Note: This is the first time I've attempted a public, shared doc with editing enabled, I might revise this depending on engagement!

[There is another shared doc I have contributed to and the 2 editors share it in suggesting mode and can approve or reject suggested changes. I recommend you do this. It protects what is there too and prevents any accidental damage and you can make it easier on yourself in terms of keeping tabs on the contributions being apt and not advertising things or suspicious links being inserted. - @byyrside]

Additional notes 19.03: Thanks everyone for contributions so far! Can I ask please that if you add or edit the text can you add your name or show in some other way (people are using colour, brackets, comments - happy to be flexible!)

Sections

1. Caveats and context to this doc
2. Resources shared so far
3. Thoughts on different platforms & methods
4. I can help!
5. I need help!
6. Things To Think About
7. Organising hangouts/tweet chats

1. Caveats and Context
- This isn't a formal list or resource, this is Thinking Out Loud. It's intended as discussion, not advice. This is me starting to think about how it could be done, not claiming expertise having done it. (If you have done it, please think about adding your name or link to your study to the 'I can help!' Section) [Update May 21st: I've run a few online workshops/meetings now with a combination of zoom/microsoft teams and trello, so do ask if you want to know more]
- Me = Sarah Knowles, Senior Research Fellow at University of York, @dr_know on twitter.
- I'm a health researcher and my codesign is within research projects with patients, carers, service users. I'm sure a lot of this applies to other settings but just FYI that's the context I'll be referring to. I tend to refer to "contributors" as meaning the people I do codesign with, the "users" or participants in other terminology.
- My interest is in codesign, as in how we work collaboratively with our contributors, how we interact in an activity that is about sharing and developing understanding or generating new ideas, not in one way communication or dissemination. (I'm sure there's crossover in thinking about digital dissemination and codesign, eg. In terms of thinking of accessibility for different audiences, but again just to be clear the context I'm working in.)
- I comment at some points that this info is for researchers, which no doubt seems very contrary to a coproduction ethos. The reality is that I absolutely think any formal guidance or recommendations should be coproduced with and tested with patients/service users themselves, but critically I think that counts as work. I don't

think that should be done without reimbursement, and I don't have any funds or means to distribute them for this, which is just a follow on of a twitter comment! So I absolutely welcome patient comments, but I don't expect them. I see this discussion as being for researchers or other professionals to kick start their thinking, and then I really hope that those with funded studies can gather some proper feedback from patients who are properly reimbursed. If any patients do wish to comment on this, I'm immensely grateful and I apologise this is currently "about you without you".

- Some others have suggested doing hangouts or zoom discussions. add your name and email to section 7 if you're interested, but then please self organise as it's not something I'm arranging myself just yet! **Update:** Kate Martin and Jonathan Broad now run a regular discussion - @katemartin_says, @QIPatient - email jono.broad@swahsn.com to be added to the list

2. Resources shared so far

- This is by wearesnook and looks like it was developed more with climate change in mind, to encourage remote working to reduce travel. I think the practical tips on running sessions are really useful for anyone prepping their first online meeting. It does assume a level of tech familiarity of participants though which I suspect we shouldn't.

- @Dan_Moxon is curating this excellent collection of resources on youth digital & online participation. See also the online hangout he recently hosted on tools for working with young people online

- Lots of academics who do remote teaching have been sharing resources which probably have relevance, eg. a padlet by Cecilia Nobre of resources around online teaching.

- Steven Blackburn and team have kicked off what will likely become a hugely useful resource here - collecting examples of "virtual PPI", including contacts for further info, and comments on challenges and benefits. Do add to this if you have examples!

- This is a research study rather than codesign - Use of Web Conferencing Technology for Conducting Online Focus Groups Among Young People With Lived Experience of Suicidal Thoughts: Mixed Methods Research - but talks about processes for online focus groups. I'm including as it talks about risk management and I think this is something we need to be mindful of. Similarly this doc, which is specifically guidance on remote therapy, may be useful.

- Some possibly useful papers- shared via Prof. Glenn Robert:
    - Näkki, P. and Antikainen, M., 2008. Online tools for co-design: User involvement through the innovation process. *New Approaches to Requirements Elicitation*, *96*.

