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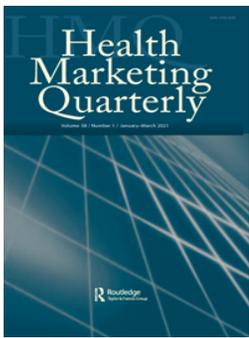
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Examining the barriers to accepting big health data from a health marketer's perspective

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ABSTRACT

Studies have shown that the sharing of big health data can improve patient management across primary and secondary care sectors. It can also reduce costs and can enhance the medical research process. Unfortunately, many big health data initiatives are being impeded because of a range of complex issues. This study was initiated to identify the said issues and develop a tool for health marketers to use to negate the barriers in big healthcare data projects. The study demonstrates how the Interactive Communication Technology Adoption Model can be operationalized to support qualitative researchers.

KEYWORDS

Big health data; health marketers; NHS; interactive communication technology adoption model; content analysis

Introduction

Back in 2013, England's National Health Service (NHS) introduced a programme called Care.data. It was designed to integrate the primary and secondary care sectors, giving commissioners a more holistic view of its existing and potential services across community, GP [General Practitioners], and hospital settings (NHS, 2013). This type of programme can also enhance the medical research process (Foley & Lie, 2019; Hemingway et al., 2018; Limb, 2016, Swenson et al., 2018), and can be positioned as the management of "big data" or "big healthcare data" (see van Staa et al., 2016). Big healthcare data reached great prominence during the 2020/21 COVID-19 pandemic, particularly with the launch of the various track and trace systems. Yet these initiatives were impeded in many countries because of concerns surrounding the protection of personal data (Fahey & Hino, 2020). A similar issue was experienced by the Care.data programme, which resulted in it being abandoned in 2016 (Godlee, 2016). Research into why the public is adverse in accepting such technology and the internet must arguably remain a priority, particularly as it has been

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demonstrated to provide clear societal benefits (see Foley & Lie, 2019; Hemingway et al., 2018; Limb, 2016; Sheng & Simpson, 2015). This “gap” and “lack of understanding” was the catalyst for embarking on this research, we have chosen to critically investigate the issues which contribute to theory and knowledge by addressing the concerns raised by Lupton (2016): i.e., there is not enough critical investigation in this area. It will focus on society’s perceived attitudes and acceptance of big healthcare from a health marketer’s perspective. More specifically, it will be restricted to those marketers linked to NHS England. The study uses Lin’s (2003) Interactive Communication Technology Adoption Model as its theoretical framework. The study’s primary aim was to develop a tool for health marketers to use to help identify perceived barriers in big healthcare data projects with possible solutions in how they can be resolved.

Big health data

The sharing of big health data is contentious, with some researchers stating it should be a “moral duty” (Kalkman et al., 2019a, 2019b) while others believe that the public should control their own data (Godlee, 2016). That said, there can be no denying that big health data can be used to make better care decisions, predict future events, understand the spread of disease and help to commission services for the healthcare providers (Foley & Lie, 2019). Fox (2017) brings a different perspective; he has implored us to be wary of technological advances in the health sector because of its possible associations to neoliberal marketing. This neoliberal marketing has links to corporate organizations and the monetizing of patient data which fuels the public’s mistrust. Such a warning is supported by Ebeling (2016), who warns that digitizing the health sector will not happen until the data ownership is resolved. These findings are all associated with Fahey and Hino (2020) work, which states that the inability to gain agreement on how best to manage privacy concerns has fueled public mistrust. This means that health services and Governmental bodies must make it clear that the need for health data privacy is sacrosanct.

Current literature also states that the general public is unaware of how the health data might be used, and who has access to it (Ritchie et al., 2015; van Staa et al., 2016). Although, Hill et al. (2013) research discovered the public become more compliant and acquiescent when they were educated on its use. This is why we have chosen to focus on understanding the perceptions of health marketers: their future campaigns could help educate society. That said, the issue of data privacy and how the data might be used is not the only concern, Krumholz (2014) believes that security factors have also caused the public and non-governmental organizations (NGOs)

to be skeptical of big health data. Brown et al. (2010) believe that these concerns can be overcome by better processes and procedures. This is supported by Botrugno (2019) who states that the implementation of ITs (which we have assumed to also included the handling of big data) must be meticulous to keep medical standards high.

