

# Majority of social media users are happy for their data to be used for research, study reveals

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Social media users cited the potential benefit for medical research as the most influential factor for them to consent to their data being used for research. Credit: University of York

Social media users are generally positive about their personal data being used for research purposes, a study by the University of York has revealed.

Social media platforms have often been used by researchers to gather data on so-called "adverse events" from drugs and [medical procedures](#), with adverse events often being under-reported in studies.

Social media users cited the potential benefit for [medical research](#) as the most influential factor for them to consent to their data being used for research.

## Concerns

However, the study revealed concerns around regulation and the ethics of using [personal data](#) for research purposes.

The qualitative study used interviews, virtual discussions and focus groups to explore views and attitudes towards the [use of social media](#) to monitor adverse events.

Some of those taking part had suffered adverse reactions to medicines themselves.

## Safety

Lead author Dr. Su Golder, NIHR Postdoctoral Research Fellow from the University of York's Department of Health Sciences said: "We found it interesting that social media users were happy for their data to be used for research, but as researchers it's important to take into account their concerns and make sure we assure people that their data will be used appropriately and safely.

"It is clear that [social media users](#) are in favour of some sort of overarching guidance for all institutions to follow and that further work is required to establish when consent is required for individual's social

media data to be used."

Dr. Golder said researchers were already aware of the huge potential benefits of using social media for research purposes.

## Helping researchers

"It could be argued that some health scandals of the past could have been averted or discovered earlier if social media was around then as the adverse effects would probably have been highlighted," she added.

"Social media has a part to play in helping researchers and our study has revealed that people are willing for it to be used under the right circumstances.

"Our findings will not only help direct future research but will also provide people managing social media websites, universities, ethics boards, pharma companies and policymakers with evidence to inform policy and guidance on the use of social [media](#) data for research."

Provided by University of York

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