- **1** Resolving embarrassing medical conditions with online health information
- 2 Sarah Redston^a, Sharon de Botte^a, Carl Smith^{b,c,*}
- 3 ^aHealth Press Ltd, Elizabeth House, Queen Street, Abingdon, UK
- 4 ^bSchool of Biology, University of St Andrews, St Andrews, UK
- 5 ^cDepartment of Ecology & Vertebrate Zoology, University of Łodz, Łodz, Poland
- 6 ** Corresponding author*. Carl Smith, School of Biology, Bute Building, University of St.
- 7 Andrews, St. Andrews, Fife KY16 9TS, UK. email: cs101@st-andrews.ac.uk

9 ABSTRACT

10 Purpose: Reliance on online health information is proliferating and the Internet has the 11 potential to revolutionize the provision of public health information. The anonymity of 12 online health information may be particularly appealing to people seeking advice on 13 'embarrassing' health problems. The purpose of this study was to investigate (1) whether data generated by the *embarrassingproblems.com* health information site 14 15 showed any temporal patterns in problem resolution, and (2) whether successful 16 resolution of a medical problem using online information varied with the type of 17 medical problem.

Methods: We analyzed the responses of visitors to the *embarrassingproblems.com* website on the resolution of their problems. The dataset comprised 100,561 responses to information provided on 77 different embarrassing problems grouped into 9 classes of medical problem over an 82-month period. Data were analyzed with a Bernoulli Generalized Linear Model using Bayesian inference.

Results: We detected a statistically important interaction between embarrassing problem type and the time period in which data were collected, with an improvement in problem resolution over time for all of the classes of medical problem on the website but with a lower rate of increase in resolution for urinary health problems and medical problems associated with the mouth and face. As far as we are aware, this is the first analysis of data of this nature.

29 Conclusions: Findings support the growing recognition that online health information 30 can contribute to the resolution of embarrassing medical problems, but demonstrate 31 that outcomes may vary with medical problem type. The results indicate that building 32 data collection into online information provision can help to refine and focus health 33 information for online users.

34 Keywords: Internet; Health communication; Online information; Quantitative results

35 **1.** Introduction

36 The Internet increasingly serves as a secondary, and even primary, source of health and medical information to the public [1-3]. The role that online health 37 38 information will come to play in the future is unclear, but it is a potentially important 39 source of information for promoting good public health [3], and may come to have as great an impact as that seen in banking, education, leisure and social relationships [2]. 40 41 The advantages of online health information are that it is almost limitless in scope, 42 unregulated, accessible from anywhere with an internet connection, available at any 43 time, potentially interactive and typically free to access, as well as having the potential 44 to combine expert advice with user-generated experience [4]. The anonymity of online 45 health information may be particularly appealing to people seeking information on 46 'embarrassing' health problems, for example those associated with sexual or mental 47 health [5,6] or body image issues, but potentially a wide range of medical conditions [7]. Some of the drawbacks of online health information are the potential for 48 49 misinformation, social isolation of users and the undermining of, and distancing from, 50 health professionals [4,8].

51 While the proliferation and impact of online health information is clearly 52 significant, its success in resolving health problems is more equivocal. Thus, while 53 variables such as the demographic profile, health status, educational attainment and 54 familiarity with social media of online users of health information have been well 55 characterized [3,9,10], no attempt has been made to quantify the outcome of seeking 56 health information online.

In this study, we analyzed data gathered over an 82-month period from *embarrassingproblems.com*, a website specifically designed to provide information on health problems that are often perceived as 'embarrassing' or difficult to discuss. During the study period the website received up to 1.2 million hits each month, providing

61 information on 77 discrete medical problems. At the bottom of each problem page on 62 the website, users are asked to anonymously record whether the information provided 63 has enabled them to tackle the given problem or whether it remains unresolved. Our 64 goal was to investigate whether the data generated by the site shows any temporal 65 patterns in problem resolution, and whether successful outcome varies with the type of 66 medical problem.

