BUILDING RESEARCH PARTNERSHIPS

EVALUATION 2012-21

Contents

Background

Building Research Partnerships is an updated version of an internationally peer-reviewed, commended, free course previously developed by Macmillan Cancer Support and the National Cancer Research Network (NCRN) in 2007[.(1)] The course was developed as a result of the annual survey of patient and public representatives, and discussions with research staff. These investigations identified a range of learning needs. All parties shared the common goals of working together more effectively and collaborating to develop good-quality research. Building on a successful partnership with the NCRN, Macmillan Cancer Support and the National Institute for Health Research developed the course to explore the area of health and social care research, as well as the various ways the public can be constructively involved in the research process.

The 'Building Research Partnerships' programme has been delivered in Northern Ireland in partnership with the Public Health Agency's HSC R&D Division and the Northern Ireland Cancer Trials Network to academic researchers, health professionals, patients, carers and the public since 2012. It is a generic programme applicable to all types of research. Originally delivered as a face to face workshop, it was successfully adapted to be delivered online during the pandemic.

Building research Partnerships has the potential to have a measurable impact on the way PPI is implemented in practice. There are clear benefits to sharing resources in a free and open way, and pooling expertise and experience through partnership working to ensure the long-term sustainability and embedding of public involvement in research.

It is a generic course applicable to all types of research. The workshop is delivered utilising a series of interactive discussions and activities involving researchers, health professionals and members of the public involved in or interested in implementing personal (patient) and public involvement in research, following the research cycle (Appendix 1).

Aims

The programme has been developed for patients, carers and members of the public who are interested in becoming involved as public partners in research, and for researchers who want to learn more about how to implement PPI in the research process with a view to building effective partnerships.

The aims of this programme are to:
(i)   strengthen mutual understanding and working relationships between researchers and the public, and
(ii)   support researchers in developing and delivering quality research that is accessible, acceptable and patient focussed.

Impact of COVID-19

During the year 2020, the impact of COVID-19 meant that all face-to-face training was cancelled and the course had to be adapted to an online version which still offered the opportunity for interaction. A 2-hour workshop was developed which combined a PowerPoint Presentation with a Dragon's Den and Question and Answer Session. An upper limit of 10 attendees was set in order to make the training more personal and give all attendees a chance to share any information and ask questions on screen. During the autumn of 2020, a pilot was undertaken on three workshops, with feedback and reflection after each, informing changes to the next. Participants were drawn from an existing waiting list. However, the limit on participant numbers was expanded to meet the demand for the workshops and as part of the online programme a Masterclass was delivered in June 2021. This combined a didactic approach with a case study presentation and a question and answer session.

Participants

During the years 2012-21, 21 workshops were held, including on-line workshops adapted for delivery during the pandemic, with a total of 410 participants. Of these, 334 attended a face to face workshop and 76 attended an on-line workshop.

Overall, participants included 292 researchers and health and social care professionals (71%), 101 service users and PPI representatives (25%) and 17 (4%) others. Of these, 98 were male (24%) and 312 were female (76%). Participants came from a range of sectors and organisations including HSC Trusts (30%), universities (36%), the voluntary sector (12%), other statutory bodies (9%) and research organisations (6%) (Table 1).

Table 1- Breakdown of Participants by Organisation

Organisation	Researchers/HSC Professionals	Service Users	Other	Total	%
Universities/HEI	137	5	5	147	36
Trusts	116	4	4	124	30
Voluntary Sector	10	34	4	48	12
Other statutory bodies	22	14	2	38	9
Other research organisations/groups	3	23	2	28	7
Not Listed	4	21	0	25	6
	292	101	17	410	100

Post Course Evaluation

After each workshop participants were asked to complete a learning and development feedback form, originally designed by Macmillan Cancer Support. Questions covered satisfaction with prior information received before the course, the format, content and pace of the course, the style of the facilitators/trainers and whether participants felt their expectations had been met. Qualitative components also asked about the most and least enjoyable parts of the course, the impact the course might have on the way participants worked, what participants might do differently as a result of the course and any recommendations for improving it (Appendix 2).

The results presented below provide a summary of responses from 304 participants who completed a course evaluation on the day or following an online workshop, giving an overall response rate of 71%. Of 304 participants who completed the evaluation, 273 responses came from 334 people who had attended a face to face workshop, a response rate of 81%, and 31 came from 76 who had attended an online workshop during the pandemic, a response rate of 41%. Analysis of responses to the quantitative component of the post learning and feedback form are broken down by the type of workshop people attended. There were few differences noted between the two groups.

Results of Post Course Evaluation

Chart 1 - Satisfaction with information and support prior to event
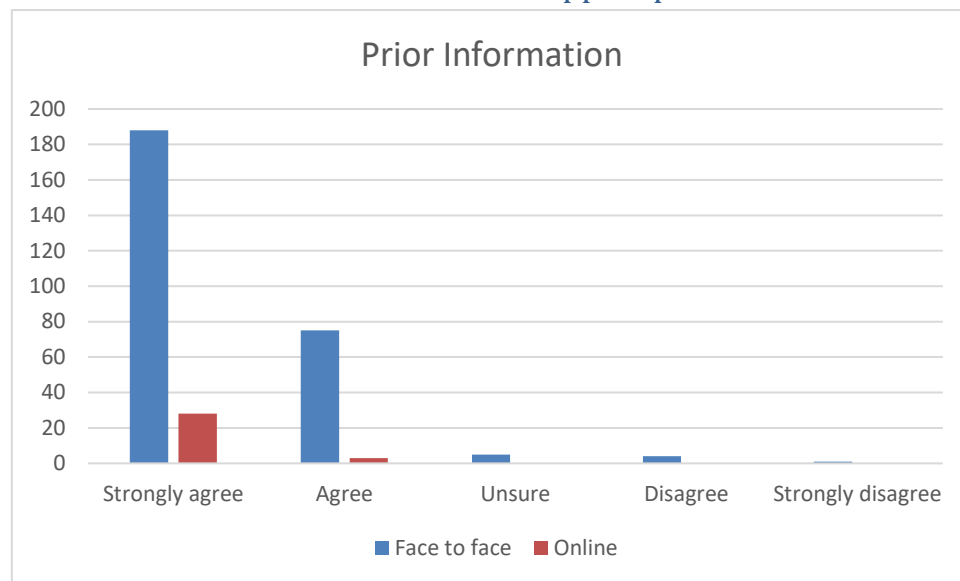
Prior Information

Chart 1 shows that overall, 294 (97%) participants were satisfied with information sent prior to the event, with 96% of those attending the face to face workshops and 100% attending the on-line workshops agreeing or strongly agreeing (Chart 1). The workshop also appeared to meet people's expectations with 284 (94%) of participants agreeing or strongly agreeing that they learned what they expected to learn at the event (Chart 2). Fourteen (5%) were unsure and 5 participants who attended the face to face workshop disagreed or strongly disagreed.

