

## Who we are

MISFIRES is an European Research Council project running from 2018 to 2023 on market failures and collaborative innovation in healthcare. MISFIRES is hosted by University College Dublin (UCD), Belfield, Ireland. For more information about UCD please visit [www.ucd.ie](http://www.ucd.ie) or you can call us with queries on +353 1 716 7777.

Prof Susi Geiger is the lead researcher for MISFIRES and oversees all the research. If you have any requests or queries about the research or the collection of data please contact Prof Susi Geiger on [susi.geiger@ucd.ie](mailto:susi.geiger@ucd.ie) or you can email [misfires@ucd.ie](mailto:misfires@ucd.ie)

## What we do

MISFIRES aims to guide new academic and policy thinking by establishing how:

1. concerned actors voice and mobilise around the notion that the healthcare market has 'failed' them;
2. concerned actors seek to negotiate and address healthcare market failures;
3. this process may lead to 'better' healthcare markets (as defined by actors).

For more information please visit our website [misfires-erc.eu](http://misfires-erc.eu)

## General statement

MISFIRES fully respects your right to privacy and actively seeks to preserve the privacy rights of those who share information with the project. Any personal information you provide to MISFIRES will be treated with the highest standards of security and confidentiality, in accordance with the EU General Data Protection Regulation (GDPR) as introduced in May 2018.

## Personal data we collect

**MISFIRES**, through the course of its research, will contact potential research participants to ask them if they would like to participate in our research. These individuals will not be identified through the use or visits to the MISFIRES website, but will be identified to us through other forums in the public domain as outlined below for each research workstream of MISFIRES.

## Legal basis for the processing of data

The legal basis for the processing of personal data in MISFIRES is through "the consent of the individual".

## Purpose of Processing

As stated above MISFIRES aims to explore healthcare markets with the view to making healthcare markets better for all. The purpose of the processing of the data is to gain information from stakeholders within the healthcare market to inform the researchers on how healthcare markets operate and how to make them better.

## Overview of the Research

### 1. Research Workstream: Diabetes

As part of this study, we are analysing the Tweets posted with the hashtag #WeAreNotWaiting on the website Twitter. Tweets are analysed through an analytical procedure called a content analysis. Twitter user handles of those who tweeted the tweets will be deleted prior to analysis. If you have posted Tweets with this hashtag between 2014 and 2018 and do not wish your Tweets to be included in this analysis please let us know through an email to [misfires@ucd.ie](mailto:misfires@ucd.ie).

We are interviewing research participants with an express interest or publicly stated interest in Diabetes device innovation, as follows:

- Recruitment for this study will be voluntary among participants that have publicly associated themselves as diabetes advocates for the #WeAreNotWaiting community and contributed to the #WeAreNotWaiting movement on Twitter (including type-1 diabetes patients, parents of children with type-1 diabetes).
- Recruitment for this study will be voluntary among patient entrepreneurs and participants from open-source diabetes communities that have publicly associated themselves with the #WeAreNotWaiting community and contributed to the #WeAreNotWaiting community on Twitter (including Nightscouts, Tidepool, DiabetesMine, OpenAPS).
- Recruitment for this study will be voluntary among participants from diabetes device manufactures (such as Dexcom).
- Recruitment for this study will be voluntary among participants from governmental bodies (including EMA and FDA).

## **2. Research Workstream: Genomics**

We will interview persons in an organizational capacity only from the following sectors

- Professionals in charge of participant recruitment in data-driven medical projects/companies
- Professionals in charge of managing participants' feedback and engagement at decision-making level in the same projects/companies
- Participant advisory board members for the initiatives/organisations mentioned above, to be interviewed strictly only in their organizational and not personal capacity.

Permission will be sought on an individual basis through contacting informants by publicly available means (e.g. LinkedIn profiles) or through recruitment through the organization in question. Recruitment for this study will be voluntary among participants that have publicly associated themselves as spokespersons for the biorights or data privacy movements.

Recruitment will be voluntary among industry representatives and persons in a public office or in an organisational capacity, who will be identified through their public or organisational roles.

Recruitment will be voluntary among participant advisory board members.

## **3. Research Workstream: Hepatitis C**

We will interview persons in an official (organizational) capacity only from the following sectors

- Spokespersons for access to medicines organisations
- Persons in a public office, e.g. from the Department of Health or the European Patent Office.
- Industry representatives (e.g. from pharmaceutical associations) in an organizational capacity

Permission will be sought on an individual basis through contacting informants by publicly available means only (e.g. LinkedIn profiles). Recruitment for this study will be voluntary among participants that have publicly associated themselves as spokespersons for the access to medicines movement. Recruitment will be voluntary among industry representatives and persons in a public office, who will be identified through their public or organisational roles.

### **Recipients of personal data**

Only the MISFIRES researchers will have access to this data and a designated 3rd party transcriber (please see the section below). All research participants will be informed about the recipients of the personal data and would need to sign a consent form approving this sharing of data prior to the data collection.

### **Transfer of personal data**

The data will be transferred to a designated 3rd party transcriber who has agreed to and signed a GDPR agreement with UCD.

No data will be transferred to any party other than those stipulated in this and the above section "Recipients of personal data".

### **Retention Periods**

Ethical approval has been granted to keep the data for 10 years for all of the above research work streams but this will be reviewed throughout the course of the project and if the data is no longer necessary it will be destroyed before the 10 years, more likely around the end of the project - 5 years. We have governing structures in place for the continual review of the data and the deletion thereof.

### **Rights to withdraw consent**

Research participants can withdraw consent at any time and can contact the lead researcher Prof Susi Geiger on [susi.geiger@ucd.ie](mailto:susi.geiger@ucd.ie)

### **Rights to lodge a complaint**

If you would like to lodge a complaint about any of the data collection or processing for any research within MISFIRES, please contact the Data Protection Commission in Ireland [www.dataprotection.ie](http://www.dataprotection.ie)

### **Google analytics**

MISFIRES uses Google Analytics to collect data in real-time about you and your visits to the MISFIRES website [misfires-erc.eu](http://misfires-erc.eu)

We use this information to understand better our website visitors and what interests them. From this we can identify ways to improve our website and the information that we provide via it. We also use the anonymised results from using Google Analytics to report to our funder but all the data is anonymised and is the aggregated result. We do not use the data to re-identify you.

For more information on google analytics privacy policy which includes details of how to opt-out please see the following website: <https://policies.google.com/privacy>

### **Security**

We take appropriate physical and technical security measures, including staff awareness training to maintain the security of personal data supplied to us and we review these measures regularly.

### **Further Information**

Further information on your data privacy rights is available on the website of the Data Protection Commissioner [www.dataprotection.ie](http://www.dataprotection.ie)

### **Contact details of UCD Data Protection Officer (DPO)**

If you have any questions or concerns in relation to the any element of the data within the MISFIRES project, please contact the UCD DPO on [gdrp@ucd.ie](mailto:gdrp@ucd.ie)

MISFIRES reserves the right to review and amend this statement at any time without notice and this statement is not to be construed as a contractual undertaking.

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