Understanding Patient Data
Steering Group Meeting Notes

Thursday 7 May 2020
10:30am - 1:00pm
Via MS Teams *(this SG meeting took place during the Covid-19 global pandemic, by recorded video call, no attribution is included in the minutes)*

Attendees:
Charlotte Augst (National Voices)
Claire Sutton (The National Care Forum)
Donna James (Wellcome/UPD)
Grace Annan-Callcott (UPD)
Harry Evans (NHS England)
Joanne Bailey (NDG Panel)
Natalie Banner (UPD)
Sir Nick Partridge (Chair)
Rachel Knowles (MRC/UKRI)
Sara Marshall (Wellcome)
Shera Chok (Shuri Network)
Tom Harrison (UPD)

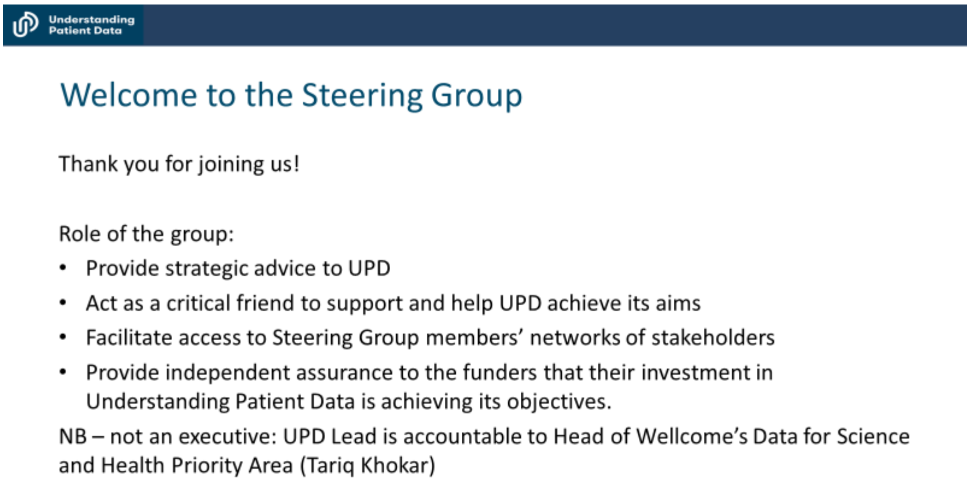
Apologies:
Beth Allen (NIHR)
Jeremy Taylor (NIHR)

1. Welcome and introductions (Nick)

- Members introduced themselves briefly covering their background and current role.

Governance and Background

2. ToR and role of the Steering Group (Natalie)



Welcome to the Steering Group

Thank you for joining us!

Role of the group:

- Provide strategic advice to UPD
- Act as a critical friend to support and help UPD achieve its aims
- Facilitate access to Steering Group members' networks of stakeholders
- Provide independent assurance to the funders that their investment in Understanding Patient Data is achieving its objectives.

NB – not an executive: UPD Lead is accountable to Head of Wellcome's Data for Science and Health Priority Area (Tariq Khokar)

- 7.2 in the ToR, the word 'minoritised', wondering whether we could rephrase that? Could we change that to 'people from minority groups'?

  - Term caused quite a lot of back and forth, D&I team within Wellcome suggested 'minoritised' instead of 'minorities' because of the implication being it's sort of an active minoritisation as opposed to the fact they are passively minorities. That was the concern they raised. Really happy to rephrase if something you'd feel more comfortable with, would just like to get the description right.
  - Just my opinion, not an expert on language, just feels victim mindset.
  - Would 'people from minority backgrounds' be better phrasing?
  - Yes I think so, what do the rest of the group think?
  - Challenging how quickly language changes in this environment. Need a bit of time to think about it.

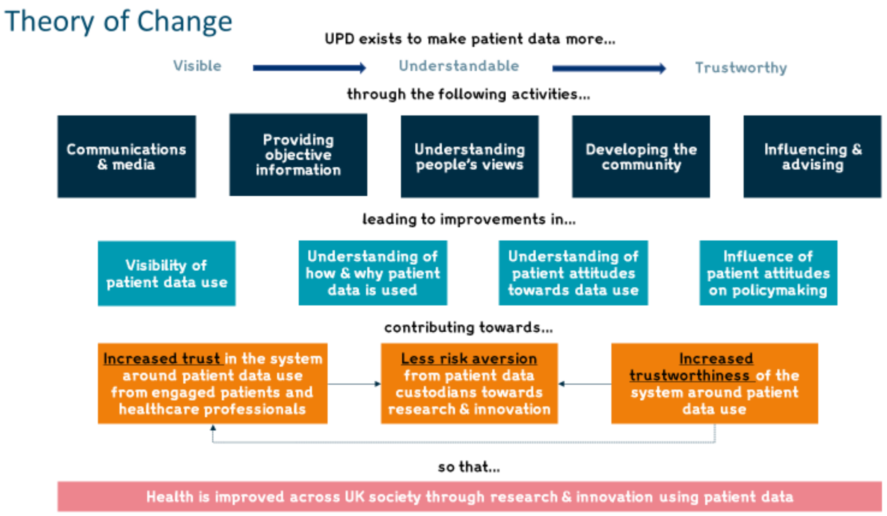
ACTION: UPD will take this away and think about the language.

