

Internet and Social Media in Research-Tools and Tips

Christina Baggott, RN, PhD, PNP-BC, CPON

Assistant Professor

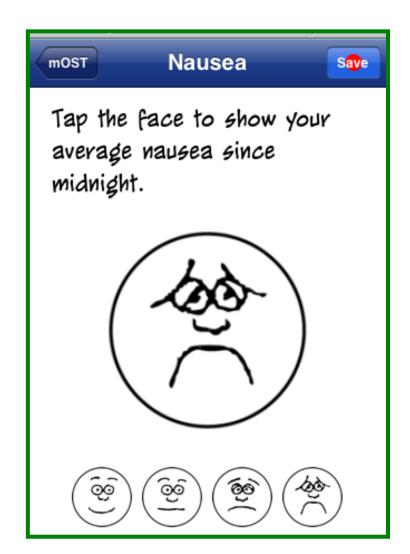
Department of Physiological Nursing

Christina.baggott@ucsf.edu



My program of research...

- Symptom assessment
 - Demographic
 - Clinical
 - Genotypic





My program of research..

Symptom management





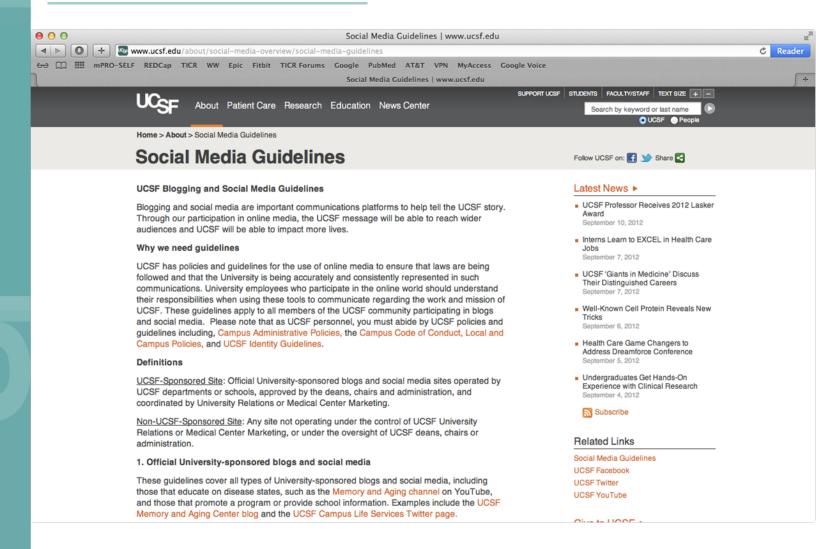
Topics Covered

- Social media research resources
- REDCap
- Qualtrics
- CHR





http://www.ucsf.edu/about/social-media-overview





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20 Excellent Social Media Networking Resources for Health Professionals via HealthWorksCollective.com