Chart 2 - I learned what I expected to learn on this event

Learned what expected
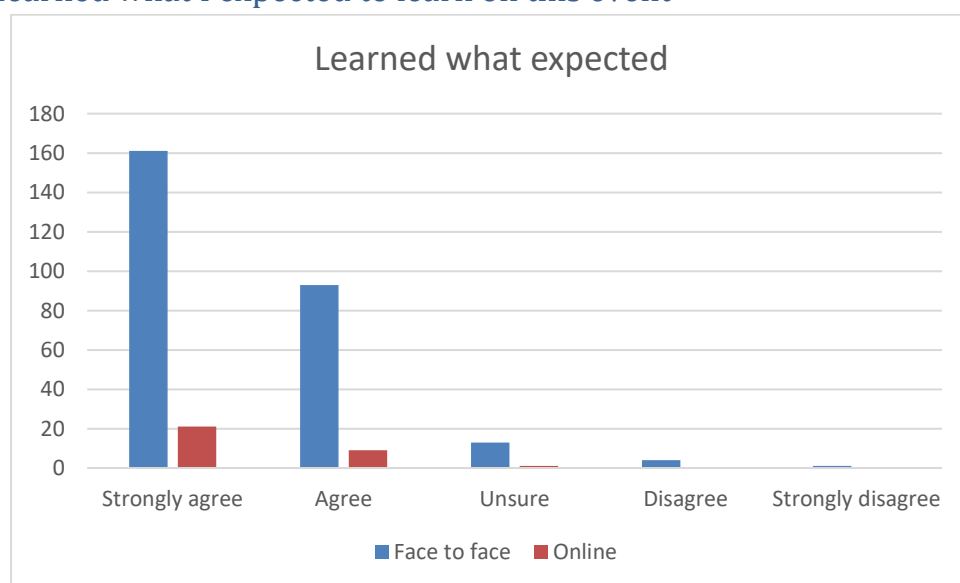
Chart 3 - The trainer(s)/facilitator(s) was/were sufficiently knowledgeable
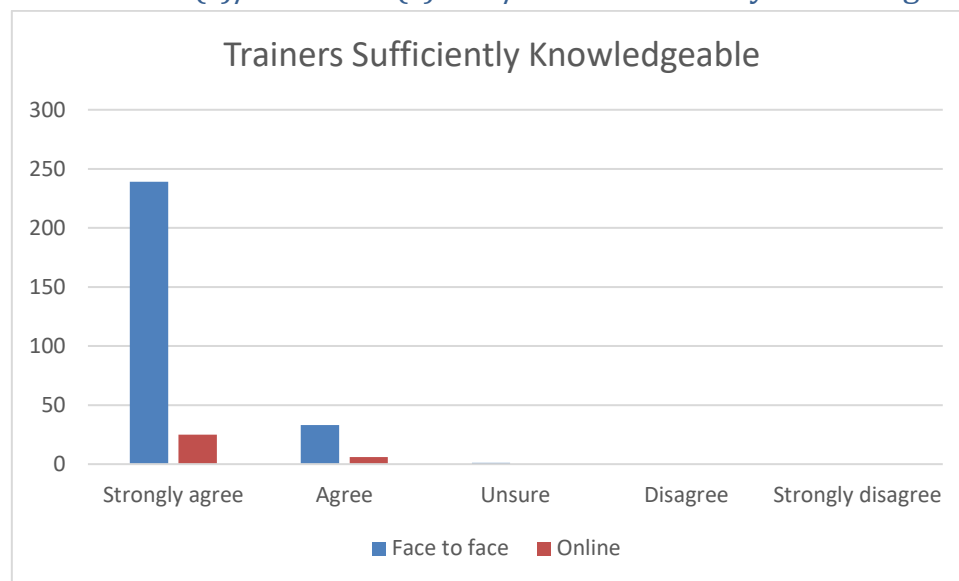
Satisfaction with the facilitators'/trainers' knowledge was also high with 303 participants, almost 100% of respondents, agreeing or agreeing strongly with this statement. One person who attended the face to face workshop was unsure (Chart 3).

Chart 4 - The trainer(s)/facilitator(s) used a range of activities to appeal to different learning styles
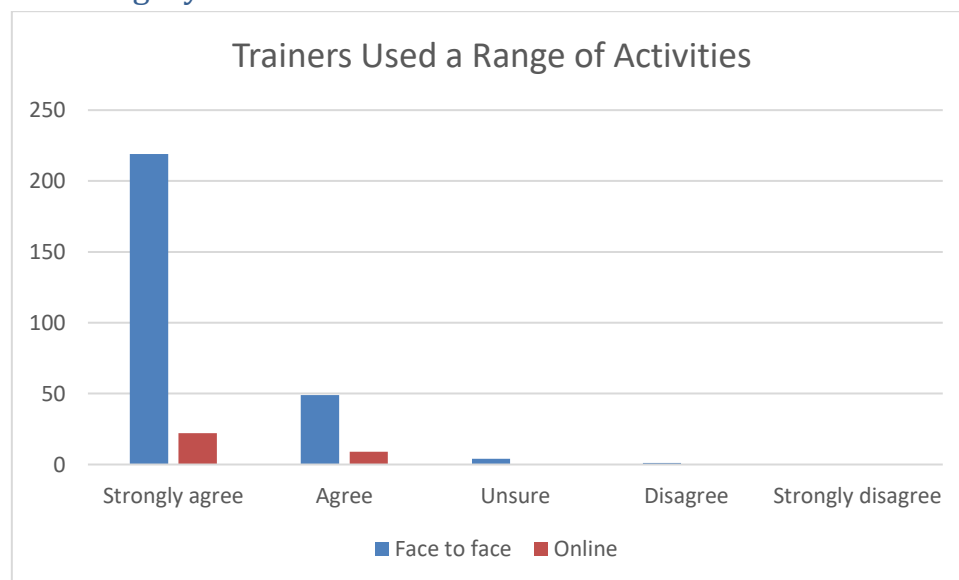
The majority 299 (98%) also agreed or strongly agreed that the facilitators/trainers used a range of activities to appeal to different learning styles with 4 people who attended the face to face workshop being unsure and 1 disagreeing (Chart 4).

Chart 5 - The trainer(s)/facilitator(s) understood my needs and made reasonable adjustments to support my learning
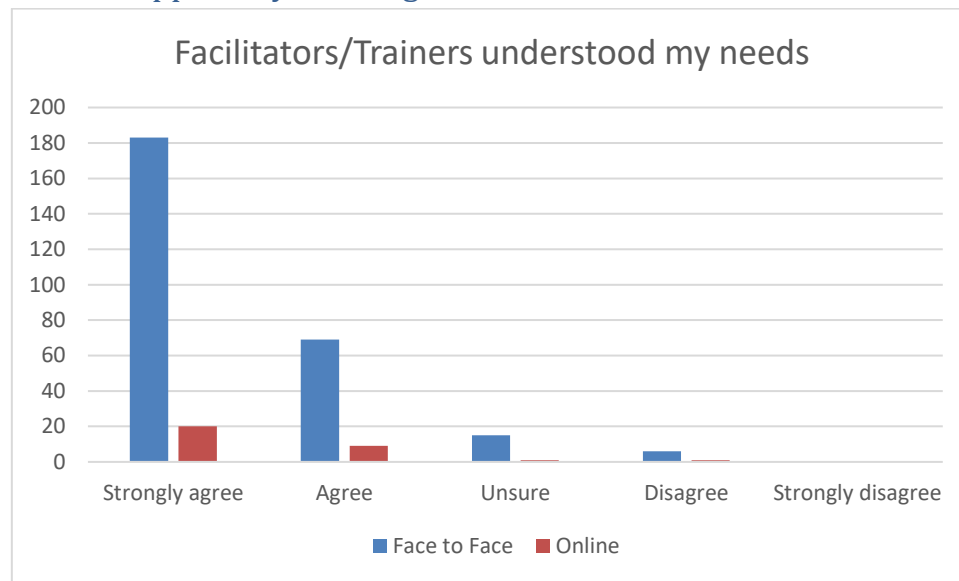
Chart 5 shows that 281 (92%) participants strongly agreed or agreed that the that the facilitators/trainers made reasonable adjustments to support their learning. However, 21 (8%) of those attending the face to face course and 2(6%) of those attending the on-line course, were unsure or disagreed.