- Näkki, P., 2013, October. Service co-design using online ideation and face-to-face testing: Case City Adventure. In *ServDes. 2012 Conference Proceedings Co-Creating Services; The 3rd Service Design and Service Innovation Conference; 8-10 February; Espoo; Finland* (No. 067, pp. 177-188). Linköping University Electronic Press.

- The NIHR INVOLVE guidance document on social media and involvement (Thanks to Louca-Mai Brady for signposting!) In the same vein, NCCPE Engaging the public through social media guide - this is more about communication, engagement and raising awareness than co-design, but could be useful for starting out on how to build an online community.

- One of the best citizen science, public engagement and patient (parent and child) involvement projects using digital media IMHO is Parenting Science Gang. Evaluation section is useful - also paper just published in Research Involvement & Engagement.

- List of examples of social research methods for 'Fieldwork in a Pandemic', including study references. Includes photovoice, journalling, cultural probes, discussion forums.

- Louisa Walsh, PhD student at La Trobe University, shared her slides on using social media for service design and improvement in hospitals.

- Section 11 of the NHS Digital guide to working with the public has suggestions for involvement online.

- Learning from part of the Leapfrog project that used Whatsapp groups for remote co-design

- NSUN (National Survivor User Network) have created this useful resource on 'Keeping in touch with each other when we can't meet face-to-face' Sarah K: Great link - this has a different angle to the research guides (more about reducing isolation and encouraging connection) but includes practical tips on eg. setting up messaging/video conferencing with widely used apps. The point about fostering connection is also worth bearing in mind - we would want remote codesign to help people feel connected, rather than emphasising distance.

- The NCCPE have published a webpage with tips for online engagement event and a shared document to capture tips for best practice and reflections on various software/ tools

- This guide on online meetings by Better Evaluation is more geared toward professional meetings, but it has practical and thoughtful suggestions on helping participants feel comfortable and connected, which I think will be helpful for anyone trying to ease contributors into a change in meeting format.

Commented [1]: Added by Bella

Commented [2]: Thanks Bella!
Hi, I designed and ran the Parenting Science Gang project. We worked with 8 virtual groups to co-create 7 experiments/research investigations, over two years. All our evaluation stuff is gathered together here http://parentingsciencegang.org.uk/evaluation/, with several summary blogposts and also downloads of the exec summary or the whole 230 page report.
We tried to make the evaluation report as complete as possible, but of course there's stuff you learn which it's hard to capture. Please give me a shout if you want to pick my brains or talk anything through. I'm @sophiacol on twitter, sophia.e.collins@gmail.com email.

Commented [3]: Added by Jessica

Commented [4]: Added by M Skrybant - PPIE Lead - NIHR ARC WM

- FutureGov have made this guide to 'remote design work' available, lots of crossover with involvement and coproduction I think, particularly the stuff on safeguarding (both for researchers and contributors) is important to think about.

- @qipatient jono.broad@swahsn.com runs a group of 40 members of the public with lived experienced who meet online to advise the Quality Improvement teams across Somerset, Devon and Cornwall on making their projects better from a patient, family and carer point of view. The group is called QuIPPs - Quality Improvement Partner Panels and was funded by the Health Foundation Q Exchange funding 2018 and was match funded by the South West Academic Health Science Network who are still supporting the project. All members of the group are trained to the same standards as NHS staff in the region on Quality Improvement Methodology.
  You can find out more by either emailing Jono or www.swahsn.com/quipps
  These panels are all virtual and use Zoom video conferencing.

- Thread by Adam Jowett on resources & examples for digital qualitative research from an ethics committee perspective:
  https://twitter.com/DrAdamJowett/status/1240190672960991233

- Rebecca: Esther van Vilet from NIHR SPCR has produced a guide to using Zoom for PPI for members of the public:
  https://www.spcr.nihr.ac.uk/files/ppi/howtousezoomforavirtualppimeetingfromcomputer.pdf

- This paper talks about using a James Lind Priority Setting method through videoconferencing.

