



Food | Consumer | Health
Designing a world-class infrastructure to facilitate research

Presenters: Monique Raats

Date: 28 September 2018

Occasion: RICHFIELDS Final Event

RICHFIELDS Data sharing survey in eight EU Member States

Monique Raats, m.raats@surrey.ac.uk
University of Surrey

www.richfields.eu

#RICHFIELDS

Coordinated by:

Wageningen Economic Research



WAGENINGEN
UNIVERSITY & RESEARCH



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 654280.



	Pre-food purchase	Point-of-sale	Post-purchase	Pre-food preparation	Point-of-preparation	Consumption
Knowledge & understanding	<ul style="list-style-type: none"> • Searching for experiences • Searching for offers • Comparing products & prices • Store/ restaurant search/ locator 			<ul style="list-style-type: none"> • Sharing knowledge & experience • Searching for information 		
Planning & organisation	<ul style="list-style-type: none"> • Creating shopping lists • Booking services • Budgeting 			<ul style="list-style-type: none"> • Documenting/ recording food • Meal/menu planning • Recipe management 		
Food purchase		<ul style="list-style-type: none"> • Placing an order 	<ul style="list-style-type: none"> • Transactions 			
Meal preparation/ cooking					<ul style="list-style-type: none"> • Using apps as cooking aids • Interacting with sensors 	
Food intake						Documenting/ recording food for: <ul style="list-style-type: none"> • Behaviour change • Medical support • Food logging

Characterising apps - Quality Criteria

Descriptive Criteria

What is it?

- Data Types
- Home page
- Contact Information
- Supported platforms
- Paid Services
- Medical Device
- Preparation Categories
- Price of IOS app
- Languages
- Itunes user rating
- Itune Genre
- Current IOS apps
- Minimum Android version

Scientific Criteria

Is it useful?

- Lifestyle Data
- Situational Characteristics
- Types of Situational Characteristics
- Product Characteristics
- External Device
- Data integration with partner tools
- What was purchased/prepared/consumed?
- What was purchased/prepared/consumed?
- What was prepared?
- Act or Intention?
- Units of purchase/preparation/consumption?

Technical Criteria

Can we access it?

- Is data accessible?
- Types of Access
- Data Formats
- Authentication
- Price
- Amount

Legal/Ethical Criteria

Can we use it?

- Terms of use
- Privacy Policy
- Data ownership
- Data usage vendor
- Personal information
- Types of personal information
- Public profile
- Privacy settings
- Device data
- Types of device data
- Cookies
- Web beacons
- Data storage

Ethical and privacy principles relevant to health research

Ethical principles	Privacy principles
<ul style="list-style-type: none">• Autonomy• Respect rights and dignity of patients• Respect clinical judgment of clinician• Duty to Provide Care• Protection of the public from harm• Beneficence• Justice• Non-maleficence (an obligation not to inflict harm intentionally)• Reciprocity• Solidarity• Stewardship• Trust• Lawfulness• Transparent project approval process	<ul style="list-style-type: none">• Accountability of personal information• Collection of personal information• Consent• Use of personal information• Disclosure and disposition of personal information• Accuracy of personal information• Safeguarding personal information• Openness/transparency• Individual access to personal information• Challenging compliance to ensure accountability is achievable• Anonymisation process for secondary uses of health data• Lawfulness• De-identification process• Data linkage

Source: de Lusignan et al. J Innov Health Inform. 2015;22(4):426–432

Key issues of ethical concern

- Essential issues of ethical concern with regard to personal data for research purposes:
 - Privacy
 - Informed consent
 - Ownership of data
- Article 830 of the Charter of Fundamental of the European Union provides every individual has the right to protection of personal data about him or her. To legitimise processing consent is pivotal.
- The GDPR emphasises consent and imposes significant responsibilities on entities that process data. For consent to be valid
 - 1) it must be freely given;
 - 2) a proper explanation of what the individual is consenting to must have been provided before the consent is obtained;
 - 3) separate consents must be given for separate purposes;
 - 4) consent can be refused; and (most important of all)
 - 5) consent can be withdrawn at any time.

