

PPI Voices Yorkshire and Humber (YH): Useful Resources

Patient and Public Involvement and Engagement (PPIE) during 'Covid 19'

What is this guide?

During the Covid-19 situation, PPIE leads have found themselves having to provide guidance to researchers on new ways of reaching out and involving people. Because research studies around Covid-19 have been prioritised and developed quickly, there has been little time to develop these new ways of working - people have had to just try things out. Many resources have been shared online. The PPI Voices Group Yorkshire & Humber (YH) have collated some of these into this document (contributing organisations are listed in the Appendix). The information is not comprehensive but judgement has been used to ensure it is illustrative of the information in circulation. All resources and the ideas contained within them need further testing/discussion and development as our collective knowledge grows.

Conducting PPI during Covid-19 and amidst social distancing rules: An Introduction

From Research Design Service (RDS) and National Institute for Health Research (NIHR):

[NIHR Information resources](#)

Running virtual / online PPI events - top tips:

These two resources provide a good introduction to the do's & don'ts of running & facilitating online PPI events. The NCCPE document also provides information on different apps (Zoom, Microsoft Teams, Google Hangouts).

[Resources for Researchers](#)

From National Coordinating Centre for Public Engagement (NCCPE):

See web link to Guide to creating and running virtual events: [Creating and running virtual events](#)

An example of guidance for running a virtual meeting (Centre for Academic Primary Care, Bristol)

- If the meeting is with a well established PPI group, who all know each other, offer the option of being able to join the PPI meeting by conference call/Skype/Zoom - check that people have the technology at home to support it. If not consider phoning them separately.
- Send out, in advance a full list of attenders. Preferably also with a thumbnail photo, a description of their role, why they are in the meeting.
- Meeting chair to dial into meeting at least 5 minutes in advance of call starting
- Meeting chair to confirm who is on the call to all parties
- Everyone who isn't speaking should mute their microphone to limit background noise
- People should state their name every time they speak, unless everyone is well known to everyone else and their voice will be recognised.
- Speak slowly and clearly, sometimes the audio quality is not great and if you speak too quickly it isn't clear.
- The Chairing needs to be stronger than usual eg go around the group asking people by name if they have comments on particular points rather than just asking. As far as is

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possible the chair should make sure individuals are able to finish speaking before next person takes turn to speak The visual cues that people use to signal if they want to speak are missing and you end up with three people trying to speak at the same time.

- Please issue notes promptly, ideally within 24 hours of the meeting.
- If a conference call meeting is not possible (or there are too many people to run a meeting like this sensibly) consider phoning each individual person to ask for their feedback and circulate a summary email of the points discussed and raised, asking for people to give any further feedback or comment if they do not agree with the summary.

Guidance for injecting happiness and warmth via online meetings (nice!)

'Action for Happiness' is a movement of people committed to building a happier and more caring society, bringing together like-minded people from all walks of life and help them take practical action, drawing on the latest scientific research. Action for Happiness has launched new guidance for hosting online groups to bring people together':

[Action for Happiness](#)

Online engagement platforms & methods

An introduction from Traverse consultancy, covering different platforms (e.g. surveys/polls, discussion boards):

<https://traverse.ltd/recent-work/blogs/brief-introduction-online-engagement-platforms>

Engaging the public through social media

A guide from the National Coordinating Centre for Public Engagement and network contributors. Covers 'why use social media?'; 'choosing the right tools/platforms (pros & cons)', 'making content shareable', 'evaluation & impact', 'managing risks'.

[What works engaging the public through social media](#)

Rapid online deliberation

Uses the example - 'understanding public perceptions of the Covid-19 exit strategy' to explore the method of 'rapid online deliberation'. This is a new engagement method based on the principles of good deliberative practice:

[Traverse blogs online](#)

From SCOPE: Various top tips and template guidance - online accessibility, tools and inclusive design:

See website: <https://bighack.org/>

Video conferencing: [Big Hack Video Conferencing](#)

Twitter: [Big Hack Twitter](#)

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Facebook: [Big Hack ways to make your facebook page more accessible](#)

Communicating to the public about science

This could be really helpful for researchers - there are tutorials about engagement with the public on science in general and, with current emphasis on the online world, it is a great template/showcase on how to use YouTube as a tool. Provides Top tips, etc.