- To better understand re the role of the SG, not knowing exactly how the previous SG worked, wondering how it's planned or being considered that the assurances given back to the funders, how's that perceived to work, not merely our existence, what more than that?
  - Annual report to funders will articulate how the money has been spent and invested which will be managed through funder's annual meeting. Essentially the funders sitting on the SG, part of the role of this Group is to indicate and show to them how we're taking on board broad range of perspectives and views and getting strategic advice and guidance from experts as we make decisions as UPD. That's what that assurance is, it's not that the SG has to provide a separate report back to the funders. The funders are in this Group to witness and be part of the process of the perspectives and experiences feeding into the thinking.
  - Opportunity for understanding of reputational issues and risks. Can be extremely useful to have early sightings of activity which may impact on funders of the Group.
  - In funding UPD one of the risks we have is our own investments, so the work UPD supports and explains that is of great interest so I take reports back to, for example, our strategy and management boards about some of the activities that're going on and ways in which they can support, and it may be able to highlight issue we have. That's the other way I would see that bullet point actively being put in place.
  - So, in a way the very membership of the funders in the SG, they're observing, hearing about things in the same way we are and observing there is some independent stakeholder discussion going on to which they can participate? So relatively informal but that's very helpful.
  - Are of course things that are therefore not our role - we're not an executive, we're here as a SG. One other element that isn't really pulled out but is crucial is helping to provide contacts and networks to help the team build up UPD's activities. One of the things that can really help is that third bullet point which is our networks of stakeholders. If you see something that's happening or made aware of and think you know UPD could help with that please don't be shy with linking the team into your networks.

- Natalie is looking for members with clinical expertise. Has proved to be bit difficult.
  - SG isn't entirely fully formed yet, couple of other people we would like to approach but needs to be post the crisis.

- Everyone happy for the ToR to be on UPD's website, subject to comment re 7.2 wording.

3. UPD's background, history and mission (Natalie)



Theory of Change

UPD exists to make patient data more...

Visible → Understandable → Trustworthy

through the following activities...

Communications & media

Providing objective information

Understanding people's views

Developing the community

Influencing & advising

leading to improvements in...

Visibility of patient data use

Understanding of how & why patient data is used

Understanding of patient attitudes towards data use

Influence of patient attitudes on policymaking

contributing towards...

Increased trust in the system around patient data use from engaged patients and healthcare professionals

Less risk aversion from patient data custodians towards research & innovation

Increased trustworthiness of the system around patient data use

so that...

Health is improved across UK society through research & innovation using patient data

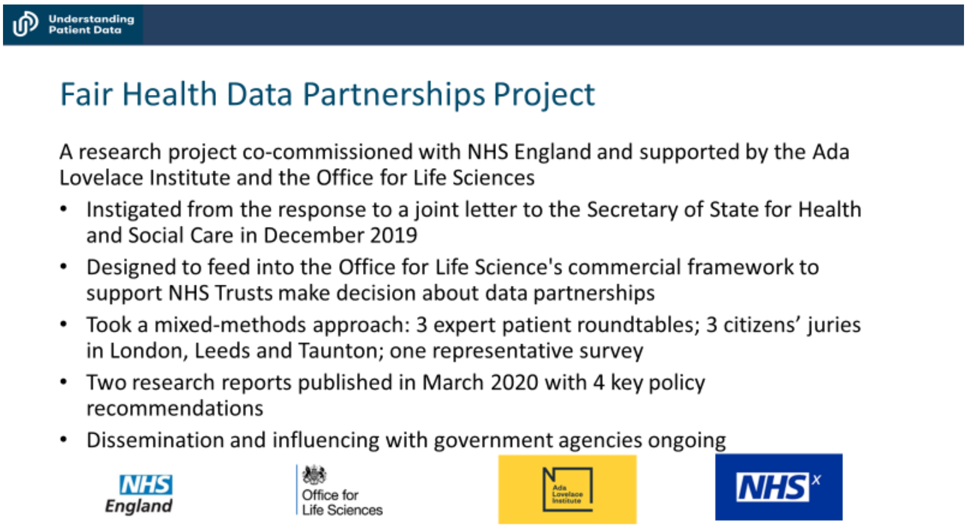
- 'Increased trust' - how might this work in light of Covid-19 crisis? Could you talk us through that?
  - Suggest we wait until the Covid-19 section of the agenda.
  - Talk through another example then.
  - Don't want to start from assumption that if you tell people true stuff they will trust you more, deficit approach that people just need educating is definitely not approach we want to take. UPD animations for example - a series designed to introduce the idea of data to people, aim to introduce the topic in a way that didn't just lead to a spike in anxiety. The animations were a way of trying to introduce the topic in a way that was accessible, not too technical, not couched in jargon and lots of layers of complexity. A way of introducing the notion of data in a way the was meaningful, accessible and resonated with people's own experiences, not abstract and out-there but about connecting the use of that information to something resonant with people, for example in the care of someone with a particular health condition. The story of data being used to inform other people's care, telling the story as a way of starting that discussion. Project with Comuzi is along similar lines.