In summary, current literature states that gaining public acceptance to use their health data more widely is only likely to happen if it can be shown that their privacy will always be protected, and security issues will be kept at a minimum. But what mediums, mechanisms, and/or models should researchers consider facilitating such a change? Truong's (2014) review of behavior change theories found Bandura's (1986) Social Cognitive Theory to be the most commonly used model. Other options included Ajzen and Madden (1986) Theory of Reasoned Action; Bandura's (1991) Social Observation Learning Theory; Rosenstock's (1974) Health Belief Model; Ajzen's (1991) Theory of Planned Behavior and Rogers (1975) Protection Motivation Theory. Each of these models could be applied to our research but they all lack an explicit technology link, which we believe to be important for this study. As such we have chosen to consider Lin's (2003) Interactive Communication Technology Adoption Model (ICTAM) as our theoretical framework. The ICTAM has been grounded from elements of Davis (1989) Technology Acceptance Model (TAM), so let's now consider the differences.

The technology acceptance model

The Technology Acceptance Model (TAM) (Davis, 1989) has been widely used by researchers and practitioners to predict and explain user acceptance of information technologies (Lee et al., 2003). The TAM has been expanded over the years to consider more specific external variables, examples include Venkatesh and Davis' (2000) TAM2 and Venkatesh et al.'s (2003) unified theory of acceptance and use of technology (UTAUT). The authors have chosen to exclude these extensions because TAM2 has the construct "Job Relevance" and the UTAUT focuses on the user. These factors are irrelevant for our research, we are looking at the acceptance of big health data from a societal point of view. Here, the general public and HCPs (in general¹) would not use the tool, they simply provide consent for their data to be used. Our logic is supported by Atkin et al. (2015) who believe that such a process can be used to identify barriers that would dissuade clinicians from adopting new technologies, although their focus was through the TAM. Atkin et al. (2015) also argue that the strengths of the TAM include, its ability to predict how its attributes can influence behavioral intention, actual use, and by the consideration of the barriers or

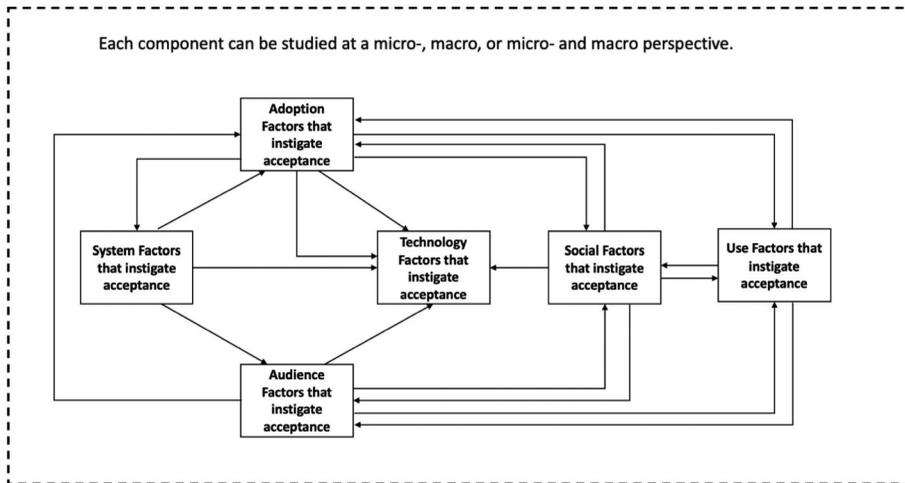


Figure 1. Interactive communication technology adoption model (adapted from Lin, 2003).

reasons of non-adoption by looking at external variables. We contend that the ICTAM has the same strengths because it was grounded from the TAM. We do concede that the ICTAM's circular framework (to be discussed in the next section) is a limitation and it is a factor that we hope to advance. In terms of acceptance within communications, the main criticism of the TAM has been its limited ability to process some of the more robust communication theories, such as the adoption of emerging media channels and contents (Lin, 2014). Lin's (2003) ICTAM (see Figure 1) considers different dimensions of technology acceptance, which we believe to be important for our study. More specifically it offers a way to look at specific factors that help shape the adoption decisions of various communication technologies (Atkin et al., 2015). As mentioned earlier, the ICTAM is a circular model with no clear start point. This makes it cumbersome for quantitative research (there are no explicit dependent and independent variables). It is however suited to qualitative studies because it can be adapted as the framework for developing the semi-structured interview questions, which is what we did.