- Gov.uk have created a list of research tools.
  https://docs.google.com/spreadsheets/d/e/2PACX-1vQ_PszsxLez8pu1kCyNYa5gOPLtntbLlE2WzbNYDx8qyf9EwvL1rJOBWXdORdnxkq9c3O_Jqk2RVO4j/pubhtml# (Trac Marshall Sigma)

3. Thoughts on different platforms and methods

a. Trello: https://trello.com/en-GB/guide/collaboration

Pros: I think this makes the project/survey/discussion really clear - visually everyone can see progress of different aspects and immediately see which tasks are still remaining. I can imagine with remote involvement it would be easy to feel distant from the project overall and unclear where your feedback was going. I wonder if this would make visible to the contributors why the contributions are made and how they're being recognised.
Sarah update May: I've been using this in PPI meetings and feedback is that contributors really like the visual structure it offers, helps them to follow the discussion, and also as I 'live edit' sections they can see their feedback is being used.

Cons: very text based? (Possibly - I might just only use it that way!) and potentially looks overwhelming if you're coming new to a project? I think you'd need some other work beforehand to introduce the project and make sure people don't feel like this is a to-do list they're obligated to work through.

b. Google docs:

In a neat example of academic irony, I'm going to announce that the method I think is worst is the one I'm using to say it's the worst... I worry google docs encourages a very text heavy interaction of people being expected to just leave their comments and edits and then the researcher trawls through them. I think this way of working is familiar (not ideal!) for researchers but not for contributors. It could be used for sharing information but I'm not sure about codesign. I would also only use it with contributors I already know are comfortable with it.

c. Cultural probes:

Befitting of a designer, Joe Langley took a different tack on the question, provoking us to think about how empathy and creativity can be included. This work on cultural probes might be of interest.
Update by Sarah K 25.3.20: I wonder if a Dear Data style project might be a way to explore with (creatively inclined) contributors what matters to them, what they are noticing in their daily life.

Pros: undoubtedly richer information gained, and I think gets closest to codesign rather than just consultation which a lot of the others may lapse into. Likely more interesting and easier to complete for some groups, but not everyone? The example in the document posted out materials. This could be a good alternative to just putting everything online, especially for groups less comfortable with tech. (I don't know if there will be restrictions on post and parcels at any point?)

Cons: not a con but just a note - this needs a lot more thought and consideration from the researcher beforehand. I think the richness would be lost if you don't think carefully about what materials you're including and why.

d. Padlet

https://en-gb.padlet.com/
Easy way of different people sharing- and can be anonymous if you want- which is helpful if people want the safety of that/could help encourage wider sharing. You can share text, images, links etc. Would be a good way to get responses and the post-it style of the boards gives an interactive feel of it means you can see it changing if people are using it simultaneously. It feels quite creative. Sarah K: Agree this is much nicer to look at than a typical list!

Cons: ?? Not sure! Rebecca: Do you have to create an account to join in with this? Could put some people off. Sarah K: I think you need an account to post but not to read but agree might be an added burden for some. Dan. You can post anonymously no account needed, although it tends to steer you towards one. Sally: sounds good, but currently "Padlet is overcapacity" so I can't see anything

   e. Online card sorting software

   https://www.optimalworkshop.com/optimalsort/
Suggested by @RawsthorneMat. Note this is a pay to use service so would need funding, though I think we need to recognise the complexity of this kind of work and pay for professionals (if we have resource) when appropriate! . [We used this at scale on the digital mental health (research) priority setting partnership it was only $99 and worked well - Mat]

   f. *Audience participation tools that allow voting and comments*

   [I can't remember the names of these at the moment but I think the Mental Elf would know! - Mat] sli.do?

   Kahoot.com
   A free and easy way to create online learning tools and quizzes (maybe even polls?). Once you have created a quiz people can take part on their phone or in a separate browser. Can be used as a great icebreaker and also people can take part anonymously. Thanks again to @JamieBGall

   Google Forms
   Easy to quickly set up surveys and gather opinions

   https://www.mentimeter.com/

   g. Zoom (first 3 paragraphs added by Rebecca)

Pros: Videoconferencing with screen-sharing option and chat box. Options to record video and audio and save chat history. Accessible from phones, tablets and computers. Do not need to install anything on a computer. Can set up a private meeting and send people a link. The host needs to 'admit' those who follow the link. Found it to be a more stable platform than Skype.

