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Who benefits and how? Public expectations of public benefits from data-intensive health research

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Abstract

The digitization of society and academic research endeavours have led to an explosion of interest in the potential uses of population data in research. Alongside this, increasing attention is focussing on the conditions necessary for maintaining a social license for research practices. Previous research has pointed to the importance of demonstrating "public benefits" from research for maintaining public support, yet there has been very little consideration of what the term "public benefits" means or what public expectations of "public benefits" are. In order to address this pressing issue a series of deliberative workshops with members of the public were held across Scotland in May and June 2017. The workshops aimed to engage a cross-section of the Scottish population in in-depth discussions of the ways that the public – or publics – might benefit from data-intensive health research. The findings reported here discuss workshop participants' understandings and expectations of health research; who they considered to be "the public" that should benefit from health research and; in what ways they felt "the public" should benefit. Workshop participants' preference was clearly for the widest possible public benefit to be felt by all, but they also acknowledged the value in research aiming to primarily benefit vulnerable groups within society. A key focus of discussions was the extent to which workshop participants were confident that potential public benefits would be realised. A crucial consideration then is the extent to which mechanisms and political support are in place to realise and maximise the public benefits of data-intensive health research.

Keywords

Public benefits, data science, health informatics, public engagement

Background

The digitization of society and academic research endeavours have led to an explosion of interest in the potential uses of population data in research (McGrail et al., 2018); this is particularly true in relation to health research (e.g., Aitken et al., in press; Wellcome Trust, 2015). However, recent years have also brought a number of public controversies, particularly regarding proposed uses of health data (e.g., Carter et al., 2015; Garrety et al., 2014). Two high-profile examples from the UK are the failed introduction of the care.data scheme to link hospital and GP records (Ramesh, 2014) and Google Deep Minds' involvement in processing health data at an NHS Trust in London (Hodson, 2016). In the case of care.data, public opposition to the programme had significant impacts and resulted in the programme being put on hold. Such controversies have drawn attention to the importance of engaging with members of the public to ensure that data is used in ways which align with public values and interests to ensure that public concerns are adequately addressed. This is essential for developing and maintaining a

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social licence for current and future practices (Carter et al., 2015).

The growing interest in potential uses of population data, and the increasing recognition of the importance of ensuring a social licence for these uses, has resulted in considerable interest in understanding public attitudes and views on these topics (e.g., Aitken et al., 2016; Davidson et al., 2013; Wellcome Trust, 2016). Accordingly there is a fast-growing body of international literature reporting findings of studies examining public attitudes towards data and health-related data science practices (Aitken et al., 2016). A consistent theme to emerge through this literature is the importance of demonstrating "public benefits" from research using population data (e.g., Davidson et al., 2013). Much of the qualitative research undertaken has discussed perceived "trade-offs" between risks to individuals (e.g., loss of privacy) and broader public benefits of research. In a systematic review of literature on public attitudes towards data linkage for health research it was found that "assurances that research would bring about public benefits – or at least that it had the potential to bring about such benefits – were widely reported to be fundamental for ensuring public support or acceptance" (Aitken et al., 2016). While previous research has revealed different sets of expectations around "public benefits" when research is conducted by public sector or commercial organisations (Davidson et al., 2013), on the whole, this literature has not examined how members of the public conceptualise "public benefits" or what their expectations are of the ways in which research might bring "public benefits" (Scott et al., 2018).

"Public benefits" are emphasised in research and governance processes, providing justification for the use of health-related and other data generated in a range of ways and promises of beneficial outputs and outcomes. Many governance mechanisms which control access to population health data require demonstrable public benefit as an element of the approvals processes before permission is granted for researchers to use "Big Data" for health and social research. For example, projects in Scotland that require access to population health data have to apply to the Public Benefit and Privacy Panel (PBPP) and are required to demonstrate that "any impact on individual privacy is clearly outweighed by the public benefit resulting from the processing [of the data]" (PBPP, no date: 3). Yet, despite being of operational significance, the concept of "public benefit" remains under-theorised and little consideration is given to what this means in practice. As Scott et al. (2018) have observed "public benefits" are "variously glossed over as impacts that are 'in the public interest', 'for the greater good', or 'leading to the improvement of health, education or economic

and social well-being'" (Scott et al., 2018: 21). Given the importance of "public benefits" for public acceptability of data uses, and its central role in determining which researchers get access to data for what purposes, it is essential that a better understanding of what the term means is generated in a way that is grounded in public views. This paper aims to provide a first step in developing such an understanding. It draws on the results of three deliberative workshops with a broad range of publics, organised as part of a programme of public engagement research around data linkage and sharing for health research. The workshops focussed on the meanings and expectations publics held and formed regarding such research use and the paper maintains that such formulations should inform research policy and governance in health-related data science.

