

Public involvement and engagement in research during the COVID-19 pandemic

Summary of a FORUM workshop held on
19 May 2020

The Association of Medical Research Charities

Over 30 years ago a small, diverse group of medical research charities formed the Association of Medical Research Charities (AMRC) to unite the sector and provide it with a leading voice. Since then our membership has grown to over 150 charities and we continue to support them in saving and improving lives through research and innovation.

- We assess our member charities' research funding processes when they apply for membership and carry out a full audit every five years, to ensure they fund the best research. We also produce guides and provide training to help our member charities maximise their impact.
- We run meetings, networks and events that connect member charities and key stakeholders, to share learning and foster collaborations that deliver benefits to patients sooner.
- We submit consultation responses, meet with policy-makers, publish position statements, and develop infographics and reports, to communicate our member charities' value and enable them to drive positive change.

The Association of the British Pharmaceutical Industry

The ABPI exists to make the UK the best place in the world to research, develop and use new medicines. We represent companies of all sizes who invest in discovering the medicines of the future. Our members supply cutting edge treatments that improve and save the lives of millions of people. We work in partnership with Government and the NHS so patients can get new treatments faster and the NHS can plan how much it spends on medicines. Every day, we partner with organisations in the life sciences community and beyond to transform lives across the UK.

The National Institute for Health Research

The National Institute for Health Research (NIHR) is the nation's largest funder of health and care research. The NIHR:

- Funds, supports and delivers high quality research that benefits the NHS, public health and social care
- Engages and involves patients, carers and the public in order to improve the reach, quality and impact of research
- Attracts, trains and supports the best researchers to tackle the complex health and care challenges of the future
- Invests in world-class infrastructure and a skilled delivery workforce to translate discoveries into improved treatments and services
- Partners with other public funders, charities and industry to maximise the value of research to patients and the economy

The NIHR was established in 2006 to improve the health and wealth of the nation through research, and is funded by the Department of Health and Social Care. In addition to its national role, the NIHR supports applied health research for the direct and primary benefit of people in low- and middle-income countries, using UK aid from the UK government.

The Academy of Medical Sciences

The Academy of Medical Sciences is the independent body in the UK representing the diversity of medical science. Our mission is to promote medical science and its translation into benefits for society. The Academy's elected Fellows are the United Kingdom's leading medical scientists from hospitals, academia, industry and the public service. We work with them to promote excellence, influence policy to improve health and wealth, nurture the next generation of medical researchers, link academia, industry and the NHS, seize international opportunities and encourage dialogue about the medical sciences.

Opinions expressed in this report do not necessarily represent the views of all participants at the event, the Academy of Medical Sciences, or its Fellows.

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Executive summary

The COVID-19 pandemic has been an unprecedented challenge for society, for the economy and for biomedical research. Public involvement in research has a powerful role to play in helping us respond to the coronavirus and support our recovery.

As with many other aspects of biomedical research, public involvement in research has been significantly affected by the pandemic and the social and economic impacts that have followed. However, public involvement will also be key to how we overcome COVID-19, through developing treatments and vaccines, improving public trust in science and helping to redesign public services.

On 19 May 2020, the Academy of Medical Sciences, the National Institute for Health Research, the Association of Medical Research Charities and the Association of the British Pharmaceutical Industry held a workshop to examine how the pandemic had affected public involvement in research, and what actions need to be taken to ensure it is central to research and recovery throughout and beyond the pandemic.

Participants from across the life sciences and health research sectors discussed a number of challenges, priorities and opportunities for patient and public involvement in the coming months and beyond.

Challenges

- **There is a lack of leadership and coordination of public involvement and engagement in COVID-19 research efforts.** While there are many examples of best practice and innovation, no single body with oversight of the area has emerged or been developed to ensure that public involvement in COVID-19 research is done, consistently, openly and inclusively.
- **The pandemic and its effects have had a major impact on public involvement across the wider research agenda,** with a worrying decrease in public involvement observed in some forms of research, such as clinical trials. The concern is that previous achievements in this field will not be regained without considerable effort.
- **The COVID-19 pandemic has disproportionately affected certain demographics more than others,** for example people from a Black, Asian, and minority ethnic (BAME) background or those from socially disadvantaged or deprived communities. This risks exacerbating existing health and social inequalities, or creating new ones.