Research methodology

This is an exploratory study; it has been designed to gain a deeper understanding of health marketer's beliefs in relation to centrally managing health information. We have also decided to critically investigate the motivations behind the health marketer's beliefs by probing further into their reasoning then comparing it with current literature. This is why our elected methodology was a qualitative one, more specifically we used Hsieh and Shannon (2005) "directed content analysis" to develop the semi-structured

Table 1. The list of themes was identified during the analysis.

Ref	Theme	Count	%	Cumulative %
1	Simple consistent messaging	55	19%	19%
2	Role of media	48	16%	35%
3	Public attitude to data use.	45	15%	50%
4	HCP attitude to data use.	42	14%	65%
5	Regulation	38	13%	78%
6	Opinion leaders	11	4%	81%
7	COVID-19	10	3%	85%
8	Care.data	9	3%	88%
9	Data use understanding	7	2%	90%
10	Information governance as a blocker	6	2%	92%
11	Complex patient conditions (data use)	6	2%	94%
12	Tole of marketeers	5	2%	96%
13	Social media	5	2%	98%
14	Opt out campaign	3	1%	99%
15	NHS Brand	2	1%	99%
16	NHS v Government	2	1%	100%
	Total	294		

interview questions, using Lin's (2003) ICTAM as the theoretical framework. Then Shaw's (2020) adaptation of Hsieh and Shannon (2005) "summative content analysis" to develop and identify the core themes. The study recruited 15 participants who, at the time of interviewing, were involved in the delivery of various national health technology initiatives through various NHS channels in England. By limiting the participants to individuals who were communications and marketing specialists, we were able to identify broader themes from individuals who had the task of convincing the general public to accept and sign up for big health data initiatives. Participants were identified with the help of contact within the NHS Digital [the "national information and technology partner to the health and social care system" in the UK (NHS Digital, 2021a)]. We, however, acknowledge that the cohort was relatively small but argued that they provided a balanced understanding of how health data is collected and used. Being able to talk to professionals that have had the experience of running data campaigns has also helped us gain a deeper understanding of the level of success and failure of historical and existing campaigns. As per Tracy (2013), gaining such an understanding of the evaluation and insights from previous studies will add further to the understanding of potential barriers. Ethics was granted via our academic institution and interviews were conducted using Microsoft Teams (a virtual video communications platform). All interviews were between 40 and 60 min and were recorded to aid transcription. The transcripts were analyzed using NVivo11.

Findings and results

The primary results of this study can be presented as themes (see Table 1). The summative content analysis approach counted the occurrence of each

theme, then its cumulative percentage. Using Pareto's 80:20 principle (see Shaw, 2020) five core themes were extracted (giving a cumulative count of 78%). These themes helped identify the perceived core factors associated with accepting the sharing of big health data. Each of these five themes will now be considered in detail. Note, examples of quotes from the participants are presented in italics with their pseudonym code at the end in brackets.

Simple consistent messaging

The first key theme identified focused on the need for simple consistent messaging. Many of the participants believed that the constant changes in health data messaging had left the public confused and distrustful of the required guidelines:

I think in the beginning, when we had daily briefing [relating to the COVID-19 pandemic], everyone was so tuned in; everyone was glued to their TV.... gradually all these other stories broke out about all this other stuff that the Government ignored the data just shone a huge light on all of the competencies. (PA07)

I speak to a lot of technical leads² and information governance leadsⁱ and I recognise it is my role as a marketer to be able to take what they're saying and turn it into something that is accessible to the public. That's really difficult, but it has to be done. (PA11)

From this theme, we have surmised that having too many messages can turn public confidence into confusion which then drives the mistrust. Many of the participants also believed that some of the current terminology used made it inaccessible to the public at large. This would again be the catalyst for reducing engagement and trust in data use. A good example of this dilemma can be explained using the recent COVID-19 pandemic. At the start of the pandemic, simple messaging led by data was easy for the public to understand as everyone played their part to "flatten the curve." For example, data sets like the Shielded Patient List (see NHS Digital, 2021b), which were set up in days, was able to provide local authorities with information on members of the public that were extremely vulnerable and enable them to provide additional support if needed.