Chart 6 - The event was structured and paced well
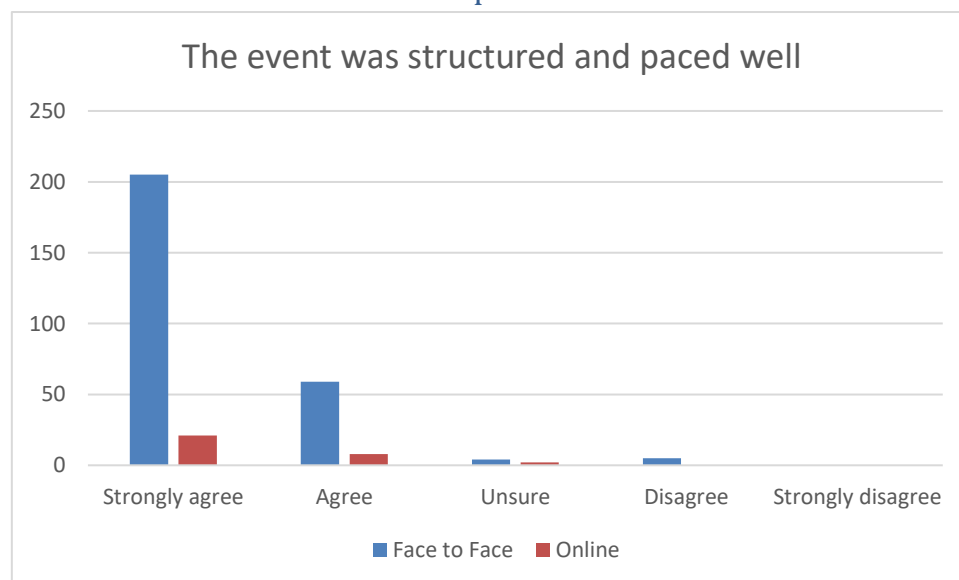
Overall, 293 (96%) participants reported that the workshop was structured and well-paced though 9 (3%) of those attending the face to face workshop and 2 (6%) of those attending on-line were unsure or disagreed (Chart 6).

Chart 7 - Materials provided to support the workshop helped me learn
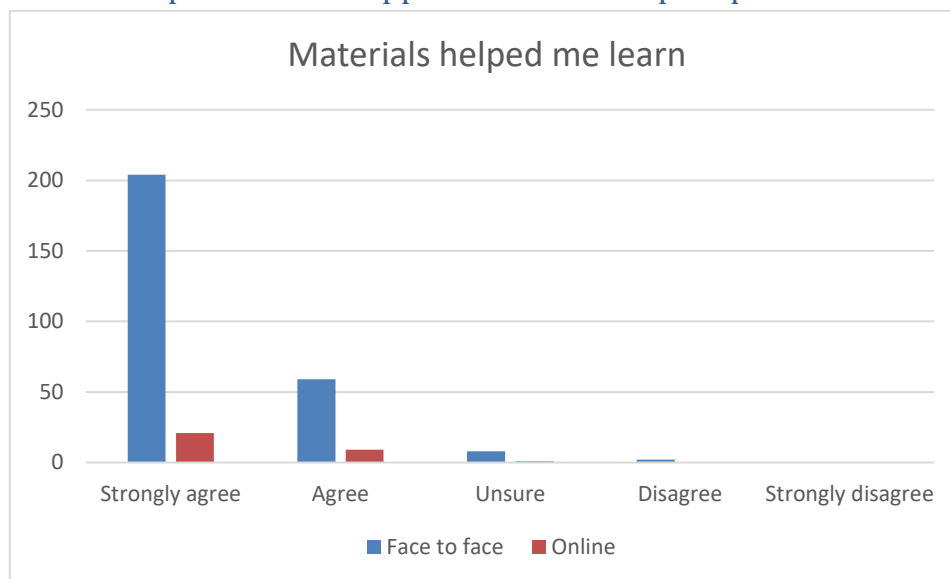
Across the two groups, 293 (96%) respondents reported that the materials provided to support the workshop had helped them learn with (10) 4% of those attending the face to face workshop and 1(3%) participant attending on-line being unsure or disagreeing (Chart 7).

Chart 8 - The trainer(s)/facilitator(s) made the subject interesting and enjoyable
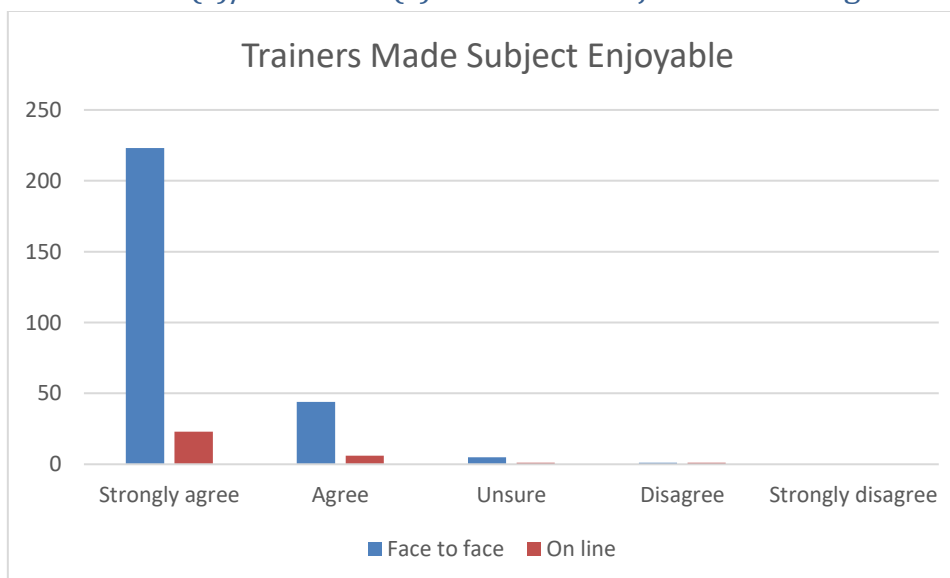
Chart 8 shows that across both groups overall, 296 (97%) participants reported that the trainers/facilitators had made the subject interesting and enjoyable.

Chart 9 - The group of learners was managed well by the trainer(s)/facilitator(s)

The Group was managed well
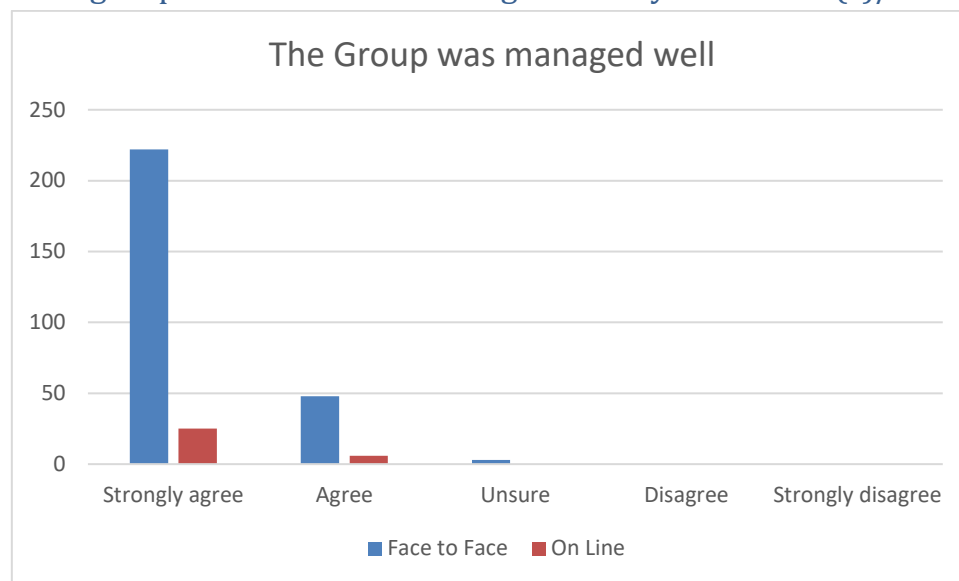
Overall, 301 (99%) respondents felt the group was managed well by the trainer/facilitator with 3 who attended face to face being unsure (Chart 9)