Deliberative methods and mini-publics

Deliberative forms of public engagement have been used to examine and address public interests in a wide range of policy areas including: health (Mitton et al., 2009); e-health (King et al., 2010); nanotechnology (Pidgeon and Rodgers-Hayden, 2007); natural resource management (Halseth and Booth, 2003); transport planning (Bickerstaff and Walker, 2001); waste management (Petts, 2005); and environmental policy (Owens et al., 2004). These approaches to public engagement are seen as means of increasing civic engagement and ensuring that plans or policies are relevant to affected publics/communities (Coleman and Gotze, 2010).

Deliberative public engagement methods represent fora for developing public-spirited reasoning to reach collective agreements (Parkinson, 2004: 379). In the ideal of public deliberation "no force except that of the better argument is exercised" (Habermas, 1975: 108). Deliberation should engage with both reasons and emotions to enable diverse forms of expression and argumentation and bring about mutual understanding (Escobar, 2011; Morrell, 2010). "For the individuals involved, this process requires an open mind, a spirit of reciprocity, and acceptance of the validity of others' arguments" (Niemeyer, 2011: 105).

A well-established approach to deliberative public engagement is that of "mini-publics". A mini-public is a deliberative forum bringing together a group of randomly selected members of the public in order to reflect the range of demographic and attitudinal characteristics from the broader population – e.g., age, gender, income, opinion (Roberts and Escobar, 2015). As such, it is intended that the mini-public represents a microcosm of "the public" (Roberts and Escobar, 2015). Engagements with a mini-public involve a mix

of information provision and deliberation (Roberts and Escobar, 2015). Deliberations typically take place in small groups and are facilitated by neutral facilitators. Through this process participants may revise or strengthen their initial views both in response to information and evidence presented as well as from exchanging ideas with other participants. As such it is important that the mini-public includes a range of perspectives and viewpoints.

Through a deliberative process mini-publics often aim to produce a statement, recommendation or report to inform policy-making processes regarding the issue under consideration. Such outputs set out positions reached through consideration of diverse perspectives and as such reflect civic-minded positions rather than private interests.

Methods

In order to engage mini publics in characterising public benefit, a series of three deliberative workshops with members of the public were held across Scotland in May and June 2017. The workshops engaged a cross-section of the Scottish population in in-depth discussions of the ways that the public – or publics – might benefit from data-intensive health research.

Three locations were chosen for these workshops to reflect different demographic characteristics. The first workshop was held in Perth, a small city in a largely rural region of central Scotland. The second workshop was held in Glasgow, Scotland's largest city. The third workshop was held in Aberdeen, a city located in the North East of Scotland. This geographic spread enabled the workshops to engage with and reflect the interests and perspectives of the Scottish public living in very different contexts and localities.

Following the mini-publics approach, workshop participants were recruited using quota sampling to reflect key demographic characteristics of the local populations in each location. Quotas were set on gender, age, professional background and level of trust in institutions (based on an attitudinal question in the sampling questionnaire). We aimed to have 20–25 participants in each workshop. In Perth there were 25 participants: 15 women and 10 men; in Glasgow 21 participants: 11 women and 10 men; and in Aberdeen 23 participants: 12 women and 11 men. In all groups people were aged between their early twenties and late seventies and included a mix of those unemployed, employed part time and in full-time employment. Participants were recruited in person on the street in each of the three cities. This method was chosen since it was considered more robust than recruiting from other pre-existing "panels", because participants are less self-selecting and so tend to be more representative

of the population and are less likely to be pre-conditioned by having previously taken part in research. Face-to-face recruitment also promotes participation compared to written recruitment (Tausch and Menold, 2016). Recruitment can be undertaken in the immediate run up to the events, so drop outs are less likely; and, participants have already met people involved in the study and participated in an initial on-street survey, so are more likely to agree to further, more intensive participation (Sixsmith et al., 2003). Potential participants were given a letter containing a brief description of what would be involved in the event; the date, timing and location; and a map to the venue and were contacted by phone two days before the event was due to take place in order to confirm their participation and to enable any drop outs to be replaced.

On the day of the event, participants were provided with further information about the study and the ways that data would be recorded and used and the potential outcomes of the research. Participants then completed a consent form. At the end of the workshop participants received £80 in cash as a thank you for their participation. This amount was chosen to reflect current best practice and a reasonable estimate of the necessary amount of money to ensure participation in a full day event taking account of the need to make the event accessible to everyone including those with childcare requirements or living outside of the city.