- 67
- 68 **2.** Methods
- 69 2.1 Background

Established in January 2000 by the healthcare publisher Health Press Ltd, the *embarrassingproblems.com* online health site (http://www.embarrassingproblems.com) provides expert information on personal health that might be considered difficult to discuss. The service is free to access. The information on the website is provided by recognized medical practitioners who write for Health Press Ltd. Individual health problems are grouped into nine broad classes of medical problem (Table 1).

76 Since February 2010, website content users have been invited to check one of 77 three boxes at the bottom of each page to indicate whether the information provided by the site has enabled them to tackle the problem ('Tackled it, moved on'), or whether they 78 79 feel the problem remains unresolved ('Tackling it' or 'Still struggling') (Fig. 1). 80 Responses were collected over an 82-month period, from February 2010 to November 81 2016. Responses were anonymous, but were problem specific. In addition, while the 82 temporal order of responses was known, the exact date of response was not recorded on 83 the site. Thus, temporal patterns in the data could be examined statistically, but could 84 not be linked to specific dates.

85

86 2.2 Data analysis

Online responses were treated as binomial data with problems scored as having been tackled or not tackled. Data for responses to specific medical problems were highly unbalanced and were subsequently analyzed by class of problem [11] (Table 1). After grouping medical problems, one class of problem ('cognitive') still showed imbalance and was subsequently dropped from the analysis.

Data were modeled using a Bernoulli Generalized Linear Model (GLM), whichtook the form:

94

95 $Outcome_i \sim Binomial(\pi_i)$

96 $E(Outcome_i) = \pi_i$

97 $\eta_i = \beta + Problem_i * Time_i$

98 logit (π_i) = η_i

99

100 *Outcome*_i is the probability of a positive outcome (i.e. problem tackled) for respondent *i* 101 assuming a Bernoulli distribution with mean π_i and variance $\pi_i \ge (1 - \pi_i)$. Problem_i is the 102 class of medical problem (Table 1) experienced by respondent *i*. *Time*_{*i*} is the time period in which respondent *i* submitted their online response. Time periods comprised 13 103 104 discrete ordinal categories, broadly taken to represent 6-month intervals over the 82 105 months of data collection. While the temporal order of these data is reliable, the precise 106 timing of responses reflected variation in site traffic and was not interpreted as 107 representing discrete Julian time periods.

To make inferences about the parameters in the model, a Bayesian approach was used. A Bayesian GLM is robust in dealing with complex datasets, unbalanced data, an inherent lack of dependency due to repeated measures, and a highly varied non-normal response variable. Bayesian models are flexible in allowing the estimation of a posterior distribution of differences between parameters and across levels of factors. These are relatively straightforward procedures using Bayesian inference, but problematic in a
frequentist framework [12,13], notwithstanding more general reservations in using
frequentist analyses [12-15].

116 Diffuse or non-informative univariate priors were put on all parameters. The 117 model was fitted in a Bayesian framework using Markov Chain Monte Carlo (MCMC) 118 with the *R2jags* package [16] in the R statistical environment [17]. Three independent 119 Markov chains were run simultaneously with a burn-in of 50,000 iterations and then 500,000 iterations for estimates of parameter and 95% credibility intervals. Chains 120 121 were thinned every 10th iteration, resulting in 50,000 Markov Chain samples for each 122 estimated parameter. Mixing and autocorrelation of chains were checked visually using 123 trace plots and the Gelman-Rubin statistic [15]. Autocorrelation was low and good 124 mixing was achieved in each case. The Gelman-Rubin statistic was estimated to be less 125 than 1.002 in all cases, indicating good convergence. Model validation showed no 126 evidence of overdispersion, heterogeneity or non-linear patterns in the model residuals 127 [18]. As part of the model-fitting process, the model was used to simulate an alternative 128 dataset. This procedure allowed the fitted values to be compared with the simulated 129 data, with probability values for each data point used to assess model fit. A probability of 130 0.49 indicated the model complied closely with the data [12]. All data from this article 131 will be made available in the Dryad Digital Repository.