We believe that our findings are not an outlier because, Sonuga-Barke (2021) and Wang et al. (2020) also support the need for simple messaging while Key and Czaplewski (2017) and Percy (2014) support the need for consistent messaging, although Key and Czaplewski (2017) and Percy (2014) advocate varying the style and voice for different channels (a factor which we will be expanded on later in the article). Vanderveer (2004) takes a different perspective, he sees simple messaging to be problematic because its development may just focus on those features which "grab the attention" but fail to change behavior. An example of this could be when the message

is based on fear or guilt. Guilt and shaming can also reduce compliance (Brennan & Binney, 2010). This means that clear, factual, and transparent information would be the best strategy to embark upon. Based on the work of Bouman (2017), we also believe that being able to show the journey of data through storytelling will enable communication professionals to find touchpoints where they can find moments to talk about health data with the public as they interact with the NHS. These small messages will build up over time and lead to a base level of understanding of how health data aids their care.

The role of the media

The second theme focused on the role that media played in explaining how health data can be used to support patient care. The first example of the quotes used is listed below.

Traditional media is much more effective at the negative side of it; they're really good at creating kind of earworms that people just sort of here once, and then they will repeat for the next 25 years. You know you hear the same story is being trotted out about USB sticks like being left on trains. (PA05)

Two-thirds of participants cited that traditional media tended to portray stories about the management “health data use” negatively. The results also pointed towards a disconnect in how data was used by journalists, with participants highlighting the fact that patient data was used primarily in articles about health trends, for example, the rise in obesity (Boseley, 2019). However, when discussing data used by third-party organizations, the focus was on the data belonging to the public. A good example of this would be the front page that ran in the Daily Mail (a national newspaper in the UK) “Now Tesco [a national grocery store in the UK] has access to your medical records: Chemists at supermarket pharmacies to be allowed to access data in an attempt to boost care standards” (White, 2015). This indicates that the tabloid journalists will opt for sensationalism because it helps with their sales, a view which is shared by Schwitzer et al. (2005). Chadwick et al. (2018, 4255) identified a more concerning issue that, “sharing tabloid news on social media is a significant predictor of democratically dysfunctional misinformation and disinformation behaviors.”

Our study also showed that false information through media channels was an area of concern for health communication professionals. The lack of credible information creates a breeding ground of misinformation, which they believe to be predominantly through social media channels. These channels have a far greater reach, and it is difficult to trace back to the source. Examples of the participant’s comments are:

With social media you probably receiving hundreds of little packets of information from completely different sources. It's much harder to counter those individual pieces of information if they are incorrect, there is also a significant impact on people's trust. (PA09)

If the right trigger [on social media] comes along, whether it's positive or negative, it can really snowball into a huge amount of interest and behaviour change that you wouldn't otherwise expect. (PA06)

The participants also believed that false stories had increased during the COVID-19 pandemic. Apuke and Bahiyah (2021) presumed that much of this is due to the speed at which false information can resonate amongst the public. One explanation could be that the propagation of misinformation is aligned with Katz and Lazarsfeld (1966) two-step flow theory. Essentially, if the information provided by a perceived opinion leader is deemed to be correct by their followers then they would believe it even if it is not. That said, the two-step flow theory can work both ways, i.e., the perceived opinion leaders counter misinformation through their communications channels (Pang and Ng, 2017). This is reinforced by Procter et al. (2013) who also showed that misinformation can be suppressed if the appropriate counter-claims are disseminated. It means that health marketers should introduce social listening as part of their core tasks and develop contingencies to manage misinformation.