Chart 10 - I found the opportunity to learn and share with other people useful

Opportunity to Learn and Share
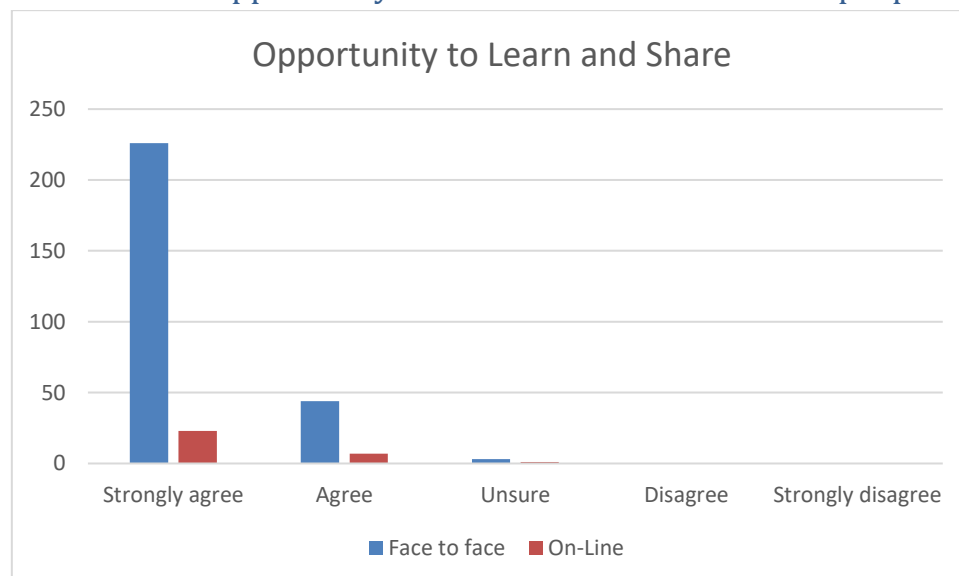
Chart 10 shows that 300 (99%) participants overall, found the opportunity to learn and share useful at the workshops with 3 who attended the face to face workshop and 1 who attended on-line disagreeing.

Chart 11 - I would recommend this event to others

Across both workshops, 294 (97%) participants would recommend the event to others although 9 participants who attended the face to face workshop were unsure and another strongly disagreed (Chart 11).

Chart 12 - Overall, I would rate this event as
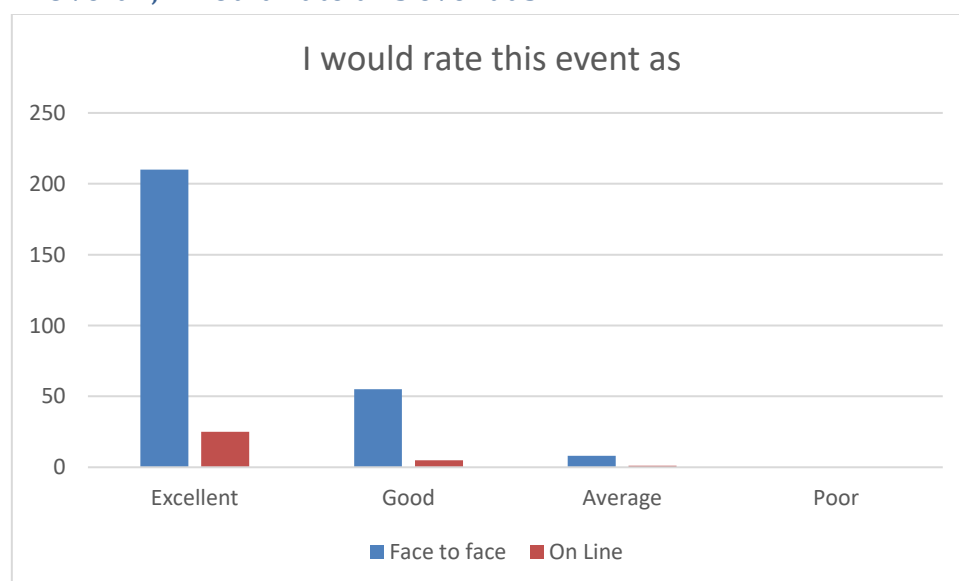
Finally, chart 12 shows that overall 295 (97%) participants rated the event as excellent or good with 265 (77%) of those attending the face to face workshop and 30 (81%) of those attending on-line rating it as excellent.

Analysis of open-ended questions from post course evaluations.

Content analysis of the open-ended questions suggested that the most enjoyable aspect of the workshop for many was its interactive and practical approach.

'*I found the exercises most valuable as it really helped explain the definitions and understanding*'

'*The open interaction and discussion among participants helped the flow and impact of the event*'

The collaborative nature of the workshop also appeared to facilitate a greater understanding of PPI in research by exploring the concept from both the researcher's and the lay perspective.

Meeting round the table – variety of people (researchers in variety of fields and other 'lays').

'Involvement of the public and how to encourage partnership. Loved having lay people at session and realised how passionate they are.'

'As a clinician I assume I know how best to engage with patients for recruitment but listening to the group I really don't but those conversations have given me ideas of how to change my current tac to be more successful in delivering something useful for patients and the project.'

'Meeting and working with lay/service users. Seeing the 'other' side of the coin'

On the other hand, service users found the opportunity to hear about research from the researchers' perspective beneficial.

'Great insight into a researcher's world and understood PPI role more too'.

'Good to have solid research examples to talk about their projects'

'Meet researchers/understanding the various research methods/cycle. Working as groups to understand, develop PPI involvement in the research process'

'Discussion with researchers – a new experience for me even though I have worked in health & social care for 20years+. The delivery of the facilitators – really made me think deeply about issues being discussed'

The appeal of the collaborative approach not only applied to those who attended the face to face workshop but was also seen as a benefit to those who attended on-line and showed one participant that zoom was an effective way to bring people together in the current circumstances.

'I saw how well zoom worked for the training format as I was worried about how I would gain meaningful discussion online with my group- I can see this works and might actually be a benefit for people as it's probably more accessible than attending in person. I will now bring the clinicians and patient groups together- I had originally planned to run the groups separately but hearing the experiences of those on the call

has made me realise that we as clinicians are actually unaware of patient perception of us and this needs to change for service improvement.

Attempts had been made when developing the online course to ensure that the interactive nature of the face to face workshop was not lost through the inclusion of break-out rooms, a Dragon's Den and/or a Question and Answer session in the Masterclass. These appeared to still give participants a sense that the workshop was both interactive and collaborative as the following quote highlights.

'This was one of the better online events I have attended due to the break out rooms. They were a good size (perhaps a little smaller but not much), encouraged cooperative learning and problem solving.'

The fact that the workshop was facilitated by a service user and not an academic or professional also appealed to participants.