Informed consent

- Foundation of principles of consent in research today:
 - Consent is the central act in research ethics, as set out in the 1947 Nuremberg Code.
 - 1964 Helsinki Declaration stipulated that valid consent is properly informed and also freely given – without pressures such as coercion, threats or persuasion.
- Seeking informed consent is central to the conduct of ethical research and, wherever possible and appropriate, potential research participants should be provided with the information they need to help them decide whether they wish to take part in research or not.

Consent processes in app mediated research

- The methods and procedures used to seek informed consent and the level of information provided should be proportionate to the:
 - nature and the complexity of the research;
 - risks, burdens and potential benefits (to the participants and/or society);
 - ethical issues at stake.
- Unique risks:
 - Risk to privacy through opportunity to gather more and different types of data through than would be possible in traditional studies - participants are potentially more easily identifiable because of diversity and volume of data being collected
 - Because of its highly structured, electronic nature, data collected through app-mediated research can be easily redistributed to third parties.

Legal/ethical criteria - Can we use it? - *Data sharing study*

- Range of data types being shared
- Data sharing context
 - Scientists in universities and publically funded research institutes need data to study the relationship between food and health.
 - Governments need data to develop and monitor nutrition policies in place to improve food and health.
 - Companies that produce or sell foods and drinks (e.g. manufacturers, retail chains, restaurants, food delivery services) need data to do research to develop and improve their products.
- Predictors of willingness to share data
 - Trust and confidence in organization handling data
 - Privacy concerns
 - Reasons for sharing
 - Values (how you see the world), dimensions:
 - Self-conservation (tradition, acceptance)
 - Self-transcendence (success, adventure)
 - Attitudes to science
 - Attitudes to food and health
 - Cooking/shopping practices
 - Perceived health

Questionnaire development procedure

- Questionnaire developed by Surrey with input from WP4-7
- Quota sample – gender: 50% women, 50% men; age: 20% 18-29, 20% 30 to 39, 20% 40 to 49, 20% 50 to 59, 20% 60+
- Questionnaire translated by RICHFIELDS partners & Surrey's networks



Rationale for country selection

Country	% high health privacy concern responses*	entered the EU	Time in EU	Region	Cuisine	Health care system type*	Role in FNH-RI in preparation
France	40-60%	1952	EU-15	Western Europe	Western	Type 4	2017 Focus Countries with a national node
Germany	20-40%	1952	EU-15	Western Europe	Central	Type 4	2018 Focus Countries with possibilities for a national node
Italy	20-40%	1952	EU-15	Southern Europe	Southern-Mediterranean	Type 1	Core country and initiative taker
Netherlands	20-40%	1952	EU-15	Western Europe	Western	Type 1	Core country and initiative taker
Slovenia	0-20%	2004	"new"	Southeast Europe	Central-Southern	Type 1	2017 Focus Countries with a national node
Spain	40-60%	1986	EU-15	Southern Europe	Southern-Mediterranean	Type 2	2017 Focus Countries with a national node
Sweden	0-20%	1995	EU-15	Nordic Countries	Northern	Type 2	2017 Focus Countries with a national node
United Kingdom	40-60%	1973	EU-15	Western Europe	Northern	Type 1	Core country and initiative taker

*Patil S, et al. (2016) Public preferences for electronic health data storage, access, and sharing – evidence from a pan-European survey. J Am Med Inform Assoc 2016;0:1–11. doi:10.1093/jamia/ocw012

**type according to Wendt (2014) Changing Healthcare System Types. Social Policy & Administration, 48: 864–882. doi: 10.1111/spol.12061

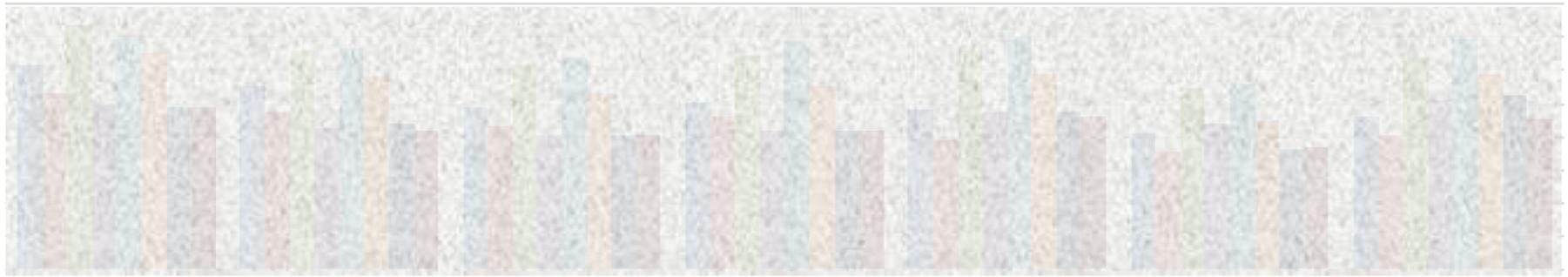
Type of data generated: % respondents producing search data



