OPEN LETTER

# COVID-19: Public and patient involvement, now more than ever [version 1; peer review: 2 approved]

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## Abstract

The research community is responding with speed to the COVID-19 pandemic, with rapid response mechanisms to fund research, shortened application turnaround times, and expedited research ethics processes. Public and patient involvement (PPI) is under pressure in this rapid response research, where it is easy for researchers and funders to dismiss PPI as non-essential, an added extra, a “nice to have”.
In this open letter, we, researchers and PPI contributors, argue that PPI is important, now more than ever. The pandemic is impacting everyone in society, with normal rules of engagement discarded. The solution to overcoming this virus will come from many different sources and many changes will emerge to healthcare delivery and to how we live our lives. It is essential that the research to find solutions is shaped by all who will be impacted: the public and the patient must be central contributors and their voice must be hear.

## Keywords

Public and patient involvement, PPI, COVID-19


This article is included in the Coronavirus (COVID-19) collection.

**Open Peer Review**

**Reviewer Status** ✓ ✓

| | Invited Reviewers | |
|---|---|---|
| | **1** | **2** |
| **version 1** 08 Jun 2020 | ✓ report | ✓ report |

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NIHR Research Design Service, Keele, UK

2 **Nana Folmann Hempler**, Steno Diabetes Center Copenhagen, Copenhagen, Denmark

Any reports and responses or comments on the article can be found at the end of the article.

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**Author roles: Murphy E**: Conceptualization, Methodology, Project Administration, Writing – Original Draft Preparation, Writing – Review & Editing; **Tierney E**: Conceptualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Ní Shé É**: Conceptualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Killilea M**: Conceptualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Donaghey C**: Writing – Review & Editing; **Daly A**: Writing – Review & Editing; **Roche M**: Writing – Review & Editing; **Mac Loughlin D**: Writing – Review & Editing; **Dinneen S**: Conceptualization, Writing – Review & Editing

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## Why does public and patient involvement (PPI) matter?

In recent years, there has been an increased emphasis on PPI in health and social care research (INVOLVE, 2015; Staniszewska *et al.*, 2018). Research funders highlight the importance of PPI, increasingly requiring that research applications include PPI. Drawing on the lived experience of PPI contributors to shape the research, good quality PPI can enhance the quality and relevance of the research undertaken (Domecq *et al.*, 2014). Moral and ethical values underpin the argument that PPI in research is an imperative: the fundamental human right to have a say and the ensuing increased public accountability and transparency, particularly in publicly funded research (Gradinger *et al.*, 2013). In Ireland, the Health Research Board (HRB) has been at the fore of promoting PPI in research and with the Irish Research Council, in 2017 launched a joint call entitled PPI Ignite, to support higher education institutions to embed PPI into their organisational structures. The use of different PPI approaches is increasingly evident in research in Ireland (Dwyer *et al.*, 2020; Ní Shé *et al.*, 2019; O'Hara *et al.*, 2017; O'Shea *et al.*, 2019; Tierney *et al.*, 2018; Walsh *et al.*, 2018).

It is worth reflecting on and comparing the approach to ethics in research with that taken to PPI in research. The former is established through international charters, is hard-wired into the policies and procedures of institutions and obtaining approval from a Research Ethics Committees is a necessary step to initiate most research studies. On the other hand, it is easy for researchers and funders to dismiss PPI as non-essential, an added extra, a "nice to have". Here, drawing on formal and informal conversations with diverse PPI partners in recent weeks, we argue that PPI should be established with similar governance and structures as research ethics and be embedded in health and social care research, both during and post the COVID-19 pandemic. While we focus here on the situation in Ireland, we believe that our thoughts will also resonate with public, patients and researchers internationally.

## COVID-19 response research

The Irish research community, in common with colleagues worldwide, has rushed to respond to the COVID-19 pandemic. We have seen rapid response mechanisms to fund research, with shortened submission, review and study start-up times, and, in Ireland, the establishment of a temporary National Research Ethics Committee (NREC) to fast track COVID-19 related ethics applications. A spirit of co-operation is evident between research groups, across Universities and Hospital Groups, with the Health Services Executive and the Irish government, facilitating collaborative working, nationally and internationally. While the response from the medical and research communities has, in many ways, been inspirational with innovative new technologies emerging, some concerns are being raised in the published literature (Glasziou *et al.*, 2020; O'Sullivan *et al.*, 2020) and elsewhere (Kiely & Heavin, 2020), questioning the speed of the response.

## PPI under pressure in COVID-19 response research

Early signs suggest that PPI is being sidelined. The 'expert voice' dominates – the voice of the clinical and public health perspectives: stop transmission, find a vaccine, find a treatment, develop new ventilators. Normal rules of engagement around almost everything in society do not currently apply. We are experiencing centralised decision-making, with no time for debate and questioning. This is not a supportive environment in which the public or patient voice can be heard. In particular, research-funding calls have not emphasised the need for PPI in research proposals and there is little public review of funding applications.

