Patient perceptions of participation in emergency medicine research projects

(Running head: Patient perceptions of research)

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Author Contributions:

EdeT and DT developed the protocol for the project. DT obtained ethics committee approval.

EdeT, JS, WS and PD collected all the data. All authors assisted DT in data analysis and interpretation. All authors contributed to drafting and critical revision of the manuscript. DT supervised the project overall. All authors take responsibility for the manuscript.

ABSTRACT

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Objective

To determine if ED research reflects patient expectations

Methods

A cross-sectional ED patient survey.

Results

309 (98.1%, 95%CI 95.7-99.2) of 315 patients believed that ED research was important. 212 (68.4%, 95%CI 62.9-73.5) would welcome involvement only 26 (8.4%, 95%CI 5.7-12.3) felt pressured to do so. 231 (75.7%, 95%CI 70.5-80.4) and 279 (91.5%, 95%CI 87.6-94.3) believed consent was necessary for observational and experimental studies, respectively. 101 (32.4%, 95%CI 27.3-37.9) disagreed with medical records being accessed without consent.

Conclusion

Patient expectations are not always consistent with current practice. The expectation of consent prior to record access is worthy of further consideration.

Keywords: emergency department, research, ethics, informed consent,

INTRODUCTION

Medical research is required to expand knowledge and inform management best-practice.¹

Research in the unique ED setting is usually clinical, often requiring patient participation.

However, patients are often acutely unwell. Few studies have examined patients' perceptions of research in this setting. Although well supported by the public in the United States² and United Kingdom¹, little is known of the perceptions of Australasian patients. We aimed to determine these perceptions across a range of domains including the value of ED research, willingness to participate, the consent process, information provision and perceived barriers and facilitators.

METHODS

This was a voluntary, anonymous, cross-sectional survey of patients presenting to a tertiary ED (February-June 2018). It was approved by the institution's Human Research Ethics Committee. Convenience sampling (9:00-17:00, Monday-Friday) of consecutive patients was undertaken (selection bias possible). Patients were excluded if they were aged <18 years, lacked capacity to consent, did not speak English or were too ill (as determined by the ED staff).

The study questionnaire was patient-administered, with assistance if necessary. It was designed for the study with questions of particular relevance to ED patients, as informed by the medical literature (see Appendix). It was examined for face-validity on six ED patients and no revision was required. Data were collected on previous ED research participation, perceptions of ED research, the nature of information that should be provided and the nature of consent for audit, observational and experimental studies.

The primary outcome was patient willingness to be involved in ED research. Secondary outcomes were perceptions about information provision and the consent process. Analysis of responses was descriptive (percentages, 95% CIs) and patient subgroups were compared using the Chi square test.

RESULTS

315 (86.8%) of 363 suitable patients participated: 165 (52.4%) males, 147 (46.7%) aged 41-65 years inclusive, 214 (67.9%) Australasian/British and 16 (5.1%) with previous research participation.

Overall, 212 (68.4%, 95%CI 62.9-73.5) patients would welcome the opportunity to be involved in research (Table). The responses of male and female did not differ ($p=0.61$) although older patients were less likely to welcome involvement ($p=0.03$, disagree/strongly disagree responses merged). 309 (98.1%, 95%CI 95.7-99.2) patients believed that research was important and only 26 (8.4%, 95%CI 5.7-12.3) would feel pressured to participate. 101 (32.4%, 95%CI 27.3-37.9) disagreed with medical records being accessed without consent. 148 (48.4%, 95%CI 42.7-54.1) reported that delayed consent due to time pressures was acceptable and 208 (68.0%, 95%CI 62.4-73.1) reported that participants should receive the study results.

More patients reported that written or verbal information about the study should be given for experimental studies ($p<0.001$) although substantial proportions believed that both types of information should be given (Figure). Patient perceptions regarding the consent process for observational and experimental studies differed. Most patients reported that consent should be obtained before enrolment, especially in experimental studies ($p<0.001$). Most patients believed that written consent should be obtained, especially for experimental studies ($p<0.001$).

Patients suggested that future ED research should be directed at specific conditions, ED efficiency and the safety of health workers. Concerns regarding research participation included privacy, risk and time commitment.

DISCUSSION

It is encouraging that almost all patients believed that ED research was important, that two thirds would welcome participation and that few would feel pressured. Overall, ED patients are more receptive of research than the general public^{2,3} although our patients' concerns about participation are similar to those reported elsewhere.⁴

Information regarding research risk and benefit is important to patients. Written or verbal information, or both, was expected by our patients, especially written information for experimental studies.

Almost all patients agreed that informed consent was required, a finding reported elsewhere.^{2,3} Written consent was seen as superior to verbal alone, especially for experimental studies. Patients place greater emphasis on the consent process as risk increases.³ One half of patients believed that delayed consent may be acceptable, a finding consistent with that of Smithline et al.³

The almost universal practice of accessing medical records without consent was unacceptable to one third of patients. However, Whiteman et al.⁵ reported that most Australians supported audit studies without consent. Again, ED patient perceptions may differ from the general public.

Current ED research best-practice includes both verbal and written information provision and, in all but low risk research, written patient consent. This practice is consistent with our patients' expectations. However, the need for consent to access medical records, as expressed by many, is not usual practice and should be explored further. As the majority of patients would welcome a summary of their study's results, consideration should be given to this expectation.

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Nil

CONFLICTS OF INTERESTS

None declared

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Table. Patient perceptions of research participation

item	patient subgroups	strongly agree n (%)	agree n (%)	neutral n (%)	disagree n (%)	strongly disagree n (%)
<i>I would welcome the opportunity to be involved in ED research (n=310):</i>						
	male	38 (23.2)	71 (43.3)	47 (28.7)	6 (3.7)	2 (1.2)
	female	39 (26.7)	64 (43.8)	33 (22.6)	9 (6.2)	1 (0.7)
	18-40	22 (25.6)	35 (40.7)	26 (30.2)	2 (2.3)	1 (1.2)
	41-65	37 (25.5)	69 (47.6)	35 (24.1)	4 (2.8)	0 (0.0)
	>65 years	18 (22.8)	31 (39.2)	19 (24.1)	9 (11.4)	2 (2.5)
<i>Overall, I believe research in the ED is important (n=315):</i>						
		195 (62.9)	114 (36.2)	6 (1.9)	0 (0.0)	0 (0.0)
<i>I would feel pressured to participate in ED research (n=308):</i>						
		6 (1.9)	20 (6.5)	90 (29.2)	112 (36.4)	80 (26.0)
<i>Accessing a patient's record without consent is acceptable for research (n=312):</i>						
		52 (16.7)	109 (34.9)	50 (16.0)	51 (16.3)	50 (16.0)
<i>If there is no time, it is acceptable to enrol a patient and consent later (n=306):</i>						
		51 (16.7)	97 (31.7)	72 (23.5)	60 (19.6)	26 (8.5)
<i>Participants should receive the results of a study they participate in (n=306):</i>						
		90 (29.4)	118 (38.6)	86 (28.1)	10 (3.3)	2 (0.7)

Figure Legend

Figure. Patient perceptions of consent for observational and experimental studies

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