Imperial College London

Mapping the Effects of Disinformation on Trust in Medicines and the Pharmaceutical Sector (PHARMAFICTION) Study

Study Management Group

Principal Investigator: Austen El-Osta
Co-investigators: Aos Alaa
Sami Altalib
Mohammad Adam
Azeem Majeed
Dumile Gumede
Saja Alnahar
Marvin Kopka
Jon Adams
Marcelo Demarzo
Xavier Tulio
Suebsarn Ruksakulpiwat

Sponsor

Imperial College London is the main research Sponsor for this study. For further information regarding the sponsorship conditions, please contact the Head of Research Governance and Integrity.

This protocol describes the "**Mapping the Effects of Disinformation on Trust in Medicines and the Pharmaceutical Sector (PHARMAFICTION) study"** and provides information about procedures for entering participants. Every care was taken in its drafting, but corrections or amendments may be necessary. These will be circulated to investigators in the study. Problems relating to this study should be referred, in the first instance, to the Principal Investigator.

This study will adhere to the principles outlined in the UK Policy Framework for Health and Social Care Research It will be conducted in compliance with the

protocol, Data Protection Act 2018 and General Data Protection Regulations (Europe) and other regulatory requirements as appropriate.

TABLE OF CONTENTS

Contents

Imperial College London

1. INTRODUCTION

1.1 Background

This study seeks to gain further insight into impact of misinformation and disinformation in the UK health and care and pharmaceutical industry.

Misinformation and disinformation (mis/disinformation) represent critical threats to public health, health system sustainability and pharmaceutical sector credibility. Within the UK, the intersection of digital proliferation and legacy regulatory frameworks has exacerbated industry constraints in addressing harmful narratives effectively.

Previous studies by the PI (Powell et al., 2021, El-Osta et al., 2025, Smith et al., 2025, El-Osta et al., 2025) highlight the importance of proactive engagement with health misinformation, particularly for improving health literacy and public trust, which are core themes identified by ABPI as strategic priorities. See **Table 1** for disambiguation of relevant terms.

The COVID-19 pandemic demonstrated the real-world consequences of this gap. False claims around vaccines, treatment efficacy, pharmaceutical intent and regulatory processes proliferated rapidly across digital platforms, leading to behavioural hesitancy and deepening mistrust. Yet beyond crisis contexts, the everyday volume of mis/disinformation continues to distort public understanding of medicines, increase the cognitive burden on health and care professionals and weaken the public's ability to discern fact from fiction. At the same time, new technologies including generative AI and social media microtargeting are accelerating both the production and reach of misleading content.

This study responds directly for a rigorous, research-led trend analysis of mis/disinformation as it affects the pharmaceutical industry in the UK. It recognises the need to map the scope and trajectory of this threat and to generate actionable insights that can inform industry communication strategies and regulatory reform. In doing so, the project will bridge evidence gaps, surface vulnerabilities and provide a comparative international perspective. By placing data and insight in the service of public trust, this work will support the community in engaging with the mis/disinformation challenge with greater confidence, coherence and impact.

This study seeks to answer the following research question: What are the knowledge, attitudes, perceptions and behaviours (KAP-B) of community-dwelling adults in the UK regarding pharmaceutical misinformation and disinformation, and what impact does it has on trust, medicine use, and the credibility of the pharmaceutical industry?

The findings of this research are expected to be scalable and generalisable- thus largely applicable to other local settings in the UK. The results of the study will be disseminated in peer-reviewed journals.

2. STUDY OBJECTIVES

Primary Aim
To characterise the scope, narratives and impacts of pharmaceutical misinformation and disinformation across the UK, in order to generate evidence that informs industry strategy, strengthens regulatory responses, and enhances public trust in medicines.

Secondary Aims

- To assess how pharmaceutical mis/disinformation affects public trust, perceptions of industry credibility, and patterns of medicine use or adherence.
- To identify regulatory and policy barriers, as well as opportunities, for more effective responses to mis/disinformation by pharmaceutical stakeholders.
- To map differential impacts of mis/disinformation across demographic groups and communication channels, highlighting populations and touchpoints most vulnerable to harm.