There are also new mechanisms to counter false information, Facebook has taken steps to remove such posts from its network (Zuckerberg, 2020) and the UK Government has produced a counter-disinformation toolkit using the RESIST model (Pamment, 2019). This RESIST model helps to recognize disinformation, look for early warning, obtain some situational insight, analyze the impact, align this to the strategic communications, and track outcomes. A health marketer must develop a balance of communicating key messages and neutralizing incorrect information. Disinformation is not the only problem, Smaldone et al. (2020) identified that information can spread between like-minded online communities with a common bond: this is similar to the two-step flow theory, only information is shared by other communities members. Depending on the type of information being discussed, this could either be positive or negative. Considering all these points and the comments of our participants we now propose that providing a balance in how health data is used in their reporting is key to aiding the public understanding and acceptance of health data use.

Public attitude to data use

The third theme is related to the attitude of the public in relation to health data use. Our results segmented the public into three distinct groups. The first is the expert patients, they have a vested interest in health data sharing

and hold a lot of knowledge in the subject, but their view is focused solely on the disease/condition they have to live with. The second is the opted-out public, they are against data sharing and want to ensure that their right to this premise is upheld. The final group is the rest of the general public, this group is usually infrequent NHS users who do not seek out information about data sharing as they already have trust that the NHS will share and use their data appropriately. In all cases, if something gives any of these groups a reason to think that their trust is compromised, they will look for information from other sources which may not be accurate. Examples of the quotes from the interviews include:

Most people would go yes, of course to sharing their data with Cancer Research UK, but if you told people your data is being sent to researchers without your permission, then people would think that's outrageous. There's still a lot of work to do to bridge that gap of understanding. (PA12)

When you talk, what was called seldom heard voices, you see that this there is no trust there when they see the NHS. I've always prided myself on the fact the NHS is a trusted brand, but in certain areas it's seen as the same as the Government and what we might do with your data. They see the NHS and Government as one of the same and just another way of getting information about them. (PA01)

We found [from user research] not that many people are interested in the subject matter [data] they trust the NHS to hold personal patient data and they happy for the NHS to just sort of crack on. (PA07)

Interestingly, this view aligns with the work of Malheiros et al. (2013). Their segmentation of attitudes is divided into the following grouping: privacy pragmatics, they look at the data ask on a case-by-case basis and are willing to make trade-offs with their data if it provides them with a benefit; privacy fundamentalists, are against data sharing and want to ensure that their rights to this are upheld; privacy unconcerned, are individuals who are not concerned about data being collected about them. It means that the message development should not adopt a “one-size fits all” approach. Another segment that researchers need to consider is the “hard to reach” sectors like those from the BAME (black, Asian, and minority ethnic) communities. Our research participants believe that the BAME community has a mistrust of the NHS which they believe is intrinsically linked to the Government. This link makes any engagement with these stakeholders harder:

When you talk, what was called seldom heard voices, you see that this there is no trust there when they see the NHS. I've always prided myself on the fact the NHS is a trusted brand, but in certain areas it's seen as the same as the Government and what we might do with your data. They see the NHS and Government as one of the same and just another way of getting information about them. (PA01)

All this means that researchers should consider the general public as moderators when designing new studies. Arguably, these differences are down to the varying attitudes of individuals. This is supported by current literature (see Ahn & Black, 2018; Bagozzi & Burnkrant, 1985 and Crites et al., 1994), which suggests that this attitude is linked to affective (does the person like the object in question?) and cognitive (an individual's belief about the object) components. Yang and Yoo (2004) believe that attitude is a powerful measure of technology acceptance and should be used to enhance any future health technology models.