Cons: People using phones and tablets have less options for changing their view etc. Some can have technical difficulties (I tried this with people aged 65+) such as getting the sound to work.You need to buy a licence to host a meeting of more than 3 people for more than 40 minutes. However, your institution may have a licence you can be added to (the University of Manchester does).

Tips: I facilitated a workshop via Zoom and found it useful to have a second person to help resolve people's technical difficulties, and a third person to take notes as we were not recording. I didn't save the chat history before leaving the meeting and I'm not sure if I can get it back now but you can change your settings to auto-save.

Zoom has excellent security if you need to convince your ethics board it's ok to use it: https://zoom.us/docs/doc/Zoom-Security-White-Paper.pdf

Also, if you're looking for a resource to read more about using Zoom for qualitative research (may be relevant to co-production) there's an open access article published in the International Journal of Qualitative Methods: https://journals.sagepub.com/doi/pdf/10.1177/1609406919874596

@JamieBGall has recently set up a new weekly Zoom event - Virtually Social - more for SciComms and Public Engagement practitioners, but in Zoom you can create break out rooms and put people into small discussion groups which are really effective

Hi, Just to say for those worried about that sort of thing that you might well have a University account for Zoom - we turned out to at Glasgow. However there's some stuff on Twitter about how Zoom is NOT secure.

More on problems with Zoom and how it might actually be classed as 'malware'.
https://www.theguardian.com/technology/2020/apr/02/zoom-technology-security-coronavirus-video-conferencing

There's an older thread on Stack Exchange about the trouble people have had knowing just what it's doing and how to delete it.
https://apple.stackexchange.com/questions/358651/unable-to-completely-uninstall-zoom-meeting-app

See zooms privacy policy here: https://zoom.us/privacy

This recent website gives some information on the security of Zoom (or lack of) especially regarding personal data and camera hacking. The article also explains how to potentially overcome some of these concerns:
- To note: Zoom doesn't sell personal data but it does give it on to third parties for 'business purposes'
- Zoom have previously enabled bypassing of security features i.e. zoom was able to access the camera without asking the computer permission. Whilst updated versions had got rid of this, it makes zooms reputation for caring about personal data questionable.

Note from Sarah K May 1st: I'm wary of this becoming a very long list of the good and bad of zoom security. My own take is that all platforms probably have security issues, zoom is just the prominent one at the moment. But it's a good point that in all data collection & discussion online we should take time to familiarise ourselves with security issues and be open about what we know/don't know with our contributors.

Commented [11]: You can set up an auto-record on Zoom, provided that everyone on the call is ok with this.

Commented [12]: Need to think about the ethics of using platforms such as zoom whta happens to that data -is it sold on for advertising? I think we need to be mindul and consider this i havd major concerns.

Commented [13]: Added by +andi.skilton@nihr.ac.uk

Commented [14]: More of a "practical" warning: Be aware if you plan on using Zoom that participants in online workshops/group-events ect. may refuse to use Zoom due to security concerns like these and drop out of the project entirely. It "breaks" your participants trust in you, when you ask them to use "dangerous" tools online.

Not quite sure how to avoid this other than perhaps not using Zoom or informing participants that you are aware about these security concerns?

h. **_Slack_**

Pros: good for project working across multiple users. Easy to make different 'channels' for different strands of a project, eg. work on shared documents, share relevant content etc. Cons: v text heavy and on free version only a limited number of messages are kept. (Just to add @munrobius here - Slack is very insecure.

i. Mural

I (@RawsthorneMat) am investigating this via the free trial version https://mural.co/education and seeing if the interaction via canvases etc allows for what we would normally do in a workshop

j. Miro

A remote whiteboard, sharing a lot with Mural. We've been using this a lot for tasks like brainwriting (written brainstorming) and meeting planning. It can be used collaboratively, and so has a lot of features that would be useful in a workshop. There is a free version which is usable and give you a good idea of what can be done, but you might well need a paid account if you want to base your work around it. Happy to share my experience (I have no connection to Miro - @danny_sherwood)