ACTION: these background slides were in the pack that everyone received, any further questions please contact Natalie.

4. Current projects (Natalie)

- A flavour of the sorts of things we do and way we work, selected a couple of projects to give you a little bit of detail on. How we work firstly in the influencing and advising space, and secondly in the objective information and comms space.

Fair Partnerships (Tom)



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Fair Health Data Partnerships Project

A research project co-commissioned with NHS England and supported by the Ada Lovelace Institute and the Office for Life Sciences

- Instigated from the response to a joint letter to the Secretary of State for Health and Social Care in December 2019
- Designed to feed into the Office for Life Science's commercial framework to support NHS Trusts make decision about data partnerships
- Took a mixed-methods approach: 3 expert patient roundtables; 3 citizens' juries in London, Leeds and Taunton; one representative survey
- Two research reports published in March 2020 with 4 key policy recommendations
- Dissemination and influencing with government agencies ongoing

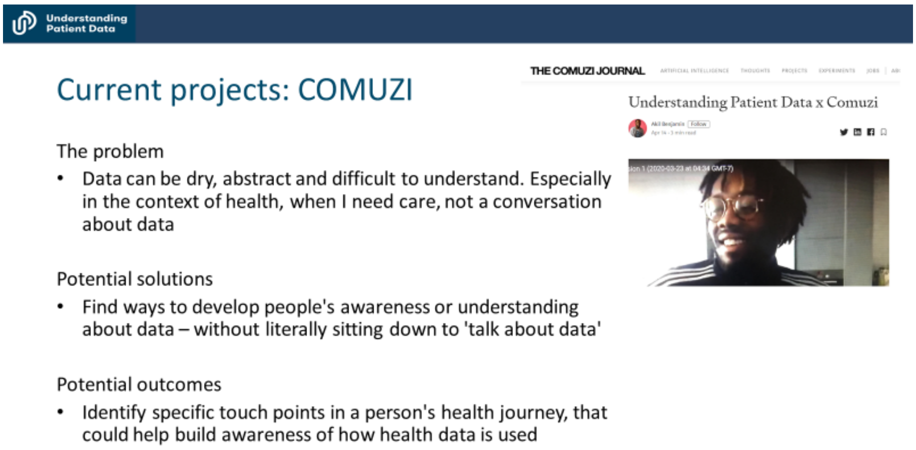
ACTION: UPD to circulate link to the Fair Partnerships report.

- The language around Trusts is interesting. Why Trusts and not NHS organisation/systems?
  - Language came from particular concerns about Trusts not being able to broker these partnerships in a way that was consistent, coherent etc. Think you're right it absolutely applies more widely to NHS organisations and systems, but the framework the OLS were trying to develop was very much focused at a Trust level, were led by them in that regard.

- Can you give any examples of the impacts?
  - Slightly early days to some extent, launched two months ago. One area we're hoping will be good impact is in the health data research innovation hubs. Just before launch there was meeting of innovation hub leads at the AMS discussing how to set up their commercial partnerships, trying to figure out what conditions were needed for those sorts of partnerships and we fed the early findings of the report into their thinking. Hoping as those partnerships and frameworks get set up we'll see whether and how much of an influence we've had on how they're shaped, but it's a little early to say we've had definitive impact.

- Was there representation from minority groups on the roundtables and juries?
  - Tried to cover a wide range of representation in the sampling. On roundtables, given the groups we had access do, don't think they were especially diverse, conscious of something we want to address in future research. The roundtables weren't necessarily hugely diverse, juries were far more representative.