The workshops were day events beginning at 10 am and ending at 4 pm. The workshops were run in such a way as to ensure a relaxed and informal atmosphere to encourage open and fluid conversations. The day was structured around a mix of facilitated small group and plenary discussions, brief presentations and videos to stimulate discussions and deliberation. While information provision was important for stimulating discussions, presentations were kept brief and throughout the day the emphasis was on deliberation and active involvement of participants. Topic guides were developed for each of the group discussions but these were used flexibly to allow conversations to follow emerging topics of interest and to enable participants to shape the agenda of the workshops. Discussions were facilitated from a neutral perspective and participants were encouraged to speak openly and freely. The presentations were delivered by members of the research team who also facilitated the discussions. The research team consisted of social scientists interested in understanding social and ethical dimensions of data-intensive health research, these interests were explained at the outset of the workshop and it was made clear that the research team did not intend to persuade or convince participants of the merits or otherwise of proposed uses of population data but

rather were interested in understanding public views around these.

At the beginning of the workshops participants were asked to agree a set of ground rules for the day. Participants suggested potential ground rules which were then agreed by the whole group. Across each of the workshops the ground rules created consistently emphasised the importance of allowing everyone a chance to speak and respecting differences of opinion. It was stressed that we were not necessarily aiming to reach a consensus about the topics that would be discussed but rather we were interested in hearing the range of views people might hold about these.

Following this the day began with small group discussions on the topic of health research very broadly, in which participants discussed their understandings and expectations of health research. This was followed by a presentation introducing the topic of data-intensive health research and giving an overview of the ways that data is currently used in health research and the governance systems in place. Small group discussions then focussed on data-intensive health research. A second presentation set out the importance of "public benefits" as a driver for data-intensive health research. This was a brief presentation which described the importance given to "public benefits" for determining applications for data access and also previous research identifying "public benefits" as crucial for public acceptability of data use. The presentation noted the difficulty in clearly defining the concept of "public benefits" and led into facilitated small group discussions around what this term means and what people's expectations of public benefits would be.

A series of videos were then shown of data scientists discussing research projects which they had either recently completed or were planning to undertake. Videos were used instead of face-to-face presentations in part as a result of practical challenges associated with securing participation of data scientists at each of the three workshops and also because this virtual presence encouraged participants to be frank and honest in their responses. The three data scientists gave an overview of their research, why they considered it important and what the anticipated public benefits of the research would be. Following the videos, workshop participants discussed the extent to which they considered each to have public benefits.

In the final session of the workshops participants were asked to come up with statements to answer two key questions: (1) Who is the public that should benefit from data-intensive health research and; (2) In what way should they benefit? Participants were given no further direction on how they should answer these questions and were not provided with examples or options to choose from, but rather were encouraged

to reflect on the discussions over the course of the day. It was reiterated that we were not aiming to reach a consensus around these issues but rather wanted to capture and reflect everyone's views.

During the workshops all small group discussions were recorded and detailed notes were taken of the plenary discussions. Following the workshops the recordings of the discussions were typed up by the research team. A narrative account of each of the workshop sessions was developed through assimilating each of the researchers' notes from the events along with the transcripts from the recordings. Notes from each session were collated and key themes and topics were identified, as well as the identification of nuanced or divergent perspectives. In reporting the workshop discussions in the following sections of this paper, we draw on transcripts of the small group discussions (which allow verbatim quotes) and detailed notes of the plenary discussions (which do not allow verbatim quotes).

The following sections of this paper will set out the findings from the workshop discussions and key considerations which emerged as central for meeting public expectations concerning public benefits from data-intensive health research.

Findings

Expectations of health research

In the first small group discussion of the day, workshop participants were asked to describe their expectations of health research and what they understood the term "health research" to mean. Participants typically responded by describing health research as being aimed at improving health or health services, and/or leading to new treatments. Across each of the workshops it was evident that health research was expected to be aimed at a clear purpose of improving health outcomes or health services.

Workshop participants described a variety of types of health research, demonstrating awareness of diverse forms that such research can take. The examples given were offered spontaneously by workshop participants. While some participants described only research undertaken in clinical settings others gave varied examples including: surveys; research around lifestyles; research in laboratories; and audit of health services. These participants noted that health research can use a variety of sources of information including donated organs or tissue samples, genetic or clinical information as well as information from medical records or surveys. While some participants did not initially think of this diversity of health research, once mentioned by others these broad approaches and methods were acknowledged as comprising health research.