■ France ■ Germany ■ Italy ■ Netherlands ■ Slovenia ■ Spain ■ Sweden ■ UK

Type of data generated: % respondents producing “opinion sharing” data

100
90
80
70
60
50
40
30
20
10
0



Share views on places to eat or drink (e.g. posting restaurant reviews on the Internet)

Share views on foods and ingredients (e.g. posting product reviews on the Internet)

Share views on cooking techniques (e.g. posting reviews of video clips on how to prepare food)

Share views on recipes (e.g. posting recipe reviews on the Internet)

Post comments about food and/or drinks on social media

Post videos of food and/or drinks on social media

Post photos of food and/or drinks on social media

■ France ■ Germany ■ Italy ■ Netherlands ■ Slovenia ■ Spain ■ Sweden ■ UK

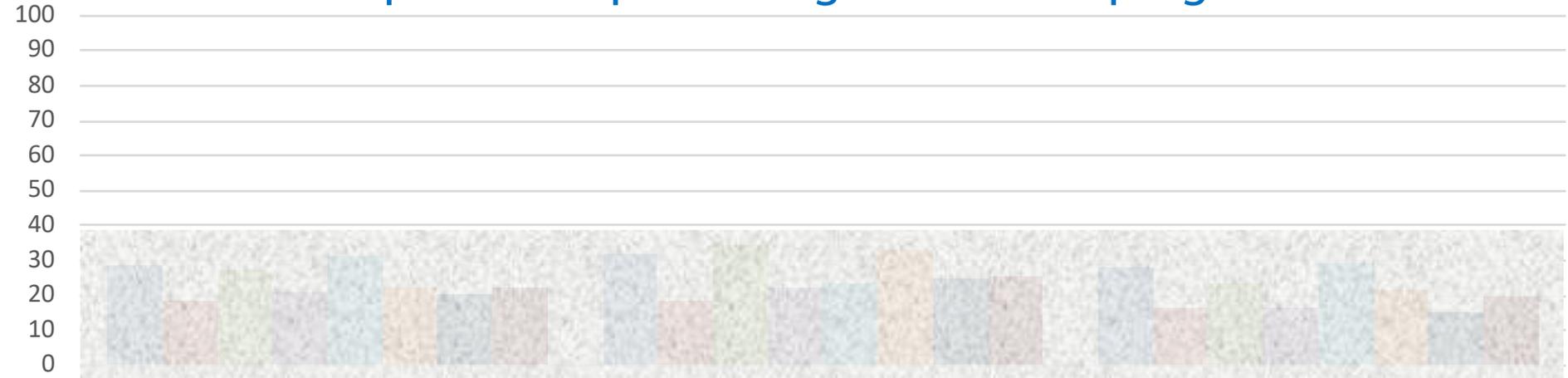
Type of data generated: % respondents producing “planning and buying” data



Type of data generated: % respondents producing “record keeping” data



Type of data generated: % respondents producing “record keeping” data



Prepared (e.g. your smart phone, kitchen appliances that record what you are doing e.g. food weighing scales or pans that record temperatures, smart meters that record how much gas, electricity or water you have used)

Purchased (e.g. location data from your smart phone, Wi-Fi login in shops or restaurants)

Eaten (e.g. location data from your smart phone, sensors in kitchenware)

■ France ■ Germany ■ Italy ■ Netherlands ■ Slovenia ■ Spain ■ Sweden ■ UK

Data sharing contexts

Parties with whom data could be shared	Data needs
Universities and publicly funded research institutes	To study the relationship between food and health
Governments	To develop and monitor nutrition policies to improve food and health
Companies that produce or sell foods and drinks (e.g. manufacturers, retail chains, restaurants, food delivery services)	To do research to develop and improve their products