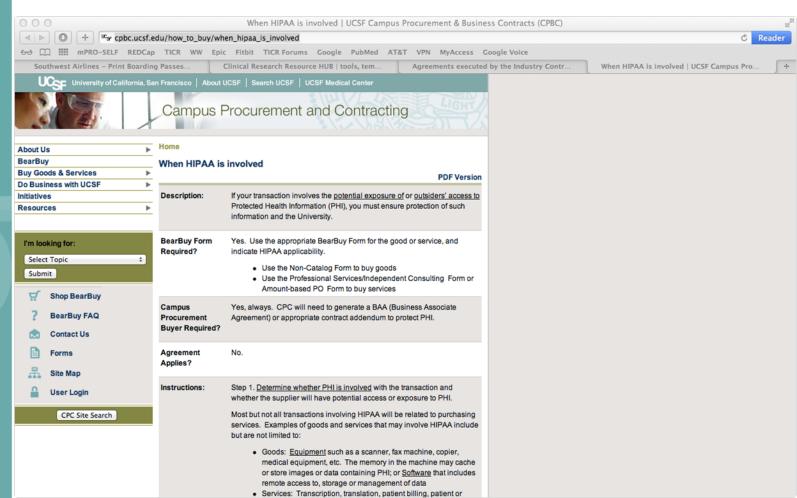
- 1. AMA Policy: Professionalism in the Use of Social Media
- Centers for Disease Control and Prevention (CDC) The Health Communicator's Social Media Toolkit [PDF]
- 3. Cleveland Clinic Social Media Policy
- 4. David Harlow, Esq. HealthBlawg
- 5. Deloitte Social Networks in Health Care: Communication, collaboration and insights [PDF]
- Healthworkscollective
- 7. Healthin30/Social Media | Social Networking
- 8. Found in Cache Hospital Social Network List Ed Bennett
- 9. IBM Social Computing Guidelines
- 10. Intel Social Media Guidelines
- 11. Kaiser Permanente Social Media Policy [PDF]
- 12. KevinMD
- 13. Lee Aase
- 14. Mashable
- 15. Mayo Clinic Center for Social Media
- 16. New AMA Policy Helps Guide Physicians' Use of Social Media
- 17. Pew Internet & American Life Project, August 26, 2011 [PDF]
- 18. Social Media Governance
- 19. Social Media Today
- 20. Web 2 0 Governance Policies and Best Practices





UCSF Privacy Issues

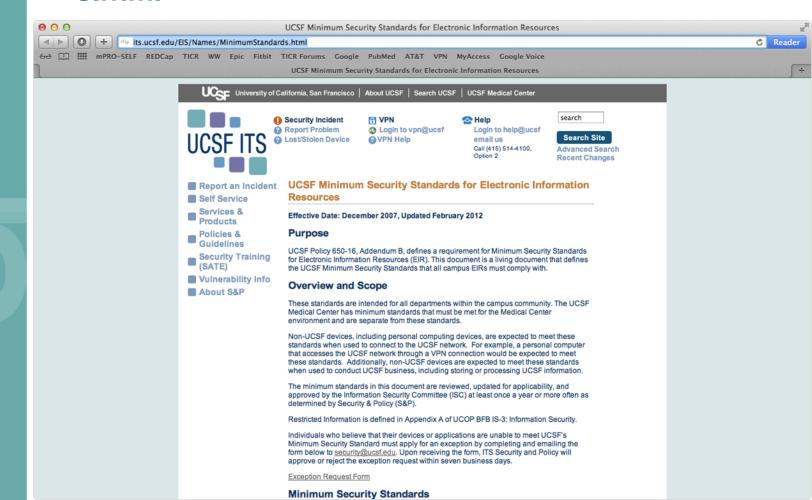
http://cpbc.ucsf.edu/how_to_buy/when_hipaa_is_i nvolved