'(The Facilitator) ……. was inspirational'

'Having lay facilitators'

'(The Facilitator) ………. speaking from experience'

However, having a mixed group of experienced researchers, health professionals and lay representatives at the one event also meant that it could be challenging to meet everyone's needs. When asked what the least enjoyable aspects of the workshop were, a few participants still thought separate workshops for services users and researchers would be better and it was apparent that some researchers did not fully appreciate the need to introduce research to lay participants in order for them to understand the process in which they were to be involved.

'Research methods – not primarily the focus of Building Research Partnerships'

'Whilst there is value in having lay people and researchers together, I feel the day would have benefited from separate sessions also'

In general, however, where there were criticisms, most were around wanting more time than was available to explore the issues in greater depth with more case studies, more tools and more resources and spread over a longer period of time rather than less.

When asked how participants intended to apply the learning from the workshop or do things differently. Most replied positively with an intention of changing their current practice based on the new knowledge gleaned at the workshop.

'I have learnt a clear difference between engagement & involvement and intend to get more involvement in research. Better PPI'

'Hope to apply learning to future HSC fellowship for PhD research study next year'

'I want to explore how PPI has been utilised in the studies I am involved in and improve the contribution opportunities in future studies.'

'I am hoping to apply what I have learnt to support application for PhD in the future'

'Think about a lot more different ways PPI can make a difference.'

'To develop a strategy on PPI in research in children with cerebral palsy ultimately to set up an advisory group.'

'I have made 'to do list' – this event has been really, really beneficial'

'Reassured as to importance of the research to patients and to take confidence in the making a difference aspect when asking people to be involved'

While these comments may be aspirational, they nevertheless suggest that participants felt they had tangible actions to take forward from the workshop and also share with colleagues.

Conclusion

The numbers attending the workshop and the range of organisations involved shows that this course is addressing a need for both researchers, health professionals and service users and the public with an interest in learning more about involvement in research. The majority of participants came from the Trusts and both Universities in Northern Ireland though a small number also attended from ROI and England. Almost 20% of participants attended an online workshop during the pandemic suggesting that although the workshop was designed to be a practical face to face learning experience originally, an online adaptation was both possible and more effective at including greater numbers of participants over a shorter space of time.

Overall, the analysis of the quantitative components of the feedback form showed high levels of satisfaction between participants across both types of workshop with little discernible differences found between the two. Though neither group could compare the experience of the other, both modes of delivery seemed to offer attendees a valuable learning environment with similar benefits. In general, participants particularly appreciated the collaborative, interactive nature of the workshop and the fact that it was led by a service user. While it could be argued that satisfaction levels could be attributed to an 'away day' effect, this would not have applied to those who attended the workshop on-line.

Unfortunately, respondents were not asked to specify their role in the evaluation so analysis of responses was not possible between researchers, health professionals and patients and public. Participants were also not asked about their learning styles prior to attending the workshops though they were asked what they wanted to learn. Adjustments were made where a disability was identified e.g. use of loop systems, however, difficulties in addressing individual needs in such mixed groups may account for the slightly lower levels of satisfaction reported when participants were asked if reasonable adjustments had been made to support their learning.

It should, however, be noted that each workshop comprised a range of expertise and experience both in PPI and research and balancing and addressing the needs of both groups could be challenging in terms of pace, content and structure of the workshop.

Long-Term Follow-up Evaluation

Before Covid-19, plans were underway to carry out a longer-term post course evaluation with participants who had attended BPR starting with the most recent years first and then working back. The on-line questionnaire was sent initially to 116 researchers and 40 service users with an email address who attended the workshops between 2017 and 2019 (Appendix 3 and 4). Fifteen responses were received from service users and 10 from researchers, 6 from health care professionals/non-researchers and 2 who classified themselves as both, giving an overall response rate of 21% with a response rate of 16% from researchers/health care professionals and 38% from service users. For the purpose of the qualitative analysis, attempts were made to draw out the differences between responses from the researchers and those in non-research posts but it was apparent that respondents often saw themselves in dual roles and making the distinction was not easy for them when it came to categorizing their roles. Two of the six non-researchers described themselves as public involvement leads. Two service users who responded did not remember attending the course and were excluded from the subsequent analysis.

Table 1 - Do you remember undertaking this workshop?

Do you remember undertaking this workshop?	Yes	NO
Service Users	13 (87%)	2 (13%)
Researchers/HSCPs	18 (100%)	0

Table 2 shows that when respondents were asked if they had been involved in research as a PPI representative or used the information from the workshop in their own research, 92% of service users and 89% of researchers said they had.

Table 2 - Since the workshop have you been involved in research as a PPI representative/used information from workshop in own research?

(N=31)

Since the workshop have you been involved in research as a PPI representative/used information from workshop in own research?	Yes	NO
Service Users	12(92%)	1(7%)
Researchers/HSCPs	16 (89%)	2 (11%)

Those service users who responded **"Yes"** (N=12) were asked to give examples of involvement activities. This they did as stated below in Box 1 though they did not comment if the workshop had changed how they were involved, or what they did with their learning, if any, from the workshop.

- *Encompass/Dental Project/put forward for the ASIST project and NHS complaints project*
- *Member of cancer services users' group and NICTN*
- *I am a public reviewer for the NIHR writing my reviews based on the topic and what was written*
- *With NICHS on its Scientific Research Committee*
- *Expert patient group and age impact process*
- *Clinical study group diabetes UK London, research partnership UK NI*
- *With NICRCF, Cancer Research UK, NI Biobank and other opportunities, too many to list here*
- *Doctoral Fellowship Panels*
- *Research Committee for 7 years, various PPI work for different organisations*
- *Bowel Cancer UK; NICRF; World Cancer Research Fund*
- *NICRCF member; PPI rep on NICAN Breast Cancer*
- *BCH lab projects*

In contrast Researchers and Health Professionals (total N=18) who responded **"Yes",** provided much more detail as to why and how they used the information gained from the workshop as stated below. Those who identified as Researchers (N=11) responded as follows:

- *As part of my role at work I planned and carried out a PPI workshop in November 2019 to develop research questions and will be holding the follow up in March to further elaborate on the findings and discussions form the first workshop. The aim is to develop a research question, apply for funding and carry out the work as co-production research.*

- *It raised my consciousness around language and presenting the findings of my research in a way that is meaningful to the public.*

- *I have used elements as part of my peer review exercises with colleagues.*

- *Helping PhD students to properly include PPI in their research activities.*

- *I attended the workshop with a PPI representative, and since the workshop we have established a dedicated group of 4 PPI reps to be involved in our specific research field. Since 2019, we have met 4 times, and the PPI members have had involvement in grant design, spoken at a symposium and generated new ideas to co-produce future research projects.*

- *Helped us frame the roles, opportunities and further training needs with our public involvement members.*

- *I discussed my research proposal with the Northern Ireland Cancer Research Consumer Forum which was successful and I have recently made a call over social media/through charities to identify patients who would be willing to participate as PPI members in my research - so hope to start shortly. Current PhD student - engaged an advisory group for project following this workshop.*

- *I am a member of the NI Ethics Committee so I use what I learned on the course to assess the quality of PPI engagement and involvement in research studies seeking ethical approval.*

- *Current PhD student – engaged an advisory group for project following this workshop*

- *I have been able to apply the framework in drafting a future fellowship application.*

Four of those who identified as Health Professionals (N=6) responded as follows:

- *To advise researchers interested in PPI and to encourage participation in the workshop.*

- *Our organisation has a group of service users, carers and members of the public interested in a particular area of health and social care. They are involved in various projects with our partner organisations. The workshop has informed good practice in our ongoing involvement of these members. We would also hope to bring the learning from this workshop to other colleagues in our organisation with a view to them providing some training/capacity to our service user group so that they can become more involved in research opportunities as they arise.*

- *Assisted with identifying partners to work across PPI.*

- *Member of ORECNI RECB.*

When those participants who had replied positively in Table 2, were asked, '**How well do you feel the training given at the workshop helped you take part in research as a PPI representative/helped you implement PPI in your research?** the majority (93%) of the total sample responded very or fairly well (Table 3).