I'm also trialling Mural and Miro to see how well they support group reviews of research findings / affinity sorts - will be doing within a project team initially, but then plan is to use whichever works best as part of a piece of remote co-production later this summer. They both look like they should do this in principle, but want to know if they'll support the detail, e.g. having traceability codes on the corners of my post-it notes. Also - not clear yet on the security side of things, looks like Miro free version might mean the boards are on an unsecured URL, mural may be the same, that wont be appropriate for my project. Also looks like will need accounts for everyone who will manipulate boards so might be expensive, but haven't spotted anything else that will do quite what I want. @sarri

k. Facebook

If it is lay publics you are trying to engage, then it is hard to beat Facebook for coverage. (Although I believe instagram and others have overtaken Facebook for younger adults.) But it's a lot easier to get people to join a facebook group (or even go to the facebook group they are already in and talk to them there…) than it is to get them to download and install random new fancy app, or set up a new log in and learn a new set up.

l. Kanbanchi

Similar to Trello - this is part of the Google Drive suite of apps. A great planning tool - as well as setting up cards and assigning owners you can also import emails from GMail; attach documents from your Google Drive and it also a Gantt chart view as well.

m. [Personal User Manuals](#)

Introduced to our from a training course these cover off key things about who you are and how you like to work. Even with video conferencing it can be hard to really get to know people. These could be a useful 'hack' to overcome the distance barrier to getting to know what makes each other tick.

n. Added: Tox project - various apps from it - https://tox.chat/ - "Tox is easy-to-use software that connects you with friends and family without anyone else listening in. While other big-name services require you to pay for features, Tox is completely free and comes without advertising — forever." I'm trying that out.

o. Added: Discord - used mainly by gamers, (and notoriously by alt-right types in Charleston) and others. It's surprisingly light, you can set up a 'server' and chat fairly fast - and all from a browser. To be really secure you can use Tor, but please note that they are much more strict with it. Using it with a browser allows text and audio chat. Downloading the app allows video, though I'm not sure how secure it is. But wow, it's light and easy and all you need is an account - easily set up with an email address, then you invite people via a weblink. Really light!

l) Microsoft Teams
- I (Camilla Babbage, @teens_tics_tech, PhD student) looked into Teams yesterday for holding focus groups for designing an app. I think this could be applied to codesign discussions too!
Pros: Teams allows you to share your screen, I have two screens connected to my computer which means I can share one of my screens which would be showing a powerpoint, then I have my focus group guide on the other side that people won't be able to see.
The video can be recorded, and it lets all others in the video know they are being recorded too.
Teams uses a live captions feature which makes it more accessible
It also creates a transcript of your video that can be edited and downloaded (I think). The transcript seems fairly accurate, not sure how well it works with lots of people talking at the same time
From what I can understand, the security seems fairly good, it has in transit and at rest encryption. It uses the same security as Office365, which the University are happy with, so I assume this is fairly secure?
Cons: Guests have to create an account using their email address if they want to use Teams
Guests can talk to members of the team in private chat, which may not be able to be disabled by you if your organisation has removed some of your admin rights. This means that members of the team can be contacted 'out of the blue' and give their personal information (email) to other members in the team.

4. I can help!

If you are experienced in online or remote codesign and would be happy to share your twitter handle/email for questions, offer an online chat, or share resources, then please add your details here!

Rebecca: I would not say I am experienced but have just run two online workshops using Zoom. Happy to share thoughts and suggestions as a result of that. Twitter handle = @RGouldingUoM

Salma: Similar to Rebecca, I've run a few online workshops. Twitter handle = @DrSalmaPatel

Miles: I've never done online co-design but guess that you would need to be much more focussed, with less time/ability to have open-ended "blank sheet" discussions. So it might be a case of starting with what is already known (from a patient/public perspective) about the topic you're researching. There's unlimited free search of all things patient experience/engagement here: www.patientlibrary.net Hope that helps. miles@patientlibrary.net

Sarah K: I can imagine new contributors might feel quite of out the loop given the distance working, signposting resources like this could be really good for those who want to feel more grounded in the wider patient experience community and work (though also need to be careful not to be burdening people by seeming to give 'homework'!)