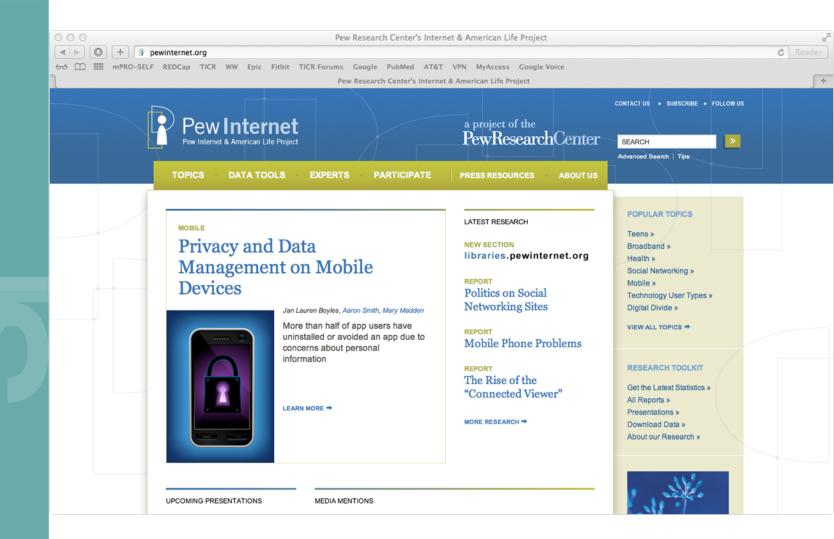
Privacy and Security

 http://its.ucsf.edu/EIS/Names/MinimumStandard s.html





Pew Internet & American Life Project

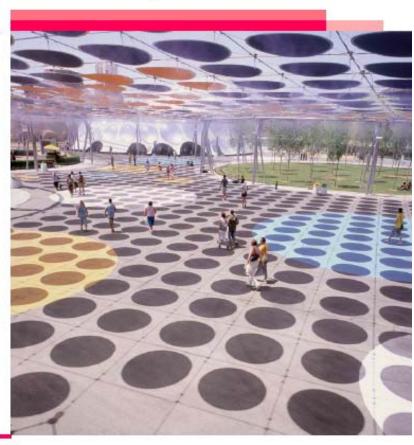




http://www.pwc.com/us/en/health-industries/publications/health-care-social-media.jhtml

Social media "likes" healthcare From marketing to social business

Health Research Institute April 2012



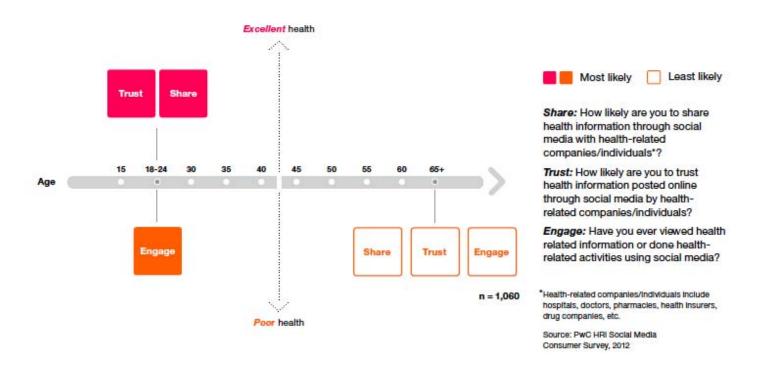


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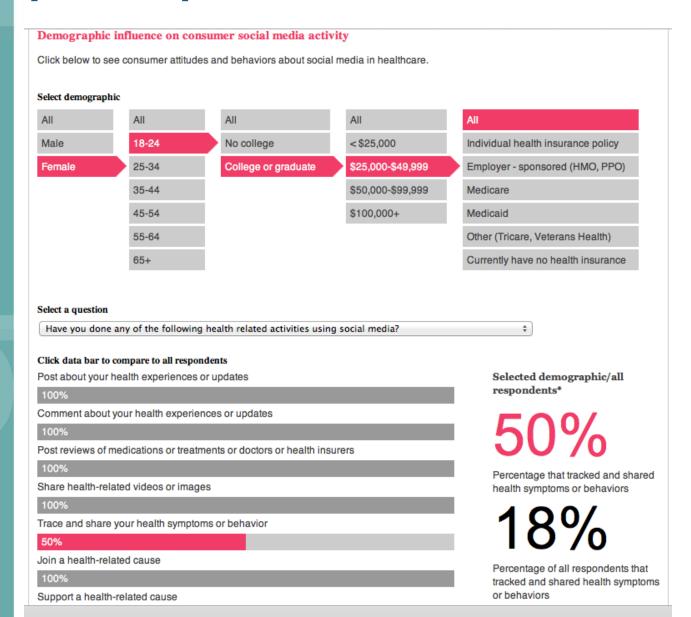
pwc Report

Figure 1: Impact of age level and health status on likelihood to engage, trust, and share about health using social media





pwc Report





REDCap

- Sanctioned by CTSA
- Not just for data collection any more...
- Easy communication with outside collaborators
- If aesthetics are important, consider Qualtrics
- Import data
- Create graphs
- Monitor usage/modifications
- Validate fields
- Use branching/skip logic
- Create paper trail, if desired
- Connect to other applications with API