When asked who they would expect to be conducting health research, in many groups workshop participants initially discussed health research conducted by charities and it was clear that this was often the first type of research that came to mind. Participants often stated that this was due to having an awareness of this research as a result of fundraising campaigns, TV adverts or leaflets (for example from Cancer Research UK). However, a broader range of research organisations were also discussed and workshop participants listed many potential researchers including those within the NHS, universities, charities or private companies. In most groups the involvement of private companies in health research was a contentious subject. Private companies were described as having a different set of objectives from academic or public sector organisations, and in some discussions commercial interests were conceptualised as being in opposition to public benefits. However, participants also noted the blurriness of lines between sectors and acknowledged that university research can also lead to commercial outputs. For example, the following discussion reflected one group's shifting position as they considered the potential involvement of private companies in health research:

> F2: the right people would be people in the NHS, in the medical profession, because they're not in it for the money. In my point of view, I don't want people to profit from it, from the data
> M1: no
> M3: but if they could cure someone
> F2: but if they could cure someone and then charge them massively
> M1: no financial gain
> F2: I don't want financial gain, yeah
> MA: what if a university research group collaborated with a pharmaceutical company?
> F2: Sometimes I would imagine that has to happen
> M3: for new drugs
> MA: in that situation there may be some profit that goes with it
> F1: yeah, there has to be some profit
> M3: without profit there won't be any progress
> F1: you need the companies involved – it's a necessary evil
> F2: so long as there is good with it
> F1: more good than bad
> F2: it's about the balance
> M3: It's never going to be 100 per cent
> F2: some people are only going to be in it for the money
> M1: that's just the way it is. (Perth, Group 1)

Similarly when asked about their expectations of university researchers, participants typically acknowledged that academic research is not necessarily independent of any financial interests:

> M2: It would depend where the university was getting the funding from. There's a chance the university could be getting their funding from a pharmaceutical company.
> F2: Again, that's trust, isn't it? You're trusting those researchers to be ethical with their findings, because you do get the picture that the money issue is always breathing down their neck
> M3: I would think, or I would hope, that universities and that were more neutral, that they don't have anything to win or lose out of it. They're looking at the bigger picture. (Glasgow, Group 3)

In discussing the different types of researchers who may be involved in health research participants acknowledged that there can be a role for commercial organisations but concerns were raised about funding and the interests that go along with that. Funding of research was an area of interest in discussions across the workshops. It was acknowledged that research could be supported by either public or private funding. Some participants expressed mistrust of private research funders, for example a large number of participants contended that private companies would suppress research results if it enabled them to increase their profits. In particular, a number of participants stated that they believed that a "cure for cancer" may have already been found but that pharmaceutical companies are holding on to it to make the most money:

> F1: People always say there's no cure for the common cold – so what chance do we have of finding cures for cancer if there's no research into it
> M1: some people say they have got a cure for cancer but they're holding it back to sell to the highest bidder
> F1: Conspiracy theories
> M1: There's truth in it
> F2: Everybody thinks that, the higher authorities are all in it for what they can make out of it
> M2: are they withholding a cure?
> F2: unfortunately not everyone has a heart, they don't care enough. (Perth, Group 1)

> M2: I believe that there is research that has been done that has proven to actually help benefit certain illness and whatnot but nothing will be done about it because the pharmaceutical companies are making far too much money from selling other products to help combat these things.
> M4: I think also the problem is that you have huge companies that are making billions and billions of pounds and that obviously promotes distrust because they're making

so much money. But at the same time, you need that level of funding to be able to produce the advances. An example would be the Ebola crisis last year, they did ten years' worth of research in nine months because the WHO just piled billions into it, and they need that funding level, and they got a cure out of it. But then at the same time, because they're so profitable, it's not necessarily ethical. (Glasgow, Group 3)

There was concern that research conducted or funded by private companies would be directed at maximising profits rather than maximising public benefits. For example, one participant in Aberdeen stated:

The money in research is directed at money-making things. Like, weight loss gets a lot of money put into it, more than malaria, which affects people a lot more than being overweight, which is generally, or can be, a cosmetic thing. It's not down to illness. Not always – sometimes it is – but, malaria, if they found a cure for that, billions of people, that would be their life improved. So...where the money is they'll research. (F1, Aberdeen, Group 3)

Furthermore, there was also discussion of the potential for governments to be involved in suppressing discoveries of new cures if they are too expensive or not aligned with government priorities:

