one big positive from that session (Academic partner).

#### 4.3.5 Workshop on Sharing Research Results

The workshop on sharing research results was held online in April 2020 due to public health restrictions relating to the COVID-19 pandemic. The workshop had two parts. The first included topics such as planning how to share research, and how to do it in such a way that it is effective and has impact; and thinking about audiences and key messages for different audiences. It explained the process for sharing research results using the traditional academic route, what it involves, and covered issues around PPI in that process. The second part covered public engagement in research, placing it in the context of public attitudes to scientific and health research and health literacy levels among the public. It focused on alternative routes for sharing research results (e.g. art exhibitions, films and teaching at primary and secondary level), and provided examples of how films and comedy have been used as tools for communicating research results.

Five participants (four academic partners and one community partner) completed an evaluation form at the end of this workshop. All rated their overall impression of the workshop, session content and audio-visual aids as 'very good', but opinions about the resources and handouts varied with responses ranging from 'fair' to 'very good'. All other aspects of the workshop - teaching strategies, the presenters' knowledge and preparation - were rated as 'very good' by respondents. All 'agreed' or 'strongly agreed' that the workshop was relevant and useful. In their feedback, respondents noted ways in which the workshop would help the partnership to achieve partnership and projects goals: develop a strategy for sharing research results; think more broadly and more creatively about sharing research results; ensure that the research would be shared widely. They liked the speakers and the suggestions and tips offered. They found the practical information and real-world examples to be the most useful aspects of this workshop. Including breakout sessions was suggested as a way to improve the workshop. A preference was expressed by one respondent for holding the workshop in person. This respondent would like to receive information on how to effectively share research results during a pandemic.

#### 4.3.6 Overall design of interactive training

Overall, the community and academic partners were very positive about the interactive training. Three issues were raised regarding the design of the interactive training generally. The first concerned the flexibility with regard to the provision of training. Some community partners had very heavy workloads, competing demands and/or their work involved a lot of travelling, all of which made it difficult to attend the workshop in person or at the scheduled time. The organising team facilitated community partners to attend the workshops online,



and recorded them for access at a later time. The flexibility that this provided was greatly appreciated.

The second issue related to inclusiveness and the extent to which the training programme accommodated people with health conditions and associated difficulties. In some workshops, a large amount of material was covered, and the workshops were long, which community partners living with health conditions such as ME/CFS found very demanding. One partnership comprised three constituent partners - the academic partner, community partner employed by a community organisation and members of the community of interest who were affiliated to the community organisation. The academic partner and community partner attended the interactive training, and a member of the patient group attended one workshop remotely. This partnership would like to see the interactive training developed so that it is more inclusive of people from communities of interest, and better facilitate their attendance so as to have their voice heard. It was recognised that developing the training to accommodate people with health conditions and associated difficulties, especially where there are communication difficulties, could be very challenging for the organising team. It would necessitate capacity-building for workshop facilitators, building capacity among people living with health conditions and would require a lot of planning.

The third issue raised in the focus groups concerned the relationships developed between the three partnerships over the course of the training. Community and academic partners pointed out that a lot has been learned from listening to the other partnerships and suggested that it would be valuable for the network of partnerships to continue to interact in some way after the interactive training ended so as to facilitate the peer support element to be ongoing throughout the programme.

From the perspective of the organising team, it was clear that more time needs to be spent on the initial partnership building phase, with the possibility of tailoring other elements or components of CES-P to the specific needs of individual partnerships.

#### 4.4 Conducting the research and including PPI throughout

In each partnership, the community and academic partners worked together to conduct research, underpinned by PPI principles, to improve the health and wellbeing of people represented by their community. This brings us to a key aim of CES-P (NUI Galway), which was to promote and foster equitable partnerships between academic researchers and community organisations, where partners work together to make joint decisions across the entire research cycle, i.e. from the collaborative identification of research priorities and questions to the sharing of research results. This section focuses on how the partnerships conducted their research projects and evaluates how the partners worked together to make joint decisions across the entire cycle of their research projects.

Earlier, it was shown that the three partnerships differ in a number of important respects: the partnership type, the community of interest that is the focus of their research, how members of the community of interest are involved in the partnership, the type of research that partnerships were doing and the approach taken to their research (see Table 2). It is worth noting here too that prior to their participation in CES-P, the experience of academic and community partners with regard to incorporating PPI in research varied greatly. All of the

above have implications for how partnerships employed PPI in the research projects. The findings in this section are organised under five headings: (1) prior experience of incorporating PPI in research; (2) identifying and settling on research priorities and questions; (3) obtaining ethical approval; (4) collecting and analysing data; and (5) sharing research findings.

#### 4.4.1 Prior experience of PPI in research

Prior to participating in CES-P, community and academic partners had varying experiences of PPI in research. Some academic partners had significant levels of experience of PPI in research, either through the use of participatory research methods, or developing and working with a PPI panel or advisory group or working with a peer researcher. One academic partner tried to include PPI in research as far as possible, but found that it can be difficult and was not always successful. Another academic partner with experience of PPI in research described it as 'tokenistic'. For one academic partner, research prior to CES-P did not typically involve PPI.

Overall, community partners had limited experience of PPI in research. One community partner had experience of taking a PPI approach to programme delivery, but experience of incorporating PPI in research prior to CES-P was limited. Those with prior experience of PPI in research described it as either 'tokenistic' or as a 'negative experience':

'... there might have been more of an element of tokenism to it ... where grant application researchers would have approached us and would say 'Oh, would you be our community/patient involvement partner?' and we would have agreed to that but ... you felt like you were the tick box for the academic institution per se' (Community partner)

One community partner was not only new to working with academic partners, but also 'completely new' to research, and, therefore, new to PPI in research.

#### 4.4.2 Identifying and settling on research priorities and questions

To understand whether research priorities and questions were identified collaboratively, it is necessary to revisit the pre-application stage. To be eligible for competitive selection, both community and academic partners were required to be involved in planning a proposed study. In the focus groups for this evaluation, community and academic partners spoke about this process of completing the application form. In all partnerships, the academic partners took the lead in writing the grant applications, and ensuring that the partnerships kept to schedule and met the submission deadline. Community partners inputted into the drafting of each application, but the extent of their involvement varied from one partnership to the next.