132

133 **3. Results**

Overall there was a statistically important increase in the probability of problem resolution among time periods across all classes of embarrassing medical problem (Table 2, Fig. 2). In addition, there was a significant interaction of medical problem with time period. There was a lower increase in the resolution of problems classed as 'urinary' and 'mouth and face' compared with the baseline class of problem ('anal')

(Table 2, Fig. 2). Improvement in resolution of problems classed as 'breast and nipple',
'gut', 'hair', 'hands, legs and feet', 'sex and genital' and 'skin' did not differ from the
improvement seen with baseline (Table 2, Fig. 2).

142

143 **4. Discussion**

144 The proliferation of online health information presents an opportunity to 145 distribute reliable, authoritative public health information. The anonymity that online information allows may be especially useful in disseminating advice on health problems 146 147 perceived to be embarrassing. Using data generated by the online health information 148 site *embarrassingproblems.com* we showed an improvement over time in the successful 149 resolution of problems for users and an interaction between embarrassing problem type 150 with time. 'Urinary' health problems and problems associated with the 'mouth and face' 151 demonstrated less improvement over time than the baseline comparator class of 'anal' 152 problems. These results provide supporting evidence for the efficacy of online health 153 information, but demonstrate that outcomes may vary with medical problem type.

154 In the present study, a temporal improvement in problem resolution was 155 observed across all medical problem types. While the reason for this trend is opaque, 156 this finding ostensibly implies that the impact of this online health information 157 improved over time. Over the 82-month time period of this study, the 158 *embarrassingproblems.com* site editors implemented a 'listen and respond' approach to 159 content provision. All user-generated comments were manually moderated before being 160 published on each problem page below the expert advice. The site's editors then 161 ensured that these comments were taken into consideration in content updates made by 162 expert authors and in other materials highlighted on the site. Although the extent to 163 which user-generated content has contributed to the resolution of any given health

problem has not been ascertained, its use in continually improving the editorial offeringon the site is likely to have had a positive effect on visitor engagement.

166 It is also possible that the improvement in problem resolution reflects a general 167 increase in confidence in online health information, particularly from sources that are 168 perceived as reliable and trustworthy. The emergence of the internet as a source of 169 health information is increasingly recognized [2]. Furthermore, the 170 embarrassingproblems.com site has had a strong authoritative presence online for 16 171 years, and the expert authorship of the information is clearly signposted. However, 172 without further data collection from the site, the underlying reason for this positive 173 trend is unclear.

174 Notably, this trend mirrors that in mainstream healthcare, where information 175 technology plays an increasing role in supporting healthcare professionals [19,20]. The 176 role of online technology in other aspects of life has been profound. The rapid growth in 177 online shopping has been attributed to the expansion in the types of goods available, 178 combined with the trust in the security and reliability of service [21]. Growth in online banking, education, leisure and social relationships has similarly expanded rapidly. In 179 180 this context, the growth in self-directed access to online health information, and 181 increasing trust in its content, is not unexpected.

182 The interaction of temporal changes in health problem resolution with problem 183 type implies variation in the tractability of healthcare problems, but also that successful 184 resolution of specific problem types has increased faster than others. Given the wide 185 variety of health problems addressed by the *embarrassingproblems.com* site, it is not 186 unexpected that its success in tackling different problems might vary among problem 187 types. For example, the successful resolution of piles, crab lice, and chronic diarrhea are 188 high in our dataset, reflecting the relative ease with which these problems can be tackled 189 with readily available proprietary medical products. Others, such as profuse sweating,

blushing and flushing, and bed-wetting in adults are medically less tractable problems and, consequently, show much lower rates of resolution. In our analysis, urinary problems and medical problems associated with the mouth and face showed the weakest improvement over time. While these findings are unambiguous in our data, an explanation for the observed variance in the temporal improvement of different problem types is opaque and will require further data collection.