M4: I often wonder if they want to find a cure for it. All the pharmaceutical companies they're making millions out of it. If they find a cure for it, what are they going to do now?
M1: You could say the same about the government – does the government really want to find cures? Because, at the end of the day, the longer people live, the more it costs to give them everything: pensions, health service, and what have you. So, do they want us to be living to 100 years old? Probably not.
F2: You lot are a load of doom and gloom!
F3: Five minutes in and we're into the conspiracy theories! [laughter]
M4: They've been researching for maybe twenty years, you'd think somebody would've found a breakthrough
M2: With all the money that's been ploughed into it.
M4: Do they really want to find a cure for it?
F3: Why would they waste money investing in trying to find it in the first place?
M1: Cos they've got to look like they're trying to find it
F3: No, they are trying to...I've never even thought that they weren't trying to. They're doing all the research and everything, they're trying to find cures [...]
M2: They make money by giving drugs. The pharmacies make money by getting the prescriptions from the

NHS and everything. Everybody makes money from it so, why would they? They don't care about the little person. (Aberdeen, Group 3)

This related to wider discussions around the ways in which benefits of health research are realised and a widely held perception that currently the benefits are not realised equitably across society and that different groups or people in different locations across the UK experience health services differently as well as experiencing different health outcomes.

Throughout these discussions a recurring theme was that the potential benefits of health research were not always or consistently realised. A range of factors were noted as limiting the realisation of public benefits from health research, these included commercial interests, political priorities and limited public funding.

Who is the public that should benefit from data-intensive health research?

When posed the question "who is the public?", workshop participants typically treated this as a straightforward and obvious question. Across all of the workshops participants almost always initially responded by stating that: "the public is everyone". However, these responses quickly became more nuanced and complex when discussions moved to think about what this meant in practice and, in particular about the ways in which "the public" could benefit from data-intensive health research. Two key considerations emerged as important in conceptualising "the public". These were scale and need.

Firstly, there were discussions around scale with workshop participants expressing a range of views on whether the public should be conceptualised as everyone globally, nationally or locally.

M3: It's us – all of us. Everyone in the world.
F4: It's society. As in, what stands below the government. The individual who goes to work every day, doesn't put a suit on, doesn't sit and make a decision on what our lives are going to be doing. (Perth, Group 3)

F2: Presumably that's just us, Joe Bloggs.
F3: Everyone
F2: We're the public, are we not?
EC: Are we? [...] When you think about "the public", who's in your mind?
F2: Myself
M1: Working class people.
F5: The people that the research affects.
M2: Or benefits.
F3: I just think everyone.

EC: In Scotland?
F3: Just everyone.
EC: In the world?
F1: In the whole wide world.
F2: It depends what the research is about. If it's merely based on Scotland, it would be the people of Scotland, I would think. People of voting age. (Perth, Group 2)

There was generally a preference that "the public" should be considered as inclusively as possible, meaning that there was a preference for research to benefit the widest possible public (i.e., benefit the maximum number of people). One workshop participant even stated that we should think of the public as "everyone in the universe" – this was stated only partially as a joke and demonstrated a strong preference to be as inclusive as possible when thinking about "the public".

However, the second key consideration – need – led to different sets of preferences. Workshop participants acknowledged that the findings and outcomes of research can have greater or lesser potential impact for different groups within the public. For example, it was acknowledged that health research could – and in many instances should – have the greatest benefits for people with major health issues or groups affected by particular conditions related to the subject of the research. This led to recognition of the value of health research being targeted at vulnerable groups who would potentially benefit the most. In this sense public benefits were conceptualised as being benefits to particular smaller groups within the public rather than benefits to the wider public as a whole. However, it was also noted that while the immediate benefits of research might be targeted at those considered to be in greatest need, in the long-term this would be of benefit to everyone in society, suggesting that the two positions were far from incompatible.

M1: I think it's everybody because even if you're not aware of it or affected by it, that doesn't mean it's not of relevance to you.
F3: Just because you're not associated with it at the time it doesn't mean it won't impact you later on in your life. (Perth, Group 3)

In what ways should members of the public benefit?

When asked in what ways the public should benefit from data-intensive health research, a very broad set of responses was given, demonstrating wide-ranging conceptualisations of "public benefits". Responses indicated that workshop participants considered that public benefits should be as broad as possible. One

participant stated that the public should benefit "in every way they are entitled to" and another stated that the public should benefit in "the most beneficial way possible". These responses highlight workshop participants' recognition of the wide range of public benefits that could be possible. Many participants were clearly avoiding giving answers which might limit the ways that benefits were pursued and demonstrated a clear preference that benefits should be maximised across society in whatever form they take.