PPI in research depends traditionally on personal relationships, on face-to-face meetings, on gradually building PPI capacity among both researchers and PPI partners. It is widely acknowledged that establishing these relationships takes time and commitment, from both researchers and PPI partners. In some research teams with an existing PPI ethos, re-assignment of key researchers to other roles, prioritising support for front-line activities, means that PPI skills may not be readily available. So in many cases, it has been easier to discount PPI in research during the pandemic, rather than find alternative ways to maintain existing, or build new, PPI relationships.

## PPI is important, now more than ever

We argue that in the research response to COVID-19 pandemic, PPI is important, now more than ever (a phrase used to first enshrine in health policy the concept of community participation in healthcare (WHO, 1978; WHO, 2008). Solving the current crisis is dependent on the response of every individual in society. PPI is about researchers finding the "nuggets of gold" that come from PPI contributors. The solution to overcoming this virus will come from many different sources and the public and the patient must be central contributors and should not be silenced.

People who have experienced COVID-19, and ICU care in particular, their family members and people living with chronic conditions can draw on their lived experience to help clinicians and researchers shape and test new treatments and new approaches to care delivery. The pandemic affects everyone in society, but it does not affect everyone in the same way. The public at large, and those from minority or marginalised groups in particular, can play an important role in shaping research that explores the impact of the pandemic on our working lives, our home life and how we are coping with our "new normal". It is important to recognise and harness the different types of knowledge and experiences brought by diverse communities and individuals: this input can help reveal the true natures of the varying experiences of the pandemic (Marston *et al.*, 2020). Separately, public review of research applications would enhance transparency, and has the potential to bring a focus on research participant fatigue, question research duplication and waste, and objectively interrogate the potential impact of the research findings.

The Irish public embraced the initial public health campaign with its emphasis on staying at home, handwashing, respiratory etiquette and social distancing and in the words of the Taoiseach of Ireland, "*thousands of lives have been saved*" (www.gov.ie, 2020). Given the extent of the restrictions on normal life to fight the virus, it seems incongruous, particularly where research is publicly funded, that the public voice is excluded when planning

research to find solutions and to explore the impact of the current restrictions.

Many changes will emerge from this pandemic. These changes will extend far beyond how we organise our healthcare systems; they will involve how we travel, work, educate our children and how we interact with other humans. To ensure successful adoption and adherence to these new ways of living, it is essential that solutions are shaped by those who will be most affected. For example, uptake of any new vaccines found will need the trust of the public. Involving the patient and public from the start in development of these vaccines will lead to increased transparency of the research and we have seen in recent years the positive impact of a public ambassador on the uptake of a safe and effective vaccine (Irish Cancer Society, 2018).

### PPI essentials in a pandemic

Now more than ever fundamental aspects of good involvement apply, but we must also find new and creative ways to ensure that the patient voice continues to be heard, both in COVID-19 rapid response research and in other research ongoing during the pandemic. Figure 1 outlines what we believe are the essential features of good involvement of public and patients in research during this pandemic. We must challenge ourselves to facilitate different formats for discussion, timings, levels of formality, and ways of communicating, tailored to the needs of different contributors, to ensure that those marginalised are represented.

## PPI responses to date

There have been some positive developments in Ireland. Some rapid response grant applications have had PPI input, while in other cases, PPI has been omitted in the COVID-19 rapid response research. Existing PPI contributors are helping other COVID-19 research teams (for example, www.iHealthfacts.ie). Some existing PPI groups have moved meetings online and other research teams are now exploring whether and how they can start new PPI initiatives. Patient and community organisations are advocating for and supporting members to move to virtual environments and to continue to work with researchers (HRCI, 2020; IPPOSI, 2020).

The international PPI response also has been mixed, with some excellent examples of existing PPI panels adapting to cope with the "new normal". The response in Australia, led by Anne McKenzie, to establish a national PPI panel available to support COVID-19 research (Telathon Kids Institute, 2020) is similar to the NREC COVID-19 established in Ireland. In the UK, Health Data Research UK established a PPI group available to work with UK researchers (HDR UK, 2020) and the Public Involvement Senior Leadership Team at the National Institute for Health Research (NIHR) has agreed new commitments for patient and public involvement, engagement and participation during the COVID-19 pandemic (www.nihr.ac.uk, 2020).