<u>How to talk about data without talking about data</u> (Grace)



Current projects: COMUZI

The problem

- Data can be dry, abstract and difficult to understand. Especially in the context of health, when I need care, not a conversation about data

Potential solutions

- Find ways to develop people's awareness or understanding about data – without literally sitting down to 'talk about data'

Potential outcomes

- Identify specific touch points in a person's health journey, that could help build awareness of how health data is used

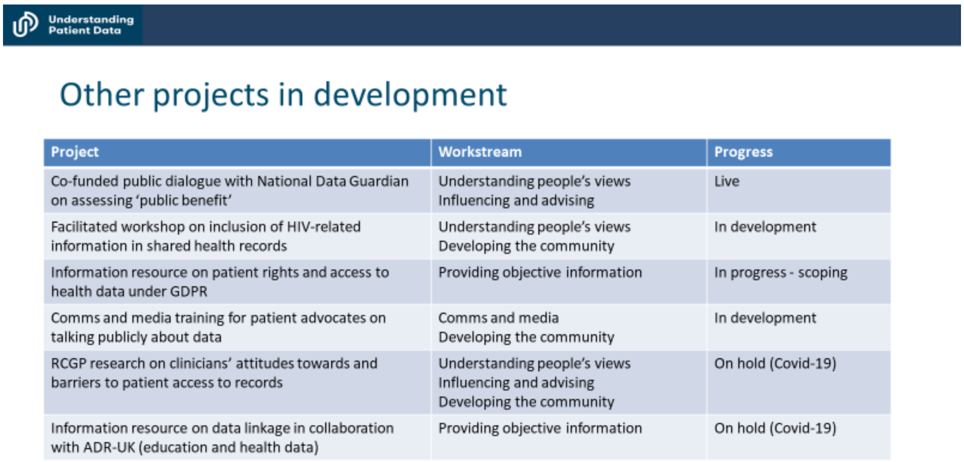
- Comuzi Lab have been doing weeknotes on this project, we could share link if you're interested in how this project has gone and what their thought processes have been as they go through this, it's quite an interesting insight. Been quite a journey for them realising the nuances, some of the technical difficulties of talking about this and in practice figuring out where and how it's possible to engage on these questions around data in way that's bit more nuanced and sophisticated than just saying 'well there needs to be a conversation'. Really excited about this project as a potential route to further thinking down the line.
    - Interested in point Grace made about when people are told 'the result is normal', how can they understand that? How those normal ranges are applied. How race influences results. Quite clear to clinicians that some results (for example kidney function) vary tremendously according to race, but I was oblivious for example spirometry results (on respiratory function) vary tremendously with race. Think in a way if you start to inform people that 'this is normal, but it might not apply to you because it varies a lot with race (and that's something we don't understand)' that can open up a door, that might open up a can of worms. Is that a good thing for that patient or does it create more uncertainty? Might be at a tangent to what you were thinking of, but it can cause difficulties and from doctor's POV how maternalistic do you want to be about it and make that decision for the patient? Or how much do you say 'in your particular case it's a bit uncertain if that is normal actually', so it raises more questions than answers often, and that's one small example.
    - Really interesting point, thank you, will take that away and think about it more. Sometimes increasing visibility of what's happening behind everything or the data used to make those decisions will open up more questions. Think that's inevitable and potentially could be a good thing.
    - Really good point, thank you for raising it. Is that a touchpoint at which a further conversation or possibility of learning something about how your health data is used and managed could be opened up rather than idea of telling people about data by leaving a leaflet in a waiting room, it's more tied to your own care journey. Hoping through this process we might be able to identify some of those challenges.

- Real opportunity to utilise those touchpoints people have through receiving care. When looking at the health journey in holistic way that's when you see there're so many places where the interaction isn't necessarily around the specific health condition or treatment, but people are seeing often care workers very frequently and building strong relationships with them, so they're having the touchpoints there. Issue of workforce possibly isn't educated enough to have those conversations, but real opportunity to build that within the workforce across social care because they do have opportunity to interact with individuals on really frequent basis.

  - Really good point and we're potentially looking at another project at some point that looks more at the workforce and capacity. One of the things we're trying to tease out or explore is how you develop that understanding without necessarily relying on workers to sit down and have that conversation about data. Almost about developing a general understanding of how the system works.
  - Really strong analogy within nursing care around brief interventions, take for instance smoking cessation.
  - Thank you, we'll take that into our follow up conversations with Comuzi. Really hopeful there'll be some tangible things to develop off the back of this.

ACTION: share link to Comuzi Lab's weeknotes on the project.