Given that workshop participants had previously described the purpose of health research as being primarily about leading to improvements in health and/or health services, it is unsurprising that many responses related to this theme. Many participants suggested that finding cures for diseases and making new drugs available was a clear way in which members of the public should benefit. In particular, cancer, dementia and mental health were often flagged as pressing conditions about which more research was needed. More broadly than just cures and increased medicalization, considerable time in the discussions focused upon improving lives; with a focus on health improvement, better quality of life and enhanced lifestyle, with people living longer and healthier lives and lives that are less stressful. Linked to better quality of life and outcomes, participants suggested that future generations should be thought about so they do not face similar health and lifestyle burdens, with better understanding and implementation of preventative measures. Participants also stated that benefits of research should be measurable, through better quality care and services. Improved allocation of resources was also a way in which participants thought the public could benefit.

Public benefits were also conceptualised in less direct ways. For example, participants considered that there can be "knock-on effects" of small numbers of people benefiting from health research. Improving health and/or quality of life of vulnerable groups was expected to lead to wider benefits for society. Therefore, participants thought that there should be proactiveness to address particular needs of vulnerable communities to ensure that communities, and society as a whole, can lead better quality lives. This was also described as requiring empowerment of individuals and communities.

The public were also described as benefitting from research through the creation and dissemination of new knowledge. Workshop participants suggested that increasing scientific knowledge is in and of itself a benefit and that members of the public could benefit from greater engagement with the scientific community. This led to discussions of the need for science to do more to publicise research results, and, in particular, to engage with the public. However, it was frequently stressed that it is not sufficient for research to create new

knowledge or understanding, rather it is considered essential that policy makers, governments and/or the health service act on research findings in order to realise the potential public benefits.

> M5: The point is, it's about what the outcome of the research is, because if it says people coming from poorer backgrounds or deprived areas [are more at risk of health conditions]...is anyone actually going to spend any money to change it? Or is just a case of–
> F2: "This is the research, we've done it, that's it".
> M4: The findings can be there but nothing's actually done. (Aberdeen, Group 3)

These discussions around the ways in which the public might benefit from data-intensive health research revealed openness to the possible forms public benefits could take and an unwillingness to set limits or constraints on what public benefits might be. However, there was considerably more interest in the likelihood of the benefits being realised. Reflecting earlier discussions around perceived barriers to realising benefits of health research, participants across all workshops were less concerned with what the benefits would be compared with assurances that any benefits would be realised. While noting that knowledge itself brought benefits, the participants wanted reassurance that further public benefits could ensue through applying knowledge to improve lives.

Responses to three research projects

The preceding sections have focussed on workshop participants' discussions of public benefits from data-intensive health research at a general level. The workshops moved on to encourage participants to consider the ways in which particular research projects might lead to public benefits.

Workshop participants were shown videos of three data scientists who presented their research and the ways in which they considered it would lead to public benefits. The three research projects presented were chosen to reflect very different subject matter. Project A related to admissions to care homes; Project B related to impacts of air pollution on babies; and Project C related to evaluating impacts of one particular illegal drug interception policy.

As a catalyst for discussions, after viewing the videos workshop participants were asked to vote on which project they considered to have the greatest potential public benefits. There was widespread agreement that each of the three research projects had – at least potential – public benefits. This reflects the finding discussed above that participants recognised the

diverse and varied forms that public benefits might take, as well as the diverse forms that research itself might take. However, there were some clear patterns regarding which projects were regarded most favourably. Voting preferences generally reflected the closeness or relevance of research subject matter to individuals' lives. For example, older participants tended to vote for Project A which related to admission to care homes. At all three of the workshops Project C (which related to interception of illegal drugs) consistently received the fewest votes yet was also always the project which generated the greatest discussion. The key discussion points which emerged unprompted in group deliberations related to: who would benefit from the project; which project would have the greatest impact; and to what extent workshop participants expected that the potential benefits would be realised.

In discussing their reasons for voting for particular projects, participants considered which project would be likely to have the greatest impact. This was discussed both in terms of which projects would benefit the most people and which would have the biggest benefit for those in greatest need – the two key ways in which these "mini publics" characterised public benefit. Project A focussing on care homes was seen to be very relevant in the context of an aging population with care homes expected to be of increasing relevance in years to come. Additionally this project was considered important since it related to benefitting vulnerable people.