Table 3 - How well do you feel the training given at the workshop helped you take part in research as a PPI representative/helped you implement PPI in your research?

(N=28)

How well do you feel the training given at the workshop helped you take part in research as a PPI representative/helped you implement PPI in your research?	Very Well	Fairly Well	Unsure	Not well	Not very well
Service Users	7	3	1	0	1
Researchers	10	6	0	0	0
Total (%)	17(61)	9(32)	1(3)	0	1(3)

Why Researchers and Health Professionals differ from Service Users in why and how they respond needs further clarification. Is it that the Workshop is not addressing Service Users needs in how to put the learning from the workshop into use? Or is it that Service Users are not learning anything new from the workshop to put into practice? Perhaps an explanation comes from Service Users responses to **"How well do you feel the training given at the workshop helped you take part in research as a PPI representative?"** One response was positive about the workshop:

- *Coming from a non HSE background it showed me how I could use experience gained in a cancer journey to enhance service elsewhere*

However, a few Service Users (N=3) expressed some dissatisfaction with the course stating it had not fully met their needs. Specifically they stated:

- *There was little coverage of the practical aspects of research. Also, I felt I was joining for the first time into an "in-crowd" who knew each other (and each other's organizations). So, pretty much an outsider*

- *I wrote as the training was geared towards research, whereas what I undertake is to look at research documents and then suggest a range of differing replies based on the context of what the subject is*

- *I think a refresher on what is expected as a PPI representative would be very helpful, as researchers are often looking for guidance*

When asked, '**How important was it to your learning process that the training was facilitated by a service user?** 96% of the total sample said it was very or fairly important (Table 4).

Table 4 - How important was it to your learning process that the training was facilitated by a service user?

(N=31)

How important was it to your learning process that the training was facilitated by a service user?	Very Important	Fairly Important	Unsure	Not very important	Not at all important
Service Users	7	5	1	0	0
Researchers	12	6	0	0	0
Total	19 (61%)	11 (35%)	1 (3%)	0	0

When asked, '**How important was it that the workshop was attended by researchers and service users in a partnership role', 97% thought it was very or fairly important** (Table 5).

Table 5 - How important was it to your learning process that the workshop was attended by researchers and service users in a partnership role?

(N=31)

How important was it to your learning process that the workshop was attended by researchers and service users in a partnership role?	Very Important	Fairly Important	Unsure	Not very important	Not at all important
Service Users	9	3	1	0	0
Researchers	12	6	0	0	0
Total	21(68%)	9 (29%)	1 (3%)	0	0

In a question designed to identify further the motivations of the Service Users, they were asked to **"give their views on any other factors which have helped them take part in research as a PPI Representative apart from this workshop/training",** it appears most were motivated by a desire to help and pass on their experiences to enhance the research process as well as being a part of that process by communicating with researchers and others, as well as networking. Also they talked to feelings that they and their contributions were valued by researchers and resulted in positive outcomes. Specifically they stated:

- *Engagement through meetings/events/networking with other members*

- *In NIHR I do this as I feel that my views might make a difference in research commenting as a critical friend as I think differently to those that write the subject*

- *I find the NICHS approach to research quite inclusive and interesting. The event with BHSCT in May of last year had lots of practical aspects*

- *Being listened to and not made to feel stupid*

- *Active participation in research with other PPI representatives and enthusiastic researchers with a genuine desire to capture the PPI lived experience to enhance the research and ultimately positive outcomes*

- *Have to be prepared to take on any PPI offers made*

- *Passing on lived experience*

- *Support from other NI*

- *Being an active Service User*

When Researchers and Health Professionals were asked to give their views on **"Any other factors which have helped you to implement PPI in your research/practice apart from this workshop/training.",** researchers were more reticent in their response with only 4 responding and, indeed, 2 of those responses were about the workshop. Of the two who described other factors, one felt the need to balance the time dedicated PPI networking with other time demands. However, whether PPI was prioritised is not made clear by that Researcher. Further, identifying the role of others in a supervisory capacity as to promoting PPI was identified as a factor. Specifically, Researchers stated:

- *Teaching the approach was planned and laid out in a very easy to understand format and made it much easier to implement. Being in a group with service users, the public, AHP and researchers gave a great broad view of what to expect and ways in which to manage different situations. There were also great advice and training on the practicalities of holding a PPI workshop.*

- *Practical application during the workshop*

- *Dedicated time to develop and maintain relationships (this has to be prioritised with other workload demands).*

- *During my PhD my supervisors were clear about the need for PPI and helped me plan how to integrate it into my studies.*

The Health Professionals who commented spoke of the benefits of working collaboratively at the workshop. Specifically, they stated:

- *Meeting likeminded colleagues at the workshop and forming a network*
- *The role play was useful to get a feel for what language was acceptable to patients/members of the public.*

- *Hearing service users co-presenting at conferences illustrated how PPI can ensure that we research what is important to the public.*

- *Ongoing experience of working with a group of service users, carers and the public, along with other regular training opportunities*

- *Working closely with clinicians helped identify key people to work with*

Service Users were also asked to give their views on **"Any factors which had made it difficult for them to take part in research as a PPI Representative."** 7 responded. Barriers to positive participation specific to the individual PPI Representatives are ill health, physical challenges like hearing loss, working full time and workload difficulties. Barriers specific to the process of participating as a PPI Representative relate to being made to feel an outsider due to the profession-specific language researchers and others use resulting in a feeling of lack of inclusiveness and not being an expert like them. Indeed, one PPI Representative left the process feeling it was a waste of time and money. Specifically, they stated:

- *Ill-health*

- *Time, working full time sometimes makes it difficult to be involved as much as I would like*

- *Language of researchers, so many of PPI representatives from HSC/Research background appear to be the 'experts', understanding exactly where my input can dovetail with the needs of researcher*

- *As a reviewer the work is intensive, you have to get your head into the subject and within a two week timescale can be a bit of a struggle if you have other workloads*

- *The ……. committees are a WASTE of time and MONEY. That's why I left*

- *I have hearing loss. I am only a volunteer with ……..and therefore do not 'speak' on its behalf. I felt like an outsider*

- *Participation has only been limited by time available as I am currently employed in a full-time capacity*

When Researchers and Health Professionals were asked to give their views on **"Any other factors which have made it difficult to implement PPI in your research/practice apart from this workshop/training.",** out of the 6 Researchers who responded all referred to external contextual factors. One Researcher mentioned that they didn't know many other teams using this approach and another the difficulty in implementing virtual PPI during COVID-19 restrictions. Two Researchers mentioned the lack of funding for PPI expertise. Two of three Researchers pointed to the difficulties in finding PPI representatives without specific agendas that they wished to advocate, and the need for training of the public.