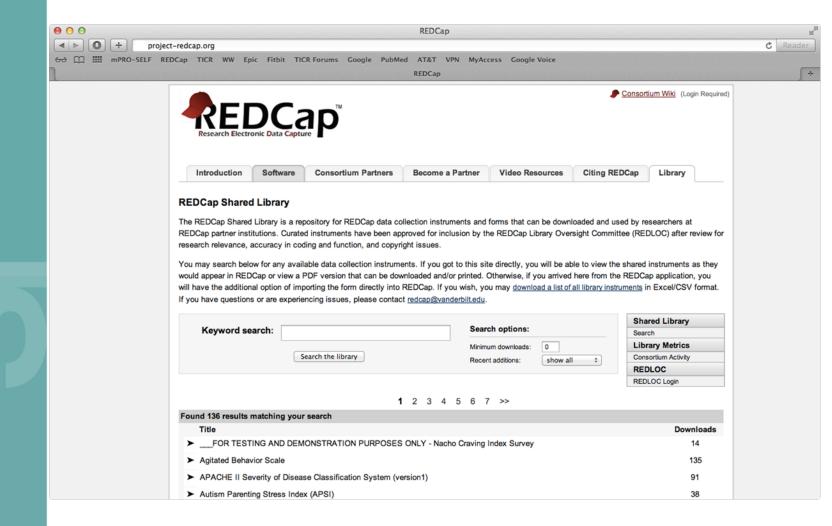
Collaborate Worldwide





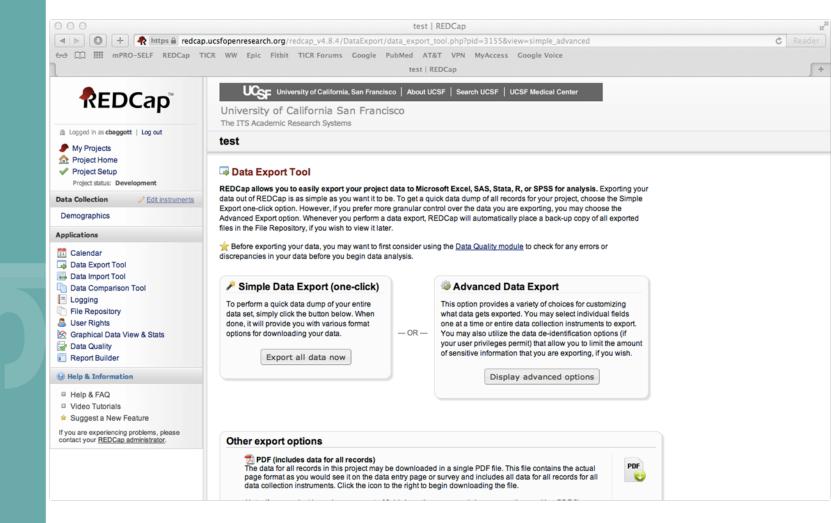


Instrument Bank





Export Data-One Click





Export: De-Indentified

De-Identification Options (optional)
The options below allow you to limit the amount of sensitive information that you are exporting out of the project. Check all that apply.
Known Identifiers:
Remove all known Identifier fields (tagged in Data Dictionary)
Hash the Study ID (converts record name to an unrecognizable value)
Free-form text:
Remove unvalidated Text fields (i.e. Text fields other than dates, numbers, etc.)
Remove Notes/Essay box fields
Date and datetime fields:
Remove all date and datetime fields
Shift all dates by value between 0 and 364 days (shifted amount determined by algorithm for each record)
What is date shifting?
Deselect all options