> M2: [Care] is putting a huge drain on resources at the moment. We're living in an older society.
> F3: People are living a lot longer. These are people who have paid into the pot for so many years and then they're just getting left... need to put more resources into it. (Perth, Group 3)

Similarly, Project B which focussed on air pollution was considered to potentially benefit the whole of society as well as the environment and non-human life. Since this project was focussing on impacts on babies, many workshop participants regarded it as potentially having the biggest public benefits as it was starting "right at the beginning of life". This was a point that was made in all workshops.

> F3: For me, if [Project B] was just air pollution, without the pregnancy component, I probably would have gone for care homes [Project A]. But because his research is mixed with the pregnancy, as a mum, I want to give my children the best start in life.
> F2: Anything to do with pregnancy is important – it's the start in life. (Aberdeen, Group 3)

Participants noted that having a poor start in life can affect the whole of the rest of life.

> F3: I voted [for Project B], we all know the risks about smoking in pregnancy and now its became unacceptable that women should be smoking because the harm it does to the baby and now we know that pollution is likely to be just as bad, no one seems to be bothered about it and we know the effects it can have on babies, more pollution smaller babies then it would force them to do something about it. That would prevent poorer health in childhood and all the things that go along with being premature and all the things that go along with it.
>
> F4: I voted for [Project B] too and I did that because it is the start of life, a baby being born, because it affects your whole life. I actually liked all of them. I worked in a dementia unit and I know how it affects everyone, the whole family, but the baby one was trying to do something at the start of life. (Perth, Group 3)

Conversely, workshop participants were more sceptical of the extent to which Project C (focussing on drugs enforcement) would have a big impact. Some participants described this as "fighting a losing battle" and said that "drugs are going to be used no matter what". Across the workshops drug use was recognised to be an area of major, but intractable, concern with significant implications for society. Drugs were described as a big problem to be tackled, but also a complex social issue. Much of the discussion about Project C related to the extent to which this research would actually have an impact in addressing problems of drug use: it was described as reaching "just the tip of the iceberg". This meant that people were less inclined to vote for this project in comparison to the others, although as the dialogue below illustrates, people had different kinds of reservations.

> M1: I didn't vote for it, not because I didn't think there would be any benefit but we have been talking about health data and I just found it much harder to directly correlate, obviously we are talking about drugs and not necessarily everyone taking these drugs will be taking them to a degree which significantly affect their health, you might get the people who take them now and again. I just thought it would be very difficult to state a clear public benefit . . .
>
> F1: with that one it's hard to see how you could do something directly with the findings, I mean maybe further down the line, but straight away, it would be difficult to get a clear public benefit from.
>
> M5: I can see the clear public benefit from that but it looks like a hard fight, it's just gonna take a long time, I just felt the other one, for me, was more beneficial. (Perth, Group 3)

While the subject matter and aims of the project were widely considered to be of high importance, workshop participants were not confident that this project would be able to make a significant difference. This highlights the importance of demonstrating mechanisms being in place to enable impact.

Drug use is a more controversial subject compared with care homes or air pollution so it is not surprising that Project C generated the most discussion. Given that workshop participants typically acknowledged that their preferences for particular projects were influenced by the extent to which they were perceived as having relevance to their own lives, as well as society more generally, the potential stigma of drug use and what they saw as its social complexity, might have had some influence in shaping responses. It is noteworthy that one workshop participant who spoke about the ways in which his own life and that of his friends and family had been affected by drug addiction made an emotional and passionate plea to fellow participants to give Project C greater consideration.

The deliberations regarding the three projects illustrate the findings reported in preceding sections of this paper. The voting exercise was intended as catalyst for discussions rather than a priority setting exercise and workshop participants typically stressed that they appreciated the potential benefits of all three projects. Not voting for a project did not mean that a participant did not believe it could bring public benefits. As such participants recognised and acknowledged the very different types of public benefits which could come from the three projects. However, the discussions consistently focussed on key considerations (which were not prompted by the facilitators): which project would be likely to have the biggest impact, and whether participants had confidence that potential public benefits would be realised. These emerged as key themes throughout discussions at all three of the workshops.