As part of the application, each of the partnerships was asked to identify specific research questions that the study would examine and how this would be accomplished. In Partnership A, people living with the health condition were embedded in the partnership, and there was a shared agreement between the partners from the outset about the priority area of focus for the research, i.e. the economic impact of ME/CFS. This remained the overall focus throughout the research. Identifying and settling on the research question was very different

for Partnership B. In this partnership, the community and academic partners spoke about the process of identifying the priority area for their research and how collaborative this process had been. They explained that the area of focus initially chosen during the pre-application stage (i.e., development of an online cardiac rehabilitation programme) had mainly come from the academic partners, although the community partners were in agreement with them.

'We did feel a little rushed and I don't think we went about it in the most partnership-driven way. I proposed an idea to [community partners] and we kind of went with that' (Academic partner).

During CES-P training, partnerships were encouraged to reflect on their research question. Partnership B took the time to do this, which promptly led to a decision to change the focus of their research (i.e., to examine attendance and non-attendance of patients with heart disease at community-based in-person cardiac rehabilitation programmes):

... we were aware from the training ... that we could change our idea, within reason and I think we had one meeting where we actually thought 'maybe we need to take a step back and do some kind of research prioritisation exercise – what are the priorities?' ... and I think we went away from that meeting and the community partners ... came back with ... feedback to the following meeting very quickly afterwards and we went with that then and we felt that was the most pressing need at the moment' (Academic partner)

Reflecting on the process of collaboratively identifying the priority area and questions for the research project, the partners reported that they had felt rushed during the pre-application stage. They attributed the limited input of community partners to the one-month timeframe between the opening of the call for funding and the application deadline, which was regarded as too short. In hindsight they would like to have had more time to work on identifying the research questions at that stage. They also explained that they found the process somewhat challenging, as, paradoxically, community and academic partners were expected to work together in a partnership to collaboratively identify research priorities and questions before training on partnership building had even begun:

'... the area of focus ... felt aligned in many ways but there was a sense of putting the cart before the horse in the sense of, you know, you were working on this application form but the foundations in terms of learning from the programme would have been very valuable even before getting to that stage of identifying a research question' (Community partner).

However, getting an understanding of community-engaged research and what it involves is, according to the organising team, part of the process of CES-P. In contrast to the other partnerships, Partnership B chose to use a PPI panel approach to involve people living with the health condition in its research. Panel members were not involved in identifying the priorities or questions for the research project at the pre-application stage, as the PPI panel was not set up until later. However, their views on the research question were sought at the first PPI panel meeting:

'We didn't have the PPI panel set up in time for that to happen. Of course, we didn't fully impose it on them either. The first PPI session initially introducing each other and what is PPI and this is what we have in mind. What do you think? (Academic partner)

Partnership C invested a lot of time during the pre-application process to ensure that a collaborative approach was taken and that members of the community of interest were involved at every stage of the research process from early on:

'We had a few meetings before even putting in the funding application to explain it all and see if people would be interested and if it was something that they wanted, if they would like to be involved and if they had ideas for topics and areas for them to have a look at ... (Academic partner)

While the focus did not change during the research project, a key learning for Partnership C was that their plan to develop, implement and evaluate an awareness-raising campaign was too ambitious, given the time-consuming nature of using a participatory approach, the competing demands on the academic and community partners, resources available to the partnership and the allocated timeframe.

#### 4.4.3 Obtaining ethical approval from university REC

Each of partnerships completed and submitted an ethics application to the university REC. An issue raised by all three partnerships was the mismatch between the initial timelines for the implementation of CES-P research projects and the timelines of the REC and its submission dates. They pointed out that it was 'unrealistic' for the partnerships to submit an ethics application before the REC's summer recess.

'... with regard to the timelines, the timelines for research implementation versus the timelines for submission dates for REC because we were moving into the summer time and REC doesn't meet so frequently so that had an impact in term of ... we were doing all the training in May / early June time and we hadn't yet defined our research question and that was unrealistic ...' (Academic partner)

One of the benefits, however, for the partnerships of completing an ethics application early on in the process is that it forced them to make decisions with regard to the approach that they would take in their research. A lot of decisions, both ethical and practical, were made at this point including with respect to research approaches, methods and processes, sample size and eligibility criteria, participant recruitment and issues around informed consent and confidentiality. Academic partners took the lead in writing the ethics application. They reported that the discussions with community partners during the course of completing the ethics applications were particularly helpful, and that decisions were driven or at least informed by the community partners because of their knowledge and experience of working with patient groups:

'... a lot of these decisions would have been driven by [names of community partners] who had experience of [name of condition] and knew this is the best way to interact with patients, these are the criteria we have to use ...' (Academic partner)

As well as contributing to decision-making, some community partners took the lead on certain aspects of the ethics applications, such as preparing participant information sheets (PIS) or consent forms, or working out participant recruitment. This was new to some community partners:

'I did a lot of work on the PIS and patient recruitment and I have never done anything like that before. It was good, initially I was 'Oh God, why did I agree to do this?', but [academic partner] sent me some samples from other applications and that got me into what I have to cover here but I still had things I felt [name of condition] patients would want to know and relatable and put in what I thought ... patients might ask and want to know and they could approach us with questions as well. [Community partner]

Writing an ethics application can be time-consuming, and was a challenge for partnerships when both academic and community partners had a lot of competing demands. Outside of CES-P (NUI Galway), an intern trainee was available as an additional resource for one partnership. The trainee attended interactive training workshops, and, under the supervision of an academic partner, took the lead on writing the ethics application. Having this extra resource was described as 'brilliant'. An unanticipated outcome of this placement is that the trainee intern is now completing a funded PhD, with the community organisation a partner in the research.

Partnerships A and B described their ethics applications as 'straightforward'. Both submitted their ethics application in August/September 2019 and ethical approval was granted soon after. However, Partnership C faced challenges with their ethics application, attributed to the project's 'layers of complexity'. This included the participatory approach used for co-designing the research, the perception of people with stroke and aphasia from a research ethics perspective as a particularly 'vulnerable' group, because of the nature of the condition and associated communication difficulties, and its association with cognitive difficulties. Accordingly, there were complex issues in relation to informed consent and multiple risks had to be considered. While ethical approval was eventually granted, the process was protracted and delayed the research project substantially.