Key priorities

- **Engaging and involving those communities disproportionately affected by COVID-19 should be a priority** to ensure that biomedical and health research produces outcomes that are relevant to these communities and can help reduce these disparities.

- **Coordination of public involvement and engagement is crucial at this time**, especially for major COVID-19 research projects and in the development of evidence-based pandemic-specific policies and adaptation of public services.
- **It is also vital that public involvement practitioners review and share best practice** with the wider community to ensure that public involvement throughout and beyond the pandemic is the best it can be and that any learnings can be addressed for future challenges.
- To prevent a chronic decrease in public involvement in research, **institutions and funding bodies should redouble their support for researchers and actively encourage them to involve the public in research whenever possible**. This can be an important feature of changing research culture as so many are rightly demanding.

Opportunities

- The measures introduced to mitigate the pandemic have meant the rapid adoption of new ways of conducting public involvement. Rapid adaptation and experimentation of new ways of working could be beneficial to public involvement in the long term and **effective new methods should continue to be used beyond the pandemic**.
- Public engagement with biomedical research has been high during the pandemic. This offers an opportunity **to harness this enthusiasm and involve and engage and involve new groups in biomedical research**.
- **The necessary switch to digital engagement offers new opportunities** to involve and engage research participants quickly, flexibly and in new ways. However, care needs to be taken to avoid digital exclusion of those who cannot or do not wish to use digital platforms.
- **Trust in science is more important than ever**. Public involvement in research, and engagement with research, can help ensure the findings of COVID-19 research are communicated in a way that builds public trust.

Introduction

Prior to the COVID-19 pandemic, public involvement in research was becoming more widespread across biomedical and health research. This increase in public involvement was due to its championing by patient leaders, charities and advocacy groups, supported by regulators and funding bodies, and backed by an increasing body of evidence demonstrating its benefits for research and health. The COVID-19 pandemic has highlighted the strengths and weaknesses in current approaches to public involvement as well presenting new possibilities for the community.

Throughout this report we use 'public involvement' according to the NIHR INVOLVE definition.¹ 'Public' encompasses patients, potential patients, carers, people who use health and social care services and general members of the public.

Public involvement at risk with new pressures

The urgency of the COVID-19 pandemic has meant that biomedical research has had to adapt to meet new research needs in previously unseen timeframes. These adaptations have resulted in many of the established regulatory and governance research processes being conducted at pace. This includes aspects such as submitting funding applications, forming collaborations, seeking regulatory and ethical approvals, carrying out laboratory or clinical based research and publishing the results of research.

Alongside these features, public involvement, which in recent years has become established as a core part of biomedical research, has also had to be conducted at speed, and in ways that overcome physical distancing and other containment measures. While the research community has been largely successful in adapting other aspects of biomedical research to these new requirements, figures from clinical trials submissions to the Health Research Authority suggest that public involvement in research has not had the same level of success.

These figures show a decrease of studies containing public involvement from 78% in 2019, to 20% in the first 40 trial submissions received during the COVID-19 pandemic.² The reasons for this are unclear but it suggests that public involvement is still be considered as a 'nice to have' rather than an essential component of research, especially when balancing the challenges of speed, containment measures and physical distancing with the need for urgent research.

¹ <https://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/>

² <https://www.hra.nhs.uk/about-us/news-updates/involving-public-covid-19-research-quest-blog-bec-hanley-and-maryrose-tarpey/>

Sustained learning to build a better system

Even before the COVID-19 pandemic, the uptake and effective use of public involvement was inconsistent.³ Despite many exemplars and best practice case studies, public involvement often remains a minor or developing component of research that is not always prioritised. It is widely agreed that the benefits of public involvement in research outweigh the investment of time required to implement it effectively and meaningfully as well as justifying its use in more research programmes.⁴

The COVID-19 pandemic has more than ever highlighted the fragile state of public involvement in research. But it is also clear that, after a slow start, there are signs that the public involvement community and its partners are now coming together to support new initiatives (see box insert) as part of the national response to COVID-19. Also that there is much to be learnt from public involvement locally and internationally at this time. It is therefore imperative that we do not lose this opportunities to use the challenges encountered, and opportunities seized throughout the pandemic to build a better system with stronger foundations for the future.