3. STUDY DESIGN

Type of study: Mixed methods study

Duration: 24 months

Study Design and Purpose
This is an applied research study that includes a qualitative interview component because it seeks to assess the knowledge, attitude, perception and behaviours (KAP-B) of community dwelling adults on the impact of misinformation and disinformation in the UK pharmaceutical industry.

We will collect data from around 50,000 participants via a short (10 minute) pseudo-anonymised electronic questionnaire survey. These individuals will receive an ethically approved SMS invite which will introduce the study and will include the ethical clearance document as well as the Qualtrics link to the eSurvey. Once respondents have clicked the link to the survey platform Qualtrics, they will be met by the eSurvey, which will start with an introduction to the study as well as an anonymity statement. Respondents who complete the survey will also have the opportunity to indicate if they are happy to be contacted for interview.

We also aim to recruit around 10-15 people in total to participate in 30-45 min semi-structured personal interviews (via telephone, Zoom, or Microsoft Teams). These individuals will be recruited by including their details at the end of the survey, personal contacts and from the community through social media advertisements at local non-NHS institutions, as well as through the Be Part of Research network. Social Media advertisements for the study will be published on Twitter/X and Facebook and will be distributed by the study team.

Individuals who are willing to participate can respond to the advert by contacting the study PI via email or by leaving their details at the end of the survey to express an interest and to learn more about study. The study team will respond to the expression of interest with a simple email to introduce the study, including an attached copy of the participant information sheet & the link to the electronic consent form. Once they fill in the electronic consent form we will download a copy from our end and store on an encrypted file. If individuals are still interested to take part in the study, they will be asked to email or telephone member of the study team to fix a time for enrolment and telephone/video interview. Respondents would be able to contact the study team via email or telephone number to learn more about the study or should they have any questions.

It will be made clear to respondents that participation is voluntary, and that even if they do not want to participate their decision will not affect their relationship with the research group. Respondents will also be advised that they may withdraw their participation at any point, even should this be after they provide informed consent and take part in an audio recorded / auto-transcribed interview without giving any explanation if they do not want to do so without affecting their relationship with the research team. You are free to withdraw from the interview even after the audio recording is made. If the participant wish the interview not be audio-recorded, we will auto-transcribe the interview (an automatic transcription software on Teams will be used to transcribe and write out the speech for easier reviewing and editing the transcript) to derive quotations which may be used in the study.

Participants will be allowed to consider their participation for at least 2 days before fixing a time for interview.

The study will involve collecting new personal data from participants. Specifically, this will involve collecting data on age, gender, ethnicity, first segment of postal code, disability, and long-term health conditions.

As this topic does not involve illness, pain management & triggers, no sensitive questions will be asked in the survey or interview. If participants consent to interviews, they will again be asked questions with a sensitive nature, however they will be reminded that they can leave the interview at any point or not answer any questions they do not want to.

We do not anticipate any safety concerns associated with this study. We will follow good practice and adhere to Imperial College policies and GDPR and data protection (DPA) 2018 act to ensure all the data collected will be pseudo-anonymised and the confidentiality of all participants will be protected.

It is not conditional that participants who complete the eSurvey volunteer for 1-2-1 interviews, and vice versa.

Imperial College London is the sponsor for this study and will act as the data controller for this study. Imperial College London will keep the personal data for:

- 10 years after the study has finished in relation to data subject consent forms.
- 10 years after the study has completed in relation to primary research data.

All responses will be pseudo-anonymised to ensure confidentiality, and only the participants' age (in years), gender, ethnicity, and employment status will be noted. Participants will also

have the choice to leave their email should they want to take part in a 1-2-1 interview. This will be done by assigning a study ID to participants during consent which could be used to address participants during the interview. The use of a study ID will then be used during the study and analysis of data, thereby keeping participant identifiable information and responses pseudo-anonymised. We will not record IP addresses of survey respondents.