Hi I'm Ann @anncarlowgirl a PhD candidate in business information systems NUI Galway. Title A sense of community model of online public engagement - I'm just finishing the write up. (I should be self isolating to keep typing!, but love to help) I worked on the public engagement platform https://thepeoplestrial.ie/

The focus of my work has been to identify the processes involved in successful online public engagement, namely identify the factors that enable participation of both government/researcher and public stakeholders. Identify levels and types of interaction that create shared value for stakeholders using the (McMillian and Chavis 1986) sense of community theory. Link to the paper here https://bit.ly/33vMH0L

Participation

1. Do the norms of participation on the platform include an identity that other participants can recognise? (Names, Pictures, Job title)

2. How is the platform moderated, do the users feel it is a safe place to participate? (presence of moderation, identity validation and the numbers of users)

Interaction

3. Can users of the platform find other users who share the same values and concerns as themselves? (staff who work in similar areas can identify with responses, potential for learning, sharing)

4. Do the norms of reply on the platform, including language promote values of positive engagement practices? (Do people share meaningful information and is the tone of the platform respectful to all users)

5. What is the role of influence on the platform? (is there evidence that users can contribute to change on the platform and can they show they have been influenced by the platform?)

Value

6. Is there evidence of satisfaction of needs fulfilment activities on the platform? (Questions answered, recognition of information shared, recognition of learning, recognition of affirmation of the quality of some aspect of service provided).

Hello, my name is Lisa Brighton and I'm a researcher at the Cicely Saunders Institute, King's College London. We developed an online forum for patient and public involvement in palliative care and rehabilitation research, which has worked quite well so far: www.csi public involvement.co.uk. Some of our experiences and learning around this are captured in this report: https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0097-z, and we have since re-designed the forum. Always happy to answer questions about this - feel free to tweet me at @lisa_brighton, or email me and our public involvement team at csi.ppi@kcl.ac.uk.

Hi, I designed and ran the Parenting Science Gang project. 'Radical co-creation' of research, led by parents of young children, funded by Wellcome. We worked with 8 virtual groups, on Facebook, to co-create 7 experiments/research investigations, over two years.

All our evaluation stuff is gathered together here http://parentingsciencegang.org.uk/evaluation/, with several summary blogposts and also downloads of the exec summary or the whole 230 page report.

We tried to make the evaluation report as complete as possible, but of course there's stuff you learn which it's hard to capture. Please give me a shout if you want to pick my brains or talk anything through. I'm @sophiacol on twitter, sophia.e.collins@gmail.com email.

Hi, I'm Alan Munro (Glasgow Uni) - I did my PhD on online collaboration 20 or so years ago on a little known thing called Email. I've actually remote-worked the whole of my current job, and have a history of remote collaboration since before the Internet was so called. I worked in CSCW for years, and did work on videoconferencing. I've also led a number of design ateliers over the years (copresent) .

I'd say one thing to think about is a 'bricolage' of approaches and software. This might find a messy-but-workable approach. Don't try to replace the copresent but find a workable alternative, not necessarily the same thing.

Hi, I'm Louca-Mai Brady (@Dr_LoucaMai) I'm not sure if this belongs in this section or the one below! I'm a researcher, trainer and facilitator with particular interests in the involvement of young people in health and social care services and research. As well as freelance work I support the involvement of young people in Moorfields paediatric research via a young people's advisory group (eyeYPAG) and the development of a youth forum. I'm also a former member of the NIHR INVOLVE advisory group, where I was involved in the development of the Guidelines for Public Involvement in Social Media. I'm particularly interested in the opportunities, as well as challenges of digital and remote involvement for inclusion and diversity in the involvement of children and young people. E.g. will such approaches work better for some than face:face but less well for others? How best to make involvement accessible and inclusive. What are the particular ethical and safeguarding challenges of digital and remote involvement when involving children and young people? I'd love to share ideas with, and learn from, anybody else working in similar areas.

5. I need some help!

Use this section to post any specific queries or requests.