RED=variables that are measured separately for the three types of stakeholders

Attitudes

- Trust (+)
- Risk (-)
- Science attitudes (+)
- Privacy concerns (-)

Values

- Self transcendence (+)
- Conservation (-)

Health

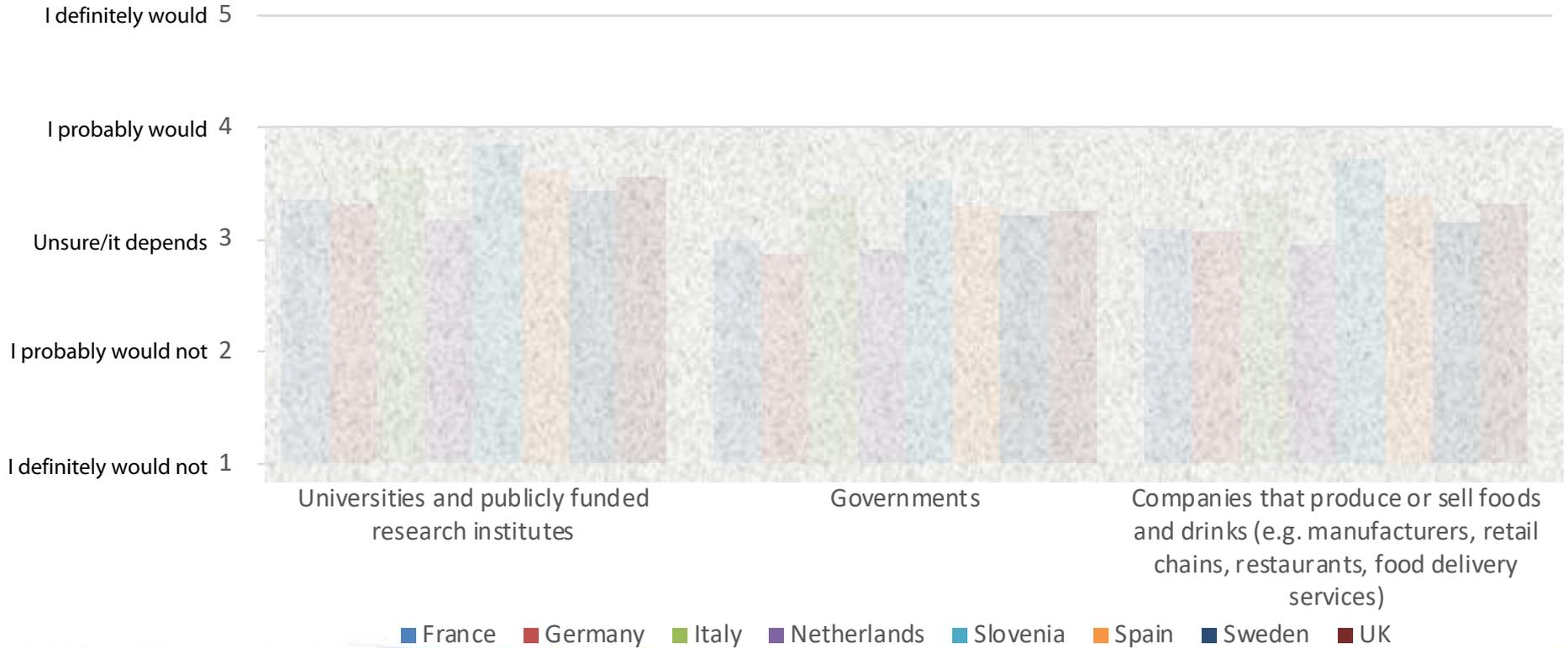
- Perceived health (+)
- Attitudes to food/health(+)
- Cooking/shopping practices (+)

Moral motivation

- Pure altruism (+)
- Reluctant altruism (-)
- Social responsibility (+)
- Warm glow (-)
- Kinship (+)
- Reputation (-)

Willingness to
share data

Willingness to share data



Willingness to share data

- Willingness to share differed both by country, $F(7, 7716) = 61.155, p < .001, \eta^2 = .053$, and by stakeholder, $F(2, 7716) = 577.249, p < .001, \eta^2 = .070$
- The interaction was significant but very weak $F(14, 7716) = 6.414, p < .001, \eta^2 = .006$
- Planned contrasts showed that participants were more willing to share with universities than with governments and companies, $F(1, 7716) = 584.073, p < .001, \eta^2 = .127$
- Participants were also more willing to share with companies than governments, but this effect was very weak, $F(1, 7716) = 47.530, p < .001, \eta^2 = .008$.