A study ID will then be used during the study and analysis of data, thereby keeping participant identifiable information and responses pseudonymous. We will not record the IP addresses of survey respondents. All data (Interview and survey data) will be pseudonymised and will be stored securely on an encrypted and secure institutional server that can only be accessed using passwords adhering to Imperial College London policies and procedures. Access will be granted to named study investigators only. The study team will use Microsoft Teams to record & transcribe functions during the interview session. Audio and video recordings will be deleted soon after the study team has transcribed them. Any information linking participants to the findings will be deleted upon completion of the study. All published data will also be anonymised, including verbatim quotations to illustrate key themes. We will follow good practices and adhere to Imperial College policies and the GDPR and Data Protection (DPA) 2018 act to ensure all the data collected will be pseudonymised and the confidentiality of all participants will be protected. The Principal Investigator will preserve the confidentiality of participants taking part in the study and fulfil transparency requirements under the General Data Protection Regulation for health and care research. Data and all appropriate documentation will be stored for a minimum of 10 years after the completion of the study. The Chief Investigator will preserve the confidentiality of participants taking part in the study and is registered under the Data Protection Act.

All data and interview transcripts (when transcribed by a member of the research team) will be stored securely on an encrypted and secure institutional server, that can only be accessed using passwords adhering to Imperial College London policies and procedures. The study team will use Microsoft Teams record & transcribe functions during the interviews. Recordings will be deleted soon after they have been transcribed by the study team. Interview and survey data will be kept pseudo-anonymous and will be stored on secure password protected Imperial College London servers.

All published data will be pseudo-anonymised also, including any ad verbatim quotations we may include to illustrate key themes.

4. PARTICIPANT RECRUITMENT

4.1 Pre-recruitment evaluations

Not applicable

4.2 Inclusion Criteria

- Study participants will include adults over the age of 18 who speak English

4.3 Exclusion Criteria

- Under 18-year of age, and those who are non-English speaking.
- No access to internet connectivity, smartphone, or personal computer (for eSurvey component)
- Participants unable to cooperate e.g., Learning disability/dementia

4.4 Withdrawal Criteria

Participants will be informed that they are able to withdraw at any point leading up to, or during, the eSurvey or interview. Participants can stop being part of the study at any time, without giving reason, and the existing information will be kept. Participants can withdraw from the survey or interview simply by exiting.

5. ASSESMENT AND FOLLOW UP

There is no follow-up for this study.

6. REGULATORY ISSUES

6.1 Ethics approval

The Principal Investigator has obtained approval from the Head of Department and approval from the Research Governance Integrity Team (RGIT). The study will be conducted in accordance with the recommendations for physicians involved in research on human subjects adopted by the 18th World Medical Assembly, Helsinki 1964 and later revisions)

The study will be conducted in accordance with the recommendations for physicians involved in research on human subjects adopted by the 18th World Medical Assembly, Helsinki 1964 and later revisions.

6.2 Consent

Consent to enter the study must be sought from each participant only after a full explanation has been given, an informational leaflet offered, and time allowed for consideration. Signed participant consent should be obtained electronically where possible for 1-2-1 or group interviews, but the tick box consent captured on Qualtrics in the case of eSurvey will indicate informed consent. The right of the participant to refuse to participate without giving reasons must be respected. All participants are free to withdraw at any time. Participants will not be able to withdraw from the survey after completion, however, should the participant request their 1-2-1 interview data to be removed, we will remove data and it will not be used in the final study.

6.3 Confidentiality

The Principal Investigator will preserve the confidentiality of participants taking part in the study and fulfil transparency requirements under the General Data Protection Regulation for health and care research. Data and all appropriate documentation will be stored for a minimum of 10 years after the completion of the study, including the follow-up period.

6.4 Indemnity

Imperial College London holds negligent harm insurance policies which apply to this study.

6.5 Sponsor

Imperial College London will act as the main sponsor for this study.

6.6 Funding

This study is not funded.

6.7 Audits

The study may be subject to inspection and audit by Imperial College London under their remit as sponsor.

7. STUDY MANAGEMENT

The day-to-day management of the study will be co-ordinated through Dr Austen El-Osta (a.el-osta@imperial.ac.uk).

8. PUBLICATION POLICY

The study results will be shared with research participants. The study will be considered for publishing if the opportunity in a peer reviewed journal.