Project ideas in development (Natalie)



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Other projects in development

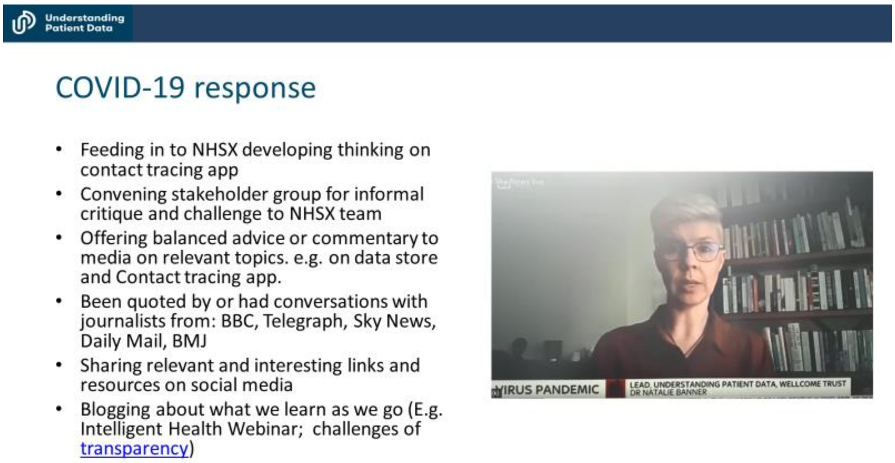
Project	Workstream	Progress
Co-funded public dialogue with National Data Guardian on assessing 'public benefit'	Understanding people's views Influencing and advising	Live
Facilitated workshop on inclusion of HIV-related information in shared health records	Understanding people's views Developing the community	In development
Information resource on patient rights and access to health data under GDPR	Providing objective information	In progress - scoping
Comms and media training for patient advocates on talking publicly about data	Comms and media Developing the community	In development
RCGP research on clinicians' attitudes towards and barriers to patient access to records	Understanding people's views Influencing and advising Developing the community	On hold (Covid-19)
Information resource on data linkage in collaboration with ADR-UK (education and health data)	Providing objective information	On hold (Covid-19)

- If members could think about this in context of the further discussion we're going to have that would be really helpful.

- Important not just to explain 'rights' to access, but why anyone would do this - how would it help with your care? So it needs to be really clear on practical benefits, I think. So worth exploring what people think is an actual benefit.
  - Fully agree, needs to be situated in what people actually need and would find useful in their own lives.

Strategy and planning

5. Response to Covid-19 **(Natalie and Grace)**



COVID-19 response

- Feeding in to NHSX developing thinking on contact tracing app
- Convening stakeholder group for informal critique and challenge to NHSX team
- Offering balanced advice or commentary to media on relevant topics. e.g. on data store and Contact tracing app.
- Been quoted by or had conversations with journalists from: BBC, Telegraph, Sky News, Daily Mail, BMJ
- Sharing relevant and interesting links and resources on social media
- Blogging about what we learn as we go (E.g. Intelligent Health Webinar; challenges of transparency)

- Suddenly data is a thing people care about. Certainly the kinds of topic areas we focus on, especially around trust and trustworthy governance, transparency etc have become so so visible and so clear in the public mind.
- What we've done to-date has been largely behind the scenes. At the early stage of the developing of the contact tracing app in particular NHSX got in touch to seek our views on the key questions and concerns they should be addressing and thinking about. We pulled together a group we thought would be able to provide some interesting insights, raise concerns constructively and really push some of the questions to NHSX as they were developing a range of data initiatives. One of first things we did was convene a stakeholder group, have blogged about the challenges of doing that, in spirit of trying to be open about some of these difficulties. This has been one of the main things UPD's been doing - feeding in to the NHSX team as they've been developing Q&As, as they've been trying to develop the contact tracing app in a way that is conducive to trust.

- Media - quite a lot of media requests, trying to tread a fine line offering balanced advice or commentary on relevant topics, through that we've been quoted and had conversations with journalists.
- Social media - shared interesting relevant links and resources, including from our networking community not just promoting ourselves and the things we're doing. The content we're sharing is getting high engagement so we're hitting the right note for our audiences.
- Blogs - tried to write about what we're learning as we go including Natalie's blog post on transparency and tried to be open about the role we've played there, Tom's written about a webinar Natalie took part in and some of the learnings from that.
- Learnings:
  1) The landscape we're operating and communicating in has drastically changed. Big question for me at the moment is how do we adapt in this new environment?
  2) Within our ToC the reason we want to work with media is to promote more balanced reporting about data, not being afraid to speak out when we need to. How we do that has become clearer so whether it's on the record commentary or off the record chats. Killing an inaccurate or scary story about data might be more of a win for us than getting our name in a big publication, we're not necessarily doing it as PR for UPD.
  3) There're journalists working in the space who understand the value of balanced and realistic commentary in this area and those are relationships we need to curate going forward.

Questions sent in by one of the funders who weren't represented at the meeting:

1) There will be a lot of interest around access to Covid-19 data and there is evidence of "honey potting" by researchers to get hands on data being collected by NHS (and NHS Nightingales and

other UK equivalents) - we need to be sure there remains consent to use data for that purpose despite the public health emergency and pressure from some researchers to use the Health and Social Care Act provisions to "short cut" access/consent. HRA has issued revised guidance, as I am sure you are aware, on consent during this emergency to handle the collection of data/materials from patients who are unable to provide it at the time of collection: https://www.hra.nhs.uk/covid-19-research/guidance-using-patient-data/

2) Good window of opportunity at the moment to highlight the benefit of using data to support research, whether this be clinical data or increasingly lifestyle data and how can we seek to maximise this, without being seen to be being overly opportunistic?
3) HDR-UK and others have been working on data driven studies, what is UPD's relationship with this work?