196 The relationship between online medical information and professional medical 197 providers is a potentially contentious one. It has been proposed that online advice may 198 undermine the work of healthcare professionals, though evidence for this is equivocal 199 [4,8]. It is also unclear whether online consumers of medical information are more or 200 less likely to seek medical advice from healthcare professionals, though some evidence 201 indicates that online information is sought in combination with more conventional 202 medical support [1,22]. Indeed, since its inception, the *embarrassingproblems.com* site 203 has encouraged content users to seek professional medical advice when appropriate in 204 conjunction with the information it provides. Thus, the role of online medical 205 information appears to be in tackling occasional health problems [1], with the 206 personalized nature of online medical health information contrasting with more diffuse 207 general health information, but complementing that from medical professionals 208 [1,22,23].

A distinction must also be made between information provision and active engagement in online discussion of health. Hitherto, studies of online health information have tended to conflate these two, yet they clearly differ. How forum content is used and how reliable and trusted information from this source is in comparison with more conventional sources is not clear.

The growth of online medical information has enormous potential to inform and empower patients and thereby facilitate improvements in healthcare outcomes [24]. In

the context of the present study, online health information that addresses problems that are perceived as embarrassing may be particularly effective, and the provision of online health information more generally may benefit from refinement and focus. Young adults are a well-represented demographic group that readily uses online health information [22], as are well-educated high-income women [10,25]. Online health information that targets these groups is evidently in demand, though the needs of online users of different racial, ethnic, and socioeconomic backgrounds is clearly also necessary.

Ultimately it is the degree of trust users place on information sources that will determine whether the potential of online health information is realized. Studies that have addressed this question indicate that information originating from public sources, presented in the English language and that adopt 'scientific' language garners most trust [22], and these are considerations in designing and distributing online health information.

229 A caveat to the present study is that the *embarrassingproblems.com* site was 230 created as a vehicle for the dissemination of medical information and not for data 231 collection. Thus, while there are clear temporal trends in the data, these cannot be 232 pinned to specific dates, which might be informative in fully interpreting patterns of 233 problem resolution. Similarly, data collection cannot be categorized by the sex, age, race 234 or social background of respondents, variables that might be instructive in assessing the 235 effectiveness of the site in providing appropriate medical information. A clear 236 implication of the findings of this study, for the *embarrassingproblems.com* site and 237 others like it, is to better tailor the site for data collection and analysis, to identify user 238 groups and their problems and, thereby, better target information provision. Indeed, the 239 specific date of each data entry on the embarrassingproblems.com site is now recorded, 240 with the aim of improving interpretation of problem resolution in future analyses. 241 Further options for improving data collection on the site will need to consider the

balance between collection of more user-specific information and the respondents'desire for anonymity.

In conclusion, we present an analysis of data gathered from an online 244 information website, which demonstrates that online medical information, across 245 246 multiple types of health problem, can contribute to the successful resolution of medical 247 problems that are perceived as embarrassing. The probability of problem resolution 248 showed statistically important temporal improvement а on the *embarrassingproblems.com* site, which may reflect both improvement of content during 249 250 the study period and increasing trust in online resources. The lower increase in the 251 resolution of problems classed as 'urinary' and 'mouth and face' is useful information 252 that will enable the site's editors to continue to refine and focus content provision in 253 these areas, showing a clear benefit to building data collection into the provision of 254 online health information.

255 Acknowledgements

Thanks to Rowena Spence and Mark Warren for statistical advice, and to Rhiannon Klyne, David Speigelhalter, Chris Sowden, Rose Thompson and Robert West for comments on the manuscript. *Funding*: This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

