

## HOW USEFUL ARE ONLINE SURVEY TECHNIQUES TO ESTABLISH THE RELATIVE PREVALENCE OF THREE TYPES OF INCONTINENCE AND ATTITUDES TO TREATMENT AND HELP-SEEKING ?

### Hypothesis / aims of study

This study had a number of aims:

1. To assess the usefulness of an online survey methodology in health services research by comparing its findings with the existing literature
2. To measure relative prevalence figures simultaneously in the same community-based adult population for three incontinence symptoms: urinary incontinence (UI), faecal incontinence (FI) and nocturnal enuresis (NE)
3. To explore attitudes and behaviours relating to help-seeking and beliefs about incontinence prevalence, impact, causes and treatments.

### Study design, materials and methods

An online survey was undertaken in the UK over two days in mid June 2008 by the online polling company which has conducted polls for the Times (London) since 2003. With the aim of reaching a sample of >1000, emails inviting participation were sent to 7000 people selected at random from a pre-established panel and stratified in terms of age, gender and region. Respondents were not informed of the subject of the survey prior to commencing their response. Responses were screened to ensure quotas were reached for specific subgroups. Data were weighted to adjust for imbalances in terms of age, gender, region and socio-economic profiles and to ensure a sample which was representative of the adult population of the United Kingdom. Urinary and fecal incontinence were defined as leakage from either the bladder (urine) or bowel (feces) which was bothersome to the respondent in the course of daily life. Respondents were asked if they currently suffered, or had suffered, UI and the same about FI. They were asked if they wet the bed; no criteria with regard to the regularity of wetting were stipulated. Subsequent questions asked about incontinence amongst family and friends, attitudes to help seeking and beliefs about the impact and treatment of incontinence.

### Results

Within the two day timeframe, the survey was completed by 1040 community-based adults (n=551, 53% female), nationally representative in terms of age, gender, region and socio-economic status. 23% (n=239) reported UI: 13% of men and 32% of women. There was a trend for the prevalence of UI to increase with age, with an indication of a slight peak in the 45-54 year age range. 11% reported suffering or having suffered FI. Unlike UI, there was little difference between genders and neither was there a noticeable age-related trend in prevalence. 6% reported bedwetting, with slightly more males (7%) than females (4%) affected. There was no marked age-related trend. Of those affected by any incontinence know to have sought help, 77% did so from a family practitioner. Of those with no incontinence, 75% said they would seek help from a family practitioner, while 23% said they did not know who they would seek help from. Around 90% recognised the serious impact of incontinence. Yet many were unsure whether treatments were available. Beliefs about the aetiology of incontinence were equally worrying, with 21% thinking male UI always relates to the prostate and 29% believing that incontinence is inevitable in women after childbirth.

### Interpretation of results

Online surveys can be conducted on relatively low budgets and within short timeframes. This study employed the same online survey agency and methods as are used by a major news publication to gather data on incontinence and compared its findings with existing evidence generated by conventional health services research methodologies.

The data collected by the online methodology appear to have validity when compared to the literature generally and to recent key research which used conventional epidemiological methods. The prevalence figures for current or previous UI amongst our population of adults are strikingly similar to those determined by the much more conventional health research methodology employed by the Medical Research Council Incontinence Study Group in adults  $\geq 40$  years (1): 23% in our study compared with 24.9% (MRC) in the total sample, 13% compared with 14.2% (MRC) in males and 32% compared with 34.2% (MRC) in females. An age-related peak in UI in our population equates to the peak in UI in women identified in the literature.

The results relating to attitudes to help-seeking and to awareness and understanding of incontinence are also in line with the literature. That the majority of those who had sought help did so from a family practitioner, and that those with no incontinence thought they would do so if affected, underlines the importance of family practitioner education in the diagnosis and management of incontinence and the need to raise public awareness of other sources of help. Misconceptions about the condition, its causes and its treatability highlight the need for more public awareness and educational efforts to address these issues.

Thus the data collected by the online methodology appears to have validity in that it is in line with existing evidence. Clearly, large and more traditional epidemiological studies produce more robust and detailed data of superior sensitivity and specificity. However, studies such as ours suggest that online methodologies may be of use in certain circumstances, especially if robust online methodologies and validation can be established.

Online surveys have limitations and further work is needed to address these: for example, does access to the internet amongst different groups affect the external validity of online surveys and do non-responders differ from responders in some meaningful way? Clearly these issues are important, although research has suggested that web-based research is no more likely to be affected by such response bias than paper-based surveys. Access is increasing by the year amongst all demographic groups. It has been proposed that online research methodologies may be appropriate in clinical areas in which patients are reluctant to speak openly; and perhaps especially appropriate for incontinence, given that many affected historically have sought answers there when their healthcare provider had no helpful advice.

With the reported UI prevalence in our study in line with the literature, the FI and nocturnal enuresis data collected simultaneously from the same population are of epidemiological interest. Hitherto UI, FI and NE have generally been researched separately and comparing their relative prevalence between separate studies must be undertaken with caution. The prevalence in our study of any FI – 10% in males and 11% in females – is markedly higher than the 6.2% and 5.7% reported by a key UK FI study (2). The 6% prevalence of any enuresis (7% in males and 4% in females) is also markedly higher than previous estimates (3). These results may suggest that the level of unreported and unidentified FI and nocturnal enuresis may be higher than previously thought amongst community-based adults.

### Concluding message

While further work is needed to establish robust protocols, address limitations and establish validity, online methods such as used in this study show promise. This study detected prevalence estimates for UI which are in line with the literature. Results relating to attitudes towards help-seeking and awareness of incontinence were also in line with the literature. In addition, the study was able quickly and easily to ask simultaneously and in the same population about the prevalence of three different types of incontinence, which hitherto have generally been researched separately. These data suggest that FI and NE may be more common than previously reported in the UK and this has implications for service provision and case-finding. Further development of online survey and even interview methods may be of particular interest in clinical areas such as incontinence, which are affected by stigma and an unwillingness amongst those affected to discuss their problems openly.

### References

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#### ***Is this a clinical trial?***

No

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#### ***What were the subjects in the study?***

HUMAN

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#### ***Was this study approved by an ethics committee?***

No

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#### ***This study did not require ethics committee approval because***

No ethical approval was required. Data were collected by a commercial polling company from a sample drawn from a large panel of people who have previously consented to take part in such research. No identifiable data were provided to the authors, in accordance with the Medical Research Council's guidance on the use of personal information in medical research and the UK Data Protection Act 1998.

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*Was the Declaration of Helsinki followed?*

**Yes**

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*Was informed consent obtained from the patients?*

**Yes**

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