- Especially in regard to contact tracing stuff huge number of questions around this. A lot of that is not our role to play in necessarily, not our expertise and we're not the ones who should be promoting the questions there. The way we've positioned ourselves so far, our role is what are the questions people are going to have, how do you address those questions and how to be on the front foot on what those questions are going to be, before you try to roll this stuff out. We're trying to remain reasonably agnostic on the tech itself. Would really like to know whether you think this is the right position? Whether we should be trying to proactively do more? Whether we should retreat from this? What should our role be in this space given it's crowded, it's noisy, there's a lot of people talking about an awful lot of things. Where does UPD sit and where does it belong in these discussions about data in relation to the Covid-19 response?

- Contact tracing app as example of wider point useful for us to discuss and unpack, I haven't really got the answers. Question has come to me on what do we recognise as data? And what kind of data is the system prepared to work with? When it was decided there was a category of 'the vulnerable' the only data that was used for that was data the NHS holds on file, it was acute data later complemented with primary care data, we all know that data is rubbish with loads of errors in it, loads of omissions and it doesn't capture people's lives. We were trying to convince the system there's a lot of vulnerable people out there who aren't reflected in that data, all sorts of comorbidities aren't reflected in the data sets the NHS holds and still today the only way you get on this list is someone having ticked a box about you 20 years ago on a file. So it's a massive problem, in that blind spot the system has about what it sees as data, untold harm is being done to people who don't get the support they need, so it's not a philosophical question it's a really practical question.

- The symptoms, for example of Covid-19, NHS 111 still says you need to have a cough and fever and crowdsourced information seems to suggest that only covers 40% of people who have Covid-19, so again the system and its insistence on what it counts as data causes harm to people because some people don't think they've got Covid-19 and soldier on infecting lots of others. Now the tracing app is the latest iteration of that problem which will completely ignore that there're local public health teams expertly trained in providing support with tracing infectious disease and they understand local patients' circumstances, which only a local team can know. Really worried how we have framed the data problem for Covid-19 we are making things a whole lot worse for people already at the receiving end of inequality and discrimination.
  - Thanks really good point and really good challenge for us, raising it is vital.
  - As usual we agree. I'd come at it at a slightly different angle as what you're talking about leads to a different issue entirely around data we've got on people of minority backgrounds because we've got very patchy data on them very difficult now to say 'we know there's a link between BME people and Covid-19'. We know if that data had been more effectively

    collected in the past we wouldn't now be in that situation. This is something UPD could be doing, which is more about making the case for collection of those kinds of data with the community groups with whom it is relevant obviously, and having that conversation about why it is really important to have information about that and the conversations between health professionals and patients, this is the situation in which that data becomes gold dust in understanding what the causes of these things are and why it is that inequalities become exacerbated by these situations. It comes back to the comment above but putting a different lens on it. Really unfortunate to be in a situation where the data is rubbish, there's lots of different layers of rubbish I think. If the data was better and if we could build on the quality and the recording, next time we're in this situation we'll be able to make better decisions off that.
  - Agree, data about 'determinants' needs to be stepped up rapidly. But also about weaving together local intelligence, deep insight into communities and lives, and central data sets that are more transactional or clinical.

- Feels like a really good point. In a sense taking a step back and making case for better data leads to better decisions. Is there any, whether it's sector, area or issue, where we do have good data on this? That we could point to as an example of 'we have good data here so we're able to make these high-quality decisions' and use that to make a positive case for why it's important?
  - This is what I mean by 'layers of rubbish' because there's some data which is wrong and other data which is incomplete and incomplete data means you can't do things like predict prevalence or makes it difficult to forecast from. If you're using it for care purposes to identify individuals who might benefit from a certain intervention you can kind of work with it, it means not everyone will receive it but at least you're getting to a proportion of that population. So data on ethnicity in primary care records tends to be accurate but not necessarily complete, and it's the completeness problem that's the issue. Guess it would be focussing on the areas where we have good but incomplete data, and flip side of that is where we have data which is fairly complete but inaccurate, what can you do about that? Kind of depends on question you're answering and why you're using that data. Sure we can come up with plenty of examples of that but it's about getting under the surface of what we mean by good quality data because there's slightly different variations on it.
  - Problem we've got with inaccurate data which was highlighted very early on in March when NHS Digital wrote to people to be shielded and wrote to 10,000 patients and their families who had already died. Didn't get much coverage but really highlights the incompleteness and inaccuracy of many of the data sets that we're operating with. Shows the scale of some of the problems we've got.