'For example, when I put in the ethics applications, I explained to the REC that our research questions would be co-designed, so I couldn't give them a list of questions, I could say the broad areas that we had discussed and this was one of the queries of the REC ... they did grant us ethical approval and they did give the condition that we would submit the codesigned questions when they were agreed' (Academic partner)

It is unclear if the REC included reviewers who have knowledge and experience of reviewing ethics applications that are informed by CBPR principles.

Research projects cannot commence without ethical approval. Evidently, when the application is not approved on first submission, ethical approval is delayed and can result in a lengthy approval process. It brings a lot of uncertainty for the partnership. Given these issues, it was suggested that in future iterations of CES-P (NUI Galway), organisers could emphasise the potential for this to happen to participants and encourage partnerships to

prepare and submit ethics applications as early as possible. The organising team pointed out that, with respect to PPI in research, ethics is an evolving area and potentially an area that needs to be explored further by PPI Ignite @ NUI Galway.

#### 4.4.4 Collecting and analysing/interpreting research data

All three partnerships used qualitative research approaches for their research projects. Partnership A decided to depart from their original plan to use a mixed-methods approach, and instead design the study entirely around focus groups with patients. This decision, which came about as a consequence of the interactive training (see Section 4.3.3), was taken to allow patients to become more involved in identifying specific topics or issues of importance to them:

‘Initially, we had planned to do a mixed qualitative, quantitative study, but as we went through the sessions and thought about it, in some ways the quantitative may be jumping the gun a bit and we would be better with open-ended questions, with focus groups or interviews. We hadn’t decided at that stage exactly what. In other words, to get patients to tell us what were the topics they felt should be covered ... a more open-ended thing that is led by what patients tell us at the focus groups ... that was the main and a big change that came out. It meant our whole approach was going to be quite different ... but, I think, a good change, to show that we could be flexible to what we were learning ...’ (Community partner)

The community and academic partners worked collaboratively to plan the focus groups and recruit participants. A research assistant was employed to assist with recruitment and data collection. The community and academic partners jointly conducted the focus groups, with the academic researcher taking the lead in facilitation. The community and academic co-leads collaboratively analysed the data. They described the iterative approach used and outlined the steps taken. Both coded transcripts separately, then shared and commented on each other’s coding. They worked jointly to agree on the coding and to identify themes. While one partner set about drafting the text for each theme, the other selected quotes to accompany the text. The partners jointly agreed on the final write-up of the findings. The approach used by this partnership aligns most closely with one of the four methodological approaches identified by Jennings et al. (2018) for involving PPI co-researchers in data analysis, i.e. collaborative data analysis approach 4: ‘development and application’. The partners reported this approach to be extremely time-consuming:

‘It’s been an iterative process and has taken a long time, but that is the nature of it. We’ll get there - normally, with the work that I do, you can do the analysis and write-up quite quickly - it’s just a slower process but more reflexive and more collaborative, it takes a bit longer’ (Academic partner)

Partnership B conducted individual interviews with patients, and data collection was nearing completion at the time of the fieldwork for this evaluation. This partnership took a different approach to data collection and analysis. The academic researchers conducted the interviews, with the help of the research assistant. Data collection had been disrupted by the Covid-19 pandemic, as researchers were prohibited from being on campus, and could not gain access to expressions of interest posted by research participants to the university from.

The partnership had to adapt their recruitment processes and replace face-to-face interviews with telephone interviews. This delayed data collection and in turn data analysis. At the time of writing, data analysis had been mainly undertaken by the academic researchers. However, plans were afoot to meet with and discuss the data analysis and interpretation with the PPI panel. The approach taken to collaborative data analysis by this partnership most closely aligns with collaborative data analysis approach 1: 'consultation', the first of the four methodological approaches identified by Jennings et al. (2018).

Partnership C is using a participatory research approach to co-design an awareness-raising campaign with members of their community of interest. The academic and community partner planned to co-design research questions and approach data collection approach and to co-analyse the data collected with members of the community of interest. At the time of the focus groups for this evaluation, this partnership was still at the early stages of this co-design process. This approach requires a substantial commitment of time, which proved to be a major challenge for this partnership, as all three parties involved had competing demands. With a heavy workload and competing organisational demands, many of which were unanticipated at the start of the programme, the community partner had little time to commit to the project for a number of months. Meetings with the community of interest were complicated as they had to be organised to fit in with the community organisation's opening times, the busy schedules of the patient group, and to accommodate the health-related needs of the patient group. All of this contributed to time delays for the project. Ultimately, due largely to heavy workloads and competing demands, the partnership submitted their ethics application two months later than the other two partnerships. However, shortly after ethical approval had been obtained, the Covid-19 pandemic erupted in Ireland. It impacted most heavily on this partnership, as data collection was about to commence at that time, but most members of the patient group involved in the co-design were 'cocooning', and it was neither possible nor safe for the community and academic researchers to meet with them face-to-face. Moving online meant making changes to the methods, amending participant information sheets and consent forms, and seeking ethical approval for these changes. Meeting virtually posed particular challenges as some members of the patient group either did not have access to technology or were not familiar with online platforms such as Zoom. At the time of the fieldwork for this evaluation, the community and academic partners were still in the process of getting the group familiar with online technology and an added difficulty was the communication difficulties that members of this group had. In both partnerships B and C, the primary concern of the community and academic partners was ensuring the health and safety of the PPI panel and research participants susceptible to Covid-19.

#### 4.4.5 Sharing research findings

The sharing of research results and learning from CES-P by the partnerships was driven by a PPI ethos. For example, two partnerships had given joint presentations at an event on PPI in research. In one partnership, the community and academic partners jointly wrote up their research findings in a paper for publication in a peer-reviewed journal (Cullinan et al., 2020). One partnership was still collecting and analysing data, and planned to involve PPI panel members in decisions around dissemination, once the results had been fed back to them. The partnership that was still at a co-design phase had not yet shared any results or learning. However, the community and academic partners had already discussed dissemination with their partners with stroke and aphasia who were most interested in

sharing research results through alternative routes and had suggested writing a song or making a video. This partnership had allocated most of its funding to dissemination, to fund costs of travel, accommodation and fees for their partners with stroke and aphasia to attend and present at a conference, which unfortunately was cancelled due to the pandemic.