³ National Institute for Health Research (2014). *Going the extra mile: Improving the nation's health and wellbeing through public involvement in research* <https://www.nihr.ac.uk/documents/about-us/our-contribution-to-research/how-we-involve-patients-carers-and-the-public/Going-the-Extra-Mile.pdf>

⁴ Ennis L & Wykes T (2013). *Impact of patient involvement in mental health research: longitudinal study* Br J Psychiatry 203(5):381-6

Responses to COVID-19

- The **NIHR** launched the new Centre for Engagement and Dissemination, building on the work of NIHR INVOLVE and the NIHR Dissemination Centre.⁵ The new Centre aims to make health and care research representative and relevant and has begun work gathering resources to support public involvement in COVID-19 and drawing together existing research that may have relevance to the pandemic.⁶ In May, the NIHR also announced five new Patient Recruitment Centres to support research participation in COVID-19 and other disease areas, and more recently has funded new research specifically looking at why certain ethnic groups have a higher risk of poor outcomes when developing COVID-19.^{7,8}
- The **Health Research Authority (HRA)** has launched a new service to connect researchers with patient and public contributors to support public involvement in COVID-19 research.⁹
- The **ABPI** is working with its partners to embed patient and public involvement within research. In response to COVID-19, it published a summary of some practical guidance from the ABPI Sourcebook, with the aim of supporting companies to work compliantly with patients and patient organisations.¹⁰
- In June, the **Medicines and Healthcare products Regulatory Agency (MHRA)** announced how it intends to improve its patient and public engagement and involvement across four key areas – Awareness, Transparency, Responsiveness and Partnership.¹¹ This publication was accompanied with the launch of guidance highlighting opportunities for patients and the public to be involved in the agency's work.¹² The MHRA have also augmented their Yellow Card System to enable the reporting of side effects associated with COVID-19 medicines and experimental treatments.¹³

A critical time for patient and public involvement

Throughout the pandemic, the public has looked towards science and research to guide policy and to deliver the solutions, both medical and non-medical, that will help mitigate its impact and save lives. Public involvement is an essential component to building and maintaining trust in science, which is needed for pandemic mitigation policies to be effective. In addition, developing the medicines and vaccines to treat the disease and control the virus will not be possible without public involvement, both to inform their development and to help communicate the results of research to the wider public. These factors combined mean that now is a critical time for researchers, and the wider research community to harness the power of public involvement in both improving research and ensuring that its results are trusted and effective.

To explore these challenges in greater detail and identify opportunities for firmly establishing public involvement and engagement as a central component of research pathways, the

Academy of Medical Sciences, the ABPI, the AMRC and the NIHR hosted a virtual workshop on the impacts and opportunities for public involvement throughout and beyond the pandemic. The workshop was co-Chaired by Professor Dame Til Wykes DBE FMedSci, Professor of Clinical Psychology and Rehabilitation at King's College London and Simon Denegri OBE, Executive Director of the Academy of Medical Sciences and former Director for Patients and the Public in Research at NIHR, brought together representatives from across the life sciences research community, including patient and service user representatives.

This report provides a summary of the discussions that took place at the meeting. It does not necessarily represent the views of all participants at the event, the Academy of Medical Sciences or its Fellows, ABPI, AMRC or NIHR.

⁵ <https://www.nihr.ac.uk/news/nihr-launches-new-centre-for-engagement-and-dissemination/24576>

⁶ https://learningforinvolvement.org.uk/find-resource/?term=&date=DESC®ion=undefined&resource_type=null&topic=covid-19%20-%20find-opportunity

⁷ <https://evidence.nihr.ac.uk/collection/mental-health-and-covid-19/>

⁸ <https://www.nihr.ac.uk/news/multimillion-investment-in-new-research-projects-to-investigate-higher-covid-19-risk-among-certain-ethnic-groups/25333>

⁹ <https://www.hra.nhs.uk/about-us/news-updates/new-public-involvement-service-covid-19-studies/>

¹⁰ <https://www.abpi.org.uk/our-ethics/patient-public-involvement/working-with-patients-and-patient-organisations-a-summary/>

¹¹ Medicines and Healthcare products Regulatory Agency (2020) *Business Plan 2020 to 2021*
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/889864/MHRA_Business_Plan_2020_to_2021.pdf

¹² <https://www.gov.uk/government/consultations/how-should-we-engage-and-involve-patients-and-the-public-in-our-work>

¹³ <https://coronavirus-yellowcard.mhra.gov.uk/>

The impact of the pandemic on public involvement in research

The initial weeks and months of lockdown had many effects on biomedical research and public involvement, some of which could be predicted, and others which were unexpected. Research labs across the country had to temporarily close, while many clinical trials were put on hold. The research community has come together in collaboration, openness, and determination to help answer the scientific questions but patients and the public have not always been included in this partnership.