260 REFERENCES

- [1] J. Kivits, Everyday health and the internet: a mediated health perspective on health
 information seeking. Sociol. Health Illn. 31 (5) (2009) 673-687.
- 263 [2] S. Reis, A. Visser, R. Frankel, Health information and communication technology in
 264 healthcare communication: The good, the bad, and the transformative. Patient
 265 Educ. Couns. 93 (3) (2013) 359-362.
- L. Kelly, S. Ziebland, C. Jenkinson, Measuring the effects of online health
 information: Scale validation for the e-Health Impact Questionnaire. Patient Educ.
 Couns. 98 (11) (2015) 1418-1424.
- J. Powell, N. Inglis, J. Ronnie, S. Large, The characteristics and motivations of online
 health information seekers: cross-sectional survey and qualitative interview study.
 J. Med. Internet Res. 13 (1) (2011) e20.
- J.E. Chung, Social networking in online support groups for health: how online social
 networking benefits patients. J. Health Commun. 19 (6) (2014) 639-659.
- I.J. Rowlands, D. Loxton, A. Dobson, G.D. Mishra, Seeking health information online:
 association with young Australian women's physical, mental, and reproductive
 health. J. Med. Internet Res. 17 (5) (2015) e120.
- M. White, S.M. Dorman, Receiving social support online: implications for health
 education. Health Educ. Res. 16 (6) (2001) 693-707.
- 279 [8] S. Dean, J. Lewis, C. Ferguson, Editorial: Is technology responsible for nurses losing
 280 touch? J. Clin. Nurs. 26 (5-6) (2016) 583-585.
- [9] M. Koo, M.C. Lu, S.C. Lin, Predictors of Internet use for health information among
 male and female Internet users: Findings from the 2009 Taiwan National Health
 Interview Survey. Int. J. Med. Inform. 94 (2016) 155-163.

- I.A. Nikoloudakis, C. Vandelanotte, A.L. Rebar, S. Schoeppe, S. Alley, M.J. Duncan,
 C.E. Short, Examining the correlates of online health information-seeking behavior
 among men compared with women. Am. J. Mens Health 18 (2016)
 1557988316650625.
- [11] E.N. Ieno, A.F. Zuur, Data Exploration and Visualisation with R. Highland Statistics
 Ltd, Newburgh, UK, 2015.
- 290 [12] A.F. Zuur, A.A. Saveliev, E.N. Ieno, A Beginner's Guide to Generalised Additive
 291 Mixed Models with R. Highland Statistics Ltd, Newburgh, UK, 2014.
- [13] F. Korner-Nievergelt, T. Roth, S. von Felten, J. Guélat, B. Almasi, P. KornerNievergelt, Bayesian Data Analysis in Ecology using Linear Models with R, BUGS,
 and Stan. Academic Press, London, 2015.
- [14] K.P. Burnham, D.R. Anderson, P values are only an index to evidence: 20th-vs. 21stcentury statistical science. Ecology 95 (3) (2014) 627-630.
- 297 [15] J.K. Kruschke, Doing Bayesian Data Analysis. Academic Press, London, 2015.
- 298 [16] Y.-S. Su, M. Yajima, R2jags: A Package for Running JAGS from R. http://CRAN.R299 project.org/package=R2jags, 2012.
- 300 [17] R Development Core Team, R: A Language and Environment for Statistical
 301 Computing. R Foundation for Statistical Computing, Vienna, 2016.
- 302 [18] A. Zuur, E.N. Ieno, N. Walker, A.A. Saveliev, G.M. Smith, Mixed Effects Models and
 303 Extensions in Ecology with R. Springer, New York, 2009.
- A.D. Black, J. Car, C. Pagliari, C. Anandan, K. Cresswell, T. Bokun, B. McKinstry, R.
 Procter, A. Majeed, A. Sheikh, The impact of eHealth on the quality and safety of
 health care: a systematic overview. PLoS Med. 8 (1) (2011) e1000387.
- J. Sligo, R. Gauld, V. Roberts, L. Villa, A literature review for large-scale health
 information system project planning, implementation and evaluation. Int. J. Med.
 Inform. 97 (2017) 86-97.
- I.B. Hong, H.S. Cha, The mediating role of consumer trust in an online merchant in
 predicting purchase intention. Int. J. Inform. Manag. 33 (6) (2013) 927-939.
- A. Mendes, L. Abreu, M.R. Vilar-Correia, J. Borlido-Santos, "That should be left to
 doctors, that's what they are there for!" Exploring the reflexivity and trust of
 young adults when seeking health information. Health Commun. 32 (9) (2017)
 1076-1081.
- 316[23]S. Nettleton, The emergence of e-scaped medicine? Sociology 38 (4) (2004) 661-317679.