A particular challenge for all partnerships was the short duration of CES-P (NUI Galway), especially the timeframe for the completion of collaborative research projects, which was found to be unrealistic.

#### 4.4.6 Mentorship

Like CES-P (MUSC), there is a mentoring component in CES-P (NUI Galway). In one partnership, qualitative research was deemed to be the most appropriate approach for their study, but both academic and community partners lacked qualitative research skills. Having identified this as a gap, the partners proactively sought additional support and training in this area and were connected to a mentor by the PPI Ignite @ NUI Galway team. The mentor held workshops with the partners covering topics such as running focus groups, transcribing interviews, undertaking thematic analysis, and continued to support and mentor the partners throughout the research process including during data analysis and write-up. The partners described the mentorship as 'critical for us,' without which they would have been forced to rely on their existing skillset and use quantitative research methods. They pointed out that 'potentially every team will have some gap' and agreed that there is 'definitely a role for CES-P in helping the partnerships to identify people to fill skills-gaps'. A gap highlighted by another partnership related to PPI group facilitation skills, a skills gap that could also potentially be addressed through mentorship.

### 4.5 Impacts of CES-P (NUI Galway)

There have been references to impacts of CES-P (NUI Galway) throughout this chapter. This section brings the findings on the impacts together into one place. Using a framework developed by Hoekstra et al. (2020), which has been slightly adapted for this evaluation, it reports on both the beneficial and challenging or negative impacts on: (1) researchers; (2) community partners (3); the relationship between partners; (4) community organisations and the university; and (5) the research process.

Both beneficial and challenging or negative impacts of CES-P (NUI Galway) were identified, although the number of beneficial impacts identified far out-weighed the number of challenging or negative impacts (Table 3). The beneficial and challenging or negative impacts listed in Table 3 are reported collectively, and it does not follow that every individual researcher, community partner or partnership experienced each impact listed.

#### 4.5.1 Positive impacts

As a result of CES-P (NUI Galway), one new community-academic partnership was formed. For two existing community-academic partnerships, CES-P (NUI Galway) provided the community and academic partners with an opportunity to work together collaboratively on a research project underpinned by PPI for the first time. An impact of CES-P (NUI Galway) was that community and academic partners began to think differently and more positively about community-academic partnerships, and attitudes among community partners towards



working in partnership with academic partners improved. CES-P (NUI Galway) provided the community and academic partners with the space to build their partnership. It facilitated partners to shift from a sole focus on the tasks involved in undertaking a research project to a focus on partnership and relationship building. CES-P (NUI Galway) provided community and academic partners with a structured framework for thinking about partnership and useful tools and resources to work on partnership building. Community and academic partners in both pre-existing and new partnerships had positive perceptions of their partnership and their counterparts before CES-P (NUI Galway). CES-P (NUI Galway) training, particularly training on partnership readiness, helped to confirm or validate these preconceptions. CES-P (NUI Galway) training on partnership helped to reassure the partners that their respective values were aligned and 'on the same page'. As a result of the training, partners began to place a greater value on their partnership. This enabled the partners to feel more comfortable and more confident moving forward in the process. Over the course CES-P (NUI Galway), the community and academic partners developed a mutual understanding of each partner's work styles, language, needs and constraints. Community partners became more trusting of academic partners.

CES-P (NUI Galway) training on research ethics impacted most strongly on community partners. Community partners developed an increased understanding of research ethics, an increased capacity to contribute to ethics applications, and an increased ability to assess research against ethical standards.

CES-P (NUI Galway) training on research methods succeeded in refreshing researchers' knowledge about quantitative research methods. Researchers were exposed to different research methods and gave them a greater appreciation of the value of qualitative research for the purposes of PPI in research. Some community partners began to view research and, in particular, qualitative research methods more positively. Through mentorship, CES-P facilitated academic and community partners to learn new research skills.

**Table 3: Beneficial and challenging or negative impacts of CES-P**

Impacts on researchers involved in CES-P	Impacts on community partners involved in CES-P	Impacts on the relationship between the academic and community partners	Impacts on the community organisation and university	Impacts on the research process
<i>Beneficial impacts</i>				
<ul style="list-style-type: none"> <li>- Positive shift in thinking about community-academic partnerships for research</li> <li>- Increased knowledge and understanding of PPI</li> <li>- Better able to distinguish between PPI in research that is tokenistic and collaborative</li> <li>- Knowledge about research methods refreshed</li> <li>- Exposure to different research methods and greater appreciation of the value of qualitative research for undertaking PPI in research</li> <li>- New research skills acquired</li> <li>- Improved PPI group facilitation skills</li> <li>- Increased motivation</li> </ul>	<ul style="list-style-type: none"> <li>- Positive shift in thinking about and attitudes to working in partnership with researchers</li> <li>- Increased knowledge and understanding of PPI</li> <li>- Better able to distinguish between PPI in research that is tokenistic and collaborative</li> <li>- Positive change in attitudes towards research and research methods</li> <li>- Increased understanding of research ethics</li> <li>- Increased capacity to contribute to ethics applications</li> <li>- New research skills acquired</li> <li>- Increased ability to assess quality of research</li> <li>- Developed PPI group facilitation skills</li> <li>- Personal benefits such as feeling more comfortable, more confident, valued, listened to, empowered,</li> </ul>	<ul style="list-style-type: none"> <li>- Having a space for partners to build a relationship</li> <li>- Facilitating partners to shift from a sole focus on the tasks involved in undertaking a research project to a focus on partnership</li> <li>- Partners pre-existing positive perceptions of the partnership (both pre-existing and new) confirmed or validated</li> <li>- Partners feeling reassured that the values of the partners were aligned and 'on the same page'</li> <li>- Access to useful resources for partnership-building</li> <li>- Partners' thinking on partnerships in research became more structured</li> <li>- Partners placing a greater value on the partnership</li> <li>- Partners feeling more comfortable and more confident moving forward in the process</li> <li>- Mutual understanding of each partner's work styles,</li> </ul>	<ul style="list-style-type: none"> <li>- One new partnership formed and two existing partnerships strengthened</li> <li>- A PPI panel established within a community organisation</li> <li>- Greater linkages between community organisations and university</li> <li>- New research projects between university and community organisation, e.g. Masters projects and one funded PhD in partnership with a community partner</li> </ul>	<ul style="list-style-type: none"> <li>-Research more relevant and useful</li> <li>-Establishing and refining research question</li> <li>-Decisions on research design</li> <li>-Enhanced ethics application</li> <li>-Collaborative data collection and analysis</li> <li>-Potentially important research findings</li> </ul>