- Problem about the centre and places - no one can see everything. If you're an MS patient or arthritis patient whether you are 'extremely vulnerable' or just 'vulnerable' depends on what tablets you take. Not plausible for people sitting in Skipton House making really important decisions to know all of that, but it's entirely plausible that those in charge of arthritis and MS care know it and the patient groups know it. Need to get much more comfortable that knowledge needs to be generated in patchwork way rather than central data set we hold that just about covers the question we need answering, which will then cause damage in these blind spots it generates.

- ONS data published today showing certain ethnic minority groups are 4x likely to die from Covid-19 compared to white population, reinforces data that's been creeping out over last 4-6 weeks. Contact tracing app a really good opportunity for us to understand what some minority groups feel about how their data is collected, the contact tracing app, and how that information's going to be used. For it to make a difference in terms of tracking and tracing we've got to engage better with communities at highest risk, so how do we increase trust and reduce risk aversion and build those relationships? Or enable the NHS and PHE to build those relationships with patient groups and communities?

- Just want to say there is a big distance between disadvantaged groups and 'the state'. Even organisations like the BRC have walked into that gap and couldn't close it. So there really isn't a shortcut to engaging through intermediaries. UPD could play a role in convening and strengthening some of those people.

- Focus on what is the role of UPD in this, given capacity we have? And what should we be handing over to others? Whether it's Ada Lovelace Institute or other players. What's the role of UPD over the next few weeks? Once IoW early trials results are published that will raise a huge number of questions. Techie stuff on the phones it works with etc etc. What's our role within that? We will at some point be asked if everybody should download this app. What should our response be? Should we be handing it over to others to answer or clearly 'cheerleading' for as much engagement with the contact tracing app?
    - The app is one major part of how people are suddenly very aware of data as an issue, but also if there're any other aspects of the Covid-19 response UPD is particularly well-placed to work on?

- Just wanted to be encouraging and positive about the work you've been doing in the past and work you've been doing more recently because that is what you do best. Style you've been working to in past shouldn't lose sight of that and continue in same vein. Along those kinds of lines what can you do that have been your strengths and continue to provide in way you already know are your best ways of working to provide calm, sensible, non-scary information. That's the way you work very well already and should continue to do that. The other way is the inward-facing, facing the system, behind the scenes work, you can provide challenge behind the scenes on areas that aren't going well and you're extremely capable of doing that but also looking at where the data's gone wrong, things we already know but we can use this whole experience to take step back and look and see where the key places are that data's gone wrong and the system can learn from and try to do better. May be something lots of others are doing as well so may not be something you do, but looking at it from UPD's unique perspective and in same way use all that and transfer that focusing on the app, for example. You're doing really positive stuff already, don't lose sight of that and keep going and keep using those methods.

- Are some really important stories about how data has been used to mobilise and change the course of the pandemic - when to step up or down on the Nightingale hospitals for example, and that use of data insight that most people wouldn't think is linked to them or their test results. Real opportunity to start taking those stories into that animation type idea (doesn't need to be animated) but is the kind of thing that would go back to idea of building trust but also allowing people to see what their role is in broader context and definitely think UPD has very strong opportunity there.

- Important opportunity to look at what other countries are doing in response to the introduction of apps, huge variety, having better idea of what have been the different challenges in different cultural contexts will be extremely important, and when thinking about minority groups and what the individual challenges might be.
    - Echo the point, have found UPD's line on this very good, this is a very tricky area. Think the work should continue with Covid-19 flavour. Would urge UPD not to be all encompassed by

  the contact tracing app as not the only area where public trust needs to be built or maintained at the moment. Maybe pulling together examples of where data has been really important as part of the response is a great way of doing that. Lots of work going on by different groups and is thinking about where the added value of UPD is, try and keep it a bit broader.
  - Thanks, agree, would like to start to move away from the app, plus the things we were trying to influence at the design stages have been incorporated into the app, our influence is now going to be much more limited. Really keen to explore other areas UPD can be useful on.

- If the question is 'should UPD condone or welcome the app?' my position would be - not as it stands - bypassing local public health teams and intelligence. And with no plans to actually take it to the communities who are suffering and dying the most.
  - UPD not taking position one way or the other, we're going to be asking the questions and saying the things that will be necessary to create trustworthy system for it but definitely not going to take political view one way or other on whether a good thing or not.

- Completely agree that less focus on the app and more focus on other data sources - the almost total absence of care home data has become really apparent of late which has caused some really slow action.
  - Yes, very good point, Health Foundation has also made good points about this.