- 318 [24] K. Dobransky, E. Hargittai, Inquiring minds acquiring wellness: Uses of online and
- offline sources for health information. Health Commun. 27 (4) (2012) 31-343.
- 320 [25] M.J. Manierre, Gaps in knowledge: tracking and explaining gender differences in
- health information seeking. Soc. Sci. Med. 128 (2015) 151-158.

322 Figure legends

Fig 1. Screenshot of the boxes that visitors to the *embarrassingproblems.com* site are asked to check to indicate successful or non-successful resolution of their problem after reading the information provided. The binomial data used in this analysis (tackled or not tackled) were generated from these three boxes.

Fig. 2. Mean fitted probability (solid line) of medical problem resolution and 95%
credible intervals (dashed lines) for different classes of medical problem for a Bernoulli
GLM estimated by MCMC as a function of time period. Time periods comprised 13
discrete ordinal categories, broadly representing 6-month intervals over the 82-month
study period.

Tell us your thoug	ghts		
Did you find what you were I	id you find what you were looking for?		
Tackled it, moved on	0		
Tackling it	\bigcirc	Submit	
Still struggling	\bigcirc	Submit	



Table 1

Number of responses either not tackled or tackled by health information provided on the *embarrassingproblems.com* online health site. Due to unbalanced results, data for 'cognitive' problems were dropped from the final analysis.

Class of problem	not tackled	tackled	total	proportion tackled (%)
Sexual and genital	25712	19847	45559	43.6
Breast and nipple	2959	2065	5024	41.1
Anal	7705	5097	12802	39.8
Urinary	4112	2724	6836	39.8
Gut	2304	1411	3715	38.0
Hands, legs and feet	4202	2291	6493	35.3
Mouth and face	2675	1398	4073	34.3
Skin	7060	3566	10626	33.6
Hair	3188	1589	4777	33.3
Cognitive	472	184	656	28.0
Total	60389	40172	100561	39.9

Table 2

Parameter estimates of probability of successful resolution of embarrassing medical problems modelled using a Bernoulli GLM. CrI is the 95% Bayesian credible interval. Credible intervals that do not contain zero are in bold to indicate statistical importance. Parameter estimates are presented for each medical problem with anal problems as the baseline category.

Model parameter	Posterior mean	Lower CrI	Upper CrI
Fixed intercept _(anal)	-0.37	-0.41	-0.34
time	0.26	0.23	0.29
problem class(breast,nipple)	0.05	-0.01	0.12
problem class _(gut)	-0.14	-0.22	-0.06
problem class _(hair)	-0.34	-0.42	-0.27
problem class _(hands,legs,feet)	-0.13	-0.19	-0.07
problem class(mouth,face)	-0.23	-0.31	-0.15
problem class(sexual,genital)	0.08	0.04	0.12
problem class(skin)	-0.34	-0.40	-0.29
problem class _(urinary)	-0.07	-0.13	-0.01
time x problem class(breast,nipple)	-0.02	-0.09	0.04
time x problem class _(gut)	-0.04	-0.12	0.04
time x problem class _(hair)	-0.04	-0.12	0.03
time x problem class _(hands,legs,feet)	0.05	-0.02	0.11
time x problem class _(mouth,face)	-0.11	-0.18	-0.04
time x problem class(sexual,genital)	0.03	-0.01	0.07
time x problem class _(skin)	0.03	-0.03	0.09
time x problem class _(urinary)	-0.10	-0.15	-0.04

Summary Table

What was already known on the topic

- The Internet is an important source of online health information and is proliferating
- The anonymity of online health information may be particularly appealing in the case of medical problems perceived as embarrassing
- The success of online health information in resolving health problems is equivocal

What this study has added to our knowledge

- Online health information can make a significant contribution to resolving medical problems that are perceived as embarrassing
- The resolution of embarrassing medical problems showed a statistically important temporal improvement
- The probability of resolving a medical problem varied with medical problem type