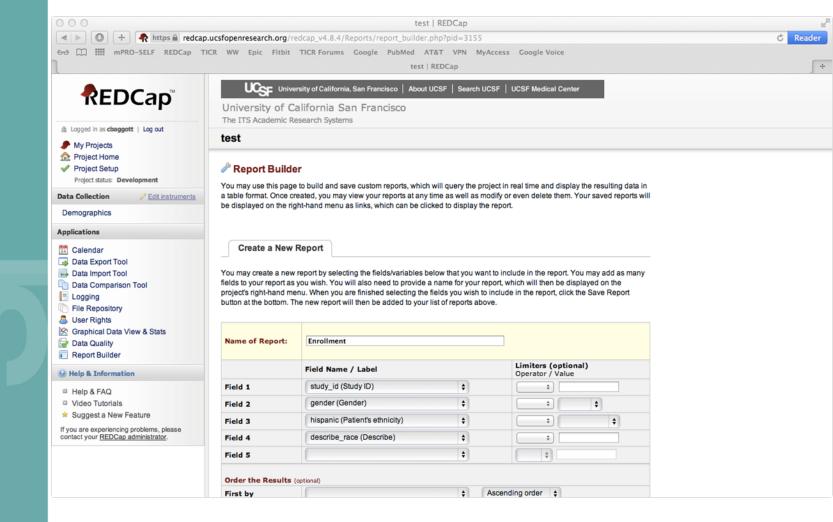


Export: Statistical Packages

		Download Syntax & Data
X	Microsoft Excel You may download the survey results in CSV (comma-separated) format, which can be opened in Excel. You have the choice of downloading the data either with the full headers and answer labels or just with the answer codes (i.e. raw data).	EXCEL CSV CSV Labels Raw
	NOTE: If you are using a version of Microsoft Excel prior to Excel 2007, due to limitations the data will only be read to 255 columns when opened.	☑ Send file?
SPSS	SPSS Statistical Analysis Software Instructions: Download and save all 3 files on the right to a common location. First, double-click on the Pathway Mapper (.bat) file, which will run quickly and invisibly. (If you are not using a Windows operating system, such as Mac or Linux, please see the Additional Instructions.) Now double-click on the *.sps file, which will open SPSS. When the file is loaded and displayed, choose Run>All from the top menu options. This action will launch the script that will automatically read in all data and manipulate data fields with labels, option values, etc. Additional instructions	Pathway Mapper Send file?
sas.	SAS Statistical Software Instructions: Download and save all 3 files on the right to a common location. First, double-click on the Pathway Mapper (.bat) file, which will run quickly and invisibly. (If you are not using a Windows operating system, such as Mac or Linux, please see the Additional Instructions.) Now double-click on the *.sas file, which will open SAS. When the file is loaded and displayed, choose Run (or Run>Submit) from the top menu options. This action will launch the script that will automatically read in all data and manipulate data fields with labels, option values, etc. Additional instructions	Pathway Mapper
	R Statistical Software Instructions: Use command read.csv('filename') to read in data file.	R CSV U
ਤਾਗਰ	STATA Analysis and Statistical Software Instructions: Download both files to common location and double-click on *.do file. This action will launch the script that will automatically read in all data and manipulate data fields with labels, option values, etc.	STATA CSV Send file?