<https://www.youtube.com/playlist?list=PLD160RWuGai9oUnAVRq-GD2njEo1XHadF>

General technological support for the online world

Choosing video calling technology:

<https://www.theguardian.com/technology/askjack/2020/mar/26/what-is-the-best-tablet-for-video-calling-grandma>

User Guides:

<https://lincsdigital.org.uk/how-to-guides/> (user guides for Zoom, email, skype, smart phones etc)

<https://www.digitalunite.com/technology-guides> (digital skills e.g. using the internet/ internet security)

Discussion & debates: PPI/Co-production during social distancing

Education and Social Research Institute (ESRI):

This is an account of an online discussion session on the implications of physical distancing for participatory research/co-Production:

<http://www.esriblog.info/co-production-during-physical-distancing-teach-out/>

The King's Fund: Covid 19: Various discussion topics, blogs, online events, etc:

Interesting Blog on working relationships, power bases and the impact of Covid-19:

<https://www.kingsfund.org.uk/blog/2020/05/impact-covid-19-working-relationships>

A webinar from COCHRANE Training:

'As governments & health services rush to find solutions to Covid-19, we must not lose sight of the importance of including patients and the public in these discussions and the development of solutions':

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<https://training.cochrane.org/resource/working-together-beat-covid-19-engaging-and-involving-patients-and-public-second-webinar>

Understanding & keeping abreast of Covid-19 research

National information on research related to Covid:

<https://www.nihr.ac.uk/covid-studies/>

Be Part of Research website which shows all the studies if you enter 'Covid-19' into the search bar:

[Covid-19 Research Studies](#)

Regional examples of collated information about studies:

Leeds: <https://www.leedsth.nhs.uk/research/covid-19-research/>

Bradford: <https://www.bradfordresearch.nhs.uk/c-sag/>

Liverpool Health Partners (LHP) - 'STOP Covid':

<https://liverpoolhealthpartners.org.uk/spark/coronavirus-covid-19-and-research-across-lhp/>

<https://liverpoolhealthpartners.org.uk/strategic-one-liverpool-partnership-for-covid-stop-covid-initiative-as-of-14th-may-2020/>

<https://liverpoolhealthpartners.org.uk/new-initiative-co-ordinates-all-covid-19-research-for-liverpool-city-region/>

Information Governance, Data Management advice, etc. during Covid 19 state of emergency

From NHS/NHSX: See general website with sample templates, guidance, updates, etc:

<https://www.nhs.uk/covid-19-response/data-and-information-governance/information-governance/>

Patient & Public Views Captured during Covid-19

Here are some of the initiatives designed to understand the perspectives of the public during the pandemic.

Healthwatch: 'We look at the issues you are telling us about accessing care during COVID-19 in three parts of England and how this information is helping NHS and social care services'.

<https://www.healthwatch.co.uk/blog/2020-05-11/covid-19-how-has-your-health-and-wellbeing-been-affected>

Kings Fund: perspectives of those shielding

<https://www.kingsfund.org.uk/blog/2020/05/shielded-voices-covid-19>

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Our Covid Voices: collecting first-person accounts of living through the 2020 Covid-19 pandemic in the UK.

<https://ourcovidvoices.co.uk/>

Finally, a hot topic for patients: video consulting

As video consulting plans are put into place for the foreseeable future, it is useful for all involved in health service research and development to be aware of the key engagement issues these raise. These guides have been produced for patients and for clinicians on the considerations of when these types of consultations are/are not appropriate:

<https://www.phc.ox.ac.uk/research/resources/video-consulting-in-the-nhs>

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Appendix

PPI Voices Yorkshire & Humber (YH) comprises representatives from the following organisations:

Yorkshire & Humber Improvement Academy	IA
Research Design Service Yorkshire & Humber	RDS YH
Yorkshire & Humber Patient Safety Translational Research Centre	YH PSTRC
Yorkshire & Humber Academic Health Sciences Network	Y&H AHSN
Leeds Biomedical Research Centre	Leeds BMRC
Leeds Clinical Research Facility	Leeds CRF
Leeds Medtech and In vitro diagnostics Co-operatives	Leeds MIC & Surgical MIC
Leeds Clinical Trials Research Unit	Leeds CTRU
Sheffield Devices for Dignity Med Tech Co-Operative	D4D
Collaboration for Leadership in Applied Health Research & Care Yorkshire & Humber	CLAHRC Y&H
Sheffield Biomedical Research Centre	Sheffield BRC
Yorkshire & Humber Clinical Research Network	Yorkshire & Humber CRN
National Institute for Health Research Academy	NIHR Academy