Impacts of the pandemic on research

The pandemic, subsequent lockdown and physical distancing measures meant that almost all public involvement in the early phases of the UK epidemic was conducted remotely – a feature that is likely to continue throughout the pandemic and perhaps beyond. There are a number of advantages to remote involvement, such as the use of digital platforms that may provide flexibility in the way people engage and the ability to engage populations that may not always have the time or capacity to be involved in research. However, there are also potential disadvantages. For example, a high reliance on digital engagement means that certain groups are excluded due to an inability to access or effectively use digital platforms.^{14,15} This could include rural groups or those from poorer sociodemographic backgrounds, who may already be underrepresented in public involvement in research. Researchers should therefore strive to ensure that digital engagement platforms, and associated involvement activities, are inclusionary and accommodate a range of engagement modalities.

The involvement of the public in research on non-COVID-19 related topics may be affected beyond just the ability of the public to access and use new digital engagement platforms. For example, the wider health and wellbeing impacts of the COVID-19 pandemic on patients and the public may affect or exacerbate other physical or mental health issues that may decrease their ability to participate in research. Researchers involving the public should try to understand and accommodate these new challenges in the way they involve patients and the public in their research.

For many researchers, formal training in how to involve the public in research is important to provide them with the necessary skills and drive to incorporate public involvement in their work.

¹⁴ Greer B *et al.* (2019). *Digital Exclusion Among Mental Health Service Users: Qualitative Investigation* J Med Internet Res 21(1):e11696

¹⁵ Robotham D *et al.* (2016). *Do We Still Have a Digital Divide in Mental Health? A Five-Year Survey Follow-up* J Med Internet Res 18(11):e309

However, the lockdown and physical distancing measures led to the postponement of many such training courses. As time has progressed, this training is moving to a digital format, although it will inevitably take time to address the backlog of delayed training courses.

During the initial weeks of the lockdown, significant amounts of non-essential and non-COVID-19 focused research was put on hold for the purposes of helping to reduce the spread of the virus and to allow researchers to help with frontline efforts. This rapid drop-off in research has throughout this period limited opportunities for public involvement in non-COVID-19 research areas, including in clinical trials. While this period may only be temporary, it has set back some clinical research involving the public, which may delay crucial findings that will improve clinical care in the future.

Medical research charities have experienced a significant drop in charitable fundraising over the period of the lockdown. As this income funds their research programmes, it is likely that many will have to scale back their research funding for some time. This will have an impact on studies that include patient involvement. In addition, the furloughing of staff throughout this period will have reduced the capacity of some charities to continue to support public involvement by the researchers they fund.

Mitigating the impact of delayed research

In the first weeks of the pandemic, the priority for clinical researchers was, quite appropriately, on delivering clinical care. This reprioritisation has affected research, much of which has been delayed. The exact impact this will have on research projects and patients has yet to be fully understood, but in academic settings non-COVID-19 related research was often postponed during lockdown, and a significant number of non-COVID-19 clinical trials were postponed or delayed.

As we emerge from the pandemic, returning to 'research as usual' alongside normal clinical care will undoubtedly take time, given the expected backlog of patients and the new requirements for physical distancing. Supporting researchers in returning to their research should be a priority for the community to mitigate the impact of delays, especially those directly involving patients such as clinical trials. It is also vital that, in the eagerness to return to research, that public involvement is not forgotten, and researchers are continued to be supported in applying it in their research.

Seizing opportunities to involve the public in COVID-19 research

Throughout the pandemic there are significant opportunities for clinical research on COVID-19, and there is a risk of missed opportunities if clinical researchers do not have the capacity to conduct research involving patients alongside delivering clinical care. Although clinical care remains the priority, researchers should be proactive in exploring how novel research that would not be possible in normal circumstances can be carried out at this time. This is especially important in the context of any future waves of infection, or to help evidence action in other countries where the initial peak has not yet been reached. It is imperative that these novel studies are also informed by effective public involvement.