- One of the key strategic issues we should have much greater focus on is chasm that exists between NHS data and social care data. If there had been less of that gap would that have allowed less of an intervention in care homes and the tragedy unfolding there? Whether now is right time to do it I don't know. Strategically using the tragedy we've seen asking if life would be different if better integration between health and social care data? What does that mean for those people in social care and their families and how do we ensure the trust the greater interaction and use of their data across health and social care? Strategically think that's hugely important so we can avoid the disaster we've seen and currently living through.

- Three ways UPD could conceptualise this:
  1) Definitely potential to shine light on lacking data on BME communities and social care data.
  2) Highlight potentially some of benefits and good case examples of data being used to make decisions - making connection between people's own information and decisions re Nightingale hospitals.
  3) Community views on data use and build those relationships with communities where we have clear-cut examples of inequalities or lack of data. Build more practical steps towards improving data quality and collection through building some more community relations and exploring people's views on data use using Covid-19 situation as starting point for discussions.

4) Longer term planning **(Natalie)**

Longer term strategy and direction

- Recruitment plan
  - Strategy and Engagement Manager recruited, start date Sept
  - Partnerships and Community Manager being recruited now (interviews underway)
  - These roles will significantly increase our capacity to build new relationships, develop projects and identify co-funding opportunities.
- Focus areas

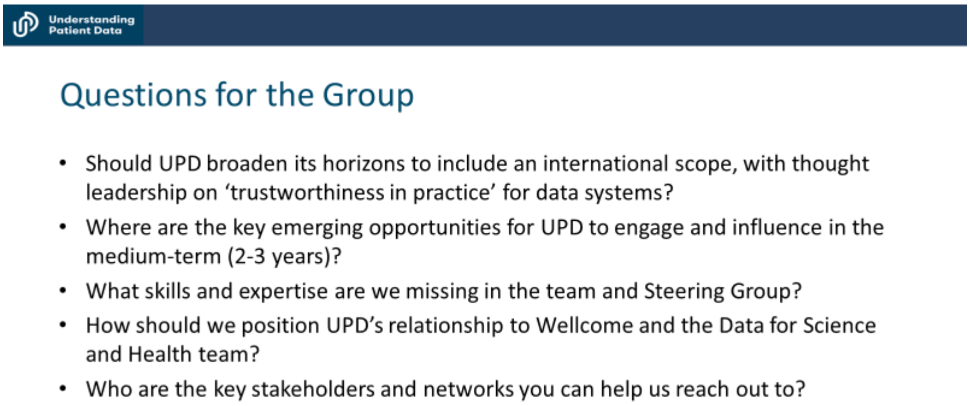
Relationships	Resources	Attitudes and engagement	Influence
Health professionals	Social care data	Diversity of views and voices	Centre of Expertise
Media	Data-driven tech	Emerging tech	Post covid-19 response
Devolved nations	Data linkage		HDR-UK Hubs

- All very contingent on things evolving and changing.

- Social care data very important, but I'd broaden it out to population health data, including wider determinants data sets held by councils.
  - Interesting, don't know enough about the data sets held in different places to be honest. May be initial piece of work for UPD to do with you to explore what's held where and where we could possibly be useful.
  - Good point, there're different levels of social care - commissioning level and local authority level and then the level held by individual care providers, in that instance not very accessible, vast majority of it still in archiving boxes in people's lofts.
  - Some councils done quite a bit of work on linking different data.
  - Interesting about the importance of whole population data for specific things whereas incomplete data ok for other uses.

  - Covid-19 has highlighted diversity and social care as key issues so worth building on for the attitudes and engagement work.

  - In addition to what's highlighted in the slide here there's a lot for us to think about in the future.



Questions for the Group

- Should UPD broaden its horizons to include an international scope, with thought leadership on 'trustworthiness in practice' for data systems?
- Where are the key emerging opportunities for UPD to engage and influence in the medium-term (2-3 years)?
- What skills and expertise are we missing in the team and Steering Group?
- How should we position UPD's relationship to Wellcome and the Data for Science and Health team?
- Who are the key stakeholders and networks you can help us reach out to?

- Let these questions percolate and mull over. We’re not going to be setting out anything in stone. Would be really grateful to continue these conversations offline. Where is UPD well-placed to do things and are we missing obvious things we should be doing? Don’t think we’ve done good enough job on D&I and conscious of building programme of work that is sensitive to that and takes those questions and concerns on board.

ACTION: SG members get back to Natalie. Further things to pick up on offline please get in touch with us.

5) Future meetings and AOB (Donna)

- SG members agreed they’re happy for the Group to be cc’d in future email communications.

- Scheduling future meetings - aim to meet in late September and then probably January 2021.

- SG members featured on UPD website - a photo with affiliation.

ACTION: Donna to set up doodle poll and send link round SG members to find date for September meeting.

ACTION: Donna remind SG members to confirm they’re happy with this and to provide a photo and affiliation information.