	<p>increased sense of accomplishment</p> <p>-Having more trust in researchers</p>	<p>language, needs and constraints</p> <p>- Increased and sustained motivation</p> <p>- Relationships forged between three partnerships</p>		
<i>Challenging or negative impacts</i>				
<ul style="list-style-type: none"> <li>- Additional time burden</li> <li>- Academic benefits, e.g. funding, publications, is limited, at least in the short-term</li> <li>- Burden of responsibility, e.g. when milestones not achieved</li> </ul>	<ul style="list-style-type: none"> <li>- Additional time burden</li> <li>- Negative impact on health and wellbeing</li> <li>- Feeling daunted or overwhelmed</li> </ul>	<ul style="list-style-type: none"> <li>- Additional time demands</li> </ul>	<ul style="list-style-type: none"> <li>- None identified</li> </ul>	<ul style="list-style-type: none"> <li>- Time demands</li> </ul>

An increased knowledge and understanding of PPI in research among community and academic partners was in evidence, arising from participation in training on PPI in health research. Both academic and community partners spoke about being able to discern the difference between PPI in research that is tokenistic and PPI in research that is collaborative. Community and academic partners developed and improved their skills in relation to facilitating PPI groups as their project went along. This is a skill that could potentially be taught as part of the CES-P training or through mentorship.

Both community and academic partners experienced personal benefits as a result of their participation in CES-P. The main personal benefit for researchers was increased motivation. The range of benefits experienced by community partners included feeling more comfortable partnering with academic researchers, gaining more confidence, feeling valued, listened to and empowered and a sense of accomplishment.

There were positive impacts for community organisations and for the university that had been unanticipated. In one community organisation, the PPI panel created for the purposes of the CES-P research project became an established PPI panel within the organisation and panel members decided to get involved in other research projects. The community and academic partners reported that participation in the PPI panel was beneficial for the panel members. Collaboration between the university and a community organisation led to new research projects at Masters and doctoral level. Greater linkages between community organisations and the university were forged that were mutually beneficial. For example, university speech and language therapy students volunteered with a community organisation and received training in supporting people living with stroke and aphasia. Through the partnership, this community organisation was also connected in with ALIVE, NUI Galway's student volunteering programme, a dedicated programme to connect students with volunteering opportunities.

#### 4.5.2 Negative impacts

PPI in health research is typically presented as being unquestionably a good thing. Its impact tends to be equated with benefit, and challenging or negative impacts are often overlooked (Russell et al., 2020). This evaluation has revealed that there are some challenging or negative impacts associated with CES-P (NUI Galway). Mitigating any negative impacts on academic researchers and community partners involved in CES-P (NUI Galway) will be an important aspect of the next iteration of the programme. Steps that could potentially be taken are included below.

Of the negative impacts, the most frequently identified was the additional time demands that CES-P places on both academic researchers and community partners. Attending the training takes time. Building and sustaining partnerships is a time-consuming process and requires a commitment of time. Conducting research collaboratively and embedding PPI in research is time-consuming. Community and academic partners are often juggling the demands of participation in CES-P with other work commitment and demands. The additional time burden has long been identified as a challenge of CBPR (Israel, 1998) and feelings of overwork and time burdens have been identified as negative impacts of PPI on those who get involved (Russell et al., 2020). This evaluation has highlighted that there is the potential

for researchers, especially those leading projects and with heavy workloads and competing demands, to feel a burden of responsibility, a negative impact that has been identified in other studies of PPI involvement in health research (Russell et al., 2020). For community partners that are new to research and new to partnering with academic researchers, CES-P can be daunting and overwhelming. There are costs associated with co-production (Oliver et al., 2019).

Partners' capacity to be involved in CES-P (NUI Galway) was addressed during the interactive training. However, there is a need to further outline the time demands of CES-P (NUI Galway) during the application stage and there may be a role for the organising team to help academic and community partners better assess their capacity to be involved in CES-P (NUI Galway) either at partnership readiness training or before training begins, and to help build the capacity of those with little or no experience of research or PPI before CES-P training commences. Ensuring that there is sufficient time for induction of community partners into CES-P could also help. It may also help community and academic co-leads, especially those with heavy workloads and competing demands, to have at least one other person within their respective organisations that they can bring into the partnership or 'buddy with' for support and with whom they can share the time demands and burden of responsibility.

Conflicts can arise in community-academic partnerships and has been identified as another challenging impact of CBPR and PPI in research. In this evaluation, community and academic partners reported that, while there was plenty of healthy discussion between them, none of the partnerships had experienced any conflict or had to resort to conflict resolution. From the perspectives of community and academic partners, good communication, openness and flexibility were key to this.

'We had plenty of moments where we raised 'this is what I think' and [name of community partner] is very good at saying when she doesn't agree with something. There have been discussions and disagreements but ... we are both very happy to compromise on things once the main goal isn't compromised. We definitely have a common understanding of what that main goal is, so long as we hit that ...'  
(Academic partner)

#### 4.6 PPI Ignite team

In all three partnerships, the academic and community partners spoke highly of the PPI Ignite @ NUI Galway team. The academic and community partners used words such as 'excellent', 'helpful' and 'supportive' to describe the organising team. They found the organising team to be 'approachable', 'flexible', 'very practical' and 'responsive', helping them to finding solutions to issues or problems that arose. As one academic partner stated: they were 'there for us.' Community partners reported that the team were accommodating of their needs, giving examples such as allowing them to attend the workshops remotely and recording the workshops and making them available to the partners. They appreciated that the team were 'mindful of the small details.' For example, when organising workshops, they paid great attention to the workshop timings, providing directions and meeting dietary requirements. In one interview, it was stressed that a lot of the success of the programme

was down to the calibre of the people that PPI Ignite @ NUI Galway was fortunate to have delivering it and that 'they just do the detail really, really well'.