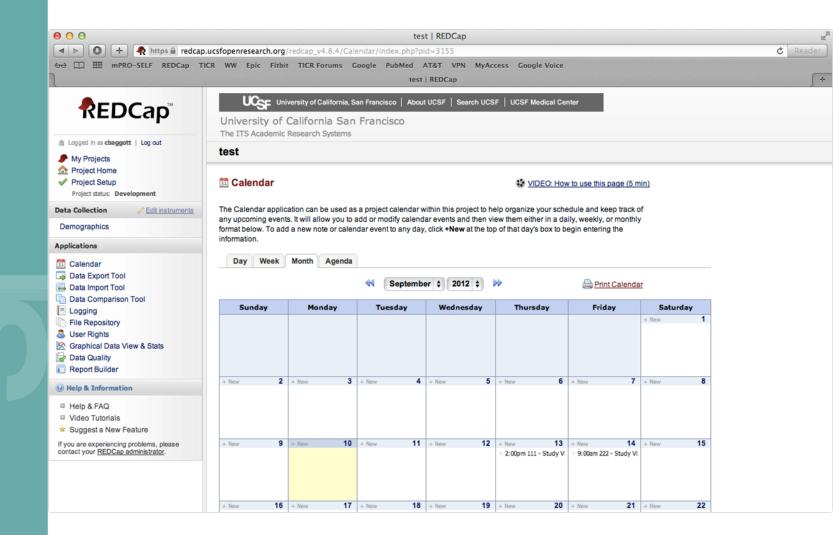


Report Builder





Schedule Study Visits





Upcoming Features

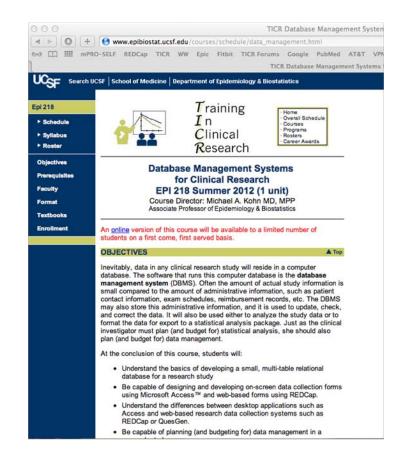
- Randomizer
- Matrix responses for Likert scales





REDCap Training

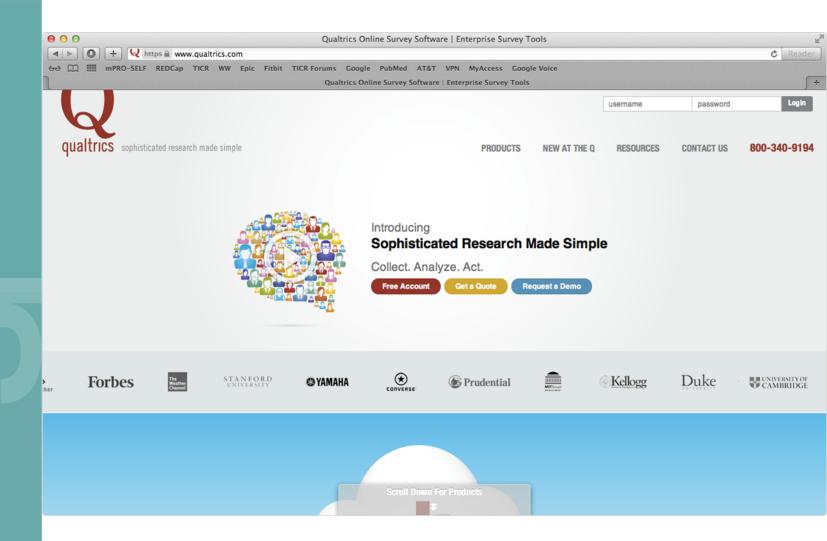
- Intermittent courses
 - Register in "Learning Center"
 - Visit booth at lunch today