Trust questions

- ... have the skills and expertise to handle the public's personal data in a way that protects their privacy.
- ... have access to the information and skills to handle the public's personal data securely.
- The way ... make the decisions to handle the public's personal data is transparent.
- The way ... make the decisions on how handle the public's personal data is fair.
- ... are fair in their use of the public's personal data.
- ... are fair in their user policies regarding the use of the public's personal data.
- ... are open and receptive to the public's' concerns about private data handling.
- ... keep the public's best interest in mind when handling their data.
- ... have the same opinions as me about handling the public's data.

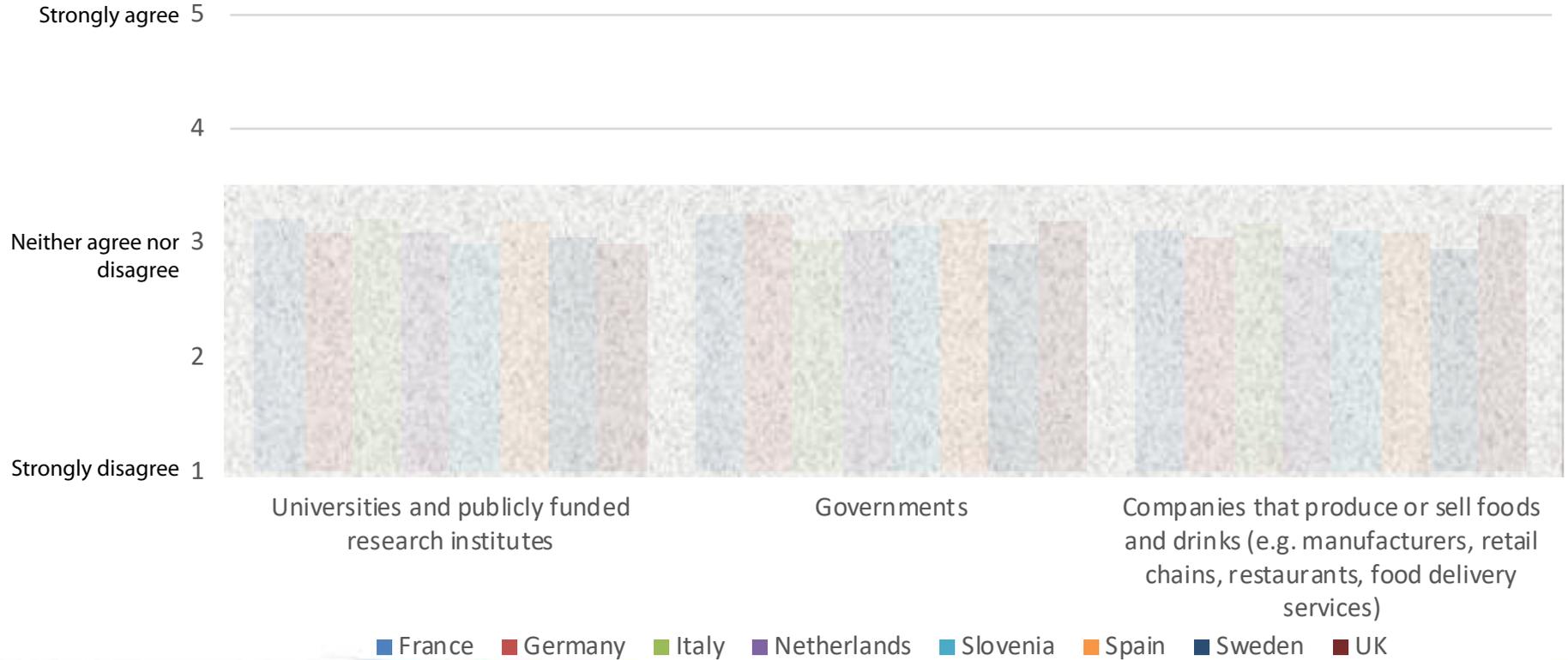
Trust in ability to handle data



Perceived risk questions

- In general, it would be risky to give my data to ...
- There would be too much uncertainty associated with giving my data to ...
- ... with my data would involve many unexpected problems.
- I would feel safe giving my data to ...