With respect to the administration of the grants, individual research accounts were set up in the name of the academic lead of each partnership, and €5,000 credited to each account by PPI Ignite @ NUI Galway. However, due to complicated administrative systems in the university, there were long delays before the funds could be released to the partnerships' research accounts. In addition, this approach proved to be administratively burdensome for the PPI Ignite @ NUI Galway team. While the rationale for taking this approach was to give academic researchers experience of managing a research account, in practice the academic leads tended to already have experience in this area, and any benefit was overshadowed by the delay in the transfer of funding. Given the administrative challenges, it would perhaps be more appropriate in future iterations of CES-P (NUI Galway) to maintain the grant funding in an account managed centrally by PPI Ignite @ NUI Galway.

## Chapter 5: Discussion and conclusions

CES-P (NUI Galway) is based on the Community-Engaged Scholars Programme developed at MUSC (see Appendix I). This is the first time that CES-P (MUSC) or a similar programme has been adopted for implementation in the Irish context. CES-P (NUI Galway) adheres strongly to the CES-P (MUSC) model. It has comparable aims and goals, uses the same funding model, and includes other key components - interactive training, mentorship and research projects - of CES-P (MUSC). The most notable difference between the two programmes is that the CES-P (NUI Galway) was initially designed as a 12-month programme, significantly shorter than the 18-month long CES-P (MUSC). The short duration of CES-P (NUI Galway) proved to be unrealistic, and duration of the programme was expanded soon after commencement. A duration of at least 18-months for future iterations of CES-P (NUI Galway) would be much more feasible and practicable. This has been a key lesson learned by PPI Ignite @ NUI Galway.

Adapting multi-component programmes such as CES-P (NUI Galway) and implementing them in a new context is a complex undertaking. This process was facilitated by the involvement of people with first-hand and expert knowledge and understanding of both the philosophy of CES-P (MUSC) and the 'nuts and bolts' of how it works in practice, and their input was highly regarded and highly valued.

The application process worked well overall. The involvement of the public in the grant review process was a positive experience for the public review panel and welcomed by others involved in the grant review process. Involving the public review panel demonstrates one way of involving the public in the allocation of research funds (Miller et al., 2018) and is consistent with CBPR principles (Israel et al., 2001). The competitive selection process revealed a somewhat contradictory aspect of CES-P, that is, community and academic partners are expected to work together in a partnership to collaboratively prepare the application and identify research priorities and questions before training on partnership building. Some community and academic partners felt that the time allocated was too short to allow partners to collaboratively prepare an application, even for existing partnerships.

A major success of CES-P (NUI Galway) is that a curriculum has been developed, which can be refined for future iterations of the programme. Another major success is that three partnerships between community and academic partners were facilitated to work together to build their partnership and undertake a research project. The three partnerships were significantly different from one another. Key differences identified are with regard to the form that partnerships take, the community of interest that is the focus of their research, how members of the community of interest are involved or linked to the partnership, prior experience of working together, the type of research that partnerships were doing, the approach taken to their research, and prior experience of PPI in research. These differences have implications for the interactive training programme, but particularly for research projects and incorporating PPI in the research. While the three are partnerships between academic and community partners, each partnership is distinct. This highlights the importance in future iterations of CES-P (NUI Galway) for tailoring the training and support to meet the distinct needs of each partnership and partners within it.

Like CES-P (MUSC), interactive training is a key component of CES-P (NUI Galway). In the former, interactive training consists of monthly three-hour group interactive training sessions that take place over a 12-month period, whereas in the latter it comprises six workshops. The addition of an introductory/induction session may be useful for some community and academic partners, and would be particularly useful for community partners who are new to research or have little experience of this type of programme or working in collaboration with academic researchers.

The interactive workshops were rated positively by community and academic partners. The workshop on CBPR partnership readiness, CBPR principles, the exercises that formed part of it and the resources made available were identified as being particularly important. Taking part in the workshop had a very positive impact on community and academic partners and on the relationship between the partners. However, there was consensus that more time should be given to this interactive training element.

The workshop on research ethics was of most value to community partners. Participation in this workshop yielded a number of benefits for community partners. Both community and academic partners would like the workshop to be more practical and suggested ways by which this could be achieved. The ethical approval process can be a time-consuming process. Obtaining ethical approval may be more complex for some partnerships. Delays in obtaining ethical approval will inevitably have implications for the commencement of data collection and subsequent stages of the research process. Hence, drafting of ethical applications needs to start early in the process and some partnerships may need some support with their ethics application. However, sufficient time needs to be given to key processes such as partnership building, building relationships with PPI contributors and co-developing research questions and research approaches before making an ethics application.

Delivering a workshop on research methods as part of CES-P (NUI Galway) is challenging because of the differing knowledge, experience and skill sets of participants. Learning about qualitative research methods, how qualitative research is valued and its usefulness for research involving patients and the public were key aspects of the workshop, and had positive impacts for community and academic partners alike and for the research design. In future iterations of this workshop, more attention could be placed on PPI in collaborative data collection and data analysis. Best practice frameworks such as the one developed by Jennings et al. (2018) might be useful in this regard. However, this may need to be accompanied by training or mentoring to equip community and academic partners with the skills to undertake collaborative data collection and data analysis.

The workshop on PPI in health research contributed to an increased knowledge and understanding of PPI in research among community and academic partners. A lesson learned during the research phase of CES-P (NUI Galway) was that facilitating a focus group with research participants is different to facilitating a group for the purposes of PPI in research. Community and academic partners would welcome guidance and training for the latter. In future iterations of CES-P (NUI Galway), this could be addressed through the workshop on PPI in health research, through mentoring, or a combination of both.

The workshop on sharing research results was very positively evaluated by the community and academic partners. While partnerships were still at a relatively early stage of sharing



research results, some had already presented at conferences or seminars and at the time of writing one partnership had published a paper (Cullinan et al., 2020). Partnerships were keen not only to share their research results but also what they have learned from participating in CES-P (NUI Galway) and incorporating PPI in research. To date, the partnerships have tended to opt for more traditional routes to share research results, most of which was done jointly by community and academic partners. However, there was a desire in one partnership to use more alternative forms of communicating research findings.