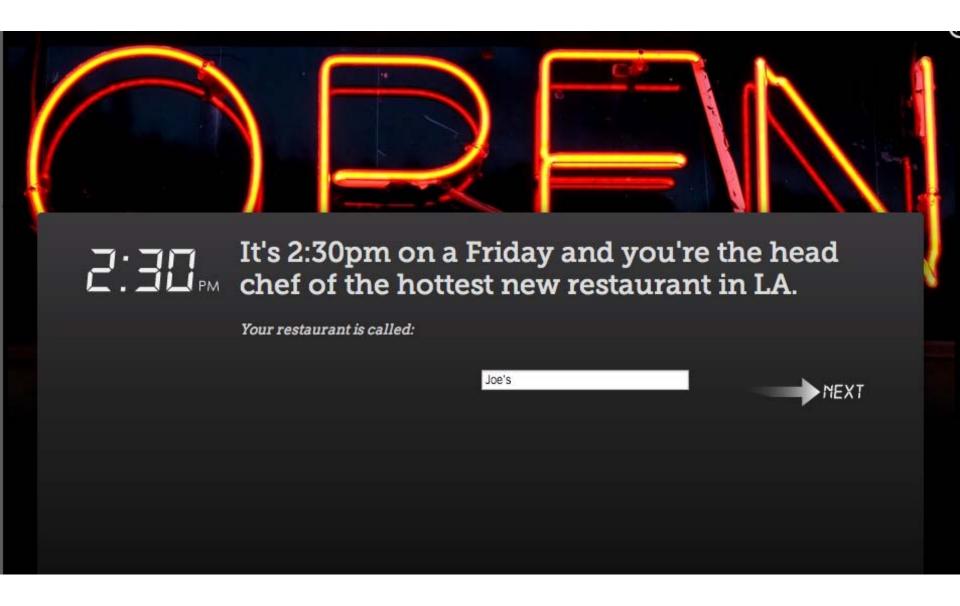


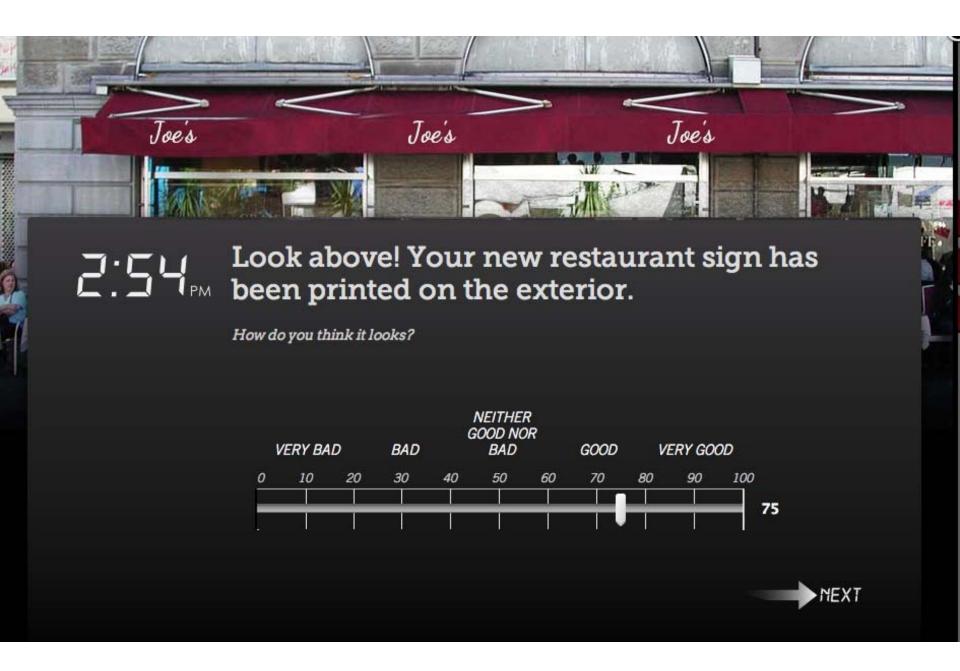




Qualtrics









Back in the kitchen, your Sous-Chef presents tonights featured menu item.

Click once on the elements you like, and twice on the elements you don't like.







Ivana Verducci, a food critic from the LA Times, arrives for a meal. The maitre d'asks for opinions on where to seat her.

Click on the image to cast your vote.