Attitudes of healthcare professionals

In addition to the importance of considering the “public attitude,” our fourth theme identified the healthcare professional's (HCPs) attitude as another key factor to contemplate. In terms of health data, HCPs maintain that they need to protect patient confidentiality and its misuse. There seems to be a communications gap as data organizations have not been feeding back to HCPs how big data could help them and their patients. An example could be, in aiding the commissioning of services or within clinical research trials. The participants interviewed do accept that with a workforce of over 1.4 million (NHS Digital, 2019) in England, they can help the communications teams in disseminating key messages. The communications teams must first work on changing HCP attitudes. Returning to the interview responses we can see examples of what they told us below:

Clinicians are very clear on the benefits of using health data for the individual care of patients. However, often it isn't clear to them how it was used beyond that because they don't see the end result. (PA03)

If we can explain the clinicians the importance of the data that they input, and then they are more likely to engage with the process, I think that's crucial, showing them how the data can come back and help them, that can close that loop. (PA09)

Disappointingly, despite these HCPs being employees of the NHS, it was identified that the trust and confidence of General Practitioners with the NHS successfully managing health data was low. Many of these GPs cited the failure care.data campaign (discussed earlier) as their primary reason:

The campaign came across as arrogant, 'We're going to use your data, and you're going to be alright with it', and GPs didn't like that... I think the assumption was that people don't really care, and it turns out they did. (PA04)

Other studies have shown that if clinical staff understand the benefits, they can feel more comfortable talking about them to patients (Denis et al., 2002). However, it was noted that although having advocacy from healthcare professionals is important, their obligation in terms of patient data is

to protect the confidentiality of the patient. If healthcare professionals are going to be used to influence behavior changes in accepting the need for big health data, then they need to have access to the appropriate communication tools, possibly even additional training, which is supported by Krumholz (2014) and Lee et al. (2012).

Role of regulation

The final theme identified was the role of regulation. Health marketers believed current regulations and governance relating to health data were hard for the public and HCPs to understand. They considered it to be complex and confusing, which made it difficult for General Practitioners to explain the importance of sharing health data with their patients.

The overwhelming message that we hear from organisations and individuals out there who need to understand the regulation and navigate regulation don't understand it... .. It feels like there's only a very few kind of real experts who really understand how to make sure that they are compliant with all the range of regulations. (PA08)

There is a habit for IG [Information Governance] teams to shovel all of this legalese into peoples in a way that we can just then say, 'Oh, they have been informed'. We know that they're not... .. It comes down to understanding what people need to know what they care about. (PA01)

Information Governance is a blocker, rather an enabler. They're seen as the 'you can't do something' team, but I think that's because that's the role we put them in. (PA04)

These findings are in line with Anderson (2007) who identified that privacy concerns were a barrier in the implementation of electronic medical records. Papoutsis et al. (2015) also found that the general public needed to have the reassurance that there is trustworthy governance in place and that their health data was being shared safely and securely. Even within the midst of the global COVID-19 pandemic, where one might posit that the general public would succumb to such concerns, it was established that the adoption of contact tracing mobile applications remained a challenge because of the said privacy concerns (Hassandoust et al., 2021).

Interestingly the research participants did not mention data breaches, hacking and malware attacks as a concern. We believe that it should be considered because the UK's Information Commissioner's Office identified that the health sector has a higher number of data breaches compared with others (ICO, 2020).

Another finding from this study was the need for better engagement amongst groups from diverse and differing social-economic backgrounds. There was a perception from the participants questioned only a select minority ever took part in their health data patient involvement groups.

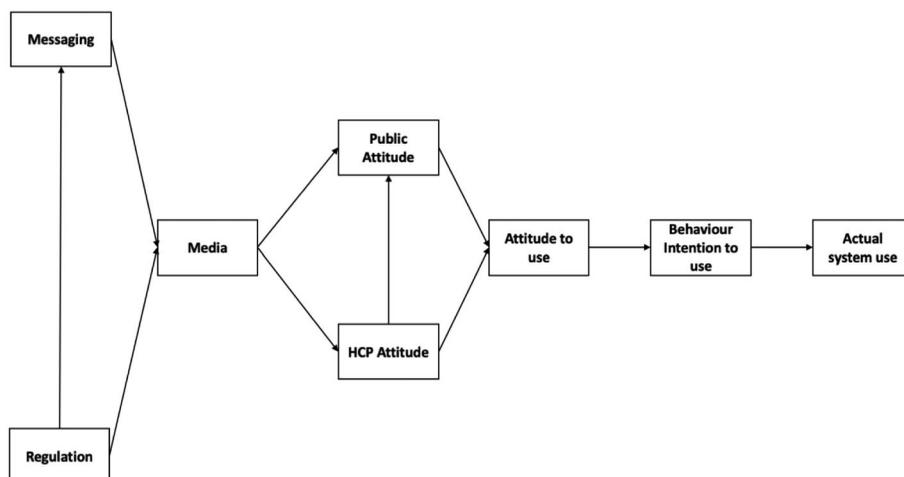


Figure 2. The proposed conceptual model.