## PPI in the pandemic: next steps

We call on all stakeholders in Ireland to take immediate steps as follows:

- **Department of Health:** establish a **National PPI Advisory Panel**, to provide the public and patient perspective to COVID-19 research plans and to increase transparency on research funding decisions, similar to the NREC COVID-19.
- **Research funders:** in all funding calls during the COVID-19 pandemic, include a public review and strongly encourage PPI in applications; be flexible in allowing funding reallocation

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|---|---|
| **Invest in PPI** | |
| *Research funders* | Strongly encourage PPI input to pandemic research proposals<br>Include public review of pandemic funding calls |
| *Research teams* | Involve PPI partners in prioritising and shaping pandemic research<br>Include PPI costs in research proposals, including pandemic-related PPI contributor expenses |
| *Institutions* | Support researchers to embed PPI approaches in their research, with time, money and administrative processes with minimal bureaucracy |
| *Patient and community organisations* | Support grant applications only where you have meaningful involvement in research planning<br>Mobilise member networks to influence research plans |
| **Continue to build PPI relationships** | Involve existing PPI partners or initiate new PPI relationships when planning pandemic research<br>Maintain contact and communication with all existing PPI partners<br>Be open and honest when setting expectations |
| **Use creative approaches** | Develop new ways of interacting, maximising virtual communication, but be aware of the digital divide<br>Facilitate PPI partners who have the capacity to respond within shorter timeframes |
| **Be inclusive** | Seek out the voice of minorities, the marginalised, those without a voice in the pandemic<br>Use individualised approaches to facilitate diversity |
| **Be additionally sensitive** | To the challenges facing people living with chronic conditions<br>To the challenges of restrictions and social isolation of all citizens<br>To the increased risk of serious illness and bereavement among PPI contributors<br>To the increased risk of financial pressures on citizens |

**Figure 1. PPI essentials in a pandemic.**

if there was initially no provision for PPI activities in studies funded under rapid response funding calls to date.

- **Researchers:** use a mixture of existing approaches and new creative ways to ensure that PPI contributors influence all stages of your research, in spite of the changed environment for working together. It is never too late in a study to begin to involve PPI partners. Prioritise diversity and develop new approaches *with* your PPI partners, asking them what works well and what is not effective.

- **PPI advocates and patient organisations:** make your voice heard, campaign for PPI in COVID-19 research in particular, and support your members to contribute.

- **Policy makers:** ensure that a diverse public voice is heard at the policy-making table.

Everyone in society is experiencing the pandemic, but not all are impacted in the same way, with health and social inequalities very evident. Now more than ever it is an imperative that a broad and inclusive public and patient voice shapes pandemic response research, is involved in research funding decisions, is heard at the policy table and is positioned to act as an advocate for the changes to health and civil society that will undoubtedly occur. Together we are stronger.

## Data availability

No data are associated with this article.

### Author information

Members of the PPI Ignite @ NUI Galway Public Advisory Panel include Anne Daly, Casey Donaghey, Jack Gaffey, Deirdre Mac Loughlin, Helen Ogbu, Tony Regan and Mary Roche.

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# Open Peer Review

## Current Peer Review Status: ✔ ✔

**Version 1**

Reviewer Report 30 June 2020

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✔ **Nana Folmann Hempler**
Health Promotion Research, Steno Diabetes Center Copenhagen, Copenhagen, Denmark

I have reviewed the manuscript titled 'COVID-19: Public and patient involvement, now more'. The aim of letter is to argue that PPI in research is important (now more than ever) in light of the COVID-19 situation. It is very relevant and provides some very good suggestions for next steps.

My comments are as follows:

Abstract

- A 'd' is lacking in the last sentence…and their voices must be heard.
- The letter argues that COVID-19 is more important than ever and I agree but some reflections on 'why' would be great and is lacking. Also, it could be noted that the letter will introduce next step or highlight the main message.
- I would suggest that the wording '… where it is easy for researchers and funders to dismiss to' is changed to '…,where there is a high risk for researchers and funders to…'.

Main text

- I would suggest that the first section 'why does public and patient involvement (PPI) matter?' could focus on PPI in relation to COVID-19 and less on PPI in general.
- The section 'PPI under pressure in COVID-19 response research' has a broad focus on PPI and COVID-19. I would suggest that it only focuses on COVID-19 research and PPI.
- Why is PPI in COVID-19 research important? It is mentioned in the letter that solving the crisis is dependent on the response of every individual, but it would be great if this could be elaborated a bit.
- Figure 1 is great.

- COVID-19 has unearthed the deep ethnic and social inequalities that exist in societies (this could be mentioned). Also, the letter points to this very important aspect – involvement of hardly reached groups. Is it possible to give some suggestions on how to involve hardly reached groups?