Overall, the community and academic partners evaluated the interactive training workshops very positively. Incorporating flexibility in to training programme was highly valued as it accommodated heavy workloads, demanding schedules and participants with health conditions. Community and academic partners would like to see the training developed so that it is even more inclusive of and accommodates the specific needs of people living with the health conditions that are the focus of the partnerships' research. Facilitating peer support between the partnerships throughout CES-P (NUI Galway) would be welcomed.

As already mentioned, the way in which the partnerships used PPI in research was linked to the way in which the partnerships had involved communities of interest in the partnership. This had particular implications for the early stages of the research process. Where the community of interest is not involved as a partner, they tend to be excluded decisions related to identifying the priority area of focus or research questions and the research design.

Mentorship proved to be extremely important in upskilling the community and academic partners in one partnership, equipping them with the research skills to carry out a study using a qualitative approach. Support to develop skills to effectively facilitate PPI groups is another area where mentorship could be of use in CES-P (NUI Galway) in the future.

CES-P (NUI Galway) had many positive impacts on the researchers, community partners, on the relationships between the community and academic partners, and on the research process. There were also positive impacts on the community organisation and the university that were unanticipated at the beginning of CES-P (NUI Galway). The funding model adopted by CES-P (NUI Galway) is to award small grants to support community-academic partnerships to undertake pilot projects and prepare a larger grant proposal. At the time of writing, the three partnerships were at different stages of completing their research projects and sharing research results. Using small grants to foster community-academic partnerships is not without its challenges (Kegler et al., 2016). Building partnerships and undertaking PPI in research takes time, and the additional time demands was one of the biggest challenges for partnerships, especially for academic and community partners whose workloads were already high and who had competing demands. The time required to build partnerships and undertake a research project should not be underestimated. While the benefits of CES-P far-outweighed the challenging or negative impacts, it will be crucial that PPI Ignite @ NUI Galway takes steps to mitigate any challenging or negative impacts in future iterations of CES-P (NUI Galway). Navigating the ethical approval process can also present challenges, especially for research projects taking a participatory approach and involving 'vulnerable groups.' This is not unique to CES-P (NUI Galway). CES-P (MUSC) also encountered challenges with the ethical review process (Andrews et al., 2013) and took a number of steps to address these challenges. The COVID-19 pandemic was a challenge that no-one could have anticipated at the start of CES-P.

It has been said that only modest results can be expected from 'micro-funding' (Kegler et al., 2016; Tenduklar et al., 2011). However, a model of CES-P, based on the original CES-P

(MUSC), had been successfully developed and implemented in NUI Galway, and the staff at PPI Ignite @ NUI Galway have now experienced and developed expertise in delivering such a programme. There is an opportunity to build on the lessons learned from the development and implementation for the next iteration of CES-P (NUI Galway). As a result, CES-P (NUI Galway) has grown a small cadre of academic researchers at NUI Galway and staff in community organisations who have the knowledge, experience and skills to build community and academic partnerships and undertake PPI in research. These community and academic partners have an opportunity to build on the research undertaken to date and the next stages is for the partnerships to consider the next steps for the partnership particularly around preparing grant proposals.<sup>5</sup> There is also the potential for this cadre of community and academic partners to support and mentor the next cohort of community-academic partnerships grant-funded through CES-P (NUI Galway).

CES-P (NUI Galway) will be of interest to the HRB as well as other funding bodies. In its new strategy, the HRB has strengthened its commitment to PPI in research. The strategy includes an action to ‘involve the public, patients and carers in HRB-funded research in order to ensure that it is relevant and usable and can catalyse cultural change in the research system’, and CES-P (NUI Galway) is particularly relevant to the implementation action 1.4.2, which is to ‘build capacity and skills for the meaningful involvement of the public, patients and carers in health research’ (HRB, 2021: 9).

The expertise gained and the lessons learned by the organising team and the community and academic partners participating in CES-P (NUI Galway) should not be lost. CES-P (NUI Galway) is a unique programme in Ireland that will be of interest to and huge value to academic and community partners who are genuinely interested in working together and using a CBPR approach to address issues of importance to people living with a variety of health conditions, and to universities.

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<sup>5</sup> Since the fieldwork for this evaluation, progress has been made in this regard, and one partnership has already submitted an application for grant funding, which if successful will enable the community and academic partners to continue their work.

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## Appendix I: The Community Engaged Scholars Programme (MUSC)

CES-P (MUSC) is a multi-component programme. First developed in 2009, it was designed as an 18-month programme that provides funding for pilot projects, interactive training and mentorship to teams consisting of a community and an academic partner who are interested in taking a CBPR approach to research. This section describes the CES-P (MUSC) and its components.

### **Background to CES-P**

The impetus to develop the CES-P (MUSC) came from the National Institute of Health (NIH). The NIH, through a grant scheme entitled the Clinical and Translational Science Award, assists universities to train and advance a cadre of researchers to take a translational approach to clinical research. Community partnerships and participation in clinical and translational research is a requirement of the funding, and universities must collaborate with community organisations to ensure community engagement in the research process (Jenkins et al., 2020).

Funded under the CTSA, the goal of staff at MUSC was to implement a new CBPR training programme at the university (Andrews et al., 2013; Jenkins et al., 2020). To inform the development of the programme, a team consisting of community and academic partners was formed. While there was a commitment within the university to community partnerships and CBPR, a perceived weakness was that many academic researchers lacked awareness and knowledge about CBPR principles and approaches, and that community partners have limited knowledge of working in partnership with academic researchers. They wanted to address these gaps through the development of CES-P (Andrews et al., 2013; Jenkins et al., 2020). In addition, at the time that CES-P was being developed, most CBPR training programmes were provided to community partners separately to academic partners. Those that targeted community-academic partner dyads were few and limited. The programme developers at MUSC addressed this by making the dyad (the community partner and the academic partner) and co-learning a focal point of the programme. This is a distinguishing feature of CES-P (Andrews et al., 2013).

The CES-P's structure and content were informed by a review of a range of existing programmes that provided education and training on community engaged research. These programmes were evaluated in accordance with needs of MUSC. University staff and a community advisory board also input into and endorsed the design of CES-P (Andrews et al., 2013; Jenkins et al., 2020).