Priorities for public involvement highlighted by the pandemic

COVID19 has highlighted a number of key challenges for public involvement in research. Almost all have their roots in issues that were apparent before the pandemic. The research community including patients and the public need to address them as a matter of priority to improve research of all types.

Public involvement and marginalised communities

The poorest outcomes from COVID-19 are in populations with some of the lowest levels of participation in research.¹⁶ This includes people who live in more deprived areas, those from Black, Asian and Minority Ethnic (BAME) groups or those who live in areas of high disease incidence but where there is a lack of available research studies in which to participate.^{17,18} In future, researchers need to seek to involve these populations in COVID-19 research. Engaging and involving these underrepresented groups will require sustained effort from the research community. Building relationships with previously unengaged groups takes time, and ideally, the relationships should be existing and ongoing prior to an urgent need such as a pandemic.

Guidance and impetus from funders and institutions

It is often unclear where the responsibility for encouraging public involvement in research lies, whether with the organisation or the research teams. The impetus to include public involvement in research projects should ideally be mandated at all levels, from funding bodies, through to institutions and to project leads. Funding bodies will have the most influence in ensuring that public involvement is an integral part of research both during and beyond the pandemic. The financial shocks that many charities and universities are experiencing may affect their ability to work closely with their researchers to ensure that public involvement remains a central component of their research.

Sharing learnings and best practice

A vital step to learning from the good public involvement practice that has emerged during the pandemic is acting to ensure that researchers share best practice, including data of who is being involved in research. This is especially important where projects are conducting public involvement in new ways, such as in highly digital forms or at very short timescales. Defining 'best practice' and what criteria should be evaluated and shared is a key step, as sharing needs

¹⁶ <https://www.pharmavoices.com/article/2018-03-diversity/>

¹⁷ Public Health England (2020). *Beyond the data: Understanding the impact of COVID-19 on BAME groups* https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf

¹⁸ Lekfuangfu WN *et al.* (2020). *On Covid-19: New Implications of Job Task Requirements and Spouse's Occupational Sorting* Covid Economics: Vetted and Real-Time Papers

to be detailed enough to truly inform future work. If possible, these learnings should be developed into new guidance to support novel ways of working in public involvement in research.

Improved coordination of public involvement activities

Despite the many positives in the way that researchers, institutions, funding bodies and others have risen to the challenges posed by the pandemic, it can be challenging for researchers and organisations to be aware of what is happening in research involving the public. It was suggested that the UK could look to international exemplars where public involvement co-ordination efforts have been established during the pandemic.

Public involvement in the adaptation of public services

The pandemic has caused a major shift in how public services, including healthcare, are delivered, but these changes have been made with such urgency that there has been little public consultation or involvement in them. As services return to normal beyond the immediate pandemic lockdown, the public should help inform and shape the way public services operate when adaptations need to be made to help contain the virus. By involving the public in this way, service adaptation can be carried out in an evidence-based way that minimises disruption and maximises acceptance for the wider public.

New possibilities for the future

The research community needs to look beyond the initial shock of the pandemic and consider how the lessons learned during this time can be used to advance public involvement in research in the future.

Harnessing new ways of doing public involvement

There are concerns that the move to digital participation in research may lead to systematic exclusion from participation. However, while avoiding digital exclusion should be a key consideration for public involvement, there are opportunities to work with digitally engaged individuals, such as young people, in an enhanced way through digital involvement. Young Persons' Advisory Groups (YPAGs), such as Eye-YPAG at Moorfields Eye Hospital NHS Foundation Trust and YPMHAG at the South London and Maudsley NHS Foundation Trust and King's College London, have continued throughout lockdown without major disruptions.^{19,20} Many YPAGs are generalist, rather than tied to specific projects and were therefore not affected by the postponement of non-COVID-19 research that took place during the pandemic lockdown. NIHR Oxford Biomedical Research Centre has also formed a new COVID-19 public involvement group with the aim of rapidly involving patients and the public in COVID-19 research at short notice.²¹

Given that new forms of engaging and involving the public, such as digital platforms, may become a more prominent part of patient and public involvement in the future, it is important that feedback on methods and platforms for engagement is sought and considered. A 'one size fits all' approach may not be sufficient in reaching and involving diverse sets of the public and patients, and there is a risk that certain groups may be excluded simply due to the methods used. This could especially be true where research is involving topics, or methods of contribution, which are particularly sensitive or personal to participants.