- *Our PPI workshop was planned by our team and I am fortunate to be in such a team. However, I don't know of many others using this approach in my workplace to develop research and not sure what the barriers are.*

- *Time. Funding - it's not fair to expect people to participate in regular meetings and so on if we cannot pay for travel expenses, parking and so on. While large studies can often include these costs in their proposal, smaller studies which may be even more meaningful to the public don't have access to this kind of funding. Training for the public - people who do engage in PPI research work often have personal reasons for doing so and become frustrated when they realise their agenda is different to that of the proposed study. We need more of these workshops so that more members of the public can understand what it means to be involved as a PPI member.*

- *Organising and conducting virtual PPI due to COVID-19 restrictions.*

- *Funding - difficult for small or emergent teams to implement INVOLVE standards for payment and reimbursement. Feels disingenuous to not be able to offer payment for time and expertise. When funding is available the administrative processes for both the PI contributor and researcher are not efficient.*

- *I have found it difficult to know where to identify patients/members of the public who would be willing to be involved in research.*

- *Not many members of the public really understand the intricacies (and limitations) of research meaning they may come on board with unrealistic expectations. Most people who do agree to engage in PPI have their own agenda for doing so and expect that to be the prominent feature of the research.*

The 3 Health Professionals who responded to such difficulties also all referred to external contextual factors as barriers, specifically they stated:

- *Sometimes there is a lack of understanding among researchers of what they need to consider in relation to involving service users, for example lead in time and support that is required, including support in preparation for the person to become involved, covering any expenses for the person etc.*

- *Sensitive research topic Covid-19*

- *Finding some way to compensate PPI partners for their time and effort*

Service Users when asked, '**If you have not applied this training to take part in research as a PPI Representative please state why?',** responded with personal reasons, such as ill health, and external reasons i.e. they had not been asked or lacked awareness of opportunities. Specifically, they stated:

- *No opportunities have presented themselves to date, but I am very keen to be involved*
- *Ill-health still ongoing*
- *Training absorbed*
- *I am not aware, and unsure of NICHS' further engagement. I also volunteer for Action on Hearing Loss, but have minimal knowledge of their research and PPI activities. Also with hearing link.*

When researchers and Health Professionals were asked, '**If you have not applied this training to implement PPI in your research/ practice please state why?',** researchers responded with external reasons and likely future use as follows:

- *Change in circumstances - was unable to proceed with PhD opportunity being pursued. However, great toolkit - will be used in current drafting of HSC fellowship application.*

- *My role was paused whilst I was asked to move sideways to cover a different position*

- *There hasn't been an appropriate opportunity yet.*

One Health Professional explained

- *I am not a researcher active in PPI but a Public Engagement facilitator.*

Overall, the majority of respondents (87%) agreed that **The Building Research Partnerships Workshop provided them with the skills and knowledge required to take part in research as a PPI Representative or to implement PPI in Research as a researcher,** but 3 service users and 1 researcher were unsure (Table 6).

Table 6 - The Building Research Partnerships Workshop provided me with the skills and knowledge required to take part in research as a PPI Representative/implement PPI in research

(N=31)

The Building Research Partnerships Workshop provided me with the skills and knowledge required to take part in research as a PPI Representative/impleme nt PPI in research	Strongly agree	Agree	Unsure	Disagree	Strongly Disagree
Service Users	4	6	3	0	0
Researchers	7	10	1	0	0
Total	11(35)	16(52)	4(13)	0	0

When asked if, "**I feel confident in my ability to make a useful contribution to research from a PPI perspective/implement PPI as a researcher as a result of undertaking this training",** again 87% agreed or strongly agreed but 13% were unsure (Table 7).

Table 7 - I feel confident in my ability to make a useful contribution to research from a PPI perspective /implement PPI in my research as a result of undertaking this training

(N=31)

I feel confident in my ability to make a useful contribution to research from a PPI perspective /implement PPI in my research as a result of undertaking this training	Strongly agree	Agree	Unsure	Disagree	Strongly Disagree
Service Users	3	7	3	0	0
Researchers	7	10	1	0	0
Total	10 (33%)	15 (54%)	4 (13%)	0(0%)	1(3%)

Finally, respondents were asked to provide **'Any Other Comments'.**

The seven Service Users who replied were mostly very positive in their comments as to the benefits of the training even asking for more such training.

- *It was an extremely well executed training which I would love to undertake again*
- *It's worth the effort to attend these courses as you do learn a lot even if you are unable to take part as much as you would like*
- *The Workshop gave me confidence, a good understanding and sparked my interest and enthusiasm for PPI and partnership in research.*
- *I think further more detailed training would be beneficial following on from this training for PPI reps*
- *Not sure if I can contribute further to these initiatives.*
- *Must be prepared to take on different kinds of work.*
- *I have been / am involved in various other similar activities - viz. MITS, PAPS etc.*

Four of the five Researchers who replied were equally, if not more positive, about the workshop

- *I think we need more workshops to meet the needs of both the public and professionals involved in research. Having people experience ... (see file line 4)*
- *The workshops are invaluable and have a huge amount of transferability across a number of disciplines*
- *I think this workshop should be a requirement for anyone undertaking research – professional, academic or member of the public*
- *This was a fantastic workshop. Well-paced and delivered by the presenter. I found it very interesting as someone who is very early in their research career and it was beneficial too for networking.*

with just one giving feedback on the size of the groups.

- *If I had any criticism of the BRP workshop it would be the very large groups did not allow for as much interaction among team members as I feel would have been needed. I think the key strength is the knowledge and experience of the team leaders and trainers. This pilot questionnaire was easy and quick to complete.*

This positivity was also echoed by the one Health Researcher who responded as follows

- *The workshop was very valuable and benefitted greatly from service user involvement. This is a general point, it is good to bring fresh service user perspectives into any workshop as there is a risk for any of us working in health and social care that we begin speaking a language which is understood across health and social care and can be irrelevant and excluding to new people and perspectives. It's good to have fresh perspectives which challenge all of us.*

Conclusion

In summary, though all groups rated the workshop highly and particularly liked the service user led approach, some differences were noted between the three groups. Service Users have both internal and external contextual factors in their approach to PPI. They invest themselves in the process resulting in positive feelings of self-worth. They want training regularly with barriers to the process of participating in PPI endeavors being related to their health and personal circumstances, the need to work for example, and a lack of understanding of the language that health researchers and professionals use that makes them feel like outsiders.

The barriers reported by researchers are competing time and demand priorities to invest in PPI, lack of funding and a feeling that PPI partners have agendas of their own.

Health Professionals see the benefits to research of the public being involved in devising research and the networking opportunities that PPI affords them as professionals. Further, they note the need of more training for both Service Users and Researchers especially around the need of a common language.

Train the Trainer Workshop

In September 2019, a Train the Trainer workshop was held with the intention of training more facilitators and building capacity to roll out the model to other organisations, in particular the universities. Participants, including service users, were targeted from the list of previous Building Research Partnership attendees but the workshop was also advertised in the HSC R&D newsletter and website.

The workshop included an ice-breaker exercise, introductions, the background to Building Research Partnerships, facilitation skills and a practical walk through of all the sessions with demonstrations of how each session should be managed. (Appendix 3). It was led by the same facilitators. Results of the post course evaluation are presented below. Thirteen attended the workshop of which 11 were female and 2 were male. Of these, 8 were researchers/health professionals, 4 were service users and one other.

Evaluation – Part 1
(N=13)

Q1. Where did you hear about this event?

- 8 received an email from HSC R&D Division or other
- 4 read the HSC R&D Bulletin
- 1 saw on HSC R&D Website

Q2 Please describe the area/s of the event that you found most valuable/most enjoyable?

- Going through all the sessions and working through some of the exercises from a facilitators perspective
- Facilitator exercises/roles
- Morning session re introductions & facilitation skills. Knowledgeable and approachable course facilitators
- Enjoyed Margaret's facilitation and developing networks
- Practice ideas of how to manage my next PPI event
- Good sized group and good icebreakers
- Great to hear service users opinions
- Good advice about facilitating and personality management
- The review of the structure/plan of the workshop (the blue page)
- All
- The very detailed folders
- The roleplay was excellent and very informative – it provided some useful techniques to help facilitate the groups and will help with future group facilitation
- Journeying through the agenda
- Very enjoyable day all round

Q3 Please describe the area/s of the event that you found least valuable/least enjoyable?

