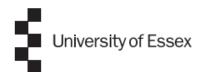




# Consent to Data Linkage: Wording and Placement Experiments

Sandra Walzenbach (University of Konstanz)
Annette Jäckle (University of Essex)
Jonathan Burton (University of Essex)
Thomas F. Crossley (European University Institute)
Mick P. Couper (University of Michigan)







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### Research Questions

Overall goal: maximize informed consent

#### RQ1:

Do variations in question wording affect <u>rates of consent</u> to administrative data linkage?

Does easier wording improve <u>objective understanding</u>, <u>subjective understanding</u>, <u>and confidence</u> in the decision?

RQ2: What effects do variation in question wording have on the <u>time taken</u> to respond to the consent question and whether respondents consult <u>additional materials</u>?

### Outcomes

- Consent rate
- Objective understanding (index of 8 knowledge questions)
- Subjective understanding
- Confidence

- Response time
- Consulted additional material (leaflet and diagram)

### What do we know?

#### Length of request / more information

mixed results concerning understanding and consent rates

(survey research: Das & Couper 2014; Edwards & Biddle 2021) (biomedical studies: Brierley, Richardson & Torgerson 2012; Enama et al. 2012; Matsui et al. 2012; Stunkel et al. 2010; Perrault & Nazione 2016; Varnhagen et al. 2005)

#### Readability (simplified wording and layout)

mixed results concerning understanding and consent rates in biomedical studies

(Antonacopoulos & Serin 2016; Cockayne et al. 2017; Coyne et al. 2003; Grady et al. 2017; Hall et al. 2013; Kim & Kim 2015; Paris et al. 2010, 2015; Perrault & Keating 2018; Tait et al. 2013; Walters & Hamrell 2008)

#### Location

early in the survey increased consent

(Sala, Knies & Burton 2014, Eckman & Haas 2017, Sakshaug et al. 2019)

### What do we know?

#### Opt-in vs opt-out

- No research on data linkage consent
- Small nudges including default options increase participation in various activities (Dinner et al. 2011; Dranseika & Piasecki 2020; Hummel & Maedche 2019; Loewenstein et al. 2015; Reisch & Sunstein 2016)

#### Response time / Additional material (medical or survey research)

- Respondents skim-read or skip additional info (McNutt et al. 2007; Matsui et al. 2012; Perrault & Keating 2018; Perrault & McCullock 2019; Desch et al. 2011; Ghandour, Yasmine & El-Kak 2013)
- No effect of reading time on consent (Ghandour, Yasmine & El-Kak 2013)
- Positive correlation with understanding (Perrault & Keating 2018)

### Data

Understanding Society Innovation Panel 11

(probability sample of households in Great Britain; fielded May-October 2018)

IP11 face-to-face (n=1363) IP11 web (n=1299)

Populus Live Access Panel

(quota sample designed to match IP respondents)

- AP 1.1 (Five experimental conditions with n~500 each; May 2018)
- AP 1.2 (repetition of some to measure consistency over time; May 2019)
- AP 2 (follow-up experiments; December 2019)

If not stated otherwise, the presented results are on data linkage requests with tax data (HMRC).

## **Experimental Variations**

		IP11	IP11	AP1.1	AP1.2	AP2
		f2f	web			
1	Easy vs. standard wording of consent question	х	х	х	х	
	Early vs. late placement in questionnaire	x				
2	Additional information wording			x		
	Consent as default			x		
3	Trust priming					x
	Sample sizes	1,363	1,299	2,563	817	1,921

Wording crossed with location in the IP11 face-to-face sample.

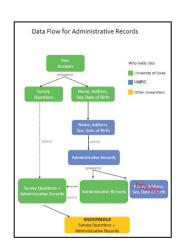
### Experimental variations

- easy vs difficult wording
- location: early vs late
- offer of more information
- opt-in vs opt-out (consent by default)
- trust priming

## 1a) Standard vs easy wording

#### Control group ("standard"):

standard Understanding Society consent question text and diagram



#### Treatment group ("easy"):

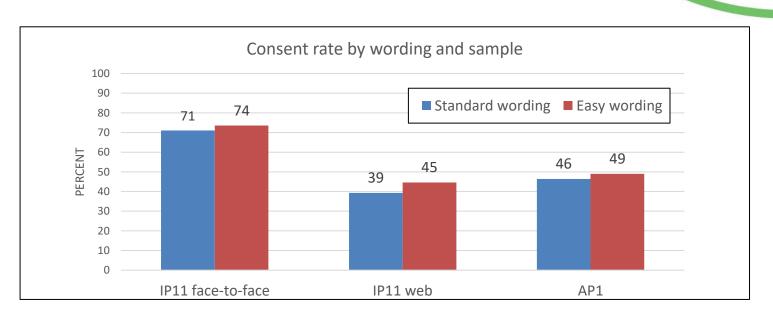
shorter sentences, avoids passive voice, uses bullet points and contains more info; more readable version of the diagram

Flesch reading ease: standard 41 – easy 63 (out of 100)