Breaking down prior barriers to research

The COVID-19 pandemic has caused massive upheaval for the research community, necessitating a change in attitudes and behaviours to accommodate this change. While this disruption has in many cases delayed important research, the way in which the research community has taken on the challenge has been lauded. Researchers have been more flexible in the way that they work, adopted new ways of working at short notice. Harnessing some of these attitudes beyond the pandemic and applying them to other research challenges would be a boon for research. However, this new flexibility has not always been reflected in the public involvement elements of research, and it is the collective responsibility of the community to ensure that public involvement benefits from new and innovative ways of working throughout and beyond the pandemic.

¹⁹ <https://generationr.org.uk/eye-ypag/>

²⁰ <https://ypmhag.org/>

²¹ <https://oxfordbrc.nihr.ac.uk/pair/are-you-interested-in-joining-a-ppi-group-to-help-with-covid-19-studies/>

Seizing the public appetite for engaging with research

Public awareness of science and research has been particularly high during the pandemic. This appetite for engaging with and contributing to the scientific effort against COVID-19 should be seized upon by the research community. Projects such as the King's College London COVID Symptoms Tracker demonstrates the willingness of the public to volunteer their time to contribute to a project that may not benefit them individually, but will benefit wider society.²² This energy should be harnessed through further engagement at a national level. This is especially true for initiatives such as Test, Trace and Isolate, the success of which is dependent public support, trust and cooperation. Participants emphasised that public involvement should extend beyond research and be an integral part of all Government initiatives related to the pandemic, with central policy decisions informed by robust public involvement.

Public involvement in communicating research findings

Public and patient involvement is beneficial to research at all stages, even after research has been published or a project has concluded. For all research, but especially that related to major public health issues such as COVID-19, post-publication public involvement can help improve the communication of research results, for example through providing feedback and helping with lay summaries and accessibility of language. By making research more accessible in this way, the implications can be better understood, and trust in research can be improved.

²² <https://covid.joinzoe.com/>

Conclusion

Reflecting on the workshop's vibrant discussions, the meeting co-Chairs proposed a series of key actions that the community should take forward to ensure the learnings from the COVID-19 pandemic result in sustained and meaningful improvements to public involvement in the future:

- **There is a clear need for a strong commitment to public involvement from stakeholders across the research ecosystem**, from the central bodies providing guidance, governance, and funding, through to individual researchers and public involvement practitioners.
- **It is vital that senior leaders across health research act as advocates for the importance and benefits of public involvement in research** to ensure that public involvement is a cornerstone of the research process even in challenging, time-pressured research emergencies.
- Similarly the **pandemic has highlighted the importance of involved and engaged communities in promoting and protecting public health** and the value of involving patient, public and community leaders in strategic decision-making at the highest level.
- **The research community should connect with groups that work closely with patients and the public beyond the field of medical research**, given the wide impact of the pandemic and opportunities to learn from successful approaches in other sectors.
- **It is paramount that the research community find innovative ways to engage and involve underrepresented groups** and those that may be affected in disproportionate or unexpected ways. Building and nurturing long-lasting, meaningful relationships with these groups should be a priority. Research involving these groups will be key to helping to reduce health disparities and inequalities.
- **The public involvement community should work more collaboratively** to ensure that all of us can benefit from the best practice and learnings that have emerged during the pandemic.

Finally, the co-Chairs reiterated the need for collective responsibility across the biomedical research sector to ensure that public involvement continues to make significant contributions to research throughout and beyond the pandemic. The partner organisations involved in the organisation of this workshop will continue to advocate for public involvement in research and seek solutions to ongoing challenges to help build an environment where public involvement in research is a valued and central component of research.

