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Patient Access to Health Information: The Future is Now

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Patient Access to Health Information: The Future is Now

❖ Patients, Professionals and the Internet: Renegotiating the Healthcare Encounter

- ✓ The 5 strands & Progress to date
 - Incidence of Internet Use
 - Patient Information Search and Evaluation
 - Virtual Health Communities
 - Stated Health Preferences

❖ Longitudinal ethnographic strand

- ✓ Qualitative research
- ✓ Consultations, interviews and diaries
- ✓ Patients and professionals use of internet

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❖ Users and non-users

- ✓ Surprising findings

❖ Other sources of information

- ✓ Professional advice

- ✓ Printed materials

- * Pamphlets * Newspapers * Friends and relatives

"...that information there, that lays it out quite clearly. Slightly expanded is the internet information and also...you were there at that consultation with..., I mean how anybody could come out feeling anything other than overwhelmingly confident in his approach and attitude..." [PC-1]

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❖ Internet user patterns

✓ Timing of use

"Because I haven't looked up anything. Until I get a diagnosis I haven't - I refuse, I've stopped myself."
[MC-1]

"when I first, erm, found out that there was a problem, um, for about the first week or ten days, err, I didn't really do anything." [PC-1]

✓ Reservations about use

"I will look sometime. I just don't really see a great benefit from it, getting tons and tons of information to digest when I've got three experts to talk to...[and] is more likely to depress you than inform you." [PC-5]

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✓ Evaluation of information

"if you're looking at the Diabetics [Diabetes UK] website then you would expect, because of where it's rooted, that the stuff in there should be stuff that you perhaps take notice of... I think you've got to be careful, which is why it's worth perhaps having a look at two or three different websites rather than just being happy with one." [DI-1]

"I've got to have faith and I've got to use my own judgement on it. I think if you get it from several sources exactly the same then of course that establishes some kind of credibility." [PC-9]

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❖ Internet saturation and overwhelm

"I think you can saturate yourself with so much information that you begin to get a bit dazzled by it." [PC-3]

"Yeah, well that's one of the reasons I don't look at it because there's an overwhelming amount of information." [PC-5]

"I looked under breast, I looked under cancer of the breast and there was a load of information, so much so that I couldn't cope with all of it....Well I was inundated, yes." [BC-1]

"Just the amount of information you can get there. It's colossal isn't it?" [PC-9]

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❖ Medical encounter - the influence of the internet - Patient perspective

"Oh the internet, you take it all in and if somebody asks you about it, you know what to answer." [PC-6]

"Well it informed me and it categorised things and actually it made me feel a little bit more hopeful, positive." [BC-1]

"I regard it as Reader's Digest knowledge and a little knowledge is dangerous so I just dipped in to have a look at what was the possible and again, the NHS Direct I thought just provided me with sufficient information and so when I got the phone call from Mr... I knew what he was talking about and went in." [PC-9]

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❖ Professional perspective

"it's helpful for the patients to - I think if they read with an open mind and come back with questions, that's fine." [PC-B]

"Well there's plenty of anecdotal evidence... you know, totally non-scientific treatments but they're out there and people access them and they occasionally come in and say 'what about this?'" [PC-C]

"But I would prefer that patients got their information from the professionals." [BC-A]

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❖ Evolving patterns of patient-professional interactions?

"In England when you used to go to the doctor's they never told you a thing and they used to speak above you, speak over your head. You would be there but you were invisible." [PC-6]

✓ Multidisciplinary team approach to health care

"they may have come under me initially, I might get them to see [oncology consultant], they may go to see [laparoscopic surgeon], but all along the way they've been given a key worker nurse with a contact number...and that person becomes their continuity." [PC-A]

✓ Findings come from secondary care

- Less relationship, more interaction

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❖ Ageing population will gravitate to the web

- average age of participants (so far) - 63

“most patients in the younger age groups now will have gone and looked up stuff on the internet and... as patients, people are getting more used to the internet and people are becoming a bit more discerning.” [PC-A]

“most of them are just slightly older than the internet generation and therefore it's not the natural thing for them to sit down at a keyboard and enter something, whereas clearly that will gradually kick in as time goes on.” [PC-1]

“Unfortunately I think it came out, you know, the use of it by the time when I got to an age when it was fairly difficult to sell it to me.” [PC-7]

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❖ E-health - a new frontier

“Well I think it's a really good piece of communication which is presently overtaking all other means of communication in the world.” [PC-7]

❖ The NHS will design services that integrate the internet

- ✓ Guidelines for professionals supporting patients in use of the internet
- ✓ Patients with higher level information, can interact in more sophisticated ways
- ✓ Power asymmetry shifts related to access to information are facilitated by the internet

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