Flesch-Kincaid Grade level scores: standard 14.5 – easy 8.2



## 1a) Standard vs easy wording



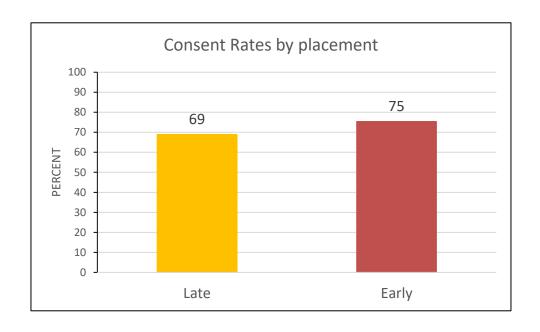


significant positive effect

n.s. non-significant difference

significant negative effect

### 1b) Location (IP11 f2f)



Consent rate (%)

Objective understanding (0-8)

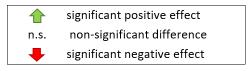
Subjective understanding (1-4)

Confidence (1-4)

Response time (median)

Consulted materials (%)

n.s.



### Experimental variations

- easy vs difficult wording
- location: early vs late
- offer of more information
- opt-in vs opt-out (consent by default)
- trust priming

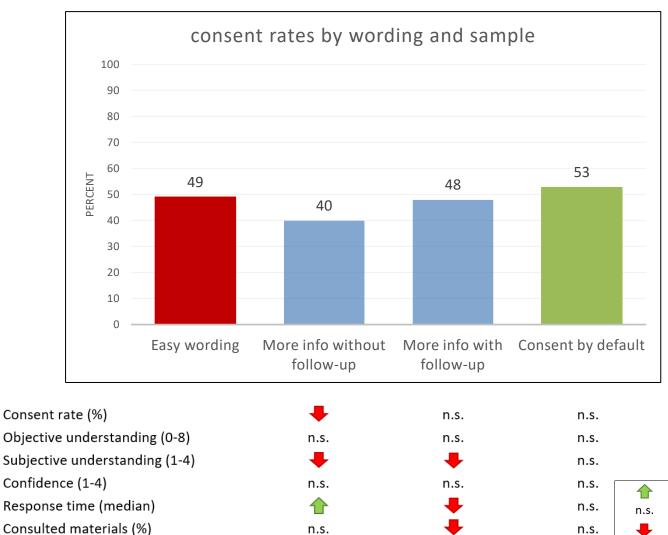
## 2a) Offer of more information

More info - no follow-up	More info - with follow-up		
Please read this <u>leaflet</u> and look at this <u>diagram</u> for further information.			
Do you give permission?	Do you give permission?		
<ul> <li>Yes</li> <li>I need more information before making a decision</li> <li>No</li> </ul>	<ul> <li>Yes</li> <li>I need more information before making a decision</li> <li>No</li> </ul>		
	For more information on the data linkage, please read this <u>leaflet</u> and look at this <u>diagram</u> .		
	Do you give permission?  o Yes o No		

## 2a) Offer of more information

More info - no follow-up	More info - with follow-up	
Please read this <u>leaflet</u> and look at this <u>diagram</u> for further information.	Of those who said they want information (20%), 55% click least one link.	ed more ed on at
<ul> <li>Do you give permission?</li> <li>Yes</li> <li>I need more information before making a decision</li> <li>No</li> </ul>	<ul> <li>Do you give permission?</li> <li>Yes</li> <li>I need more information before making a decision</li> <li>No</li> </ul>	
Only 24% of those who indicated they wanted more information clicked on the additional material.	For more information on the data linkage, please read this <u>leaflet</u> and look at this <u>diagram</u> .  Do you give permission?  Yes  No	

## 2b) More info / consent by default



(AP1.1)

significant positive effect

n.s. non-significant difference
significant negative effect

### Experimental variations

- easy vs difficult wording
- location: early vs late
- offer of more information
- opt-in vs opt-out (consent as default)
- trust priming

### 3) Trust Priming (AP W2)

Screen before consent question was varied:

```
"The next question is about linking the information you provide in
this survey, to data that
```

(HM Revenue and Customs or HMRC) /

(The National Health Service or NHS)

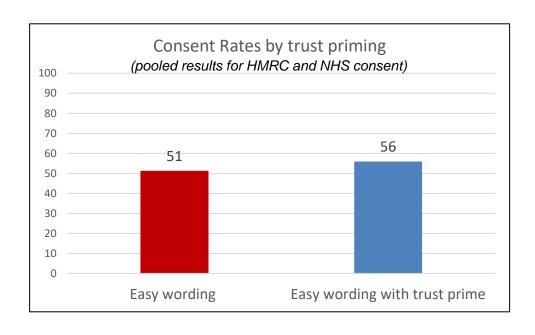
hold about you."

#### In treatment group:

"(HMRC) / (The NHS) is a trusted data holder."



## 3) Trust Priming (AP W2)



Consent rate (%)	1
Objective understanding (0-8)	n.s.
Subjective understanding (1-4)	n.s.
Confidence (1-4)	n.s.
Response time (median)	n.s.
Consulted materials (%)	n.s.

significant positive effect

n.s. non-significant difference

significant negative effect

### Conclusion

#### 1) Easy wording

- ...helps mostly objective understanding (and sometimes subjective understanding); tends to increase consent rates
- Web respondents were less likely to click on additional materials
   Early placement helps consent

#### 2) Additional information conditions

had no or detrimental effects on consent and understanding.