Annex I - Agenda

Patient and public involvement and engagement during the COVID-19 pandemic: developments, learnings and creating a better system - agenda

Tuesday 19 May 2020, 13.00-15.30

Digital workshop using Zoom

	Session 1: Key learnings from ongoing COVID-19 public involvement and the need for a system-level approach
12.50-13.00	Participants to dial in
13.00-13.15	Introduction and overview from the Chairs <i>The co-chairs will provide an overview of the workshop, including the format, and key aims and intended outcomes.</i>
13.15-13.40	COVID-19: the role and impact of public involvement so far <i>Five 5 minute case studies demonstrating how public involvement has been applied during the COVID-19 pandemic and where the key opportunities and challenges lie.</i> <i>Speakers:</i> <ul style="list-style-type: none"> • Jim Elliot, Public Involvement Lead, Health Research Authority • Jeremy Taylor OBE, Director, NIHR Centre for Engagement and Dissemination • Rachel Bosworth, Director of Communications, Medicines and Healthcare products Regulatory Agency • Thomas Kabir, Head of Public Involvement, The McPin Foundation • Jo Harby, Director of Information and Involvement, Cancer Research UK
13.40-13.50	The need for a system-level approach for adoption of public involvement at pace and scale Sheuli Porkess, Executive Director, Research, Medical and Innovation, Association of the British Pharmaceutical Industry
13.50-13.55	5 minute break
	Session 2: Addressing challenges and building a better system
13.55-14.45	Breakout session on the opportunities of public involvement throughout the COVID-19 pandemic and beyond <i>Participants will be divided into breakout groups to discuss the challenges of conducting and embedding public involvement during the COVID-19 pandemic and beyond:</i> <ul style="list-style-type: none"> • <i>What are the examples of good involvement that have been carried out during the pandemic?</i> • <i>What are the opportunities to engage and involve public and patients/carers/service users throughout the pandemic?</i> • <i>How can existing involvement continue, and new involvement created, throughout the pandemic and beyond?</i>
14.45-14.50	5 minute break
	Session 3: Open discussion and next steps
14.50-15.20	Reporting back followed by open discussion <i>The co-chairs will lead a discussion to collate proposed next steps, and identify the potential actors who could lead sector-wide coordination for each step.</i> <i>Guiding questions:</i>

	<ul style="list-style-type: none">• <i>As we emerge from the pandemic, how do we ensure the system is better prepared for proactive and efficient public involvement?</i>• <i>More broadly, how do we embed public involvement across the system so that it can be adopted and applied effectively?</i>
15.20-15.30	Summary and chairs' remarks
15.30	Close

Annex II - Participants

Co-chairs

Professor Dame Til Wykes DBE FMedSci, Vice Dean (Psychology & Systems Sciences) & Professor of Clinical Psychology and Rehabilitation, King's College London
Simon Denegri OBE, Executive Director, Academy of Medical Sciences and former Director for Patients and the Public in Research, National Institute for Health Research

Speakers

Rachel Bosworth, Director of Communications, Medicines and Healthcare products Regulatory Agency
Jim Elliot, Public Involvement Lead, Health Research Authority
Jo Harby, Director of Involvement & Information, Cancer Research UK
Thomas Kabir, Head of Public Involvement, The McPin Foundation
Sheuli Porkess, Executive Director, Research, Medical and Innovation, Association of the British Pharmaceutical Industry
Jeremy Taylor OBE, Director, NIHR Centre for Engagement and Dissemination

Attendees

Beth Allen, Senior Manager: Impact, Intelligence, Engagement and PPIE, Department of Health and Social Care
Sonya Babu-Narayan, Associate Medical Director, British Heart Foundation
Louise Barr, Associate Director, Policy and Communications, MSD
Matthew Bonam, Pharmaceutical Project Director, AstraZeneca
Aisling Burnand, Chief Executive, Association of Medical Research Charities
Tina Coldham, Former Chair, NIHR INVOLVE
Alison Cook, Director of External Affairs, British Lung Foundation
Angela Coulter, Chair, Public Advisory Board, Health Data Research UK
James Cusack, Director of Science, Autistica UK
Richard Evans, Programme Manager for Experimental Medicine and Precision Medicine, Medical Research Council
Steve Gilbert OBE, Serious Mental Illness Living Experience Consultant, Steve Gilbert Consulting
Bec Hanley, Facilitator, Shared Learning Group on Involvement and the Charities Research Involvement Group
Jillian Hastings-Ward, Independent Chair of Participant Panel, Genomics England
Liane Hazell, Research Involvement Manager, National Cancer Research Institute
Neha Issar-Brown, Head of Population & Systems Medicine, Medical Research Council
Annette Jack, Chair, Social Action for Health
Kate King MBE, Adviser on lived experience, The Mental Health Act Review 2018
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