### **Funding model**

The funding model adopted by CES-P is to award small grants to community-academic partnerships to undertake pilot projects and prepare a larger grant proposal. The community-academic partnership is a focal point of CES-P from initial submission of an application for funding through to the completion of the programme. The community-academic partnerships are selected through a competitive request for applications. Pre-application information sessions are held to provide information about the CES-P to interested community and academic partners. The applications are reviewed by a panel of both community and

academic professionals, and scored according to a pre-determined set of criteria (Andrews et al., 2013; Jenkins et al., 2020).

### **CES-P design**

CES-P is designed around interactive training sessions, mentorship and pilot projects. Successful applicants conduct a pilot research study, while simultaneously undergoing interactive dyadic training. Learning needs see Jenkins

### **Interactive training sessions**

The interactive training component of CES-P consists of monthly 3-hour group interactive training sessions that take place over a 12-month period. CES-P is aimed at promoting learning about CBPR and developing the capacity of both community and academic partners to undertake CBPR and the capacity of the overall partnership. The training includes sessions on CBPR that covers the history, definitions and principles of CBPR, and places a key focus on CBPR partnership readiness. This stems from an understanding that community-academic partnerships are complex and time consuming, that experiences can be positive and negative, and although many community-academic partnerships are formed to undertake CBPR projects, not all are successful at implementing their projects. It recognises the need to pay more attention to the 'readiness' of community-academic partnerships to collaborate and engage in all aspects of the CBPR process, since (Andrews et al., 2012). Training on 'readiness' is informed by a model of CBPR Partnership Readiness developed by Andrews et al. (2012) who explored the concept of partnership readiness, its key dimensions and indicators, and arrived at the following definition of CBPR readiness:

'the degree to which academic–community partners 'fit' and have the 'capacity' and 'operations' necessary to plan, implement, evaluate and disseminate CBPR projects that will facilitate mutual growth of the partnership and positively influence targeted social and health needs in the community (Andrews et al., 2012: 559-560).

Readiness is therefore conceptualised as multidimensional with three key dimensions - goodness of fit, capacity, and operations, with indicators developed for each of these dimensions (Andrews et al., 2012). Goodness of fit refers to the compatibility and suitability of the partners for the research project. It is considered an important building block for a successful partnership and production of research. There are four key indicators of 'goodness of fit' – shared values, compatible climate, mutual benefit, and commitment. Capacity refers to the ability and capability of the partners, their organisations and the community to conduct CBPR as well as the capacity for social change and sustainability. Capacity is specific to each partnership, issue or project and can change rapidly during the course of the study. The indicators are effective leadership, inclusive membership, complementary competencies, and adequate resources. Operations refers to the operating structures and process (see Stockdale et al., 2006). A partnership has an infrastructure with leadership and defined processes. The key indicators of operations are congruent goals, transparent communication, conflict resolution and equal power. CBPR partnership readiness is an iterative and dynamic process. Adequate readiness (i.e. goodness of fit, capacity, operations) lays the groundwork to achieve preferred outcomes including a sustainable partnership and products, policy change and mutual growth.

Andrews et al. (2011) have developed a CBPR Partnership Readiness Toolkit (Andrews et al., n.d) to operationalise the CBPR Partnership Readiness Model, its dimensions and key indicators. It is a practical tool used in the CES-P to promote dialogue between the partners. The toolkit is in workbook format, and partners work dyadically through a series of guided exercises to assess their partnership readiness along the three key dimensions, and develop an action plan that is based on their assessment and discussions.

The interactive training also includes sessions on research methods, including data collection and analysis and approaches to and methods for undertaking a process, outcome and impact evaluation (Andrews et al., 2013). Research ethics is among the topics covered in the training.

### **Mentorship**

CES-P has a mentorship component, whereby partnerships teams identify a mentor to complement and enhance the partnership. Mentorship is intended to help guide the partnerships through anticipated challenges and to assist with addressing gaps in knowledge and expertise (Andrews et al., 2013).

### **Pilot project**

A substantial component of the CES-P is the development and implementation of a CBPR pilot project by each team. Over a 12-month period, each partnership team develops the preliminary ideas for the project identified on the partnership's application, and implements the project, adhering throughout to the principles of CBPR. Specific deliverables include submitting an ethics application, conducting a pilot project, and preparing a grant proposal. (Andrews et al., 2013).

After successfully completing the CES-P, participating team members are expected to: understand the concepts and components of CBPR; assess and leverage domains and key indicators of CBPR readiness for the partnership and potential research project; integrate CBPR principles in grant proposals and research implementation; communicate with audiences in both academic and community settings about CBPR principles and components; implement a pilot CBPR initiative; and build foundations for sustainability of the partnership and CBPR products (Andrews et al., 2013). In the long-term it is intended that CES-P will help 'build a cadre of community-academic partnerships that are successful in securing extramural funding to conduct research and program initiatives that are meaningful, useful, and influence the health of participating communities' (Andrews et al., 2013 check).

### **Evaluations of CES-P (MUSC)**

CES-P (MUSC) has been running since 2009 and over its first eight years awarded grants to 30 community-academic partnerships. The amount of funding awarded to partnerships is small. After CES-P's first year, it increased from \$5,000 to \$10,000 per partnership, based on feedback that smaller funding levels were limiting community participation (Jenkins et al., 2020). The programme is continually evaluated (Jenkins et al., 2020). The number and types of partners that inquire about the programme is monitored, as is the number and type of applicants. Proposals are reviewed using Green et al.'s (2003) Guidelines for Participatory Research. The type of partnerships that are selected is monitored. Each training session is



evaluated using standardised forms. Each team's progress is tracked. CBPR partnership readiness is assessed using qualitative interviews and each community-academic partnership performs a self-assessment using a questionnaire assessing adherence to CBPR principles developed by Braun et al. (2012). Delivery of the programme is evaluated using a fidelity checklist (training sessions, attendance, use of mentors, activities, pilot grant implementation). Outcomes in relation to partnership maintenance and sustainability over time are tracked (Andrews et al., 2013).

Andrews et al. (2013) have reported that the first three cohorts consisting of 14 CBPR teams (with each team consisting of at least one community partner and one academic partner) that had completed CES-P (MUSC) have produced relevant results. Outputs from the teams include presentations (n=40) and co-authored publications (n=4). Twelve partnership submitted grant applications, eight of which were successful and were awarded grant funding (Andrews et al., 2013).