- None
- Sometimes the conversations were hijacked off-topic
- Good overview provided for all sections of the day and very well run in terms of timing etc – enjoyed it all
- Exercise with envelopes – didn't find it linking completely
- Going again through clinical research scenarios
- I enjoyed it all
- One member telling 'their' story and experiences that were not relevant to the course/subject at hand

Q4 How do you intend to apply what you learnt on the event? What will you do differently? What do you think will be the effect of this?

- All session information and managing course participants
- I will use the learning to facilitate groups of patients and staff to disseminate my research findings and plan future work. I am also happy to act as a facilitator for BRP workshops next year
- How to facilitate groups, meetings and focus groups will be very useful to me. I think the skills I have learned from this course will benefit myself and enhance the output from groups I will facilitate
- Will be influencing my facilitation of groups
- My current job and planned future work is PPI based and this will be very helpful for planning and delivery
- Looking forward to facilitating a table at the event
- To listen more
- Apply to teaching and learning
- I hope to apply the PPI into my future research and the facilitation of BRP sometime soon. The skill taught will also be applied in other group meetings in my work
- In depth knowledge and facilitation tools
- Take my turn when asked to facilitate a workshop

Q5 What recommendations would you like to make for future events?

- None – really well paced throughout
- All good

Any other comments

- Thank you and thank you (names of public contributors) for their input into the workshop
- Really enjoyable and well run throughout
- Thank you. Encouraging meaningful two-way involvement in research between researchers and patients/public is extremely important. I think the culture within research is changing but researchers/academics still need more encouragement, I think!

Train the Trainer Evaluation – Part 2

Participants were requested to consider a number of statements relating to course organisation, facilitation and content. Participants were then requested to rate the statements on a scale ranging from Strongly Agree to Strongly Disagree. The results below come from the immediate feedback surveys from professionals and members of the public who answered the questions.

	Strongly Agree	Agree	Don't Know	Disagree	Strongly Disagree
I was satisfied with the information and administrative support I received prior to the event	77%	15%	8%		
I learned what I expected to learn on this event	69%	31%			
The trainer(s)/facilitator(s) were sufficiently knowledgeable about the subject	92%	8%			
The trainer(s)/facilitator(s) used a range of activities to appeal to different learning styles	85%	15%			
The trainer(s)/facilitator(s) understood my needs and made reasonable adjustments to support my learning	77%	8%	15%		
The event was structured and paced well	92%	8%			
The event materials used helped me to learn	92%	8%			
The trainer(s)/facilitator(s) made the subject interesting and enjoyable	100%				
The group of learners was managed well by the trainer(s)/facilitator(s)	62%	38%			
I found the opportunity to learn and share with other people useful	85%	15%			
The venue and refreshments were satisfactory	77%	15%	8%		
I would recommend this event to others	92%	8%			

100% of attendees rated the event as excellent

Conclusion

While the Train the Trainer workshop appeared to be highly rated, the Pandemic prevented opportunities for facilitators who had been trained to utilize these skills as co-facilitators at future workshops with only two subsequent face to face workshops enabling this opportunity in the autumn of 2019. However, this model has the potential for further development and expansion of the Building Research Partnerships programme to other organisations across the region.

Overall Conclusion

Overall, findings suggest that this practical workshop in Public Involvement in research has been successful in reaching a wide audience, is equally successful when delivered on line or face to face and provides both researchers, health professionals and service users and the public with a collaborative learning experience. While the on-line course was more cost-effective, face to face workshops may still address the needs of some groups and so should not be completely abandoned.

A Train the Trainer model has the potential to build capacity to enable the roll out of the workshop to other organisations where there is a high demand for this type of training. Further work should address the longer-term impact of the course between the different types of participants and look at ways to build and sustain partnerships following the course.

The report also highlighted ongoing barriers to effective PPI on both the part of researchers and the public. These included a lack of time, difficulty in identifying partners and opportunities, a lack of funding, lack of knowledge and ill health. Organisations who are advocating and supporting PPI including the DoH, PHA and universities should acknowledge these barriers and work together to find solutions to address them.

Recommendations

- The Building Research Partnership Programme should continue to be supported by the Public Health Agency as an on-line resource with face to face workshops being provided where particular needs are identified.

- Further consideration should be given to the needs of service users pre and post workshop with the aim of ensuring parity of involvement and sustaining research partnerships in the future.

- Post course evaluations should include a breakdown of participants' roles and analysis of the impact on how the workshop is received and implemented in the longer term between different groups.

- A Train the Trainer Model should be continued to build capacity for further roll out, particularly to the university sector where demand is high.

Appendix 1 - Programme

'Building Research Partnerships'

9.30am – 4:00pm

09.30am	Registration
10.00am	Welcome and Introductions *(Session 1)*
	Who is research for? *(Session 2)*
	Why is Personal and Public Involvement Important? *(Session 3)*
	Tea/Coffee break
	Involvement throughout the Research Cycle *(Session 4)*
12.40pm	**Lunch**
1.10pm	Partnerships – Roles and Responsibilities *(Session 5)*
	Communicating Research *(Session 6)*
	Comfort break
	Current research and patient involvement & Funding Applications *(Session 7)*
	Sharing learning and action planning *(Session 8)*
4.00pm	**Close**

Appendix 2 - Learning and Development Feedback Form

Learning and Development Feedback Form

Q1. Please describe the area/s of the event that you found **most valuable/most enjoyable**

Q2. Please describe the area/s of the event that you found **least valuable/least enjoyable** and/or areas that could have been developed further

Q3. How do you intend to apply learning to PPI work to increase effectiveness?

Q4. What will you do differently as a result of the course?

Q5. What potential impact will this change have?

Q5. What recommendations would you like to make for future events?

Please tick the relevant box to show whether you agree or disagree with the following statements.

	Strongly agree	Agree	Unsure	Disagree	Strongly disagree
I was satisfied with the information and administrative support I received prior to the event					
I learned what I expected to learn on this event					
The Trainer was sufficiently knowledgeable about the subject					
The Table Facilitator(s) were sufficiently knowledgeable about the subject					
The trainer(s)/facilitator(s) used a range of activities to appeal to different learning styles					
The trainer(s)/facilitator(s) understood my needs and made reasonable adjustments to support my learning					
The event was structured and paced well					
The event materials used helped me to learn					
The trainer(s)/facilitator(s) made the subject interesting and enjoyable					
The group of learners was managed well by the trainer(s)/facilitator(s)					
I found the opportunity to learn and share with other people useful					
The venue and refreshments were satisfactory					
I would recommend this event to others					
Overall, I would rate this event as…	Excellent	Good	Average	Poor	Very poor

If you have any other comments or suggestions then please write them here:

Appendix 3 - Train the Trainers

'Train the Trainers'

25th September 2019

9.30am – 4:00pm

09.30am	**Coffee & Registration**
09.45am	Introductions – who is here?

What is BRP? – aims and objectives

Facilitation Skills

- o People we might meet at Building Research Partnerships (BRP)

11.30am	**Tea/Coffee break**

(Facilitating BRP) Sessions 1,2 & 3

1.00pm	**Lunch**

(Facilitating BRP) Sessions 4,5 & 6

3.00pm	**Comfort break**

(Facilitating BRP) Sessions 7 & 8

Round Up

4.00pm	**Close**

Personal and Public Involvement (PPI)   **Involving you, improving care**

References

1. Nunn J. Building Research Partnerships. NIHR and Macmillan Cancer Support. 2015.