**Is the rationale for the Open Letter provided in sufficient detail?**
Yes

**Does the article adequately reference differing views and opinions?**
Yes

**Are all factual statements correct, and are statements and arguments made adequately supported by citations?**
Yes

**Is the Open Letter written in accessible language?**
Yes

**Where applicable, are recommendations and next steps explained clearly for others to follow?**
Yes

***Competing Interests:*** No competing interests were disclosed.

***Reviewer Expertise:*** My research focuses on ethnic and social differences in the field of diabetes with a particular focus on development and implementation of interventions that improve diabetes management in hardly reached groups. In particular, I am interested in aspects that shape health behaviour change and motivation. With a background in public health, my work is positioned at the intersection of epidemiological, health services research, applied research and education research. I make use of a variety of methods, among these the design-based approach, where the target group is actively involved in the research process, which in my opinion, is where 'the real' innovations, in relation to improving care and support, occur.

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.**

Reviewer Report 24 June 2020

https://doi.org/10.21956/hrbopenres.14166.r27513



**Steven Blackburn**
[1] School of Primary, Community and Social Care, Keele University, Keele, UK
[2] NIHR Research Design Service, Keele, UK

This is a very clear and well written article on an important issue in light of the current environment. The authors provide compelling argument to ensure that public involvement remains central to research. As this is an open letter with an objective to persuade the research community, one might not expect inclusion of alternative viewpoints. However, justification of a few statement of facts made may be warranted. For example, there are "early signs that PPI is being sidelined" - what is this based on? The article does not provide any evidence from funders or other research institution to support this argument. It might be worth including recent concerns raised by the UK Health Research Authority about the absence of public involvement in COVID-19 research studies recently. To provide more balance, the article could be strengthened by considering some of the reasons why research teams have not undertaken public involvement, and whether these are justified.

Other than these minor modifications, then in my opinion, the public interest of this paper is worthy of publication.

**Is the rationale for the Open Letter provided in sufficient detail?**
Yes

**Does the article adequately reference differing views and opinions?**
No

**Are all factual statements correct, and are statements and arguments made adequately supported by citations?**
Partly

**Is the Open Letter written in accessible language?**
Yes

**Where applicable, are recommendations and next steps explained clearly for others to follow?**
Yes

***Competing Interests:*** No competing interests were disclosed.

***Reviewer Expertise:*** Research Fellow in Patient and Public Involvement and Engagement

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.**

# Comments on this article

**Version 1**

Reader Comment 22 Jun 2020

**Ailsa Donnelly**, Patient Research Partner, Manchester, UK

This Open Letter is both timely and important. The authors equate the need for Patient and Public Involvement (PPI) with the need for ethics in research, but point out that PPI is often overlooked in the rush

and flurry for funding to accelerate COVID-19 research. This is perhaps understandable, but there are risks attached.

COVID-19 is an extraordinarily wide ranging and indiscriminate disease and research on it will be long term. It is therefore important to set out some fundamentals now, before the lack of PPI becomes established practice. A top down approach, lacking input from patients and carers, may mean unusual symptoms and effects of the disease are missed (e.g. lack of smell/taste). Excluding members of the public in the design and implementation of policies to restrict the spread of the virus runs the risk of public non-compliance. Absence of lay review in assessing which research proposals to fund may mean that chosen projects concentrate on the research priorities of the researchers, rather than the patients or public, and do not reach their maximum potential.

As mentioned in the Letter, some researchers are already working with established PPI groups and deserve credit for doing so. COVID-19 must not be used as an excuse to decrease PPI in research, but should instead be seen as an opportunity to increase it and expand it. This disease has touched everyone's lives, sometimes in several different ways, and many people will be anxious to help research into it however they can. It appears to attack the BAME community and those living in poverty disproportionately, and their voices are all too often lacking in PPI; this is a chance to redress that. Younger, previously healthy people are developing longer-term effects from COVID-19. Their voice too is often missing from PPI, and we must not forget those who find themselves in a new role as 'carer'. This is a real chance to increase diversity in PPI in all areas.

Use of online technology and resources has soared during lockdown, and this may be both more inclusive and more exclusive: it enables some to participate who otherwise could not have done so (e.g. for reasons of disability, caring responsibilities or geography) but also excludes those without online access and skills. This is not a new tension but one which has suddenly become much more relevant, and ways to address it must be sought. Technology also facilitates international participation and co-operation, crucially important during a pandemic.

The authors have set out some very useful 'PPI essentials in a pandemic' in Figure 1. It is not too late to implement many of these even in research which has already started; as they say, flexibility at this early stage is vital. However, the more quickly 'PPI essentials' become embedded as specific principles in COVID-19 research the better and more effective that research will be. It would be such an excellent and encouraging start if these 'essentials' were adopted (and adapted if necessary) on an international basis. We don't have to start from scratch; let us share existing expertise and knowledge to improve PPI and COVID-19 research nationally and internationally. The final sentence sums it up: 'Together we are stronger'.

***Competing Interests:*** No competing interests were disclosed.