#### **Consent by default**

has no significant effect on consent or any other observed outcome.

#### 3) Trust priming

- ... significantly increased consent
- ... did not affect objective or subjective understanding, confidence in the consent decision, or response time

## Thank you for listening!

sandra.walzenbach@uni-konstanz.de

https://www.iser.essex.ac.uk/research/projects/ understanding-and-improving-data-linkage-consent-in-surveys

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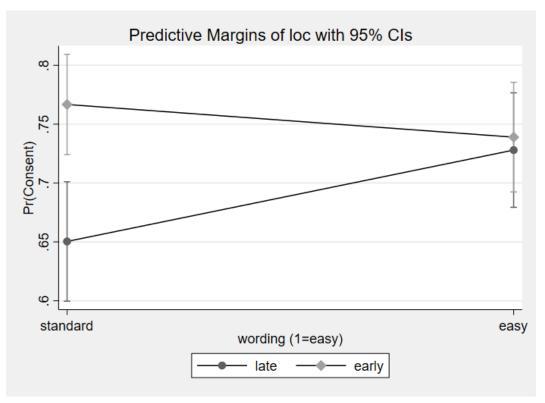
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### 1c) wording\*location (IP11 f2f)



Estimates from logistic regression of consent on wording and location

- → Early placement helps consent.
- → Combination of standard wording and late positioning is particularly detrimental to consent.

#### Standard consent question wording

We would like to add records held by HM Revenue and Customs, or HMRC, containing information on your employment and self-employment history, your income, National Insurance contributions and tax credits. All information will be used for research purposes only by academic or policy researchers under restricted access arrangements which make sure that the information is used responsibly and safely.

Please read this <u>leaflet</u> and look at this <u>diagram</u> {Version B} explaining how we would like to attach your HMRC records to the answers you have given in this study.

Do you give permission for us to pass your name, address, sex and date of birth to HMRC for this purpose?

- 1) I have read the leaflet and am happy to give consent
- 2) I do not want to give consent

#### Easy consent question wording

We would like to add records held by HM Revenue and Customs, or HMRC, to the answers you have given in this study. If you agree:

- We will send HMRC your name, address, sex and date of birth so that they can identify the records they
  have about you. The HMRC records contain information about your current and previous employment,
  your income, National Insurance contributions and tax credits.
- We will not send HMRC the answers you have given in this study.
- HMRC will send us your records. These will contain an anonymous identification number but not your name, address, sex or date of birth.
- We will add the HMRC records to the answers you have given in this study.
- We will make the combined anonymous data available for academic and policy research purposes only.
- Access to the data will be restricted and controlled, to make sure that researchers use the information responsibly and safely.
- This will not affect the way that you deal with the HMRC in any way.

Please read this <u>leaflet</u> and look at this <u>diagram</u> {Version A} for further information.

Do you give permission for us to pass your name, address, sex and date of birth to HMRC for this purpose?

### Wording of consent requests

#### Consent as default

Press "next" to continue.

I do not want HMRC records to be added to my answers to this survey.

#### Additional information without follow-up

Please read this leaflet and look at this diagram (Version A) for further information.

Do you give permission...?

Yes

I need more information before making a decision

No

## Wording of consent requests

#### Additional information with follow-up

```
[PAGE 1]
Do you give permission...?
Yes
I need more information before making a decision
No
```

[PAGE 2]

For more information on the data linkage, please read this leaflet and look at this diagram.

Do you give permission...?

Yes

No

#### Objective understanding of data linkage

To help us understand whether the explanation we gave you about linking HMRC data and your answers to this study was clear or unclear, here are a few statements about how the linkage is done. Please specify whether you think each of the statements is true or false.

Answer categories: True/false for each row

- Every researcher can access the combined data via the Internet
- HM Revenue and Customs will combine the information they have with your answers to this study
- Researchers using the data will only have access to anonymous data
- The combined data can be used by HM Revenue and Customs to check that you have been paying your taxes.
- HM Revenue and Customs will send us the information they have about you.
- Your name, address, sex, and date of birth will be saved with the linked data.
- We will send your name, address, sex, and date of birth to HM Revenue and Customs.
- HM Revenue and Customs will send us future data about you, unless you object in writing.

#### Subjective understanding of consent request

How well do you think you understand what would happen with your data, if you allowed us to link it to records held by HM Revenue and Customs?

Please select one only

- 1 I do not understand at all
- 2 I understand somewhat
- 3 I mostly understand
- 4 I completely understand

#### Confidence in linkage consent decision

We are interested in how people decide whether or not to give us permission to add data held by HM Revenue and Customs to the answers they have given in this study.

How confident are you about the decision decisions you made? *Please select one only* 

- 1 very confident in my decision
- 2 confident in my decision
- 3 somewhat confident in my decision
- 4 not confident in my decision