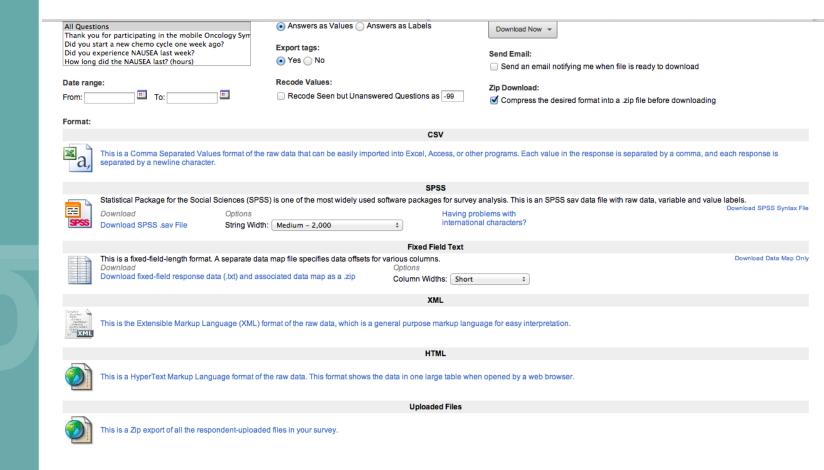


View Responses

Select: All None With Selected: View Delete Advanced Options Advanced Options										
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	Response ID	Respondent	Response Type	Start Time	End Time	Duration	Actions			
	R 50dEQyjzvxzBTko	148	IP Address	15 May 2012 04:11 PM	15 May 2012 04:36 PM	24m 43s	~			
	R 5i4uuXnKyt3J1hG	149	IP Address	15 May 2012 08:13 PM	15 May 2012 08:28 PM	14m 34s	▼			
	R 7afdzbqn696esQs	150	IP Address	17 May 2012 11:10 PM	17 May 2012 11:29 PM	18m 52s	~			
	R 5aNjyQTCQJTc2uU	153	IP Address	22 May 2012 11:05 AM	22 May 2012 11:44 AM	38m 57s	▼			
	R_3QaeOGjgpod3XcE	155	IP Address	22 May 2012 10:36 PM	23 May 2012 09:40 PM	23h 4m 50s	▼			
	R_emKqvePS0l5slQU	155	IP Address	28 May 2012 01:54 PM	28 May 2012 01:58 PM	3m 41s	-			
	R_cPamp47FW1x6y6U	156	IP Address	29 May 2012 10:13 AM	29 May 2012 05:17 PM	7h 4m 4s	~			
	R_dbuYVDZIOrJheOU	151	IP Address	04 Jun 2012 08:59 PM	05 Jun 2012 09:16 PM	1d 0h 16m	▼			
	R_1NgCShZMu9IFGZu	157	IP Address	13 Jun 2012 09:56 PM	13 Jun 2012 10:11 PM	14m 58s	~			
	R_733WQBgmjQMgf88	152	IP Address	21 Jun 2012 04:05 PM	21 Jun 2012 04:30 PM	24m 31s	▼			
	R_0jstQ3H8PkDHTw0	158	IP Address	26 Jun 2012 10:39 AM	26 Jun 2012 11:19 AM	39m 53s	▼			
	R_7Wnu4xPx6YQA4Go	159	IP Address	27 Jun 2012 08:34 PM	27 Jun 2012 09:32 PM	58m 9s	▼			
	R_aXVyJNwHrdxXBmQ	160	IP Address	02 Jul 2012 10:01 PM	03 Jul 2012 11:18 AM	13h 17m 7s	_			
	R_0fBV0QB5DznJpnm	161	IP Address	11 Jul 2012 05:01 PM	11 Jul 2012 05:16 PM	15m 7s	▼			
	R_9XBGwq7QqINd0TH	162	IP Address	18 Jul 2012 12:07 PM	18 Jul 2012 01:19 PM	1h 12m 33s	▼			
A D . D										



Export Data





CHR Issues with Technology Research

- REDCap and Qualtrics preferred tools
 - Security
 - Privacy
 - Other platforms may be approved, but may require additional scrutiny
 - TIME
- Pre-Testing is essential
 - Considered similar to other pilot research
 - Maybe exempt if meets criteria
 - Create stand alone application
 - Can be cloned for future research



Exempt Research

Exempt Category 2: The research involves the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observations of public behavior, *except* where any of the following conditions exist:

- a. Information obtained is recorded in such a manner that the human subjects can be identified, directly or through identifiers linked to the subjects; AND
- Any disclosure of this information outside the research could reasonably place the subject at risk of criminal or civil liability or be damaging to the subject's financial standing – which may include loss of insurability or employability – or reputation; or

Note: UCSF requires expedited or full committee review – and does NOT exempt – research in category 2 under the following circumstances:

 The research deals with sensitive aspects of the subject's own behavior, such as illegal conduct, drug use, sexual behavior, or use of alcohol, AND will not be conducted in an anonymous fashion.

OR

- The study involves any of the following subject populations:
 - children (people under 18 who do not have the legal right to consent for themselves

or

prisoners.



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