I would just love to see more of a commitment being made to meaningful public engagement. I still feel that it's very much still seen as a tick box exercise and that that bothers me. (PA11)

More diversity of voices in engagement is really important. From what I've seen, it often tends to be the same kind of people who were involved in kind of advocacy around, any kind of health issue, but especially around data. (PA03)

A possible solution to this dilemma is to build on the work of the UK's OneLondon data programme (OneLondon, 2020). It instigated a “public deliberation in the use of health data” using 100 people that reflected the diverse population of London who provide them with detailed recommendations and conditions that they strongly believe should be met if the use of health data were to be expanded (HDRUK, 2020). Although the initial consultation was successful, we will need to wait before the full results are out. The key “take-away” reflects Papoutsi et al. (2015) earlier findings, in that, the public needs to have the reassurance that there is trustworthy governance in place and that their health data is being shared safely and securely.

Having reviewed the five core themes, we now believe that a new conceptual model can be presented which would supplement Lin's (2003) interactive communication technology adoption model particularly for scholars who wish to embark on quantitative studies. This conceptual model can be seen in Figure 2. The authors posit that the “attitude to use” variable is the culmination of the effects accredited to “public attitude” and “HCP attitude” in relation to desired behavior change. This conclusion is based on the work of Bronfenbrenner (2005) and his “Bio-Ecology Theory,” where the public and HCP groups become separate microsystems. Patient data can only be amalgamated if they give their consent to do so.

In some cases, as identified in the study, it would be some HCPs (particularly General Practitioners) who would guide patients. If these HCPs were against the change then it could have a negative impact on the public.

Some readers may be perplexed by the model, and question if Davis (1989) TAM model would be more appropriate. Our conceptual model has similarities with the TAM, we have however removed the “perceived usefulness” and “perceived ease of use” variables because the authors argue that they are irrelevant for the general public. The public would only experience an indirect impact of such a system. From an HCP point of view, they already have historical local data on their patients which they use. The authors have also assumed that the integration would be seamless, and data would flow across multiple channels. The authors acknowledge that this is a limitation for this study, however, it will allow for future testing without additional cause and effect variables.

Limitations and future research

The authors are aware the small sample size of the participants is a limiting factor for this research. They do, however, argue that the quality of the participants (i.e., existing healthcare marketeers) provides a unique perspective of the issues and adds to our understanding of the theory and knowledge of the said domain. Further research encompassing different international settings and/or the inclusion of the general public would enhance the knowledge. A larger quantitative study would also allow other researchers to test the propositions of the new model.

Conclusion

This study has taken steps to address Lupton’s (2016) concerns by critically investigating why there is poor engagement with the sharing of Big Health Data. From a health marketer’s point of view, the message development and its delivery channel mechanism were identified as the most important factors in facilitating acceptance and behavior changes of the general public and healthcare professionals. It should also be noted that these messages also relate to sources outside of the health marketer’s domain (i.e., other bodies, of which they have no control over). This means that health marketers should monitor the keywords associated with their campaign and implement counter strategies if fake news or misinformation has been disseminated. Regulations, particularly those relating to privacy, were another factor that was identified as having a direct and indirect effect on public and healthcare professionals’ behavior intentions. Again, the regulation’s message content and channel distribution can affect attitudes and perceptions.

Overall, we found that messages must be simple and consistent, but different variants were required for different segments. These variants needed to focus on the specific concerns of that segment. Our conceptual model can be used as a tool to evaluate healthcare messages relating to digital data. It could be adapted for other healthcare messaging but further research would be needed to test its efficacy.

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Notes

1. It is accepted that some HCPs may be users (i.e., for their research or patient care) but at this stage our focus is on how such HCPs may advise their patients on accepting big health data programmes.
2. The term “lead” refers to the head of department.

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