Perceived risk in sharing data with ...



Moral motives for sharing food-related data

PURE ALTRUISM	<p>I think that by sharing food-related data I could save someone's life</p> <p>By sharing food-related data I could help others</p> <p>By sharing food-related data I would be doing the right thing</p>
WARM GLOW	<p>After sharing food-related data I would feel proud by helping</p> <p>Sharing food-related data would make me feel physically good</p> <p>The world would be a better place if everyone who could would share food-related data</p> <p>After sharing food-related data I would feel good about myself</p>
RELUCTANT ALTRUISM	<p>Someone has to share food-related data</p> <p>I would have to share food-related data because other people can't</p> <p>I cannot trust others to share food-related data</p>
SOCIAL RESPONSIBILITY	<p>By sharing food-related data I would be responsible for helping others</p> <p>By sharing food-related data I would be having a personally rewarding experience</p> <p>By sharing food-related data, I would be fulfilling my duty to society</p> <p>By sharing food-related data, I would be giving back to the community</p>
REPUTATION	<p>If I shared food-related data, I would show people that I am a good, kind person</p> <p>By sharing food-related data, I would let my friends know that I am a good, kind person</p> <p>By sharing food-related data, I would let potential romantic partners know I am a good, kind person</p>
KINSHIP	<p>If I shared food-related data, there is more of a chance of my family benefitting from it</p> <p>If I shared food-related data, there is more of a chance of my close relatives benefitting from it</p> <p>If I shared food-related data, there is more of a chance of my friends benefitting from it</p>

Modelling

- Three models, predicting willingness to share with universities, governments and companies, respectively
- Enter all variables; backward elimination
- Produces a very parsimonious model that explains over 40% of the variance for all three outcomes
- **Predicting willingness to share data (β s and R^2 s)**

		Universities	Governments	Companies
β of the final model	Trust	.499	.433	.405
	Risk	-.118	-.100	-.030
	Moral motivation	.210	.255	.279
Final model vs null	χ^2 (3)	3391.4, $p < .001$	3844.9, $p < .001$	3184.0, $p < .001$
Explained variance: final model (full model)	R^2	.42	.46	.41
				All $ps < .001$

Maximizing the public's willingness to share food-related data

- Richfields will to identify appropriate means of:
 - maintaining and if possible growing trust
 - maintaining and if possible growing moral motives
 - maintaining and if possible lessening perceived risk

Recommendations from the framework for the design of the ethical and legal aspects of RICHFIELDS

- (1) use of pseudonymisation with appropriate safeguards for unauthorised reversal of pseudonymisation
- (2) use of appropriate technical and organisational measures to ensure GDPR compliance
- (3) systems for dealing with queries and requests from data subjects
- (4) appointment of a Data Protection Officer
- (5) mechanisms for handling freedom of information (FOI) requests
- (6) use of suitable data protection clauses for trans-border data transfer
- (7) obtaining insurance to cover liability in the event of data breaches
- (8) the establishment of an independent ethics committee with remit to monitor the activities of RICHFIELDS, its protocols on matters relating to security, transfer of data to third countries, assessing genuineness of requests from data users and procedures for dealing with ethically suspect requests, and procedures for handling requests from data subjects.

Particular thank you to:

- Questionnaire development team:
 - **RISE:** Anne Norman
 - **Wageningen University & Research:** Anouk Geelen, Marcus Maringer, Muriel Verain
 - **University of Surrey:** Lada Timotijevic, Charo Hodgkins
- Questionnaire/data managers: Morro Touray, Matthew Peacock (University of Surrey)
- All those involved in translation process



www.richfields.eu

#RICHFIELDS

Coordinated by:

Wageningen Economic Research



WAGENINGEN
UNIVERSITY & RESEARCH

Partners:



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 654280.

Thank you
Any questions?