Discussion

Each of the three workshops resulted in open and wide-ranging discussions leading to nuanced and complex positions regarding the ways that data-intensive health research might bring public benefits. The workshop discussions demonstrated that "public benefits" were conceptualised in a number of different ways and participants had varied expectations of what this implied for actual research practice. Nonetheless, there was a clear consensus that public benefits should be to individuals, specific groups and to society more widely. It is interesting to note that no one spoke of societal benefits in terms of economic benefit, although this is often portrayed as a form of public or societal benefit by governments and funding agencies. For example,

The European Commission Strategy Centre recently called data "the lifeblood of the global economy" (European Commission, 2017), whereas benefits to the economy through new data-driven industries were never mentioned by workshop participants. Where economic dimensions were raised, these related to potential impacts on individuals or groups within society. For example, when discussing care homes and the pressures of an aging population, workshop participants were typically concerned with the economic impact on individuals through a pressured care system and how that affected health and wellbeing. In considering how best to generate and sustain a social license for health-related data science, funders and researchers may need to more clearly articulate how economic benefits would result in wider social impact.

Workshop participants had a broad and inclusive approach to conceptualising both the public and public benefit. They did not perceive a conflict between desiring wide benefit for society as a whole and promoting the needs of particular groups. Indeed, they recognised the role of indirect public benefits – those accruing to society when the pressing needs of some are met. It was generally acknowledged that targeting benefits for those in need was appropriate and necessary. This resonates with a recent study which examined public sector professionals' expectations of public benefits and found that when evaluating the relative value of different public benefits some focussed on the number of people benefitting, others focussed on the level of need of those benefitting and, for others it was the potential for long-term impacts (Scott et al., 2018).

Workshop participants were unwilling to narrowly define or constrain public benefits and preferred to keep this definition open recognising the very many forms public benefits could take. They were more concerned with the likelihood that benefits would be realised – that research would make a difference – a theme consistent across all workshops. The discussions highlighted the need for action in response to research findings, suggesting that ensuring impact itself was an important component of achieving public benefit. They recognised the wider processes involved in this, beyond the research community itself to include policy makers and practice communities. Across all the workshops there was widespread agreement that, currently, the benefits of health research are impeded by commercial or political interests. There was considerable scepticism of the extent to which necessary mechanisms and political support are in place to enable research to lead to public benefits. This indicates that workshop participants recognised that the pathways between research and impact are not straightforward or inevitable and reflects widespread awareness of the importance of

maintaining relationships between research and policy – and more broadly science and society. There was consensus that there needs to be commitment and willingness by all stakeholders involved in the research process to implement findings and maximise public benefits. Workshop participants were much less concerned with what form public benefits would take, compared with seeking assurances that potential benefits would be realised. Addressing this area of concern may be vital for securing public support and establishing a social license for future health-related data science and demands transparency regarding how impact can be achieved.

Study limitations

The research was undertaken following a "mini-publics" approach which aimed to engage with a cross-section of the Scottish population. Participants were sampled to represent demographic characteristics broadly representative of local populations in each of the locations. Nevertheless, the total number of participants in the study was 69 and as such is not sufficient to claim that the sample is representative of the wider Scottish population. Deliberative public engagement methods are effective for enabling in-depth examination of participants' viewpoints and rationales but are time and resource-intensive which constrained the scope of this study. The aim of this qualitative, deliberative research was not to produce a set of findings which could be generalised or be considered representative. Rather it intended to explore the ways in which members of the public would engage with this important subject and examine the range of views that would be expressed. In that context, it is noteworthy that the findings produced were broadly consistent both within and between each of the workshops.

The responses reported throughout this paper were generated through discussion, with few prompts from the facilitators. The research team did not set out to examine public views on any particular potential types of benefits but rather to explore how members of the public would conceptualise public benefits and what their expectations are. Future research might usefully engage the public in discussions of particular potential outcomes and research aims.

Conclusions

This research has demonstrated the value of engaging with members of the public to address conceptually, socially and ethically challenging issues related to current and future health-related data science practices.

The social licence for the research use of health and other "Big Data" needs to be continuously negotiated

as public expectations, preferences and views shift in response to changing contexts and experiences. The boundaries of acceptability will need to be renegotiated on an ongoing basis to ensure that actual practices align with public values and concerns. This may be of particular importance when considering economic benefits, particularly but not only with respect to commercial involvement in research (Davidson et al., 2013; Wellcome Trust, 2016).

The nuanced discussions at each of these workshops have demonstrated the value of bringing together diverse groups to discuss conceptually challenging topics enabling considered and informed opinions to be developed. As noted by Scott et al. (2018: 32) "there is a need for further direct engagement with the public to better understand where their boundaries of acceptability lie within the context of data sharing". This study reaffirms much of the literature concerning deliberative public engagement methods, in demonstrating the value of these methods for informing and examining public attitudes around complex subject matter.

Declaration of conflicting interests

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Ethical approval

This research was granted ethical approval by the Usher Institute Ethics Committee.

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