- I am particularly concerned about the effects of isolation on those (such as some older people and people with ongoing mental health distress) who are already isolated. Does anybody have experience of working digitally with older people, especially in a context where we may not be able to lend technology (and don't have the budget to buy it for them!)? @danny_sherwood
[A good person to ask about this would be Neil Chadborn @nchadborn - Mat]
[We involved people with dementia and visual and/or hearing impairments in some research. Not much done virtually, but there could be some transferable learning]

Beth - I'd be interested in chatting about co-production with older people. Let me know if you fancy a zoom beth.bareham@ncl.ac.uk or @BKBareham - I'm concerned about a) what remote approaches would be accessible to older people and b) calling on them as contributors at this time, given this is a vulnerable group who may have bigger concerns than co-production
    - Beth (see above) I also have concerns about practitioners as contributors at this time - I want to do my best at this intervention co-design, but don't want to be calling upon practitioners who presently have bigger concerns than an intervention for late life alcohol use. Perhaps a more flexible as and when approach would be best suited to this.

Commented [23]: Added by Bella

6. Things To Think About:

1. Does the group we're working with have familiarity with remote communication - do they use Skype? Do they have/need accounts for the platforms you're using, what tech requirements are there?
2. Majority of people access the internet on their phone - is the method you're suggesting compatible with this?
3. In health research we may be asking people to share very private or sensitive things. How do we respect this with online collaboration? What guidelines about confidentiality do we need? Are there ways for people to post individually or privately?
4. Creating a sense of shared community, working toward a shared goal, can be the toughest part of any involvement project. How do we foster this when working remotely or online? (And yes, my response to this is along lines of: I will show them my pretty cat and we will all discuss how pretty my cat is and then we will have the shared attribute of Cat Admiration) More seriously, a lot of people are going to be feeling alone over the next few weeks, months. Can we find a way that codesign can be actually a means of connecting, of feeling less isolated? Added by someone: I think engagement work here can help - cf. building online communities as a 'precursor' to involvement. This is how we work - building either place-based, condition-based, interest-based, etc communities either virtually or in person - to then progress onto active involvement/co-creation of research. We also specialise in co-creation of engagement - so as to ensure that we are being appropriate and relevant in our engagement. More here.
5. Raised by several people on twitter, question whether you need synchronous input (where everyone is in contact at a specific time, mimicking a typical design meeting, this would also include tweet chats) or could have more open ended mechanisms. Eg. A forum or hashtag where people can post at different times more suitable for them. I think this could be a great opportunity to think about how we do codesign differently, rather than just trying to replicate how we do things face to face.
6. How do we get away from just text? Is this a great time for a photo voice project?
7. How do we build in evaluation of these methods as we try them out - thinking about both quantitative metrics (eg. Number of engagements, demographics of those involved) and qualitative (how did it feel, perceived advantages and disadvantages compared to face to face). Added: Some good widgets that do this cf. digital marketing
8. In the U.K. involvement activity doesn't require formal ethics approval in the way research studies do, but nevertheless we still have to think about issues like consent and safeguarding. How do we navigate these online, and particularly in public spaces?
9. We need to be just as respectful of burden as we would be when running face to face event. We shouldn't assume for example that it's easier to do something at home - people may have caring responsibilities, people may struggle with new tech. This is a good time for a Mark Brown quote: *"if you are trying to introduce tech into someone's life, you are climbing into their bed, their pocket, their living room, their house. Have some respect. Wipe your feet. Don't go through the drawers. You're a guest."*

Commented [24]: Very important we need to be mindful people will be at home/inside and may not have the privacy or the space to engage -will they feel safe/comfortable?

Commented [25]: Thank you for this quote - really applicable! I may use this in some of our Involvement@York communications/promotion, if that's alright?

10. <mark>Do you need to consider additional resources for involvement? Buying phone credit for a participant -making sure they have the technology.</mark>

7. Organising hangouts/tweetchats

Please add and discuss here.
Update by Sarah K 19.03: I think @katemartin_says is organising something at the moment.

Kate Martin and myself will be hosting a Zoom call to discuss where we go next with the great things that you have all put in this document, many thanks from Jono. Please see the invite link below and watch out for an email from kate and myself asking you to join us.

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Hello, please can you add me and my job-share Victoria Wilson to the mailing list for joining a Zoom call? We are coordinators for PPI&E at the Centre for Academic Primary Care, University of Bristol (julie.clayton@bristol.ac.uk and victoria.wilson@bristol.ac.uk)
But we understand if you need to limit numbers. Meanwhile, this is a great discussion thank you everyone!